

The Psychological Experience of HIV and Aids by Newly Diagnosed Infected Patients at Hospital A of Vhembe District, Limpopo Province

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Abstract

South Africa has one of the fastest growing rates of new HIV infection in the world. It is estimated that 5.7 million people in South Africa were infected with HIV. A combination of poverty, illiteracy, migrant labour, commercial sex workers and disruption of family and communal life has increased the individual's risk of infection. The purpose of this study was to explore and describe the psychological experiences of HIV/AIDS by infected persons in Hospital A in the Vhembe district of Limpopo Province. The research design was qualitative, exploratory and descriptive, using the phenomenological approach. The target group for this study were males and females who visited the institution seeking health care, whose blood samples were found to be HIV positive, between the ages of 18 and 49 years at Hospital A in the Vhembe district of Limpopo Province. A convenience sampling method was used. Data was collected through in-depth unstructured one-to-one interview. Three phases suggested by Miles and Huberman were used which are: data display; in data reduction and lastly during data interpretation. Measures to ensure trustworthiness and ethical issues were ensured. The effects of HIV/AIDS on the infected persons were identified and the following theme and sub-theme: Psychological experiences, factors contributory to psychological imbalance and observations. Living with HIV/AIDS poses tremendous psychological and physical challenges to those who are infected. The experience of HIV-related symptoms is a significant part of that challenge. The physical and psychological symptoms are profoundly disruptive and impact on almost every aspect of daily life.

Keywords: Psychological experiences; HIV; AIDS by infected persons

Introduction and Background

Human Immuno Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) has risen to alarming proportions worldwide. According to UNAIDS [1], there were 40 million adults and children living with HIV/AIDS worldwide and 5 million people were newly infected. Approximately 10% of the world's population infected with HIV lives in sub-Saharan Africa [2].

HIV/AIDS is a major health and social problem facing South Africa. It is estimated that 5.7 million people in South Africa were infected with HIV. A combination of poverty, illiteracy, migrant labour, commercial sex workers and disruption of family and communal life has increased the individual's risk of infection. In addition, 1500 new infections daily are reported or estimated. It has been estimated that 33 million people suffer from one form of sexually transmitted disease or another. According to Kite [3] it is estimated that six youths are infected by HIV/AIDS every minute. Media reports show the ever-increasing rates of infection with this disease. The increase is also age-related. According to Herbst [4] and UNAIDS (2006), of over 43 million people, an estimated 2.9 million (7%) were infected with HIV by the end of 1997 and by 4.3 million by end of 2006 respectively. Of these, half were women aged 15-49. Among pregnant women, 16% were HIV positive.

HIV/AIDS in South Africa has long been a controversial subject. In 2008, government under the presidency of Jacob Zuma started moving towards a determined and comprehensive response to HIV/AIDS in South Africa. Meanwhile the formal health care sector has been overwhelmed by HIV/AIDS in South Africa. Up to 80% of hospitals beds in already under-staffed and under-resourced hospitals have been occupied by patients with HIV/AIDS related illness [5].

According to HIV/AIDS and STI National Strategic Plan of South

Africa (NSP) 2007-2011, HIV/AIDS is one of the main challenges facing the country. The HIV/AIDS epidemic in South Africa is one of the most severe in the world.

The Sunday Times of 9 July 2000 reported about the deliberations at the world conference on AIDS and the law. At that conference, Judge Cameroon could not hold back the tears as he recalled the story of a man he knew well who was fired from his job because he had AIDS. The man was later found hanging from the rafters of his single room. From observing how the media reports about HIV/AIDS, it appears as if people fear this kind of illness. People who are informed of their HIV positive status become depressed because of the horror caused by "the big disease with the little name" [6]. Those who are not sufferers, the generalised others, are also grabbed by morbid fear, to the extent that they may kill the sufferer.

Statement of the Problem

While working in the psychiatric ward, the researcher sometimes nursed and counselled persons who, after being informed about their HIV positive status, became depressed or psychotic. Those admitted to medical wards with positive HIV/AIDS status and opportunistic

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infections were also observed to be depressed, showing signs of being tearful, not talking to people when spoken to, isolating themselves, and refusing to eat and participate in ward activities.

One lady was admitted to a medical ward, and became psychotic after being told about her status. She was fighting people, screaming, and asking forgiveness from God. Other patients, after being told about their status, would be depressed to the extent of being absolutely mute. Some patients were transferred to a psychiatric ward because they were behaving bizarrely after being told of their status; some cutting or mutilating themselves and smearing blood all over, or roaming around aimlessly, yet talking to themselves.

Various studies have investigated the psychological impact of HIV and HIV related stigma. It was found that HIV related stigma does exist independently contribute to psychological distress in people living with HIV/AIDS (PLWHA). Stigmatisation by families and health workers often threatens the fundamental human need, namely the need to belong [7,8].

Stigma and family rejection might have contributed to psychological distress to newly diagnosed HIV infected patients. It is in this light that the researcher undertook the study to increase understanding of the psychological experiences of HIV/AIDS by infected persons in Hospital A in the Vhembe district of Limpopo Province. The study sought to answer the following question “what are psychological experiences of HIV/AIDS by newly diagnosed infected patients in hospital A in Limpopo Province”.

Objectives

The objective of this study was to explore and describe psychological experiences of HIV/AIDS by newly diagnosed infected patients in hospital A in the Vhembe district.

Significance

The research findings will recommend to the Department of Health and Welfare in the Limpopo Province that they provide outreach programmes, education and training services to people, particularly those vulnerable to HIV/AIDS. Furthermore, through the Department of Health and Welfare in Vhembe district, this study should enable the Department to create links between HIV/AIDS programmes and local communities. The study will further contribute to the development of the provincial HIV/AIDS programmes, helping them to focus on the psychological care of HIV/AIDS sufferers. The findings could also assist in restructuring the content of nursing programmes regarding the psychological care of persons with HIV/AIDS.

Findings could contribute to the restructuring of the health professional curriculum to become research based. Knowledge about caring for infected patients will be increased, taking into consideration the psychological part of counselling and management of HIV/AIDS, and avoiding discrimination or stigmatisation.

Research Design

The research design was qualitative, exploratory and descriptive, using the phenomenological approach. Through the qualitative approach the research strove for understanding of the inner feelings and experiences of individuals brought about by the disease. It was concerned with gaining insights into the nature of the experiences the infected persons have of this phenomenon. The findings will be applied and adjusted to many situations to guide understanding, forestalling the need for further research [9,10]. According to Brink [10]

researchers who wish to explore the meaning or describe and promote understanding of human experiences such as pain, grief, hope, caring, mutilating surgery, and so on, would find it very difficult to quantify the data [10]. Qualitative methods would be more appropriate and effective alternative methods to use in such cases. It was for this reason that the researcher chose to use qualitative methods since the topic under study seeks to understand human experience of mental disequilibrium, and is very sensitive. Qualitative methods, as the name implies, all focus on qualitative aspects such as meaning, experience and understanding, and they all study human experience from the viewpoint of the research subjects and in the context in which the action takes place. In this study researchers were exploring the unknown life world of those infected by HIV/AIDS so as to get to know their life world.

A phenomenological approach was used in this study as the researcher attempted to understand the perceptions and perspectives of those infected with HIV/AIDS to get an in-depth knowledge of their experiences.

Population and Sample

Population is a group whose members possess specific attributes that a researcher is interested in studying [11]. The target group for this study were males and females who visited the institution seeking health care, whose blood samples were found to be HIV positive, between the ages of 18 and 49 years at Hospital A. These were clients who came to check their blood results and underwent a check-up as requested by the health care staff. The hospital routinely provides VCT to suspicious patients who come for consultation at the outpatient department. At the time when the study was conducted the VCT unit tested 403 patients in one month, 56 patients tested positive and 17 were admitted presenting HIV/AIDS related problems including psychological distress. In this study the non-probability convenience sampling method was used. Convenience sampling entails the use of the most conveniently available persons or objects for use as subjects in a study [12]. The HIV positive persons who were admitted in the psychiatric ward presenting psychotic disorder were sampled. It is assumed that psychotic patients need more support because they have low threshold to control their innermost feelings. The interview would provide further counselling and suggesting coping mechanisms to reduce stigma and to increase patient understanding of the disease since they were newly diagnosed. In this study a sample of six patients that is four (4) females and two (2) males who gave consent to be interviewed were obtained to participate in the in-depth individual interview.

Data Collection

The in-depth free type individual unstructured one-to-one interview, also sometimes referred to as the in-depth interview, merely extends and formalises conversation [13].

Interviews were conducted by two of the researchers, since the researchers had been counselling cases of HIV over a period of time and this enhanced their interview skills. Such interviews were tape recorded in order not to miss any information. Open-ended questions were put to clients. Another reason for self-administering the interviews was for maintenance of as much confidentiality as possible. Included were probing techniques that were used to find out more detailed information. Reflection was also done in order to find out whether the researchers attach the same meaning as that of the participant to avoid misunderstanding [14]. The researchers observed all the cues, their physical status, mannerisms and facial expressions. Each participant was told that the duration of the interview would be one hour and thirty

minutes because of the sensitivity of the question asked. Sometimes the participants cried or paused. The researcher used facilitating communication techniques such as minimal responding, clarification and rephrasing to encourage the participants to speak openly and freely about their experiences [15,16].

Field notes were also taken in order to enable the researchers to report fully about the aspects which were observed and could not be recorded on tape. They were taken immediately after the interview for purposes of describing the situation in totality to ensure that no collateral information was lost.

Data Analysis

Data analysis is a systematic organisation and synthesis of research data, and the testing of research hypotheses using those data [14]. For qualitative data analysis the three phases suggested by Miles and Huberman [17] were used which are: data display was done, where taped information was transcribed verbatim; in data reduction, data was re-read data and similar statements, segments and units identified; lastly during data interpretation, patterns and structures that connect the categories and corresponding codes for sorting and organising the data were identified.

Trustworthiness

The principles outlined by Lincoln and Guba [18] were followed to ensure the trustworthiness of the study. Credibility was achieved through spending time with each participant to gain her confidence. The participant was instructed to turn the tape recorder off if she felt uncomfortable being recorded. Participants were purposively sampled and, entering into the second session of interviewing women, prolonged the engagement, increased probing of information and enhanced data saturation. Tape recordings as well as field notes written during interviews increased the confirmability of the research. Transferability was ensured by complete description of research method, in-depth discussions of the data obtained and interpretation of the research findings in the study report. In-depth literature control on the topic of the study and verbatim quotes cited in the findings will enable readers to do self-evaluation of their own experiences of sexual assault.

Ethical Considerations

Permission to conduct the study was sought from higher degree committee of the School of Health and ethics committee at the University of Venda, the Limpopo Department of health and Social Development and the hospital management and trauma unit.

The participants were protected by maintaining the ethical standards such as sufficient information regarding participation was provided in the informed consent form; assurance of confidentiality and anonymity where even the researcher could not link the names of the participants with any information that was given to her; freedom from exploitation was ensured by the researchers' avoidance of abusing their privileged position and individual participants was regarded as autonomous being with the right to make choices without being coerced. The participants were also informed of their right to withdraw from the study at anytime without fear of being victimized [19]. The researchers as part of the health professionals established relationships with patients and provided emotional support before approaching them to request their participation. In a similar study conducted in the United Kingdom researchers used women who they had offered support and established relationships in the past year as participants [20].

Results

The effects of HIV/AIDS on the infected persons were identified and the following theme and sub-theme as reflected in Table 1 were extracted from the information provided by the participants: Psychological experiences, factors contributory to psychological imbalance and observations. Living with HIV/AIDS poses tremendous psychological and physical challenges to those who are infected. The experience of HIV-related symptoms is a significant part of that challenge [21]. The physical and psychological symptoms are profoundly disruptive and impact on almost every aspect of daily life. This study therefore looked into the experiences of those infected by the HIV/AIDS virus.

Theme	Sub-theme
1. Depression & Hopelessness	Extreme sadness/depression Neurologically based behavioural changes Social withdrawal Feelings of worthlessness Decrease or increase in appetite Insomnia or hypersomnia Fatigue or loss of energy Diminished interest or pleasure in almost all activities. Feelings of guilt Ideas of self-deprecation Hopelessness Helplessness
2. Self-destructive behaviour	Hanging self with a rope Jumping over high walls/cliff Shooting self with a gun Banging own head against walls Cutting own major blood vessels Using carbon dioxide to kill self e.g. car exhaust pipes Taking overdose of sleeping tablets Not eating food/starving self Suicidal ideation
3. Rejection and stigmatisation	Thrown out of house/left in the house by wife/husband/brothers and sisters Discriminated by others e.g. friends Isolated or not willing to mix with the person infected Being labelled by the illness or called by such illness or names Dismissed from employment because of illness Being judgmental/blaming
4. Anxiety and fear	Panic disorder Anxiety Fearfulness Gastro-intestinal complaints e.g. Diarrhoea Sweating Restlessness Difficulty in concentrating or mind going blank Irritability Preoccupations about death Worry Anticipatory grief reactions Anticipating the worst Low self esteem or feelings of worthlessness Emotional detachment

Table 1: Psychological experiences of HIV/AIDS by infected patients at first diagnosis.

The biographical data describe that ages of the participants ranged from 18 to 60; two (2) women were in the middle 40s of age and they were holding professional qualifications and working. The male participants were 18 and 24 years of age and both presenting symptoms of substance abuse.

Discussion of Findings

Depression and hopelessness

All participants interviewed looked very sad, after being asked how they felt. After being told of their status, they would cry/weep and later answer still with sad faces and low tone of voice to show that the information that they were HIV positive had affected them and they became stressed. One participant said that he felt as if people who talked and laughed were laughing at him, and it was worse if they were pointing fingers towards him. Those who had known their status for some time pointed out that they had lost appetite and had not been sleeping well since then. However, depression was more pronounced in one participant who had his CD4 and subset cell count checked and found that the doctor was saying that they were too low, implying that the immune system was very low. He also lost hope for himself. This was a clear indication that the participant was depressed. Another participant verbalised the fact that he saw an advertisement for a job and went to apply for this job. After filling in forms he was told to go for a blood test for HIV. He says he felt that he was worthless since he was not going to be employed because of his status. All participants expressed that they had lost hope because there was no cure for the virus they had contracted. This is supported by the following quotation *"Hearing the nurses talk about my name and my status while in the ward made me cry, and I was depressed for quite some days and lost hope on the confidentiality issue. I do not know how many other patients heard them talk like that in the middle of the ward."*

According to Jin et al. [22], 79% in a group of HIV-infected individuals in their study developed major depression within six months of knowing their seropositivity. Over half of the HIV+ group had suicidal thoughts, and one-third had either made a plan for suicide or had attempted suicide.

According to Murphy et al. [23], the episodes of depression may then be triggered by stress, difficult life events, side effects of medication, or the effects of HIV on the brain. Whatever its origins, depression can limit the energy needed to keep focused on staying healthy, and research shows that it may accelerate HIV's progression to AIDS. Treatment for depression in the context of HIV or AIDS should be managed by a mental health professional, for example, a psychiatrist, psychologist, or clinical social worker, who is in close communication with the physician providing the HIV/AIDS treatment. This is especially important when antidepressant medication is prescribed, so that potentially harmful drug interactions can be avoided [23].

Self-destructive behaviour

A participant who spoke about attempting to commit suicide by starving himself looked very malnourished, but at that time he said that he had started eating again. There were no visible scars on any participants and requesting the participants to take off their clothes fell beyond the scope of this study. Three of the participants verbalised that they had suicidal inclinations. Among those, two of them had stopped the attempt because their relatives came into the house when they were about to commit suicide. That was a serious issue that indicated that there was anger and depression among the infected people. One informant said *"I was found by my younger brother, when I was about*

to hang myself, I was on top of the boxes with the rope on my hand, he asked me what I was doing and I felt so ashamed. All I did was to step down and cried."

Some studies found that being HIV+ was related to engaging in self-destructive behaviour. A study by Jin et al. [22] demonstrated that over half of the Chinese HIV+ group had suicidal thoughts, and one-third had either made a plan for suicide or had attempted suicide after they learned of their seropositivity. Engaging in self-destructive behaviour was demonstrated by Thompson et al. [24] as a way of coping. Alcohol misuse enabled HIV positive individuals to escape from reality of everyday living. Alcohol was used as "liquid courage" to help with disclosure to family and others. It allowed them to progress disclosure by claiming a loss of inhibition, allowing them to move to a more empowered state [24].

Rejection and stigmatisation

Four of the participants cried as they related their experience of being rejected by significant others. It showed that the experience had affected them negatively. Participants felt that they were being marginalised. Three of the participants verbalised that they were being rejected by their family members, some by their own brothers, sisters and spouses. Stigmatisation was also an issue here because one of the participants stated that he hated himself for having the virus because he frequently tried to figure out where he might have acquired the HIV virus. One informant said *"Community members used to say that I had AIDS because I was too thin and they continually stigmatised me despite the fact that I had not disclosed to them, unless those I told did tell them."* Stigmatization by family and often considered an important source of unconditional love and support. Stigmatization by family may thus threaten a fundamental human need, namely the need to belong [7].

A study by Simbayi et al. [8] also demonstrated that a substantial number of participants reported AIDS related discrimination and stigma since testing HIV positive. A greater proportion of men lost their job or place to stay. The concept "stigma" has been defined by different scholars in a wide range of different circumstances, particularly in relation to health. In the study done by Parker et al. [25] they reported that from leprosy, urinary incontinence and mental illness the concept of stigma has been applied in a wide range of circumstances, particularly in relation to health.

Parker and Aggleton [25] quote in their article the research done on stigma in relation to HIV/AIDS. According to the broader literature on stigma, it tends to be understood as being expressed in highly emotional terms for example anger and other negative feelings towards people living with HIV/AIDS. That in turn leads to the belief that they deserve their illness, avoidance and ostracism. There is support for coercive public policies that threaten their human rights. This stigmatisation of people living with HIV/AIDS has been documented among members of the society in general, but particularly alarming is its existence among health service providers [26]. Previous research shows that many PLWHA assume that health professionals are knowledgeable about HIV and thus expect them to be at ease with them. When health professionals' actions suggest otherwise, disappointment and subsequent psychological distress may ensure [7].

Anxiety and fear

All of the respondents interviewed looked very anxious and sensitive when talked to, and when asked the reason for such anxiety, the answer would be that there was no problem. The researcher observed that all of them had their eyes wide open, and at times when

you talked to them they would not be able to answer at once, since they seemed to be absorbed in thinking of something else and as if seeking clarification over what was said. Anxiety is a feeling of apprehension caused by an anticipation of danger which may be internal or external. In this case anxiety is caused by the internal thoughts of an infected person. Perhaps participants were afraid that God was really punishing them, as one writer said, "Bishop Michake Dlamini from Niniva church of God said, 'God is punishing us for our sins'" [27], claiming that this is written in the Bible. Perhaps they were anxious because they thought people knew or could see that they were HIV positive. It could be that they were haunted by the words that God was actually punishing them as some people may have told them. They also worried about dying. They are worried that death had come, as if they had been told that they would die the next day or very soon thereafter. The participant showed indifference to feelings by saying: "*A zwo ngo vhuya zwa mmbavha lini, ndo farea sa muthu munwe na munwe*". (*la belle indifference*) as if he was not worried about being HIV positive. Which indicated a patient's inappropriate attitude towards a serious problem, that is the patient seems to be unconcerned about what appears to be a major impairment [28]. In expressing fear the informant said the following "*I heard the nurse informing the other nurse giving report about me, but I managed to hear what she was saying, that I am HIV positive, I cried bitterly although I was not sure and who else heard the news about me, that remained my headache*." Stressful life events are associated with high levels of depression and high levels of satisfaction with social support and adaptive coping is associated with lower levels of depression [23]. However, Murphy et al. [23] suggest that episodes of depression may be triggered by stress, difficult life events, side effects of medications, or the effects of HIV on the brain.

Recommendations

Based on the findings, HIV/AIDS is a serious problem, which the majority of people of all age groups still lack knowledge of today, the youth being the most vulnerable group. From the research, the majority of those interviewed did not have much information about HIV. They say they thought it does not exist. In this study the age range of the participants was from 18 years up to 49 years. The 18-year-olds fall among the youth. The high infection rate among the youth is confirmed by the report of the U.S. spokesman that infection starts from 15 years of age to 49 years [29].

- Community mobilisation by lobbying political organisations is essential. This is aimed at unleashing resistance to such stigma and discrimination through the use of a rights-based approach in the form of campaigns [30]. The campaigns create a socially transformed climate where stigmatisation and discrimination are no longer tolerated by community members themselves. Campaigns must emphasise that even infected people have the right not to be stigmatised and discriminated against.
- There is a need to empower voluntary health workers with proper counselling skills by Health Care professionals if care of the infected people is to be left entirely in their hands, as it is presently reported that nurses rarely visit. The empowering of voluntary health workers is suggested as it is strongly felt that there is a need for continuous psychotherapy to support the clients so that they can cope with their plight.
- Nurses and health workers need to be cautioned about the need for and the importance of maintaining confidentiality regarding HIV/AIDS, and the pain the infected people experience, when confidentiality is not maintained.

- They need to include Frankl's model of logotherapy during their post-counselling sessions so that the infected persons realise their need to survive or something to live for. Logotherapy is an approach to psychotherapy based on the existential model and developed by Frankl. The focus is on the search for meaning in the present experiences [31]. This type of psychotherapy would help the infected to see the need to speak out about their illness. People infected with HIV would see the need to realise that despite being infected, one still has the responsibility to love oneself, and to live one's life to the full even though one is infected. Fear of death, which is the worst terror, would be minimised. Education about logotherapy and confidentiality should be part of the curriculum and be emphasised, and nurses need to be reminded about related legislation.
- Strong support systems are a necessity. This is possible and can be achieved by counselling the relatives and spouses of infected people when the clients are ready to disclose their own status. Relatives and loved ones are always pillars to support whoever is facing a crisis situation. Pastors of religion and traditional healers need to be trained to counsel those who visit them with such problems. Non-governmental organisations need to be supported by the Department of Health, since they are the ones who are doing much of the work in caring for the infected, and as support systems.
- It was realised that religious people are not involving themselves in matters of HIV/AIDS as much as expected. They are involved in many encounters with populations that seek help from them, but they provide such help without talking about HIV/AIDS. There is a need to encourage such religious people by empowering/equipping them with knowledge regarding HIV/AIDS. They are at strategic points where, if campaigns are held, such information would reach many. The Department of Health, nationally, provincially and at local level, should direct this request to religious leaders and health professionals at their churches to get involved in HIV/AIDS issues and campaigns.

Limitations of the Study

The study was limited to a sample of 6 HIV infected patients who experienced psychotic behaviour at first diagnosis and admitted in the hospital. Therefore the experiences of other patients who were found HIV positive and did not present themselves with psychotic behaviour remain unknown. The study lacks follow up in terms of the CD4 and viral load count for the patients who participated in the study and did not establish thereafter whether the patients have started the ARV regimen.

Conclusion

Depression and hopelessness were explicit from the data. All participants experienced fear and depression caused by different stressful experiences. All participants appeared very sad, due to the fact that they did not know what would happen to their family members and their loved ones when they were killed by HIV/AIDS. The fact that the disease does not have any cure caused the participants to express fear of imminent death. Self-destructive behaviour was noted from about 50% of the participants. Participants had suicidal inclinations. They all attempted suicide and failed to succeed as they were found by their relatives. Most of the participants feared to disclose their status for fear that they were going to be stigmatised and rejected by their family members, their loved ones and eventually the community.

The participants feared that the stigma of HIV/AIDS may also follow their children. Many other problems associated with HIV/AIDS like discrimination, unemployment and leaving children with no one to take care of them were expressed by the participants. Emotional distress like crying was also identified in one participant who complained that nurses did not maintain confidentiality over her HIV/AIDS status.

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