



**THE PSYCHOLOGICAL CONSEQUENCES OF HIV AND AIDS AND EFFECTS OF ART THERAPY ON HIV AND AIDS POSITIVE PATIENTS UNDERGOING ART THERAPY.**

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**Abstract:** The purpose of the study was to identify situations contributing to the escalating of psychological sufferings experienced by HIV and AIDS positive patients on ART therapy. The HIV and AIDS positive patients who are on ART do suffer some psychological difficulties. According to the results, the HIV and AIDS positive patients on ART; do developmental alteration, memory loss, stress, depression, suicidal thoughts and others, eventually committing suicide. The psychological consequences and effects of ART therapy, most often cause patients default treatment and subsequently developing opportunistic infections. The objectives of the study were to identify issues of stigmatization and discrimination; to reveal whether the patients do suffer from depression; ascertain the amount of stress that they experience; identify the level of knowledge and understanding that health professionals and the patients have on ART therapy; to determine whether the patients do experience suicidal thoughts; to identify whether they do experience mental alteration. In conclusion, it is evident from the study that psychological impacts of HIV and AIDS and antiretroviral related therapy if not well addressed contributes immensely to issues of suicide, depression and stress as well as mental alteration.

**Key Words:** Psychological consequences, HIV and AIDS, Effects of antiretroviral

**Back Ground Information:** The Kingdom of Swaziland is a landlocked country sharing borders with Maputo (Mozambique) in the east,

Kwa-Zulu Natal Province (Republic of South Africa) in the South and Mpumalanga Province (Republic of South Africa) in the North and West. The country has a population of 1 018 449 and is evenly distributed across the country, Swaziland Census Report (2007)<sup>1</sup>. The age group 15 to 49 constitutes half of the total population (50.1%) with more females (51.1%) than males (49.3%). Life expectancy has decline from 60 in 1997 to current 43.13 years.

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**Health Status of The Population:** Swaziland currently has the highest HIV prevalence in the world, with an estimated HIV prevalence rate of 26% in age group 15-49 years (SDHS, 2007)<sup>2</sup>. The HIV prevalence among pregnant women has increased from 3.9% in 1992 to 41% in 2010. The crude death rate per 1,000 population increased from 13 in 1990 to 26.2 in 2005 (World Bank, 2006)<sup>3</sup>, while infant mortality rate has increased from 94.4 per 1,000 births in 1990 to 108 in 2005. The HIV epidemic has resulted in an upsurge of Tuberculosis (TB), with incidence increasing from 300 per 100,000 in 1990 to over 1,000 per 100,000 population in 2003 (SDHS 2007)<sup>2</sup>. It was estimated that in 2010 the number of adults living with HIV would be 177,196. Using the eligibility criteria of CD4 cell count 350, about 77,156 are in need of ART and projected that by 2015, 97,108 people will be in need of ART out of the 198,668 of adults who will be living with HIV/AIDS (UNAIDS, 2010)<sup>4</sup>. By the end of September 2010, 55,296 (64.1%) people were actively on treatment comprising of 49,907 adults and 5,389 children (MOH 3RD Quarter M&E Report, 2010)<sup>5</sup>.

A number of abnormalities documented in people infected with HIV and such abnormalities include among other things psychiatric and/or psychological difficulties in the likes of mental alteration or memory loss. This was eluded by Joseph & Bhatt (2008)<sup>6</sup> which stated that a central nervous system involvement which results to depression, stress or mental alteration may be a consequence of HIV. Hence, the researcher in this study sought to explore and describe psychological difficulties and effects of ART therapy experienced by HIV and AIDS positive individuals undergoing ART therapy in Swaziland.

**Problem Statement:** There is a serious problem regarding the holistic nursing intervention for HIV and AIDS positive individuals who are also undergoing ART therapy in Swaziland. It looks like credibility

and effectiveness of the ART therapy is jeopardized by the services offered by the health professionals more especially nurses. In as much as it is known and assumed that for the effectiveness of any therapy in HIV and AIDS, like-wise the ART therapy, a holistic approach has to be followed, a thing that is not usually done. In most cases, much attention is often given to the physical aspect of personality of the HIV and AIDS positive individuals with little attention paid to psychological consequences emanating from the five aspects of personality namely the physical, mental/cognitive, emotional, psychosocial and spiritual, due to the dreadful impacts of the disease and the effects of the ART therapy. The HIV and AIDS positive patients and on ART, end up developing conditions like stress, depression, suicidal thoughts and with others eventually committing suicide. Some of the patients end up defaulting treatment and subsequently developing opportunistic infections that most often complicate the HIV and AIDS condition.

**Objectives of the Study:** The broad objective was to explore and describe psychological consequences of HIV and AIDS positive patients who are also on ART therapy. The first specific objective was to identify issues of stigmatization and discrimination of HIV and AIDS positive patients and on ART. The second objective was to reveal whether HIV and AIDS positive patients and on ART do suffer from depression due to HIV and AIDS and the ART Therapy. The third objective was to ascertain the amount of stress and mental alteration that come along with HIV and AIDS condition and the ART therapy. The fourth objective was to reveal the level of knowledge and understanding that health professionals and HIV and AIDS patients had on ART related therapy. The fifth objective was to determine whether HIV and AIDS positive patients who are on ART therapy do experience suicidal thoughts associated with HIV and AIDS and the use of ART therapy.

**Justification:** The identification of the psychological consequences of HIV and AIDS positive patients who are also on ART therapy will help the HIV and AIDS positive patients to understand issues leading to psychological sufferings and the ill-effects that come along with the ART therapy. The understanding of the various psychological suffering will help the HIV and AIDS positive patients who are on ART therapy to reach out for help in time for the purpose of preventing unnecessary complications of the disease and also to avoid patients relapse due to the psychological sufferings. The study will also help the HIV and AIDS positive patients towards accepting their HIV status, attaining a positive openness, having interactive attitudes with other non-infected people, and thus reducing the stigma attached on the condition. This should also acquaint HIV positive patients on HIV and AIDS, and ART therapy with issues and complications of the disease, consequently reducing stress and depression among the HIV and AIDS positive population and further reducing cases of treatment noncompliance that could result to therapy failure. In addition, government will benefit in the sense that the HIV positive patients will be able to comprehensively manage themselves the psychological sufferings consequently minimizing the government expenditure on the psychological sufferings emanating from the disease. The study will also act as a point of reference document for health professionals on how best they can strengthen the ART therapy and awareness on HIV and AIDS campaigns as far as offering of holistic caring of HIV and AIDS positive patients and also on ART therapy.

#### **Literature Review**

**HIV, AIDS and Depression:** The progression of human immunodeficiency virus (HIV) infection from exposure to active acquired immunodeficiency syndrome (AIDS) involves a complex interplay between medical stages and psychosocial factors (Janssen, 2005)<sup>7</sup>. Common

initial reactions to the diagnosis of HIV infection are shock, denial, and anger (Schweitzer, Mizwa, and Ross, 2010)<sup>8</sup>. Schweitzer, et al (2010)<sup>8</sup>, further states that depression can occur soon after diagnosis and often worsens with the onset of disease symptoms. According to the researcher, it can be concluded from the latter observations that, “relative risk of persons with AIDS committing suicide could be many times greater than that of the general population”. Both patients and their families often experience feelings of acute suffering and prolonged grieving throughout the illness, (Schweitzer, et al, 2010)<sup>8</sup>.

A model of the interrelationship between the medical stages and common psychosocial issues during HIV progression need to be applied for the purpose of assisting family physicians and other health care providers to realize when counseling their patients (Janssen, 2005)<sup>7</sup>, since the usual disease progression from infection to death has been estimated to occur over a 10-year or longer period. Roy (2007)<sup>9</sup> reveals that psychiatry illnesses like depression and stress are common in HIV infected patients. Roy (2007)<sup>9</sup> further states that the prevalence of depression in HIV infected clinic populations range from 22% to 38 percent. Younger age, unemployment, lack of health insurance, low CD4 cell count, HIV and related symptoms, not having a partner and poor quality of social support are significant predictors of depression. Sledjeski, Delahanty, and Bogart (2005)<sup>10</sup>, does say that HIV infected people are to suffer from comorbid psychiatric illnesses such as depression.

**Stress Due to HIV, AIDS and The Art Therapy:** Koopman, Gore-Felton, Marouf, Butler, Field, Gill, Chen, Israelski, & Spiegel, (2010)<sup>11</sup> state that HIV infected people often manifest a high degree of reluctance in as far as participation on long-term projects is concerned. They state that very often these people express fear that their times are nearer. James (2006)<sup>12</sup>, sates that positive patients find it hard and stressful to adhere to ART therapy

because of its time and diet restrictions and also due to the facts that it has to be taken for the entire lifespan of an individual without taking any breaks. Such a claim is supported by an article in the Health Section South African Star; March (2003:13)<sup>13</sup> which states that HIV infected people finds it too stressful to queue for their medication at the respective Voluntary Counseling and Testing Centers.

Testing positive for HIV is usually very traumatic for patients. They frequently experience a crisis of reaction that includes feelings of severe shock, a sense of unreality, and some form of denial. Feelings of anxiety and guilt can often be overwhelming. Depression may occur during this crisis period, especially if the patient has a premorbid history of depressive episodes. Common symptoms of depression characteristic of patients who test positive for HIV include feelings of helplessness and worthlessness. These are provoked by the terminal nature of the illness, by fear of social stigmatization, and loss of friends or family support. Personal fears are often compounded by the patient's direct knowledge of friends and acquaintances that have died of AIDS. This may lead the patient to suicidal ideation.

Other patients according to Wilson (2008)<sup>14</sup> will respond to their diagnosis by fighting back, vowing not to be a victim of the disease, and determining to become the first person to be cured of HIV or AIDS. In their struggle these patients frequently mobilize and strengthen their resources to take action against the disease, or they place intense and often unrealistic emphasis on nutrition, vitamin supplements, exercise, and "clean living". Wilson (2008)<sup>14</sup>; in addition, states that, some patients experiment with black market drugs in their search for an undiscovered miracle cure. Such experimentation may be allowable as long as patients are encouraged to inform their physicians of such drug use so that the physician can monitor potential side effects and discourage the use of drugs that have

documented dangerous toxicities. To the extent to which they are able, physicians should encourage and support these efforts by their patients to grapple with their personal and social situation.

#### **HIV and AIDS Stigmatization**

Openness about being HIV positive helps people accept their HIV or AIDS as part of their everyday life according to UNAIDS (2000)<sup>15</sup> being open reduces distress on the infected individual and is one way of doing something on the stigmatization and discrimination haunting HIV infected people. However, it is essential to point out that HIV positive people should not be forced to go public.

Due to the above psychological consequences due to HIV and AIDS and the effects of the ART it becomes clear that there is need to equip the health professionals with much advanced knowledge on counseling strategies and techniques so that they may execute their therapeutic interventions effectively and adequately to their clients and to further intensify their teaching programs so as to disseminate qualified and quality information on HIV and AIDS and related symptoms and/or diseases

According to the UNAIDS (2012)<sup>16</sup> HIV is a retroviral, so drugs against HIV are called anti-retroviral drugs. Giving ARV in the correct way, with adherence support is called ARV therapy which is shortened as ART. ARVs prevent the HIV from entering the infected cells center. History has proven that every drug has its own side effects or negative impacts. The study therefore seeks to explore in depth the impact of the ARVs and the disease HIV and AIDS prognosis focusing on psychological consequences in the form of depression, stress, suicidal thoughts, and mental alteration to mention but a few.

**Suicide Tendencies Due to HIV and AIDS:** A number of patients declared HIV infected and undergo art therapy often experience suicidal thoughts and actions. This is supported by

Mcintosh & Rosselli (2012)<sup>17</sup> quality of life and depressions are factors that lead to these transient suicidal thoughts which may occur throughout the process.

#### **Altered Mental Status Due to HIV and AIDS**

They include anxiety, depression, problems with memory and concentration and cognitive function all of which can be or have negative effects on the compliance to medication. Behavioral changes that include altered sleep patterns and eating habits due to time and diet restrictions could be common to those taking ART (Bajko, 2014)<sup>18</sup>. Moreover, insomnia which causes erratic sleep patterns and relationship with mania and depression has also been linked with ART. What usually exacerbates factors such as depression is the fact that the drugs have to be taken daily and for the rest of one's life. This is according to [www.acqoul.dealing.edu](http://www.acqoul.dealing.edu). Since previous studies have shown that ART causes mental difficulties due to pharmaceutical properties, such as observations stresses the need for further research to be conducted in this area and that since there is support available to the people relating to the physical side effects then therefore in the hope for better health care there is need to offer the same support TO THOSE experiencing psychological impacts and more over education should be provided to psychologists, psychiatrists and counselors involved in the care of HIV positive people.

#### **Research Design and Method**

**Research Design:** An exploratory descriptive quantitative research design was utilized in this study to explore more about the phenomenon and be able to describe in depth the psychological consequences of HIV and AIDS and the ART therapy, (Burns and Grove, 2009)<sup>19</sup>.

**Research Methods:** The Research methods used in the study included sampling method, data collection method and data analysis method (Burns and Grove, 2009)<sup>19</sup>.

**Study Setting:** The study was conducted in one of the referral hospitals in Swaziland.

**Sampling Method:** Convenient and purposive sampling techniques were utilized when selecting research respondents into the sample of the study, (Burns and Grove, 2009)<sup>19</sup>.

**Target Population:** The population of respondents who participated in this study were HIV and AIDS positive people attending ART related services in one of the referral hospitals in Swaziland (Brink, 2003)<sup>20</sup>.

**Convenient and Purposive Sampling:** The researcher used the convenient sampling technique because the researcher sampled respondents that happened to be found at ART clinic at the time of assigning respondents into the sample of the study (Burns and Grove, 2009)<sup>19</sup>.

**Sample Size:** A total of 130 research respondents formed the sample for the study.

#### **Data Collection Method**

The data collection process was categorized into three main stages which were, permission to precede, data collection and data handling.

**Permission Proceed:** Permission to conduct study was sought from the Scientific Ethics Committee in the Ministry of Health, Swaziland. Respondents were also requested to fill the consent form before participating in the study, following a full explanation of the study purpose, objectives and benefits.

**Data Collection:** Semi-structured questionnaires and observational method of data collection were used to collect data in the study.

**Data Handling:** The researcher checked questionnaires for completeness and accuracy of collected data at the end of each session. Quality checks were done scrutinizing every questionnaire at the site of data collection. The questionnaires with raw data were counted and then kept in a safe place at the end of every data collection day.

#### **Data Analysis and Presentation**

Data was analyzed by the use of a computer package (SPSS version 17)

#### **Research Rigor**

**Internal Validity:** Internal validity is the degree to which changes in the dependent

variable can be attributed to the independent or experimental variable (Brink, 2003)<sup>20</sup>. This was ensured by making sure the different stages in the research were scientifically related with other different topics in the study. For example, the background information and the justification are both related to the topic. Variables used in the developing of the objectives were from the background information and problem statement. The very same variables used for objectives derivation were used for formulation of questions for data collection.

**External Validity:** This means the degree to which the study findings can be generalized to other than people and other settings (Brink, 2003)<sup>20</sup>. To ensure external validity the researcher had the following questions in mind; with what degree of confidence can the study be transferred from the sample to the entire population? And will the findings hold true for other times and place?

**Reliability:** Reliability means the consistency and the dependability of a research instrument to measure a variable (Brink, 2003)<sup>20</sup>. To ensure reliability, the data collection tool was given to an expert (the project supervisor) to check its accuracy and it was first piloted to see if the questions were producing the desired or expected result.

**Objectivity:** Objectivity means the extent to which two independent researchers would arrive at a similar judgment or conclusion (i.e. judgment not biased by personal values or beliefs) considered a desirable attribute within the positivist paradigm (Burns and Grove, 2009)<sup>19</sup>. The researcher ensured that the variables were derived from the literature and the variables were used to develop the specific objectives of the study. The questionnaire was developed from the objectives of the study.

**Ethical Consideration:** Permission to conduct the study was sought from the administrator of the ART centers where the study was done. The permission was also obtained from the HIV centers where the study was also done. A permission/concern to interview the HIV

positive people was obtained after the purpose of the study and its benefits to both health workers and the HIV infected people at large was explained. Research respondents were given assurance that the gathered data would be held confidentially, and that such right would be observed with dignity and respect it deserves.

Every respondent who participated in the study did so voluntarily without being forced, intimidated or tricked in any way to participate in the research. All participants had to consent to partaking in the study through willingly filling a consent form. Participants were advised that any person who wished to withdraw from the study was allowed to do so without any charge or infringement inflicted to them for their withdrawal. Respondents were not compelled to answer every question on the questionnaire, but he/she had to answer those questions which he/she was more comfortable with. However, if the respondent felt the study was worth it to be answered, then they could attend to all the questions asked.

#### **Discussion and Interpretation of the Results**

**Demographical Information:** A total of 78 out of 130 participants (60%) were females and 39 out of 130 (40%) were males and this is congruent to the fact that females have higher health seeking behavior than males. According to Swaziland National AIDS Programme Report (2011)<sup>21</sup>, 70% females are on HAART as compared to 30% males who are also on HAART.

According to the Swaziland Demographic Health Survey (2007)<sup>2</sup> 30% of youth aged (19-24), are badly infected and affected by HIV and AIDS. On the other hand, Swaziland Demographic Health Survey (2007)<sup>2</sup> states that a whopping 42.6% of youth in Swaziland are affected by HIV. What is also striking is the number of participants in the age group 39-44 which is 30% of the total number of HIV positive individuals and this high figure to us is indicative of the intergenerational sex between the adults and the youths which defeat the

efforts to control the spread of HIV in the country.

A total of 65/130(50%) of unemployed female research respondents did not have any formal occupation and this observation is supported by Swaziland National Aids Programme (2011)<sup>21</sup> quarterly report which states that women's sexual life decision is compromised by their occupational status.

A substantial number of the participants 39/130 (30%) were uneducated and this observation correlates well with United Nations Children Emergency Fund annual reports (2006)<sup>22</sup> which states that 6/10 people were uneducated in the African sub-Sahara region.

A total of 65/130 participants which is (50%) were single and this high number correlates well with Swaziland Action Groups Against Abuse that a lot of people (44%) who falls on marital age group are living as single.

**Mental Alteration:** There was a high number of participants 91/130 (70%) who stated that they did experience forgetfulness compared to 39(30%) who stated that they did not. A significant number of 104/130 (80%) responded that their sleep pattern was being disturbed by the ART related therapy. This is supported by Kelly (2009)<sup>23</sup> who states that ART related therapy causes mental alteration due to their pharmaceutical properties. In addition, Kelly(2009)<sup>23</sup> state that behavioral changes that include altered sleep pattern eating habits due to time and diet restrictions could be common to those taking ART related therapy. Moreover, insomnia which causes erratic sleep pattern and has relationship with depression and mania has also been linked with ART related therapy.

**Stigmatization:** A total of 78/130 (60%) participants stated that they were timeously stigmatized by their loved ones and family members and they felt that their right as HIV positive people were violated and that posed unnecessary strain on their lives. According to the researcher the latter observation was a threat to the whole purpose of disclosure. Emlert

(2006)<sup>24</sup> regarding the importance of disclosure stated that openness is one way of dealing with stigmatization and discrimination haunting HIV positive individuals. And if done well it reduces mental stress on the infected individual. The participants, 78 out of 130 (60%) further stated that they felt that they were outcasts since they were also deserted by their loved ones.

**Depression:** A total number of 78/130 (60%) research respondents, stated that they sometimes felt dejected and overpowered by their HIV positive status, and consequently they felt worthless and helpless. This finding was supported by Wilson, (2008)<sup>14</sup> who states that an HIV positive individual after testing positive under goes a crisis period and common symptoms include worthlessness, helplessness, anger and denial. Wilson, (2008)<sup>14</sup>, in addition, states that "this is common with those who previously enjoyed dependency from families and friends but no longer experience such". Moreover, this is further worsened by loss in peers' friendship. The average number of depression of 62.2% as observed by Wilson, (2008)<sup>14</sup> correlates well with a study conducted by Kelly(2009)<sup>23</sup> on HIV positive patients which revealed that combed psychiatric illnesses including depression are common in HIV positive patients. It further revealed that the prevalence of depression on HIV positive patients on ART related therapy ranged from 22% to 38%. This was attributed to the poor quality of social support and the use of non injection drugs. This is evident in the above prescribed results of worthlessness, feeling of isolation and decline in activity which is because of poor quality of social support and in part due to the ART related therapy itself. The result are also in line with statistics of patients committed to the Swaziland national psychiatric center of patients diagnosed of depression where 48% of them have depression emanating from HIV and its related therapy (Swaziland National Aids Programme annual report, 2011)<sup>21</sup>.

**Suicidal Ideation:** A total of 104/130 (80%) stated that they found life no longer worth living because of their HIV status and the quality of life they were leading. This is supported by Kelly (2012)<sup>23</sup> who stated that poor quality of life and depression factors leading to transient suicidal thoughts may occur throughout the course of HIV disease. Kelly (2012)<sup>23</sup> further stated that high prevalence rate of depression was closely related with suicidal thoughts and ideation. This was further echoed by Wilson (2008)<sup>14</sup>, who stated that HIV positive people have a relative risk of committing suicide many times than the general population. Both the family and the patient experience acute suffering and grief for the rest of the illness.

**Stress:** A total number of 95/130 (73%) stated that they timorously experienced bouts of lack of concentration in their daily cues and that was quite disturbing especially to those who were schooling or working because they could not be productive as expected. Ballard (2000)<sup>25</sup> who states that HIV does affect the central nervous system causing memory lapse, impairment of short term memory and psychomotor slowing and if severe enough may cause AIDS DIMENSIA COMPLEX which can further cloud one concentration span. The above prescribed claim is quite evident in the 73% above who articulated that their concentration levels were grossly tampered with (reduced). Moreover, a total of 78/130 (60%) HIV positive participants projected their anger and frustration to other people as part of their defense mechanism. This observation was supported by James (2006)<sup>12</sup> who stated that HIV positive people find it difficult and stressful to adhere to ART related therapy because of its time and diet restrictions and that it has to be taken lifelong. Because of such stressors HIV positive people find it difficult to deal with anger accordingly. Consequently they often project their anger to other people. Another reason given by the participants was that most often they are preoccupied by feelings that they approach their

end times so this tampers grossly with how they control their anger.

**Limitations of the Study:** There was scarcity in obtaining the required information due to the sensitivity attached to HIV related issues and also the sample population was small and collected in only one referral hospital which makes the study results not easily generalizable to the entire population of HIV and AIDS positive patients who are also on ART Swaziland.

#### **Recommendations**

- Focal individual psychotherapies and psycho pharmacology for depressed people have to be instituted and moreover social support interventions like support groups and cognitive behavioral groups have to be formed to meet the needs of depressed HIV positive people.
- Intensify teaching programmes on HIV, transmission, and treatment to disseminate quality information so as to alleviate the current prevailing stigma on those infected and affected.
- Teach clients and their immediate families about the ART related therapy pharmaceutical side effects and also how to deal with them so that they could fully comprehend them when surfacing.
- Health professionals should encourage HIV positive clients to ventilate their fears, concerns and worries regarding their status so as to deconstruct and reconstruct whatsoever schema regarding stress, depression and suicidal issues.
- Health professionals should teach HIV positive clients together with their families to set alarm beeps on their wall watches or cell phones to remind them when to take their medication to counter act the mental alteration of forgetfulness.

Lastly HIV positive clients should be warned against taking naps during the day to avoid insomnia at night about d to report every medication that tempers with their sleep pattern health professionals to get necessary help.

**Conclusion:** It is evident from the study that psychological impacts of HIV and AIDS and antiretroviral related therapy effects, if not well addressed consequently contributing immensely to issues of suicide, depression and stress. Hence, a comprehensive approach when treating HIV positive patients, should be applied for the purpose of empowering them with adequate knowledge and skills so that they can cope well with the burden that comes with the disease. This means that health care professionals should go beyond addressing the physical symptoms of the disease and rather, in addition, utilize knowledge from psychotherapists, psychiatrists, mental health social-workers, psychologists and mental health/psychiatric nurses in as far as the alleviation of the severity of psychological consequences is concerned.

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