CHAPTER 4: RESISTANCE AND THE ROLE OF ADHERENCE IN ANTIRETROVIRAL THERAPY (ART)

4.1 Introduction

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, the initial enthusiasm for these drugs has been dampened somewhat by the discovery that they require near-perfect adherence to prevent virus replication and mutation. Strict adherence to the antiretroviral treatment regimen is essential in order to obtain the desired benefit and to avoid the emergence of drug resistance and clinical failure.

Regarding the issue of adherence, Friedland (2003:39) states “Added to the challenge of more widespread and equitable access to antiretroviral therapy in South Africa and elsewhere, is the issue of adherence to these therapies. Clinicians need to develop and employ strategies to support antiretroviral adherence that are practical, relevant and appropriate to the African context.”

The multidisciplinary team involved in the field of HIV/AIDS, faces additional challenges with the greater availability of ART, particularly concerning matters of adherence. The researcher is of the opinion that the issue of adherence to ART has brought to the forefront the importance of multidisciplinary teamwork within health settings. It calls for health providers to work together towards a common goal.

For ART to be successful, education is at the core of the treatment programme. Patients must be educated with regards to the importance of adherence and the potential of developing resistance to ARV medication. As previously quoted, Isselbacher, *et. al.,* (1999:1910) confirm the above: “The cornerstone of HIV prevention strategy is education, counselling and behaviour modification”.

The social worker, who renders services to HIV/AIDS patients referred for ART, should focus on the provision of information in order to ensure the development of insight with regards to treatment, and, also, interventions that will motivate, support and promote adherence.

4.2 Adherence

Adherence is defined by the *R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment* (South Africa, 2003:4) as the act or quality of sticking to something, or of adhering to something.

Adhere is also defined by *The Concise Oxford Dictionary* (1995:272) as: “to behave according to; follow in detail, faithfully observing a rule”.

Adherence is also defined by Bartlett (2005:68) as the degree to which a patient carries out the clinical recommendations of a treating physician, that is, takes the correct dose of medication at the right times, every day.

Adherence behaviour is defined by Mosby’s Pocket Dictionary of Medicine, Nursing & Health Professions (2006:34) as “self-initiated action taken to promote well-ness, recovery, and rehabilitation”.

Compliance is defined by *Dorland’s Illustrated Medical Dictionary* (1994:388) as: “the act of conforming. Compliance, the act or an instance of complying, obedience to a request, command”. The term "adherence" is preferable to "compliance", as compliance implies that some prompting is necessary to ensure that the medication is taken, whereas adherence is voluntarily carried out by the individual.

Adherence to ART, specifically, means how correctly a person manages to take his/her ART medication. It is important to take this medication exactly as prescribed, by sticking rigidly to the suggested dose and timetable, while also observing instructions concerning food. Taking too little of the drug (by missing

or reducing the doses), could allow drug levels in the blood to fall to inadequate levels, thus allowing viral replication to occur, and, therefore, increasing the risk of resistance.

Carter (2004:1) summarises adherence to HAART as:

- Taking all the medicine in the right quantities;
- Taking the pills at the right time;
- Taking the medication with or without food according to instructions; and
- Checking for interaction with any other medication or drugs.

The *Foundation for Professional Development* (2005:153) has differentiated between two different types of adherence:

- Ritual (more passive) treatment adherence behaviour manifested by absolutely following "to the letter" a prescribed therapeutic regimen, e.g. a patient continuing to take medicine without consulting doctor/health team even when he/she experiences serious uncomfortable/undesirable side effects.
- Regarding adherence in general, Kaplan, Sadock & Grebb (1994:11), postulate that in general, about one third of all patients comply with treatment, one third sometimes comply with certain aspects of treatment and one third never comply with treatment.

Venter (2005:22) reports and warns against "adherence overkill, multiple demands before initiation of ART, for example, for multiple visits before initiating ART or demand to disclose a patient's HIV status". The researcher is of the opinion that disclosure cannot be demanded, since this would go against the individual's right to privacy and confidentiality, as well as the basic social work principles, such as self-actualisation. The role played by the social worker in the assessment of patients with regards to disclosure and referrals to alternative support and networking, is essential.

Most experts (Gerberding and Sande, 1999:1470; Isselbacher, *et al*., 1999; & Kasper, *et al*., 2005:1853) accept the following treatment principles:

In terms of ART, adherence means adhering to a regimen, while for the patient, it means:

- Taking all the pills and doses in the manner prescribed by the doctor;
- Maintaining certain lifestyle patterns, such as avoiding unsafe sexual practices in order to avoid infection by other strains of HIV or drug-resistant viruses;
- Attending follow-up appointments, collecting scripts;
- Maintaining a healthy diet; and
- Other therapeutic behaviours as indicated e.g. exercise and adequate sleep.

According to the Foundation for Professional Development: (2006), HAART is very complex, requiring a very committed and well-informed patient, and the following is presented in their HIV/AIDS management guidelines / protocol (South Africa, 2003) for lay counsellors.

- Different drugs have different requirements;
- Different drugs have different side- effects;
- Treatment is a life-long commitment;
- There is the issue of resistance, which has to be explained and understood, especially regarding why drugs cannot often be re-used;
- There is a strict monitoring and adherence procedure;
- ART drugs interact with other drugs, including herbs;
- Sexual behaviour modification has to be maintained; and
- Patients should never commence therapy until they are fully aware of and accept the implications of the treatment decision.

As previously stated by the present researcher, she opines that both compliance and adherence refer to the act of maintaining a treatment regimen. Adherence captures the increasing complexity of medical care by characterising

patients as independent, intelligent, and autonomous people, who take more active and voluntary roles in decision-making regarding their treatment.

Rier & Indyk, (2006:137) discuss the use of the term “concordance”, as it promotes power sharing between provider and patient, respecting the patients’ perspective. According to the above, concordance is based on the notion that the work of prescriber and patient in the consultation, is a negotiation between equals. The aim therefore is a therapeutic alliance between them. “Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment”.

Adherence is an aspect that should be addressed by the multidisciplinary team involved in HIV/AIDS and ART. The need to assess and counsel patients regarding adherence, prior to treatment as well as at the time of the initiation of ART, is strongly indicated. Continuous assessment, monitoring and support are further indicated. The social worker, with specialized knowledge and skills, is equipped to be part of the multidisciplinary team that renders a service in this regard.

4.3 Resistance

Literature differentiates between three types of treatment failure: virological, clinical and immunological, as explained in the previous chapter. In many cases the effects of anti-HIV drugs decrease over time, and a major cause of treatment failure is the development of resistance (Gerberding and Sande, 1999:1470 and Isselbacher*, et al*., 1999:1853).

HIV replicates at very high levels producing up to 28 billion particles per day. When HIV, RNA is converted to viral DNA, the mechanism is prone to error and the virus does not rectify mistakes. Inhibition of the reverse transcriptase enzyme, often places pressure on the transcription process and in the presence of low plasma levels of the drugs, causes selective mutations, which may lead

to drug resistance. Once the mutation arises, a new population of drug resistant virus develops which over time will become dominant and cause further disease progression and virological failure (Foundation for Professional Development, 2006).

Resistance can develop whenever the HIV continues to reproduce whilst ARV medication is being taken. Resistance is an important reason why many ARV drugs have limited or short-term effects. Whenever HIV is still able to reproduce in the body of someone who is on ARV medication, it is extremely likely that resistant strains will eventually emerge and the viral load will increase. A micro-organism is most likely to develop resistance to a drug if the blood level of the drug is too low to prevent it from reproducing, but high enough to affect how it evolves in one's body (Abdool Karim & Abdool Karim, 2005:514).

Studies have indicated that the risk of viral load rebound is related to the point to which viral load falls after commencing treatment, called the "nadir". The lower the nadir, the lower the risk of rebound, and therefore, the less the risk of resistance. People whose viral load falls, and remains, below 50 copies, are at a much lower risk of developing resistance. However, resistance may emerge even in these people, over the long term (Isselbacher *et al*., 1999:1853; Spencer, 2004:10 & Van Dyk, 2004:66).

Cross-resistance

Once the HIV develops resistance to one drug, it may also be resistant to other similar drugs; thus cross-resistance occurs. A single mutation or set of mutations in the virus can produce resistance to several different drugs within the same class. This means that once resistance to one drug has emerged, this virus population may also be resistant to drugs, which the patient has not yet taken.

Cross-resistance may affect all currently available anti-HIV drugs to a greater or lesser extent. For example, it is possible that if one develops resistance to a protease inhibitor (PI) or a non-nucleoside reverse transcriptase inhibitor (NNRTI), the patient will also be resistant to all other inhibitors in the same

group. By using two or more ARV drugs (combination therapy), one could delay resistance, since a virus that is resistant to one of the drugs, may still be controlled by the other(s).

Several tests have been developed so as to indicate to which drugs a patient is resistant, and also, the level of resistance to these. Currently, it is not known how useful these tests will be in guiding treatment decisions. Where resistance typing is available and affordable, this will assist in making an informed decision. In resource-poor situations and in the current South African circumstances, these tests remain a luxury and are mainly used after second-line regimen failure. Two types of drug resistance tests are available.

Genotypic testing

This type of testing characterizes the nucleotide sequence of reverse transcriptase and protease. It then compares the test result with an existing data pool of mutations, which confirms resistance. Mutations can be detected before phenotypic resistance occurs. Only dominant species are detected. For the test to be conducted, a viral load of >1000 copies/mLis required. This test is less expensive and has a shorter turnaround time than phenotypic testing. (Spencer, 2005:30)

Phenotypic testing

This is a quantitative assay, which is analogous to bacterial antibiotic resistance testing and also requires a viral load of >1000 copies/mL. It is currently not freely available in resource-poor settings because it is very costly (Spencer, 2005:30).

With the great advances that have been made in ART, most literature confirms Miller's (2005:23) view, that in addition to all the challenges of ART, the patients must be educated with regards to the potential development of resistance to ARV drugs and its consequences as well as the implications of non-compliancy and the resulting importance of adherence. The social worker possesses the necessary skills to facilitate the development of insight and provide clarity regarding this complex issue.

4.4 Predicting Adherence

Unfortunately, there are no absolute predictors of adherence. It is not possible for healthcare providers to reliably predict which individuals will ultimately be adherent to their treatment plan, since adherence does not correlate with gender, cultural background, socio-economic or educational level. It is known that people with a persistent alcohol problem, or those who are acutely depressed, will experience difficulty with adherence, so these issues must be thoroughly addressed prior to the commencement of ART.

British HIV Association (BHIVA:2003) suggest that the terms, low and high adherence, be used in preference to adherence and non-adherence. Low adherence can be described as adherence below the expected levels, which would enable successful responses to treatment. Low adherence increases the risk of treatment failure and disease progression, with the further threat of the transmission of a resistant virus. Omitting to take all the doses, taking an incorrect dose, or taking a drug in such a manner that insufficient quantities are absorbed, may lead to a more rapid development of resistance to the drug and the patient may cease to benefit from it. The consequences of low adherence are serious, because not only do they pose the threat of disease progression to the individual, but also to public health, due to acquired resistance (the increase in transmission of a resistant virus to newly infected individuals). High adherence describes adherence levels expected to enable successful treatment responses.

Barriers to adherence as outlined by Horizon (2003:33), and supported by the researcher are:

- Communication difficulties;
- Low literacy levels;
- Inadequate knowledge or awareness of HIV disease;
- Inadequate understanding of the treatment regimen;
- Discomfort with disclosure of HIV status;
- Patient attitudes and beliefs in treatment efficacy;

- Depression and other psychiatric problems;
- Alcohol and or active drug abuse;
- Difficult life conditions;
- Unstable living conditions;
- Negative or judgmental attitude of health providers; and
- System barriers.

The researcher holds the view that the individual circumstances of patients must always be taken into account concerning adherence issues. Venter (2005:23) states that wellness programmes usually call for an improved diet, the cessation of smoking, moderating the consumption of alcohol, the practice of safer sex, adequate exercise, and participation in support groups, routine clinic visits, and disclosure. There have been reports that people have been denied access to ARVs because they have not fulfilled one or all of the above criteria, each one of which is notoriously difficult to implement among the general population. Provision must be made for individual circumstances.

The said researcher promotes a thorough biopsychosocial assessment of each patient, taking into account the rights of the patients as independent, autonomous individuals, as well as their right to medical care National Health Act, 2003 (Act No. 61 of 2003) and with regards to the decisions concerning their treatment.

Discrimination and the denial of a patient's access to ART as well as the demand for certain behaviour, for example, that patients disclose their status; that, patients be accompanied by a "buddy" or a person to provide support; that they need to attend multiple clinic visits before initiating ART, and that patients need to produce identification documents, before treatment can be initiated, are contraindicated by the *Bill of Rights, in the Constitution of the Republic of South Africa 1996* (Act No. 108 of 1996).

Predictors of good adherence to therapy that have been noted are:

Availability of emotional and practical types of support, such as informed family and friends, adherence support groups, community-based case managers, peer educators, and a trusting relationship with the healthcare team;

- The ability to fit medication into a daily routine;
- The understanding that poor adherence leads to resistance;
- Feeling comfortable taking medication in front of people;
- Keeping clinic appointments;
- Belief in medication, by both patient and provider;
- Personal determination;
- Improvement of symptoms while on therapy; and
- Availability of adequate food and regular meals.

The researcher concurs with the *British HIV Association* (BHIVA: 2003) (2003) view that support for adherence should be provided to all patients on HAART. ART should not be withheld on the basis of assumptions regarding adherence. The researcher is further of the opinion that adherence support is an ongoing process which begins prior to the initiation of ART, with continuous monitoring throughout the treatment.

The social worker can motivate and provide ongoing emotional support to patients by employing various techniques such as clarification, catharsis, confrontation, interpretation and offering advice. Also, by simply listening, explaining, reflecting and summarizing, the patient can be successfully guided with respect to the development of insight into their treatment.

4.5 Strategies for Measuring Adherence

Adherence to therapy is difficult to measure accurately. The methods employed to measure the level of adherence include self-reporting by individuals, the doctor's estimates, tablet counting, pharmacy refills, and measurement of drug levels.

No measurement of adherence is completely accurate. Adherence to HAART can be measured by employing a range of methods. The purpose of

measurement tools is to support and emphasise adherence, not as a tool to "catch out" patients. Furthermore, the dynamics of provider-patient relationships may clearly impact on the willingness of individuals to disclose problems.

The said researcher distinguishes between some objective measurements of adherence, such as medication management, patient support and campaigns. Subjective measurements, as reported by Horizon/Population (2005:8), some of which were mentioned above, are: self-reporting, pill counts, pharmacy records, electronic devices and measurement of drug levels. The researcher is of the opinion that some modes of measurement appear to be more accurate than others and that no one measuring tool can be established as the one and only form of measurement.

- **Self report**

  Patients can be prompted to report pill taking during any period or day in self reporting. Self-reporting agrees well with the actual intake of medication and viral load. It is inexpensive and easiest to implement in a clinic setting. Clients should be approached in a matter-of-fact and non-judgmental manner, and questioned with regards to the most recent days and missed doses.

- **Routine and random pill counts**

  One of the most common modes concerning measurement of adherence, as evident from the literature, is clinic-based counting of tablet returns. It provides a reasonable estimate, in the majority of cases, and can be carried out at every visit. The counselling team can also perform a surprise tablet count at the patient's home once in a while, which is not always feasible due to the heavy workload of counsellors. A problem that occurs with respect to pill counting is that patients can dump pills prior to visits. It may also promote a sense of distrust between the patient and provider. This problem could be overcome by another available method, namely Electronic Medication Monitoring (MEMS), which has data incorporated into a memory chip.

- **Pharmacy and medical appointment records**

  The pharmacy staff can play a major role in adherence issues by reporting their issuance of drugs, since in any case; they are required to maintain records of medication dispensed to patients. By monitoring the patient’s medical appointment records, patients failing to keep their medical appointments can be contacted.

- **Biological markers of effectiveness of treatment and drug level monitoring**

  Adherence levels can also be monitored by means of a laboratory investigation of the drug plasma concentration, plasma HIV1 (Viral load), RNA and CD 4 cell counts.

- **Direct observation (DOT)**

  DOT is an intensive programme in which patients take their medication under the supervision of adherence staff. In the case of ART it is not practical to observe whether all the doses are being taken.

Most HAART regimens comprise multiple doses and treatment is lifelong. Therefore, only some doses are observed for a fixed period of time. This is called modified DOT or directly administered antiretroviral therapy (DAART),

which can be carried out at health centres, in community-based organizations or even at a patient's home. DOT seems to provide a better account of adherence, since patients are unable to prepare their returns in advance; however, this is labour-intensive. Our present primary care service is not able to provide this support continuously for a twice- daily regimen.

Measuring pill-taking behaviour has its limitations and the present researcher wishes to emphasize that none of the measuring aids are perfect. Adherence is still an individual matter. A thorough assessment of the biopsychosocial matters influencing, or imposing on, adherence is indicated for each patient (Webster & Barr, 1999:1-16). The social worker should promote alerting strategies to enhance adherence by means of education and constantly reminding team members and patients being monitored.

4.6 Medication Alert Strategies to Enhance Adherence

The use of medical alerts and reminders, such as pillboxes, can overcome some of the scheduling demands. These methods are also associated with good adherence. There are a variety of alerts available to assist patients to remember to take their medication, since forgetfulness is a very common reason why people do not take their medication. Horizon (2005:8) distinguishes between the following methods of enhancing adherence counselling: medication diaries, pill boxes, a "buddy" system, incentives, electronic devices such as pagers, alarms, beepers:

- **Pill diaries and medication charts or booklets**
  Confusion over which pills to take, when and what; times to eat or avoid food may be a problem when starting a new combination. A written daily schedule which patients can tick off after taking a dose could be helpful. Patients who experience difficulty with which pills to take, when to take them, and with remembering or understanding medication schedules will benefit from clear written instructions. A written daily schedule, on which the prescription is specified, can be ticked off after taking a dose. This is

a useful tool in order to identify patterns of use and reasons for missing doses.

- **Labelling pill boxes**

  Labelling pillboxes for dosing and dosing instruction cards can be supplied by the provider, doctor, and pharmacist or adherence counsellor, while taking into account the literacy level of the patient. Patient planners, such as newsletters, videos, or booklets, are also recommended in order to reinforce the central role which patients themselves play in managing their own adherence.

- **Pill charts**

  Pill charts are used to visually display pills (their colour and shape), while the names and dosage for each medication are used by the nurse or health provider during counselling.

- **Electronic devices**

  If the problem seems to be forgetfulness and a need for a reminder is apparent, cell phones, computers, alarmed or programmable wristwatches or alarm clocks, can be useful. The alarms are saved in the memory, the watch does not have to be reset every day and an eight-letter message can be set to scroll across the watch or cell phone together with an alarm. Computer technology, with message software-scheduling programmes, can also be adapted for this purpose. Electronic devices need to be discreet to avoid stigmatism and confidentiality-related issues. Internet-based confidential reminder services are also available.

- **Telephone reminder**

  Telephone reminders are being tried out in some studies of adherence. This is labour-intensive and its high costs are borne by the staff only, and also, patients must have a telephone available at all times.

- **Medication containers/Pill boxes**

  Special containers are available for storing and transporting pills. These partitioned containers can be filled once a week, or every few days, with the individual daily doses. Some versions allow one to take out a single day's dose, or several, if need be. Attention should be paid to ensuring that the box is large enough and that the drugs are suitable for storage outside of their original container. Some pills deteriorate if not stored correctly. Patients who are illiterate or very ill may need assistance to fill the pillboxes correctly.

- **Incentives**

  Incentives such as telephone cards, transport and food or shopping coupons, movie tickets, or tickets to sports events can be employed to motivate patients.

- **"Buddy" system**

  The "Buddy" system relies on a friend or family member to assist and remind the patient to take medication regularly and on time, offer encouragement to persevere, help to keep hospital appointments and provide support. *The National Guidelines* (South Africa, 2004) promote HIV/AIDS status disclosure to at least one friend, family, buddy or patient advocate.

  Venter (2005:22) warns that disclosure to a "buddy" may appear to be adopted as a form of punishment, rather than a mechanism to provide adherence support. As noted previously, disclosure cannot be forced, since this would go against the individual's right to privacy and confidentiality, as well as basic social work principles, such as self-actualisation. The role of the social worker is to assess patients with regards to disclosure and referral to alternative support and networking.

- **Mass-media adherence campaigns**

  Another adherence intervention, which could play a major role in adherence issues, includes mass-media adherence campaigns. Most people will respond to education, support and re-education.

The above strategies to enable and support patients to organize their treatment and take responsibility for their health can be supported, particularly, at each phase of the treatment with ART. The social worker possesses the necessary skills to educate patients regarding adherence and to facilitate alert strategies and reminders.

4.7 Adherence Support during the Different Phases

Healthcare workers are faced with a clear and extremely important responsibility to provide comprehensive information, to ensure that this information is understood, and to obtain the active consent of the patient to treatment. A responsible attitude to therapy is crucial in all healthcare facilities.

Adherence issues can be divided into different phases, which correlate with the different stages of antiretroviral medication:

- The pre-treatment phase – screening, supporting and educating patients regarding ART; Initiating phase – the day the patient is initiated with ART and educating patients regarding pill-taking matters; Monitoring adherence – would be the entire period a patient is on ART, which is, presently, lifelong; and Step-up adherence – when low adherence is suspected or reported or treatment failure is reported.

4.7.1 Phase 1: Patient pre-treatment (preparation)

Patient assessment and preparation is important in the pre-treatment phase and needs to be carried out over a few sessions prior to the initiation of HAART. This will lay the foundation for improved adherence and is an ongoing process between the provider and patient.

Thorough pre-treatment, and education, are vital in order for patients to develop a full understanding of ART, prior to commencing therapy. Realistic expectations in terms of expected health benefits, possible side effects, and the daily tablet burden, need to be explored. The patients should have a treatment plan. Furthermore, it is recommended that everyone commencing therapy must attend a number of pre-treatment education sessions. The initial assessment of patients by an experienced counsellor or social worker should include establishing the following:

- Patient's health history;
- Prior ART used;
- Medication (including traditional medicines) currently being taken;
- Patient's beliefs and attitudes concerning HIV and ART;
- Sources of social support;
- Socio-economic situation; and
- Barriers to adherence.

The above adherence support strategy is not to exclude people from ART, but rather, to reinforce daily medication-taking behaviour from the initiation phase onwards. The aim is to identify potential problems prior to commencement of ART.

The preparation of patients for treatment readiness should also include the following:

- Introduction to the treatment;
- Review social circumstances;
- Establish a treatment programme;
- Discuss the proposed adherence strategy and principles (why and how ART works, reasons for adherence, what happens to the viral load and CD4 count when on ART);
- Detail of specific medications, number of tablets and dosing instructions; and
- Expectations on the part of the clinic team of a patient on therapy.

The *National Guidelines* (South Africa, 2004) recommends a readiness assessment screening 2 - 4 weeks before starting ART, including a thorough clinical assessment, and also information and education sessions.

The researcher strongly advocates the involvement of the social worker in the pre-treatment or preparation phase. During this phase problems can be identified and addressed before they impose burdens on adherence to ART. A thorough assessment of the patient's biopsychosocial circumstances should form the basis for service delivery to HIV/AIDS patients prior to initiation of ART. The patient must be aware that adherence counselling for the patient, as well as treatment counselling, is available.

4.7.2 Phase 2: ART Commencement

Most literature confirms that, in most cases, ART is not an emergency treatment and that the patient should be fully prepared and motivated prior to commencing it. A pharmacist, with specialized knowledge of medication, should play a major role in educating patients regarding adherence issues.

Horizon (2005:36) recommends that the assessment of a patient's readiness before commencing ART should include the following:

- The patient should demonstrate an understanding of the disease and accept her/his health status;
- The patient should demonstrate an understanding of his/her treatment regimen and follow-up plan;
- The patient should appear to make a commitment toward adhering to treatment. The patient should appear to be ready to begin HAART.
- Potential barriers should have been identified and addressed to the best possible extent.

Government (South Africa, 2004) recommends the re-assessment of a patient's readiness:

- A pill count, if a 28-day supply of co-trimoxazole was supplied;
- Provision of a detailed description of the drugs;
- Discuss further information and adherence issues with the patient and his/her counsellor or advocate;
- Reinforce drug dosing details before the patient leaves the clinic;
- Ensure that instructions are clearly written on the container with a permanent marker;
- Ascertain/confirm the patient's acceptance of his/her status and ART;
- Ensure that the medical criteria are met – severe medical contra-indications (active disease that is not stabilised, including depression) should be absent; and
- Ensure understanding of the importance of adherence to and attendance at all scheduled pre-treatment visits.

The researcher argues that the assessment of the patient's biopsychosocial circumstances should be completed at the commencement or initiation of the treatment. Problems should have been identified, addressed and referred to appropriate team members. Upon the initiation of ART, the role of an experienced pharmacist and adherence counsellor, with specialized knowledge of the specific regimen, is strongly indicated.

4.7.3 Phase 3: Monitoring adherence

There is evidence that adherence decreases as time progresses. Thus, monitoring and support of adherence are essential.

Principles of monitoring

- At each visit the adherence should be monitored;
- An ART pill-returns count (note doses missed) would be ideal, but this would depend on the clinic load and capacity. The goal is >95% doses taken. Patients with adherence <80% require increased adherence support;
- Missed/late clinic visits should trigger concerns about adherence;
- Routine discussion of adherence with the counsellor (education) is recommended. This should be an open-ended discussion, with time for

questions and repetition. Feedback from therapeutic counsellors to the rest of the team is important in order to obtain a better profile of the patients and their environment;

- Continued monthly visit with therapeutic counsellors for the first three months, and quarterly thereafter; and
- Encourage participation in a support group. Patients must meet with the multi-disciplinary team for group and individual information sessions.

The researcher asserts that the continuous involvement, of the social worker throughout the treatment of HIV/AIDS patients with ART, which is lifelong, is strongly indicated. Monitoring and support of adherence is essential. New problems can be identified and addressed before they affect adherence to ART. Follow-up assessments of the patient's biopsychosocial circumstances should be carried out regularly, and an open-door approach is advisable.

4.7.4 Phase 4: Managing of low adherence

The discovery of a non-adherent patient should not come as a surprise. Management of low adherence is indicated when adherence is <80% at any visit, with or without viral or clinical failure.

A correlation between adherence and virological response to ART has been found. Fully effective adherence levels have not been defined for HAART, but as mentioned above levels below 95% have been identified with a poor response. Other data suggest that levels near 100%, if not 100%, provide the greatest benefit: thus, the better the adherence the better the virological response (Kasper, *et al.,* 2005:1853; Van Dyk, 1999: -16 & Bartlett, 2005:68). The indication is that a patient's adherence to ARV should be >95% in order to expect a 78% increase in viral load. Asking a patient to achieve 95% adherence at all times is not a small matter. Life factors, such as deaths, new relationships, financial stresses, and side effects, can result in a decrease in adherence.

According to the Guidelines of the Gauteng Provincial Government's Comprehensive Care and Treatment of HIV/AIDS and TB rollout plan for

Antiretroviral Treatment (South Africa, 2004:4), the success of ART hinges on tablet-taking behaviour. Ideal adherence means that a patient must take more than 95% of their doses (i.e. missing less than 3 doses in a month). If patients take less than 95% of their doses, they risk developing viral resistance, and ultimately, virological failure. Patients who take <80% of their doses are unlikely to have any durable virological suppression. They should be urgently targeted for an adherence improvement programme.

Some indications that would constitute low adherence and could adversely affect short or long-term adherence are:

- Missing a dosage;
- Altering a dosage (take too much or too little);
- Terminating the medical regimen;
- Self-medication with other drugs;
- Missing healthcare appointments;
- Skipping or shortening periods, between medications;
- Not following dietary requirements;
- Experiencing an alcohol or drug abuse relapse (Horizon/Population Council, 2005:7)

Around 400 B.C. Hippocrates observed that patients often do not tell the truth about whether or not they are taking prescribed medication, and cautioned his physicians to be alert to this fact. Unfortunately, more than 2000 years later, adherence is still a problem for patients and their providers. When someone's health and their survival/lives are at stake, it is difficult to understand why they will not follow their doctor's instructions, and why they do not want to play an active role in their own care.

According to the DSM IV (1994:683) the reasons for non-compliance with treatment may include discomfort resulting from treatment (e.g. side effects of the medication); the expense of the treatment; decisions based on personal value judgments, religious or cultural beliefs with regards to the advantages and

disadvantages of the proposed treatment; maladaptive personality traits or coping styles (e.g., denial of illness); or the presence of a mental disorder (e.g., Schizophrenia, Avoidant Personality Disorder). The latter category should be applicable only when the problem is sufficiently severe to warrant independent clinical attention.

As discussed in the previous chapter the, CD4 count is one of the most useful markers of the state of the immunity in a person, since its well-defined role assesses response to antiretroviral therapy. The CD 4 count in conjunction with the viral load remains the cornerstone of judgment of the progression of HIV. If the role of the CD4 count is well explained in counselling, patients tend to gain a better understanding of ARV treatment. The CD4 count is used as a reflection of the damage incurred by the immune system as well as of the restoration of the immune system in patients on ART. Thus, the level of CD4 cells in the peripheral blood is the key parameter to note in monitoring any changes within the immune response. It is reported in Bartlett, *et al*., (2005:3) that a CD4 count should increase by 50% after 8 months of treatment.

The social worker's role in the prediction and management of low adherence cannot be overestimated. A comprehensive assessment of a patient's circumstances can provide insight into problematic circumstances and the way in which these can impose on adherence, for example, alcohol abuse. The patient can be supported by the development of insight in order to understand the influence of their behaviour on adherence and, ultimately, their health.

4.7.5 Step-up adherence package for people with reduced adherence or virological failure

Patients should not feel that they are being judged for not succeeding, but rather, that adherence is being monitored in order to allow the healthcare team to advise them and offer support additional to what has been mentioned.

The researcher advocates that because of the myriad of physical and psychosocial problems associated with HIV/AIDS, adherence should be

supported by an experienced adherence team. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide adherence counselling and support. Each team member is expected to contribute his/her own knowledge and skills directed at supporting adherence to ART. (South Africa, 2004:4)

Suggested steps for management of low-adherence:

- At the outset of the treatment patients should be advised that certain behaviour is counter-productive for effective ART treatment and may jeopardize his/her prognosis. These discussions should be documented, e.g. alcohol abuse.
- Patients should be monitored and any inappropriate behaviour or changes in their circumstances should be addressed by the appropriate team members and documented.
- Patient, family and healthcare team responsibilities for participating in all aspects of healthcare management need to be clarified. Notes of this meeting should be recorded in the patient's file.
- If these measures fail to change the patient's behaviour for the better, a meeting should be held between the healthcare team and the patient. The mutual responsibilities of the clinic and the patient should be set forth at this meeting and the patient should understand that failure to uphold his/her part could result in treatment failure.
- Try to reach an accommodation with the patient so that she/he assumes greater responsibility for his/her well-being.
- If the patient has the ability to understand the need for certain restrictions, i.e. diet, alcohol and medication – and has chosen to be non-compliant, then that is his/her choice.
- If the patient fails to comply, the patient should or could be given advance notice of his/her treatment failure.
- Discharging a patient from a treatment programme should be pursued as an option only when all else has failed.

- The therapeutic counsellor/nurse, or doctor, needs to re-educate the patient (and "buddy") concerning the importance of adherence. The long-term benefits need to be re-emphasised.
- Evaluate the support structures, including the family situation; are they appropriate; how can these be improved? What alternatives are there?
- Consider the use of pill boxes and/or daily dosing diary.
- Insist on participation in a support group or link with a patient advocate.
- Consider doing a psychological profile.
- Redo the assessment for substance abuse.
- Increase home visits by therapeutic counsellors/patient advocates to a daily or weekly frequency, at a minimum (spot pill counts to be done at home). Consider directly-observed therapy for an agreed period.

The researcher emphasises that it is not easy for anyone to maintain such high levels of adherence. Many South Africans struggle to complete a 5-day course of antibiotics or 6 months of tuberculosis therapy. ART demands twice-daily medication, every day, including weekends, and for life. No clinic system possesses the capacity to take responsibility for monitoring every dose taken. The social worker should incorporate the abovementioned strategies in her counselling and other delivery of services to HIV/AIDS patients on ART.

4.8 Special groups with regards to adherence

The researcher argues that, in adherence issues, the different stages of psychological development, as discussed by Louw, Van Ede, & Louw (2005:149), as well as other life-influencing matters, should be taken into account. For example, to assess adherence issues in a child will hold a different dimension to those of an adult. Discussion of adherence issues with a mentally disabled person will take on yet another dimension.

The said researcher would like to propose the following groups in adherence:

- **Neonatal (0-28 days); Infancy (28 days-2 years); Childhood (2 years-12 years)**

In working with children, adherence issues can only be discussed with the primary caregiver, parents or guardians. Hanging over the process of adherence for any HIV positive child, is the potential or actual death of one or both parents, other family members or of the children themselves. This reality influences the child's perception of life, both in its possibilities and vulnerabilities.

The same antiretroviral drugs are used with children as with adults, except that the dosages are smaller and adjusted according to the age and weight of the child. Children who use ART exhibit normal growth and development. Physical functioning can be improved, complicated infections can be prevented, and the child's life can be prolonged and restored, together with the child's quality of life (Van Dyk, 1993).

- **Adolescents (12 years-20 years)**

  In discussing adherence with adolescents, the focus will be different from that of children and adults, since different issues will be taken into account. Adolescence teenage development brings with it its own complications. As adolescents struggle to achieve independence, some find medication adherence, or the lack thereof, an obvious way to assert their autonomy.

  Adolescents and young adults do have many unresolved issues and such matters should be discussed with the greatest of support. The adolescent can be motivated to take responsibility for their own lives.

- **Adults (21 years-60 years); Elderly (60 +)**

  In these groups, adherence issues can be discussed, taking into account the biopsychosocial functioning of the individual. Children often support their parents in adherence issues.

- **Couples**

  In couple counselling, confidentiality should always be ensured first. Also, matters such as disclosure, the client's readiness for disclosure, domestic

violence, and gender-related issues, should be taken into consideration in such counselling.

The researcher associates herself with Saloner's (2004:88) view, that couple counselling or couple therapy is a much more complex intervention and should be referred to somebody sufficiently skilled to carry it out.

- **Pregnant women**

  With regards to pregnant women, adherence should focus on prevention of mother-to-child (PMTCT). If possible, and if the issue of confidentiality allows for it, the prospective father should be included in adherence counselling

- **Mentally and physically disabled or terminally ill people**

  As with children, adherence issues should be discussed with the primary caregiver. The mentally, and/or physically disabled person often demonstrates no insight into the treatment programme and are not able to take care of themselves and would thus not be able to adhere without support.

- **Substance abusers**

  Groups with special needs include drug users and alcoholics. Dependency issues should be considered and resolved on an individual basis, as it could affect adherence. Networking and referral to the appropriate team member and or institution is advised.

The said researcher emphasises that adherence is an individual matter, so that all circumstances and factors including the patient's life–stage, and other life-influencing matters, should be taken into account when assessing patients for adherence to ART.

4.9 Factors Influencing Adherence to Art

The researcher firmly believes that without a thorough assessment of the patient's biopsychosocial circumstances, adherence issues cannot be

addressed. Single interventions, to support adherence without taking into account all the enablers and barriers of adherence, will prove to be unsuccessful. In addition to assessing individual circumstances, factors with respect to the provider and the regimen, need to be assessed.

The assessment of a person's total functioning will always be arbitrary, with a degree of overlap between factors, because human interaction is so complex. Green and Shellenberger (1991:19) postulate that the biopsychosocial approach to health and wellness is the result of the interaction of biological, psychological and social factors. Identifying and predicting adherence has become a significant challenge for health care professionals.

The said researcher shares the view of British HIV Association (BHIVA, 2003:3) that low adherence is not restricted to certain social classes, but is widespread and unpredictable. Adherence rates vary over time, not just between individuals, but with the same individual. Adherence is considered to be a variable behaviour, rather than a stable characteristic of an individual.

Horizon/Population (2005:8) also distinguishes between disease characteristics, treatment regimens, patient variables, clinical settings and patient-provider relations. The myriad of factors which may contribute and influence an individual's adherence to ART can be divided into 3 main categories: patient, provider, and regimen factors, which will be discussed by the author hereafter.

4.9.1 Patient Factors

Adherence support must be provided to all patients on the premise that any individual is capable of adherence. Low adherence is widespread and predictions concerning adherence cannot be made on the basis of socio-demographic characteristics. To withhold treatment solely on the grounds of assumptions with regards to an individual's personal circumstances, cannot be justified (British HIV Association (BHIVA, 2003:3).

The researcher supports the opinion of Venter (2005:23) that the individual circumstances of patients must always be taken into account where adherence issues are concerned. Wellness programmes usually call for an improved diet, the cessation of smoking, moderating alcohol, the practice of safer sex, exercise and participation in support groups, as well as the routine clinic visits, and disclosure. There have been reports that people have been denied access to ARV's because they have not fulfilled one or all of the above criteria, each one notoriously difficult to implement among the general population.

The biopsychosocial factors, that could influence adherence, mentioned below, will be discussed in more detail in the following chapter.

4.9.1.1 Physiological / biological factors influencing ART

Kaplan, *et al.*, (1994:1) postulate that the biological system emphasises the anatomical, structural and molecular substrate of disease and its effects on the patient's biological functioning. As a result the researcher believes that the physical wellness or performance status of respondents will influence adherence.

The Karnofsky's Scale, which is widely accepted as a measuring tool for performance, can be utilized in an attempt to try and measure the more subjective side of a patient's functioning. The scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage:
http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

4.9.1.2 Socio, cultural and socio-economic/interactional issues and characteristics

Predictors based on socio-demographic characteristics, for example, gender, race, age and education level, produced inconsistent results. The desire to link low adherence to deprived social groups is a well-established tendency. Low adherence is not restricted to certain social classes but is widespread and unpredictable (British HIV Association (BHIVA, 2003:3).

Cockerham (2001:54) holds the view that the time is rapidly approaching when racial/ethnical HIV/AIDS differences will no longer be based primarily on comparisons between whites and blacks. Living conditions associated with poverty however influence the onset and cause of a variety of health problems. Socio-economic status and, particularly, poverty, knowledge, education, literacy and access to medical treatment, are consequently important in adherence issues. The researcher corroborates this perspective and is further of the opinion that the language of educational and adherence material should take literacy levels into account.

4.9.1.3 Psychological matters influencing adherence to ART

According to Kaplan, *et al.*, (1994:1), the psychological dimension of the biopsychosocial model emphasises the effects of psychodynamic factors in order to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated towards obtaining help.

The involvement and education of family members, as well as community interventions, such as adherence groups, may be of assistance. Supportive and non-judgmental attitudes of the providers will encourage patients to be honest with regards to their adherence and the problems they may experience. It is vital that the patient commits to adherence to the treatment plan and understands that this is a chronic disease.

4.9.2 Provider Factors Influencing Art

Responsibility for successful, long-term viral suppression must lie with the individual who is on therapy, but it is equally vital that selection criteria for ARV therapy be set up and communicated to providers and the public. A trusting relationship between the patient and care providers is essential, as noted earlier.

Because monitoring and supporting adherence is essential, the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November* (South Africa, 2003:4), has

acknowledged the need for psychosocial support for patients and makes provision for social workers, dieticians, lay counsellors and a support structure.

4.9.2.1 Multidisciplinary Team Members Involved in Rendering Services to the HIV/AIDS Patient on ARV

"A multi-disciplinary health team can be defined as a team whose members represent the widest possible spectrum of individuals and organisations concerned with, or involved in, any aspect that has a bearing on the health and welfare of the community, in an attempt to provide effective, comprehensive health care that will assist in the achievement of optimal health for all people." Dennil *et al.*, (1995:111).

Adherence is a team effort: the cooperative effort between an active and engaged patient, a communicative and responsive team, strong support from family and friends, and a free flow of communication between all Significant persons, both in the social and professional setting must support adherence behaviour because of the myriad of physical and psychosocial problems associated with HIV/AIDS. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide counselling support.

Each profession is expected to contribute its own knowledge and skills directly to the decision-making process. Information is assessed according to its applicability to the needs of the patients, rather than on the basis of professional hierarchy.

According to Nason (1990:310), successful teamwork is the "allowance for the independence and equality of the contributing professions and its pressure for a consensus about group goals and priorities." According to Davidson and Clarke (1990:273), collaboration and co-operation have to be the major characteristics of the multi-disciplinary health team for it to meet the needs of the patients.

There must be a clear role-identity, which will enable each team member to perform his/her role. Even though there could be an overlap of roles amongst the team members, collaboration could facilitate the team's efforts in order to provide a comprehensive service. This also applies to ART matters, where all the team members are required to work together for the benefit of the patients. No team member must be perceived as being more important than the others.

For all healthcare team members, specific training regarding ART and adherence should be offered and updated periodically. In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide counselling support. The counselling services should be monitored and supervised by a professional like a qualified and experienced social worker. Supportive and non-judgmental attitudes and behaviours will encourage patient honesty regarding adherence and their problems.

The multi-disciplinary team should meet and assess patient readiness. They should take all the available information into account. The support of the physician is crucial and very significant, since the treatment plan cannot succeed unless the physician is consistent. Inconsistencies create conflicting messages for the patient and staff. It is important for the entire staff/team to meet with the physician, in order to discuss their concerns and to determine the level of support that they will receive in managing the patient, since the staff needs to feel safe when setting limits with non-compliant patients.

The multi-disciplinary team, concerning adherence matters, is defined by the present researcher as a group of people, professional or non-professional, each with his/her own specialist knowledge, working together to enable optimal social functioning of patients, the family and the community, with the ultimate goal of adherence to ARV and successful treatment. The researcher is of the opinion that the ARV adherence team should commit itself to the following:

- An individualized treatment plan must be developed for each patient. ARV staff should act consistently with the treatment plan;

- The health team must commit to a feasible mechanism for communication between visits and to timely and appropriate responses to adverse reactions;
- There is evidence that adherence may wane over time, even in highly adherent patients; ongoing support and monitoring are therefore important. If there is sub-optimal adherence, there should be extra support;
- Provide education and advice. Specific training regarding ART and adherence should be offered;
- Improve/develop problem-solving and life-skills of patients;
- It is essential to ensure that the health team receives adequate training on ARTs and that this training be updated regularly for all healthcare team members;
- As a process, (ongoing) assessment involves gathering, organising, and making judgments regarding information. As a product, assessment is a verbal or written statement concerning the functioning of the group (client) and its members, which is useful in the development of intervention plans;
- A trusting relationship between the patient and members of the healthcare team is essential. Initiating and supporting patients on ART should be an intensive process, yet one that should provide one with the satisfaction of treatment success.

Due to the acute needs of the patients, the needs of the staff taking care of them are often overlooked. For persons involved in the care of patients with HIV and AIDS, both paid as well as volunteers, burnout is a common issue due to the tremendous emotional and psychological stress that accompanies work where recurrent illness, hardship and death is a constant aspect to which people are exposed. Furthermore, many staff members are themselves infected and affected by HIV and AIDS, which makes their involvement very challenging.

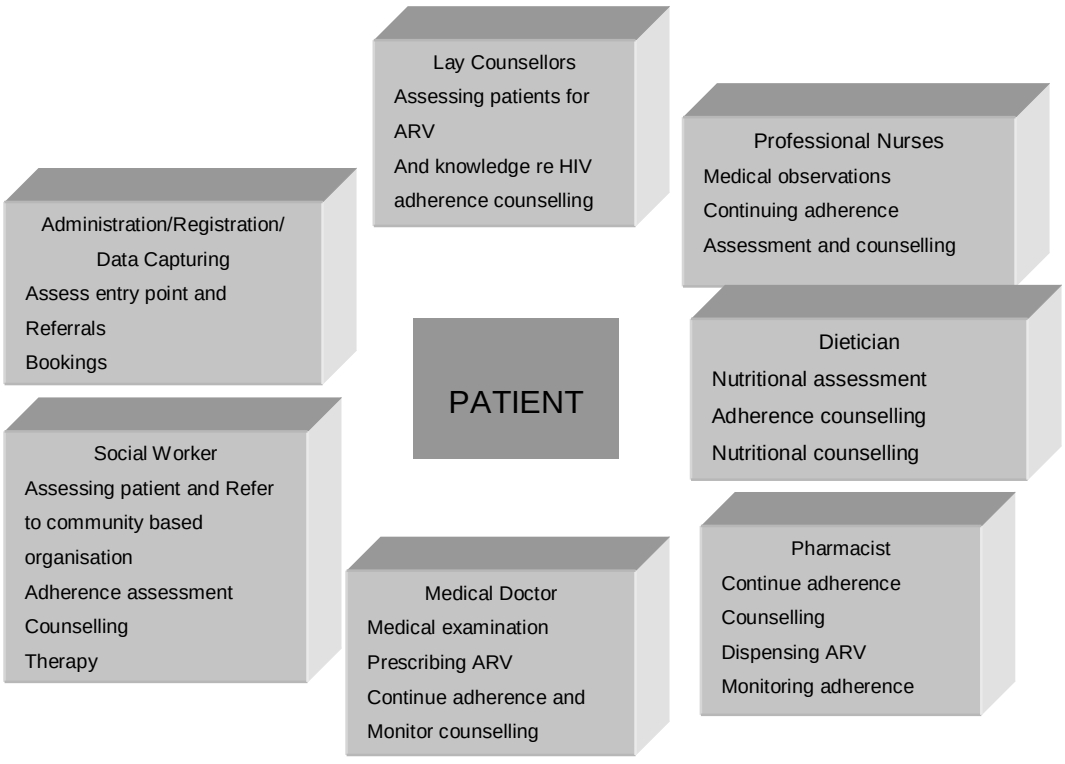
The provision of time and structured programmes for debriefing and grief management for staff members is recommended. Given the constraints on time resources, and the availability of trained psychologists, social workers can play an important role in supporting co-workers and team members. The

development of staff support-programmes will assist healthcare facilities to attract and retain personnel and will offer benefits that stretch far beyond the HIV and AIDS care and treatment programme. Motivated and talented persons who have committed their lives to caring for persons living with HIV and AIDS are essential and precious commodities. Therefore, team members should be supported, continuously trained and educated since HIV/AIDS is a dynamic illness with new research and reports reaching us via the media daily.

Each facility and HIV healthcare team must develop strategies and programmes that meet the individual needs of their site and team members. Working in the field of ART is challenging, provides hope, and motivates patients in an otherwise dark situation.

The team approach, with its different perspectives, emphasises and demonstrates the value of each member, particularly the contribution of the social worker as a mediator and facilitator. The present researcher will summarize the role of each team member as far as adherence is concerned.

Figure 3: Adherence team members



4.9.2.2 Administration staff

The administration staff plays an important role in ARV matters, and are usually the first team members to meet the patient. They receive referrals, do the bookings and are responsible for data capturing. They should:

- Be aware of confidentiality;
- Be aware of procedure, regarding ARV referrals, protocols and guidelines;
- Maintain an open door policy between the administrative staff and the rest of the multidisciplinary team; and
- Take responsibility for keeping records, filing and statistics. (South Africa, 2003).

4.9.2.3 Counsellors

In this study, counsellors refers to lay counsellors. The *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November* 2003 (South Africa, 2003:4), specifically makes provision for lay or voluntary counsellors and social workers to address the psychosocial needs of patients.

A strong emphasis is placed on counselling in the realm of HIV/AIDS. Terms like VCT, PMTCT, pre-test, post-test, and adherence counselling, are now well known in terms of HIV/AIDS matters. The Department of Health (South Africa, 2003) makes special provision for counselling and lay counsellors, but the researcher is of the opinion that counsellors should not be labelled and fragmented into adherence counsellors or VCT counsellors. The counsellors working at ART sites are voluntary, lay counsellors, specifically trained in HIV/AIDS/ART matters, who should be able to render a holistic and comprehensive service with regards to the assessment of patients.

Counselling is a procedure used by the helping professionals to guide individuals, families, groups and communities towards the development of insight, with the aim of improving the social functioning of the client. As suggested, counsellors need not be formal healthcare providers or

professionals, but can include teachers, health educators, religious and community leaders, youth group workers; and members of self-help groups and can also provide supportive counselling.

There is often confusion and role-blurring between the social workers and the lay counsellors at the ARV clinics. The researcher has found from her experience, that social workers need more recognition and have a need to fullfil more of a managing role in training, monitoring and supervision of these lay counsellors. The lay counsellors often see themselves as being on the same level of the social worker and expect the same recognition. No provision was made for the Psychologist in the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November* 2003 (South Africa, 2003:4) and they are very seldom part of the team at an ARV clinic in South Africa.

Although the Department of Health places a high priority on counselling, the encounters of the present researcher have revealed that there are no general or minimum standards for lay counselling services, nor any formal monitoring, training and support for counsellors. The said researcher feels strongly that people in such a position of responsibility regarding the most intimate circumstances of patients, should adhere to common standards. The recruitment of lay counsellors, and the motivations for their involvement, specifically in HIV/AIDS matters, should be explored. There is no register for either counsellors or support groups where credibility and motivation can be evaluated. The standardization of counselling services could increase confidence in counselling in general and demonstrate to patients and the general public a commitment to high standards and abilities. The public service should start turning the abovementioned situation around by being both a guardian of standards and supporter of the committed support structure. The said researcher concurs with Baran, Byrne & Branscombe (2002:88) that self-interest, often equated with egoism (an exclusive concern with one's own personal needs and welfare rather than with those of others), features strongly in counselling. The researcher has through her experience at the ART clinics, found that inexperienced and unsuitable lay counsellors are often employed by

the Department of Health. These counsellors are often HIV positive, unemployed; in need of the stipend they receive for their services. Unfortunately nepotism features strongly in the appointment of such counsellors by the Department of Health. This is also the experience of most social workers at other ART sites.

Counsellors in general, including both lay and professional counsellors, should be skilled and trained to conduct thorough assessments of clients.

- Conduct an assessment of the patient's circumstances;
- Improve the patient's knowledge concerning HIV/AIDS as a disease and also antiretroviral therapy, including side effects;
- Provide patients with information regarding treatment, including expectations;
- Integrating the treatment regimen into the patient's daily routine, encourage family involvement and provide reminder cues;
- Support and monitor adherence;
- Help the patients to set goals and to develop a positive attitude, beliefs, perception, self-efficacy and commitment;
- Facilitate a support system regarding disclosure;
- Identify and address barriers; and
- Receive regular training regarding HIV/AIDS, ART and adherence matters.

4.9.2.4 Dietician

The government seeks to implement a Comprehensive Nutritional Programme for HIV/AIDS patients, together with the implementation of the nutrition supplementation intervention programme, in addition to the existing nutrition programmes, which includes the National Emergency Food Programme and the Nutrition Supplementation Intervention for TB and HIV (South African, 2004).

The tasks of the dietician in adherence matters are:

- Assessment of the nutritional status of each patient;

- To support the introduction and use of anthropometric measurements in the assessment of patients;
- To ensure nutritional risk screening;
- To implement nutritional care plans for individuals/groups of patients in order to contribute to the patient's general health and adherence;
- Continuous nutritional evaluation of each patient on a monthly basis;
- Nutritional education on healthy balanced eating habits and hygienic food practices;
- Comprehensive nutritional counselling services;
- Identification and treatment of HIV-related food interactions;
- Referring the patient to the relevant multi-disciplinary member for further treatment;
- Assessing the use of herbal medicine, traditional medicine and vitamins by patients;
- To liaise with members of the multi-disciplinary team to ensure that the nutritional needs of patients are met (Tshwane District Hospital. ART Guidelines, 2005).

4.9.2.5 Physician

The physician assumes overall responsibility for, and control over, the patient's treatment. She or he takes the patient's history, noting any features that may prove of value at the examination, assessment and treatment stages.

The physician's role is very significant, since the treatment plan cannot succeed unless s/he is consistent in diagnosing and treating. The physician, while working closely with the other healthcare team members, is in charge of ensuring that the patient is considered in totality: that readiness, nutritional, mental and social states are firmly established in order to determine the optimum course of action available.

The above forms part of all the responsibilities of the doctor in charge of all clinical aspects of the patient's care, treatment and management. Specific tasks of the physician are:

- Examine the patient, while adopting the integrated approach;
- Administer ARVs, making whatever adaptations that the specific situation and circumstances of each patient demands;
- Request clinical tests;
- Diagnose symptoms. Deals with any medical problems and opportunistic infections;
- Monitor the patient's response to treatment; deals with drug side-effects, and immune reconstitution, being guided by such responses in working out an appropriate modification or change;
- Prepare the patient in a case of treatment failure and possible palliative care;
- Perform an educational role such as restating the role of adherence to ART;
- Refer patients to other health specialists, such as psychiatrists, psychologists, mental health nurses, phlebotomist, in order to perform clinical tests and also palliative support to one or more members of the multi-disciplinary healthcare team.

It is important for the entire staff/team to meet with the physician to discuss their concerns. The AIDS epidemic has shown, more than any other illness that the physician is not the "Messiah" with all the answers, and that multidisciplinary team members should address the psychosocial dimensions of a patient's life. The doctor has to give the patient hope at all times, over and above the counselling provided by other healthcare team members (Tshwane District Hospital, ART Clinic protocol, 2005).

4.9.2.6 Pharmacist

The pharmacists should take responsibility, not only for assisting the patient regarding pill-taking, but also adherence. Patients should be encouraged always to mention their problems to the ARV pharmacist. Pill-taking can be a problem, depending on their size, shape and texture, and the pharmacist should play an active role in counselling patients. The specific roles of the ARV pharmacist are to:

- Ensure that the pharmacy facility is safe and adequate and meets the necessary requirements;
- Ensure proper control over the procurement, storage, prescribing, issuing, dispensing and record-keeping procedures;
- Dispense and counsel in private to ensure patient confidentiality;
- Clearly label dispensed medication;
- Counsel in detail patients whose treatment has been initiated with regards to all aspects of ARV medication such as medication storage, usage, reconstitution, drug interactions, side effects, adherence issues and the use of a diary card;
- Reinforce adherence at every visit, to all the above aspects of medication.

The researcher is of the opinion that the pharmacist bears a heavy responsibility with regards to educating the general public, concerning the importance and responsibility of not only adherence, but all pill-taking regimens, especially with respect to chronic disease. The community should be educated by means of mass campaigns concerning adherence, in general, and the importance of treatment. Furthermore, information leaflets should accompany medication instructions for patients, regarding side-effects and contra-indications of ART.

4.9.2.7 Professional nurse

HIV/AIDS has also dramatically shifted the emphasis of the role of the nursing professional, as stated by Van Dyk (1992:63): “AIDS forces the nursing profession to re-examine its role in health care and to shift its emphasis from curing to caring.” The researcher would like to add to this that the nursing profession has now also, shifted the emphasis of their role from caring to counselling and managing HIV/AIDS patients. More and more nursing professional's play the role of counsellors and/or manage HIV/AIDS programmes. The professional nurse in ART matters is responsible for:

- Monitoring the overall health status of patients;
- Assisting the physician with the examination of the patient;

- Noting and monitoring treatment failure or non-response;
- Observations, blood tests and pathology;
- Monitoring of therapy, including side effects, adverse events and psychosocial problems. Informing the physician of problem areas;
- Monitoring and adherence-related follow-up and data collection;
- Adherence counselling for patients. Continuation of adherence counselling, working in close collaboration with other team members, especially the physician;
- General management of the patient, once inducted into the programme;
- Prophylaxis therapy;
- Referral and liaising with the different specialities involved in case management, for example TB services, other specialists, home-based care; and
- Working in close cooperation with other disciplines or members of the multi-disciplinary team.

4.9.2.8 Social worker

For the purpose of this section, the social worker as team member will be briefly discussed. A detailed discussion of the social worker follows in chapter 5.

The social worker operates within the scope of the multi-disciplinary team, where all the members of the team are concerned with providing the patient with a comprehensive service. The major function of the social worker in this context is to improve the quality of life of the patient and his/her social functioning by supporting adherence.

The government recognizes the social work profession as part of the multidisciplinary team, which renders services to HIV/AIDS patients referred for ART. The intervention of social workers in an ART setting demands experience and knowledge regarding HIV/AIDS, ART, and a high level of outcome evaluation skills.

The social worker must understand the interaction between the individual, social and medical systems. Knowledge of the biopsychosocial model would be an advantage in service-rendering within a health setting. The social worker, as a facilitator, must also be prepared to contribute to the development of clinical pathways in order to enhance treatment outcomes. The specific roles of the social worker regarding ART matters in a healthcare setting will be discussed in more detail in the next chapter. The specific roles of the social worker in an ART setting, as experienced by the present researcher, are:

- Being able to conduct a thorough biopsychosocial assessment of patients;
- Motivating patients and developing their insight in preparation for treatment, thereby ensuring adherence;
- Providing continuous supportive counselling throughout the treatment period;
- The social worker's role regarding counselling is further indicated as being an advocate for the patient's rights, educator and supervisor of standards in counselling.
- Knowledge of the applicable community resources, and knowing when it is appropriate to refer a patient;
- Possessing efficient therapeutic skills, e.g. in crisis intervention, skills in short-term and bereavement counselling;
- Possessing respect for the rights of patients, their, confidentiality and stigmatisation;
- Possessing adequate skills to implement the social work methods and techniques, e.g. casework, group and community work;
- Functioning in an inter-disciplinary team or the ability to collaborate and be assertive;
- Educating other professionals, students, and patients, as well as the community, regarding the roles and tasks of the medical social worker, the psychosocial effects of HIV/AIDS treatment on the patient and his/her family; and
- Innovating, facilitating, organizing and co-coordinating services.

4.9.3 Other community support

As the HIV/AIDS epidemic escalates, healthcare needs and the means of satisfying the needs of people infected and affected by it also increase. New dimensions of care and support evolve, and bring with them new members to be included in the multidisciplinary team in the provision of holistic care and support to HIV/AIDS

The researcher considers that a wide variety of non-professional and indirect service providers should be, and are currently, involved in HIV/AIDS matters, other than the involvement of the professional health team directly involved, as discussed. A tight network of community organisations involved in service-delivery to people infected or affected by HIV, including people living with HIV, the faith sector, employers, hospices, home based care organizations, support groups, traditional healers, various government departments, non-government organizations (NGOs), education institutions, and all relevant partners should be fully informed and trained about ARV support.

- **Faith-based organisations**

  Religious and spiritual counselling is important, since many people are members of some religious or spiritual denomination. The role of faith-based organisations should be to motivate and support people regarding treatment, promote stable relationships and emphasise norms and values in general. Faith has always been supportive in illness, but certain faith-based organizations who promote faith healing, praying, holy water and other means of healing, could jeopardize and confuse patients and create barriers to adherence to ART (Viljoen, 2005:23).

- **Traditional healers**

  Anecdotal and early scientific evidence warns of significant interactions between traditional and Western medicine. Alternative healing methods and the influence of culture and beliefs should not be underestimated. Traditional healers are encouraged by the government to become involved

at all levels, which have proven to be relatively successful (Viljoen, 2005:430).

Health-seeking behaviours are largely affected by cultural norms and personal belief systems. A large percentage of patients, specifically in S.A. with its diverse cultures, have deeply rooted traditions with regards to maintenance of health and treatment of illness and utilise traditional health practitioners or indigenous medicines, as their first point of contact for healthcare. Traditional health practitioners are more accessible and hold positions of authority within the community and thus their advice is widely respected.

The researcher is of the opinion that as a well-established and accepted form of healthcare in South Africa, it is essential that traditional medicine and its practitioners be recognized, respected, and engaged in co-ordinating care for HIV-positive patients that wish to utilize both disciplines. Traditional practitioners could play an important role in raising public awareness and promoting acceptance of VCT as well as adherence to TB and antiretroviral therapy. Rossouw (2006:18) postulates that traditional healers and traditional medicine has become one of the most complex issues when dealing with ART. The WHO (2005) estimates that 80% of African populations consult traditional healers.

- **Networking with community organizations (NGOS)**

  The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003 (South Africa, 2003:4) has acknowledged the need for psychosocial support of patients and makes provision for social workers, dieticians, lay counsellors and other support systems as well as the involvement of NGOs at each ART site.

  Community support should be provided to patients in a confidential and nurturing environment. When referring patients to community organizations (NGOs) it is essential to make use of community resources where credibility

and confidentiality can be guaranteed. HIV/AIDS is a sensitive and traumatic experience for patients who fear discrimination. Issues regarding HIV/AIDS always carry a sexual connotation, which is a sensitive issue in all cultures. Patients perceive their status as confidential and do not want to share it with strangers or the general community.

- **Education and training**

  The involvement and education of family members, as well as community interventions, such as adherence groups, is essential in supporting the patient regarding adherence. There is rarely a need to rush the commencement of ART and patients should be educated about adherence. The Government's Rollout Plan for Antiretroviral Treatment (South Africa, 2003:4) does make provision for such education.

A study undertaken by O'Brien (1990:212) on dialysis patients shows that people tend to cope with health and illness-related problems according to the knowledge they possess. Friedland (2003:370) claims that, in the USA, studies have found that low literacy levels are associated with poorer adherence. The current researcher however holds that illiteracy should not be an excluding factor in assessing patients for adherence to ART, but that education and knowledge regarding HIV/AIDS and ART should rather receive priority because they constitute a means of developing insight, and may contribute to the improvement of motivation and adherence to ART.

The said researcher believes that education regarding adherence to ART at all educational levels is important. A culture of health education and awareness is needed for the successful implementation of ART. The service provider's role in the successful implementation and adherence to ART cannot be overemphasized.

4.9.4 Regimen Factors Influencing Adherence to ART

Regimen factors influencing adherence issues were considered in the previous chapter. Antiretroviral drugs, like most chronic medication, are not without

negative aspects. Regimen complexity is an important contributor to poor adherence.

The treatment regimen, pill burden, drug interactions, drug toxicity, adverse events, co-commitant illnesses, side-effects and contra-indications influence adherence. Heyer and Ogunbanjo (2006:5-9) postulate that good adherence is associated with low pill-burden. Optimum treatment regimens selected by patients include: two, or less, pills per day, no dietary restrictions, small pills, and all drugs combined into one pill, and once-a-day dosing.

Adverse drug events are constantly reported and linked with poor adherence. Multiple drugs are often prescribed for HIV infected patients for: prophylaxis of opportunistic infections, as antiretroviral medication, side-effects of medications, and treatment of concomitant illnesses, both acute and chronic. Patients may seek medical care from more than one practitioner or healthcare facility. Patients also make use of over-the-counter and traditional or herbal remedies, as well as illicit and recreational drugs. As access to ART expands in South Africa, the potential for drug interactions with ARV drugs, becomes increasingly important (Cohen, Andrews & Maartens, 2002:42). Scheduling demands, including clinic visits, work difficulty, fitting medication and clinic visits into a daily routine, are consistently associated with decreased adherence.The researcher wishes to summarize by reiterating that the myriad factors that contribute to, and influence adherence to ART, discussed above, according to the three main categories, patient, provider and regimen factors, make ART and adherence to it a very complex issue for people infected and affected by HIV/AIDS including the multidisciplinary team involved in service rendering.

4.10 Summary

The aim of this study is to explore the biopsychosocial circumstances related to adherence that should be assessed when screening patients for ART, describe the factors influencing adherence to ART, and formulate guidelines to support ARV adherence screening that are practical, relevant and appropriate in the African context. In this chapter the present researcher explored adherence to

ARV treatment, in order to obtain the desired benefit and to avoid the emergence of drug resistance and clinical failure. Adherence calls for meticulous adherence to medical regimens, and continual support between health providers and patient.

Matters that were discussed are: resistance; adherence; predicting of adherence; special adherence groups; patient, providers and regimen matters influencing ART; with a specific focus on the adherence team. Support during the different adherence phases and strategies to support adherence, such as medication alerts and measuring adherence, were also discussed.

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

In the next chapter, the researcher will explore the biopsychosocial factors influencing the adherence of HIV/AIDS patients to ART. Factors that will be discussed include the three dimensions of health and illness, namely, biological, psychological and social. The role of the social worker in utilizing the biopsychosocial model in assessing HIV/AIDS patients for ARV therapy will also be considered. A guideline for utilizing the biopsychosocial model in assessing the HIV patients for adherence to ART will be proposed.