

**UNIVERSITY OF MALAWI
KAMUZU COLLEGE OF NURSING**

**PSYCHOSOCIAL EXPERIENCES OF PEOPLE LIVING WITH
HIV/ AIDS AT LILONGWE CENTRAL HOSPITAL HOME BASED
CARE, IN LILONGWE.**

BY

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DECLARATION

I declare that this dissertation is completely the result of my own work and that it has not been submitted for any other degree at Kamuzu College of Nursing.

Signature.....Date.....

CANDIDATE

Signature.....Date.....

SUPERVISOR



DEDICATION

This dissertation is dedicated to my parents; Mr. and Mrs. RT Ghambi, my only brother Loftus, my sisters; Fiona, Sapila and Jane and lastly to my best friend Eric Kenamu. Without their love, patience, support and encouragement the four years could have been a failure.

MAY GOD CONTINUE TO SHOWER BLESSINGS UNTO YOU.

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ABSTRACT

HIV/AIDS has caused a lot of havoc across the world. This is havoc, because it mostly affects people who are in their prime of life. Many children have remained orphaned because of this deadly disease

Having seen the condition worsening like this, this is why the researcher decided to look at psychosocial experiences of people living with HIV/AIDS at Lilongwe Central Hospital Home Based Care in Lilongwe.

The convenient sample size of twelve people living with HIV/AIDS was employed in the study. Ten of them were males and two of them were females. The ages ranged from 25-52 years with an average of 39years.

Roy's adaptation model was used in this study as a theoretical framework.

Data was collected using an interview schedule and it was summarized in form of frequency tables and content analysis.

Findings from this study will benefit patients living with HIV/AIDS on how to live positively with their condition. The findings will also help guardians, health care Providers NGOs and the Government on how to give comprehensive care to people living with HIV/AIDS.

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ABBREVIATIONS

AIDS: Acquired Immune Deficiency Virus

ANW: Argentine Network Women Living With AIDS.

GALZ: Gays and Lesbians of Zimbabwe

HIV: Human Immuno Deficiency Virus

HBC: Home Based Care

LCHHBC: Lilongwe Central Hospital Home Based Care

MDHS: Malawi Demographic Health Survey

MOHP: Ministry of Health and Population

NGOs: Non Governmental Organisations

NAPHAM: National Association of People Living With HIV/AIDS

PLWA: People Living With HIV/AIDS.

STIs: Sexually Transmitted Infections

TAWG: Tanga Working Group

WB: World Bank

WHO: World Health Organisations

VCT: Voluntary Counselling and Testing

DEFINITION OF TERMS

Psychosocial: Mind and behaviour of a person in relation to others

Cognition: being aware something

Community A group of people sharing the same boundary and having
common interests

HBC: The care of chronically ill patients in their home environment
using locally available resources

Gays: homosexuals

Lesbians: homosexual women

Experiences: process of gaining knowledge or skill by doing and seeing
things

INTERVIEW: meeting with somebody for formal consultation.

(Definitions from advanced learner's dictionary).

1.0 INTRODUCTION

AIDS is an abbreviation for Acquired Immune Deficiency Syndrome. Human Immune Deficiency Virus (HIV) causes it. It reduces the body's immunity, making it more susceptible to attacks by opportunistic infections (Wilkinson's, 1987). This disease is killing most of the people in the world. It especially threatens the developing countries and poor marginal groups aggravating poverty. More dangerously, it incapacitates people at ages when they are most needed for support of young and the elderly (Mac Graff,1994). People with HIV/AIDS have psychosocial experiences. Psychosocial experiences are other experiences, other than physical that an individual may face due to his condition. These may be economical, work related or to do with daily life. This is why the author has decided to know both positives and negatives experiences.

1.1 BACKGROUND

AIDS is causing a lot of havoc across the world. It is estimated that in 1996 there were approximately 3.1 million new HIV infections throughout the world, an average of 8,500 new infections per day (Matsebula. 1997). He went further to explain that the total number of people living with HIV infections is currently estimated at 22.6 million of which more than 50% are women and 1 million are children.

In 1994 AIDS was identified as the biggest threat to Africa's economic development and yet it has taken more than a decade for most countries to recognise its seriousness and introduce measures to arrest the spread of this disease (Games, 1999). Similarly AIDS has posed a challenge to Malawi's development. It was first diagnosed in 1985 and has at least affected 25% of the urban workforce. According to Malawi Government and World Bank research conducted in 1998 on experiences of people living with HIV/AIDS, it was

estimated that those people who were already HIV positive are likely to die by the year 2008 (Mkandawire 1999). It is now recognized that Africa AIDS constitutes a humanitarian crisis of immense proportions (Kerr, 1989).

The impact of HIV/AIDS on health, social and economic life in the region is very enormous. Life expectancy in some countries like Malawi and Zambia is already beginning to decline. Mortality has been increased especially in children under the age of five years.

Malawi was reported as having the highest rates of HIV infection in the world with an average of twenty five people being infected with HIV, six developing AIDS and five dying from AIDS every hour (Liomba, 1994).

People living with HIV/AIDS have psychosocial experiences that need to be looked into. In a study done by Barnett (1993) in London on assessment of the needs of people living with HIV/AIDS, the results indicated that a broad range of services were being used by people living with HIV/AIDS. This was reflecting their physical and psychosocial needs and in a way of exploring their living experiences.

On the other hand, Renne (1990) stated that HIV/AIDS has complex social and political dimensions which needs much attention and that there are other psychological issues in people living with HIV/AIDS that need to be addressed. Tuju (1992) agreed to say that the psychological issues of PLWA include fear of unknown and the tendency to depersonalise, fear of contagion, fear of death, denial, helplessness, anger and over identification.

On the same issue Osei-Hwidie (1993) went on to explain that many people react to AIDS with denial, panic and stigmatization. Many families and individuals are unwilling to share their diagnoses due to the essence of guilty and shame associated with behaviour, which

leads to HIV infection. PLWA also fear community conclusions that may lead to withdrawal of the service to the infected and the family (Miller 1991).

This HIV/AIDS impact and effects on psychological, spiritual, physiological and socio-economic lives of people have been greatly felt by individuals, families' religious communities and the entire nation. There is no vaccine or cure for HIV/AIDS, hence the importance of educating the community on prevention and care messages. Malawi Government started its effort on community education to prevent the spread of the disease in 1992 (Sisya, 1997). It is not only the government that is helping to prevent the spread of HIV/AIDS in Malawi but non governmental organisations have also responded to the need of HIV prevention with imaginative and innovative community based programme. This is not a new concept. The modern concept of a nurse who provides care to families in the homes was visualised and established in 1859 by William Rathbone of Liverpool and Florence Nightingale. They had no hospital in their country but they could train people in their homes to care for the sick to lessen the burden of illness and most of the people recovered. Later on, things improved in their country, Nightingale founded a school for training of visiting nurses on the grounds of Liverpool Infirmary. This home-based care nursing is also practiced in South Thailand. Nurses are assisted by La Tribe University (Australia) in sharing skills with village women so that they can manage those sick with different conditions including HIV/AIDS and STIs more effectively and efficiently. Similarly, in Malawi HBC is practiced. Home-Based Care is defined as the care of chronically or terminally ill patients in their home environment using locally available resources. In 1990, a needs assessment was carried out and findings were that patients were willing to be cared for at home (MOHP, 1995). They went further to weigh the advantages of home-based care. The findings indicated that guardians accepted to take responsibility provided the basic resources and skills were readily available. This consists of food, shelter,

clothing and medication. Home Base Care has its goals. The main goals are that the patient should be cared within family structures and it allows family to care for the patient while doing household work and integrates care with HIV education which promotes acceptance of the disease and the prevention of HIV (MOHP, 1995). The last goal is to reduce hospital congestion.

1.3 *SIGNIFICANCE OF THE STUDY*

With proper focus on the HIV/AIDS impact to the nation, it is worthy realising that people living with HIV/AIDS need comprehensive care. They need information about sexual activities that reduces the risk of infection and re-infection. They need support to accept their HIV status and feel confident about living with proper care.

HIV greatly affects people who are in the prime stage of life, leading to loss of people's lives and reduced productivity in many aspects of life. A large number of children remain orphaned and the elderly are left without people to care for them and this impinges their social and psychological areas of their life.

The results from this research will therefore help families of people living with HIV/AIDS to understand the relationship between the physical illness and the psychosocial support that their relatives need. This also applies to the nation at large, the Government, and NGOs.

1.4 *BROAD OBJECTIVE*

To find out the psychosocial experiences of people living with HIV/AIDS at Lilongwe Central Hospital Home Based Care in Lilongwe.

1.5 *SPECIFIC OBJECTIVES*

-To find out the positive psychosocial experience of people living with HIV/AIDS at Lilongwe Central Hospital Home Based Care in Lilongwe.

-To find out the negative psychosocial experiences that the people living with HIV/AIDS are going through at Lilongwe Central Hospital Home Based Care in Lilongwe.

-To find out which psychosocial areas should be encouraged in people living with HIV/AIDS at Lilongwe Central Hospital Home Based Care in Lilongwe.

-To find out what measures can be put in place in order to remove stressors in people living with HIV/AIDS, so that they can live a longer period.

-To find out which physical areas need to be encouraged in PLWA at Lilongwe Central Hospital Home Based Care in Lilongwe.

-To find out how spiritual life is helping PLWA at Lilongwe Central Hospital Home Based Care in Lilongwe.

CHAPTER 2

2.0 LITERATURE REVIEW

2.1 *HIV/AIDS*

With basis on reliable research studies it is clear that many people are infected with HIV/AIDS and that the pandemic has many negative impacts worldwide. According to Kaplan, (2000), it was estimated that more than 18 Million people are infected with HIV/AIDS worldwide. This explains how many people will die of the pandemic in the coming years. Most of the people will die of AIDS and economic hardship will come in because; most of the countries will have to put more money in the health sector to help people who are suffering. People, especially children will lack support, because they will have nobody to look after them. They will suffer because of the death of their parents (Kaplan, 2000).

Similarly, in a Malawi AIDS assessment study done by Malawi Government, in conjunction with WHO (1998) it was evident that the majority between the age range of 15 to 49 is infected with HIV/AIDS. The findings were; about a third of 15 to 49 year olds in Blantyre and Lilongwe districts are estimated to be HIV positive. This therefore implies that many youths are likely to die of AIDS in some few years to come; yet the Government of Malawi is also depending on these individuals. Most of these people will die in their productive ages, when they will be needed most both by their families and by the government. These negative effects are indications of further spreading of HIV. This then calls for concerted efforts in the fight against HIV/AIDS, so that problems of increasing number of orphans, underdevelopment, individual and community suffering of the victims and their families are reduced.

2.2 *PSYCHOSOCIAL EXPERIENCES*

Most of the countries in Africa are concerned about the psychosocial problems that people living with HIV/AIDS are facing. For instance in Zimbabwe, PLWA, gays and lesbians are discriminated both in the work place and in the community (Hall, 2001). He further explained that PLWA are often isolated and suffer the complications of HIV/AIDS. At present, it is difficult for gay men to join support groups and to disclose their sexual preference because of homophobia and negative attitudes. Although the situation is like that, other parts of this country have started helping these people living with HIV/AIDS. People living with HIV/AIDS are advised to join support groups that are sensitive to their need to protect the uninfected partners. This is why Zimbabwe came up with the association called Gays and Lesbians Association of Zimbabwe (GALZ) in 1998(Hall, 2001).

Similarly in Uganda, in a study done by Mac Graff (1994) in Kampala, people did not allow ambulances to transport AIDS patients leaving them to die at home Emergency rooms from the same hospital overreacted to the diagnosis neglected people with AIDS and mistreated their families (Cechi, 1986).

Here in Malawi it has also showed that AIDS disease has a lot of stigmas attached to it. According to a study on 20 people, conducted by the Malawi Demographic Health Survey (1999) looking at bio psychosocial experiences of people living with HIV/AIDS it was found out that 80% of HIV/AIDS problems are psychological.

Mkandawire (1999) concurred by giving an example of a 27-year-old man, who said "People look at me as a living corpse and blame me for contracting the disease. They view AIDS as a shameful condition" She went further to explain clearly how most of the people stigmatise people living with HIV/AIDS. If the person is diagnosed sero positive, people associate it with casual sex. However, it is not only casual sex, which can spread AIDS, but

also use of the same razor blade toothbrush, mother to unborn child and from a spouse through sexual intercourse.

In a same study conducted in Lilongwe district by Mkandawire (1999) on experiences of people living with HIV/AIDS at Area 23, female subjects reported that immediately they disclosed to someone of their HIV/AIDS status, they were resented, isolated and stigmatised. They were viewed as outcasts. The findings were that 40% of the subjects were divorced and they reported that their husbands left them immediately they informed them of their HIV/AIDS status. They said it was as if the words 'sex' and 'immorality' were printed on their face. On the other hand, men reported that their wives provided psychological support.

MDHS (2000) conducted a survey to identify or evaluate the level of stigma attached to AIDS and condoms. Subjects were asked whether somebody should disclose her status if she is HIV positive. The results were 26% of women and 17% of men thought HIV individuals should be allowed to keep their status in private. Some of the reasons for not disclosing their status were; programs aimed at assisting people with HIV patients and their families were not available. Programs designed to assist in the support and care of AIDS affected persons were hindered by fear of association with HIV/AIDS and the last one was discrimination in the work place against those infected with HIV/AIDS.

In another study conducted by MDHS (2000), 200 subjects were asked, if people living with HIV should be allowed to work in shops or offices. Results indicated that 49% of women and 53% of men think that they should work. This means that about a quarter of adults harbour some level of stigma against HIV infected persons. In line with this, Malawi Government has allowed people living with HIV/AIDS to form organizations where they would support and assist each other in different ways. This is a positive step towards

reduction of stigma hence promote positive living in people living with HIV/AIDS. Here in Malawi there is an association of PLWA and it is called Nation Association of People living with HIV/AIDS in Malawi (NAPHAM). It aims at promoting health through self-care and support. They care for one another when they fall sick and now they are trying to involve their families. They also promote self-reliance through income generating activities (Chikafumbwa, 1995). Most of the people living with HIV/AIDS have benefited a lot both physically and psychologically.

2.2.1 PERSONAL TESTIMONIES

People living with HIV/AIDS share testimonies on how they are living with their status and the response to their condition. The southern Africa high court judge, campaign for gay and human rights who declared his homosexuality three years ago disclosed that he has HIV/AIDS. "I am living with AIDS, the choice to speak is available to me because I have a job position that is secure, because am surrounded by loved ones, friends and colleagues who support me and because I have access to medical care", he told the judicial court commissioner (Cameron, 1999). One needs to accept his condition and consider his psychological and social areas so that he can adapt to the new condition and start a new life.

Another judge also stated that "taking care of oneself is not a matter of finding a good doctor but one needs to care for herself mentally, emotionally spiritually and sexually. No matter how one can claim to be prepared but receiving the result of being HIV positive often brings about shock, anger, depression bargaining sickness of the mind among the reactions. Death though intangible, it becomes real. I believe HIV is another living thing. I am sharing my life with this virus as well as my body. When I die, HIV dies along with me" (Matsebula, 1992). A certain person living with HIV/AIDS spoke those words. He was tortured psychologically and socially.

2.2.2 LIVING POSITIVELY WITH HIV/AIDS

To live positively with AIDS means that a person has gone through the grieving process after being diagnosed HIV and then has accepted his status. Due to the growing number of people living with HIV/AIDS, different countries have reacted positively to the pandemic. They have allowed people to form associations with government support. Women living with HIV/AIDS in Zimbabwe explained that they are in a support project aimed at whimpering them to live positively and plan for the future, with the support of other organisations in Harare. This include counseling, legal advice on their family and inheritance rights, health and nutrition advice including a scheme of bulk buy and resell food supplies such as mealy meal, dried fish Soya products to earn their living (Phillip, 1999).

However, women and men around the world feel isolated when they learn of their diagnosis. Women especially have difficulties in contacting peers in the same situation yet this provides great psychological benefits. When a woman at the clinic in Zimbabwe was asked if she would like to meet other women with HIV, she responded by asking the person to give her the telephone number of those HIV persons. After the discussion they could make plans to meet each other and they realised that they were not wrong or criminals. In Zimbabwe women have formed a group in which they verbalise the problems they are facing. This includes HIV problems, supporting each other and having fun (Richardson and Bolle, 1992).

The AIDS department of the Catholic Diocese of Ndola, in Zambia, which was set up in 1993, has developed community activities to support and care for people living with HIV/AIDS. These activities include nursing, spiritual and pastoral care social welfare, prevention activities and human and legal rights (Magwere, 2001). Six hundred volunteers

support almost 12000 people with HIV/AIDS in the form of food, clothes, school fees and medicines.

Support is also given to children orphaned by AIDS through home visits and provision of food, school fees and legal advice. Volunteers also provide bereavement counseling and spiritual support. However limited resources and a harsh economic climate pose a challenge to coping with large number of orphans. Worker's at the program have identified ways of supporting the increasing number of children headed household and coping with the long term psychological effects of HIV/AIDS on children as the main challenges for the future (Macheta 2001). This clearly indicates that the burden of caring orphans has lessened in some areas of this country.

The Tanga working group (TAWG) based in the Tanga region of Tanzania is an Alliance of people living with HIV/AIDS Traditional healers, Biomedical Health workers, Botanists and Social Scientists. They provide Pre and Post Test counseling as well as family counseling. The people living with HIV/AIDS are provided with traditional medicines and Biomedicine's to treat opportunistic diseases (Cameron, 1999). This organization is helping a lot, by reducing the pains of people living with HIV/AIDS.

Similarly, People living with HIV/AIDS in Africa benefited a lot from the Belgium donation of drugs. They appreciated the donation, which came from Janssen Pharmaceutical of Belgium. These drugs are used to treat fungal infections related to AIDS for example oral Esophageal candidiasis. These drugs are micronazole and Ketaconazole (Merson, 1993). Most of the countries have shown interest in helping PLWA and this has lessened the burden of this disease.

Association of women living with HIV/AIDS in Canada is helping participants find way on how to cope with their condition. This association has provided women most directly

affected by the pandemic with a voice at global and regional levels. They have an association of sero-positive women in many countries. At the national and community levels, sero-positive women are joining to make the ideal of living positively with the virus a reality. They aim at supporting each other to lessen the burden of this killer disease. The national women and HIV project in Canada created coalition of HIV positive women by supporting regional networks and developing communication tools (Canadian Aids Report, 1995). Such supporting networks should be encouraged to lessen this pandemic.

The Argentina network of women living with HIV/AIDS (ANW) gives information about AIDS, helps to access treatment and medication through state and private services and make referral to NGOs and governmental social services.

People living with HIV in London receive help from the Terrence Higgins Trust. Terrence Higgins was one of the first persons to die of AIDS. This Trust provides direct social care to people with HIV of AIDS. They offer emotional, practical support to minimise the confusion, fear and isolation that may result from AIDS. Some of the problems that they assist these people with HIV/AIDS are homelessness, harassment, eviction and other serious housing problems. At a time of diminishing public housing in the UK more than 60% of clients with HIV infection were found to require housing options and in 1991, they successfully placed 85% of requesting clients in safe and inexpensive accommodation (Karlin 1993)

2.2.3 RIGHTS OF PEOPLE LIVING WITH HIV/AIDS

Everyone is entitled to all human rights without discrimination based on actual or suspected HIV status. People living with HIV/AIDS have the same rights as sero negative. They have rights to education, employment, health, travel, liberty, marriage, procreation, privacy, social security and scientific benefits.

Both sero- negative and sero-positive people share responsibility to avoid further HIV infections. People with HIV/AIDS and political or social marginalised people have the right to take part in formulating and implementing HIV/AIDS policy and program (Macmillan & Scheinman). This confirms that even if one has HIV/AIDS it is of no reason that she should be denied her benefits and rights. Respecting that the rights of HIV/AIDS people are equal to those of the uninfected colleagues.

CHAPTER 3

3.0 THEORETICAL FRAMEWORK

3.1 *ROY ADAPTATION MODEL*

Adaptation is being able to cope satisfactorily. Roy adaptation model sees people as possessing a set of interrelated system within them and that they can adapt to the ever-changing world. He explains that the best way to understand a person is to study him as sets of interconnected biological, psychological and social system that influence behaviour. She describes her nursing model as a Bio-psychosocial model of nursing. She further identifies that each system within an individual exists in a state of constant interaction with the environment, striving to maintain relative balance both within itself and its relationship to the outside world. In this way each system within the person is motivated towards conditions of homeostasis and aims to achieve within limits. She also looked at the areas on maintenance of relative balance in physiological systems relating to fluid balance and regulation of food intake. The second referred to the tendencies that enable individuals to cope with new psychological and social experiences. She believed that in much the same way as there are limits to the extent to which food and water can be satisfactory ingested at one time. There may be limits to these at one time, there may also be limits to social experiences that a person can adequately deal with. Further more she explained that people are organisms concerned with maintaining their physiological and psychological systems within a range of conditions unique to themselves.

According to Roy such a set of conditions makes up a person` adaptation level and new stimuli that fall within the range of possibilities, are likely to be reacted to more favourable than those that fall outside it. Therefore a person`s adaptation level is little to the ones that

fall outside his adaptation level compared to that average of adaptability within which it is possible to deal adequately with experiences.

Roy's model of nursing urges that there exists four principal systems of adaptation influencing behaviour and these are physiological, self-concept, role function and interdependency systems.

The psychosocial model recognises the importance of the effect of the condition of the individual as a whole other than concentrating on the condition alone (Burke, 1996). Roy's model integrates information from other disciplines and applies to nursing perspective. It views people as a system. This system comprises of physiological, biological and social aspects. Rambo (1984) concurred that although these sub-systems are studied separately, in reality they intercover and balance to produce functioning person inseparable psychological, biological and social needs.

3.2 APPLICATION OF THE MODEL TO THE STUDY

Roy adaptation model provides an excellent framework that benefits this study. It was chosen because of its emphasis on viewing a person as a system that has sub-systems as biological, psychological and social parts. She explains of how people can adapt to different situations. This model has already explained that every person strives to attain state of relative psychological and physiological equilibrium. This means that if a person is diagnosed HIV, his physiological and psychological parts are disturbed; a new stimulus has entered his life and is not within his adaptation level. This is so because he has never suffered from the disease before. To adapt to this new condition, he effects change in his stimuli, so that it must fall within his adaptation level to enable the individual cope more effectively. For him to cope with this situation he needs to consider the physical, social, and psychological areas. On physical he should make sure he eats a balanced diet. This consists

of proteins, carbohydrates and vitamins to prevent frequent attacks from opportunistic infections. The person living with HIV/AIDS has to use Roy's` interdependency principal. He has to interact with others to avoid loneliness, which may cause a lot of stress in his life. In this there is need to stimulate a positive response from the body to maintain an individuals` social integrity.

The primary role of a person living with HIV/AIDS is to accept the status. He has to take care of himself by being faithful to one partner, using condoms during sexual intercourse, drug compliance and to eat a balanced diet. By doing these things mentioned above he is going to maintain his self-image as system and will adapt and adjust to the pains of the new status positively.

CHAPTER 4

4.0 METHODOLOGY

4.1 DESIGN

Descriptive design was employed to obtain information on psychosocial experience of people living with HIV/AIDS who attend Lilongwe Central Hospital HBC. This is an appropriate design because it explores more on the problem. By observing and comparing, the researcher was able to gain holistic views.

4.2 SETTING

The study was conducted at Lilongwe Central Hospital Home Based Care. This place is where health services for HBC are offered. When people are counseled on HIV testing, they go for it and come back with the results whether positive or negative and they are helped accordingly. People who attend this Home Based Care are those who are terminally ill patients.

4.3 SAMPLING

A convenient sample of 12 subjects of which 2 were men and the remaining 10, were women was employed. This is because of economic and practical reasons. This refers to money for conducting the research and time needed to analyse the data. The other reason for having a small sample was that most of the male patients were very sick that they failed to respond to the questions.

4.4 INSTRUMENT DEVELOPMENT

An interview schedule was used to collect data. It comprised of section A, which contain demographic data, this helped the researcher to know which sex or age range that is affected mostly by HIV/AIDS and section B, which contain psychosocial experiences of people living with HIV/AIDS, who attend Lilongwe Central Hospital Home Based care. In addition to that, the interview schedule had physical and spiritual experiences section. It was chosen as a tool because it is easy to clarify questions when misunderstandings arose. However, it has its own disadvantages, the researcher can be biased. (Polit & Hungler, 1989).

4.5...INSTRUMENT MESUREMENT

A pilot study was conducted. The pre-testing was done on two people. Pre-testing helps to ensure reliability and validity of the instrument (Polit and Hungler, 1989)

4.6 ETHICAL CONSIDERATION

Before conducting the study clearance was obtained from the Clinical Director of LCHHBC. This was done to ensure protection of human subjects. Informed consent was obtained from each subject involved before the commencement of this research. To maintain confidentiality identification numbers were used on the interview schedule forms. The interview was conducted on one to one basis in a private area in order to ensure privacy and subjects did not mention their names to maintain anonymity.

4.7 DATA ANALYSIS

Data was analysed using descriptive statistics. In addition to that, content analysis was used on information obtained through open-ended questions, according to their similarity of responses.

CHAPTER 5

5.0 PRESENTATION OF FINDINGS

5.1 *DEMOGRAPHIC DATA*

Twelve participants were interviewed. Ten of these participants were females representing 83% and two of them were males, representing 17%. Their ages ranged from 23-52 with an average of 37 years. The interview was conducted on people living with HIV/AIDS at Lilongwe Central Hospital HBC. The people interviewed were those who were willing to give out information about their psychosocial experiences and they were not severely ill. Out of the 12 participants 7 were married, 2 divorced and 3 widowed. All participants belonged to different churches. Five belonged to Roman Catholic, 3 Islamic members, 2 C.CAP members, one Faith of God member and lastly one Assemblies of God member. Out of the 12 participants 9 participants reported that they are housewives. The remaining number (n=3) belonged to different occupations and these are self-employed job (saloon), taxi driver and builder.

5.2 *PSYCHOSOCIAL EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS.*

5.2.1 THE DECISION TO GO FOR HIV TEST

When asked to explain on what made these participants go for the HIV test, they explained that they were sick for a long time. The period for their sickness ranged from 3 months to 1 year. Some of these patients were admitted in the hospital.

Table 1: Conditions that people living with HIV/AIDS at LCHHBC suffered from before going for HIV test.

Condition	Frequency	Percentage
Tuberculosis	5	42
Malaria	4	33
Skin rash and itching	3	25
Diarrhoea and vomiting	1	8
Oedema	1	8
Fever, heart palpitations, leg pain back pain and anaemia	1	8

During these illnesses these patients (n=12) frequently visited the hospital due to severe pain they had. They were weak and uncomfortable. The other reason that made these participants to go for the test is that they wanted to know the source of their long illnesses. Counsellors from LCH counselled them on Voluntary Counselling and Testing (VCT) and finally they opted to go for the test.

5.2.2 FIRST DIAGNOSIS

These participants had different dates for their first diagnosis. The period of their diagnosis ranged from 1994 to 2002. Two participants were diagnosed in 1994 and 1996 and they showed confidence and were open to explain on what is happening in their lives. They expressed happiness during the interview and said that they thank God for keeping them alive up to now. They said that they received a lot of support from LCHHBC church friends and relatives. At first they thought they would die soon. The remaining ten participants

explained that they have accepted their statuses but during the interview they were not as confident as those who were diagnosed in 1994 and 1996.

5.2.3 IMMEDIATE REACTION AFTER THE DIAGNOSIS

When participants were asked on the immediate reaction after the diagnosis some of them (n=5) explained that they were shocked and disappointed with the news. The reasons were that they did not know how they contracted the disease. One commented, "In marriage I was a good person with one sexual partner, I know it is my husband who brought this disease in our family. As of now he died a year ago due to Tuber culosis problem and I know that soon I will follow him."

Another source of disappointment for one of the participants, was that she had taken almost 7 years without having sexual intercourse with her husband till he died. She went further to comment that "I was hopeless because I knew that my future had been doomed."

On the other hand, the remaining participants (n=7) explained that they were not shocked with the news because they were sick for a long time. At the time of the test, they just wanted to prove if it was really true that they have HIV. The other area that made these participants to take the news positively is the way they were counselled before the test by the counsellors at LCH. One explained, "I had known already that I had AIDS I just wanted to prove through the hospital. As of now I have a plan to start National Association Of People Living with HIV/AIDS in Malawi (NAPHAM) in our area."

5.2.4 ACCEPTANCE OF THE CURRENT STATUS

Most of the participants (n=12) explained that they have accepted their statuses. They explained that it is through LCHHBC, church, friends and relatives who have helped them to accept their statuses.

On contrary, one participant showed that she has not yet accepted her status. She was crying during the time of interview. She explained that she feels pity of herself that she will die soon.

5.2.5 DISCLOSURE OF THEIR STATUSES

Participants were asked whether they disclosed their statuses, the results showed that most of them (n=9) disclosed their statuses to their spouses. They explained that counsellors explained to them that it is not good to disclose to relatives because they may have negative influences leading to breakage of their marriages.

Another reason for not disclosing was the fear of stigma attached to HIV/AIDS and discrimination in their communities.

On the other hand, some participants (n=3) thought it was not good to disclose their statuses. One commented, "I cannot disclose my status to my husband because she is going to divorce me, so I don't even have parents, I am the first born in our family. The only person who looks after our family is my grandmother who has grown old as of now."

Table 3: People whom participants disclosed their statuses to.

Number of participants	People whom participants disclosed their status to
7	Spouses
1	Church elder
1	Mother and sister
1	child

The one who disclosed her status to the church elder explained that his husband died and she had nowhere to disclose her status and also wanted to be helped spiritually.

5.2.6 REACTIONS OF THE PEOPLE WHO GOT THE NEWS

Most of the participants (n=5) who disclosed their statuses to their spouses explained that they showed understanding and showed continuous love and support.

On the other hand one woman explained that his husband said “I told you already that you should stop going out with other men, because all what you were doing outside this home I was told by people. Now you have received your reward.” The relatives were shocked

having heard of their relatives’ statuses but as of now they are used to the situation at hand.

When participants were asked to explain whether they have experienced any positive experiences since they were diagnosed sero- positive, most of them showed that they still have positive experiences. They reported that their spouses still show them love and support. Participants also explained those staff from LCHHBC helps them both physically and psychologically. They explained that for every visit done by the nurse they are offered medications and flour for cooking porridge called Tadzuka. If they are very sick they are referred to the hospital and volunteers visit them in their homes to help them in household chores. Psychologically they are counselled and helped in prayers.

The other area of support they explained was the church. They said the members from their churches visit them in their homes. They support them through prayers, sharing the word of God. Sometimes they help them with money or something of any kind.

They explained that they thank all different types of people who offer support to them.

5.2.7 NEGATIVE EXPERIENCES

The participant who was blamed by her husband for bringing the disease in the family explained that since she disclosed her status to her husband she has never had any positive experience. She commented, “Since I disclosed my status my life is miserable, I don’t

receive any help from my husband. I lost three kids and now I have a baby who is three months.”

Another participant also explained that “Am pregnant, I have only two kids and I lost six kids.”

One of the major negative experiences reported by these people was food. They explained that instead of them having AIDS as the only problem in their lives but shortage of food has also set in forth. Sometimes they became weak because they have nothing to eat.

5.3 *PHYSICAL EXPERIENCES*

When participants were asked if they know the role of a balanced diet in People Living With HIV/AIDS (PLWA), most of them had knowledge on it (n=11). They went further to explain each group by giving examples. They explained that they do not eat because of lack of money as already explained.

Other participants explained that sometimes they do not have the appetite to eat due to loss of appetite and sometimes they have oral thrush. This oral thrush makes it difficult to chew or swallow foods.

When the researcher went on to know if participants had knowledge on alternating rest and exercises in PLWA, only a few had knowledge (n=3). On the remaining participants, (n=9) education was done and the rationale for each was given.

Another area asked was concerning physical part. The researcher wanted to know whether the participants have physical disabilities or abnormalities due to the HIV/AIDS status, the results indicated that a few had problems.

Table 4 Abnormalities experienced by participants since they started suffering.

Number of Participants	Abnormality/Problem experienced
1	Genital sores
1	Karposis Sarcoma on the leg
1	Tinea corporis on the face
1	Coughing with severe chest pain
1	Generalise pain
1	Menorrhagia

One participant who said that she had genital sores explained that she experiences a lot of pain when urinating and defecating. She went further to explain that the sores sometimes bleed. As of now, she was given a cream to apply on the sores. The other participant who was also worried about his condition was the one with karposis sarcoma who wondered whether he is going to walk again. On the other hand, the remaining participants, shown in the table (n=4), were worried whether they will recover from their ailments.

CHAPTER 6

6.0 DISCUSSION

6.1 *PSYCHOSOCIAL EXPERIENCES*

6.1.1 THE DECISION TO GO FOR HIV TEST

In this study participants were asked to explain the reasons why they decided to go for this test. All participants (n=12) explained that they were very sick for a long time. Some of them were admitted in the hospital. They were suffering from different conditions. These conditions included tuberculosis (42%), malaria (33%), skin rash and itching (25%), diarrhoea and vomiting (8%), oedema (8%) fever (8%), heart palpitation, leg pains, back pains and anaemia (8%). This is in agreement with the findings of Mkandawire (1999) in a study done on experience of people living with HIV/AIDS which indicated that subjects had long-standing physical problems and this is what made them go for the HIV test. These problems included weight loss due to tuberculosis (70%). Other participants had malaria attacks, headache fever and shingles (herpez zoster).

In another study done by Medion (1999) on physical problems faced by PLWA, the results indicated that 90% of PLWA develop skin rash and have frequent malaria attacks.

Furthermore, another study was done by Bunnett (1999) in Zambia to find out why people decided to go for Voluntary Counseling and Testing(VCT), the study indicated that out of 40 PLWA, 35 of them were sick at one point in time for a long time. This is why they opted for testing to know the source of their illness.

Indeed, people living with HIV/AIDS experience physical problems. This is so because their immune system has been reduced therefore they are susceptible to opportunistic infections like those mentioned above.

6.1.2 IMMEDIATE REACTIONS AFTER BEING DIAGNOSED SERO

POSITIVE

Participants had different reactions after being diagnosed sero positive. Five participants (42%) were shocked and disappointed with the news. The reasons were that they did not know how they contracted the diseases and some of them were hopeless because they knew that their future was doomed. Similarly in a research done by McCann and Wardsworth (1992) on immediate reactions after being diagnosed sero positive out of 100 participants almost 85 participants had some degree of depression and hopelessness. There was a great variation between individuals. The degree was said to change depending on events. A few participants felt suicidal after the diagnosis. Burnett (1992) concurred that most of the problems faced by people living with HIV/AIDS (PLWA) are fears of death and what the future might hold. In his study on psychological needs of PLWA, the results were that participants had fear of becoming ill, increased dependency, hospitalisation, pain, fear of losing home, financial security and fear of what others will react after the diagnosis.

The most common fear in PLWA is death. They know that HIV/AIDS has no treatment and that there is nothing they can do about it but they have obligations to fulfil in their families before they die. On the other hand, other participants explained that, they were not shocked with the news because they were sick for a long time. The other way that made people to have those positive experiences are, the environment in

which they were counseled in. that is, psychological, physical and social preparation. Similarly in a study done by Wordswoth (1992) out of 100 participants, 15 % explained that they found they could turn to someone for emotional support and they already knew their status because of the death of their husbands.

6.1.3 PARTICIPANTS ACCEPTANCE OF THEIR SERO POSITIVE STATUS

Most of the participants (n=11) explained that they have accepted their status. They explained that it was through Lilongwe Central Hospital Home Based Care, church, friends and relatives who have helped them to accept their status. These participants living with HIV/AIDS have accepted their status because they are able to meet volunteers, nurses and counselors in the home based care where they verbalise experiences. People from the church help these people in prayers and sharing the word of God. In so doing, they socialise and ventilate their feelings so they feel relieved. On the contrary one participant showed that she has not yet accepted her status. She was crying during the time of interview. She explained that she feels pity for herself that she will die soon. This is in agreement with the results of the study done by Tuju (1992) on psychological need in PLWA. The participants explained that after the diagnosis they were confused and remained helpless. After some time reactions changed. They started living positively with AIDS. The most common fears were related to the future.

6.1.4 DISCLOSURE OF STATUS AND REACTIONS

In this study participants were also asked if they disclosed their status and what were the reactions to those people who got the news. The results showed that most of the participants (n=9) disclosed their status to their spouses. They explained that

counselors explained to them that it was not good to disclose their status to their relatives because they may have certain influences that may lead to the breakage of their marriages. Although they were advised like that, some participants thought it was worthy while to disclose their status to other relatives and friends. The people who got the news reacted differently, some showed continuous love and support, to others, this led to miserable lives in their families. Consequently, in a study done by Beedham and Burnett (1992) on impact of HIV/AIDS on relationships, those who were in a stable relationship, revealing of HIV positive status resulted in the breakdown of their marriages. For some it involved immediate rejection through the partner ending the relationship with an explanation of feeling unable to cope with what the future might hold. One commented, "My husband just got up and left, he said he could not cope and didn't want to think about it himself. He was obviously scared, so he run away." In addition to that in another study done by Mc Cann and Wardsworth (1992) on the relationship between participants and their relationships it had become distant or disrupted because of HIV status and the partners were no longer supportive.

6.1.5 ADAPTATION OF THE NEW CONDITION AND POSITIVE EXPERIENCES

Most of the participants (n=9) have accepted their statuses although some had taken time to do so. Factors that lead to acceptance of their statuses were counseling sessions before testing, prayers from the church and support from their families. Others explained that they have received a lot of support from LCHHBC.

Participants who explained that counselors had provided conducive environment for counseling and they had encouraged them to participate actively.

This is in agreement with Roy adaptation model. Roy model sees people as possessing a set of system within them and that they can adapt to the ever-changing world. She explained that the best way to understand a person is to study him as sets of interconnected biological, psychological and social systems that influences his behaviour. Roy further explains that there are a set conditions that makes up a person adaptation level and the stimuli that fall within the range of possibilities they are likely to be reacted to more favourably than those that fall outside it. Therefore a persons adaptation level compares to that average of adaptability within which it is possible to deal with adequately with experiences. Similarly in a person who has been diagnosed sero-positive. It means a new stimulus has entered his life and it is not within his adaptation level, so as to cope effectively. For him to cope with the situation he needs to consider physical and psychosocial areas. This is why these people need support from relatives so that they should not feel lonely. Furthermore, they also need prayers and food to eat so that the holistic approach is reached.

The primary role of a person living with HIV is to adapt and adjust to the pains of the new status and then live positively with the condition. By doing the things mentioned above, he is going to maintain his self-image as a system.

Similarly, studies done by Reid (1995) on positive experiences of PLWA, the results revealed that those participants who had positive experiences belonged to a social group and have a chance to share experiences and discuss problems openly.

WHO (1990) also stated that the most important outcome of the formation of self-help groups have been the recognition of PLWA.

Another source that has proved to be effective in supporting PLWA is the church. Participants explained that they receive physical, spiritual and psychological support from the church. This is consistent with William (1992) in a study done on support groups of PLWA. He concurred that with terminally illnesses like AIDS, people find spiritual support helpful with subsequent results from anxiety about the future of their families. It is also evident that as death approaches spiritual support become more important not just for the dying person but also for other family members as well.

6.1.6 NEGATIVE EXPERIENCES

Most of the participants explained that some of the negative experiences they are going through after being diagnosed sero-positive. One of the participants commented that since she disclosed her status to her husband. her life was miserable and the husband did not give any support. Most of the spouses may feel that the sickness of their loved ones and relatives is a burden in their families. This is true according to general systems theory, if one member of the family is sick, everybody in that house is concerned and people fail to do their work properly. This is similar to Mkandawire (1999) found. She conducted a study on experiences of people living with HIV/AIDS at Area 23. The results showed that some participants immediately disclosed their status, they were resented, isolated and stigmatised. They were viewed as outcasts. It was also reported that 40% of the subjects were divorced and they reported that their husbands left them immediately they informed them of their HIV/AIDS status.

In the same study, participants also explained that counselors advised them not to disclose their status to relatives for fear of breakage of their marriage, stigma attached to the disease and discrimination in their communities

This is similar to a study done by MDHS (2000) where they wanted to find out the level of stigma attached to AIDS. The participants indicated that 26% of women and 17 % of men thought that PLWA should be allowed to keep their status in private. The reasons were that the programmes designed in the support and care of AIDS affected persons were hindered by fear of association with AIDS. The other reason was discrimination in the work place against those infected with HIV/AIDS.

In the same study they looked at PLWA whether they should be allowed to work. Results indicated that 49% of women and 53% of men thought they should be allowed to work. This means a quarter of adults harbour some level of stigma against PLWA.

Participants were also asked on their physical experiences. This comprised of any abnormality or problem that has been brought by the disease. Participants explained that they had problems like genital sores, karposis sarcoma on the leg, tinea corporis on the face, coughing with severe chest pain and menorrhagia. Similarly, in a study done by Stewart (1990) on AIDS related stresses, participants were asked to explain the stressful situation related to AIDS condition. Out of 72 participants 56 reported that illness interfered with the ability to fulfil work education and community responsibilities.

On the contrary, in the study done by Stewart (1990) results indicated that more participants had mental problems.

In addition to that Nicholas (1994) conducted a study on pain in persons with AIDS. The results indicated that 41% had chest pains associated with tuberculosis, 28% had oral cavity pain associated with oral thrush. Wanapel (1993) concurred that most of HIV/AIDS patients have pain. This is for both drug and non-drug users. The most type of pain reported was abdominal.

Lastly in a study done by Schoboid and Derdirian(1990) the findings were that PLWA their emotional endurance is impaired by anxiety, fear of dying, disability and disfigurement. PLWA face emotional endurance. These changes can become severe that the patient can no longer maintain personal hygiene or react physically.

6.2 CONCLUSION

The purpose of this study was to look at the psychosocial experiences of people living with HIV/AIDS who attend LCHHBC in Lilongwe. The findings of this study reveal that people living with HIV/AIDS have psychological, social and physical problems that affect the way they adapt to self-care management of the condition. The data was analysed using content analysis and later classified into sections. The participants complained of stigmatisation, shortage of drugs and food to keep their life going.

From the findings, the researcher can conclude that bio-psychosocial support is a very important aspect in the management of people living with HIV/AIDS. These people need to adapt to their new condition as Roy explained in her adaptation model. It is therefore necessary to maintain a balance in all these aspects for HIV people to live a healthy life. However, these results cannot be generalised because the researcher used a small sample.

6.3 IMPLICATIONS FOR NURSING RESEARCH

The author came across one study, which was done in Malawi on experiences of people living with HIV/AIDS. Since the sample involved in this study was small and thus not generalized, there is need to replicate this study and do it on a large scale to compliment this one on experiences of people living with HIV/AIDS.

In so doing more knowledge will be generated that can give a good base for the management of the disease in this developing world.

Lack of research literature for Malawi implies that whatever HIV/AIDS patients are being taught at the moment is borrowed from the developed countries where studies on experiences of people living HIV/AIDS are frequently done. This is a problem to use such borrowed literature because their setting is completely different from ours.

6.4 LIMITATIONS OF THIS RESEARCH

In this research, the researcher had met limitations especially on the culture. Participants did not give more information on their condition as compared to the studies that she had read from other countries.

The other limitation was financially; the researcher did not have enough money to employ a large sample so that it could be generalized. The ratio of male to female participants was 2 to 10 because most male participants were very sick.

6.5 RECOMMENDATIONS

Considering that people living with HIV/AIDS have positive and negative experience the researcher recommends the following

PLWA need to be encouraged to live positively with their status. This can be achieved, through provision of bio-psychosocial help from relatives, friends and the nation at large. Furthermore, support groups need to be encouraged whether in form of home based care, National Association of People Living with HIV/AIDS, or spiritual groups. In these groups they learn how to take care for themselves and to prevent other opportunistic infections so to enable them live positively.

Emphasis should also be put on education. The nations need to be taught clearly that they are so many ways one can contract HIV/AIDS. It can also be spread through use of one toothbrush, razor blade and from spouses. Education should also be done on that HIV/AIDS could attack anybody.

Therefore it is the duty of every person whether health personnel or not to help PLWA to live positively with their status. In so doing, the problem of stigmatization of AIDS and discrimination in the work place or the community will be addressed.

6.6 ISSUES FOR FURTHER RESEARCH

This research needs to be replicated and conducted on a large scale i.e. including more males and adolescents who are affected and infected with HIV/AIDS. There is need to conduct a study on people who are caring for the people living with AIDS aiming at knowing the problems they face when delivering the care to these people.

Furthermore there is need to conduct a study on physical experiences of people living with HIV/AIDS. This has to look at the medication they are receiving i.e. Anti retroviral drugs (ARV). PLWA have to explain how these drugs are helping them and the side effects. The other part that needs to be looked into thoroughly is the food that these people need to eat with their present status for them to live positively.

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APPENDICES

APPENDIX 1 INTERVIEW SCHEDULE

COUNTRY MALAWI

TITLE PSYCHOSOCIAL EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS WHO
ATTEND LILONGWE CENTRAL HOSPITAL HOME BASED CARE IN LILONGWE

SECTION A DEMOGRAPHIC DATA

1 Sex

0.1 Male

0.2 Female

2 Age

0.1 15-20

0.2 21-25

0.3 26-30

0.4 31-35

0.5 36 and above

3 Marital status

0.1 Single

0.2 Married

0.3 Widowed

0.4 Divorced

4 Occupation

0.1 Office work

0.2 Business

0.3 Unemployed

5 CHURCH

0.1 Roman Catholic

0.2 C.C.A.P

0.3 Seventh Day Adventist

0.4 Moslem

0.5 Others

SECTION B: PSYCHOSOCIAL EXPERIENCES

4 What made you go for the HIV/AIDS test?

5 When was it first diagnosed?

6 What was your immediate reaction when you heard that you're HIV positive?

7 How did you come to accept your status?

8 Did you disclose to anyone of your sero status?

9 If yes, whom did you disclose to?

10 What was their reaction?

11 What positive experiences have you gone through after being diagnosed sero positive?

12 What did you do to cope with these experiences?

13 What negative experiences have you gone through after being diagnosed sero positive?

14 What is the relationship like in your family after being diagnosed sero positive?

SECTION C: PHYSICAL EXPERIENCES

15 Is there any abnormality/problem that has been brought by the disease? if so, explain?

16 Do you know the role of balanced diet in a person living with HIV/AIDS?

17 If yes describe the role of the balanced diet in a person living with HIV/AIDS?

18 How is this balanced diet helping you?

19 Do you know the role of doing exercises and alternating with rest in a person living with HIV/AIDS?

20 If yes explain the role of doing exercises and alternating with rest in a person living with HIV/AIDS?

SECTION D SPIRITUAL EXPERIENCES

21 Do you go to church?

22 Did you disclose your status to the church?

23 If yes how is it helping you to earn your living?

APPENDIX 2 CONSENT FORM

Dear participant,

REQUESTING YOUR CONSENT TO PARTICIPATE IN A RESEARCH STUDY

I am a student at Kamuzu College of Nursing pursuing Bachelor of Science in Nursing. As a requirement of the program, I am supposed to conduct a research study. My title is on psychosocial experiences of people living with HIV/AIDS who attend LCHHBC in Lilongwe.

I would like therefore to request for your consent to participate in the study. As a participant in this study you will be required to respond to questions, which the interviewer will ask you. There are no risks associated with this study. To ensure anonymity no names will be required. Thanks for giving in your time.

Participant

I understand the explanation of my role as a participant.

I hereby give consent t participate

Signature.....

Date.....

APPENDIX 3

University of Malawi,
Kamuzu College of nursing,
P/Bag 1,
Lilongwe.
3rd October 2002.

The Clinical Director,
Lilongwe Central Hospital,
P.O. Box149,
Lilongwe.

Dear Sir,

REQUEST TO USE LILONGWE CENTRAL HOSPITAL HBC AS A RESEARCH SITE

I am a fourth year student pursuing a Bachelor of Science in nursing program. As a partial fulfilment of the degree program I am supposed to conduct a research on the area of interest. The title of the study is psychosocial experiences of people living with HIV/AIDS who attend LCHHBC. The purpose of this letter is to ask permission to work with the patients who attend LCHHBC by asking them questions concerning their psychosocial experiences after being diagnosed sero-positive.

Looking forward to your favourable consideration.

Yours faithfully

Lusayo Roosevelt Ghambi (fourth year generic student)

APPENDIX 4 TIME LINE

Activity	Month	Year
Problem Identification	March	2002
Literature Review	March	2002
Proposal Write- Up	April	2002
Seeking clearance and data collection	October	2002
Data Analysis	November	2002
Dissertation	November	2002
Typing, binding and submission of the dissertation	November	2002

APPENDIX 5 RESEARCH BUDGET AND STATIONARY

ITEM	COST
4 reams of paper at K400.00each	1,600.00
5 pens at K10.00 each	50.00
3 pencils at K5.00 each	15.00
3 folder at K30.00 each	90.00
3 diskettes at K60.00 each	180.00
Rubber at K15.00	15.00
3 stamps at K10.00	30.00
Total	3480.00