

## **The Experiences of People Living with HIV/AIDS, On Antiretroviral Medications**

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### **Abstract:**

*This study has been conducted specifically to explore the experiences of people living with HIV/AIDS and taking antiretroviral medications in Nairobi. This study specifically sought to: describe individuals' feelings before and after initiation of antiretroviral medications; ascertain whether there is stigma associated with taking antiretroviral medications; Identify support mechanisms available for people taking antiretroviral medications; describe challenges individuals face as a result of taking antiretroviral medications, and establish coping mechanisms available for antiretroviral medication related challenges.*

*This study was a cross sectional qualitative inquiry that used in-depth interviews to explore the experiences of people on antiretroviral medications in Nairobi. The results showed that before taking antiretroviral medications, participants were feeling hopeless, sad and frustrated. However, when they started the antiretroviral medications, their feelings changed positively to feelings of hope and courage. Family support is crucial for good adherence to antiretroviral medications; though these medications pose the greatest challenge of treatment side effects. In summary, this study showed that antiretroviral medications are a greatest investment in the physical, medical and psychosocial welfare for people living with HIV/AIDS.*

### **Introduction:**

The Human Immunodeficiency Virus (HIV) infection is a global pandemic, causing disease and death in nearly every country in the world. HIV-1 is the strain of the virus that causes disease in most of the world, including Kenya. HIV is a human retrovirus capable of producing profound immune deficiency by gradually destroying T-helper (CD4) lymphocytes; thus, inhibiting the body's ability to fight-off many diseases. Infection with HIV can result in a cluster of symptoms that are recognized as the Acquired Immunodeficiency Disease Syndrome (AIDS). HIV slowly degrades the body's ability to ward off infections and other illnesses and was considered a terminal illness when identified in the early 1980s. Although AIDS-related deaths are declining, the number of people living with HIV/AIDS continues to increase. The total number of people living with the virus in 2008 was more than 20% higher than the number in 2000, and the prevalence was roughly threefold higher than in 1990 (UNAIDS, 2009). The continuing rise in the population of people living with HIV reflects the combined effects of continued high rates of new HIV infections and the beneficial impact of antiretroviral therapy.

### **Review of Literature:**

In several recent studies, people living with HIV and AIDS have still reported high stigma and discrimination experiences (Gilbert & Walker, 2009; Simbayi et al., 2007; Wolfe et al., 2006). Logie and Gadalla (2009) conducted a meta-analysis on relationships between HIV-related stigma and a range of demographic, social, physical, and health characteristics in North America, and found high stigma level was consistently and significantly associated with lack of social support, poor physical health, poor mental health (including depression), lower age, and lower income. Smith et al (2008) found a negative, homogenous correlation between stigma and disclosure. Some recent studies, for example, Dlamini et al (2009) have linked AIDS stigma to

lower adherence to anti retroviral therapy. There have been relatively few studies on the pathways of AIDS stigmas experienced by people living with HIV and AIDS. Pearson et al. (2009) found one year after initiating anti retroviral therapy in Mozambique, participants reported no change in stigma, a decrease in perceived social support, and an increase in depressive symptoms, and Kaai et al. (2007) found in a study cohort of people on antiretroviral therapy in Mombasa, Kenya, that levels of internalized stigma decreased significantly after 12 months on treatment and social support remained high at follow-up.

However, this study was limited due to the fact that there was no control group to compare these findings.

### **Objectives:**

- Describe individuals' feelings before and after initiation of antiretroviral medications
- Ascertain whether there is stigma associated with taking antiretroviral medications
- Identify family support mechanisms available for people taking antiretroviral medications
- Describe challenges individuals face as a result of taking antiretroviral medications
- Establish coping mechanisms available for antiretroviral medication related challenges

### **Method:**

In this chapter, the techniques and methods used to design, collect, and analyze the data for this research are explained. This study used a qualitative inquiry for the reason that I wanted to explore deeply into the individual experiences of people living with HIV/AIDS on anti retroviral medications. The ultimate aim was to gain insight into participants' attitudes, behaviours, value systems, concerns, motivations and aspirations with regard to taking anti retroviral medications. This allowed for more diversity in responses as well as the capacity to adapt to new developments or issues during the research process itself and provided richness and depth of explorations and descriptions.

### **Participants:**

A convenience sample of three men and three women participated in this study. Three people from each gender were conveniently chosen because they volunteered to be interviewed provided confidentiality and privacy were guaranteed; and I seeking experiences from both gender for comparison purposes. In order to participate in this research, eligible individuals were receiving medical care at this Nairobi health care clinic, were HIV infected, on antiretroviral medications for at least the past twelve months from this clinic and were aged 30 to 50. The age ranges of 30 to 50 were chosen because the researcher assumed that age bracket would have a lot of experiences to share given in that age group people usually have a lot of responsibilities, alongside relationship issues and cultural, and society expectations. This sample provided a distinguishing benefit because it allowed exploration of lived experiences of the participants and offered richness with which to explore counseling related knowledge.

### **Design:**

This was descriptive and cross-sectional qualitative design which described the experiences of people living with HIV/AIDS on Antiretroviral medications in Nairobi, Kenya. The design is descriptive because participants were given the opportunity to narrate their experiences in their own language using their own meanings. It is cross-sectional due to the fact that I interviewed each of the research subjects once with no intention of follow-up interviews. Epistemologically, the use of this interpretive paradigm was paramount to allow participants describe their phenomena using their own words with regard to taking antiretroviral therapy through the use of individual interviews. The data in word source document was arranged according to the guiding questions in the interview guide.

## Procedure:

In-depth interviews were conducted using semi-structured guides. The interviews were also audio-taped and there were notes made by the interviewer. Audio-tapes were listened to and transcribed verbatim. The transcript and the notes from the interviews were aggregated and computer typed into one data source in word. This formed the source document for analysis.

## Results:

The participants' discussions focused on their experiences with taking antiretroviral medications largely in line with the objective of this study which was to explore participants' experiences relating to taking antiretroviral medications. Five major themes emerged: a) duration on antiretroviral medications, b) feelings before and after initiating antiretroviral medications, c) perceptions of stigma as a result of being on antiretroviral medications, d) challenges associated with taking antiretroviral medications and e) coping mechanisms.

All the participants were taking antiretroviral medications for over three years. However this period varied from three years to twelve years. Majority of the participants knew that they were HIV positive at least seven years before being initiated on antiretroviral medications and this emanated from severe attack by a major infection or out of curiosity. One participant put it this way *"I knew I was positive in 1998... In 1998 I was diagnosed and first I was put on treatment for six months only injections for TB and treatment for TB that time I thought I was cured and went to work, back to work in 2001. In 2004 the disease came with a bang and I was thinking I was cured, so I was very you understand? Very am sickly. I was taken to hospital, this time I was working in West lands Restaurant so I was taken to Coptic Hospital and stayed there for 60 days again with very big or high resistant TB, Typhoid, Malaria and chest problems, each for, with breathing problems after treatment that is when I then started taking the ARV in 2005 to date. When I started the ARV in 2005 my CD4 counts were 17, very low and after six months it went up to 174 and my weight rose from 39 – 63kgs and now am is, is 86kgs, am even controlling it"* (participant no. P0.1 ). Another participant said *"It was in the year 2003 I decided to test myself because I was alone in a VCT centre out of curiosity. I almost fainted when it read positive so I decided to confirm with the senior lab technologist because I was almost in a state of denial"* (participant no. P0. 4)

Understanding how the study participants felt before getting on to life-long medications is relevant for the analysis of our findings. In this study half of the participants explained their feelings before antiretroviral medication initiation (P01, P04 and P06). Feelings of hopelessness, frustration and fears of death were palpable among the study participants. *"I was so stressed then, depressed and so low, I hated myself a lot and did not believe I could make it"* (participant P04). Another participant said *"I felt very bad, drugs were very expensive that time I knew I was positive, was like the end of my life and then I lost hope completely especially when I gave birth in 1992 at Kenyatta National Hospital and my child died"* (participant P03). Others experienced fears of death. *"I felt like I would die too like my --- that time there was no counselling and if one knew was positive, that was a death sentence"* (participant P03). Another participant echoed the same words like the one above *"I say I was quickly dying!"* (Participant P06).

However, these feelings were reversed as individuals started antiretroviral medications.

Hope was restored because of starting on life-long medications as they hoped to live longer and plan future activities, achievements and relationships. Hope helped them to compare the inevitable bad days and increased their capacity to appreciate the restoration of good health because of taking antiretroviral medications.

## **Discussion:**

This study was a cross sectional qualitative inquiry that explored participants experiences for the period they had been on antiretroviral medications. The findings are varied touching on a number of issues but on the overall, patients appreciate the role of antiretroviral medications in their lives as they have been able to regain and restore normality in as far as physical and psychosocial functioning is concerned which were slowly but surely diminishing.

HIV infection is generally associated with immorality in the Kenyan society and many people infected with this disease may have feelings of having committed an abomination or eroded cultural, traditional norms and values. In this study, the principal investigator found that participants' feelings before being initiated on antiretroviral therapy were predominantly negative; that is feelings of hopelessness and feeling frustrated. This suggests that the feelings of hopelessness meant that society had rejected them as un-worthy living and this is comparable with the person-centred notion of self-structure (Rogers, 1951; Chantler, 2005). This is also comparable to a study by Roberts et al (2001) in which they examined risk for depressive symptoms and perceptions of stress among HIV positive men and women; where investigators were interested in exploring the role that acute stressful life events might play in the development of these forms of emotional distress, and in testing whether or not psychological diatheses including neuroticism, low self-esteem, and dysfunctional attitudes moderate the association between acute negative life events and emotional distress and found that negative events might have acted as an additional burden over the ongoing chronic stress of HIV illness, and ultimately contributed to the development of depressive symptomatology. These findings were consistent across analyses based on our aggregate measure of vulnerability and each of its three individual components (neuroticism, low self-esteem, and dysfunctional attitudes).

## **Summary:**

As people living with HIV/AIDS start taking antiretroviral medications, feelings of hope, courage and joy, which had been deprived by HIV disease, are restored. However, due to feelings of discrimination and stigma, they restrict their pleasant feelings to themselves and their immediate family members they consider important in their lives.

Social support from families is crucial for patients taking antiretroviral medications.

Anti retroviral therapy related side-effects are the biggest challenges facing people living with HIV/AIDS in Nairobi. In summary, this study has increased on our understanding of the experiences of people living with HIV/AIDS taking life-long medications and it adds new knowledge on the already existing body of knowledge about the experiences of people living with HIV/AIDS not only in Kenya but in the entire world in general.

## **Implications of the study:**

The present study provides evidence that there are a multitude of issues that require counselling in this population. The findings of this study have implications for counselling practice including the type of counselling models best suitable for people living with HIV/AIDS taking antiretroviral medications. Adherence counselling and the coping and stress management theories are paramount for people struggling with ARV-related side-effects. Wood et al (2003) argues that adherence is the strongest determinant of patient survival. The complex issues of medication compliance demonstrate that evidence-based practice in psychological care of HIV patients is critical and suggests how important it is to focus counselling efforts by using evidence best practice approaches available.

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