UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF NURSING SCIENCES

FACTORS CONTRIBUTING TO THE LOW TURN UP OF HIV EXPOSED CHILDREN FOR FOLLOW UP CARE BETWEEN 12 TO 18 MONTHS IN CHONGWE, CHIPATA, LIVINGSTONE AND NDOLA DISTRICTS

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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal clinic</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>CBV</td>
<td>Community Based Volunteer</td>
</tr>
<tr>
<td>CD4</td>
<td>Cluster of Differentiation</td>
</tr>
<tr>
<td>CHAZ</td>
<td>Churches Health Association of Zambia</td>
</tr>
<tr>
<td>CIDRZ</td>
<td>Centre for Infectious Disease Research in Zambia</td>
</tr>
<tr>
<td>CRS</td>
<td>Catholic Relief Services</td>
</tr>
<tr>
<td>CSO</td>
<td>Central Statistical Office</td>
</tr>
<tr>
<td>DBS</td>
<td>Dried Blood spot</td>
</tr>
<tr>
<td>DHO</td>
<td>District Health Office</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic Acid</td>
</tr>
<tr>
<td>DNS</td>
<td>Department of Nursing Sciences</td>
</tr>
<tr>
<td>FP</td>
<td>Family Planning</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HBM</td>
<td>Health Belief Model</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>LTFU</td>
<td>Loss to Follow Up</td>
</tr>
<tr>
<td>MCH</td>
<td>Maternal and Child Health</td>
</tr>
</tbody>
</table>
MDG
Millennium Development Goals

MTCT
Mother to Child Transmission

NAC
National HIV/AIDS/STI Council

NVP
Niverapine

OI
 Opportunistic Infection

OPD
Out-Patient Department

PCP
Pneumocystis Jirovechii pneumonia

PMTCT
Prevention of Mother to Child Transmission of HIV

RHC
Rural Health Centre

SD
Standard Deviation

SMAGS
Safe Motherhood Action Groups

SPSS
Scientific Program for Social Statistics

STIs
Sexually Transmitted Infections

TBA
Traditional Birth Attendants

UNAIDS
United Nations program for HIV/AIDS

UNICEF
United Nations International Children’s Emergency Fund

UNZA
University of Zambia

UTH
University Teaching Hospital

VCT
Voluntary Counselling and Testing

WHO
World Health Organisation

ZDHS
Zambia Demographic Health Survey
DECLARATION

We, Chipukuma Helen Mwiinga, Longa Mwanza Regina, Mwanza Violet and Nthala Flora hereby declare that the work on which this research is based is original (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is been or is to be submitted for another degree at this or any other university.

Signed: ..........................................................  Date: 07/06/2013

CANDIDATE

Signed: ..........................................................  Date: 7/6/2013

CANDIDATE

Signed: Mwanza ..........................................................  Date: 07-06-13

CANDIDATE

Signed: ..........................................................  Date: 7/6/2013

CANDIDATE

Signed: ..........................................................  Date: 11/06/2013

SUPERVISING LECTURER
STATEMENT

We, Chipukuma Helen Mwiinga, Longa Mwanza Regina, Mwanza Violet and Nthala Flora hereby certify that this study is entirely, the result of our own independent investigation. The various sources to which we are indebted are clearly and gratefully acknowledged in the text and in the references.

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DEDICATION

This study is dedicated to all our beloved ones for their understanding, support, prayer and encouragement throughout the course of our studies and this project in particular;

Mr Mwiinga Kelvin H, my dear husband, our lovely son Lushomo Mwiinga, my grandmother Mrs Ellie Hachandi and all who helped look after our son in my absence - Chipukuma Helen Mwiinga.

Mr Longa Derrick my dear husband, our two lovely daughters, Mumbi and Zhuana and my family at large- Longa Mwanza Regina.

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ABSTRACT

The impact of loss to follow up of HIV exposed children continues to be a challenge that needs to be addressed especially in communities where people think that HIV testing of HIV exposed children can only be done at 6 weeks. There is an increasing impact of loss to follow up despite the efforts by Ministry of Health and collaborating partners to mitigate the loss to follow up of HIV exposed children. This was observed in HMIS report from 2009 to 2011 where out of 18,037 exposed children who were testing at 6 weeks only 4,519 returned for testing at 18 months representing a 25% drop out in 2009. Similarly 2010, out of 22,494 exposed children who tested at 6 weeks, 7,589 returned for testing at 18 months representing a 33.7% drop out. The dropout rate continued to increase in 2011, which was 34.5% where out of 13,655 who were tested at 6 weeks only 4,724 returned for HIV testing at 18 months.

Aim

This study aimed at determining the factors contributing to low turn up of HIV exposed children at 12 and 18 months in four selected districts namely; Chipata, Chongwe, Livingstone and Ndola.

Method

A descriptive study design was used. Data were collected using a structured interview schedule from 200 randomly selected respondents in the four selected districts. Data were entered and analysed using Microsoft office excel and SPSS spreadsheets.

Results

The study revealed that the majority 184 (92%) of the respondents had high knowledge on follow up care services, majority 149 (75%) had a positive attitude towards utilisation of follow up care services and 151 (76%) had good utilisation of follow up care services at 6 weeks.

Despite the majority having high knowledge and positive attitude towards follow up care, the majority 163 (81%) did not take their children for HIV testing at 12/18 months. The following were the reasons for not taking their children; 50 (31%) of the respondents said that they did not take their children for HIV testing because they were busy, 46 (28%) was due to stigma, 30
18%) said their children were fine, 23 (14%) was due to being guilty, 8 (5%) was due to long
distance while 6 (4%) was due to long waiting time.

Conclusion

The study revealed that majority of the respondents had knowledge and positive attitude towards
follow up care. Despite the respondents having positive attitude towards follow up care, the level
of utilization of follow up care services particularly HIV testing at 12 and 18 months was low
since 81% did not take their children for follow up care. The findings show that respondents had
various reasons for not taking their children for HIV testing. The main reason for not taking their
children for HIV testing was that they have a busy schedule as mothers/caretakers spend most of
their time trying to make ends meet.

The study targeted the mothers/caretakers as respondents. There is therefore need to conduct an
in-depth study from the service providers’ point of view which may reveal other factors
contributing to low turn up of HIV exposed children at 12 and 18 months.
CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Mother to Child Transmission of HIV (MTCT) is one of the modes of transmission of HIV for children and most of these children live in the developing world. According to UNAIDS (2005), there were about 2.3 million children less than 15 years living with Human Immune Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in the world. The majority of these children are in Sub-Saharan Africa. According to the Ministry of Health (MOH, 2007), the prevalence rate of HIV in Zambia is at 14.3%. It is higher in females than males whereby 1 in 6 females and 1 in 8 males have the HIV virus (MOH, 2004).

According to the National Protocol Guidelines – Integrated Prevention of Mother to Child Transmission (PMTCT) of HIV (MOH, 2010), 90-95% transmission of HIV is through sexual contact; 30-40% is through breastfeeding and 0.3-0.4% through needle stick injury.

In the effort to reduce the increasing rate of HIV infection among the infants and young children in the country, the Ministry of Health (MOH) established the PMTCT program in 1999. Approximately 80,000 infants are at risk of acquiring HIV (MOH, 2010).

PMTCT services include the following activities; counselling and testing of pregnant women for HIV, assessment for Antiretroviral Therapy (ART) eligibility for HIV positive women where those with CD4 count above 350 cells/mm³ are commenced on Antiretroviral (ARV) prophylaxis. Those who have less than 350 cells/mm³ must be started on full ART regardless of gestation age and follow up care of HIV exposed infants for ARV prophylaxis (MOH, 2010).

HIV testing of infants is done at six (6) weeks through collection of Dried Blood Sample (DBS) for analysis of Polymerase Chain Reaction in the Laboratory. HIV testing at 12 months and 18 months of age is done by performing a rapid test using determine reagents. Children are also commenced on cotrimoxazole prophylaxis to prevent them from acquiring opportunistic infections such as Pneumocystic Jiroveci Pneumonia (PCP). In addition, children are assessed for any health problems as they attend the children’s clinic. The children who are found to be HIV positive are referred to ART clinic for continued care (MOH, 2010).
According to the report by National Aids Council (NAC) in 2003, many women avoided PMTCT for the fear of negative reaction from their spouses. NAC also estimated that 1,600,000 adults are living with HIV in Zambia and 130,000 are children. In 2007, 51% of those in need of treatment were receiving it (NAC, 2003). As shown from the NAC report of 2004, only 4% of the total numbers of patients on ART were children under 15 years of age. Therefore, this highlights the gap that exists in paediatric HIV and AIDS treatment. Additionally, treatment literacy for children between 0-14 years in terms of HIV and AIDS are not adequately addressed.

There are so many challenges that Paediatric ART is faced with, some of which are: limited screening of children with previous history of HIV exposure, inability to diagnose HIV infection early in the newborns and infants, and limited human resource at local hospitals. The effect of these challenges is that there is delay in diagnosing HIV in infancy, delay in treatment and hence increase in infant morbidity and mortality (MOH, 2010).

Despite the above challenges, solutions to these challenges have been tried some of which are the establishment of PMTCT in January, 1999 by MOH with the following package: Integration of PMTCT in all maternal, newborn and child health services; introduction of more efficacious regimes and extended Nevirapine (NVP) for infants during the breastfeeding period recommended by WHO; monitoring Antenatal Care (ANC), utilization of about 90% and encouraging women to attend their first antenatal clinic by 14 weeks of gestation, improving acceptance of HIV testing among antenatal mothers to 100%, improving adherence to ART by HIV positive women to 90%, increasing the proportion of women delivered by skilled health workers from 47% to 70%, male involvement where men are also tested with the women for HIV infection and early infant diagnosis at 6 weeks of birth. In addition to standard training and supplies, exceptional transport, infrastructure support, and staff retention incentives are important (MOH, 2010).
1.2 PROBLEM STATEMENT

Mother to Child Transmission of HIV (MTCT) accounts for 95% of HIV infection in children (MOH, 2010). The total number of children living with HIV are 130,000 representing 7.5% of all infected (MOH, 2010). National AIDS Council, 2003 further reports that of all the people in need of ART, only 4% of all those receiving ART are children when the target is to provide ART to at least 95% of all HIV positive children.

The following table illustrates the number of children exposed to HIV and those that were tested from 2009 to 2011.

<table>
<thead>
<tr>
<th>HIV exposed children</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live births exposed children 18 month ago</td>
<td>25,315</td>
<td>26,663</td>
<td>15,884</td>
</tr>
<tr>
<td>HIV test to HIV exposed at children 6 weeks</td>
<td>18,037</td>
<td>22,494</td>
<td>13,655</td>
</tr>
<tr>
<td>HIV test to HIV exposed children at 12 months</td>
<td>5,676</td>
<td>9,890</td>
<td>5,671</td>
</tr>
<tr>
<td>HIV test to HIV exposed children at 18 months</td>
<td>4,519</td>
<td>7,589</td>
<td>4,724</td>
</tr>
</tbody>
</table>


The table above shows a drop in the number of the children that were expected to be followed up especially at 12 months and 18 months of age. It is important to note that despite all the solutions that are in place, the question still remains: why is there a decrease in the number between those that are tested at 6 weeks and the number of those that return to the health centre for follow up care?

The dropout rate continued to increase from 25% in 2009 to 34.5% in 2011 as calculated from those tested at 6 weeks and at 18 months. This discrepancy calls for need for research as to why these children are not coming for follow up care services.

The consequences are that there is increased infant morbidity and infant mortality rate which is about 119/100,000 live births (CSO, 2007); the children get sick and are not able to attain their best education due to drop outs, there is an increase in malnutrition, there is an economic strain on the parents and the government and the children are stigmatized by fellow pupils and also in the community (CSO, 2007).
1.3 FACTORS CONTRIBUTING TO LOW TURN UP FOR FOLLOW UP CARE OF HIV EXPOSED CHILDREN BETWEEN 12 AND 18 MONTHS

SERVICE FACTORS

- Negative Staff Attitude
- Inadequate Documentation
- Inadequate Logistics
- Lack of Male Involvement
- Lack of Community Involvement
- Lack of Sensitization
- Shortage of staff
- Inadequate Infrastructure

SOCIO-ECONOMIC FACTORS

- Religious beliefs and customs
- Illiteracy
- Poverty
- Disclosure of HIV status
- Lack of Social Support

DISEASE FACTORS

- Stigma
- Denial
- Depression

Factors contributing to low turn up of HIV exposed children for follow up care from 12 to 18 months
1.3.1 DESCRIPTION OF THE FACTORS

Factors contributing to the high dropout rate in follow up of HIV exposed children are categorised as follows:

A. SERVICE FACTORS

These are factors related to accessibility and availability of the health services. They include the following:

**Attitude of health care providers:** The health care providers’ attitude towards their clients or work can greatly affect their ability to deliver quality service to clients. Negative attitude of the health care providers could be due to pressure of work resulting from inadequate numbers of trained staff, lack of motivation, non availability of supplies or sometimes due to the inadequacies in the training. Provision of information to clients on PMTCT is an integral part in the prevention of Mother to Child Transmission (MTCT) of HIV. Health providers may sometimes impose their own feelings on the clients and influence their freedom to make decisions (MOH, 2010).

Additionally, negative attitude of staff at the health centres may lead to inadequate documentation in the PMTCT registers. Data regarding current need for co-trimoxazole prophylaxis globally are difficult to obtain as many countries have only recently began to collect and report data on this intervention (UNICEF, 2009).

Furthermore, many infants are not identified because of limited use of child health cards showing HIV exposure status. There is also absence of systems where health workers are supposed to provide care to children and make assessment of HIV exposure as a routine part of their initial interaction with the child (UNICEF, 2009).

**Shortage of staff**

Economic challenges faced by the skilled health providers force them to leave the country for greener pastures hence leading to shortage of staff (MOH, 2010). Shortage of staff at the health facilities has resulted in poor quality services such that they cannot go to outreach centres to reach out to the children in far flung areas (Bweupe, 2010). Shortage of staff may also lead to
limited integration of PMTCT services within Maternal and Child Health (MCH) and ART programmes. The weak links between these programmes and other child health services may be due to traditional practice or vertical programming. This makes it difficult to monitor mothers and infants as they are often seen separately at clinics even when they are both in need of PMTCT services, bringing other factors such as time, transportation and costs into play as additional barriers.

Shortage of staff may also be in form of lack of appropriate training of health workers in the delivery of follow up care services. In addition the HIV and AIDS pandemic has contributed to shortage of staff in that a lot of them may be sick and could have died from the disease (Bweupe, 2010).

**Logistics**

Testing for HIV at six weeks has been a challenge due to few diagnostic centres as currently there are only three centres in the country that test for HIV (MOH, 2010). If there were many diagnostic centres, treatment could be started early in infancy from the health centres. Test results could be promptly provided and acted upon leading to early initiation of treatment if the baby is HIV positive. In most cases health workers continue to wait and test only at 18 months with HIV antibody test. Cotrimoxazole prophylaxis which is important for prevention of opportunistic infections may not be readily available in some centres. Mothers get discouraged when they take their children for follow up care and find that cotrimoxazole is not available.

Additionally, there is limited supply of child health cards that show HIV exposure status (UNICEF, 2009). There is also lack of clarity on sharing of supplies across programmes, inadequate procurement policies and procedures, problems with storage and distribution may hinder implementation of follow up care programmes.

**Distance to Health Centres**

Distance to Health Centres could be one of the barriers to accessing follow up care services as some women could be living very far and some could be living in places where roads are impassable and the only form of transport available could be an ox-cart which could take long to reach the health facility. The mothers may not have enough money to use for transport to take
them to the nearest health facility. The other contributing factors to distance are game parks and rivers. This therefore may be a drawback in the implementation of follow up care services (Bweupe, 2010).

Community Involvement

Lack of community involvement and poor understanding of PMTCT services in the community which could be seen as a service for women only, may hinder the delivery of follow up care services. If the community is not adequately involved in the activities such as follow up of HIV exposed children and sensitization in the community may lead to non compliance to the service on the part of the mothers. Furthermore, it is critical to inform and mobilize communities to ensure that HIV exposed infants and children are identified, their families are aware of available services for prevention and treatment for young infants and children and the benefits of early use of follow up care services (UNICEF, 2009).

Inadequate Infrastructure

Inadequate infrastructure may hinder the provision of quality health care services. This is so as the mothers with HIV exposed children may be accessing health care services together with those whose children are not exposed (MOH, 2010).

B. SOCIO-CULTURAL AND ECONOMICAL FACTORS

Religious, Beliefs and Customs

Religious beliefs that HIV is related to promiscuity and punishment from God may lead to stigma and discrimination that may influence utilisation of follow up care services. These beliefs may influence one’s knowledge, attitude and practice in line with the follow up services offered by service providers. For example, the Zionists do not believe in conventional medicine.

Married women have to take up their submissive role and give allegiance to their spouses at all times. As a result, they fail to make decisions on behalf of their babies because they are totally dependent on their husbands. It is also a custom that it is a woman’s responsibility to care for a child hence may lack support from their partners. Therefore, mothers may even go to traditional healers to seek treatment when their children are unwell (Bweupe, 2010).
Educational level

Education has been seen to be important if one has to safeguard himself or herself of the many risks involved in life than if one was illiterate. Most of the people especially in rural areas have low educational levels hindering them from acquiring information on HIV and AIDS prevention which may be available through reading. The low educational levels can also lower participation in activities dealing with HIV and AIDS but instead may tend to perpetuate the practices that are harmful; their attitude will be negative to any campaigns against HIV and AIDS.

The educated parent would have foresight and his or her attitude will be positive towards the PMTCT services offered (Bweupe, 2010).

Poverty

Most of the women in rural areas barely survive due to lack of income. They have many commitments like caring for their children and selling at the market to earn a living. Women of low socio-economic status may have no access to information because they cannot afford radio, magazines, and newspapers where they can acquire information about PMTCT services. This may influence the utilisation of follow up care services.

Disclosure of HIV status

Women may not disclose their HIV status to their husbands for fear of divorce as they are economically dependent on their husbands, therefore, they may not take their children for follow up care. In addition, women are afraid to disclose their HIV status to their husbands for fear of abandonment or being held responsible for their HIV status.

Socio-cultural factors which dictate divorce for married women found to be HIV positive may prevent them from utilising follow up care services. The culture of women getting consent from their husbands to access health services may influence women’s utilisation of follow up care services. This may prevent the women from accessing follow up care services (Bweupe, 2010).

Male Involvement

Male involvement may mean that men choose to come to the clinic with their partners to be counselled and get tested for HIV, support their partners in coping with HIV infection and
support them financially with transport to the clinic as they take their children for follow up care. However, men may not be involved in the follow up care of their HIV exposed children and this may discourage the mothers from accessing follow up care services as they lack support from their partners (Richter, 2012).

C. DISEASEFACTORS

Denial

Mothers who are diagnosed with HIV may deny the results leading to depression and fear of being stigmatized by the community.

Additionally, HIV and AIDS is a chronic condition which includes the stage and duration of HIV infection, associated opportunistic infections and its related symptoms. This may make women to be reluctant to take their exposed children for follow up care for fear that they may get depressed if the results turn out to be positive (NAC, 2010).

Disease burden

Increased disease burden could lead to shortage of logistics such as co-trimoxazole, DBS collecting kits, Rapid HIV testing kits used in follow up care of HIV exposed children. It could also cause shortage of staff due to HIV infection where some members of staff could be dying of HIV. Sometimes the mother could be too unwell to take her child to the clinic of which if she were well, she could have taken the baby for follow up care (MOH, 2010).

Stigma and Discrimination

Stigmatising and discriminating behaviours can play out within families, communities, businesses, organisations and health centres, media, Government policies and are even self-directed. HIV infected women may experience HIV and AIDS related stigma and discrimination and suffer a range of consequences such as alienation from families, friends, exclusion from communities, increase in the risk of violence and inability to access or control their property and resources. These consequences may lead to people avoiding getting tested, knowing their HIV status, knowing how to protect themselves and others, delaying disclosure of their status to their
partners and from receiving treatment, care and support in time (National AIDS/STI/TB Council, 2009).

Some mothers could be stigmatized in the community and they may stay away from taking their children for follow up care at the clinic. Stigmatization of women and their children could also come from their partners who may not support them financially and socially but threaten them with ending the relationship (Bweupe, 2010).

1.4 THEORETICAL/ CONCEPTUAL FRAMEWORK

Theory- This is a formulation of apparent relationships among several principles that relate to the topic of interest (Gillies, 1994).
1.4.0 DIAGRAM OF THEORETICAL FRAMEWORK

Perceived barriers
Distance to the health centre
Availability of logistics, knowledge

Perceived severity
Opportunistic infections
Malnutrition
Mortality

Perceived susceptibility
HIV exposure

Self efficacy
Utilization of follow up care services
Knowledge
Decision making

Taking HIV exposed children for follow up care

Cue of action
Sensitization through Mass media, campaigns, posters, advice from fellow HIV positive mothers

Increased turn up of HIV exposed children for follow up care

Perceived Benefits
Prevention of transmission of HIV,
Prevention of opportunistic infection
Early diagnosis and treatment, reduced mortality
1.4.1 HEALTH BELIEF MODEL

This is the most commonly used theory in health education and health promotion. It was developed in the 1950s. The underlying concept of the model is that health behaviour is determined by personal beliefs or perceptions about the disease and the strategies available to decrease its occurrence (Stretchter and Rosenstock, 1997). It has the following constructs:

1.4.1.1 PERCEIVED SUSCEPTIBILITY

This is an individual’s assessment of his or her chances of getting the disease. Personal risk of susceptibility is one of the most powerful perceptions in promoting people to adopt healthier behaviours. The greater the perceived risk, the greater the likelihood of engaging in behaviours to decrease the risk. This is what can promote HIV infected mothers and the community at large to be willing to access follow up care services to decrease the susceptibility to HIV and AIDS infection of their exposed children.

It is only logical that when people believe they are at risk of the disease, they will be more likely to do something to prevent it from happening.

1.4.1.2 PERCEIVED BENEFITS

An individual’s opinion as to what will stop him or her from adopting the new behaviour in decreasing the risk of developing disease. People tend to adopt healthier behaviours when they believe the new behaviour will decrease their chances of developing the disease. Perceived benefits play an important role in adoption of the secondary prevention behaviours such as screening. Therefore, when mothers and the community realise the benefits of follow up care services, they will be willing to take their children for follow up care services.

1.4.1.3 PERCEIVED BARRIERS

This is an individual’s own evaluation of obstacles in the way of him or her adopting a new behaviour. Perceived barriers are the most significant in determining behaviour change. In order for the person to change behaviour, he or she needs to believe the new behaviour outweigh the consequences of continuing the old behaviour. This enables barriers to be overcome and new behaviours to be adopted.
If mothers and the community realise that the advantages of follow up care outweighs the disadvantages of not taking their exposed children for follow up care services, they will be motivated to start taking their children for the service.

1.4.1.4 PERCEIVED SERIOUSNESS

This is an individual’s judgement pertaining to the severity of the disease. Parents should consider the seriousness and consequences of not utilizing follow up care services in order to prevent the exposed children from consequences like opportunistic infections due to late diagnosis. These make them realize the seriousness and be able to utilize the follow up care services.

1.4.1.5 CUES TO ACTION

These are external events that prompt a desire to make a health change such as health education, messages through the media, poster, and advice from fellow women. These will prompt some women to seek follow up care services as they will be scared of consequences. A cue to action helps someone to actually making a health change other than just wanting to make a health change.

1.4.1.6. SELF EFFICACY

It looks at a person’s belief and the ability to do something. People generally do not try to do something new unless they think they can do it. If someone believes a new behaviour is useful (perceived benefits), but does not think he or she is capable of doing it (perceived behaviours), chances are that it will not be tried.

If the parents believe that utilizing follow up care services will help reduce child morbidity and mortality, and have adequate knowledge they will be prompted to take action by utilizing the services.

Health Belief Model provides a useful frame work for designing both long term and short term behavioural change strategies, and influences peoples’ decisions to take action and prevent complications of not seeking PMTCT services (Stretcher and Rosenstock, 1997).
1.5 PROBLEM JUSTIFICATION

HIV and AIDS is a major health problem in Zambia and Mother To Child Transmission accounts for 95% of HIV transmission in children (MOH, 2010). The consequences are that there is increased infant morbidity and infant mortality rate which is about 119/100,000 live births (CSO, 2007).

The Health Management Information System report (2009-2011), shows that there is a reduction in the number of children tested at 6 weeks and subsequent follow ups. This is because the dropout rate continued to increase from 25% in 2009 to 34.5% in 2011. In addition, National AIDS Council (2003) reports that 130,000 children are living with HIV and AIDS while Ministry of Health (2010) reports that, approximately 80,000 infants born annually are at risk of acquiring HIV through mother to child transmission.

However, government in collaboration with other partners such as Centre for Infectious Diseases and Research in Zambia (CIDRZ) help in transportation of Dried Blood Spot samples to diagnostic centres and supply of cotrimoxazole for prevention of Pneumocystic Jirovecii Pneumonia (PJP), Catholic Relief Services (CRS) and Churches Health Association in Zambia (CHAZ) help in the sensitization on PMTCT services in the community and formulation of support groups in the community for HIV infected women in order to improve the follow-up care (MOH, 2010). Despite all these efforts, there is still a high drop-out rate of children being followed up.

Therefore, there is need to carry out research to determine the actual factors contributing to the reduced number of HIV exposed children being followed up. The research findings will help in making recommendations on how to intensify follow up of HIV exposed babies.

The findings of this study will be of great benefit to the policy makers, Maternal and Child Health (MCH) Coordinators, Nurse managers, Nurses and other health care professionals as well as the Non-Governmental Organizations and the community at large to design strategies that will help to improve the follow up of HIV exposed infants and in turn may contribute to the reduction of child morbidity and mortality to meet the Millennium Development Goals (MDG) number four (4) which is to reduce the childhood morbidity and mortality by two thirds between 1990 and 2015 of the under five (5) mortality rate (MDGs Status Report, 2005)
1.6 OBJECTIVES

1.6.1 General Objective
To determine the reasons for low turn up of HIV exposed children aged 12 to 18 months for follow up care.

1.6.2 Specific Objectives
a) To determine knowledge levels of mothers on follow up care of HIV exposed babies.
b) To determine the relationship between attitude of the mothers/caretakers and the utilisation of follow up care of HIV exposed children.
c) To determine the relationship between educational levels of the mothers and follow up of HIV exposed children.

1.6.3 RESEARCH QUESTIONS
a) What are the knowledge levels of HIV positive mothers concerning the follow up care of their exposed children?
b) What are factors contributing to the low turn up of HIV exposed children for follow care?
c) Is there a relationship between educational level of the mothers and low turn up of HIV exposed children for follow up care?

1.7 HYPOTHESES
There is no association between low turn up of HIV exposed children for follow up care and the following factors: Education level, attitude and knowledge level of the mothers/caretakers.

1.8 CONCEPTUAL DEFINITIONS OF VARIABLES

**KNOWLEDGE**: This is the understanding of information about a subject which a person gets by experiencing or knows by people generally (Basavanthapa, 2006).

**FOLLOW UP**: To continue or add to something already done by doing some related thing (Kurewa et al, 2010).
ATTITUDE: this is a hypothetical construct or general feeling about something (Moazzam et al, 2012).

1.9 OPERATIONAL DEFINITIONS

Knowledge:

- This is the understanding of mothers on how the babies can acquire HIV infection.
- Measures to prevent HIV spread from the mother to the baby.
- Importance of follow up care at the clinic such as receiving prophylaxis such as Antiretroviral drugs, cotrimoxazole and having them tested at 6 weeks, 12 months and 18 months.
- Consequences of not taking their children for follow up care such as late diagnosis increases morbidity and mortality.

HIV exposed children

These are children born from HIV positive mothers who have not yet been diagnosed with HIV.

Follow up care: The services provided to a child who has been exposed to HIV at birth throughout breastfeeding period or until the status of the child is known or confirmed.

Low turn up: Less than half of HIV exposed children taken for follow up care according to schedule.

Sensitisation: This is to inform the mothers and the community about the importance of follow up care of HIV exposed children, and the availability of follow care services.

Attitude: The respondents’ way of perceiving follow up care. This can be positive or negative.

Loss To Follow Up: This is a child who is not taken for follow up six months after the scheduled visits (at 12 and 18 months) and not declared deceased by parents or caregiver.

Low educational level: This refers to mothers/care takers who had no formal education and those who had attained primary education (Grades 1-7).
Medium educational level: This refers to mothers/caretakers who had attained secondary education (Grade 8-12).

High educational level: This refers to mothers/caretakers who had attained Tertiary education (College and University).

1.10 VARIABLES AND CUT-OFF POINTS

Variables are qualities, properties or characteristics of persons, things or situations that change or vary in a study (Burns and Grove, 2009).

Dependent variables; It is the response, behaviour or outcome that the researcher wants to predict or explain. Changes in the dependent variable are presumed to be caused by the independent variable. The dependent variable can also be called an effect or outcome variable or a criterion measure (Burns and Grove, 2009).

- Follow up care

Independent variables; it is a stimulus or an activity that is manipulated or varied by the researcher to create an effect on the dependent variables. The independent variable is also called an interventional, treatment or experimental variable (Burns and Grove, 2009).

- Knowledge
- Attitude
<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>INDICATOR</th>
<th>CUT OFF POINT</th>
<th>QUESTIONS</th>
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<tr>
<td><strong>Dependent variable</strong></td>
<td>Good</td>
<td>16 – 25</td>
<td>11 - 20</td>
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<td>Follow up care</td>
<td>Fair</td>
<td>8 – 15</td>
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<td></td>
<td>Poor</td>
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<td><strong>Independent variables</strong></td>
<td>High</td>
<td>6 – 11</td>
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<td>i. Knowledge</td>
<td>Low</td>
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<td>ii. Attitude</td>
<td>Positive</td>
<td>6 – 11</td>
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<td>negative</td>
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CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews studies that have been conducted in the area of follow up care of HIV exposed children. This literature review focuses on published and non published researches conducted globally, regionally, and nationally. Literature review is an organized written presentation of what has been published by scholars and it includes a presentation of research conducted in the selected field of study (Burns and Grove, 2009).

Literature review helps the researcher to get acquainted with what has been done on a study before, thereby minimizing the possibilities of unintentional duplication and increasing the probability that the new study will make a distinctive contribution to knowledge. Literature review also helps the investigator to have relevant knowledge on the research strategies and specific procedures and instruments that might be of use during the study. The investigator looked at the studies done according to knowledge, follow up and attitude.

Many researchers have focused their studies on general PMTCT services which have the following four (4) components:

- Preventing HIV infection in women of reproductive age 15 to 49 years of age.
- Avoiding unintended pregnancies among HIV infected mothers.
- Preventing transmission of HIV from an infected woman to her infant during pregnancy, labour, childbirth and breastfeeding through HIV counselling and testing, ARV Therapy for those eligible and safer infant feeding practices.
- Providing follow up and care, support and treatment to HIV infected women, their infants and their families.

This Literature review focuses on the fourth component of PMTCT specifically on follow up care of HIV exposed children. However, a number of studies on follow up care of HIV exposed children have been conducted in various regions of the world and these studies have come up with different findings and recommendations. In Zambia little has been done in the area of determining factors contributing to the low turn up of HIV exposed children.
2.2 KNOWLEDGE

This is the understanding of information about a subject which a person gets by experiencing or knows by people generally (Bassavanthappa, 2006). In this study, knowledge is the understanding of mothers on how the babies can acquire HIV infection, what can be done to prevent HIV spread from the mother to the baby, importance of follow care at the clinic which include; receiving ARV prophylaxis, cotrimoxazole for prevention of PCP and having them tested at 6 weeks, 12 months and 18 months. Inadequate knowledge about the consequences of not taking their children for follow up care such as late diagnosis increases morbidity and mortality (WHO, 2010).

In 2009, WHO and UNICEF reported that in 2007, about 2 million children below the age of 15 years were living with HIV of which more than 90% of them as a result of MTCT of HIV. About 370 000 children were newly infected with HIV, and 270 children died from related HIV causes. The same report indicated that care and treatment services for HIV infected children are slowly expanding in resource constrained settings; there are still limited treatment services (WHO, 2012).

One of the main challenges countries need to address is the absence of mechanisms to systematically identify and follow up HIV exposed infants at and after birth. If HIV exposed children are identified early -a prerequisite for receiving cotrimoxazole prophylaxis and early ART, systems need to be in place to ensure health workers consider the possibility of HIV infection in infants at birth and consider screening at all clinics or other health encounters thereafter. Ante natal care messages for HIV infected women need to routinely include anticipatory guidance aimed at improving post natal follow up of mother – infant pairs including emphasis of follow up care of HIV exposed children at 12 and 18 months through information, education and communication of the parents and care givers. It is also crucial to inform and mobilise communities to ensure that HIV exposed children are identified and the families are aware of available services for prevention and treatment for young infants and children, and the benefits of early use of follow up care services (WHO and UNICEF, 2009).

A study was done in Eastern Uganda to determine knowledge levels in HIV positive mothers on Prevention of Mother-to-Child Transmission of HIV/AIDS (PMTCT) service. This was done
following the increased rate of HIV transmission in children. MTCT was the second major mode of HIV transmission and accounted for over 90% of HIV transmission among all the children infected with HIV in Uganda (Katushabe, 2007).

In response to this, the government of Uganda in collaboration with UNICEF and other partners introduced interventions countrywide to PMTCT of HIV/AIDS with the goal to reduce infant mortality and morbidity due to HIV and AIDS. The interventions included: HIV counselling and Testing, Antiretroviral drugs that reduce MTCT of HIV, improved antenatal and postnatal care, family planning, supportive and continued counselling.

In all, a total of 150 pregnant women receiving antenatal care were surveyed. It was found that a substantial majority (63%) of the mothers did not know about PMTCT services being offered in the hospital. The respondents who had little or no knowledge of the services were mostly below 20 years of age (61%) and had low education levels (63%) (Katushabe, 2007).

Women who were aware of the PMTCT services were 25 years and above and those who had attained secondary education. Some of the factors responsible for the knowledge gap were: Inadequate information during the health talks, messages on how MTCT occurs, the timing and the alternative of PMTCT services were not clear to the women.

In Zambia, the 2010 National guideline by MoH, reported that community volunteers such as Traditional Birth Attendants (TBAs), Safe Motherhood Action Groups (SMAGS), Home based care givers and Community lay counsellors can play an important role in the delivery of quality follow up care services. Furthermore, the report goes on to say that the orientation of traditional leaders, religious leaders on safe motherhood, follow up care services of HIV exposed children can be highly beneficial as they can influence their community to follow positive health seeking behaviours which will benefit the individual and the community as a whole (MoH, 2010).

A study was done in Itexhi Tezhi, a rural government hospital in southern province of Zambia in 2009 by Cheelo et al on “Involving the Community Based Volunteers to mitigate low return to follow up of HIV exposed infants in Itexhi Tezhi hospital in Zambia”. It was done in response to the challenge faced by the Antiretroviral Clinic where HIV exposed babies were not being brought back for follow up care. They introduced the use of registers to track the HIV exposed babies and send them to the clinic for cotrimoxazole prophylaxis, dried blood spot (DBS) and
monitoring for opportunistic infections (OIs). The mothers were encouraged by the Community Based Volunteers to go for follow up care to take their children for growth monitoring and cotrimoxazole collection dates.

The results of the study showed that from January to June 2009, 117 babies born in the catchment area were HIV exposed and 44 (38%) were taken for follow up care. This low turn up of babies for follow up prompted the involvement of Community Based Volunteers (CBVs) in the dissemination of information on importance of follow up care and tracking of HIV exposed children. In July to December 2009, 202 HIV exposed babies were born, 128 (63%) were taken for follow up care (Cheelo, 2009). From this study, it was noted that the Community Based Volunteers helped to track HIV exposed babies. Through sensitization, mothers had an increase in the knowledge on follow up care.

2.3 FOLLOW UP

This is to continue or add to something already done by doing some related thing. In our study, these are services that are provided to a child who has been exposed to HIV at birth throughout breastfeeding period or until the status of the child is known or confirmed.

In 2010, a study was done by Bratstem et al in western Kenya entitled “Retention of HIV infected and HIV exposed children in a Comprehensive HIV clinical care programme”. The aim of the study was to describe incidence rates and risk factors for loss to follow up among HIV infected and HIV exposed children in a large HIV treatment programme. The study was done at 23 clinics where more than 100 000 patients were followed and 20% of these patients were children( UNAIDS, 2010) The study defined loss- to- follow- up as being absent from the clinic for more 3 months if on combination of antiretroviral treatment and more than 6 months if not. The proportional hazard models with time independent and time dependent covariates were used to model factors associated with loss to follow up. There were 13,510 children for analysis comprising 3,106 children who at enrolment were HIV infected and 10,404 children were HIV exposed (Ibid). The overall of loss to follow up was 18.4%.

The independent risk factor to becoming loss to follow up among the HIV infected children was severe immune suppression. Among the HIV exposed children 20.1% became lost to follow up.
In dependent risk factors for loss to follow up more were being severely low weight for height (Ibid).

The conclusion of the study was that there is a high rate of loss to follow up among these highly vulnerable children, particularly among the HIV exposed. The data suggest that HIV infected and HIV exposed children are at especially high risk for loss to follow up if they are sick or malnourished. The HIV exposed children had the highest rates of loss to follow up and from the study the results suggest that food supplementation for HIV exposed children could reduce loss to follow up by acting as an incentive to continue in care pending on HIV diagnosis.

Other studies that were done in Malawi, Mali and Zambia by Kalembo and Zymbo in 2012 on the Fear of HIV Test, Stigma and Discrimination indicated fear of HIV exposure were the main reasons for the lost to follow up. Women feared reactions of the partner or husband, fear of losing the husband and believed that the woman's infection and pregnancy would spark off a chain of death after delivery with the baby, herself and then her husband dying. Women also feared the response of their families believing that they will be ignored, isolated and openly disgraced and blamed (UNAIDS, 2010).

In 2004, a study on improving identification and follow up of HIV exposed children in Zimbabwe was done by Mahomva et al. The study was done in response to increased HIV infection acquired perinatally in children. It was estimated that 40,000 acquire HIV infection in Zimbabwe annually, 90% of the infection occurring perinatally. Data from a mother–infant follow up clinic over a three year period thus 2003 to 2006; only 35% of babies born to HIV positive mothers were enrolled in to review and started on cotrimoxazole prophylaxis at 6 weeks of age (Mahomva et al, 2004).

However, less than half of the children enrolled were known to be alive and tested for HIV at 18 months of age. It was found out that mothers did not turn up for follow up because of poor integration of services in resource limited settings making health workers not consistently and effectively identify, over time mothers living with HIV and their HIV exposed infants in need of care and treatment services. Health workers may not effectively communicate availability of care and support services that are appropriate at various points during lifespan of the mother and infant.
Therefore, if mothers receive adequate information on follow up and the need to attend the clinic for these services, there may be no or few Loss to Follow up (LTFU) of HIV exposed children. There is need to integrate follow up services for HIV positive mothers and their exposed children. Health care services need to be closer to the women’s homes for easy access to follow up care services for their exposed children. Women should access follow up services where ever they may be and not at a fixed location.

Furthermore, a study was done in Zimbabwe with the objective to follow up mothers and children on the PMTCT programme highlighting the LTFU and mortality (attrition) over a period of five (5) years. Pregnant women who were either HIV positive and HIV negative respectively were enrolled at 36 weeks gestational age in three (3) peri urban clinics around Harare offering maternal and child health services. The follow up was to be done from birth and twice yearly up to five (5) years. The following figures show the women that were enrolled: 479 HIV infected mothers and 571 HIV negative mothers. Out of the 479 HIV infected mothers, 445 were followed up and 495 HIV negative mothers were followed up out of the 571 respectively. During the follow up period, 227 HIV positive mothers turned up and 239 HIV negative mothers turned up for follow up care. On the part of the HIV exposed children, 401 were enrolled and 247 turned up for follow up care whereas 441 unexposed children were enrolled and 232 turned up for follow up care (Kurewa et al, 2010).

This study showed that 58 HIV exposed children and 22 non exposed children died during the period of follow up and attrition contributed to loss to follow up care (Ibid). The infant was considered loss to follow up if he or she was not brought for scheduled visit and not declared deceased by either parents or care giver. It should be noted that complete follow up of HIV exposed children ensures maximum compliance and retention. It also allows correct timing of interventions such as early initiation of Cotrimoxazole prophylaxis.

Another study was done in Zomba District, Malawi to assess PMTCT program outcomes under routine conditions to identify areas for improvement. Overall PMTCT effectiveness indicated by HIV-free survival at 18-20 months was much lower under routine program conditions than results from study populations would suggest (Lettow et al, 2011). The findings were that, follow-up HIV testing for HIV-exposed infants was poor. Only 28% of exposed infants were followed and tested at least once by 18-20 months of age (Lettow et al, 2011).
Recent studies from Mozambique, Kenya and Uganda were done by Lettow et al, 2011, show similar low uptake and high dropout rates of HIV-exposed infants and children for HIV diagnoses and care. Loss to follow up of exposed infants and children among our study population reflects a lack of systematic follow-up by health facilities as well as some lack of knowledge or denial of the importance of infant follow-up among HIV-infected mothers (Ibid).

Another study was done to measure survival rate among HIV-infected children in Zambia prior to the availability of antiretroviral therapy. In this study, the children were followed up approximately 9 months up to 3 years of age and assessed the survival rates, risk factors for mortality and circumstances at the time of death according to HIV-infected or HIV-exposure status (Sutcliffe, 2008).

The total number of children who were followed up was 492 (Sutcliffe, 2008). It was discovered that 105 children were HIV infected and 260 children were sero positive but uninfected, then 39% and 5% died during the study respectively (Sutcliffe, 2008). The estimated survival probability from 9 months through 36 months of age was 52% among the initially HIV-seropositive children (Ibid).

The conclusion from the study was that one-half of HIV infected Zambian children were alive at 9 months of age and survived to 3 years. There is an urgent need for the prevention of mother to child transmission of HIV and the early diagnosis and treatment of HIV infection in Sub Saharan Africa. For children who are exposed and interventions are instituted early their survival rate is high (Ibid).

A clinical and pathological study of children with PCP was done in 2003 at the University Teaching Hospital in Lusaka by Dr Lishimpi (NAC, 2010). The objective of the study was to assess the prevalence of PCP in children dying of respiratory disease. The study was done on 264 deaths from pulmonary disease at UTH, where lung post-mortem material was obtained and subjected to histopathological examination and Polymerase Chain Reaction for PCP-Deoxyribonucleic acid (DNA). The oropharyngeal washings of DNA were extracted and PCR performed to detect the presence of Pneumocystis Jirovecii. The findings were that; 35% of children aged one month to fourteen years who died from pneumonia in UTH had PCP, 93.2% of these children were missed clinically, and 87.5% were co-infected with HIV out of which 63%
died. This study concluded that PCP is an AIDS defining infection in Zambian children below the age of one year (NAC, 2010).

The deaths of the children who were missed clinically would have been prevented if they had received the necessary follow up care which could aid in their survival. This survival could be enhanced by the following interventions; provision of early antiretroviral prophylaxis and follow-up care, adherence and treatment support, regular clinical and laboratory monitoring.

2.4 ATTITUDE

This is a hypothetical construct that represents an individual’s like or dislike for something. Generally attitudes are the results of either direct experimental or observational learning from the environment (Moazzam et al, 2012). In our study, this is the respondents’ way of perceiving follow up care of HIV exposed children which can either be positive or negative.

Many studies in settings with high prevalence of HIV have reported low coverage of PMTCT services, but there have been few reports from low HIV prevalence settings, such as Asian countries. An investigation was carried out on the access of HIV-infected pregnant women to PMTCT services in the well-resourced setting of Hanoi, the capital city of Vietnam.

In a study done by Nguyen et al, 2008, fifty-two HIV positive women were enrolled in a study. The in-depth interviews and bi-weekly meetings were conducted to elicit their experiences in accessing PMTCT services. The women were enrolled in the study at different stages of pregnancy, between 12 weeks and 40 weeks. Basic information on their characteristics was collected when the women entered the cohort. They were interviewed for an average of two hours about their ante natal care (ANC) seeking behaviours in relation to PMTCT and about their use of and access to PMTCT services including: HIV testing and counselling, ARV prophylaxis for them and their children, and replacement feeding (Nguyen et al, 2008).

The findings were that, only 44% and 20% of the women had received minimal and comprehensive PMTCT services, respectively (Nguyen et al, 2008). Nine women did not receive any services. Twenty-two women received no counselling. The women reported being limited by lack of knowledge and information due to poor counselling, gaps in PMTCT services, and fear of
stigma and discrimination. HIV testing was done too late for optimal interventions and poor quality of care by health staff was frequently mentioned (Nguyen et al, 2008).

One possible reason for under-use of PMTCT services is that women did not receive adequate counselling on PMTCT options. In this study, 22 women did not receive any counselling although they tested positive for HIV (Nguyen et al, 2008). Not only the quantity but also the quality of the counselling did not meet the required standards. The results revealed an emphasis in pre-test counselling on prevention of transmission of HIV, and not on what the test means, or what to do if it is positive. In the post-test counselling, again the emphasis was on disclosure and harm reduction, not on the needs of the women for care and protection. Even MTCT and how to prevent it only appeared in a small proportion of the interviews. Even when women did get ARV combination prophylaxis, they often did not receive good explanations about how to use the drugs, or they were not used correctly by the health staff. Many infected women expressed their dissatisfaction in the way that some counsellors treated them (Nguyen et al, 2008).

In a setting where PMTCT services were available, HIV-infected women and children did not receive adequate care because of barriers to accessing those services. The results suggested key improvements would be improving quality of counseling and making PMTCT guidelines available to health services. Women should receive early HIV testing with adequate counseling, safe care and prophylaxis in a positive atmosphere. The negative attitude of staff may affect the delivery of follow up care services.

A survey in seven provinces in Vietnam revealed that the knowledge of health staff on routine post-delivery care was quite sufficient and the quality of routine reproductive services at district and community level was good. Nevertheless, the health workers were unfriendly and unkind towards HIV-infected women during post-delivery care, which led to perceived stigma and discrimination among the women receiving care. The study showed that, inappropriate communication about HIV status can result in the women's avoiding the health services, which means they will not come back later to access the continuous treatment, care and support they need (Nguyen et al, 2012).

According to the study that was done by Dr Tshibumbu in 2006 on 'factors influencing men’s involvement in PMTCT of HIV programme in Mambwe District of Zambia', the results showed
that socio-cultural and service factors were found to negatively influence men’s involvement. In addition, the demographic characteristics such as age and level of education were positively associated with an increase in the level of male involvement while the duration of the relationship with the female partner was negatively associated with the level of men’s involvement (Tshibumbu, 2006). The attitude of male partners may negatively or positively influence the mothers/care takers in taking their HIV exposed children for follow up care.

2.5 CONCLUSION

The global, regional and national picture regarding follow up care continues to be a challenge. Some studies have shown that there is an increase in the child morbidity and mortality rates in relation to HIV and AIDS due to the following factors: late diagnosis, shortage of cotrimoxazole and inadequate follow up on PMTCT services and socio-cultural factors like lack of male involvement.

Many studies have been done on why follow up care of HIV exposed children has poor response or yielded unsuccessful results or progress. Inadequate knowledge on the importance of follow up care continues to contribute to poor or underutilisation of follow up care services for HIV exposed children.

In addition, the attitude of staff and care takers towards this service could be a source of apathy towards gaining more understanding on follow up care. Some studies have shown that women were limited by lack of knowledge and information due to poor counselling, gaps in PMTCT services, and fear of stigma and discrimination. Therefore inadequate knowledge and negative attitude of mothers and caretakers as well as the staff may affect the delivery of follow up care services.
CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 INTRODUCTION

Methodological designs are used to develop the validity and reliability of instruments to measure research concepts and variables (Burns and Groove, 2005).

The research methodology includes the description of the study participants and how the study participants are selected, research settings, a description of tools and techniques that are used to collect data. It also describes how the researcher ensures validity and reliability and the ethical considerations made. The research methodology also describes how the pilot study will be conducted, the plan for data analysis and plans for dissemination of the research findings.

3.2 RESEARCH DESIGN

According to Burns and Groove (2005), a research design is the researcher’s overall plan or strategy for answering research questions or testing the hypotheses. The researchers used a non-interventional, descriptive design which employs a quantitative approach. A descriptive design is the design that is used to identify a phenomenon of interest, identify variables within the phenomenon, develop conceptual and operational definitions of variables, and describe variables. A descriptive design is a non experimental research design which provides an accurate portrayal or account of characteristics of a particular individual, event, or a group in real life situations for the purpose of discovering new meaning, describing what exists, determining the frequency with which something occurs, and categorizing information (Burns and Grove, 2005).

Descriptive studies are usually utilised to determine the extent or directions of attitude or behaviours (Basavanthappa, 2006). The researchers used a quantitative type of descriptive study to identify knowledge levels of HIV infected mothers towards follow up care services of their HIV exposed children.
3.3 RESEARCH SETTING

Burns and Grove (2005), defines a research setting as a physical environment and conditions in which data collection takes place in a study. It is conducted in a natural setting or real life situation.

The study was conducted in the following districts; Chongwe, Chipata, Livingstone and Ndola districts of Zambia. The places were chosen because they were convenient to the researchers and cost effective as the research was not funded.

CHONGWE DISTRICT PROFILE

Chongwe District is situated 48 km east of Lusaka the capital city of Zambia. It is one of the four districts of Lusaka Province. It has a land area of about 10500 square kilometres with 92% of the area lying on a plateau and 8% is a valley. The physical features in the area include streams, rivers, hills, mountains and varsity savannah vegetation.

Chongwe District shares boundaries with Lusaka District on the west, Kafue District on the south, and Chibombo District on the northern, Luangwa, Nyimba and Mkushi districts are on the east and northeast respectively. The district has 38 health centres, and two hospitals (Chongwe DHMT Action Plan, 2012-2014). The research was done at Chongwe Rural Health Centre.

Demographic Profile

The district population between 2012 and 2014 will reach 200 191 (CSO, 2010), with an annual growth rate of 3.2%. The population for 2012 is 187 969 with a population density of 22 people per square kilometre. According to the latest CSO Report for 2010, the total number of males and females in the district is 93 934 and 94 035 respectively representing 50% to 50% sex ratio (Chongwe DHMT Action Plan, 2012-2014).

Health Services:

In addition to Preventive & Curative services, the district provides laboratory services which include CD4 count at Chongwe District Hospital, Chongwe Rural Health Centre and Mpanshya Health Institutions, while X-ray services are found at Chongwe District Hospital and Mpanshya Mission hospital. A total of 30 out of 40 health institutions provide PMTCT services in the
district. The ART service is only provided at Chongwe RHC, Kanakantapa RHC, Mikango Camp hospital and Mpanshya hospital.
The district has an HIV prevalence rate of 14%. (Chongwe DHMT Action Plan, 2012-2014).

NDOLA DISTRICT PROFILE

Ndola district has a Total Population of 514, 273. The district has the 43 health centres and 2 hospitals namely: Arthur Davison Children’s Hospital and Ndola Central Hospital which are referral hospitals. ART services are provided in all the health centres. Arthur Davison Children’s Hospital is a referral hospital for children from 0 to 14 years. It is found on the copper belt province in North rise Ndola District (MoH, 2011).
The hospital has the following departments: Medical, Surgical, Dental, Radiology, Physiotherapy, Pharmacy, ART and Administration. It offers preventive, curative and rehabilitative services. This setting was selected for convenience and easy accessibility by the researcher.
The commonest languages that are spoken in the district are Cibemba and English (Ndola DHMT Action Plan, 2010-2012).

CHIPATA DISTRICT PROFILE

It is the biggest District in the Province, having the largest population with a surface area of 6,112 sq km, the largest part of this area is a plateau while the rest of the area is surrounded by a range of hills. The district has good farming soils and a savannah type of climate. The district has the total population of 46,484 (MoH, 2011).

PRESENT HEALTH FACILITIES

The district has 43 health centres, one general hospital and one Mini hospital. The HIV prevalent rate is 11% in the district. The majority of the people are engaged in small business such as “sala” and “Tuntemba”. The tribes found in the area are Chewa, Ngoni and Tumbuka. The services offered include curative, supportive, preventive, labour and referral services. The district also offers PMTCT and ART services. The district works in collaboration with CIDIRIZ, CRS and CARE International in the delivery of both PMTCT and ART services. (Chipata DHMT Action Plan, 2010-2012). The study was done at Kapata Health Centre.
LIVINGSTONE DISTRICT PROFILE

Livingstone District lies in the Southern Part of Zambia. It is 481 kilometres South of Lusaka and located between 25-30° east longitude and 26.30° and 180° – 17.30° South Longitude with an average altitude of 900 – 1,200 meters above sea level. It has a land surface of 1,427 square kilometres. The District shares its borders with Kazungula District on the Eastern, Northern and Western sides, the Zambezi River which lies on the Southern forms the international border with Zimbabwe.

Livingstone is the National tourist capital with the main geographical features being the Victoria Falls, Maramba and Nasanzu streams that are tributaries of the Zambezi River. The Victoria Falls (Mosi-o-Tunya – the smoke that thunders), Livingstone museum and the National Game Park are the major tourist attractions. The opening of the Sun Hotels and many lodges has led to an increase in the number of tourists visiting the district. The number of commercial sex workers and traders visiting the district is equally on the increase. This in turn has increased the demand for health services in the district.

Livingstone district is surrounded with three chiefs namely: Musokotwane, Mukuni and Sikute. These greatly influence the lifestyle within the district such as polygamous marriage. The main ethnic groups are Tonga, Tokaleya and Lozi but now other tribes are there.

The people of Livingstone mostly engage in small scale business, cross border trading and fish mongering, even employment through the tourism industry. The District is an entry point for traders, tourists and truckers. The influx of truck drivers and visitors who have to spend days away from their families has attracted an increase in the number of commercial sex workers and in return contributes to the high prevalence of HIV/AIDS that stands at 27.3 (Livingstone DHMT Action Plan, 2010-2012).

PRESENT HEALTH FACILITIES

The district has a total of 12 health centres with a total catchment population of 151, 271, all offering PMTCT services and 3 of which, offer ART services. There is an HIV/AIDS coordinating Centre – Sepo, 2 Health Posts – Hillcrest, and a Fast Truck Dental Clinic. In addition there are 12 private surgeries which offer OPD, MCH/FP services. The district still
depends on Livingstone General Hospital for first level referral services and for CD4 count machine. The district has no PCR machine for early diagnosis for HIV exposed Children hence sends samples to Lusaka. The study was be conducted at Mahatma Gandhi Clinic, the second Largest Health Centre in the District which also offers ART, MCH and PMTCT services. The clinic is convenient and affordable or feasible for the researcher.

3.4 STUDY POPULATION

3.4.1 A target population is the entire population in which the investigator is interested and would like to generalize the result of the study (Burns and Grove, 2009). The target population in this study will be 200 HIV positive mothers and or caretakers of the HIV exposed children aged 12 to 24 months.

3.4.2 Study population is a group of individuals who meet the sampling criteria and from whom the sample will be drawn. In this study, it refers to the HIV positive mothers or caretakers with their HIV exposed children aged 12 to 24 months who are lost to follow up in Chipata, Chongwe, Livingstone and Ndola districts.

3.4.3 The accessible population can be defined as the aggregate of cases that conforms to designated criteria and that are accessible as subjects for a study (Burns and Grove, 2005). These will be HIV positive mothers and or caretakers of HIV exposed children aged 12 to 24 months in the catchment area.

3.5 SAMPLE SELECTION

Burns and Grove (2009), defines Sample selection as a process of selecting a portion of the population for the study to represent the whole population. The investigators used the probability method of sampling to come up with a sample size that met the requirements.

Probability sampling is a method which is likely to represent the target population and simple random sampling technique was used. It is the most basic & simplest form of probability sampling. The main characteristics are that; it involves one stage selection process, each unit has an equal or independent chance of being drawn, and that the accessible population can be identified or listed. This process involves defining the population, making a numbered list of all units in the study population, calculating the sample size, assigning a consecutive identification
number to each element in the sampling frame and using “lottery” method or a table of random
to select the required number of respondents (Basavanthapa, 2006).

A fishbowl technique with replacement was used where each number from the sampling frame
was written; slips were put in a container and shaken vigorously. A slip was drawn, number
noted and the selected slip was replaced. The container was shaken again to select a second
number. This was repeated till the calculated sample size of our respondents was reached and if
the number was selected twice the duplicate was ignored. However, this method is time
consuming and it does not ensure that characteristics in the sample will be similar to the whole
population.

3.5.1 Inclusion criteria are also known as eligibility criteria. This specifies the characteristics
of the population (Burns and Grove, 2005). The researchers recruited HIV exposed children aged
12 to 24 months using the baby-mother follow up registers at Arthur Davison Children’s
Hospital, Kapata mini Hospital, Chongwe and Mahatma Gandhi Health centres.

3.5.2 Exclusion criteria; this specifies the characteristics that are absent in the study population
(Burns and Grove, 2005). The sample excluded HIV exposed children below 12 months and
above 24 months, HIV exposed children who were up-to date with the follow-up care schedule
and HIV exposed children who tested positive and were referred for continuity of care.

3.6 SAMPLE SIZE

According to Burns and Groove (2009), a sample size is the number of subjects or participants
recruited and consented to take part in the study. In this study a total of two hundred (200)
respondents were included in the sample. The sample will comprised of fifty (50) respondents
from each of the study areas. The reasons for selecting this sample size include limited time as
well as inadequate material and financial resources on the part of the researcher.
3.7 DATA COLLECTION TOOLS

A data collection tool is an instrument used to collect data (Burns and Grove, 2005). In this study, a semi structured interview schedule which has both open-ended and closed-ended questions were used to collect data from the respondents.

The open-ended questions were used to enable participants to express their feelings of which their responses triggered new insight for the researcher. However, these questions are difficult to tabulate because the researcher can categorise responses subjectively which may introduce bias. The closed-ended questions were used where subjects were expected to give limited responses such as Yes or No. The advantages of using closed-ended questions are that they are simple and they offer a list of possible options or answers from which respondents must choose. However, respondents have limited choices which are sometimes called forced-response questions (Basavanthapa, 2006).

Advantages of using an Interview schedule

- The interview schedule was a relatively simple method of obtaining data in the study.
- The tool was flexible and the researchers explored responses and tailored the interview to the situation.
- The tool provided an opportunity for the researchers to appraise its validity as they were present to observe what was happening.
- Analysis and interpretation of data was easily accomplished as the interviewer was present to observe other non-verbal responses (Basavanthapa, 2006).

Disadvantages of using an Interview schedule

- The instrument was unable to probe a topic in depth without becoming lengthy.
- The interviewee had little or no choice in the date, time or the place of the interview.
- It was difficult to make comparisons of one interviewer’s data with another interviewer’s data.
- It was costly and time consuming (Basavanthapa, 2006).

The structured interview schedule comprised of six sections; biographic data (section A), knowledge on follow up care services (section B), follow up care(section C) and Attitude of staff
as perceived by mothers and or caretakers and attitude of mothers and or caretakers on follow up care services (section D), Service related factors (section E) and Socio-economic factors (section F).

3.8 VALIDITY

Validity is the degree to which an instrument measures what it is supposed to measure (Polit and Hungler, 2001). In this study, validity was measured by conducting a pilot study. A semi-structured interview schedule included questions pertaining to factors that were identified as having an influence on the problem of mother’s knowledge and attitude on follow up care services of HIV exposed children. To ensure validity of the instrument in this study, questions were made simple and brief for the participants and research assistants to understand. The researcher also consulted current sources of literature on the topic under study and experts on the topic were also consulted. Any questions that were not clear from the pilot study were corrected.

3.9 RELIABILITY

Reliability is the degree of consistency of measure obtained in the use of a particular instrument. The measure is reliable if it gives the same results each time the same situation or factor is measured. It is concerned with consistence and dependability (Burns and Grove, 2009).

In this study the researcher ensured reliability by standardizing the measurement tool. The research tool was tested before the main study was conducted using a pilot study in an environment with similar characteristics as the environment in which the main study was conducted. This was done to ensure stability of the data collection tool. The instrument was able to bring out the accurate information whereby if the same instrument were to be used after some time, it would produce the same responses. Inaccuracies in the instrument were corrected where necessary and it helped to eliminate biases and minimise errors during data collection.

3.10 DATA COLLECTION TECHNIQUE

Data collection technique is a process used to gather information used in addressing the problem under study (Burns and Grove, 2005). It consists of systematic collection of information from respondents to address the objectives of the study. In this study, data was collected by using an interview technique. Mothers or caretakers were allowed to sit comfortably, consent obtained
and confidentiality was assured. The interview was a one to one verbal communication between the researcher and participant during which information will be obtained for the study. Each interview lasted at least 30 minutes. The respondents were approached with confidence, confidentiality and anonymity was assured. Data were collected over a period of about 16 days and a range of three to five interviews were conducted per day. The procedure was done starting with self introduction of the investigator to the respondent, an explanation of the purpose of the study, reassurance of respondent on confidentiality and anonymity, and informing the respondents on how the feedback would be provided.

After getting consent, the researcher (interviewer) ready out the questions to the respondents, the researcher entered the responses as given by the respondents. At the end of the interview, the researcher went through the interview schedule to check for consistency in the answers given and for its completeness.

Finally the researcher asked the participants for any questions, comments or contributions regarding the study and then thanked them for taking part in the study.

3.11 PILOT STUDY

A pilot study is a smaller version of a proposed study conducted to refine the methodology (Burns and Grove, 2009). The purpose of the pilot study is to assess the feasibility of the study and make necessary adjustments to the interview schedule before the major study is carried out. The pilot study was conducted at another health institution with similar characteristics. The pilot study was conducted on 10% of the total sample (10% of 200 = 20) therefore; participants for pilot study were 20.

The findings of the pilot study were that; there were some changes on HIV test schedule where HIV exposed children are tested at 6 months unlike previously when they were being tested at 9 months. Apart from the trained health care providers, there is also active involvement of Community Based Volunteers in delivery of follow up care services at the health centre.

3.12 ETHICAL AND CULTURAL CONSIDERATIONS

The development and implementation of research should be ethically and culturally acceptable. Ethics are a system of moral values that are concerned with the degree to which research
procedures adhere to professional, legal and social obligations to the study participants (Polit and Hungler, 2001).

Ethical and legal issues have a deep concern for the human welfare and sensitivity for the rights of the research participants. Ethical issues were addressed by requesting permission to conduct the study, from the School of Medicine, Head of Department of Nursing Sciences, Chongwe, Chipata, Ndola and Livingstone District Health Offices (DHOs), and the health centres. Participants were requested to consent before they were included in the study.

The ethical principles that were considered in the study included the following;

- **Confidentiality** - confidentiality is an assurance that neither the identities of participants in the research will be revealed to anyone else, nor will the information that the participant provides individually be published or divulged (Burns and Grove, 2005). This was achieved by interviewing the mothers or caretakers in privacy and one participant interviewed at a time.

- **Anonymity** is the researcher’s ability to keep the respondents nameless (Burns and Grove, 2005). The investigators maintained anonymity by insuring that only serial numbers were used on the questionnaires and not the respondent’s names.

### 3.13 PLANS FOR DATA ANALYSIS

Data analysis is the process of categorizing, scrutinizing and examining the research data (Burns and Grove, 2005). Data analysis was done using a computer software Scientific Package for Social Statistical (SPSS) and Microsoft Excel. The researchers also used the frequency tables and graphs for presentation of data and cross tabulations to show the association and relationships between variables.

### 3.14 PLANS FOR DISSEMINATION OF FINDINGS

After collecting and analyzing data the investigators compiled a report for the purpose of disseminating findings to authorities and participants. Other copies of the report were submitted to the Department of Nursing Sciences (DNS) under the University of Zambia (UNZA), UNZA Medical Library, Ministry of Health (MOH) and the DHOs where the research was conducted from.
CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The purpose of this chapter is to present information on how the research data were analysed and what information was obtained. Data were collected from respondents using an interview schedule. Two hundred (200) respondents participated in the study, fifty (50) from each of the four selected districts of Zambia namely; Chipata, Chongwe, Livingstone and Ndola. A pilot study was conducted at Kalingalinga Urban Clinic in Lusaka.

4.2 DATA ANALYSIS

Data analysis is the systematic organisation and synthesis of research data, and the testing of research hypothesis using those data (Burns and Groove, 2005).

After data collection, data were checked for completeness and inconsistencies on a daily basis. The data were analysed using Statistical Package for Social Sciences (SPSS) and Microsoft Excel soon after interview schedules. There was sorting, verification of responses, coding and entering of data on the Excel and SPSS data master sheet for the quantitative data. The data master sheet was partitioned into 6 categories namely demographic data, knowledge, follow up care, attitude, service related factors, and socio-cultural and economic factors.

The qualitative data, which were derived from open-ended questions, were analysed using content analysis. Each response was transcribed, read and reread to get the concepts in the responses. The concepts were derived from the characteristics of the responses, and then developed into themes that were used to categorise the content into meaningful groupings.

4.3 PRESENTATION OF FINDINGS

Data has been presented on frequency tables and cross tabulations. Frequency tables are suitable because they summarize the findings in a meaningful way, which is easy to understand. Cross tabulation of dependent and independent variables was done to show the relationship among variables so that meaningful inferences could be drawn. Pie charts, graphs and bar charts have
also been used to present the data in a meaningful way to enable the reader to understand the findings easily.

SECTION A: DEMOGRAPHIC DATA

Figure 4.1: Age Distribution (n=200)

![Age Distribution](image)

Majority of the respondents 118 (59%) were in the age category of 25-34 years while 5 (2.5%) were above 45 years of age.

Table 4.1: Marital Status (n=200)

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>165</td>
<td>82.5</td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
<td>4.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Divorced</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Separated</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 164 (82%) were married, while the rest were either single, widowed, divorced or separated.
Table 4.2: Number of Children (n=200)

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>138</td>
<td>69</td>
</tr>
<tr>
<td>4-6</td>
<td>51</td>
<td>25.5</td>
</tr>
<tr>
<td>7-9</td>
<td>11</td>
<td>5.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>

Most of the respondents 138 (69%) had 1-3 children, while the rest had more than three children.

Figure 4.2: Education Level (n=200)

Most of the respondents 105(52.5%) had attained primary school education, 75(37.5%) had attained secondary education level, 11 (5.5%) had college education and 1 (0.5%) had attained University Education.
Figure 4.3: Occupation (n=200)

Most of the respondents 109 (54.5%) were self-employed and 63 (31.5%) were housewives.

Table 4.3: Monthly Income (n=200)

<table>
<thead>
<tr>
<th>Income</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above KR2000</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Below KR500</td>
<td>119</td>
<td>59.5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>

Majority of the respondents, 119 (59.5%) earned below KR500 per month while 65 (32.5%) earned between KR500 and KR2000.
SECTION B: KNOWLEDGE OF MTCT

Table 4.4: MTCT (n=200)

<table>
<thead>
<tr>
<th>Heard about MTCT</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>184</td>
<td>92</td>
</tr>
<tr>
<td>NO</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>

Majority of the respondents 184 (92%) had heard about Mother to Child Transmission (MTCT) of HIV while 16 (8%) of the respondents had not heard.

Table 4.5: Source of information of MTCT (n=200)

<table>
<thead>
<tr>
<th>Source</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media</td>
<td>58</td>
<td>29</td>
</tr>
<tr>
<td>Health centre</td>
<td>184</td>
<td>92</td>
</tr>
<tr>
<td>Relatives</td>
<td>11</td>
<td>5.5</td>
</tr>
<tr>
<td>Friends</td>
<td>27</td>
<td>13.5</td>
</tr>
<tr>
<td>Church</td>
<td>1</td>
<td>0.5</td>
</tr>
</tbody>
</table>

*Multiple responses

Majority of the respondents 184 (92%) had heard about MTCT from the Health centre while the least 1 (0.5%) had heard from the church.
Majority of the respondents 185 (92.5%) said that MTCT meant transmitting HIV to the baby while 15 (7.5%) said that they did not know the meaning of MTCT.

Table 4.6: Mode of HIV transmission from mother to child (n=200)

<table>
<thead>
<tr>
<th>Contracting HIV</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>During pregnancy</td>
<td>39</td>
<td>19.5</td>
</tr>
<tr>
<td>Labour/delivery</td>
<td>90</td>
<td>45</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>101</td>
<td>50.5</td>
</tr>
<tr>
<td>All of the above</td>
<td>75</td>
<td>37.5</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3</td>
<td>1.5</td>
</tr>
</tbody>
</table>

*Multiple responses

Majority of the respondents 101(50.5%) said that HIV transmission occurs during pregnancy while 75(37.5%) said that transmission of HIV occurs during pregnancy, labour and breastfeeding.
SECTION C: FOLLOW UP CARE

Table 4.7: Knowledge of follow up care (n=200)

<table>
<thead>
<tr>
<th>Heard about follow up care</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>184</td>
<td>92</td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>TOTAL</td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>

Majority of the respondents, 184 (92%) had heard about follow up care of HIV exposed children while 16 (8%) of the respondents had not heard.

Table 4.8: Source of information about follow up care (n=200)

<table>
<thead>
<tr>
<th>Source</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health centre</td>
<td>177</td>
<td>88.5</td>
</tr>
<tr>
<td>Media</td>
<td>22</td>
<td>11</td>
</tr>
<tr>
<td>Family member</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Peers</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

*Multiple responses

Majority of the respondents 177 (88.5%) heard about Follow up care from the Health centre, 22 (11%) got the information from the media, 8 (4%) heard from family members and 4 (2%) got the information from peers.
Figure 4.5: Services offered during follow up care of HIV exposed children (n=200)

*Multiple responses*

Majority of the respondents 153 (76.5%) said that HIV testing is one of the services offered during follow up care, 126 (63%) said provision of drugs, 106 (53%) said counselling and 16 (8%) said immunization was offered as a service.

Table 4.9: When to take the child for follow up care (n=200)

<table>
<thead>
<tr>
<th>When to take the child for follow up care</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>When child is sick</td>
<td>59</td>
<td>29.5</td>
</tr>
<tr>
<td>As per schedule</td>
<td>148</td>
<td>74</td>
</tr>
<tr>
<td>For drug supplies</td>
<td>106</td>
<td>53</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>0.5</td>
</tr>
</tbody>
</table>

*Multiple responses*

Majority 148 (74%) of the respondents stated that follow up care service should be utilised as per follow up schedule and 106 (53%) said that follow up care was for drug supplies.
Figure 4.6: Age to test the child for HIV (n=200)

*Multiple responses*

Majority of the respondents 122 (61%) said that the child should be tested at 6 weeks, 98 (49%) said at 12 months, 77 (38.5%) said at 18 months and 25 (12.5%) did not know when the child should be tested.

Table 4.1.0: Child taken for HIV testing at 12/18 months (n=200)

<table>
<thead>
<tr>
<th>Took Child For HIV Testing</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>37</td>
<td>18.5</td>
</tr>
<tr>
<td>No</td>
<td>163</td>
<td>81.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Eighteen per cent (18.5%) of the mothers took their children for HIV Testing at 12/18 months while 163 (81.5%) did not.
Table 4.1.1: Duration to receive HIV Rapid test results (n=37)

<table>
<thead>
<tr>
<th>Duration to receive results</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same day</td>
<td>34</td>
<td>92</td>
</tr>
<tr>
<td>2-7days</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>15- 30 days</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>37</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority 34 (92%) of the respondents said that they got the HIV rapid test results on the same day, 2(5%) said they got their results between 2-7 days while 1 (3 %), said that they got the HIV rapid test results between 15-30 days.

Figure 4.7: Reason for not taking the child for HIV testing (n=163)

Reason for not taking the child for HIV testing

- Stigma 28%
- Guilty 4%
- Busy schedule 18%
- Long Distance 5%
- Child is well 31%
- Long waiting time 14%

Forty Six (28%) of the respondents portrayed stigma as the reason for not taking the child for HIV testing, 50 (31%) said that they had a busy schedule, 8 (5%) said it was due to long distance to the health centre, 30(18%) said their children were well and 6 (4%) complained of long waiting time to be attended to at the health centre.
Table 4.1.2: Knowledge on benefits of follow up care (n=200)

<table>
<thead>
<tr>
<th>Benefits of follow up care</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficial</td>
<td>191</td>
<td>95.5</td>
</tr>
<tr>
<td>Not beneficial</td>
<td>9</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 191 (95.5%) said follow up care was beneficial while 9 (4.5%) said it was not.

Table 4.1.3: Explanation of benefits of follow up care (n= 191)

<table>
<thead>
<tr>
<th>Benefits of follow up care</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of HIV</td>
<td>90</td>
<td>48</td>
</tr>
<tr>
<td>Knowing HIV status</td>
<td>85</td>
<td>45</td>
</tr>
<tr>
<td>Early treatment</td>
<td>58</td>
<td>31</td>
</tr>
<tr>
<td>Counselling</td>
<td>15</td>
<td>8</td>
</tr>
</tbody>
</table>

*Multiple responses*

Ninety (48%) of the respondents said that the benefits of follow up care was prevention of HIV transmission, eighty five (45 %) said that it was for knowing HIV status of the child, while 58 (31%) of the respondents said that it was for early treatment and 15 (8%) said that follow up care was for counselling.
SECTION D: ATTITUDE

Table 4. 1.4: Taking Child for follow up care (n=200)

<table>
<thead>
<tr>
<th>Ever taken child for follow up</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>154</td>
<td>77.5</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
<td>23.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

One hundred and fifty four (77.5%) of the respondents took their children for follow up care while 46 (23.5%) did not take their children for follow up care.

Figure 4. 8: Reception by staff (n=154)

Majority of the respondents 70 (45%) stated that the reception by the staff was good, 68 (44%) said the reception was very good, and 15 (10%) said it was fair and the least was 1 (1%) who said that the reception by the staff was poor.
Table 4.1.5: Support from health staff (n=154)

<table>
<thead>
<tr>
<th>Support from the staff</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>57</td>
<td>37</td>
</tr>
<tr>
<td>Agree</td>
<td>93</td>
<td>60</td>
</tr>
<tr>
<td>Disagree</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>154</td>
<td>100</td>
</tr>
</tbody>
</table>

Ninety three (60%) of the respondents agreed that the staff were supportive in provision of follow up care, while 57 (37%) strongly agreed that the staff were supportive and 4 (3%) disagreed that the staff were supportive in provision of follow up care services.

Figure 4.9: Willingness to utilise follow up care services (n=200)

Willingness to utilise follow up care services

![Graph showing willingness to utilise follow up care services]

One hundred and ninety four (97%) of the respondents were willing to utilise follow up care services while 6 (3%) were not willing to utilise the follow up care services.
Table 4.1.6: Reasons for not utilising follow up care services (n=6)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td>2</td>
<td>33</td>
</tr>
<tr>
<td>Stigma</td>
<td>4</td>
<td>67</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>6</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Two of the mothers who were not willing to utilise follow up care services were in denial while 4 still had stigma.

SECTION E: SERVICE RELATED FACTORS

Table 4.1.7: Time taken to reach the health centre (n=200)

<table>
<thead>
<tr>
<th>Time taken to reach the clinic</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 30 minutes</td>
<td>73</td>
<td>36.5</td>
</tr>
<tr>
<td>30 minutes-1 hour</td>
<td>89</td>
<td>44.5</td>
</tr>
<tr>
<td>1 hours-3 hours</td>
<td>30</td>
<td>15</td>
</tr>
<tr>
<td>More than 3 hours</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 89 (44.5%) took 30 minutes to one hour to reach the Clinic while 8 (4%) took more than 3 hours.

Table 4.1.8: Provision of follow up care services (n=185)

<table>
<thead>
<tr>
<th>Provision of services</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>154</td>
<td>83</td>
</tr>
<tr>
<td>Fair</td>
<td>26</td>
<td>14</td>
</tr>
<tr>
<td>Poor</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>185</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 154 (83%) said the provision of follow up care services was good, 26 (14%) said the service provision was fair and 5 (3%) said the services were poor.
Majority of the respondents 82 (44.5%) took 30 minutes to one hour to be attended to while 7 (4%) took more than 3 hours to be attended to.

Table 4.1.9: Staffing levels at the health centre (n=200)

<table>
<thead>
<tr>
<th>Adequate staff</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>48</td>
<td>24</td>
</tr>
<tr>
<td>No</td>
<td>152</td>
<td>76</td>
</tr>
<tr>
<td>TOTAL</td>
<td>200</td>
<td>100</td>
</tr>
</tbody>
</table>

Most of the respondents 156 (76%) said that the staff were not enough at the health centre while 48 (24%), said that the staff were enough.
Table 4.2.0: Availability of follow up care logistics (n=185)

<table>
<thead>
<tr>
<th>Availability of supplies</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always available</td>
<td>157</td>
<td>85</td>
</tr>
<tr>
<td>Sometimes available</td>
<td>28</td>
<td>15</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>185</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 157 (85%) said that the supplies were always available at the health centre while 28 (15%) said the supplies were sometimes available.

SECTION F: SOCIO-CULTURAL AND ECONOMIC FACTORS

Table 4.2.1: Disclosure of HIV status (n=200)

<table>
<thead>
<tr>
<th>Disclosed HIV status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>176</td>
<td>88</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>12</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

One hundred and seventy-six (88%) which is the majority of the respondents had disclosed their HIV status while 24 (12%) had not disclosed.
Multiple responses

Majority of the respondents 144 (81%) disclosed their HIV status to their partners, 68 (38%) to their sisters, 11 (6%) to their brothers and 82 (46%) disclosed to their mother.

Table 4.2.2: Attitude of family members towards the HIV exposed child (n=178)

<table>
<thead>
<tr>
<th>Attitude towards the child</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>158</td>
<td>89</td>
</tr>
<tr>
<td>Fair</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Poor</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>178</td>
<td>100</td>
</tr>
</tbody>
</table>

One hundred and fifty-eight (89%) of the respondents said that the relationship of family members towards the child was good, 14 (8%) said it was fair and 6 (3%) said that the relationship was poor.
Table 4.2.3: Reasons for not disclosing HIV status (n=22)

<table>
<thead>
<tr>
<th>Reasons for not disclosing</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-stigma</td>
<td>18</td>
<td>82</td>
</tr>
<tr>
<td>Denial</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>22</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Eighteen (82%) of the respondents said that they did not disclose their HIV status to their family members because of self-stigma and 4 (18%) said that it was due to denial.

Table 4.2.4: Community support (n=200)

<table>
<thead>
<tr>
<th>Receiving community support</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>26</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>174</td>
<td>87</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>200</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

The majority of the respondents 174 (87%) did not receive any support from the community.

Figure 4.1.2: Organisations offering support (n=22)

Out of the respondents 12 (55%) received support from the church whilst the least 4 (18%) received support from the employer.
CROSS TABULATION TABLES

Relationship among Knowledge, Attitude and Follow up care of HIV exposed children between 12 to 18 months

This section highlights the relationship that exists among the three main variables in the study; knowledge, attitude and follow up of HIV exposed Children aged between 12 to 18 months. There are five (5) cross tabulation tables in this section; Respondents’ level of education and knowledge of follow up care, level of knowledge in relation to follow up care of HIV exposed children aged between 12 to 18 months, respondents knowledge in relation to follow up care, respondents attitude in relation to follow up care and respondents’ attitude in relation to the knowledge levels.

<table>
<thead>
<tr>
<th>Level of education</th>
<th>Knowledge of follow up care</th>
<th>Total</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>Low Education Level</td>
<td>10 (63%)</td>
<td>102 (55%)</td>
<td>112</td>
</tr>
<tr>
<td>Medium Education level</td>
<td>5 (31%)</td>
<td>71 (39%)</td>
<td>76</td>
</tr>
<tr>
<td>High education level</td>
<td>1 (6%)</td>
<td>11 (6%)</td>
<td>12</td>
</tr>
<tr>
<td>TOTAL</td>
<td>16</td>
<td>184</td>
<td>200</td>
</tr>
</tbody>
</table>

Among the respondents who had high knowledge of follow up care, 102 (55%) had low educational level, 71 (39%) had medium educational and 11 (6%) had high educational level while among the respondents who had low knowledge of follow up care, 10 (63%) had low educational level, 5 (31%) had medium educational level and 1 (6%) had high educational level. The level of significance is at 0.081.
Table 4.2.6: Relationship between access of follow up care and support from health staff

<table>
<thead>
<tr>
<th>Child taken for follow up care</th>
<th>Support from health staff</th>
<th>Total</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>Yes</td>
<td>57 (100%)</td>
<td>93 (100%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>57</strong></td>
<td><strong>93</strong></td>
<td><strong>4</strong></td>
</tr>
</tbody>
</table>

The majority of the respondents 93 (60%) who had taken their children for follow up care agreed that the staff were supportive while only 4 (3%) of the respondents who took their children disagreed of the staff being supportive. The level of significance is at 0.000 infinite.

Table 4.2.7: Relationship between utilization of follow up care and knowledge level

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Follow up care</th>
<th>Total</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Good</td>
<td>143 (95%)</td>
<td>184</td>
</tr>
<tr>
<td></td>
<td>Fair</td>
<td>38 (83%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>3 (100%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>8 (5%)</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8 (17%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>151</td>
<td>46</td>
<td><strong>200</strong></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>0.003</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Majority of the respondents 143 (95%) who had good utilization of follow up care had high knowledge of follow up care while 8 (5%) of the respondents who had good utilization of follow up care had low knowledge in follow up care. The level of significance is at 0.003.
Table 4.2.8: Relationship between attitude of respondents towards follow up care and Utilization of follow up care

<table>
<thead>
<tr>
<th>Follow up care</th>
<th>Attitude</th>
<th>Total</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>115 (77%)</td>
<td>36 (71%)</td>
<td>151</td>
</tr>
<tr>
<td>Fair</td>
<td>33 (22%)</td>
<td>13 (25%)</td>
<td>46</td>
</tr>
<tr>
<td>Poor</td>
<td>1 (1%)</td>
<td>2 (4%)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td><strong>149</strong></td>
<td><strong>51</strong></td>
<td><strong>200</strong></td>
</tr>
</tbody>
</table>

Among the respondents who had good utilization of follow up care, 115 (77%) had a positive attitude towards follow up care services while only 1 (1%) of the respondents had poor utilization of follow up care services. Out of the respondents who had a negative attitude towards follow up care services, 36 (71%) had good utilization of follow up care while only 2 (4%) had poor utilization of follow up care services. The level of significance is at 0.972.

Table 4.2.9: Attitude of mothers towards follow up care and Knowledge of follow up care

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Attitude</th>
<th>Total</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>137 (92%)</td>
<td>47 (92%)</td>
<td>184</td>
</tr>
<tr>
<td>Low</td>
<td>12 (8%)</td>
<td>4 (8%)</td>
<td>16</td>
</tr>
<tr>
<td>TOTAL</td>
<td><strong>149</strong></td>
<td><strong>51</strong></td>
<td><strong>200</strong></td>
</tr>
</tbody>
</table>

Majority of the respondents 137 (92%) who had a positive attitude towards follow up care services had high knowledge of follow up care services, while 12 (8%) had low knowledge of follow up care services. Similarly, majority 47 (92%) of the respondents who had a negative attitude towards follow up care services had high knowledge of follow up care services while only 4 (8%) had low knowledge of follow up care. The level of significance is at 0.116.
Table 4.3.0: Total knowledge, attitude and utilisation of follow up care services of HIV exposed children.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>200</td>
<td>0.00</td>
<td>11</td>
<td>9.44</td>
<td>2.37</td>
</tr>
<tr>
<td>Attitude</td>
<td>200</td>
<td>1</td>
<td>12</td>
<td>8.87</td>
<td>3.41</td>
</tr>
<tr>
<td>Follow up care</td>
<td>200</td>
<td>3</td>
<td>25</td>
<td>17.61</td>
<td>3.74</td>
</tr>
</tbody>
</table>

Knowledge levels ranged from 0.00 to 11. The mean was 9.44 and standard deviation was 2.37. Attitude scale ranged from 1 to 12. The mean was 8.87 and the standard deviation was 3.41. Utilization of follow up care services ranged from 3 to 25. The mean was 17.61 and the standard deviation was 3.74.

COMMENTS/SUGGESTIONS BY RESPONDENTS

This section focuses on the comments and suggestions that were made by the respondents that participated in the study on how they thought follow up care services of HIV exposed children in the four selected districts of Zambia.

More than half of the respondents 127 (63.5%) commented that waiting time before being attended to is too long therefore suggested that there is need to improve on staffing level at the health facilities.

Most of the respondents 174 (87%) commented they are in need of support in terms of food supplements so as to improve the nutritional status of their children.

Most of the respondents 191 (95.5%) said that follow up care services are beneficial and should therefore continue being provided. However, the majority express worries on lack of privacy in health facilities as there are no specific rooms for provision of the services.
CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 INTRODUCTION

The discussion contained in this chapter is based on the data collected for the study which was aimed to determine the factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months in four selected districts of Zambia namely; Chipata, Chongwe, Livingstone and Ndola. The results were based on the analysis of data obtained from a sample of 200 mothers/caretakers with HIV exposed children.

5.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

The sample included mothers/caretakers where the findings showed that 35 (17.5%) were in the age category of 14 -24, 42 (21%) were in the category of 35– 44, 5 (2.5%) were 45 years and above. The majority of the respondents 118 (59%) were in the age category of 25-34 years (Figure 4.1). This indicates that HIV prevalence is high among mothers in the age category of 25-34 years as this age group is sexually active (MOH, 2010). However, all age groups are affected therefore health education should be targeted to all age groups.

The findings further show that majority of the respondents 165 (82%) were married, 9 (4.5%) were single, 14 (7%) were widowed, 10 (5%) were divorced, and only 2 (1%) of the respondents were separated (Table 4. 1). The results have shown that most of the respondents were married. From the findings, it indicates that HIV prevalence is high among married women which could be attributed to cultural practices. For example; married couples are not allowed to use condoms regardless of the HIV status and they are expected to be submissive to their husbands (Bweupe, 2010). This increases the incidence of HIV exposed children especially that married women are expected to bear children. Therefore, it is important for the health care providers to give health education on the importance of male involvement starting from antenatal to ensure support in seeking follow up care services.

Table 4.2 shows that majority of the respondents 138 (69%) had one to three children, 51 (25.5%) of the respondents had four to six children and 11 (5.5%) had seven to nine children. The findings show that the majority of respondents were still in the child bearing age with few
children ranging from 1-3 meaning that more HIV exposed children were yet to be born from these mothers. Therefore there is need to sensitize couples and the community at large on the importance of follow up care services of HIV exposed children with emphasis on prevention of HIV transmission to the baby.

The study also shows that the respondents represented various categories in the level of education with those who had low education level (no formal education and primary education) in the majority at 112 (56%), 76 (38%) of the respondents had medium education level (secondary education), 12 (6%) of the respondents had high education level (tertiary education) (Figure 4. 2). The findings are in contrast with Bweupe (2010) in the study on women’s reasons for not participating in follow up visits where he discovered that the low education levels can also lower participation in activities dealing with HIV but instead may tend to perpetuate the practices that are harmful; their attitude will be negative to any campaign against HIV and AIDS. Bweupe (2010) also concluded that the educated parent would have foresight and his or her attitude will be positive towards the PMTCT services.

Figures 4.3 shows that most of the respondents 109 (54.5%) were self employed, 63 (31.5%) were housewives, 18 (9%) were unemployed, 8 (4%) were in formal employment while only 2 (1%) of the respondents were students. This result shows that majority of the respondents could be busy with their businesses as they are self employed hence they have no time to take the children for follow up care.

The findings show that 119 (59.5%) of the respondents earned below KR500 every month, while 65 (32.5%) earned between KR500 and KR 2, 000, 16 (8%) earned above KR 2, 000 (Table 4. 3). This is attributed to low level of education making it difficult for them to find meaningful employment. This means that the income of the respondents is very low such that they engage themselves in income generating activities. The findings also agree with Bweupe (2010) who found that many women are committed to caring for children and selling at the market to earn a living.
5.2 DISCUSSION OF EACH VARIABLE

5.2.1 KNOWLEDGE OF FOLLOW UP CARE

The findings revealed that majority 184 (92%) of the respondents had heard about MTCT of HIV while 16 (8%) of the respondents had no idea of MTCT of HIV (Table 4. 4). These findings are supported by Cheelo (2009) in his study ‘Involving the Community Based Volunteers to mitigate low return to follow up of HIV exposed infants’ who said that with sensitization by community based volunteers, mothers have an increase in knowledge on follow up care.

Most of the respondents 184 (92%) received information on MTCT of HIV from the health centre. This could be attributed to the involvement of the community based volunteers who are involved in dissemination of information on PMTCT services (Cheelo, 2009). The other sources of information 58 (29%) was from the media, 27 (13.5%) from friends, 11 (5.5%) from relatives and 1 (0.5%) from the church (Table 4. 5). The findings also agree with Cheelo (2009), in his study on involving the community based volunteers to mitigate low return to follow up of HIV exposed infants in Itezhi Tezhi where he noted that the community based volunteers helped track HIV exposed babies through sensitization. The findings are further supported by MoH (2010) in the protocol guidelines which reported that community volunteers such as community lay counsellors play an important role in the delivery of quality follow up care services.

Figure 4.4 shows that the majority of respondents 185 (92.5%) knew the meaning of MTCT of HIV while 15 (7.5%) did not know the meaning of MTCT of HIV. This could be attributed to the involvement of the community based volunteers who have helped in the dissemination of information (Cheelo, 2009).

The findings show that the majority of respondents 101 (50.5%) were that the mode of HIV transmission occurs during breastfeeding, 90 (45%) occurs during delivery, 39 (19.5%) occurs during pregnancy. Responses for those who knew all the modes of transmission (pregnancy, labour/delivery and breastfeeding) were 75 (37.5%), while 3 (1.5%) did not know the modes of transmission of HIV (Table 4. 6). This calls for more emphasis on modes of transmission during health talks since the responses from the findings were less than 50% on all the modes of transmission of HIV. These findings agree with Katushabe (2007), in his study about
‘knowledge, attitude and constraints of PMTCT services’ where he discovered that mothers were not knowledgeable on how MTCT occurs due to inadequate information during health talks.

5.2.2 FOLLOW UP CARE

The majority of respondents 184 (92%) had heard about follow up care of HIV exposed children while 16 (8%) of the respondents had no idea about follow up care services (Table 4. 7).

The reasons for those who said that they had no idea of follow up care could be that they had a negative attitude towards follow up care as they went to the clinic late. It could also be that they went to the clinic late when the health education was already given hence they did not benefit from it. The majority of the respondents could have heard about follow up care due to the involvement of the Community Based Volunteers on sensitizing the mothers/caretakers about follow up care services. The findings are in agreement with Cheelo (2009), who from his study concluded that through sensitization mothers had increased knowledge on follow up care.

Table 4. 8 shows that most of the respondents 177 (88.5%) got the information about follow up care from the health centre which could be attributed to the involvement of the Community Based Volunteers on sensitizing the mothers/caretakers about follow up care services. Twenty two (11%) got the information from the media, 8 (4%) from family members while only 4(2%) got the information from the peers. These results indicate that follow up care of HIV exposed children is not being discussed among family members, friends and even on the media. Deliberate programs about follow up care services should be aired on the media to reach out to many people. Communities should be encouraged to form or revamp support groups to promote sensitization on importance of follow up care among the peers. There is also need for community based volunteers to sensitize people at community and family level. These programs will serve as a continuous reminder for the mothers/caretakers to make use of the follow up care services.

The findings from figure 4. 5 show that the majority of the responses 153 (76.5%) were that HIV testing was offered as a service during follow up care of HIV exposed children. This means that most mothers/caretakers associate follow up care with HIV testing. The other responses 126 (63%) indicated that follow up care was for provision of drugs, 106 (53%) counselling, while 16 (8%) said that it was for immunization. Majority of the responses 148 (74%) said that follow up care services should be utilized as per follow up schedule, 106 (53%) said that follow up care
was for drug supplies, 59 (29.5%) said that follow up care was to be utilized when the child is sick while 1 (0.5%) did not know when to utilize follow up care services (Table 4.9). According to the findings most of the respondents are knowledgeable about when to utilize follow up care. The findings do not agree with Katushabe (2007) in his study about knowledge, attitude and constraints of PMTCT services in a regional hospital in Eastern Uganda who said that respondents had little or no knowledge about follow up services offered.

Majority of the respondents 122 (61%) said that the child should be tested at 6 weeks, 12 (49%) said at 12 months, 18 (38.5%) said at 18 months and 25 (12.5%) did not know when the child should be tested, 13 (6.5%) said that testing should be done 6 weeks after weaning while 12 (6%) said that children should be tested at 10 weeks (Figure 4.6). The findings indicate that most mothers consider 6 weeks to be the age at which HIV testing is done and less than half of the respondents know that exposed children should be tested for HIV at 6 months, 12 months and 18 months. This could be the reason why most mothers do not take their children for HIV testing according to schedule as they have not perceived the susceptibility of their children to acquiring HIV.

Therefore, there is need for health care providers and community based volunteers to emphasize on the importance of follow ups for HIV testing according to schedule. There is also to integrate follow up care services for HIV positive mothers and their exposed children with other routine health programmes to promote access to follow up care services. The findings are consistent with Mahomva et al (2004) in a study on improving identification and follow up of HIV exposed children in Zimbabwe who said that health workers may not effectively communicate availability of care and support services that are appropriate at various points during lifespan of the mother and the infant.

Table 4.1.0 shows that the majority of respondents 163 (81.5%) did not take their children for HIV testing at 12/18 months while 37 (18.5%) of the respondents took their children for HIV testing at 12/18 months. All the respondents were captured as loss to follow up from the health centre registers, however, the findings show that 18.5% of the respondents had actually taken their children for HIV testing at 12/18 months. This can be attributed to poor recording in the registers at the health facilities. Therefore, there is need for a systematic follow up by health care providers that will ensure documentation of those who are tested. On the other hand the findings
indicate that majority of the respondents were loss to follow up because the mothers/caretakers probably did not understand the benefits of HIV testing for their HIV exposed children. These findings are consistent with Mahomva et al (2004) in the study on improving identification on follow up of HIV exposed children in Zimbabwe where he found that out of the total number of HIV exposed children that were enrolled into a review and follow up program at 6 weeks of age, less than half of the children were known to be alive and tested for HIV at 18 months of age. The findings also agree with Lettow et al (2011) in the study to assess PMTCT program outcomes under routine conditions to identify areas for improvement where it was discovered that follow up HIV testing for HIV exposed infants was poor and only 28% were tested at least once by 18 to 20 months of age.

The findings in table 4.1.1 show that, the majority 34 (92%) of the respondents who took their children for HIV testing received the HIV results on the same day. The result indicates that time taken to receive results is not a discouraging factor as the majority of the respondents received the results the same day, 2 (5%) of respondents received results after 2 – 7 days, while 1 (3%) received the results after 15–30 days. The late receiving of results could be a discouraging factor for taking children for HIV testing as the results are expected to ready the same.

Figure 4.7 shows that the majority of respondents 50 (31%) said they did not take their children for HIV testing because they were busy, 46 (28%) was due to stigma, 30 (18%) said their children were fine, 23 (14%) was due to being guilt, 8 (5%) was due to long distance while 6 (4%) was due to long waiting time. The findings show that respondents had various reasons for not taking their children for HIV testing. The outstanding reason for not taking their children for HIV testing was that they had a busy schedule which could be attributed to high poverty levels such that the mothers/caretakers spend most of their time trying make ends meet.

The findings from this study agree with Mahomva et al (2004) in the study on improving identification on follow up of HIV exposed children in Zimbabwe where it was found that mothers did not turn up for follow up care because of poor integration of services in resource limited settings, making health workers not consistently and effectively identify over-time mothers living with HIV and their exposed infants in need of care and treatment services. The findings also agree with the study done by Kalembo and Zyanbo (2012) on the fear of HIV test where it was discovered that stigma and discrimination were the main reason for the loss to
follow up. However, the findings do not agree with Braitstem et al (2010) in the study on Retention of HIV infected and HIV exposed in a comprehensive HIV clinic care program where it was concluded that the high rate of loss to follow up is due to sickness and malnutrition of the HIV exposed children.

In order to break these barriers to follow up care, there is need for mothers to receive adequate information on follow up care and the need for them to access these services.

Therefore, it is important to involve mother’s partners and the community as a whole to improve the low coverage of follow up. There is also need for health care providers and community based volunteers to promote formation or revamping of support groups in the communities where they can discuss issues of stigma, guilt and other issues related to care of the exposed children. Health care services need to be closer to the women’s homes for easy access to follow up care services for their HIV exposed children. Women should access follow up care services wherever they may be and not at a fixed location.

Table 4.1.2 shows that the majority of the respondents 191 (95.5%) knew the benefits of follow up care. The result can be attributed to the sensitization done at the health centre. The remaining 9 (4.5%) of the respondents did not know the benefits of follow up care. However, the respondents had various explanations on the benefits of follow up care as indicated in table 4.1.3 where 90 (47%) responses were for prevention of HIV transmission, 85 (45%) were for knowing HIV status, 58 (30%) responses were for early treatment while 15 (8%) responses were for counseling. Despite majority of the respondents claiming to have knowledge on benefits of follow up care, they could not fully explain the importance of follow up care as shown from the findings of the study. Therefore, there is need to intensify counseling on the benefits of follow up care.

5.2.3 ATTITUDE TOWARDS FOLLOW UP CARE

Table 4.1.4 shows that the majority of respondents 154 (77.5%) took their children for follow up care while 46 (23.5%) did not take their children for follow up care. This indicates that most mothers had taken their children for other follow up care services before 12 months apart from HIV Testing at 12 months owing to the involvement of the Community Based Volunteers at the Health centres. These findings agree with Cheelo (2009) who in his study on involving the
community based volunteers to mitigate low return to follow up of HIV exposed infants in Itezhi Tezhi Hospital in Zambia where he discovered that the coverage rate improved from 38% to 63% after involving the Community Based Volunteers in the dissemination of information on importance of follow up care and tracking of HIV exposed children.

Figure 4.8 shows that majority of the respondents, 70 (45%) said that the reception was good, 68 (44%) stated that the reception by the staff was very good, 15 (10%) said that the reception was fair and the least was 1 (1%) who said that the reception by the staff was poor. At the same time, the results in Table 4.1.5 indicate that the majority 57 (37%) of the respondents strongly agreed that the staff were supportive, while 93 (60%) agreed that the staff were supportive and 4 (3%) disagreed that the staff were supportive. This was done to assess whether the attitude and support portrayed and given respectively by the staff contributed to the mothers not taking their children for follow up care services. However the results obtained indicate that the reception by staff was not bad as the majority of respondents said the attitude was very good or good. Therefore it could be concluded that it is the attitude of mothers that is related to them not bringing their children for follow up care services and not the staff attitude or their support.

Figure 4.9 shows that 194 (97%) of the respondents were willing to utilise follow up care services while 6 (3%) were not willing to utilise the follow up care services. Additionally, table 4.1.6 shows that 2 (33%) of the mothers who were not willing to utilise follow up care services were in denial while 4 (67%) were not willing to utilise the services because of stigma. This indicates that the issues of stigma and denial are still a problem in the community. Therefore, formation of support groups where HIV issues are openly talked about can help reduce denial and stigma. Those affected should be able to openly talk about their experience so that others learn from them.

Despite the majority of the respondents being willing to utilise the follow up care services and viewing them as being beneficial, they did not take their children for the services, because they did not perceive the susceptibility of their HIV exposed children getting infected beyond the six weeks period. This therefore makes them respond poorly to the follow up care services offered. The findings do not agree with Nguyeni etal (2008) in his study on “Dealing with a positive result; Routine HIV Testing among women in Vietnam” where he concluded that health workers were unfriendly and unkind towards HIV infected women during post-delivery care, which led to
perceived stigma and discrimination among women receiving care. It was further concluded that inappropriate communication about HIV status can result in the women’s avoiding the health services which means they will not come back later to access the continuous treatment, care and support they need.

This calls for continuous education on the follow up care services using various means like cues from media through Television (T.V), radio and drama performances so that the women realise the need for them to access and utilise these follow up care services till their exposed children are discharged or referred for further management.

SECTION E

5.3 SERVICE RELATED FACTORS TO FOLLOW UP CARE

Table 4.1.7 shows that majority of the respondents 89 (44.5%) took 30 minutes to one hour to reach the Clinic, 73 (36.5%) took less than 30 minutes, 30 (15 %) take 1-3 hours while 8 (4%) took more than 3 hours. In this study, the results indicate that distance to the clinic is not a hindrance for the mothers to take their children for follow up care as most of them take less than one hour to reach the health centre. This means that the services are as close to the people as possible as distance is not an outstanding barrier. The services are equitably distributed and are accessible except for the 4%.

Table 4.1.8 shows that the majority of the respondents, 154 (83%) said that the provision of follow up care services was good, 26 (14%) said that the provision of follow up care services was fair while 5 (3%) said that the services were poor. These results indicate that generally, the service provision of follow up care services did not discourage the mothers from returning for follow up care services The findings do not agree with Nguyen et al (2008) who concluded that health workers were unfriendly and unkind towards HIV infected women during post-delivery care, which led to perceived stigma and discrimination among women receiving care

Results in Figure 4.1.0 show that the majority of the respondents 82 (44.5%) took 30 minutes to one hour to be attended to, 68 (36.5%) took less than 30 minutes to be attended to, 28 (15%) took 1 hour to 3 hours to be attended to, and 7 (4%) took more than 3 hours to be attended to. These results indicate that most mothers are attended to within an hour which is acceptable considering
the services being offered. This can also be attributed to the community based volunteers who assist in provision of the follow up care services. Otherwise qualified trained staff are perceived not to be enough as shown in table 4.1.9. Therefore, time taken to be attended to cannot be considered as a factor for the mothers to have a negative attitude towards follow up care services.

In table 4.2.0, majority of the respondents 157 (85%) said that the supplies were always available at the health centre while 28 (15%) said that the supplies were sometimes available. This indicates that mothers are rarely sent back home without drug supplies hence it might not be a factor that can make mothers to have a negative attitude towards utilization of follow up care services.

SECTION F

5.4 SOCIO-CULTURAL AND ECONOMIC FACTORS

Table 4.2.1 shows that the majority 176 (88%) of the respondents had disclosed their HIV status while 24 (12%) had not disclosed. The Majority of the respondents 144 (81%) disclosed their HIV status to their partners, 21 (38%) to their sisters, 11 (6%) to their brothers and 82 (46%) disclosed to their mother (figure 4.1.1).

This shows that the mothers are likely to have support from the people they disclosed to. Having family support entails that mothers can have confidence to access follow up care services but them not accessing follow up care services could mean that the people disclosed to might not really know their roles. This therefore means that family awareness of follow up care services should be emphasized. However, Tshibumbu (2006), in the study on factors influencing male involvement in PMTCT of HIV program in Mambwe district of Zambia, concluded that social cultural and service factors were found to negatively influence men’s involvement in PMTCT programs. For example, men could not assist in taking their HIV exposed children for follow up care as they believe that it is the work of women. It can be concluded that there could be other social cultural factors that are making these partners not to support the women to be taking their children for follow up care services despite the women disclosing their status.

Table 4.2.2 shows that 158 (89%) of the respondents said that the relationship of family members to the child was good, 14 (8%) said it was fair and 6 (3%) said that the relationship was
The findings showed that the relationship between the HIV exposed child and the person disclosed to is good. This also indicates that family stigma is not so much of an issue. Despite these findings, mothers have continued not to take their HIV exposed children for follow up care. This indicates that there is still need to sensitize the family and the community on the importance and benefits of follow up care services.

Table 4.2.3 shows that the majority of the respondents 18 (82%) said that they did not disclose their HIV status to their family members because of self-stigma and 4 (18%) said that it was due to denial. This indicates that stigma and denial are still a problem in the community. Therefore, there is need to encourage formation of support groups where HIV discussions can be done openly to help reduce denial and stigma since the majority of the respondents 174 (87%) as shown in table 24 did not receive any support from the community and only 26 (13%) did.

Among the few who received community support (figure 4.1.2), most of the respondents 12 (55%) received support from the church, 6 (27%) received from the support group and 4 (18%) received support from the employer. This indicates that organizations are not fully involved in HIV follow up care programs at community level. Therefore, there is still need to improve on sensitization at all levels which includes the church, support group and the employers.

5.5 RELATIONSHIPS AMONG KNOWLEDGE, ATTITUDE AND FOLLOW UP CARE

This section looks at the relationship that exists among the three variables in this study which include knowledge, attitude and follow up care.

The study reveals that among the respondents who had high knowledge of follow up care, 102 (55%) had low educational level, 71 (39%) had medium educational level and 11 (6%) had high educational level while among the respondents who had low knowledge of follow up care, 10 (63%) had low educational level, 5 (31%) had medium educational level and 1 (6%) had high educational level (Table 4.3.7). The findings are in contrast with Katushabe, (2007) where, he discovered that the respondents who had little or no knowledge of PMTCT services (63%) had low educational levels. The differences could be due to the fact that there is adequate information during health talks which includes messages on how MTCT occurs, the timing and the follow up care services are made clear to the women. From the above findings, the level of significance is
at 0.081. We therefore, fail to reject the hypothesis of this study which states that ‘there is no relationship between education level and knowledge of follow up care.

The study also reveals that majority of the respondents 93 (60%) who had taken their children for follow up care agreed that the staff were supportive while 57 (37%) of the respondents who took their children strongly agreed of the staff being supportive. The study also shows that only 4 (3%) disagreed that the staff were supportive (Table 4.3.8). The findings do not agree with Nguyen et al (2008) in his study on “Dealing with a positive result; Routine HIV Testing among women in Vietnam” where he found that health workers were unfriendly and unkind towards HIV infected women during post-delivery care, women did not receive adequate counselling on PMTCT options which led to perceived stigma and discrimination among women receiving care. This therefore shows that despite the health workers being supportive the mothers/caretakers do not fully utilize the follow up care services particularly taking of their HIV exposed children for HIV testing at 12 or 18 months. The level of significance is 0.000 infinite. From the findings, we reject the hypothesis that states that there is no relationship between follow up care and support from health staff.

Furthermore, the study also reveals that the majority of the respondents 143 (95%) who had good utilization of follow up care had high knowledge of follow up care while 8 (5%) of the respondents who had good utilization of follow up care had low knowledge of follow up care. Among those who had fair utilization of follow up care services, 38 (83%) had high knowledge while 8 (17 %) had low knowledge of follow up care. Only 3 respondents who had high knowledge had utilization of follow up care (Table 4.3.9).

These findings agree with Cheelo (2009) who in his study on involving the community based volunteers to mitigate low return to follow up of HIV exposed infants in Itezhi Tezhi Hospital in Zambia, where he discovered that the coverage rate improved from 38% to 63% after involving the community based volunteers in the dissemination of information on importance of follow up care and tracking of HIV exposed children. The level of significance is at 0.003 therefore, we reject the null hypothesis which says that there is no relationship between levels of knowledge and follow up.
From the Table 4.4.0 most of the respondents 115 (77%) who had good utilization of follow up care services had a positive attitude towards follow up care services while 36 (71%) of the respondents who had good utilization of follow up care services had a negative attitude towards follow up care services. Among the respondents who had fair utilization of follow up care services, 33 (22%) had a positive attitude while 13 (25%) had a negative attitude towards follow up care services. Additionally, among the 3 who had poor utilization of follow up care services, 1 (1%) had a positive attitude towards follow up care services and 2 (4%) had a negative attitude towards follow up care services. These results indicate that a positive attitude of mothers towards follow up care services might lead to good utilization of follow up care services. The results also show that among the respondents who had a negative attitude towards follow up care services, the majority (71%) had good utilization of follow up care services.

The findings indicate that there is no statistical significance (P value of 0.972) between attitude of mothers and utilization of follow up care services. We therefore fail to reject the null hypothesis that there is no relationship between attitude of mothers and utilization of follow up care services.

The study reveals that majority of the respondents 137 (92%) who had a positive attitude towards follow up care services had high knowledge of follow up care services, while 12 (8%) had low knowledge of follow up care services. These findings are in line with Cheelo (2009) who discovered that the coverage rate improved from 38% to 63% after involving the Community Based Volunteers in the dissemination of information on importance of follow up care and tracking of HIV exposed children.

The study also agrees with MOH 2010 National Guidelines of Zambia where it was reported that community volunteers such as Traditional Birth Attendants (TBAs), Safe Motherhood Action Groups (SMAGS), Home based care givers and Community lay counsellors can play an important role in the delivery of quality follow up care services. Furthermore, the report goes on to say that the orientation of traditional leaders, religious leaders on safe motherhood, follow up care services of HIV exposed children can be highly beneficial as they can influence their community to follow positive health seeking behaviours which will benefit the individual and the community as a whole.
Similarly, the findings show that among the respondents who had a negative attitude towards follow up care, the majority (92%) had high knowledge of follow up care while only 4 (8%) had low knowledge of follow up care services (Table 4.4.1). With the level of significance being at 0.116 we therefore fail to reject the hypothesis that there is no relationship between attitude of mothers towards follow up care and knowledge of follow up care service.

5.6 IMPLICATIONS TO THE HEALTHCARE SYSTEM

5.6.1 UTILISATION OF FOLLOW UP CARE

The burden of providing follow up care to HIV exposed children falls onto the healthcare system. HIV infection is one of the most dramatic challenges to the public health system in Zambia. The follow up care of HIV exposed children presents one of the most complex issues that nurses in particular have to deal with especially with the introduction and scaling up of Prevention of Mother to Child Transmission of HIV (PMTCT) services. In Zambia, there is an urgent need to expand the knowledge base in our communities through sensitization on the importance of utilisation follow up care services. Once the expansion of knowledge is properly followed by health workers and Community Based Volunteers, the implication is that mothers / care takers will be taking their HIV exposed children for follow up care at 12 and 18 months there by reducing the extra burden placed on the health care system in terms of finances and human resource when managing these children when they get sick.

5.6.2 ADMINISTRATION

Follow up care of HIV exposed children is a challenge and therefore, improving compliance requires commitment in leadership, collaboration with cooperating partners, accessibility of the services, feedback on compliance and loss to follow up rate, documentation and individual accountability. Follow up care services cannot be delivered adequately if the necessary supplies required to provide the services are not in constant supply. Similarly, health workers cannot properly deliver the follow up care services if they do not document and report the loss to follow up rates to the Administrators who are to strategies on the best way to deliver the follow up care services that are to yield desired results. Once the system of proper tracking is in place through proper documentation and integration of services, health workers will be able to trace the loss to follow up easily.
The Ministry of Health through the District Health Offices, need to see to it that the follow up care services are integrated with other programmes/ activities in all the departments of the health centres so that HIV exposed children are easily traced. The District offices should also motivate Community Based Volunteers through refresher courses and incentives such as bicycles as tracing these children is not an easy task. Management should also ensure that evaluation meetings are held with members of staff and Community Based Volunteers where they can brainstorm on strategies to improve provision of follow up care services.

The management in collaboration with the various NGOs dealing with PMTCT in particular follow up care services, should conduct sensitization campaigns to local radio stations, through drama performances, posters brushers and support groups on the importance of follow up care as well as step up the training program at the community level to enhance full participation.

5.6.3 NURSING EDUCATION

Although majority of the respondents had high knowledge and positive attitude towards follow up care services their utilization of follow up care services was low particularly taking their HIV exposed children for testing at 12 and 18 months. It is therefore important that trainers involved in teaching health workers should emphasize on the importance of follow up care services of HIV exposed children right from the training schools where they are being trained from since the component of PMTCT already exists in their curriculum. It will be beneficial to the students if the component of follow up care of HIV exposed children is emphasized on how to improve strategies in tracking the loss to follow up. The teaching sessions can be done with the help of other studies that have been conducted elsewhere which have shown improvement in follow up care services after employing new strategies.

5.6.4 RESEARCH

Follow up care of HIV exposed children is very important when it comes to prevention of HIV transmission from the mother to the baby and, reduction in child morbidity and mortality. There are few studies that have been done on follow up care of HIV exposed children in Zambia. It is therefore important that further research is conducted to determine whether administrative sanctions would improve adherence to recommendations of follow up care services. This will help reduce loss to follow up of HIV exposed children.
5.7.0 RECOMMENDATIONS

The study suggested intended changes in the follow up of HIV exposed children and those who have authority were identified to make changes in the program.

5.7.1 To the Government

The government through the ministry of health as a policy making body should ensure that follow up care services are integrated with other programs/activities in all departments of health facilities.

There is need to allocate funds to health institutions specifically to facilitate the tracking of HIV exposed children who are lost to follow up.

The government needs to work with stakeholders who are specialized in follow up care services of HIV exposed children focusing on follow up care promotion by sensitizing the community as well as training the Community Based Volunteers in following up of these children.

The Government needs to increase the funding for research programs to allow more research to be done on follow up care of HIV exposed children so that loss to follow up is reduced.

There is need for the government to translate Information, Education and Communication (I.E.C) materials into local languages for easy communication in the communities.

5.7.2 To the District Health Office management

The management should ensure that there is improvement in follow up care of HIV exposed children by conducting follow up care campaigns so that the community is aware and the members are encouraged to utilize the services.

The management should ensure that funds are released for tracking the loss to follow up of HIV exposed children.

The management should ensure that they lobby for more health workers from the Ministry of Health who are the employers to improve on staffing, hence improving in delivery of the services.
The management needs to ensure that there is supervision of service provision at health facilities through conducting performance assessment, technical support, peer review meeting and district integrated meetings to share information and experiences. Management should ensure that maternal and Child Health (MCH) Coordinators take keen interest and an active role in spearheading the follow up care programmes and quick feedback to health facilities on their performance especially those performing badly. This information in turn will need to be shared with the neighbourhood health committee as well as the Community Based Volunteers to assist in reducing loss to follow up care.

5.7.3 Health facilities

There is need to intensify health education on follow up care of HIV exposed children in order to reduce loss to follow up.

Emphasis should be placed on schedule for follow up care so that mothers/ caretakers know exactly when they should take their HIV exposed children particularly for HIV testing.

There is need to identify and train more community based volunteers some of whom should spear head PMTCT program at community level and to be able to trace the lost to follow up.

5.7.4 To the community

The community should be encouraged to form support groups where there is none or revamp those inactive ones to assist in follow up care services since social support has been found to be one of the most important motivators of compliance to follow up care.

Community leaders should be encouraged to participate in all follow up care programs of HIV exposed children such as sensitization meetings and review meetings in conjunction with the health centre leadership.

There is need for each household to be encouraged to discuss issues concerning HIV to reduce stigma and discrimination and thereby improving access to follow up care services.
5.8.0 DISSEMINATION OF FINDINGS

Dissemination of findings involves the measures that would be undertaken to make known to the relevant authorities and the study participants what the study has measured.

The findings of the study will be disseminated to the District Health Offices (DHO) and health facilities in the four selected districts.

Further, the results of the study will be disseminated by submitting a copy of the research report to the University of Zambia - Department of Nursing Sciences, Medical Library, the Ministry of Health and a copy for the researcher.

5.8.1 LIMITATIONS OF THE STUDY

The study was hampered by budget constraints which resulted in the selection of only 200 respondents. This also contributed to the limited techniques used in gathering the information as only one technique was used which involved the use of questionnaires. This limited the generalization of the findings.

Literature was also another limitation to the study as most of the literature used on follow up were articles that were either written or studies conducted outside Zambia.

The sample size of 200 respondents was too small to generalize the findings onto the general population.

The criteria used to determine the sample size was dependent on the availability of resources. The period in which the study was conducted was too short and that the study was not funded thereby limiting manpower.
5.8.2 CONCLUSION

The study was conducted to determine the knowledge, attitude and utilization of follow up care by mothers/ caretakers of HIV exposed children in four selected districts of Zambia namely; Chipata, Chongwe, Livingstone and Ndola. A non experimental descriptive study design in which a questionnaire was used to collect the required data on 200 conveniently selected samples.

The study revealed that most of the respondents had high knowledge and positive attitude towards follow up care. Despite the respondents having positive attitude towards care, the level of utilization of follow up care services particularly HIV testing at 12 and 18 months was poor.

Therefore, there a lot that needs to be done to improve utilization of follow up care services by the respondents such as following some of their suggestions brought up like; improving on staffing levels in the health facilities in order to reduce on waiting time to be attended to, improving on privacy during the provision of the follow up care services and providing support in terms of food supplements to improve the nutritional status of their HIV exposed children.

The findings also show that respondents had various reasons for not taking their children for HIV testing. The outstanding reason for not taking their children for HIV testing was that they had a busy schedule which could be attributed to high poverty levels. This is because of had low educational levels such that they could not be in formal employment where they could earn enough income for their families. Therefore, the mothers/caretakers spend most of their time doing personal businesses in order to make ends meet.

The study targeted the mothers /care takers as respondents but there is need to conduct an in-depth study from the service providers point of view which may reveal others factors contributing to low turn up of HIV exposed children at 12 and 18 months. Therefore, as one considers conducting research on follow up care of HIV exposed children, it would be wise to realize that follow up care is a challenge to both the mother/ caretakers and service providers.
It is also important that the research is conducted on a larger scale for proper generalisation of findings. In addition, there remains some follow up care strategies on knowledge and attitude to prevent loss to follow up of HIV exposed children that need to be addressed.
REFERENCES

- Central Statistical Office (2007), *Demographic Health Survey*, Lusaka Zambia


APPENDIX I

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF NURSING SCIENCES

SEMI-STRUCTURED INTERVIEW SCHEDULE

TOPIC: FACTORS CONTRIBUTING TO LOW TURN UP OF HIV EXPOSED CHILDREN FOR FOLLOW UP CARE BETWEEN 12 TO 18 MONTHS

DATE OF INTERVIEW: ..............................................

PLACE OF INTERVIEW: ...........................................

NAME OF INTERVIEWER: ...........................................

QUESTIONNAIRE NO: ................................................

INSTRUCTIONS TO INTERVIEWER

1. Introduce yourself to the respondent
2. Explain the purpose of the interview
3. Get written consent from the respondent and do not force them to be interviewed
4. Assure the respondent that his/her names and/or addresses will not be written on the interview schedule and that all responses will be held in strict confidence to ensure anonymity
5. Encourage respondents to answer all questions
6. Write or tick responses in the space provided
7. Give the respondent an opportunity to ask questions at the end of the interview
8. Thank the respondent at the end of interview
SECTION A

DEMOGRAPHIC DATA

1. Age on your last birthday .................................. years

2. Marital status
   a. Married ( )
   b. Single ( )
   c. Divorced ( )
   d. Widowed ( )

3. How many children do you have? .........................

4. Level of education
   a. No formal education ( )
   b. Grade 1-7 ( )
   c. Grade 8-12 ( )
   d. College ( )
   e. University ( )

5. What do you do for a living?
   a. Formal employment ( )
   b. Self employed ( )
   c. Housewife ( )
   d. Student ( )
   e. Unemployed ( )

85
6. Income
   a. Above K 2,000,000
   b. Between K500,000- K2,000,000
   c. Below K500,000

SECTION B

KNOWLEDGE

7. Have you ever heard of MTCT?
   a. Yes
   b. No

8. If yes, what is the source of your information?
   a. Media
   b. Health Center
   c. Relatives
   d. Friends
   e. Church

9. What is the meaning of MTCT?
   a. Transmitting the virus from the mother to the baby
   b. Giving herbal medication to the baby
   c. Mother touching the baby
   d. Don't know
10. How can the baby contract HIV from the mother?
   a. During pregnancy ( )
   b. During labour and delivery ( )
   c. During breastfeeding ( )
   d. All of the above ( )
   e. Don’t know ( )

SECTION C

FOLLOW UP CARE

11. Have you ever heard about follow up care of HIV exposed children?
   a. Yes ( )
   b. No ( )

12. How did you know about follow up care of HIV exposed children?
   a. From Health Center ( )
   b. Mass media ( )
   c. Family members ( )
   d. Peers ( )
13. What services are offered during follow up care of HIV exposed children?

(Tick appropriate answers)

a. Provision of drugs for prophylaxis
b. HIV testing
c. Counselling
d. Immunisation

14. When are you supposed to take the child for follow up care?

(Tick appropriate answers)

a. When the child is sick
b. As per schedule
c. For drug supplies
d. Don’t know

15. At what age is the child supposed to be tested for HIV?

a. 1 month 2 weeks (6 weeks)
b. 2 months 2 weeks (10 weeks)
c. 12 Months
d. 6 months
d. 18 Months
e. 6 weeks after weaning
g. Don’t know
16. Did you take your child for HIV testing at 12 or 18 months?
   a. Yes ( )
   b. No ( )

17. If yes to question 16, how long did it take for you to receive the HIV rapid test results?
   .........................................................................................

18. If no to question 16, why?
   .........................................................................................

19. Do you know the benefits of follow up care?
   a. Yes ( )
   b. No ( )

20. If yes to question 19, explain
   .........................................................................................
   .........................................................................................
   .........................................................................................

SECTION D

ATTITUDE

21. Did you take your child for HIV follow up care service at six weeks?
   a. Yes ( )
   b. No ( )
22. If yes, how do you perceive the reception of health workers at the clinic?
   a. very good (   )
   b. good (   )
   c. fair (   )
   d. poor (   )

23. Were the health staff supportive?
   a. Strongly agree (   )
   b. Agree (   )
   c. Disagree (   )
   d. Strongly disagree (   )

24. Are you willing to utilise follow up care services?
   a. Willing (   )
   b. Not willing (   )

25. If not why?........................
SECTION E
SERVICE RELATED FACTORS

26. How long does it take you to reach the Health centre?
   a. Less than 30 minutes ( )
   b. 30 to 1 hour ( )
   c. 1 hour to 3 hours ( )
   d. More than 3 hours ( )

27. How is the provision of follow up care services?
   a. Good ( )
   b. Fair ( )
   c. Poor ( )

28. How long does it take for you to be attended to?
   a. less than 30 minutes ( )
   b. 30 to 1 hour ( )
   c. More than one hour ( )

29. Are the staff providing follow up care services enough?
   a. Yes ( )
   b. No ( )

30. Are the supplies always available at the clinic?
   a. Always ( )
   b. Sometimes ( )
   c. Never ( )
SECTION F
SOCIO-CULTURAL AND ECONOMIC

31. Does any family member know about your HIV status?
   a. Yes ( )
   b. No ( )

32. If yes to question 31, who?
   a. Partner ( )
   b. Sister ( )
   c. Brother ( )
   d. Mother ( )
   e. Not applicable ( )

33. How do they relate with your child?
   a. Good ( )
   b. Fair ( )
   c. Poor ( )
   d. Not applicable ( )

34. If no to question 31, why?

..............................

35. Do you and your child receive any form of support from the community?
   a. Yes ( )
   b. No ( )
36. If yes to question 35, who gives the support?
   a. Church ( )
   b. NGO ( )
   c. Employer ( )
   d. Support group ( )
   e. Not applicable ( )

37. Do you have any comment?
   ........................................................................
   ........................................................................

THANK YOU VERY MUCH FOR YOUR COOPERATION
## MARKING KEY FOR STUDY VARIABLES

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<td>b. Labour/ delivery</td>
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<td>c. Breastfeeding</td>
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<td>d. All of the above</td>
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<td>c. Family members</td>
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<td>What services are offered in follow up of HIV exposed children?</td>
<td>a. Provision of drug&lt;br&gt;b. HIV testing&lt;br&gt;c. Counseling</td>
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<td>When are you supposed to take the child for follow up care?</td>
<td>a. When the child is sick&lt;br&gt;b. As per schedule&lt;br&gt;c. For drug supplies</td>
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<td>At what age is the child supposed to be taken for HIV testing?</td>
<td>a. 6 weeks&lt;br&gt;b. 6 months&lt;br&gt;c. 12 Months&lt;br&gt;c. 18 months&lt;br&gt;d. 6 weeks after weaning</td>
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<td>Have you ever taken your child for HIV testing?</td>
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<td>How long did it take for you to receive HIV rapid test results</td>
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<td>If yes, how do you perceive the reception of health workers at the health centre?</td>
<td>a. very good</td>
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<td>b. good</td>
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</tr>
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<td>c. fair</td>
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<td>d. poor</td>
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<td>Where the staff supportive?</td>
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<td>b. Agree</td>
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<td>c. Disagree</td>
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<td>d. strongly disagree</td>
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<td>Are you willing to utilise follow up care services?</td>
<td>a. willing</td>
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<td>25</td>
<td>If not willing, why?</td>
<td>Denial/stigma</td>
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APPENDIX II

University of Zambia,
School of Medicine,
P.O Box 50110,
LUSAKA.

27 September, 2012.

The District Medical Officer
Lusaka District Office,
P.O Box 50827,
LUSAKA.

U.F.S: The Head,
Department of Nursing Sciences,
School of Medicine,
P.O Box 50110,
LUSAKA.

Dear Sir/Madam,

RE: PERMISSION TO CARRY OUT A PILOT STUDY-KALINGALINGA CLINIC

We are 5th year undergraduate students in the Department of Nursing Sciences, School of Medicine, University of Zambia. In partial fulfilment of the Bachelor of Science Nursing degree programme, we are required to conduct a research study. The title of our study is “Factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months”. We will particularly conduct this study among mothers and or care takers to HIV exposed children who have not turned up for follow up care six months from the expected due date.

We are therefore requesting for permission to conduct a pilot study at your institution prior to the main study. We wish to conduct the Pilot study between 1 and 2 October 2012.

Your consideration will be highly appreciated.

Yours faithfully,

Chipukuma Helen
Longa Mwanza Regina
Mwanza Violet
Nthala Flora
APPENDIX III

University of Zambia,
School of Medicine,
P.O Box 50110,
LUSAKA.

28th September, 2012.

The District Medical Officer
Chipata District Health Office,
P.O Box
CHIPATA

U.F.S: The Head,
Department of Nursing Sciences,
School of Medicine,
P.O Box 50110,
LUSAKA.

Dear Sir/Madam,

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY

I am a 5th year undergraduate student in the Department of Nursing Sciences, School of Medicine, University of Zambia. In partial fulfillment of the Bachelor of Science Nursing degree programme, am required to conduct a research study. The title of my study is "Factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months". I will particularly conduct this study among mothers and or care takers to HIV exposed children who have not turned up for follow up care six months from the expected due date. I am therefore requesting for permission to conduct my study at Kapata Mini Hospital. I wish to conduct my study between 8th October and 2nd November 2012.

Your consideration will be highly appreciated.

Yours faithfully

Flora Nthala
The District Medical Officer  
Livingstone District Health Office,  
P.O Box  
LIVINGSTONE

U.F.S: The Head,  
Department of Nursing Sciences,  
School of Medicine,  
P.O Box 50110,  
LUSAKA.

Dear Sir/Madam,

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY

I am a 5th year undergraduate student in the Department of Nursing Sciences, School of Medicine, University of Zambia. In partial fulfillment of the Bachelor of Science Nursing degree programme, am required to conduct a research study. The title of my study is "Factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months". I will particularly conduct this study among mothers and or care takers to HIV exposed children who have not turned up for follow up care six months from the expected due date.

I am therefore requesting for permission to conduct my study at Mahatma Gandhi. I wish to conduct my study between 8th October and 2nd November, 2012.

Your consideration will be highly appreciated.

Yours faithfully

Helen Chipukuma
University of Zambia,
School of Medicine,
P.O Box 50110,
LUSAKA.

28th September, 2012.

The District Medical Officer
Chongwe District Health Office,
P.O Box 25
CHONGWE

U.F.S: The Head,
Department of Nursing Sciences,
School of Medicine,
P.O Box 50110,
LUSAKA.

Dear Sir/Madam,

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY

I am a 5th year undergraduate student in the Department of Nursing Sciences, School of Medicine, University of Zambia. In partial fulfillment of the Bachelor of Science Nursing degree programme, am required to conduct a research study. The title of my study is “Factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months”. I will particularly conduct this study among mothers and or care takers to HIV exposed children who have not turned up for follow up care six months from the expected due date. I am therefore requesting for permission to conduct my study at Chongwe Rural Health Center. I wish to conduct my study between 8th October and 2nd November, 2012.

Your consideration will be highly appreciated.

Yours faithfully

Violet Mwanza
University of Zambia,
School of Medicine,
P.O Box 50110,
LUSAKA.

28th September, 2012.

The Medical Superintendent,
Arthur Davison Children’s Hospital,
P.O Box
NDOLA

U.F.S: The Head,
Department of Nursing Sciences,
School of Medicine,
P.O Box 50110,
LUSAKA.

Dear Sir/Madam,

RE: PERMISSION TO CARRY OUT A RESEARCH STUDY

I am a 5th year undergraduate student in the Department of Nursing Sciences, School of Medicine, University of Zambia. In partial fulfillment of the Bachelor of Science Nursing degree programme, am required to conduct a research study. The title of my study is “Factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months”. I will particularly conduct this study among mothers and or care takers to HIV exposed children who have not turned up for follow up care six months from the expected due date. I am therefore requesting for permission to conduct my study at your institution. I wish to conduct my study between 8th October and 2nd November, 2012.

Your consideration will be highly appreciated.

Yours faithfully

Regina Mwanza Longa.
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<th>Time Dates</th>
<th>Frame Duration</th>
<th>Responsible Person</th>
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</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td></td>
<td></td>
<td><strong>K 11,990,000</strong></td>
</tr>
<tr>
<td>INFORMATION DESSEMINATION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refreshments and snacks</td>
<td>10,000</td>
<td>1 day</td>
<td>800,000</td>
</tr>
<tr>
<td>x20people x 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SUBTOTAL</strong></td>
<td></td>
<td></td>
<td><strong>K 800,000</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>K 15,487,000</strong></td>
</tr>
<tr>
<td>CONTINGENCY 10%</td>
<td></td>
<td></td>
<td><strong>K 1,548,700</strong></td>
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<tr>
<td><strong>GRAND TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>K 17,035,700</strong></td>
</tr>
</tbody>
</table>
APPENDIX VI

BUDGET JUSTIFICATION

ALLOWANCES

The researchers will need lunch and transport allowances to enable them travel from their residential places to selected communities for data collection. The researchers will also need funds to train the research assistants, pay them lunch and transport allowances. Researchers will also need funds for refreshments during dissemination of the findings.

STATIONERY AND SECRETARIAL SERVICES

Funds will also be required for typing services. These services consist of printing research proposal, questionnaires, photocopying and printing and binding of the final research reports for submission.

CONTINGENCY

The contingent of 10% of the total amount for the budget is added to the whole budget to cover unforeseen expenses being required during the research study.