VIEWS OF HEALTH SERVICE PROVIDERS ON THE NEED FOR SUPPORT SERVICES FOR HIV-POSITIVE MOTHERS IN THE RURAL AREAS OF LESOTHO: AN ECOLOGICAL PERSPECTIVE

By

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DECLARATION

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ABSTRACT

HIV/AIDS is one of the worst pandemics affecting the world today. It cuts across all boundaries and many people are infected as well as affected. The virus has reached all the corners of the globe, but the most hit by it is Africa, especially southern Africa, which carries more than half of the population infected and affected by HIV/AIDS. The top five countries whose populationsare infected with HIV are in southern Africa.

Lesotho is amongst the top three on this list and also has problems of poverty and a high unemployment rate. Women and children, who are the target groups that are most affected by poverty, are also those living in rural areas. Thus, being an HIV-positive mother living in the rural areas of Lesotho means one has to deal with poverty, the inaccessibility of services and the psychological impacts of HIV.

The aim of the study was to gain a better understanding of the views of health service providers on the need and accessibility of support services for HIV-positive mothers in the rural areas of Lesotho from an ecological perspective. To achieve this aim, the objectives were: to offer an overview of the phenomenon of HIV and describe the psychosocial needs and sociocultural circumstance of HIV-positive mothers in the rural areas of Lesotho, and to discuss the HIV-positive mothers' need for support services from an ecological perspective.

Both quantitative and qualitative research approaches were used. The research utilised exploratory and descriptive design. Purposive sampling was used to select the 30 participants who took part in the study. Data was gathered by means of semi-structured questionnaires that were administered during individual interviews. The questionnaires were formulated on the basis of information retrieved during the literature review.

The findings of the study reveal that HIV-positive mothers living in the rural areas of Lesotho have economic, social and cultural circumstance as factors hindering their treatment and prevention of HIV/AIDS. They are also faced with the psychological impacts of HIV, and the findings revealed that disclosure was the key to addressing their problems.

The findings also show that most mothers receivedemotional, instrumental, informational and appraisal support from their families at the micro-level of the ecological perspective. The other levels – meso, exo and macro – provided only limited support for the mothers. The

recommendations are that these mothers need social support at all levels of the ecological perspective to meet their needs

OPSOMMING

MIV/vigs is een van die ergste pandemies in die moderne wêreld. Dit ken geen grense nie, en vele mense ly hetsy daaraan of daaronder. Die virus het reeds alle uithoeke van die aarde bereik. Tog gaan Afrika, veral Suider-Afrika, die swaarste daaronder gebuk, en word meer as die helfte van die totale populasie wat aan of onder MIV/vigs ly hier aangetref. Die vyf lande met die hoogste MIV-infeksiesyfers ter wêreld is almal in die streek geleë.

Lesotho is een van die drie lande boaan hierdie lys, en het terselfdertyd te kampe met die probleme van armoede en ’n hoë werkloosheidsyfer. Vroue en kinders, synde die groepe wat die ergste deur armoede geraak word, woon ook meestal in landelike gebiede. ’n MIV-positiewe moeder in die landelike gebiede van Lesotho moet dus armoede, ontoeganklike dienste sowel as die sielkundige uitwerking van MIV trotseer.

Die doel van hierdie studie was om vanuit die ekologiese perspektief ’n beter begrip te vorm van gesondheidsdiensverskaffers se sienings oor die behoefte aan en toeganklikheid van steundienste vir MIV-positiewe moeders in die landelike gebiede van Lesotho. Om hierdie doel te bereik, was die oogmerke om ’n oorsig van die MIV-verskynsel te bied, die psigososiale behoeftes en sosiokulturele omstandighede van MIV-positiewe moeders in die landelike gebiede van Lesotho te beskryf, en die moeders se behoefte aan steundienste vanuit die ekologiese perspektief te bespreek.

’n Kwantitatiewe sowel as ’n kwalitatiewe navorsingsmetode is gevolg, en die navorser het van ’n verkennende en beskrywende ontwerp gebruik gemaak. Doelgerigte steekproefneming is gebruik om die 30 studiedeelnemers te kies. Data is met behulp van semigestruktureerde vraelyste gedurende individuele onderhoude ingesamel. Die vraelyste is opgestel op grond van inligting wat in die literatuuroorsig bekom is.

Die studie bevind dat ekonomiese, maatskaplike en kulturele omstandighede MIV/vigs-behandeling en -voorkoming vir MIV-positiewe vroue in die landelike gebiede van Lesotho belemmer. Daarbenewens moet hulle die sielkundige uitwerking van MIV die hoof bied, en die studie dui op openbaarmaking as die sleutel om hul probleme te hanteer.

Die bevindinge toon ook dat die meeste moeders emosionele, fisiese, inligting- en bevestigende steun van hul families op die mikrovlak van die ekologiese perspektief ontvang. Die ander vlakke – meso, ekso en makro – bied slegs beperkte steun.

Die studie kom tot die gevolgtrekking dat hierdie moeders op alle vlakke van die ekologiese perspektief maatskaplike steun moet ontvang om in hul behoeftes te voorsien.

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CHAPTER 1

INTRODUCTION

1.1. PRELIMINARY STUDY AND RATIONALE

According to Van Dyk (2008:48), the first recognised case of Acquired Immune Deficiency Syndrome (AIDS) was recorded in the USA in 1981 when a very rare form of pneumonia suddenly appeared simultaneously in several patients, and this virus soon moved to Africa. In May 1986 the virus was given the name Human Immunodeficiency Virus (HIV), and it is in this year that HIV was first recognised in Lesotho.

There are two types of HIV associated with AIDS, namely HIV-I and HIV-II. HIV-I is associated with infections in Central, East and Southern Africa, with Lesotho being part of the latter, while HIV-II was discovered in West Africa (Cape Verde Islands, Guinea- Bissau and Senegal) and is mostly restricted to West Africa. HIV-II is structurally similar to HIV-I, but HIV-II is less pathogenic than HIV-I and has a longer latency period, with slower progression to disease, lower viral counts and lower rates of transmission. HIV-I, on the other hand, progresses rapidly and has a higher risk of infection (Van Dyk, 2008:4). These viruses are associated with AIDS because their progression leads to AIDS, in which the body's immune system is at total failure and death awaits.

HIV/AIDS is a disease that is killing millions of people on a daily basis, and it does not only affect the health of a person, but also their psychosocial wellbeing (WHO, 2005: online). Although HIV is recognised predominantly as a health problem, the epidemic has multiple social and economic dimensions that affectits host. According to Malgas (2005:11), HIV/AIDS is now considered to be a chronic illness and is a stressor from a medical, social and economicpoint of view.

According to the Lesotho Ministry of Health and Social Welfare (2010:2), Lesotho has the third highest HIV prevalence in the world, with an adult prevalence of 23.2%, bearing in mind that Lesotho is among the least developed countries in the world. According to Cohen, Lynch, Bygrave, Eggers, Vlahakis and Hilderbrand (2009:4), the government of Lesotho has shown commitment in addressing HIV/AIDS, despite the lack of resources for health. The country introduced a range of innovationsthat are absent from the policies of its better resourced neighbours. In 2007, national antiretroviral (ART) guidelines were revised to raise the threshold of initiation from CD4 counts of less than 200 cells/mm^3 to less than 350 cells/mm^3.

These guidelines included a number of treatment innovations, including tenofovir, disoproxil and fumarateas first-line therapy for adults, a state-of-the-art protocol for the prevention of mother-to-child transmission (PMTCT), which includes triple therapy for mothers, and early infant diagnosis by DNA polymerase chain reaction testing and initiation of ART for all HIV-positive infants younger than 12months(Cohen *et al*.,2009:4).

Transmission of HIV takes place in three ways, namely through unprotected sex, the bloodstream and from mother to child.

Unprotected sex is one of the ways in which a woman can get pregnant and thus become a mother by having a biological child. According to Jackson (2002:83), sexual intercourse between men and women is responsible for 70% of all HIV infections in the world, and the risk is greater when sores or sexually transmitted infections are present.

Socio-economic circumstances, geographical location, and cultural and religious belief also are important in creating a risky environment for sexual HIV transmission. This can be seen in the traditional culture of Basotho men, who are allowed to have more than one wife. In cases where both women become mothers and are infected with HIV, if one happens to die, the other is left with the heavy responsibility of taking care of the children of both mothers. Some religions do not allow the use of condoms and this makes sexual transmission of HIV easy. These practices expose the already HIV-positive mothers to re-infection.

Infection through blood transfusion has to go through one's bloodstream for one to become infected. According to Jackson (2002:167), blood transmission of HIV can take place through unscreened blood or blood product transfusion. A mother can infect her child through this transmission during birthing.

Mother-to-child transmission (MTCT) or vertical transmission of HIV is one of the major causes of HIV in children (Van Dyk, 2008:41). According to UNAIDS (2010:63), key findings in 2009 were that 370 000 [230 000 to 510 000] children were infected with HIV through mother-to-child transmission. This is a drop of 24% from five years earlier. However, the rapid expansion of delivery of effective advances in preventing mother-to-child transmission is being held back by inadequate access to antenatal and postnatal services.

More than 60% of HIV transfer from the mother to child occurs during labour and delivery, and the main reason is contact with the mother's blood and mucus in the birthing canal during the birth process. This can be prevented by avoiding unnecessary artificial rupture of the

membranes in the hours before delivery, choosing elective caesarean sections for mothers with high viral loads, and totally avoiding episiotomy (Van Dyk, 2008:42).

About 20% to 30% of babies are infected during breastfeeding (WHO, 2000a), and factors that aggravate MTCT during breastfeeding are deficiency of vitamin A in the mother or child, breast diseases such as mastitis, cracked nipples, thrush and gastroenteritis in the infant. This is where the issue of formula milk feeding comes in as a way of preventing the mother from infecting her child through breast milk. But, with the poor economy of Lesotho, bottle feeding is not sustainable, especially in rural communities, where most of the population is poor and resources are very scarce. It is in such cases that support services by social workers could play a role.

In cases where exclusive breastfeeding can be practised with no health issues, newly married women are scared to tell their in-laws, as the practice at times clashes with certain cultural beliefs that a child should take certain medication to be protected from evil spirits (Scott Hospital, Annonnate).[i]

HIV/AIDS brings a lot of complications toa mother's life, and health services usually are given first priority, which others factors, such as psychosocial support, not being given much attention. Nevertheless, these are among the main factors that contribute to the well-being of a mother. According to the WHO (2009) there are many risk factors that are associated with mortality and morbidity in Lesotho, and the biggest risk factor is HIV/AIDS. The latter is also known to bring about other risk factors, such as mental problems in the mother due to shock and denial of being diagnosed with it, and largely caused by discrimination and alienation by the family and community.

Risk factors for mothers, such as mental illness and many other diseases caused by HIV, can be prevented in many different ways. In September 2012, the Department of Health in South Africa launched a campaign to build a more caring, supportive society for people living with and affected by HIV/AIDS. According to the Education Training Unit (2013), this campaign organised campaigns for emotional support, community support and medical treatment. The emotional support campaign focused on how people with HIV/AIDS and their families live.

Community support and awareness campaigns and public events have been held to mobilise the community and medically defaulting people are followed. A free 24-hour helpline run by professionals with knowledge of HIV/AIDS was launched. HIV-positive people can call at

anytime if they feel depressed and lonely or need to ask questions. This helped South African mothers to cope with their daily stresses caused by HIV, as living with it is a challenge, and this contact improved their health.

Immense stress and heartbreak is felt by children's mothers who are HIV positive, and there is a need for them to receive high-quality and on-going care, treatment and support from health-care providers and communities alike. Many HIV-positive mothers also experience extreme psychological stress over what will happen to their children if they should die.

According to Edwards (1995:16) in 1973 Germain introduced an ecological metaphor as a perspective for practice in social case work more than 20 years ago. Despite the historical commitment of social work to the person-in-environment, most direct practice has not gone beyond the individual's internal processes and the family's interpersonal process. Attention to physical and social environments and culture, and to their reciprocal relationships with people, was rare. This inattention was due mainly to the lack of available concepts about environments and culture and how they affect and are affected by human development and functioning.

In the ecological perspective, Germain and Gitterman (1996:8) describe that life transitions can act as a source of stress for any person. All life transitions are accompanied by biological changes that interact with psychosocial, social and cultural factors, as well as physical settings that cause increasing demands on and stress for the individual. In order to adapt to new life stages, the individual and his/her environment need to reach a goodness offit (Edwards 1995).

The ecological perspective makes clear the need to view people and environments as a unitary system within a particular cultural and historic context. Both person and environment can be fully understood only in terms of their relationships, in which each continuously influences the other within a particular context. Ecological thinking embraces indeterminacy in complex human phenomena. This perspective explains the relationship between the environment and the person in that each influences the other over time (Germain & Gitterman, 1996:8). Thus, for any type of support services within the context of the ecological perspective, the transactions between the environment and those to whom the services are being offered should also be addressed.

The provision of health support services within the community has been seen to bring out the best services, as the community feels that they are involved in decision making concerning

their lives. Studies reviewed by Merzel and D'Afflitti (2003:557) see community-based intervention and services as a setting in which the community is primarily defined geographically and as the location in which interventions and services are implemented and provided. Different support services can be provided, such as counselling, primary healthcare, which entails a physician, testing of HIV/AIDS, psychological health services and many other needed services.

1.2 PROBLEM STATEMENT

HIV/AIDS is a disease that is killing people on a daily basis. It does not only affect the health of people, but also their psychosocial wellbeing and their economic situation (WHO, 2005). Lesotho is one of the poorest and least developed countries in the world. It has the third highest prevalence of HIV, with 23.1% of its population found to be HIV positive, and 340 000 of these are women (UNAIDS, 2013).

HIV-positive mothers living in the rural areas of Lesotho are severely affected due to the lack of development, which has resulted in scarcity of available support services specifically designed for them. Lesotho also facesa shortage of human resources and this result in greater pressure on health-care service providers due to high demand for services (Bangdiwala, Fonn, Okoye and Tollman, 2010:297).

According to Castaneda (2000:557), the availability of local support services is critical to the provision of HIV/AIDS care and prevention services for women. Because fewer social, health and mental services exist in rural areas in general, women's access to the needed services may be restricted and services are more limited in scope than in urban areas.

There are a few support services in the rural communities of Lesotho, such as the Elizabeth Glassier Foundation (www.pedaids.org), which provides free PMTCT services, comprehensive and family-centred HIV/AIDS prevention, care and treatment services, community mobilisation for increased uptake and adherence to HIV/AIDS services, and community health-care workers, who help with door-to-door visitation of patients to offer psychosocial support. There is also a Mothers to Mothers organisation (www.m2m.org), which offers tracking of defaulters and psychosocial support groups monthly, which are conducted by HIV-positive mothers.

Unfortunately none of these support services addresses the contextual problems of accessing services. These problems range from long walking distances to the facility in harsh weather

conditions, including snow, lack of transportation and many other hardships related to poverty and cultural circumstances surrounding these mothers.

According to Alexander, Kanth, Manoharan, Maria and Joseph (2014), a study carried out in Bangalore, India on the users and utility of an HIV/AIDS helpline showed that telephone helplines are very good for finding information on HIV/AIDS, PMTCT services, care and support, and details of other helplines such as social welfare, and can help in reaching out to those who are far to reach and living in remote rural areas. This is one of many social support services that can be beneficial in addressing the needs of HIV-positive mothers in Lesotho's rural areas by having many different professionals available at the call centre to address different problems a mother might have.

According to Castaneda (2000:560), very little systematically derived information is available regarding the care and support needs of women who currently live with HIV/AIDS in rural communities. This study aims to explore the existing situation of health support services offered to mothers in rural areas through the views of health service providers. It will provide recommendations that can inform policy formulation on support services, which are sensitive to geographical location, economic needs and cultural circumstances surrounding HIV-positive mothers living in the rural areas of Lesotho.

1.3 AIM AND OBJECTIVES OF THE STUDY

1.3.1 AIM

The aim of the study was to gain a better understanding of the views of service providers on the need of support services for HIV-positive mothers in the rural areas of Lesotho from an ecological perspective.

1.3.2 OBJECTIVES OF THE STUDY

To reach the aim of the study, the following objectives were formulated:

- To offer an overview of the phenomenon of HIV and describe the psychosocial needs and sociocultural circumstance of HIV-positive mothers in the rural areas of Lesotho.
- To discuss these HIV-positive mothers' need for support services from an ecological perspective.
- To investigate forms of social support available for HIV-positive mothers in the rural areas of Lesotho through the views of health service providers.

1.4 CLARIFICATION OF KEY CONCEPTS

For the purpose of the study, the following terms are defined:

1.4.1 SUPPORT SERVICES

There are many different types of support services that can be provided for HIV-positive mothers: counselling services, 24-hour phone line services, social services provided by social worker and support groups services, amongst others.

Counselling is the major support service that HIV-positive mothers need. According to Van Dyk (2005:174), counselling is a facilitative process in which the counsellor, working within the framework of a special helping relationship, uses specific skills to assist clients to develop self-knowledge, emotional acceptance, emotional growth and personal resources.

1.4.2 SOCIALSUPPORT

According to the Ministry of Health and Social Welfare (2010:107) psychosocial support is an on-going process of meeting emotional, social, mental and physical needs, all of which are essential for meaningful and positive development. It goes beyond meeting physical needs, and places great emphasis on psychological and emotional needs and a need for social interaction.

An HIV-positive status brings with it many different psychosocial impacts and experiences, such as fear, loss, grief, denial and anger, for an individual and her family and community. For the individual and those around her to deal with all these impacts and experiences, there is a need for guidance, thus a health service provider is needed.

1.4.3 SOCIAL WORKER AS HEALTH AND SUPPORT SERVICE PROVIDER

A social worker plays an important role in health support service provision, for she can offer counselling as well as make the necessary referrals when need arises. She can also help mothers form their own support groups and connect them to the necessary donors to fund projects that can enhance their living. The social worker's role is to enable the client to verbalise his or her concerns (Nicholas, Rautenbach and Maistry, 2010). From this basis the social worker enables the client to engage in realising solutions so that the client will embrace his or her problem-solvingabilities.

1.4.4 ECOLOGICAL PERSPECTIVE

The ecological perspective emphasises whole entities or systems and, instead of looking for linear causality, approaches or highlights the interactional patterns that are formed through the relationship among parts (Moore, 1997:557). The ecological perspective refers to the adaptability of systems to change. For example, people can be open to change in order to adapt to the environment and survive because of the connections between systems. Change in one system may affect other parts connected to the system.

1.5 RESEARCH METHODOLOGY

1.5.1 LITERATURE STUDY

According to Babbie and Mouton (2001:87), a literature study aims to avoid duplication and suggest possibilities in the research field to explore. Castaneda (2000:554) says the basic element that influences care and prevention service delivery to women in rural communities is the often greatlydispersed geographical areas in which they live.

Studies have been done on support services for HIV-positive mothers living in rural areas. Teasdale and Besser (2008:60) did a study on enhancing PMTCT programmes through psychosocial support and the empowerment of women in relation to the mothers-to-mother model of care. The study focuses on adherence to medication through counselling and dealing with the stigma and stress brought by HIV/AIDS. It emphasises that counselling support services can only work if the mother is willing to come to the facility, but it does not address factors that can hinder the mother from coming even though she may be willing to; factors such as poverty, long walking distances to the facility, harsh weather conditions, cultural beliefs and many others. Castaneda (2000:557) says that because fewer social, health and mental services exist in rural areas in general, women's access to needed services maybe restricted and services are more limited in scope than in urban areas.

According to Castaneda (2000:554), geography can be a physical barrier that makes service access difficult, but if women have coercive or abusive partners, transportation can also become an arena of social control over women's activities in rural areas. She further states that agencies in rural communities often have to provide services to large geographic areas with limited staff. These factors further constrain their ability to develop and provide services that are sensitive to women's needs, such as addressing their health needs as well as offering them psychosocial support.

The literature study was undertaken on the research topic so as to gain better understanding and to find a framework. Material from different sources, such as books, journals, the internet and many other informative materials, was used to describe the psychosocial needs, economic and cultural circumstances of HIV-positive mothers, and their needs for support services from an ecological perspective.

1.5.2 RESEARCH APPROACH

The research approach that was used for this study is a combination of quantitative and qualitative methods. The reason for choosing the combined method approach is because these methods complement each other and provide better and more data for the study.

The quantitative approach, according to De Vos, Strydom, Fouche, and Delport (2012:91), is more effective than the qualitative approach in reaching a specific and precise understanding of one aspect (or part) of an already well-defined social problem, while the qualitative approach aims to answer research questions that provide a more comprehensive understanding of a social problem from an intensive study of a few people.

According to Burns and Grove (2009:54), in selecting the qualitative method the researcher should consider the following questions: "What is the most appropriate methodology and why? Which method of data collection will produce the richest set of data? How should that data be analysed? What checks should be taken to maximise the accuracy of the findings?" Thus the researcher decided to use both quantitative and qualitative data collecting methods for the study, as it seems to be the best approach for the study.

1.5.3 RESEARCH DESIGN

An exploratory and descriptive research design was used in this study. De Vos et al. (2011:95) say exploratory and descriptive designs are conducted to gain sight into a situation, phenomenon, community or individual. A descriptive research design provides information on a particular field through the provision of a picture of the phenomenon as it occurs naturally (Brink, Van der Walt andVan Rensburg, 2012:112). The descriptive design was used more for the qualitative data, as the study looked deeply at the phenomenon of support services for HIV-positive mothers while considering the ecological factors that affect them.

1.5.4 POPULATION AND SAMPLING

Population is a collection of objects, events or individuals having some common characteristics that the researcher is interested in studying (Mouton, 1996:134). The population of a study is that group (usually people) about whom the researcher wants to draw conclusions (Babbie & Mouton, 2001:100).

According to De Vos (2011:390), sampling is also utilised in qualitative research, although it is less structured, less qualitative and less strictly applied than in the case of quantitative research. The reason for this is that data collecting methods in qualitative research are observation and interviewing, and thus qualitative data needs in-depth information, hence non-probability sampling is the best way to collect that data.

According to Brink*et al*. (2012:138), non-probability sampling requires the researcher to judge and select those participants who know most about the phenomenon and who are able to articulate and explain nuances. The type of non-probability sampling used was purposive or judgemental sampling. Brink *et al*. (2012:141) say this type of sampling is based on the judgment of the researcher regarding participants or objects that are typical or representative of the characteristics and representative attributes of the population.

Reasons for selecting purposive sampling for this study were to understand the psychosocial needs and economic and cultural circumstances of HIV-positive mother, and their need for support services from an ecological perspective, which means that health service providers who work directly with these mothers were needed. They can provide the needed information and help to identify ways in which improvements can be made, for they interact with these mothers routinely and know their needs.

The sample of the study consisted of 30 participants: nine nurses, eight counsellors, four doctors, eight community village health workers, and one social worker (the hospital and clinics are served by only one social worker).

The criteria for selecting participants were that they should be:

- Employees of Scott Hospital and its clinics
- Working directly with HIV-positive mothers
- Doctors, nurses, social workers, counsellors as well as community health workers who fall within the catchment area of Scott Hospital.
- Be able to participate in the study in English

1.5.5 METHOD OF DATA COLLECTION

Surveys often rely on semi-structured questionnaires as the main tool for gathering information. Questionnaires can be administered either in person by the researcher, or be sent to the respondents by post or email (so-called self-administered questionnaires).

The study used a semi-structured questionnaire during face-to-face interviews. This type of interview follows an outline of questions, but not all of the probes, transitions and follow-ups are established prior to the interview. The interviewer is given freedom to deviate from the interview questions as needed to pursue serendipitous findings and fruitful directions (Vanderstoep and Johnston, 2009:224). Face-to-face interviews allow a wider channel of communication and allow the researcher to ask follow-up questions based on the participants' response to previous questions. This allows a deeper exploration of issues (Vanderstoep & Johnston, 2009:88).

According to Mcburney and White (2004:244), personal interviews have the advantage that the interviewer can establish rapport with the people being interviewed. The interviewer can direct the attention of the respondents to the material and motivate them to answer the questions. The interviewer may be able to notice when the respondents seems to misunderstood the question and explain its meaning and probe for more complete answers.A tape recorder was used with the permission of the intervieweesso as to assist the researcher to refer back if some data was missed. Face-to-face interviews can provide both quantitative and qualitative data.

1.5.6 PILOT STUDY

According to Giddens and Birdsall (2001648), most research studies are preceded by pilot studies in order to pick up problems not anticipated by the researcher. A pilot study is a trial run in which the questionnaire is completed byfew people. Any difficulties can then be ironed out before the main survey is done.

A pilot study was conducted for the semi-structured questionnaire with one nurse from the hospital and one from Scott clinic, one counsellor from the hospital and one from the clinic, one doctor, and two community health workers from different villages that fall under Scott Hospital.

1.5.7 METHOD OF DATA ANALYSIS

According to De Vos *et al*. (2011:339), data analysis is the process of structuring and assigning meaning to the mass of collected data. This process is described as messy, ambiguous, time consuming, creative and fascinating. Quantitative and qualitative data are analysed differently.

Quantitative methods of analysis fall into four categories, which are descriptive, association, causation and inference. For this study, descriptive analysis was used for the quantitative data analysis, and exploratory analysisfor the qualitative data narrative (De Vos *et al*., 2011:251). Before analysing the data one has to make sure of the measurement level of the data collected. Therefore variables are divided into two broad classes, namely categorical and numerical data (De Vos *et al*., 249:251).

Descriptive analysis aims to describe the distribution of the numerical samples, which are the frequency, central tendency and dispersion, by analysing univariately through focusing on one variable, and the descriptive statistics are used to describe and synthesise data (Polit & Beck, 556:2008). Averages and percentages are examples of descriptive data that were used in the analysis of the quantitative data in this research.

Qualitative data analysis is the non-numerical examination and interpretation of observations for the purpose of discovering underlying meanings and patterns of relationships (De Vos *et al*., 2011:398).

The data collected thorough the semi-structured questionnaire was coded and presented by means of tables and figures. This allowed for the data to be interpreted and supported by the literature.

1.5.8 METHOD OF DATA VERIFICATION

According to De Vos *et al*. (2002:351), all research must answer to norms that stand as criteria against which the trustworthiness of the project can be evaluated. These norms are credibility, transferability, dependability and conformability. According to Brink *et al*. (2012:171), trustworthiness in terms of validity and reliability in "qualitative validity' refers to the employment of procedures to ensure the accuracy of the findings. Persistent observation of nonverbal communication was applied by trained, qualified researchers during the collection of the data.

Credibility is the goal to demonstrate that the enquiry was conducted in such a manner to ensure that the subject was accurately identified and described.Transferability is the extent to which the findings can be applied to other contexts and settings or other respondents. Dependability, on the other hand, is where the researcher attempts to account for changing conditions in the phenomenon chosen for the study, as well as changes in the design created by increasingly refining understanding of the setting. A recorder was used during the collection of data so as to assist the data collector to go back on information missed during the interviews. Finally, conformability captures the traditional concept of objectivity (De Vos *et al*., 2002:351).It is important to know if the findings of the study can be confirmed by another study. Enquiry audit, reflexivity and triangulation were used to enhance conformability. Data collection was done in English and thus the participants had to know English.

1.6 ETHICAL ASPECTS

According to Brink *et al*. (2012:34) there are three ethical principles that guide researchers during the research process: respect for persons, beneficence and justice. These principles are based on the human rights that need to be protected in research, namely the rights to self-determination, privacy, anonymity and confidentiality, fair treatment and being protected from discomfort and harm. All of these ethical principles were applied thoroughly throughout the research without any compromises. All the participants were treated with respect, were voluntarily involved in the research and were informed in full of the type of research they were involved in.

The following ethical considerations were relevant for the research:

- Avoidance of harm: According to De Vos (2011:115), the researcher has an ethical obligation to protect participants, within all possible reasonable limits, from any form of physical discomfort that may emerge from the research project. There were no indications of the participants being harmed while participating in the research.
- Voluntary participation: Participation should at all times be voluntary and no one should be forced to participate in a project (De Vos, 2011:116). Every participant was asked to grant permission to be interviewed and if they declined their decision was not questioned. Those who agreed to participate signed a consent from to indicate that they agreed to participate in the study.
- Debriefing of respondents: These are sessions during which subjects get the opportunity, after the study, to work through their experience and its aftermath, and

where they can have their questions answered and misconceptions removed (De Vos, 2011:122).

- Scientific honesty and other responsibilities: According to Brink *et al*. (2012), the researcher must demonstrate respect for the scientific community by protecting the integrity of scientific knowledge.Fabrication, falsification, manipulation of design methods, plagiarism and forgeries are to be avoided at all costs. Trained and experienced data collectors were hired to assist in collecting the data and independent data analyst were resourced to assure that there was no fabrication and manipulation of the data design methods.

Ethic committees are in charge of assessing whether researchers have contemplated enough ethical considerations before beginning the research they plan to do. They can become active in consulting researchers and discuss with them suggestions for the ethical planning of a project (Flick, 2009:222). Thus an application was submitted to the Ethics Research Committee at Stellenbosch University for approval for the project.

An application to conduct research within the hospital premises and clinics of Scott Hospital was sent to the hospital‘s superintendent.

1.7 LIMITATION OF THE STUDY

The literature study indicates that research material was not easily available. Little literature could be found pertaining to ecological support services for HIV-positive mothers living in the rural areas of Lesotho.

Most participants had tight work schedules and it was very difficult to interview them, as they had to attend to their clients or patients’ needs. Some health-care service providers did not want to participate in the study because it was conducted in English, and unfortunately for the researcher there was no funding to get a translator, so she only could select those who could comfortably speak English.

1.8 CHAPTER LAYOUT

The research study has five chapters. Chapter1 serves as an introduction to the study and presents how the study was conducted.

Chapter 2describes the psychosocial needs and sociocultural circumstances of HIV-positive mothers in the rural areas of Lesotho. In Chapter 3 the nature of support services needed by HIV-positive mothers is discussed. Chapter 4 presents data from the empirical study in the form of diagrams, figures and tables which have themes, sub-themes and categories, and this is followed by a discussion of the data collected. The last chapter draws conclusions and makes recommendations based on the findings of the study.

CHAPTER 2

THE PHENOMENON OF HIV AND THE PSYCHOSOCIAL NEEDS AND ECONOMIC AND CULTURAL CIRCUMSTANCES OF HIV-POSITIVE MOTHERS IN THE RURAL AREAS OF LESOTHO

2.1 INTRODUCTION

The socio-economic impact of HIV/AIDS on individuals, households and nations is already substantial and is increasing as the pandemic grows. HIV/AIDS-infected individuals face a number of the same stressors confronted by other patients with chronic illness, such as long-term discomfort, physical deterioration, financial dependence and eventual death (Baingana, Thomas & Comblain, 2005:11). People affected by HIV infection face greater emotional strain than most people do, and they are usually shocked, angry, depressed, afraid, guilty or confused, or have any number of these emotions at once (Bartlett & Finkbeiner, 2001:5).

According to Dageid and Duckert (2008:182), the millions of people living with HIV/AIDS are in urgent need of effective care and support interventions. Such interventions should take people's reported needs, coping strategies and social context into account. Medical treatments that delay HIV-related illness are among the successes in the AIDS crisis. However, as people live longer with HIV infection they become increasingly vulnerable to multiple emotional and social problems. Progressive immune system deterioration, the onset of symptomatic illness, as well as other HIV-related events, precipitate psychological distress (Kalichman, Sikkema & Somlai, 1996:589).

Most people living with HIV/AIDS in Africa do not have access to resources to meet their basic needs such as nutrition and food security. Mental healthcare, adherence to medication and psychosocial support may have little relevance if these needs are not fulfilled (Baingana *et al*., 2005:21). Additional treatment adherence obstacles include poor referral systems, geographic factors and distance to clinic, cultural beliefs and practices, and inadequate

availability of government healthcare systems and services to offer complex case management. These challenges may need to be considered when evaluating the phenomena and status of HIV prevalence and treatment adherence in Lesotho.

This chapter is about meeting the first objective of the study by providing an overview of the HIV/AIDS phenomenon and the psychosocial needs, psychosocial impacts of HIV on mothers, disclosure, and the economic and cultural circumstances of HIV-positive mothers in the rural areas of Lesotho.

2.2 THE PHENOMENON OF HIV/AIDS

According to the basic indicators of UNICEF (2012), Lesotho has an HIV prevalence of 23.1% in a population of 1.89 million people. Of the infected population, 340 000 are women, and 150 000 children have been orphaned by HIV so far. There are three main modes of HIV transmission, which are mother-to-child transmission (MTCT), blood transfusion and unprotected sex. This section will focus more on the mode of mother-to-child transmission (Van Dyk, 2007:63).

The diagnosis of HIV infection is based mainly on the testing of blood samples. There are two broad classes of tests, and these are HIV antibody tests, which react to antibodies that have been formed in reaction to the virus, and tests that detect the actual virus (HIV) or viral elements in the blood The virus can be spread through blood transfusion, intravenous drug use, needle stick injury or body blood fluid contamination. The disease can also be spread during mother-to-child transmission during pregnancy, childbirth and breastfeeding (Van Dyk, 2007:64).

Antenatal care is often the entry point for women into the health-care system. In many countries it is also the first time a woman will undergo, or be offered, HIV testing if she has not sought out testing previously. Therefore, pregnancy can open a Pandora's box of health issues for women, particularly when HIV/AIDS is a concern. Should a woman test positive for HIV during pregnancy she is faced with a cascade of complex and sensitive decisions (Duoll, 2006:279). These decisions depend on the social context and resources available, and women often lack the information, support and resources to make informed choices. The importance of actively involving HIV-positive women in the decision-making process, either as lay coaches/counsellors or patients, is highlighted by the complexity of pregnancy and HIV-related decision making.

According to the National Abandoned Infants Assistance Resource Centre (2012:2), medical advances mean that women with HIV are living longer and healthier lives, and many of them are having children. However, having a child also means there are chances of infecting it. Antenatal clinics are the place where mothers get information about modes of transmission of HIV from them to their babies, and are offered packages called mother baby packs that include ARV drugs for both the mother and the baby to be born.

2.2.1 MODES OF TRANSMISSION FROM AN HIV-POSITIVE MOTHER TO CHILD

According to Van Dyk (2008:41), mother-to-child transmission or vertical transmission of HIV is one of the major causes of HIV infection in children and accounts for 90% of HIV in children. HIV can be transmitted from an infected mother via the placenta during pregnancy, through blood transfusion during birth, and lastly through breastfeeding. An in-depth discussion of these modes of transmission follows.

2.2.2 PREGNANCY

First, infection of mother to child happens during pregnancy and there are many different factors that contribute to this infection. According to the Ministry of Health Lesotho (2013:4),a high maternal viral load, sexually transmitted infections (STIs), viral, bacterial or parasitic placental infection, poor maternal nutritional status and chorioamnionitis (from an untreated STI or other infection) are contributing factors of mother-to-child transmission (MTCT) during pregnancy.

For HIV-positive mothers it is ideal that, as soon as they find out they are pregnant, they go for antenatal services so that they can be medically checked if they are not at risk of any STIs,and if the mother is not yet on ARVs she should immediately be initiated. In Lesotho a mother is provided with medication for a maximum of two weeks when newly initiated so as to monitor how the treatment is going. This has problems, as some women only come once due to a lack of resources and psychosocial support, as some fear coming to the facility will disclose their status (Scott Annotate, 2013).

2.2.3 CHILDBIRTH

The second mode of transmission from mother to child happens during childbirth. This may be due to the rupture of membranes for more than four hours, invasive delivery procedures that increase contact with the mother's infected blood or body fluids (e.g. episiotomy, foetal scalp monitoring), pre-term delivery or low birth weight (Ministry of Health, 2013:4). The

National PMTCT (2013) guidelines for Lesotho recommend that mothers deliver at a facility with a skilled birth attendant, as this contributes to a reduction of mother-to-child transmission during birth. Unfortunately not every mother can afford to deliver at a health facility due to factors such as a lack of financial resources and a lack of transportation to deliver her to the facility if she happens to go into labour at night or lives miles away (Scott Annotate, 2013).

2.2.4 BREASTFEEDING

The third and last type of transmission happens during breastfeeding. The contributing factors of mother-to-child transmission during breastfeeding are prolonged breastfeeding, mixed feeding, particularly during the first six months of life, breast abscesses, nipple fissures, mastitis, poor maternal nutritional status, and oral diseases like thrush and sores in the baby (Ministry of Health Lesotho, 2013:4). According to the Lesotho prevention of mother-to-child transmission (PMTCT) guidelines (2013:57), an HIV-positive mother should exclusively breastfeed her child for six months while she is adherently taking her antiretroviral treatment, whilst giving the baby cotrimoxazole to reduce the chances of the baby being infected through breast milk.

Although most communities in Lesotho may have access to ART-related services in terms of medically based interventions, there still remains a significant deficit in psychosocial support services and programming for the wellbeing of HIV-positive mothers living in the rural areas of Lesotho.

All humans have needs and these needs need to be met in order for them to live a fulfilling life. According to Castaneda (2000:560), very little systematically derived information is available regarding the care and support needs of women who currently live with HIV/AIDS in rural communities, and how these women cope with their illness in the context of communities where there maybe few other women with HIV/AIDS. The range of human needs conceptualised by Henry Murray and Maslow's hierarchy of needs will be used to identify the possible needs of these mothers so as to understand how they can be assisted by professionals.

2.3 THE RANGE OF HUMAN NEEDS

According to Louw and Edwards (1997:446), Henry Murray set himself the task in the 1930s of listing all the different human motivations that psychologist have identified. He wanted to

know what the needs are that people seek to satisfy. He proposed a list that included biological drivers and psychological needs and few of those needs relevant to this study will be discussed. These needs are abasement, achievement, affiliation, defence, nurturance and succorance, and they will be discussed below.

2.3.1 ABASEMENT

Abasement is about submitting passively to external forces, accepting injury and resigning oneself to fate. Acceptance of an HIV-positive status is the first step to quality adherence and longer positive living (Louw &Edwards, 1997:446).When a mother has accepted her HIV status, the most conducive way of showing this is by adhering to medication and coming to terms with being infected with HIV and living a positive life.

2.3.2 ACHIEVEMENT

Achievement is about accomplishing something difficult, overcoming obstacles and obtaining a high standard of living. It is a desire to achieve success for the intrinsic satisfaction of doing well. The motivation for achievement has practical effects on the way people approach everyday situations (Louw & Edwards, 1997:446).Overcoming the fear ofliving with HIV and accepting it can be seen as an achievement for an HIV-positive mother, for it is easier for her not to submit to life stressors such as depression and anxiety. Also, when a mother takes her child who was conceived while already HIV positive for testing, and finds that she did not transmit HIV to her baby, this can also be considered as an achievement for a mother.

2.3.3 AFFILIATION

Affiliation is to draw near others and co-operate or reciprocate, to win affection and to be loyal. It refers to the need people have to spend time with others. It plays an important part in human well-being. Loneliness and shyness may contribute to personal unhappiness. According to Louw and Edwards (1997:726), in 1959 anAmerican psychologistby the name of Stanley Schacter, found that people have different degrees of need of affiliation. Some people cope with social isolation more readily than others.

According to Swartz, De la Rey, Duncan and O'Neil (2011:317), the need to affiliate or share a sense of belonging with others is fundamental to the well-being of humans as individuals. Moods and feelings in response to external events can influence the desire to affiliate or interact with others. An HIV-positive mother may have the need to isolate herself due to her

HIV-positive status and fear of being judged or discriminated against, and this may end up making her lonely and unhappy and she may lose interest in even taking care of her health.

2.3.4 DEFENCE

According to Louw and Edwards (1997:726), defence is the need to defend oneself against assault, criticism or blame to conceal or justify a misdeed. In the rural areas of Lesotho, not many men go to health facilities to voluntarily know their status, but women are more active in knowing their status and, when they become mothers, making use of antenatal clinic HTC services is greatly encouraged. Even though this is a good health practice it is a problem for HIV-positive mothers with partners, as they may be blamed for bringing the virus into the family. At times it may get so bad that the husband may assault his wife.

According to Moteetee (2005:32), the Lesotho Sexual Offences Act of 2003 protects women and children against violence. However, when mothers are assaulted they do not report these cases for they fear that reporting it will be humiliating for their children (Scott Annotate: 2013). Mothers need to understand their right to be protected and not to be blamed for the virus, and that no one has the right to criticise them. Most mothers in the rural areas are not very aware of their rights. There is a need for them to be fully aware of their rights and to protect them.

2.3.5 NURTURANCE

Nurturance is gratifying the needs of an infant, or any object that is weak, tired, helpless or defeated (Louw & Edwards, 1997:726). Every mother has a need to satisfy her children's needs, and mothers are usually the bearers of everything affecting them, no matter how painful it may be. In Lesotho, breastfeeding a child is seen as the pride of a mother, but HIV-positive mothers may at times not enjoy this pride, especially if they are too sick to breastfeed their children and health professionals fear that the chances of infection maybe high if she breastfeeds. Such conditions are in cases where a mother may have developed mastitis on her nipples and they are cracked and a child cannot breastfeed (Ministry of Health Lesotho, 2013).

2.3.6 SUCCORANCE

Succorance is about having one's needs gratified by a caring person, to be nursed, supported, protected, loved, guided and consoled (Louw &Edwards, 1997:446). Every human being needs to be loved and cared for. An HIV-positivemother who has children to worry aboutalso

needs someone to help carry the burden of the illness. Mothers in the rural areas of Lesotho who have partners usually do not stay with them, as most Basotho men leave to work in South African mines. This leaves HIV-positive mothers to address the life of being positive with her children and the surrounding community, which at times is difficult, especially if the community is not very supportive. These mothers need a support system that will always be there for them whenever they feel they need a shoulder to cry on.

Now that the human needs conceptualised by Murray have been discussed, as well as their relevance to the study, the next section will explain the psychological needs of humans by looking at Maslow's hierarchy of needs, in order to assist HIV-positive mothers.

2.4 PSYCHOSOCIAL NEEDS OF HIV-POSITIVE MOTHERS

According to Swartz*et al*. (2011:238), Maslow (1970) proposed that human motivation rests on a hierarchy of needs. He thought that, when humans have fulfilled basic needs, they can go on to fulfil more complex desires. According to Louw and Edwards (1997:446), a contrasting approach to human motivation is to allow people to talk about the things that matter to them, and to systematically note down what they say. This may lead to insights into human motivation. Maslow's hierarchy of needs, according to Louw and Edwards (1997:449), are the following: physiological needs, safety needs, love and belonging needs, esteem and self-actualisation needs. These needs shall be discussed below, and are presented in Figure

2.1.

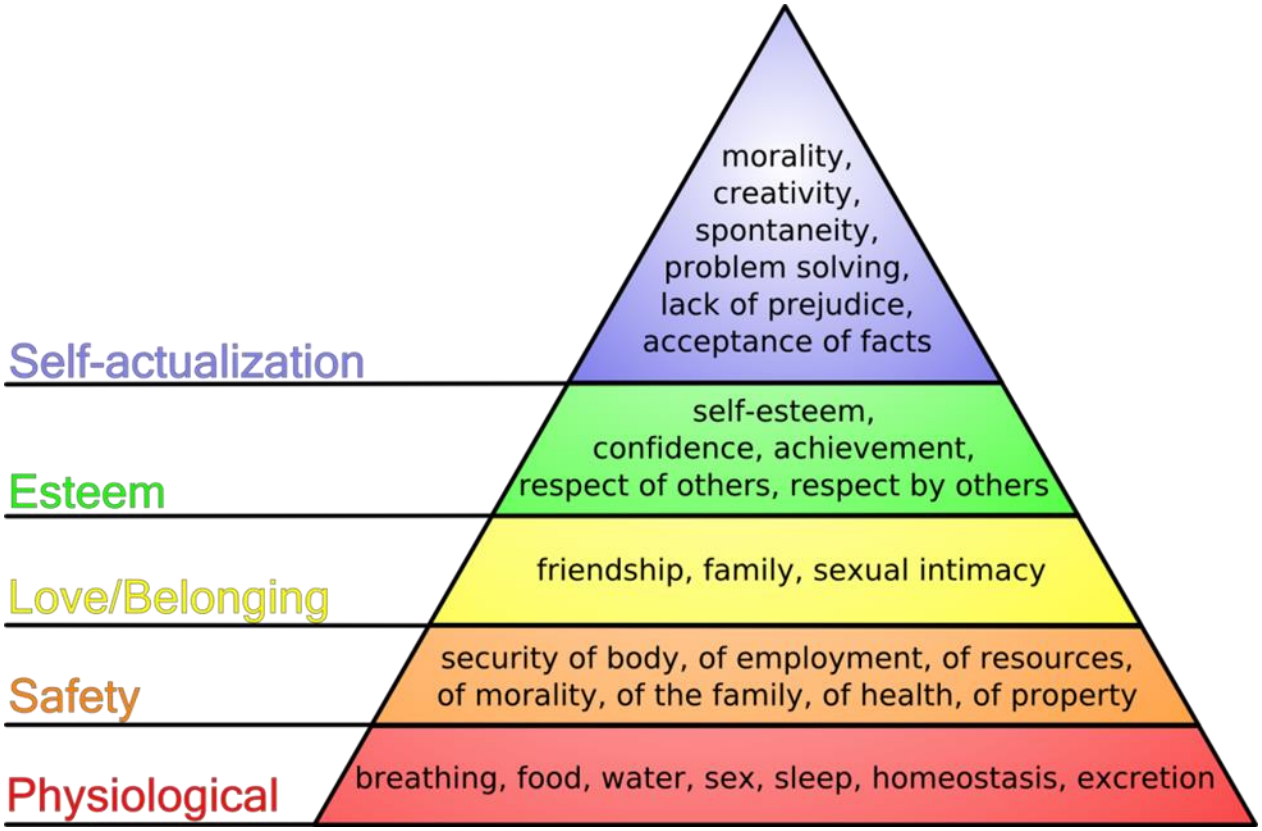

Figure 2.1 Maslow's hierarchy of needs
Source: en.Wikipedia.org (2014)

2.4.1 PHYSIOLOGICAL NEEDS

Physiological needs are about immediate survival, shelter, food and sleep. They are the lowest and most basic needs that humans need to survive their daily lives (Poston, 2009:348). Physiological needs are influenced generally through the cravings we have as human beings. If the body is being deprived of oxygen it will surely react to it (Poston, 2009:349). With regard to an HIV-positive mother's life, even though the mother may want to take her ARVs according to prescription, if she does not have food to eat before taking her medication it is going to be very difficult to hold down the medication and not vomit, and the body cannot survive on medication only;it also needs a balanced diet.

Shelter as one of the physiological needs also plays a major role in providing a secure place for medication where it will not be exposed to an environment that can negatively affect it, such as sun or fire, or a safe place where children cannot reach it. In the rural areas of Lesotho this may be a problem, especially in families where the whole family lives in a hut or one-roomed house, which is used as a kitchen, bathroom and bedroom (Scott Annotate: 2013). Problems with shelter may jeopardise the quality of ARVs and can contribute to the

development of opportunistic infections such as TB or pneumonia in cases where a member of the family has the disease and passes it on to others due to a lack of proper ventilation.

2.4.2 SAFETY NEEDS

According to Poston (2009:350), safety needs are more psychological, and differ depending on where an individual lives. A mother may feel the need to be protected from discrimination due to her HIV-positive status; she may also feel the need to protect her children from any form of discrimination or harm due to her status. She also has the health of her children to worry about, especially if she has an infected child, for children with HIV are liable to opportunistic and dangerous infections such as tuberculosis and pneumonia.

Safety needs are not only about a mother's children and her status. They can also be about her daily life. Some women are afraid to ask their partner to use a condom or even afraid of the reaction of their partners if they are to disclose their status. Safe houses for mothers who may suffer abuse from their partners can help while a counsellor is helping the family involved to solve disputes.

2.4.3 LOVE AND BELONGING NEEDS

These needs are about acceptance, feeling safe and comfortable, and being supported, which usually result in long-term survival. Quality of life has been associated with the social support available to people living with HIV and to higher levels of life satisfaction (Roger, Migliardi & Mignone, 2012:488). An individual needs support in order to accept her status and live positively with it. In addition, support also needs to be continuous in order for mothers to adhere to their medication. Adherence results in long-term survival, as ARV adherence prolongs the life of those who are infected with HIV.

According to Roger *et al*. (2012:497), a study on social support conducted by Klepac, Pikla and Relja (2007) suggested that quality of life is also influenced strongly by one's perceptions of social and family support. This study demonstrated that, regardless of other people's views, if the individual perceived that their social support was sufficient, improvements in individual resilience could be attained (Roger *et al*., 2012:497). Providing a link to community-based organisations that can promote social support for women living with HIV has clear implications for improved physical and emotional health.

2.4.4 ESTEEM

According to Germain and Gitterman (1996:17), self-esteem represents the extent to which one feels capable, significant, effective and worthy. It is the most important dimension of self-concept and is a major influence in human thinking and behaviour.

Esteem is about recognition and achievement, setting goals and achieving them. According to Poston (2009:351) this is the highest platform in the category of deficit needs. The process of growth, when addressing one's self-esteem, builds the bridge to one's awareness. Maslow's hierarchy addresses two levels of esteem, which are the lower level and the higher level. The lower level form of esteem is met when an individual has established a level of status, recognition, fame, reputation and appreciation, to name just a few. These areas in a person's life take work to maintain.

Being diagnosed with HIV often may bring result in low self-esteem in an individual, and may also have a negative impact on an individual's reputation, for in Africa the infection is associated with deficit behaviour. A mother infected with HIV does not only have to deal with society judging her, but also her own consciousness and accepting her status. She may end up not respecting herself and always trying to make others accept her by stopping to take her ARV medication and claiming she was misdiagnosed and does not have any HIV.

2.4.5 SELF-ACTUALISATION

According to Swartz *et al*. (2011:238), the self-actualisation need is the highest level of need. It refers to the complete development of the self and becoming the best person one can be. Conditions necessary to satisfy this need include not being distracted by lower-level needs, being able to love and be loved, being free of self-imposed and societal constraints, and being able to recognise one's own strengths and weaknesses.

With self-actualisation, being able to pinpoint how one truly feels about something is often a little more challenging to figure out, or it can be the determining factor for how well one is connected with one's self and abilities. For an HIV-positive person to reach self-actualisation means she has to fully accept her status, adhere perfectly to treatment, not be afraid to disclose, and be at the point to support others by offering her personal journey to self-actualisation as motive; for a mother to reach these stage she needs support so that she can later support others.

According to Marrow, Costello and Boland (2001:502), in a study done on the psychosocial needs of HIV-positive mothers, some participants reported that they often faced barriers to participating in psychosocial support groups, even when they were in a state of readiness to participate. Even though the group was addressing topics in which they were particularly interested, they faced barriers due to a lack of transportation and being responsiblefor child care, as this is usually the responsibility of a mother, or scheduled times clashed with other duties.

The needs of mothers, as well as their hierarchy in achieving them, has been discussed in this section. Mothers need professional assistance to be able to identify these needs. This will assist them to know which needs need to be met first. For example, physiological needs need to be met first in order to be able to meet safety needs. HIV/AIDS plays a significant role in impeding the meeting of these needs, especially in poorly resourced countries like Lesotho. Due to this factor the next session will look at the psychological impacts brought about by HIV/AIDS in meeting these needs.

2.5 PSYCHOSOCIAL IMPACT OF HIV ON MOTHERS

There are many different psychosocial impacts that HIV-positive mothers deal with on a daily basis. Van Dyk (2008) has identified some of them, which are discrimination, stigmatisation, bereavement and stress. These psychosocial impacts will be discussed below.

2.5.1 DISCRIMINATION

HIV/AIDS-related discrimination remains one of the greatest obstacles to people living with HIV infection or AIDS. Discrimination concerns are one of main reasons why people do not have an HIV test or get their ARV treatment if infected (Van Dyk, 2008:131).

According to Baingana *et al*. (2005:22), stigma and discrimination can be a challenge to psychosocial intervention for a number of reasons. For example, in attempting to avoid discrimination, people may be less likely to adopt strategies that prevent AIDS infection and spread, such as condom use, revealing status to sexual partners, and adherence to treatment regimens. Thus, in developing a support services programme for HIV mothers, issues such as stigmatisation should always be considered.

2.5.2 STIGMA

Stigma occurs when a person is devalued because of a trait such as race, gender or illness.A major factor that distinguishes HIV/AIDS from other chronic or terminal illnesses is stigma associated with the disease. This stigma comes from a lack of knowledge about HIV and how it is transmitted (Skinner & Mfecane, 2004:159).

According to the National Abandoned Infants Assistance Resource Centre (2012:9), stigma and discrimination contribute to infected women's vulnerability by inhibiting them from seeking help and support for their condition. The stigma surrounding HIV/AIDS can severely impact those infected or affected by the virus. Prone to both stigma internalisation and stigma management, they are less likely to seek social support for fear of rejection and isolation. This prevents people from talking about and acknowledging HIV as a major cause of illness and death, and prevents people from seeking counselling and obtaining medical care and psychosocial care.

Social reactions to a disease evolve as new information about the disease becomes available, such as information on effective treatments. However, much of the HIV-related stigma is symbolic. A study comparing attitudes to HIV-positive people pre- and post-HAART in the UK, and a US telephone survey of the general population comparing AIDS stigma in 1991 and 1999, found that, although overt expressions of stigma declined, one-third of respondents in 1999 expressed negative feelings towards HIV-positive people. Thus, despite changes in the epidemic, which should lead to decreasing stigmatisation of HIV, the negative effects of stigma continue to take a toll (Herek, Capitanio & Widaman, 2002:374).

2.5.3 DEPRESSION

According to Ownyby, Jacobs, Waldrop-Valverde and Gould (2010:73), depression is among the most common neuropsychiatric disorders that affect Individuals with HIV infection. It has a dramatic effect on patients' quality of life. Depression has an important impact on the course and outcome of HIV infection through its effects on patients' adherence to medication regimens and via psychoneuroimmunological mechanisms. In spite of its importance, it is likely that depression is under-recognized and under-treated in patients with HIV infection.

According to Tsai, Bangsberg, Frongillo, Hunt, Muzoora, Martin and Weiser (2012) depression is recognised as a strong predictor of non-adherence to medical treatment plans. Depression is associated with worse HIV outcomes, including immunologic decline,

progression to AIDS, and AIDS-related mortality. There is an urgent need for HIV care providers to recognise and treat depression in their patients or to refer their patients to mental health specialists for diagnosis and treatment when necessary. This needs trained and qualified professionals and, with the support services being offered in Lesotho, where psychosocial support is mainly offered by other HIV-positive mothers or community health workers who have been informally trained, it may be very difficult to identify a client who is depressed or even refer her to the necessary support service to deal with her problems.

2.5.4 BEREAVEMENT

Bereavement is an experience of pain and grief felt when a person loses someone or something of value, or if the loss of that person or thing is anticipated (Mphale, Thlomola, Phatela, Rants'o & Nthane, 2010:108). Despite advances in HIV treatment and a reduction in AIDS-related deaths, families will continue to lose loved ones to AIDS. Bereaved women are particularly concerned about loss and coping issues related to their children, deceased partners or spouse and family responsibilities (National Abandoned Infants Assistance Resource Centre, 2012:9)

According to AVERT (2012) despite the increased availability of ARVs, death is still a common outcome of HIV/AIDS, and millions of children will lose one or both parents to HIV/AIDS. When a mother is progressively deteriorating due to HIV, it is important for her to plan for her children's future in terms of who will take care of them, whether that person is willing to take care of the children, and are resources are available to take care of such children, and if that person seems to be abusing children they should know where they can go to report it and get help.

2.5.5 STRESS

Stress is the eternal response to a life stressor and is characterised by troubled emotional or physiological states, or both. Prolonged stress, together with a lack of effective coping and personal vulnerability, can lead to physiological, emotional or social dysfunction (Edwards, 1995:817). Being HIV positive causes emotional stress in mothers and they question where and how they got infected, and whether the community will accept her. The intake of ARVs is a lifetime commitment and it needs an individual with a solid support system, else the chances of defaulting are high.

According to Van Dyk (2008:274), some people experience acute stress disorder after an HIV-positive diagnosis, or after the death of the significant other. An acute stress disorder is an anxiety disorder that develops in response to an extreme psychological or physical trauma. The acute stress can be accompanied by feelings of dissociation, emotional unresponsiveness, numbness and withdrawal from social contact. When a mother experiences such feelings she needs a strong support system that will be able to easily identity the signs and help the mother go through the stress. Stress can also cause a fear of accessing treatment and disclosing HIV status.

The psychological impacts of HIV discussed above have different effects on HIV-positive mothers. To some extent they impede a mother from living a fulfilling, happy life. Not only can other psychological impacts such as stigma and discrimination hinder a mother from disclosing her HIV status, but this may endanger her life medically for she may prefer not to take treatment so as not to be associated with HIV/AIDS.

2.6 DISCLOSURE

According to Van Dyk (2007:220), disclosure can help people accept their HIV status and reduce the stress of coping on their own. It helps ease access to medical services, care and support, including access to antiretroviral therapy. Disclosure can help people protect themselves and others, especially if they happen to have accidents and blood is involved, it can also help reduce the stigma, discrimination and denial that surround HIV, it promotes responsibility and it may encourage the person's loved one to plan for the future.

Even though disclosure is encouraged due to its positive benefits, it can be accompanied by negative consequences such as problems in relationships with sexual partner, family, friends and community members, or the risk of losing one's job. Mothers need guidance on how to disclose their own status and, with the help of health professionals that can assess the situation beforehand, be ready for the consequences, such as being in a position of losing a partner or job.

According to Anglewicz and Chintsaya (2011:998), disclosure is important for the health of HIV-infected individuals. It is necessary for women and men to inform others of their condition in order to receive emotional and physical support. For some it is necessary to disclose an HIV-positive status to a spouse in order to facilitate access to antiretroviral HIV treatment. The people to whom a mother usually will disclose her status will be discussed.

2.6.1 DISCLOSING TO A SPOUSE AND FAMILY

According to Marks and Crepaz (2001:79), disclosure to a sex partner is important because it informs that partner of his or her risk. An assumption underlying post-test counselling is that seropositive persons who disclose their status to sex partners at risk for infection are more likely to engage in safer sex compared with the situation in which disclosure is withheld

According to Bartlett and Finkbeiner (2006:22), one of the first practical concrete problems most people face after their diagnosis of HIV is deciding whom to tell. So, firstly a person has to decide whom they are obliged to tell about their status. For HIV-positive mothers, telling a spouse and family is really important so that she can get the support from the family and openly take the ARV treatment so as to prevent her baby from being infected. But disclosure to a spouse and family in Lesotho at times can bring family problems, especially if the results are discontent and the mother is the one with HIV-positive results. The husband may decide to leave or chase the wife from home (Scott Annotate, 2013).

2.6.2 DISCLOSING STATUS TO CHILDREN

Disclosing of the status of the mother to children is important so that the children can be aware of what is happening to their mother and be able to assist her with proper care and protection when she needs help. Not every HIV-positive mother who is pregnant sticksto the PMTC programme and at the end of the day they pass the infection on to their children. This is a tragedy, but life has to continue and the mother has to live with the consequences of having an HIV-positive child, and as the child gets older there is a need for the mother to make her child aware of the HIV-positive status.

According to Waugh (2003:174), a study of families with HIV-infected children attending a South London clinic (where 77% of the families were of African origin) found that parents thought that their children had a partial understanding of their illness and understood the clinic visits and treatments. All of the participants considered that disclosure should wait until the child was old enough not to tell other people indiscriminately. Parents viewed disclosure as inevitable, but to be delayed as long as possible.

2.6.3 DISCLOSING TO FRIENDS AND COMMUNITY

According to Kalichman, DiMarco, Austin, Luke and DiFonzo (2003:316), a fear of disrupting relationships, particularly by evoking stigmas that can result from disclosure of HIV, is a common barrier to disclosure. For many people, disclosure decisions must balance the need for social support specific to coping with HIV/AIDS against the potential loss of what could otherwise be generally supportive relationships.

In a study conducted by Kalichman *et al*. (2003) on disclosure,they found that the majority of people living with HIV/AIDS disclosed their HIV status to family members and friends, and that HIV status was disclosed to friends significantly moreoften than to family members (Kalichman *et al*., 2003:329). Mothers can disclose their status to friends and the community because the need social support and can get it from friends and communities, for some women stay far from their families and relatives (Scott Annotate, 2013).

According to Tracy and Whittaker (1990:462), social support can be provided spontaneously through the natural helping networks of family and friends, or can be mobilised through professional intervention. Families, friends and the community can provide informal support to a mother, and institutions such as clinics, hospitals and many others provide formal support to mothers.

2.6.4 DISCLOSING TO SUPPORT GROUP

According to the National Abandoned Infants Assistance Resource Centre (2012:15), group counselling for women with HIV can be helpful in treating depression, reducing social isolation, increasing coping resources, and obtaining support. Groups are helpful because people often feel relief when they learn that others have had the same experiences. Listening to others' challenges can offer a woman a better perspective on her own problems and help her learn new ways to cope with her illness.

There are many different challenges that mothers face due to HIV, and they need support in addressing these day-to-day problems, but for support to be accessed at times there is also a need for funding. For mothers to get to formal support institutions, running costs are included in order to run such institutions and provide services, and this is where the socio-economic status of the country plays a huge role.

2.7 SOCIO-ECONOMIC AND CULTURAL SITUATION OF LESOTHO RELATED TO HIV/AIDS

According to Baingana *et al*. (2005:3), the consequences of AIDS have been felt across all populations groups and the disease is most prevalent among impoverished people with fewer resources for coping. The relationship between poverty and AIDS is evident, since as much as 80% of HIV infections occur through sexual transmission and the person's economic position often predicts the frequency and nature of sexual activity.The poor are likely to be driven into trading sex to meet basic needs, have less choice over condom use, and may be forced to have multiple partners for economic protection.

According to Giddens (2013:249), access to goods, services and facilities in small villages and sparsely populated areas is not as extensive as in more settled areas. In most industrial societies, proximity to basic services such as doctors, schools and government services is considered a necessity for leading an active, full and healthy life. Rural residents, however, often have limited access to such services and are dependent on the facilities available within their community. According to Roger *et al*. (2012:488), HIV/AIDS disproportionately affects economically disadvantaged and stigmatised communities, placing an increased demand on caregivers with already limited resources. This increased burden greatly affects those living with HIV, as well as those within their social support networks.

According to African Peer **Review** Mechanism **Report** (2010:11), Lesotho is predominantly a country with a rural economy, with 76% of its population dwelling in the rural areas. The country has very limited natural resource endowments, including agriculture and grazing land, but is richly endowed with water. Poverty is widespread, with about 56.7% of the population living below the poverty line, and the declining population growth, coupled with high prevalence of HIV/AIDS, means that the country has limited human resources.

The PSE survey carried out by Gorden, Adelman and Ashworth (2000) found that women comprised 58% of all adults living in poverty. One of the important elements isthe gendered division of labour, both inside and outside the home. The burden of domestic labour and the responsibility for caring for children and relatives still fall disproportionately on women, and this has an important effect on their ambition and ability to work outside the home (Giddens, 2013:539).

Widespread poverty and high income inequality in the country suggest that a large segment of society cannot achieve individual or collective self-reliance. Poverty is widespread in rural

areas, with high unemployment rates (African Peer Mechanism, 2012:14). A large number of women are employed in factories, which are based in towns.For mothers who are lucky to have a job, they have to wake up early in the morning, prepare for their children to go to school and then prepare themselves for work. They then have to wait for transport, for there is not much transport in the rural areas. They need the jobs to survive, but the job also occupies most of their time, as they leave their homes early and come back very late (Scott Annotate, 2013).

2.7.1 THE EFFECTS OF WORK FOR HIV-POSITIVE MOTHERS

As was mentioned above, work occupies a larger part of our lives than any other single type of activity. Even where working conditions are relatively unpleasant and the tasks dull, work tends to be a structuring element in people's psychological makeup and the cycle of their daily activities.

According to Halpern (2005:1), time is a valuable resource for all working adults, but for working parents the constant sense of time urgency (e.g. getting home from work before the sitter has to leave, getting into work in time for an early meeting) is an on-going stress because the time demands are often competing. This gets worse when a mother is HIV positive and is breastfeeding, as mixed feeding in not recommended and thus a mother has to hurry home so that the baby does not go hungry.

According to the Lesotho Labour Code Wages Amendment Notice (2011:983) paragraph K (1), an employee who has completed more than one year of continuous service with the same employer in the textile, clothing, leather clothing and leather manufacturing industry shall be entitled to receive two weeks' paid maternity leave.Paragraph K (2) says an employee who has completed more than one year of continuous service with the same employer other than in textile, clothing and leather manufacturing shall be entitled to receive six weeks' paid maternity leave before confinement and six weeks maternity leave after confinement. Women Working Worldwide (WWW) has shown their concern about this discrimination towards women and maternity leave and acted upon it by staging a march in 2013 against the government, and also wrote a report on it.

This code is not only discriminative against women working in textile factories, but it also affects the lives of HIV-positive mothers negatively, as it affects their breastfeeding in that they can exclusively breastfeed for only the two weeks. It can be argued that a mother could express her milk and store it, but the environment of the manufacturing sector is not

conducive to this practice. Furthermore, WWW (2013:3) says mothers receive only R300 for the two weeks' maternity leave, which is not enough to raise a new-born baby, and this usually forces mothers to go back to work right after the two weeks. This can negatively affect HIV-positive mothers living in the rural areas who managed to get jobs in the sector, as their income is usually not enough to cater for transport, households expenditures and purchasing formula milk to practise exclusive formula feeding. Thus the mother is eventually pushed into practising mixing feeding and increasing the chances of infecting her child with HIV.

HIV-positive mothers living in the rural areas of Lesotho who are lucky to have jobs would have a less stressful life if the above needs could be addressed in the work policy of Lesotho. This would allow the mother to provide for her children economically while also addressing the health issues surrounding her HIV status and be able to practise recommended practices such as breastfeeding in order to prevent new infection from mother to child. The PMTCT guidelines focusing on the issues of prevention should also consider including a timeframe according to which working mothers should be provided the opportunity to breastfeed their children. In addition, it should consider the cultural practices of mothers, for some cultures believe a child should breastfeed for two years or perform cultural rituals that may expose the child to be infected.

2.8 CULTURE

In addition to the socio-economic situation, culture plays a big role for the Basotho. As soon as one becomes pregnant there are cultural rituals that one has to perform, but now some cultural practices clash with medical practices when it comes to dealing with HIV. For example, drinking traditional medication for protection usually acts against ARVs, as the medication may cause potency to the drugs or cause the placenta to weaken and fluids from the mother may go through to the child who might get infected. Another example is when the mother is at the stage of delivering, when traditional medicine is prepared to assist the labour, but this medication can cause a problem by causing the membranes to rupture and the child maybe infected during the labour of the mother (Scott Annotate :2013).

According to Giddens (2002:21), culture is about aspects of human societies that are learned rather than inherited. They form the common context in which individuals in a society live their lives. A society's culture comprises both intangible and tangible aspects – the beliefs, ideas and values that form the content of culture, and tangible aspects – the objects, symbols

or technology that represent that content. Fundamental to all cultures are the ideas that differentiate what is considered important, worthwhile and desirable. These abstract ideas or values give meaning and provide guidance to humans as they interact with the social world.

In Basotho culture it is very important for a mother to keep her pregnancy a secret to protect it from witchcraft. This means the mother takes time before she goes for her antenatal clinic visit, but unfortunately the longer she waits the more she puts her child at risk of being infected. Some mothers are single parents and have no support. So waiting for some time before going to a clinic can emotionally drain her, especially when she knows that she is positive and what her status can do to her child but, due to respect for culture, the child may suffer. According to the Ministry of Health (2013:71), health-care workers need to be aware of migration patterns related to cultural traditions surrounding childbirth, particularly of the first child.

2.8.1 CULTURAL TRAITS

Cultural traits are closely related to overall patterns in the development of society. The level of material culture reached in a given society influences, although by no means completely determines, others aspects of cultural development. Much of the cultural paraphernalia,such as cars, telephones, running water and the internet, depend on technological innovations that have been made only very recently in human history (Giddens., 2002:30).

These innovations have contributed a lot in addressing and reducing the HIV/AIDS virus, for there is a lot of information provided about HIV/AIDS on the internet, and there are forms of transportation to take people to health facilities to get professional medical help. But this is a different story for mothers residing in the rural areas of Lesotho, as the culture of internet usage is a faraway dream; some do not even know what a computer is and have never even seen one. There is a need for the introduction of a culture of computer usage, as well as using computers to acquire the necessary knowledge about it. The gradual change of culture can be done through the socialisation of people, whereby the innovations such as use of condoms can be introduced to the community, preferably by a trained community member.

2.8.2 SOCIALISATION

Socialisation is the primary channel for the transmission of culture over time and generations. Culture pertains to those aspects of society that are learned, rather than inherited (Giddens., 2002:26). For example, for a new mother to be in the culture of Basotho she is taught about

raising a child, and there are laws and regulations that one is taught about, such as giving a child food at the age of three months, for it is believed the baby is then old enough to take soft foods such as porridge and softly cooked vegetables.

Due to the HIV pandemic this is a problem, for the mother is encouraged to breastfeed a child exclusively for a full six months without any additional foods. Now a young mother who does not know much and does not have any support will listen when her in-laws tell her that tradition is that she mix feeds the baby. Young mothers need support from their in-laws and parents when attending an antenatal clinic so that they can learn about safe ways of breastfeeding the child together and avoid any cultural disputes.

According to Green and Smith (2004), a review of the treatment and support needs of HIV-positive women noted constraints that impinged on their coping ability and mental state. These included socio-economic deprivation, gender inequality, gender-based violence, women's role as primary caregivers and pregnancy. Women's dependence on men makes it difficult for them to control their sexuality and negotiate safe sex, and this exposes women living with HIV to re-infection.

2.9 CONCLUSION

This chapter gave an overview of the phenomenon of HIV/AIDS and the psycho-social needs, economic and cultural circumstances of HIV-positive mothers in the rural areas of Lesotho. It gave a basis of what needs mothers may have and why they need to be addressed. The following chapter will discuss the needs of the mothers from an ecological perspective in relation to how their needs are addressed in Lesotho and how best they can be addressed through the consideration of the ecological perspective.

CHAPTER 3

THE NEED OF HIV-POSITIVE MOTHERS FOR SUPPORT SERVICES

3.1 INTRODUCTION

In the previous chapter the general needs of HIV-positive mothers were discussed; this chapter will discuss their support needs from an ecological perspective. According to Baingana et al. (2005), poverty in Africa is predominately rural, with rural populations tending to be poorly organised and often isolated beyond the reach of special safety nets and poverty programmes. Masis and Smith (2009:313) argue that African women are more vulnerable to HIV/AIDS than their male counterparts due to their inferior social status. In Southern Africa, especially in the rural areas, women are often treated as legal minors. Customs can bar them from owning or inheriting property, or the laws entitling them to do so are not enforced.

Those living in the rural areas have poor access to communication systems, such as radios, newspapers, television and the internet, which are all important technologies for the dissemination of anti-AIDS messages. The paucity of health-care facilities in rural areas requires that sick people walk long distances to the nearest health-care facility (Mukotsanjera, 2008:12). Lack of access to health services and underfunded services prohibit poor people from accessing medicines that treat infections associated with HIV/AIDS (Masis& Smith, 2009:314).

There are many different needs that HIV mothers have apart from dealing with the disease itself and taking ARV treatment. Mothers are also faced with the need for specialised professionals such as psychiatrists to assist them with mental problems brought about by the impact of HIV/AIDS on their brains. According to Citron, Brouillette and Beckett (2005:32), cognitive complaints are common in HIV disease, for it enters the central nervous system shortly after infection and, as it progresses, it causes cell injury to the brain. When a mother's brain is damaged, even though she may have overcome the challenges of poverty and could walk to the facility, when she reaches this stage she can no longer do things for herself and usually her family and children have to take care of her. This may bring fear to other mothers, thinking it is the medication causing problems. Thus, hospitals should have services that can

cater for such patients, and that kind of service is not available in Lesotho (Scott Annotate, 2013).

This chapter is about discussing the needs of HIV-positive mothers for support services. It will look at the ecological system, theoretical ecological concepts, physical and social settings, support services, and the nature of support services that can be used to meet the needs of HIV-positive mothers.

3.2 ECOLOGICAL SYSTEMS THEORY

According to Berben, Dobbels, Engberg, Hill and De Geest (2012:639), Urie Bronfenbrenner (1977) was the first person who focused specifically on the multiple environmental levels influencing a person's behaviour. In Bronfenbrenner's model, behaviour is viewed as being affected by, as well as affecting, factors at multiple levels of the environment.

According to Johnson and Yanca (2007:13), the ecological perspective bridges some of the gapsin the cause and function debate. In an ecological view, the function or societal side is made more relevant to people's everyday lives by including the environment in a comprehensive manner. From an ecological perspective, a need is a condition of the relationship between a person and the environment. A mutually beneficial interaction between person and environment is desired and, when needs are met, a state of congruity exists. Then there is harmony or "fit" between the person and the environment.

Unmet needs reflect an imbalance between the responses of the person and the environment to each other. Sometimes needs are not met because there are insufficient resources. More often, the interaction between the person and the environment is not balanced in a way that can sustain the needs of either one or both over time. This results in a state of incongruity – that is a lack of agreement or harmony between the person and the environment (Johnson &Yanca, 2007:13). Within the context of this research, Bronfenbrenner's Ecological Systems Theory was used to identify the needs of HIV-positive mothers and how best these needs can be met, considering the psychosocial wellbeing of the mothers, their cultural and economic situation, as well as their geographical location.

3.2.1 SUB-LEVELS OF THE ECOLOGICAL SYSTEM

Bronfenbrenner (1994:37) argues that in order to understand human development, one must consider the entire ecological system in which growth occurs. This system is composed of

five socially organised subsystems that help support and guide human growth. They range from the microsystem, which refers to the relationship between a developing person and the immediate environment, such as schools and family, to the macro-system, which refers to institutional patterns of culture, such as the economy and bodies of knowledge.

According to Bronfenbrenner (1997:9), the ecological environment is visualised as extending beyond the immediate situation that directly affects the developing person. The connections between other persons present in the setting, the nature of these links and their influence on the developing person are all of equal importance.

Figure 3.1 provides an overview of the sub-levelsof the ecological environment.

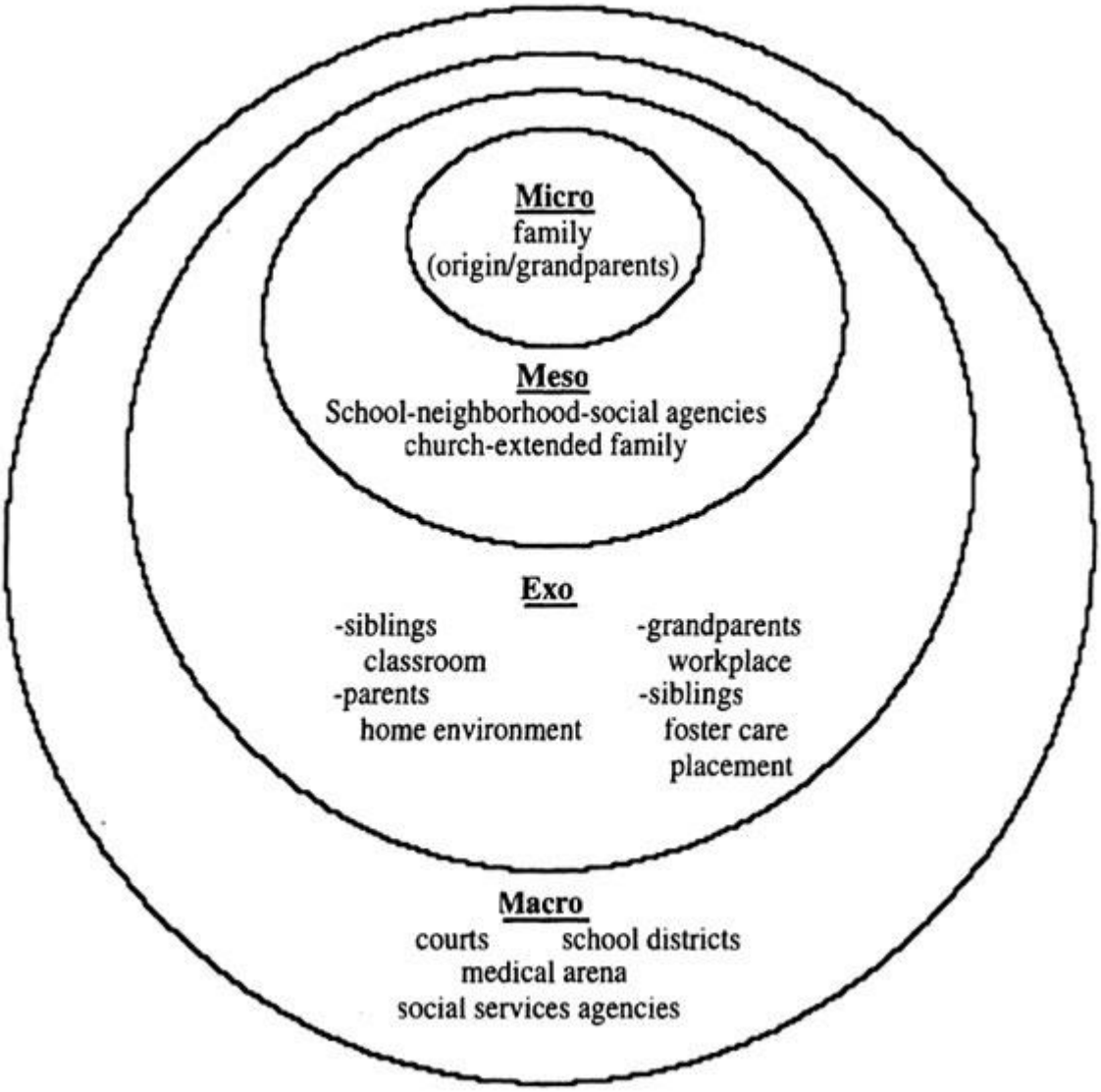

Figure 3.1 Sub-levels of the ecological system
Source: quod.lib.umich.edu 1999

The various sub-levels of the ecological environment will now be explained.

3.2.1.1 Microsystem

The microsystem is a pattern of activities, social roles and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical, social and symbolic features that invite, permit or inhibit engagement in sustained, progressively more complex interaction with and activity in the immediate environment. It is within the immediate environment of the microsystem that proximal processes operate to produce and sustain development (International Encyclopaedia of Education, 1994:37). In providing healthcare and support services for a mother, the provider should be aware of the mother's origins and social roles she has in the family. For example, in forming support groups a provider has to bear in mind what time the group will meet so it does not clash with house duties, such as cooking or cleaning the house.

3.2.1.2 Meso-system

The meso-system comprises the linkages and processes taking place between two or more settings containing the developing person (International Encyclopaedia of Education, 1994:37). According to Parker (2011:42), the links between the microsystems is defined as the meso-system. The stronger and more diverse the links between the microsystems, the greater the positive influence of the meso-system on the developing person.

For example, if professional health-care providers merge with traditional healers and community leaders to fight against HIV and all its negative consequences such as stigma and discrimination, as well as to fight poverty, it would be easier to achieve the goals of healthcare. According to Berben *et al*. (2012:640), meso-level factors refer to the practices or the characteristics of the health-care organisation where the patient is being treated, for example the time available for consultation and interventions implemented in daily clinical practice to enhance patients' medication adherence. If a health-care professional is working with too many mothers daily, those who have psychological problems may be missed due to the little time they spend in the consultation room and the health professional may not be aware of the signs. In cases where the extended family can provide any form of support, the health service provider should always consider it, but only with the permission of the mother. This can help in cases where a mother is not able to come to a health facility for things such as a refill of medication and can send a relative where possible.

There are also support groups supported by organisations such as Elizabeth Glaser Paediatric Foundation (EGPAF) and the mothers to mothers support group. These support groups are run by HIV-positive mothers who have been trained in facilitating emotional support group sessions. They meet on a weekly basis (Scott Annotate, 2013). These types of support groups can be facilitated by professionals to assist HIV-positive mothers who conduct the sessions in areas where the mothers are not well trained to identify symptoms of withdrawal and depression.

3.2.1.3 Exo-system

The exo-system comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes in the immediate setting in which the developing person lives (International Encyclopaedia of Education, 1994:37). The policies that are made for HIV for community health centres, clinics or hospitals affect an HIV-positive mother, for example if the facility policy says an HIV-positive mother can be given a supply of ARVs for only one month. This affects the mother in that she has to find transport money every month to get her medication at the facility, which at times she may not have. This means there are chances of her defaulting.

The church also play a big role in the lives of most Basotho women, as this is where they turn to in order to find answers and find spiritual healing (Scott Annotate, 2013). According to Nelson, Rosenfeld, Breitbart and Galietta (2002:213), understanding the relationship between spirituality and psychological well-being requires an understanding of the relationship between institutional religion and spirituality. Spirituality may be particularly important for individuals facing terminal illness because of the many physical, psychological and social stressors that often accompany life-threatening diseases (Nelson *et al*., 2002:213). Thus it is important for health-care service providers to consider churches as one of the places where HIV-positive mothers can get support.

According to Prado, Feaster, Schwartz, Pratt, Smith and Szapocznik (2004:221), religion and religious institutions have often provided African Americans with emotional, economic and social support. He further says religious involvement appears to have physical health benefits for HIV-seropositive individuals.

3.2.1.4 Macro-system

The macro-system consists of the overarching pattern of micro-, meso- and exo-system characteristics of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, lifestyles, opportunity structures, hazards and life course options that are embedded in each of these broader systems. The macro-system may be thought of as a societal blueprint for a particular culture or subculture (International Encyclopedia of Education, 1994:37). According to Visser (2007:25), the macro-system includes the attitudes and values of people and policies that govern behaviour.

Within the context of this research, Bronfenbrenner's (1975) Ecological Systems Theory can be used to assess the needs of HIV-positive mothers from an ecological perspective while providing them with healthcare. This model has the potential to identify barriers that hinder mothers from accessing services and how their needs can be met. According to Laubscher (2013:11), logistical barriers are closely linked to socioeconomic status. These include financial barriers, such as cost of treatment services, transportation and language differences.

The Ecological System Theory and its subsystems were discussed in the previous sections in relation to how they can be used to identify and assess the needs of HIV-positive mothers. The discussion of ecological concepts will follow next. These concepts make clear the need to view people and their environment as a unitary system while assisting them.

3.3 ECOLOGICAL CONCEPTS

According to Edwards (1995:816), Germain introduced an ecological metaphor as a perspective for practice in social casework more in 1973. Despite social work's historical commitment to the person-in-environment, most direct practice had not gone beyond the individual's internal processes and the family's interpersonal process. Attention to physical and social environments and culture, and to their reciprocal relationships with people, was rare. This inattention was due mainly to the lack of available concepts about environments and culture and how they affect and are affected by human development and functioning.

According to McKendrick and William (1991), the ecological perspective looks at human development and functioning, including the health and illness of an individual. There are exchanges between the individual and the social environment, the physical setting and the cultural context. The ecological perspective makes clear the need to view people and environments as a unitary system within a particular cultural and historical context. Both

person and environment can be fully understood only in terms of their relationship, in which each continuously influences the other within a particular context. Ecological thinking embraces indeterminacy in complex human phenomena.

According to Edwards (1995:817-819), there are many different original ecological concepts, and those that relate to this research are life stressors, coping measures, relatedness and habitat and niche, of which discussion will follow.

3.3.1 LIFE STRESSORS

According to Edwards (1995:817), life stressors are generalised by critical life issues that people perceive as exceeding their personal and environmental resources for managing them. Life stressors include difficult social or developmental transitions, traumatic life events, and any other life issues that disturbs the existing fit. Life stressors and challenges differ in meaning and emotional tone. A stressor represents serious harm or loss and is associated with a sense of jeopardy. HIV is one of the biggest life stressors in that it does not only affect the physical being, but also the resources of its host, in that one needs to eat a healthy diet and be able to always go to the facility for check-ups and to collect medication. This is the biggest challenge for mothers in rural areas, as there are high levels of unemployment and poverty.

Stress is the internal response to a life stressor and is characterised by troubled emotional or physiological states, or both. Prolonged stress, together with ineffective coping and personal vulnerability, can lead to physiological, emotional or social dysfunction (Social Work Encyclopedia., 1995:819). Being HIV-positive causes emotional stress for mothers when questioning where and how they got infected, and questioning if the community will accept them. Intake of ARVs is a life-time commitment and it needs an individual with a solid support system, or else the chances of defaulting are high.

Poverty is one of the main life stressors that affect most people in rural areas due to unemployment, and it is more severe for HIV-positive mothers. According to Clemen-Stone, McGuire, Eigsti and Brooks (2002:406), income is the most common measure of socio-economic status and provides a basis for formulating health policy. Poverty coexists with many risk factors that influence health. Studies have shown that socio- economic status is a determinate of illness, death and other health outcomes. Addressing the needs of HIV-positive mothers is not only about dealing with their health issues, but also their socio-economic status,which plays a major role in their health (Clemen-Stone *et al*., 2002:406).

3.3.2 COPING MEASURES

Coping measure are special behaviours, often novel, that are devised to handle the demands posed by life stressors. Successful coping depends on various environmental and personal resources (Edwards, 1995:819).Support is one of the biggest coping mechanisms that are needed to cope with HIV/AIDS. A community that is well mobilised, equipped and well educated about HIV can contribute to managing stressful encounters brought by it, but at times resources are needed to provide support. Availability of resources in rural areas is very scarce, so communication and sharing of available resources using the barter system can be considered one of the ways of addressing the strains caused by HIV in communities with scarce resources. As the disease is so highly stigmatised, it places people living with HIV/AIDS (PLWHAs) at risk of social isolation and they need to be in a position where they are able to access support (Malgas, 2005:18).

3.3.3 RELATEDNESS

According to Germain and Gitterman (1996:15), relatedness is based on Bowlby's attachment theory, which proposes that relatedness is an innate capacity of human beings, built into the genetic structure of the species over evolutionary time because of its survival value. Relatedness also incorporates ideas about loneliness, isolation and supportive networks. Such social networks can become very important support systems that buffer the impact of life stressors or serve as coping resources for both problem solving and managing negative emotions in the face of life stressors (Germain & Gitterman, 1996:15).

The community can cause a life stressor for a mother who is HIV positive by discriminating against her due to her status, and this can bring with it loneliness and also contribute to defaulting, as she may want to hide her status and not go to the health facility to get her medication due to fear of rejection by family and friends. When a mother has a strong supportive network of family and friends she has better chances of coping with discrimination from society, unlike a mother who does not have any family and friends to turn to for support. A strong network of support helps in adherence.

3.3.4 HABITAT AND NICHE

According to Germain and Gitterman (1996:20), in the science of ecology, habitat refers to the place where the organism can be found, such as home ranges and territories. Metaphorically, human beings' particular physical and social settings within a cultural context

represent their habitat. For humans, physical habitat maybe rural or urban and include dwellings, transportation, recreation facilities and religious structures. Habitats that do not support the growth, health and social functioning of individuals and families do not provide community amenities to an optimum degree and are likely to produce isolation, disorientation and helplessness.

Niche refers to the position occupied by species of organisms within a biotic community, that is, their place in a community's web of life. These niches are shaped and sustained by society's tolerance of the misuse of power in political, social and economic structures. Community niches that interfere with health morale and social functioning are critical environmental elements in community social work. In order to help reconstruct damaging niches, social workers and other health-care providers must participate in efforts to influence local, state and federal policies through professional associations, political coalitions and the press (Germain & Gitterman, 1996:20).

Culture indeed plays a big role in HIV, for women in Lesotho are considered minors and men are decision makers. Thus, most married mothers would prefer to tell their husbands that they are HIV positive and have to take ARVs. Also, the in-laws are the ones who have a say in the breastfeeding of a child, which at times is a problem, especially if the mother has cracked nipples and was told not to breastfeed as she would infect the child, but the in-laws insist that it is their culture for a child to breastfeed. Health-care providers need to deal with such issues while being very sensitive towards culture, and should involve community leaders in addressing such problems.

3.3.5 PHYSICAL AND SOCIAL SETTINGS

Physical and social settings can influence an individual's behaviour, for they provide a venue in which individuals may be linked by various forms of social interaction and meaning-imbued physical space and attendant behaviour norms. Hence, settings may increase individuals' HIV risk by promoting higher risk behaviours or engaging with higher risk individuals. All social and physical settings that make up rural communities construct women's day-to-day experiences and their ability for personal change and self-determination within them. The ecological perspective emphasises an understanding of these social and physical settings and how they affect women's health and wellbeing (Castaneda, 2000:561).

To be effective and sustainable, HIV-prevention interventions need to be sufficiently powerful to counteract prevailing social norms and diffuse through the targeted community to

provide social reinforcement for behaviour change (Latkin & Knowlton., 2005:102).With growing awareness of the role of social structural and environmental influences on HIV risk behaviours, structurally focused interventions are increasingly advocated. Broadly considered, the terms structural and environmental factors often refer to those factors outside of the individual that may affect risk behaviours.

According to Latkin and Knowlton (2005:102), risk behaviours are not randomly distributed within a population. Rather, risk behaviours are generated and perpetuated through socially and environmentally structured social interactions. An ecological perspective of behaviour emphasises dynamic, social processes through which individuals adapt to their social organisations, structures and environment, which are modified by individuals' behaviours.

For many individuals, HIV prevention may be a concern, but not a priority. Among disadvantaged individuals, HIV may be a lower priority compared to meeting basic needs of food, shelter and safety. The challenge for intervention is to link HIV prevention to individuals' other priorities. For example, training in interpersonal communication skills for risk-reduction negotiation should be applicable to participants' other interests, such as improving valued inter-personal relationships. By integrating HIV prevention with goals relevant to the population it is possible to increase participants' motivation (Latkin & Knowlton, 2005:106).

Addressing the needs of mothers by assessing their environmental, social and economic problems is not an easy task. Different professionals or specialists have to be involved, but if they work together and try to come up with general support services that can assist these mothers it would be easier for them to meet the needs of these mothers. There are many different support services that can be used; the following have been identified for the study and will be discussed below.

3.4 SUPPORT SERVICES FOR HIV-POSITIVE MOTHERS

There are many different types of needs that HIV-positive mothers have, and thus different support services have to be available to address such needs. According to Castaneda (2000:557), the availability of local support services is critical to the provision of HIV/AIDS care and prevention services to women. Battered women's shelters, rape crisis services, mental health, housing, affordable day care, transportation, drug and alcohol rehabilitation and employment services are essential for reducing women's risk for HIV/AIDS. Because

fewer social, health and mental health services exists in rural areas in general, women's access to the needed services may be restricted and services are more limited in scope than in urban areas.

As ARVs and other treatments become widely available, the benefits of testing have started to outweigh the disadvantages. Although more people are testing, the quality of treatment, advice and follow up and access to a regular, lifelong supply remain real concerns. Even when treatment is available there are huge barriers to ensuring that women can improve their health. Examples are long distances to get to the clinic, long queues, stock-outs of vital medication, out-of-date medication, lack of advice and help with side effects, and complications in accessing second- and third-line treatment (Bell, Mthembu, O'Sullivan & Moody, 2007:118).

According to Trickett (2009:259) there is one consistency in the literature favouring a movement toward multilevel interventions, and that is the assertion that they rest on an ecological approach. One example is a study by Smedley and Syme (2001:157) which examined a wide range of social and behavioural research that was intended to promote the health and wellbeing of individuals, their families and their communities and found an emerging consensus that research and intervention efforts should be based on an ecological model.

3.4.1 NATURE OF SUPPORT SERVICES

Social support is important for successful coping. There are three functional types of social support: emotional support, for example through affection, comforting and encouragement, resulting in a sense of belonging and personal worth. Secondly there is informational support, which increases one's knowledge base, and lastly there is instrumental support, which is practical assistance with daily living (Dageid & Duckert, 2008:185).

According to Glanz, Rimer and Viswanath (2008:190), the provision of social support is one of the most important functions of social relationships. The term social networks refer to linkages between people that may provide social support and may also serve functions other than providing support. Social networks give rise to various social functions, such as social influence, control, compassion and support. The seminal work by House (1981) cited in Glanz et al, (2008) says social support is the functional content of relationships that can be categorised into four broad types of supportive behaviour or acts, and these are emotional support, instrumental support, informational support and appraisal support. A discussion shall follow of each of these kinds of support.

3.4.1.1 Emotional support

According to Glanz *et al*. (2008:190), emotional support involves the provision of empathy, love, trust and caring. According to Gordillo, Fekete, Platteau, Antoni, Scheneiderman and Nöstlinger (2009:523), receiving emotional support from significant social network members, such as partners, families or friends, may counteract the negative impact of HIV on psychological wellbeing.

In addition, Dageid and Duckert (2008:186) mention that, among individuals with HIV, greater engagement in spiritual activities is tied to better psychological adaptation. In their study, Dageid and Duckert (2008) found that many women turn to religion and tribal leaders to find support and comfort. Thus, in providing healthcare for HIV-positive mothers, professional health-care providers should also consider these people and work together in providing the mother with complete care, not just medical care.

3.4.1.2 Instrumental support/concrete support

According to Glanz *et al*. (2008:190), instrumental support involves the provision of tangible aid and services that directly assist a person in need. There are many types of instrumental or concrete support services that can assist in meeting the needs of HIV-positive mothers, and unconditional cash transfers shall be discussed as an example of such services.

The social welfare sector in Lesotho is an example of such services as it aims to alleviate human suffering and facilitate social economic development. It enhances the potential of marginalised groups to improve their quality of life. Its services include child welfare, youth services, and support of mentally ill persons. It also includes health and social welfare priorities, and essential public health interventions. But there are other forms of instrumental support systems which Lesotho can adopt in order to assist HIV positive mothers living in the rural areas of Lesotho and their discussions follows.

a) Unconditional cash transfers

According to Dageid and Duckert (2008:182), the millions of people living with HIV/AIDS are in urgent need of effective care and support interventions. Such interventions should take peoples' reported needs, coping strategies and context into account. Bell *et al*. (2007:114) state that tension exists between the needs of people living with HIV and the economic and social realities in many developing countries, where health-care services for the entire population are grossly under-resourced.

Case, Hosegood and Lund (2005:467) say government intervention can take any form, one of which is the direct provision of cash. While cash transfers have long been a standard part of welfare systems in advanced industrial countries, they have been less commonly found in lower and middle-income countries. This calls for states and countries like Lesotho to consider Mexico's Progresa programmes in assisting the needs of the poor and vulnerable, such as HIV-positive mothers.

According to Aguero, Carter and Woolard (2006:1), Mexico's Progresa programme is the best-known cash transfer programme, and has two key design features that may mediate its nutritional impacts. First, cash transfers are conditional on the household meeting certain required behaviours: Older children must attend school, and younger children must visit clinics for regular check-ups and nutritional monitoring (where, among other things, they are given supplements).

In addition to those conditions, Progresa cash transfers are also assigned to women. Unlike market-driven income, which may have been generated by increases in returns to asserts owned by men, these targeted cash transfers have been designed to bolster the bargaining power of women with the idea of giving more weight to their preferences, which are presumed to be more child-centric.

Aguero *et al*. (2006) further explain that cash transfers are used as new policies to increase the nutrition and human capital of children from poor families. Despite improvements over the last two decades, child malnutrition remains a serious health problem in developing countries and is the main contributor to child mortality. This situation is made worse by HIV/AIDS, and an HIV-positive mother is negatively affected by the poor nutrition of her child in that, even if she maybe sick with mastitis and is advised not to breastfeed her child, she will continue doing so due to a lack of resources to buy baby milk and soft foods.

The South African government has used cash transfers to assist children of poor families under the age of 14 years and these cash transfers are unconditional. In a study of the impact of unconditional cash transfers on nutrition, Aguero *et al*. (2006) found that the nutrition of young children is of importance, not only because of concern for their immediate welfare, but also because nutrition in the formative stage of life (0 to 3years) is widely perceived to have a substantial, persistent impact on the physical and mental development of a child.

In Lesotho, the type of cash transfers that the government offers are for of older persons aged 70 and for children who are orphans. The government of Lesotho is already addressing issues of poverty by providing free primary education and food at school. For an HIV-positive mother living in rural areas and surrounded by poverty, this is a very great form of support for her children, as she has to worry less about how to pay fees for her children and what they will eat when going to school. But now the question is what about when a child is still young and not yet at the stage of primary level; should the state not consider the wellbeing of such a child even though it may have parents who are unable to provide for their child.

The government of Lesotho could consider copying the Mexican Progresa programme and modifying it to its own systems, just like the South African has done by introducing the Child Support Grant. This would have to be done carefully, however, as some may argue that it might promote a dependency syndrome in mothers.It can also be argued, however, that the provision of money for mothers to buy milk and other basic necessities for a child can help in curbing mother-to-child transmission during breastfeeding, as there would be no need for mixed feeding.

3.4.1.3 Informational support

Informational support is the provision of advice, suggestions and information that a person can use to address problems. According to Mo and Coulson (2013:2) a growing body of literature has shown that online support groups can provide a valuable source of information, advice and support, as well as provide a medium through which individuals living with HIV/AIDS can interact with each other. It has been shown that online support groups allow disclosure of emotions and insights, which is associated with psychological benefits. There are many different types of informational support that can be used to assist in meeting the needs of HIV-positive mothers, and a few of these shall be discussed in the following sections.

a) e-Health services in meeting the needs of HIV-positive mothers

Health systems in low- and middle-income countries continue to face considerable challenges in providing high-quality, affordable and universal care. In response, policymakers, donors and programme implementers are searching for innovative approaches to eliminate the geographical and financial barriers to health. This has resulted in interest in e-health: the use of information and communicationstechnology (ICT) for health and mobile technology for health (Lewis, Synowiec, Lagomarsino & Schweitzer, 2012:332).

According to Coleman (2012:1), e-health emerged early in the 21st century and is an all-encompassing term for the combined use of electronic information and communications technology (ICT) in the health sector. It is further pointed out that, while some definitions associate e-health strictly with the internet, the term broadly refers to an electronic exchange of health-related data collected or analysed through electronic connectivity for improving the efficiency and effectiveness of health-care delivery.

According to Hage, Roo, Offenbeek and Boonstra (2013:2), e-Health services are any form of interactive communications and information technology aimed at enhancing a community's quality of life and/or individual health outcomes. According to Geissbuhler and Shorbaji (2011:394) there are many definitions of e-health. Eysenbach (2001) defines e-health as an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the internet and related technologies.

i) Different types of e-health services

Internet and social media-based services are developed for purposes ranging from economic development to empowerment and bridging the digital divide (Hage*et al*., 2013:6). Examples of such services are WhatsApp and Facebook, which most people access on their phones and are cheaper ways of communicating. Radios and television are also part of social media, where mothers can learn a lot about tackling their everyday problems by listening to programmes that deal with such issues.

Video conferencing and tele-health are typically applied in services aiming at enhancing quality of life by improving both the accessibility and quality of those health services. These can be used in clinics that are in remote areas where there are no specialists (Hage *et al*., 2013:6). Specialists can videoconference with patients instead of patients travelling long distances under harsh conditions and end up not making it to the hospital. It can also save mothers time and money for transportation, which is already a hassle to get.

Telecommunications applications (mobile phones) are used, like the internet and social media, to achieve a wide range of outcomes. Examples include saving health-care costs by diagnosing a patient's problems from mobile phone photographs, and enabling learning among rural woman by sending them voicemail messages.Telecommunications are studied as a medium for reinforcing or changing social structures in view of long-term wellbeing (Hage *et al*., 2013:6). Mothers can also use phones to communicate about things such as side effects

by explaining what is happening to them over the phone. A health professional can then assist and, if it is felt that a mother should come to the facility, she only has to come then, or she can be directed to where she can access the necessary service.

Community networks can be used for their ability to improve access to information, and particularly local information. These are believed to be able to bridge the gap between rural and urban areas. This can be achieved through writing in local newspapers, where people are provided a chance to write what they would like to be informed about.

Web portals are usually believed to improve access to information, such as health-related and market information. A computer lab is usually implemented in a school setting and has an educational purpose (Hage *et al*., 2013:6). This is where mothers can come to look for information and even learn how other people with the same problems cope.

According to Hage *et al*. (2013:2), rural communities have a greater need for e-health services because of the greater demand for health-care services and the scarcity of alternative services and health personnel. But the implementation of e-health services may be challenging due to the lack of infrastructure, security and many other things.

Contextual factors promoting e-health can be divided into three categories: socio-economic variables, which entail geographical isolation, demography and occupation status; individual resources and capabilities, which entail that when an individual has non-local ties it can assist with easy communication with relatives; and the need for e-health, because if an alternative supply of information or service is low, e-health can serve as substitute. Needs that motivate people to adopt e-health include: having greater anonymity, becoming self-reliant, helping others to understand e-health and gaining access to information and services.

The South African government, through the Department of Communication and in partnership with the South Africa Post Office, rolled out 700 Public Internet Terminals (PIT), with the fundamentalobjective being to create a communication infrastructure through which the public will have access to government information and services (Coleman., 2012:1).

Coleman (2012) defines PIT as a stationary personal computer that is designed for public use with unique requirements of applications, software, hardware and connectivity in a particular location. PIT works like a kiosk that allows citizens to pay taxes and access public information. However, the PITs found in rural communities in South Africa do not provide information on health.

The study concluded that PIT services can be extended to include a community basic health education portal to educate withcommunity members on basic health issues and to allow them access to health services and information. Lesotho can copy South Africa by placing PIT services in most rural areas, especially in the mountainous areas, which are considered to be hard to reach places due to lack of routes to get there when offering health services. This can really help HIV-positive mothers with many health issues affecting not only them, but also their families and the community at large.

ii) Use of e-health services

According to Lewis*et al*. (2012:332), developing countries are experiencing an unprecedented increase in the number of users of cell phone and internet technologies, as well as a decline in the price of devices and services. As a result it can be easier to explore e-health services, as this is also the case in Lesotho.

First, the main purpose for which health programmes use information and communication technology is to extend geographic access, with the main purpose being to overcome distance between physician and patient by replacing a traditional office visit. This includes what would traditionally be called telemedicine (for example videoconferencing with patients in the rural areas, helplines, instant messaging with a health practitioner for medical advice).

Second, the purpose is to facilitate communication between health workers/programmers and patients outside regular office visits.Subcategories can include encouraging patient compliance, enabling emergency care or general health education. It can also help with improving diagnosis and treatment, as well as clinical assistance, where the health-care worker involved does not have special knowledge of the problem of the client. Information and technology in health programmes can help toimprove data management so as to keep records of patients. It can help in mitigating fraud and abuse and making sure that any assistance meant for patients is not taken advantage of (Lewis *et al*., 2012:334).

3.4.1.4 Appraisal support

According to Glanz*et al*. (2008:190), appraisal support involves information that is useful for self-evaluation purposes and should include constructive feedback and affirmation.

According to international recommendations, women should choose health-care services on the basis of information adapted to their situation and given to them before or during counselling. Health professionals play a prominent role, since they should also provide

guidance and support. Counselling on infant feeding has been defined in international recommendations, emphasising relational more than technical content as a helping relationship. This is usually one-to-one communication specific to the needs of the individual. In providing counselling to a mother, a counsellor has to:

- Listen to her,
- Help her to understand the choices that she has to make,
- Help her to decide what to do, and
- Help her to develop confidence to carry out her decision (Glanz*et al*., 2008:190).

This helps the mother evaluate herself, especially when she takes her child for testing to see if she has not infected the baby. In situations where the mother has successfully breastfed the child and not infected her, she should be given praise for achieving such a difficult task. In a situation where a mother has infected a child, however, a counsellor should also encourage the mother and advise her on which steps to take, without judging or blaming her for infecting the baby.

There are many different types of support that can assist in meeting the needs of HIV-positive mothers, in various ways and on various levels. These types of support, as well as examples of them and how they can be applied and utilised in relation to helping mothers living with HIV in the rural areas of Lesotho,were discussed.

3.5 CONCLUSION

This chapter has discussed different ecological and systems theories that can be applied to see how the needs of the mothers can be identified and addressed. Social support was identified as one of the most important ways of meeting these needs, and different types of support services that could help meet the needs of the mothers were discussed. Many women have different needs, and not all needs can be met. However, the following chapter will focus on identifying the needs of HIV-positive mothers through the views of health service providers, as they work with these mothers on a daily basis and know the problems they have and how best they can be assisted. This was achieved through the collection of data using a semi-structured questionnaire during face-to-face interviews.

CHAPTER 4

SITUATIONAL ANALYSIS OF SUPPORT FOR HIV-POSITIVE MOTHERS LIVING IN THE RURAL AREAS OF LESOTHO

4.1 INTRODUCTION

The previous chapters provided an overview of the phenomenon of HIV. The psychosocial needs and sociocultural circumstances of HIV-positive mothers in the rural areas of Lesotho were discussed in Chapter 2, and a literature review of HIV-positive mothers' need for support services from an ecological perspective was offered in Chapter 3.

The literature review in the above-mentioned chapters served as a foundation for the empirical study, which investigates how health service providers consider the needs of HIV-positive mothers in the rural areas of Lesotho.

Data was collected by means of a semi-structured questionnaire, which consisted of open-ended and closed-ended questions. The researcher administered the questionnaire individually to each participant by means of filling in the questionnaire. In doing so, the researcher could ensure that the participants understood all the questions and terminology in the questionnaire. Furthermore, the participants' confidentiality was respected and they were debriefed after the interview. The data which was collected by means of the semi-structured questionnaire was then coded and represented by means of tables, graphs and figures. This allowed the researcher to identify consistent and relevant patterns within the data.

In this chapter the results of the empirical study are presented and discussed. Where relevant, the data is presented in tabular, figure or narrative form in order to best capture the findings of the study.The findings of the empirical study are verified against the literature review.

4.2 RESULTS

The results are presented in the same sequence at the questions were set in the questionnaire.

4.2.1 IDENTIFYING DETAILS

4.2.1.1 Professional profile

The participants were asked to provide details about the category of profession they fall under. These identifying details were used for a profile of the participants, a breakdown of which is presented in Figure 4.1.

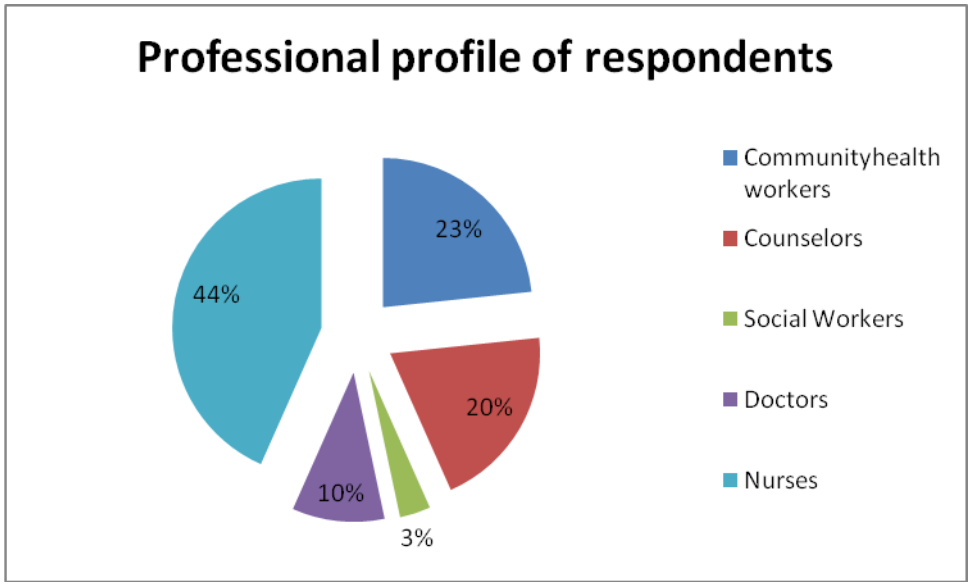

Figure 4.1 Professional profile of respondents (n = 30)

The figure above reveals that almost half of the respondents were nurses who were thirteen (44%), and the second highest number of respondents were community health workers who were seven (23.3%), followed by six (20%) counsellors, three (10%) doctors and one (3%)social worker.

These professional represent the professionals who met the criteria for inclusion in the study and who participated in the study.

4.2.1.2 Experience as health-care service providers

The work experience of the participants as health-care service providers was investigated. The table below presents the findings.

Table 4.1: Years of service as health-care service provider

Years of service as healthcare provider	Professional category											
	Doctor		Counsellor		Community health-care worker		Social worker		Nurse		Total	
	f	%	F	%	f	%	f	%	f	%	f	%
0-5	2	6.7	2	6.7	0	0	1	3.3	3	10	8	26.7
6-10	1	3.3	4	13.3	4	13.4	0	0	4	13.4	13	43.4
11-15	0	0	0	0	2	6.7	0	0	2	6.7	4	13.4
16-20	0	0	0	0	0	0	0	0	2	6.7	2	6.7
21-25	0	0	0	0	0	0	0	0	0	0	0	0
26-30	0	0	0	0	0	0	0	0	0	0	0	0
31-35	0	0	0	0	1	3.3	0	0	2	6.7	3	10
Total	**3**	**10**	**6**	**20**	**7**	**23.4**	**1**	**3.3**	**13**	**43.5**	**30**	**100**

n = 30

The table above shows that the doctors had experience of ten years and below, as one (3.3%) doctor's experience ranged between six and 10 years and two (6.7%) doctors' experience ranged between zero and five. For the counsellors, two (6.7%) participants' experience ranged between zero and five years, and four (13.3%) participants' experience ranged between six and 10 years. Participants who were community health-care workers hadmore experience, because theirexperience ranged between six and 10 years for four (13.3%) participants, followed by two (6.7%) whose experience ranged between 11 and 15 years and one (3.3%) whose experience ranged between 31 and 35 years. The hospital had one (3.3%) social worker in employment, whose experience ranged betweenzero and five years. Nurses hada wide range of years of experience, with three (10%) participants whose experience ranged betweenzero and five years, and four (13.3%) participants whose experience rangedfrom six 10 years, two (6.7%) whose experience rangedfrom 11 to 15 years, another two (6.7%) participants whose experience ranged between 16 and 20,and two (6.7%) whose experience ranged between 31 and 35 years.

4.2.1.3 Years of working with HIV-positive mothers

The health-care service providers who participated in the study were askedhow long they had been working with HIV-positive mothers. The table below offers the findings.

Table 4.2: Years of working with HIV-positive mothers

Years of working with HIV positive mothers	Professional category											
	Doctor		Counsellor		Community health-care worker		Social worker		Nurse		Total	
	f	%	f	%	F	%	f	%	f	%	f	%
0-2	1	3.3	2	6.7	0	0	1	3.3	2	6.7	6	20
3-4	2	6.7	0	0	0	0	0	0	0	0	2	6.7
5-6	0	0	1	3.3	3	10	0	0	4	13.3	8	26.6
7-8	0	0	3	10	3	10	0	0	3	10	9	30
9-10	0	0	0	0	1	3.3	0	0	1	3.3	2	6.7
11+	0	0	0	0	0	0	0	0	3	10	3	10
Total	**3**	**10**	**6**	**20**	**7**	**23.3**	**1**	**3.3**	**13**	**23.3**	**30**	**100**

n = 30

From the table above it is evident that one (3.3%) doctor's experience ranged was less than two years, while two (6.7%) doctors' experience ranged betweenthree and four years. As for the counsellors, two (6.7%) participants' experience was less than two years, while one(3.3%)had experience ranging betweenfive and six years of working with HIV-positive mothers. Three (10%) participants had experience that ranged betweenseven and eight years.

Three (10%) of the community worker participants had experience that ranged betweenfive and six years of working with HIV-positive mothers, while three (10%) had been working with HIV-positive mothers for betweenseven and eight years and one (3.3%) had an experience that ranged betweennine and 10 years. One (3.3%) social worker had been working with HIV-positive mothers for less than two years.

Nurses, who were a larger group of participants, had two (6.7%) participants whose experience of working with HIV-positive mothers was below two years, four (13.3%) whose experience rangedbetweenfive and six years, and three (10%) whose experience ranged betweenseven and eight years. One (3.3%) nurse participant had a range of experience of nine to ten years. There were three (10%) participants who had more than eleven years' experience of working with HIV-positive mothers.

4.3 WORKLOAD

The health-care service providers who participated in the study were asked to stipulate their work load, which is illustrated in Figure 4.2.

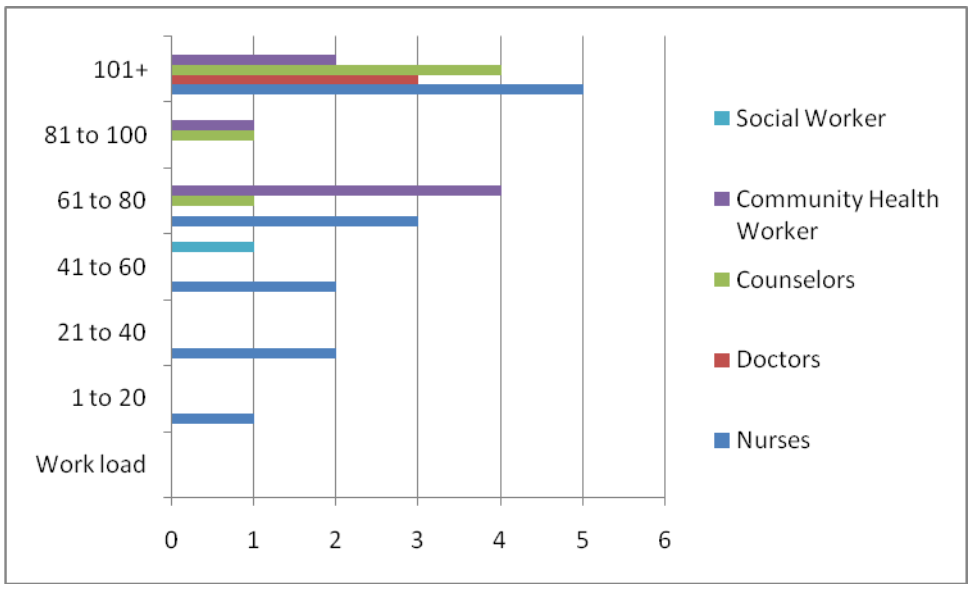

Figure 4.2 Workload of the health-care service providers per month (n = 30)

From the above figure it is evident that one (3.3%) nurse participant has a workload ranging from one to 12 clients per month, while two (6.7%) nurse participants have a work load ranging from 21 to 40 clients or patients per month. Two (6.7%) other nurse participants saw 41 to 60 patients per month, and three (10%) nurse participants saw 61 to 80 patients per month. Finally, one group of five nurse participants saw more than 101 patients per month. All three doctors saw more than 101 clients or patients per month.

For counsellors, the results were: one (3.3%) had a range of 61 to 80 patients per month, and one (3.3%) saw 81 to 100 patients per month. Four (13.3%) counsellors had a range of more than 101 patients or clients per month. One community health-care worker (3.3%) had a range of 61 to 80 patients or clients per month, and another one (3.3%) saw 81 to 100 patients or clients per month. The remaining four (13.3%) had more than 100 patients or clients per month.

One (3.3%) social worker who works in the hospital saw 41 to 60 patients or clients. The difference in workloads amongst professions such as nurses, doctors and counsellors is influenced by whether they are employed by the hospital or clinics,as the flow of intake and treatment of patients is different. For example, the Anti-Retroviral Therapy (ART) Corner, the department that provides ARV services in the hospital or clinics, has a large number of patients or clients compared to the children's ward.

4.4 MODES OF MOTHER-TO-CHILD TRANSMISSION OF HIV

As was discussed in Chapter 1, there are three main modes of HIV transmission. According to Van Dyk (2008:41), HIV can be transmitted from an infected mother via the placenta during pregnancy, through blood transfusion during birth and through breastfeeding.

The participants were asked to state which of the three modes of mother-to-child transmission was the highest among the mothers they are working with and to motivate the reasons for their answers. The figure below presents the findings, followed by discussions of the reasons the participants provided for choosing the highest mode, whichare provided in tables.

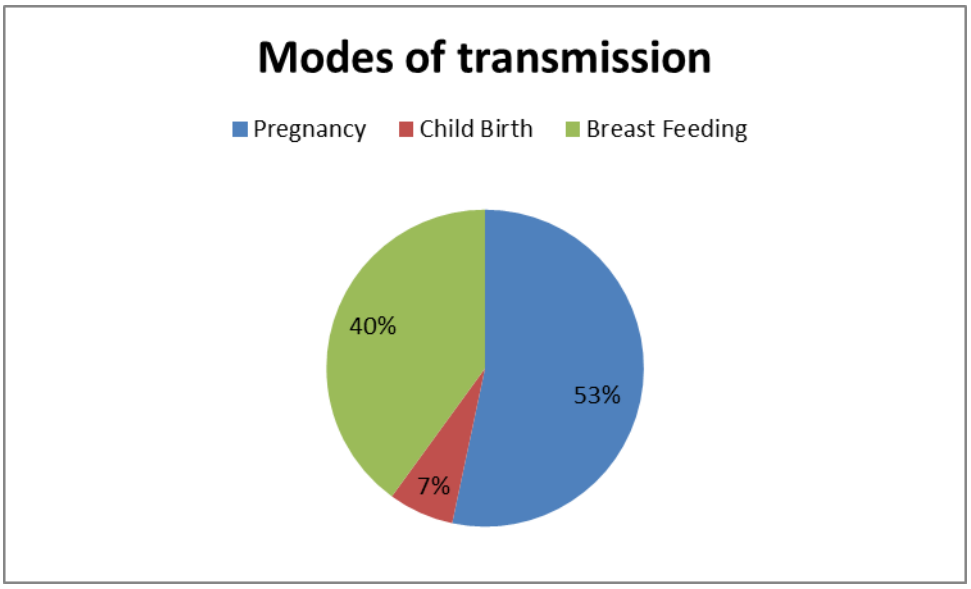

Figure 4.3 Modes of mother-to-child transmission of HIV(n = 30)

Form the above figure it is evident that pregnancy is the highest mode of mother-to-child transmission, with16 (53%) participants selecting it, followed by breastfeeding, selected by 12 (40%) participants, and lastly two (7%) participants said childbirth.

In the table below the participants' reasons for selecting pregnancy as the highest mode of mother-to-child transmission are presented.

Table 4.3Reasons for selection pregnancy as highest mode of mother-to-child transmission

Theme: Modes of mother-to-child transmission		
Sub-themes	**Categories**	**Narratives**
Pregnancy	Adherence	"Most mothers or pregnant women *do not adhere* to medication."[1]
	Attendance of antenatal clinic	"Some pregnant mothers *do not attend antenatal at all*." "Some *delay to attend antenatal clinic*."
	Disclosure and denial	"They *hide their statuses* and even change facilities where they were diagnosed with HIV."

n = 30

According to the table above,16 (53%) participants said pregnancy was the highest mode of mother-to-child transmission among the mothers from the rural areas of Lesotho to whom they render services. The reasons given by participants included that mothers"*do not adhere to medication*",and that "some mothers*delay to attend antenatal clinic*".These findings correspond with the views of Van Dyk (2007:32),that transmission occurs in utero as early as the first trimester. Thus it is important for an HIV-positive mother to attend a clinic as early as possible to prevent infecting her child during pregnancy.

According to Jones, Baker, Lydston, Camile, Brondolo, Tobin and Weiss (2006:79), adherence to human immune-deficiency virus treatment regimens is critical for optimal disease management. However, some mothers are in denial and do not disclose (they "*hide their statuses* and *even change facilities* where they were diagnosed with HIV").

In the table below the participants' reasons for selecting breastfeeding as the highest mode of mother-to-child transmission are presented.

[1] For the sake of emphasis, the author of this thesis has italicised various portions of quotations by participants.

Table 4.4 Reasons for selection of breast feeding as the second mode of mother to child transmission

Theme: Modes of mother-to-child transmission		
Sub-themes	**Categories**	**Narratives**
Breastfeeding	Mixed feeding	"*Lack of funds* to practise exclusive formula feeding and problems with mother's health." "*Prolonged time of breastfeeding* for up to two years while PMTCT guidelines recommend maximum one year."
	Adherence	"Mothers *do not adhere* to their medication while breastfeeding, they also do not take their children for check-ups at the clinic." "They do not *assist their children in adherence* of medication and do no not take them for *check-ups*."

n = 30

Breastfeeding was the second highest mode of transmission, with twelve (40%) participants saying it is the highest mode of transmission amongst the HIV-positive mothers from the rural areas they work with. The factors promoting HIV infection through breastfeeding ranged from mixed feeding("*lack of funds* to practise *exclusive formula feeding* and problems with mother's health") to adherence (parents "do not *assist their children in adherence* of medication and no not take them for *check-ups*"). According to Berben *et al*.(2012:636), non-adherence is defined as a deviation from a prescribed medication regimen, and can result in serious consequences, including poor clinical outcomes and increased health costs(For instance, when "mothers *do not adhere*to their medication while *breastfeeding*."). This increases chances that the mother might infect her child through breastfeeding.

In the table below, the participants' reasons for selecting childbirth as the highest mode of mother-to-child transmission are presented.

Table 4.5 Reasons for selection of childbirth as the lowest mode of mother-to-child transmission

Theme: Modes of mother-to-child transmission		
Sub-themes	**Categories**	**Narratives**
Childbirth	Home delivery	"*Lack of funds* to get to the facility or pay medical bills." "*Lack of transport*, especially for those who go into *labour during night time*".
	General health	"They have *untreated STIs and a low CD4 count*."

According to Van Dyk (2007:32), 60% of mother-to-child transmission occurs during labour and delivery. This form of transmission has the highest rate of infection, but the findings in thetable above shows that only two (7%) of the participants said mothers infected their children through this mode. The reasons they gave for this were general health problems, such

as"*untreated STIs* and a *low CD4 count*". The participants were also concerned about mothers who delivered at home and said this was due to many different factors, which includeda "*lack of transport*, especially for those who go on *labour during night time*".

4.5 NEEDS OF HIV-POSITIVE MOTHERS

According to Maslow's hierarchy of needs diagram in chapter 2.4, the developmental nature of motivation is that a lower need (for example physiological needs) must be adequately satisfied before the next higher need (safety need) can fully emerge in a person's development. In Figure 4.4, the extent to which the needs of HIV-positive mothers are met according to the views ofthe participantsis presented. Participants were also asked to motivate the answers they provided in selecting the needs of mothers.

The hierarchy on human needs was used to determine the extentto which mothers' needs are met.

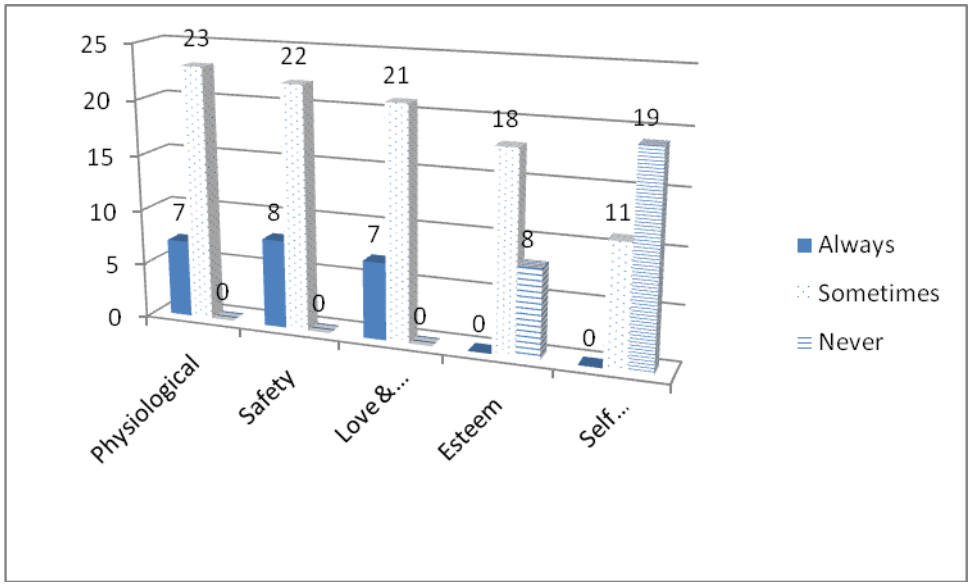

Figure 4.4 Extent to which mothers' needs are met(n = 30)

The participants' reasons for their answers will be discussed in the section below.

4.5.1 PHYSIOLOGICAL NEEDS

According to seven (23.3%) participants, the mothers' needs were always met, while 23 (76.7%) said they were sometimes met. This is evident fromthe narratives provided by the participants. They said mothers"*struggle to make ends meet*" due toa "*lack of resources*". Some, however, get assistance as the "*government provides food supplements*".These help mothers to meet some of their needs.

Struggling to meet physiological needs is affected by many different factors, such as "*high unemployment rates and extreme poverty*."According to Mbirimtengerenji (2007:616), unless and until poverty is reduced or alleviated, there will be little progress in either reducing transmission of the HIV virus or enhanced capacity to cope with its socio-economic consequences. There is a need to take a multi-sectoral approach with a number of capacity-building programmes to combat the scourge (Mbirimtengerenji, 2007:616).

4.5.2 SAFETY NEEDS

With regard to safety needs, eight (26.6%) participants said HIV-positive mothers' needs were always met, while 22 (73.4%) said they were sometimes met. None of the participants said the mothers' safety needs were never met.The reasons they gave for why these needs were not met are that"most mothers *live alone with their children*"or that"they are *widows*"and they stand the"*risk of being attacked*"and they were"*abused by their spouse*".

According to the National Abandoned Infants Assistance Resource Centre (2012:6), many women with HIV/AIDS have experienced violence and abuse. Childhood physical and sexual abuse are linked to high risk behaviour among women, including low rates of condom use.Although rates of intimate partner violence among HIV-infected women are similar to rates among HIV-negative women, it is suggested that the abuse HIV-infected women receive is more frequent and severe (National Abandoned Infants Assistance Resource Centre, 2012:6). This is where different organisations and communities intervene in order to assist the mothers to meet their safety needs. Respondents referred to"*police services that protect* mothers from *abuse and neglect*" and stated that the"*community plays a role in achieving safety needs*".

4.5.3 LOVE AND BELONGING NEEDS

Regarding love and belonging needs, seven (23.3%) participants said HIV-positive mothers' needs were always met, and 21 (70%) participants said they were sometimes met. Two (6.7%) participants did not provide an answer. The reason they gave is that these needs were met by "children usually because they*love unconditionally*".

The reason why needs were not metwasthat they do not get support.For example, "[*spouses or husbands stay at their work places*"and "they are not there to provide *emotional support to their wives"*.Mothers were also abused by means such as"*emotional abuse*due to being HIV positive." According to Roger *et al*. (2012:488), love and belonging needs are about

acceptance, and feeling safe and comfortable. If mothers are abused and not comfortable, their love and belonging needs are not met.There were no participants who said the mothers' love and belonging needs were never met. Thus it can be concluded that HIV-positive mothers living in the rural areas of Lesotho have their love and belonging needs met, even though this is not always the case.

4.5.4 ESTEEM NEEDS

According to Gordillo *et al*. (2009:524), people living with HIV who are satisfied with the amount of support available to them tend to experience less psychological distress, a higher quality of life and more self-esteem. FromFigure 4.4 it is evident that very few mothers have support related to this need, as 18 (60%) participants said the HIV-positive mothers' esteem needs were sometimes met and eight (26.7%) participants said they were never met, while four (13.3%) participants did not respond to this section of the question.

Disclosure seems to contribute in assisting to meet self-esteem needs, especially when the other lower human needs are met.Disclosure can assist mothers to be "*comfortable with their status*". The participants said mothers' needs were not met because "they *obey their husbands* even in situations where they do not agree with them, and this *brings about esteem* issues to the mother" and they "lack *physical and emotional support*". These findings correspond with Maslow's hierarchyof needs discussed in Chapter 2, according to which it is difficult for upper-level needs to be met if lower-level needs are not met, as physical and emotional support are from the lower levels of the hierarchy of needs.

4.5.5 SELF-ACTUALISATION

With regard to self-actualisation needs, 11 (36.7%) participants said they were sometimes met, while 19 (63.3%) participants said they were never met. One of the respondents said they are met because "the *government provides free education* and *bursaries*".

To support why they saidmothers' self-actualisation needswerenot met, the participants said it was"*rare to find a mother whose needs are all met*."According to Johnson and Yanca (2007:13), unmet needs reflect an imbalance between the response of the person and the environment to each other. Sometimes needs are not met because there are insufficient resources available.The participants said mothers "*do not have funds to cater for even their most basic needs*". According to Swartz *et al*. (2011:238), the self-actualisation need is a high level of need. It refers to the complete development of the self and becoming the best person

one can be. Conditions necessary to satisfy this need include not being distracted by lower-level needs. Looking at the findings on the extentto which the lower needs of HIV-positive mothers are met, it is very difficult for these mothers to reach self-actualisation.

4.6 PSYCHOLOGICAL IMPACT EXPERIENCED BY MOTHERS LIVING WITH HIV IN THE RURAL AREAS OF LESOTHO

Participants were asked to rank the psychological impacts experienced by mothers living with HIV in the rural areas of Lesotho. The rankings were calculated by the frequency with which the impact was selected by the participants in the rankings from 1 to 7 provided. The rankings are presented in Table 4.6 and are discussed individually.

Table 4.6The highest psychological impact experienced by mothers living with HIV.

Impact	Ranking	Frequency
Stress	**1**	**7**
Depression	**2**	**6**
Stigma	**3**	**5**
Low self-esteem	**3**	**5**
Discrimination	**5**	**4**
Denial	**6**	**2**
Bereavement	**7**	**1**

n = 30

4.6.1 STRESS

According to Table 4.6, the health-care workers identified stress as the highest psychological impact that HIV-positive mothers experience. According toseven (23.3%) participants, stress was the highest psychological impact experienced by mothers living with HIV. According toEdwards (1995:817), stress is the internal response to a life stressor and is characterised by troubled emotional or physiological states, or both. Prolonged stress, together with effective coping and personal vulnerability, can lead to physiological, emotional or social dysfunction. According to Van Dyk (2008:274), some people experience acute stress disorder after an HIV-positive diagnosis, or after the death of the significant other. An acute stress disorder is an anxiety disorder that develops in response to an extreme psychological or physical trauma.

4.6.2 DEPRESSION

Six participants (20%) said depression was the highest psychological impact experienced by mothers living with HIV. According to Gleitman, Reisberg and Gross (2007:614), depression centres on feelings of sadness, hopelessness and broad apathy about life. Furthermore, Ross

and Deverell (2004:54) define depression as anger turned inward towards oneself. They give an example that the people may feel anger towards themselves for not having prevented the illness.

HIV-positive mothers may feel angry towards themselves, especially because HIV is preventable. The depression from anger can get worse if the mother happens to infect her baby through one of the three transmission modes discussed in Chapter 2. According to Tsai, Bangsberg, Frongillo, Hunt, Muzoora, Martin and Weiser (2012:1), depression is common among people living with HIV/AIDS in the U.S., and the treatment of depression is important clinically because, if depression is not treated, it may result in worsened HIV-related outcomes. They further state that several cross-sectional studies have described an association between food security and depression amongst people living with HIV. This relates to Maslow's theory, discussed in Chapter 2, which states that, when the lowest form of needs are not met(physiological needs) it is difficult to meet higher needs.

4.6.3 STIGMA

Five participants (16.7%) said depression was the biggest psychological impact experienced by the mothers living with HIV. According to Musingafi, Rugonye and Zebron (2012:105), one of the reasons why stigma is high is because some people with HIV stigmatise themselves. Consciously or not, some people with HIV think that their identity and worth have been damaged or spoiled because they have HIV. This is sometimes called 'internalised stigma'.

Bond, Chase and Aggleton (2002:353) did a study on stigma, HIV/AIDS and the prevention of mother-to-child transmission in Zambia and found that, in the household and family setting, stigma was manifested in the forms of verbal abuse, rejection, eviction and imposed restrictions on the person. People with HIV/AIDS were subjected to blame, bitterness, anger, denial and the withdrawal of treatment and care, sometimes leading to blatant neglect

4.6.4 LOW SELF-ESTEEM

Five participants (16.7%) said low self-esteem was the highest psychological impact experienced by mothers living with HIV. In Chapter 2, where self-esteem is discussed,Germain and Gitterman (1996:17) say it represents the extent to which one feels capable, significant, effective, and worthy. It is the most important dimension of self-concept

and is a major influence in human thinking and behaviour. The findings reveal that, according to the participants, being HIV positive influences one's thinking and behaviour.

According to Gordillo*et al.*(2009:528), self-esteem influences interpersonal relationships because individuals' feelings of self-worth have a bearing on both their beliefs and social behaviour. Low self-esteem may damage interpersonal relationships because it promotes a self-protective interpersonal style.

4.6.5 DISCRIMINATION

Four participants (13.3%) said depression was the highest psychological impact experienced by mothers living with HIV.According to the National Abandoned Infants Assistance Resource Centre (2012:9), discrimination contributes to infected women's vulnerability by inhibiting them from seeking help and support for their condition. Disclosure is often avoided because women fear abandonment, rejection, discrimination, or upsetting family members.

Many HIV-infected individuals have voiced fears that disclosure would disrupt their current or future relationships, reputation or employment status (National Abandoned Infants Assistance Resource Centre, 2012:9).

4.6.6 DENIAL

Two participants (6.7%) said denialwas the highest psychological impact experienced by mothers living with HIV. According to a study conducted by Nam, Fielding, Avalos, Dickinson, Gaolathe andGeissler (2008)on the relationship of acceptance or denial of HIVstatus with antiretroviral adherence among adult HIV patients in urban Botswana, thekey concept described by participants associated with good or excellent adherence was acceptance of HIVstatus, whereas individuals experiencing adherence difficulties described aspects of denial. Participants who had accepted their status described having developed a new perception of 'self', where they identified with being HIVpositive and accepted their new image of 'self' with the virus. It is evidentthat denial is one ofthe hindering factors for one to reach the self-actualisation needs of Maslow discussed in Chapter 2.

4.6.7 BEREAVEMENT

One (3.3%) participant said bereavement is the highest psychological impact experienced by mothers living with HIV. According to Stroebe, Stroebe and Hansson (1999:34), the powerfullyand deeply felt cravings for nurturance or security during the bereavement period

can be transformed into needs for food, alcohol or sex. They say that loss of a loved one has been suggested as one of the key factors buffering the bereaved from the detrimental effects of loss (Stroebe*et al*., 1999:17). The findings show that some HIV-positive mothers living in the rural areas of Lesotho may not have the social support to help them deal with their loss due to HIV, or it is selected as the least impact because some mothers may experience the dying of a family member as relief, especially if that member was sick and becoming a burden on the family.

4.7 DISCLOSURE OF HIV STATUS

According to Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2008:312), literature reviews seem to favour disclosure by persons living with AIDS (PLWA), but this also has the potential of negative results, such as being stigmatised and discriminated against. The choice to disclose or to conceal one's status remains that of the infected person. However, both disclosure and concealment might have negative result such as social isolation, diminished access to health and social services, and a diminished sense of personal control(Greeff*et al*., 2008:312).

Participants were asked to identify people or groups to whom motherswould prefer to disclose their HIV status. Figure 4.5 shows the different people and groups to whom mothers preferred to disclose, and the findings are discussed per people and groups.

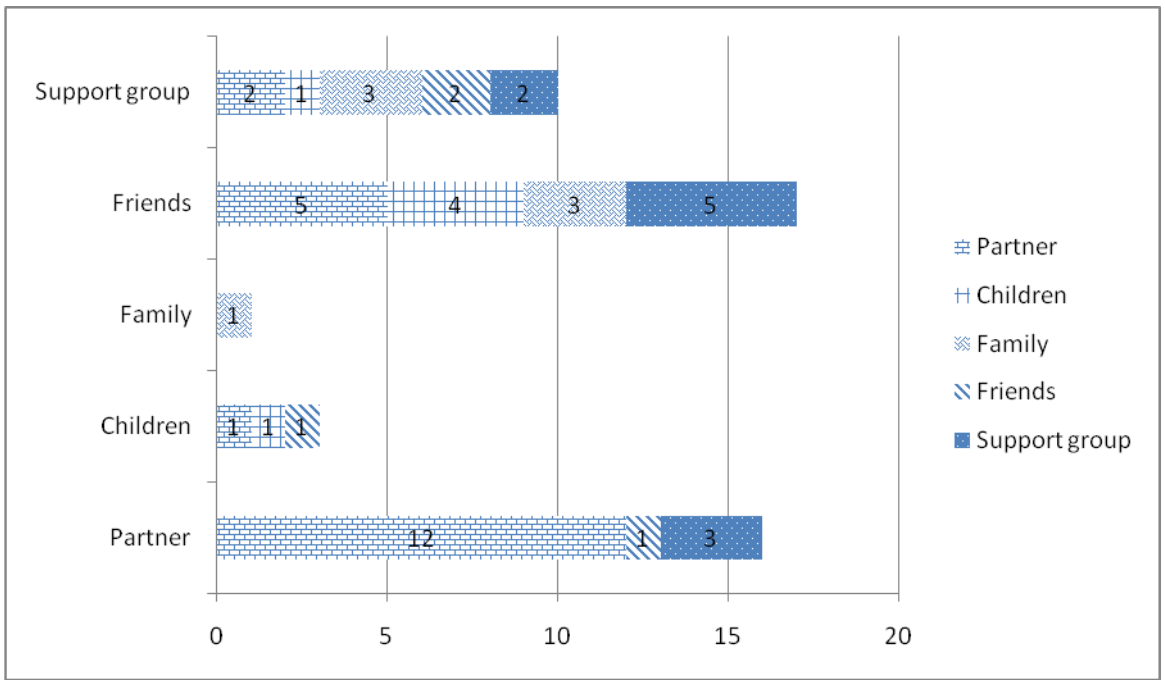

Figure 4.5 People to whom mothers disclose their HIV status (n = 30*)

*Participants were allowed to select as many people as they wanted

According to Kalichman*et al*. (2003:316), people living with HIV/AIDSneed to disclose their HIVstatusto receive social support. They further state that disclosure of HIVstatus varies depending on several factors, such as being comfortable with the status orthe types of relationshipsthe infected person has.

4.7.1 Disclosing to a partner or spouse

In the table below the participants' reasons for disclosing to a partner or spouse are presented.

Table 4.7 Reasons for disclosing to a partner or spouse

Theme 1:Choice of people to disclose to		
Sub-theme 1	**Categories**	**Narratives**
Partner/Spouse	Disclosure	"*Share*all health-related matters with *their spouse* and make decisions together especially when it comes to traditional practices as they are usually from the man's family." "Disclose to *their spouse*so they can also go to health centres and *test*."

n = 30

Twelve(40%) of the participants said HIV-positive mothers preferred to disclose to partners only, while four(13.3%) participant said mothers preferred to disclose to their partner and other people. According to Figure 4.5, disclosing to a partner or spouse rates the highest, which means that, according to the participants, mothers prefer to disclose to their spouses or partners more than to anyone else. They"disclose to *their spouse* so they can also go to health centres and *test*".Looking at what Greeff*et al*. (2008) says about disclosure being a disadvantage, some mothers maybe accused of bringing the HIV virus into the family when she discloses, and this may expose her to abuse by the partner or isolation from those to whom she discloses.

4.7.2 Disclosing to children

In the table below the participants' reasons for disclosing to children are presented

Table 4.8 Reasons for disclosing to children

Theme 1: Choice of people to disclose to		
Sub-theme 2	**Categories**	**Narratives**
Children	Love	"Mothers are usually *close to their children*." "Most of the time children are most *understanding* depending on age of course and have *no discrimination*toward their parent."
	Support	"So that children *can assist when sick*, also remind mother to take medication." "For *care and support*."
	Safety	"So they can take necessary precautions such as putting on gloves when helping out their parents."

n = 30

Children were selected by a few participants, with one (3.3%) participant indicatingthat some HIV-positive mothers disclose to their children only, and two(6.7%) participants said HIV-positive mothers disclose to their children and other people. They all gave different reasons for these. The reasons for the low rate of disclosure to a child can be seen in a study conducted by Waugh (2003) onfamilies with HIV-infected children attending a South London clinic, where parents viewed disclosure as inevitable, but tried to delay it for as long as possible.

The findings show that some mothers disclosedto their children in order to get emotional support and get their love. They believed that"children are most *understanding* depending on age of course and *have no discrimination*." According to the National Abandoned Infants Assistance Resource Centre (2012:10), a mother's disclosure of her HIV diagnosis to her children can be particularly important to address, as it may affect the children's adjustments and the mother-childrelationship.

The decision to disclose to children involves weighing the pros and cons of disclosing. It is often based on the child's perceived ability to handle the information without being psychologically harmed (National Abandoned Infants Assistance Resource Centre, 2012:10). According to the participants, mothers disclose to their children because they are hoping to get support from their children– "[s]o that children *can assist when sick*"and "[f]or *care and support*".Mothers may also disclose to their children to protect them from being infected while nursing her when sick, "so they can take *necessary precautions*".

4.7.3 Disclosing to family

In the table below the participants' reasons for disclosing to family are presented.

Table 4.9 Reasons for disclosing to family

Theme 1: Choice of people to disclose to		
Sub-theme 3	**Categories**	**Narratives**
Family	Support	"For *care and support*."
	Information and safety	"Because they are people *staying within the household*." "Inform the family so as to be *precautious in nursing* them when sick."

n = 30

According to one (3.3%) participant, HIV-positive mothers disclose to their families only, while six (20%) participants said they disclose to their family and other people. The participants said mothers disclose to families and also to other people"for *care and support*".According to a study conducted byKalichman*et al*. (2003:329),participants who had disclosed fully to immediate family members, specifically parents and siblings reported more social support from those relationships. Across relationships, however, there was a close association between disclosure of HIV status and perceived social support. The participants also indicated that mothers disclose so as to "*inform* the family so as *to take precautions* in nursing them when sick". It is not only about taking care of themselves, but also protecting those who love and care for them from being infected.

4.7.4 Disclosing to friends

In the table below the participants' reasons for disclosing to friends are presented.

Table 4.10 Reasons for disclosing to friends

Theme 1: Choice of people to disclose to		
Sub-theme 4	**Categories**	**Narratives**
Friends	Support	"For *support and assistance* in adherence." "Trust and love." "True fiends *listen and support* as well as encourage."

n = 30

Seventeen (56.7%) participants indicated that HIV-positive mothers living in the rural areas of Lesotho disclose to friends and other people. According to the participants there are no mothers who disclose to their friends only. The participants said the reasons for mothers to disclose to a combination of friends and other people are "[*t*]*rust and love*"and because"[t]rue fiends *listen and support* as well as encourage". The findings show that disclosing to friends can provide appraisal support, as Glanz*et al*. (2008) state in Chapter 3, that listening is a form of appraisal support.

4.7.5 Disclosing to support group

In the table below the participants' reasons for disclosing to support groups are presented.

Table 4.11 Reasons for disclosing to support groups

Theme 2: Choice of groups to disclose to		
Sub-theme 1	**Categories**	**Narratives**
Support group	Support	"Free to *talk and share* problems as well as challenges." "*Provide a sense of belonging* and *do not feel discriminated or isolated* amongst each other." "For *care and support*." "Free to talk and share problems as well as challenges."
	Information	"They *offer guidance and advice* to each other." "*Easier to ventilate* amongst people going through the same problems."

n = 30

Nine (30%) participants said HIV-positive mothers living in the rural areas prefer disclosing to a support group and other people, while only two (6.6%) participants indicated that mothers disclose to a support group only.The participants said mothers "*talk and share* problems".According to a study conducted by Gillett and Parr (2010:343),women gain confidence to disclose to relatives and partners after meeting other people living with HIV at their support group. Participants said support groups"*provide a sense of belonging*".The reason for disclosing in a support group is because it "*offers guidance and advice"*.This finding shows that mothers can get both emotional and informational support at themeso-level of the ecological perspective through support groups.

4.8 SOCIAL SUPPORT OFFERED TO HIV-POSITIVE MOTHERS

Social support refers to the resources others provide, giving the message that one is loved, cared for, esteemed and connected to other people in a network of communication and mutual obligation. In addition to these forms of socio-emotional support, people may provide tangible support (money, transportation and housing) or informal support, such as advice and personal feedback (Zimbardo, McDermatt, Janzz&Metaal, 1995:431). The following section presents the findingson four different kinds of social support (emotional support, instrumental support, informational support and appraisal support)offered to HIV-positive mothers living in the rural areas of Lesotho, as discussed in Chapter 3.

4.8.1 EMOTIONAL SUPPORT

According to Gordillo*et al*. (2009:524), emotional support provides assistance in attempts to alleviate or prevent distress through actions such as empathy and understanding. Greater amounts of emotional support have a more positive effect on people living with HIV.

The figure below showsthe emotional support available to HIV-positive mothers living in the rural areas of Lesotho at the micro-, meso-, exo- and macro-levels of the ecological perspective. It will be followed by tables with themes, sub-themes and categories and narratives that are discussed in relation to each other.

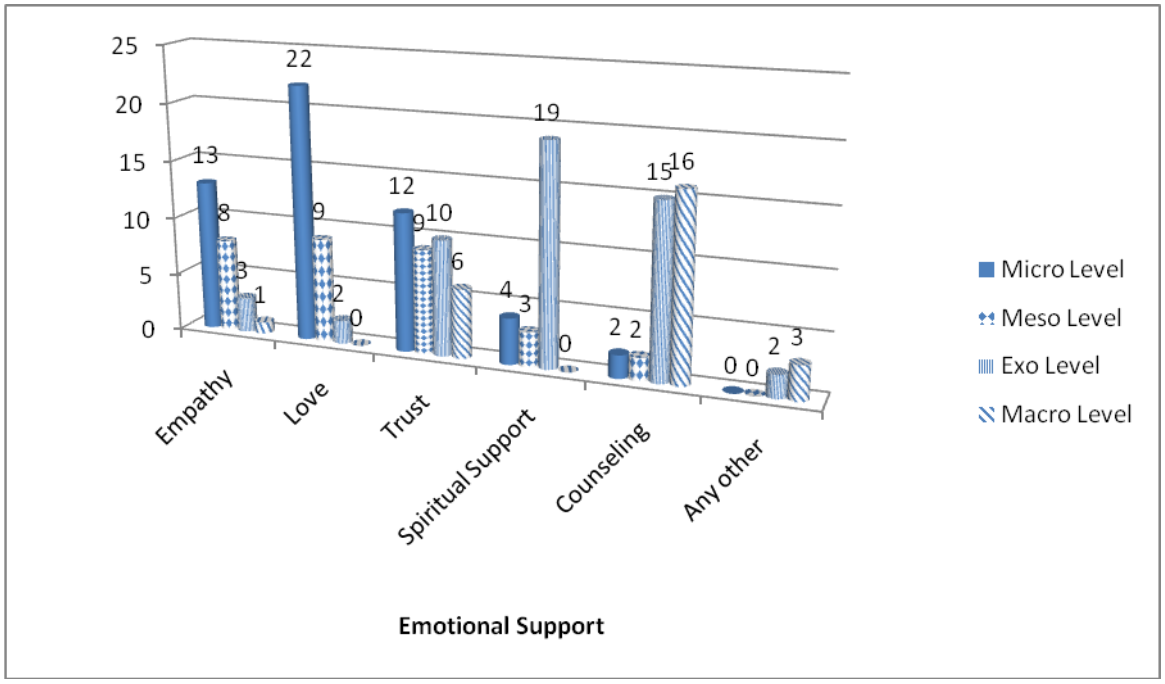

Figure 4.6 Types of emotional support mothers receiveat ecological level(n = 30*)
*Participants were allowed to choose more than one type of emotional support that they thought the mother was getting at the four different levels.

4.8.1.1 Emotional support at micro-level

In the table below, the nature of emotional support provided by people at the micro-level is presented.

Table 4.12 Emotional support at micro-level: Family

Theme 1: Emotional support		
Sub-theme 1	**Categories**	**Narratives**
Micro-level	Family	"Provides *love and empathy*" "Essential for *psychosocial support*" "Sense of *compassion and affection* which usually provides *sense of belonging and love*"

n = 30

According to13 (43.3%) participants, mothers get empathy from the family, while 22 (73.3%)participants selected love and 12 (40%) participants said mothers get trust from family. Three (10%) participants indicatedthey get spiritual support and two (6.7%) participants said they get counselling.

The participants said the emotional supportthat HIV-positive mothers living in the rural areas get from their family helps them in many different ways:"*love and empathy*"and "*psychosocial support*".According to Gordillo*et al*.(2009:524),emotional support provides coping assistance in attempts to alleviate or prevent distress through actions such as empathy and understanding. The participants said mothers also had their belonging and esteem needs met by family: "*compassion and affection*" and mothers feel a "*sense of belonging and love*".

4.8.1.2 Emotional support at meso-level

In the table below, the nature of emotional support provided by people at the meso-level is presented.

Table 4.13 Emotional support at meso-level: Friends and support groups

Theme 1: Emotional support		
Sub-theme 2	**Categories**	**Narratives**
Meso-level	Friends	"Feel *supported and cared* for." "*Neutralise feelings of loneliness and blame*"
	Support group	"Support groups are built of people who are either infected or affected so they have a better chance to *understand* the position of HIV-positive mothers." "Provides *trust*, which is essential for disclosure." "Promote *positive living*."

n = 30

At the meso-level,friends and support groups provide emotional supportaccording to eight (26.7%) participants, who said mothers get empathy from friends and support groups, while love and trust were selected by nine (30%) participants. Regarding spiritual support, onlythree (10%) participants said mothers get it at the meso-level, andtwo (6.7%) participants said they get counselling support at the meso-level.

The participants said the emotional support HIV-positive mothers living in the rural areas get from friendshelps them in many different ways, such as helping the mothers to"*neutralise feelings of loneliness and blame*". According to Gordillo*et al*. (2009:523), emotional support can counter the negative impact of HIV on psychological wellbeing.

Jones*et al*. (2006:84) say that emotional support and expressive interventions have been found to have salutary effects on women with chronic illness. The say support groups usually provide a supportive environment in which specific issues or concerns related to HIV/AIDS can be discussedopenly, emotions can be expressed and a sense of acceptance can be engendered among participants and feel that there is"good *adherence and support* in cases of discrimination".The study conducted by Jones *et al*.(2006) concluded that mothers who are in a support group may have an opportunity for social comparison, adherence behaviour and physical health by seeing others in similar situations and the benefits of adherence, and therefore follow in their footsteps.

4.8.1.3 Emotional support atexo-level

In the table below, the nature of emotional support provided by people at the exo-level is presented.

Table 4.14 Emotional support atexo-level: Hospitals, clinics and churches

Theme 1: Emotional support		
Sub-theme 3	**Categories**	**Narratives**
Exo-level	Hospitals	"Hospitals *provide counselling and provide information* on how to deal with HIV." "The counselling sessions and *psychological support* they get from hospitals helps them take the right choices in regard to adhering to their medication and preventing further infection either to their children, partners or other people."
	Clinics	"Clinics are normally the immediate place where HIV-positive mothers can easily access services and go for *on-going counselling*." "Helps in dealing with *denial*."
	Churches	"Providing scriptures and sermons that encourage *acceptability and non-judgmental* behaviour." "Churches offer *spiritual support* such that most HIV-positive mothers see that they are worthy to be loved."

n = 30

The exo-level is hospitals, clinics and churches. Three (10%) participants said mothers get empathy at this level, two (6.7%) participants said HIV-positive mothers get love from churches – they are"*worthy to be loved*" – while ten (33.3%) participants said mothers get trust from the hospitals, clinics and churches. Counselling also has a high number, with

fifteen(50%) participants saying that mother get counselling at this level, and two (6.7%) participants selected other forms of support.The participants said the emotional support HIV-positive mothers living in the rural areas get at the clinics and hospitals helps them in many different ways to meettheir needs – for instance, "[*t*]*he counselling sessions and psychological support*".

With regard to spiritual support,19 (63.3%) participants said mothers get spiritual support.In particular, "churches provides*piritual support*".According to Prado*et al*. (2003:221), there is evidence that the stress brought on by chronic illness leads to increased religious involvement. For HIV-positive mothers this may be due to "*acceptability and the non-judgmental sermons*" preached.Jones*et al*. (2006:84) say that acceptance, availability and nurturing have been found to be the most helpful aspects of emotional support. Mothers do get emotional support from churches.

4.8.1.4 Emotional support atmacro-level

In the table below, the nature of emotional support provided by people at the macro-level is presented.

Table 4.15 Emotional support at macro-level: Government and social service providers

Theme 1: Emotional support		
Sub-theme 4	**Categories**	**Narratives**
Macro-level	Government	"The *government is responsible for making policies that are favourable to HIV-positive* people and also medication."
	Social service provider	"For *social counselling and support*." "*Linking with other service* providers for relevant services."

n = 30

At the macro-level the government and social service providers provide support. One (3.3%) participant said mothers get emotional support at the macro-level, while six (20%) participants said mothers get trust. Sixteen (53.3%) participants said social service providers assist with "*social counselling and support*",andthree (10%) participants selected other forms of support.

The participants said the emotional support HIV-positive mothers living in the rural areas get from the government helps them in many different ways becauseit assists by"*making policies* that are *favourable to HIV-positive people*".Social welfare service providers assist mothers by "l*inking them with other services providers*

4.8.2 INSTRUMENTAL SUPPORT

According to Turney (2013:34) it is documented that instrumental support is linked to health and wellbeing among adults. He further states that health benefits of parents' instrumental support may extend to their children. This could be related to prevention of mother-to-child transmission, as a healthy mother can exclusively breastfeed her child without worrying about transmitting HIV to her child. However, a mother who is sick, for example with sores on her nipples, stands a high chance of transmitting the disease to her child, even if she practises exclusive breastfeeding.

The figure below shows instrumental support available for HIV-positive mothers living in the rural areas of Lesotho at the micro-, meso-, exo- and macro-levels of the ecological perspective. It will be followed by tables with theme, sub-theme and categories and narratives, which are discussed in conjunction with each other.

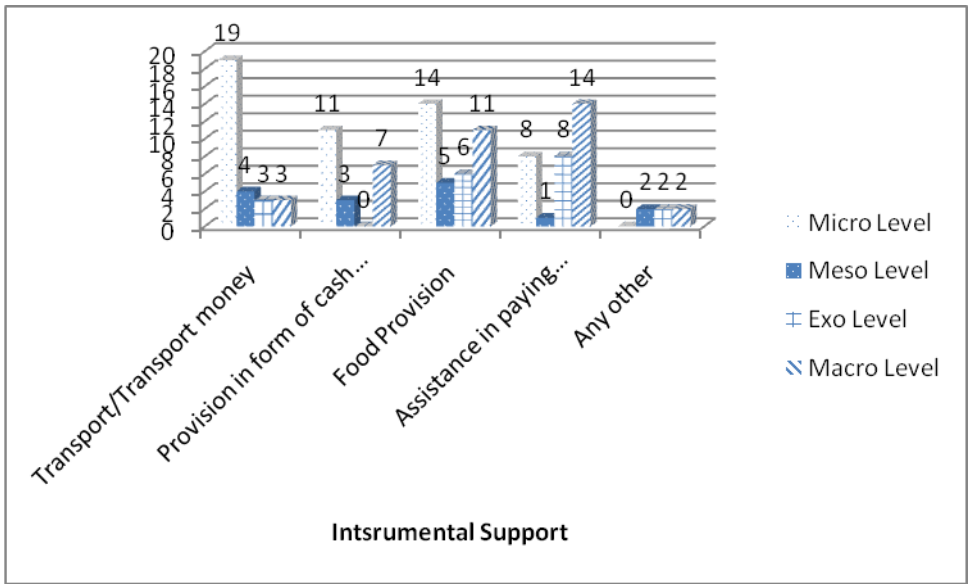

Figure 4.7 Types of instrumental support mothers receive at ecological level(n = 30*)
*Participants were allowed to choose more than one type of instrumental support they thought the mother was getting on all four different levels.

4.8.2.1 Instrumental support atmicro-level

In the table below, the nature of instrumental support provided by people at the micro-level is presented.

Table 4.16 Instrumental support at micro-level: Family

Theme 2: Instrumental support		
Sub-theme 1	**Categories**	**Narratives**
Micro-level	Family	"It helps meet the *physiological needs* as the family helps in provision of *finances and food*." "*Provides transport money* so the mothers can go for check-ups." "Helps in *paying medical bills and day-to-day expenses*."

n = 30

Nineteen (63.3%) participants said that HIV-positive mothers living in the rural areas of Lesotho get instrumental supportat the micro-level from families in the form of transport/transport money(the family "*provides transport*"), while 11 (36.6%)participants said mothers get instrumental support in the form of cash assistance(for example, "*money for other health services*"). Fourteen (46.6%) participants said the mothers get support in the form of food provision(thereby taking care of "*physiological needs* as the family helps in *provision of finances and food*"). According to Kalichman*et al*. (1996:590), instrumental support can directly alleviate the psychological distress associated with chronic illness and can indirectly buffer the effects of stressful life. For assistance, eight (26.6%) participants said mothers get support from their families in the form of medical expenses being paid.

4.8.2.2 Instrumental support atmeso-level

In the table below, the nature of instrumental support provided by people at the meso-level is presented.

Table 4.17 Instrumental support at meso-level: Friends and support groups

Theme 2: Instrumental support		
Sub-theme2	**Categories**	**Narratives**
Meso-level	Friends	"Helps in achieving physiological needs by *sharing food*." "Help each other by lending each other money so as *topay for transport* to go to the facility or *cover medical expenses*." "*donations of old clothes*"
	Support groups	"Provide *cash aid* to needy families of HIV-positive mothers so they can have access to basic needs, such as food." "Helps in *food provision* especially for mothers who are ill and cannot take care of themselves."

n = 30

At the meso-level,friends and support groups provide support. Four (13.3%) participants said mothers get instrumental support from friends and support groups in the form of transport or transport money. Three (10%) participants said friends help mothers with cash"*to pay for transport*", while five (16.7%) participants said they help with food provision by"*sharing food*".

According to Turney (2013:34), for parents with limited economic resources, having a friend available to provide financial support or in-kind support maybe necessary for economic survival. One (3.3%) participant said mothers get assistance in paying medical expenses from friendswho "*cover medical expenses*" andtwo (6.7%) participants said mothers get forms of instrumental support such as "*donations of old clothes*".

4.8.2.3 Instrumental support atexo-level

In the table below, the nature of instrumental support provided by people at the exo-level is presented.

Table 4.18 Instrumental support atexo-level: Hospitals, clinics and churches

Theme 2: Instrumental support		
Sub-theme3	**Categories**	**Narratives**
Exo-level	Hospitals	"The hospital social worker may recommend the mother should be *assisted in either transport* or find ways to assist mothers such as *referring* her to social development ministry to get help from the government." "The hospital management may decide to let the mother or her family member go *without paying the medical fees* they accumulated during their stay in hospital due to their poverty."
	Clinics	"Works as government or private organization's *agency to distribute food* to those considered needy." "Distributors of *food supplements* and *water cleaning detergents*" to mothers and also to those that live in areas where there is no transportation."
	Churches	"Some churches make *donations* to church members so that can be able *to pay for their medical expenses*." "*Donation of food and at times shelter* at the church."

n = 30

At the exo-level, hospitals, clinics and churches provide instrumental support. Three (10%) participants said mothers get instrumental support of transport or transport money, but provision of cash assistance was not selected by anyone. Six (20%) participants said mothers get instrumental support of food provision, andeight (26.7%) participants said mothers get instrumental support of assistance in paying for medical bills. In particular, "churches make *donations to pay for their medical expenses*". Two (6.7%) participants selected other options, which they explained as donations of clothes and blankets.

The participants said theinstrumental support HIV-positive mothers living in the rural areas get from hospitals and clinics helps them in many different ways to meet their needs. Instrumental support at this level ranged from"*distributing donated food"*by clinic and hospitals to"*paying for their medical expenses*
"*assisted in either transport*"by churches, as well hospitals and clinics.

4.8.2.4 Instrumental support at macro-level

In the table below, the nature of instrumental support provided by people at the macro-level is presented.

Table 4.19 Instrumental support at macro-level: Government and social service providers

Theme 2: Instrumental support		
Sub-theme4	**Categories**	**Narratives**
Macro-level	Government	"Government *assists in paying medical bills* for the poor." "*Provides food donations* with the help of international organisations such as WHO, UNAIDS and others." "*Subsidises medical services*." "*Blankets and formula milk* for needy mothers who are HIV positive and have children who are under two years old."
	Social service provider	"There is some form of *social service provision* for poor mothers, such as *nappies or formula milk* for their children." "*Paying for medical bills*."

n = 30

At the macro-level, the government and social service providers provide instrumental support. Three(10%) participants said mothers get support in the form of transport/transport money, seven (23.3%) participants selected cash assistance and 11 (36.7%) participants selected food provision – the"*provision of food donations*and paying [the]*medical bill*". According to Turney (2013:33), health benefits of parents' instrumental support may extend to children.The government and social service providers are the highest assisters in paying for medical expenses, with14 (46.7%) participants stating that they provide"*nappies or formula milk* for their children" and also assist with "*paying for medical bills*".Two(6.7%) participants selected other forms of instrumental support, which they explained to be "*blankets and formula milk*".

4.8.3 INFORMATIONAL SUPPORT

Informational support is defined by House (1981) as information provided by another during a time of stress. Informational support assists the mothers to solve problems (Langford, Bowsher, Maloney & Lillis,1997:97). The figure below showsthe informational support available to HIV-positive mothers living in the rural areas of Lesotho at the micro-, meso-, exo- and macro-levels. It will be followed by tables with theme, sub-theme and categories and narratives, which are discussed in conjunction with each other.

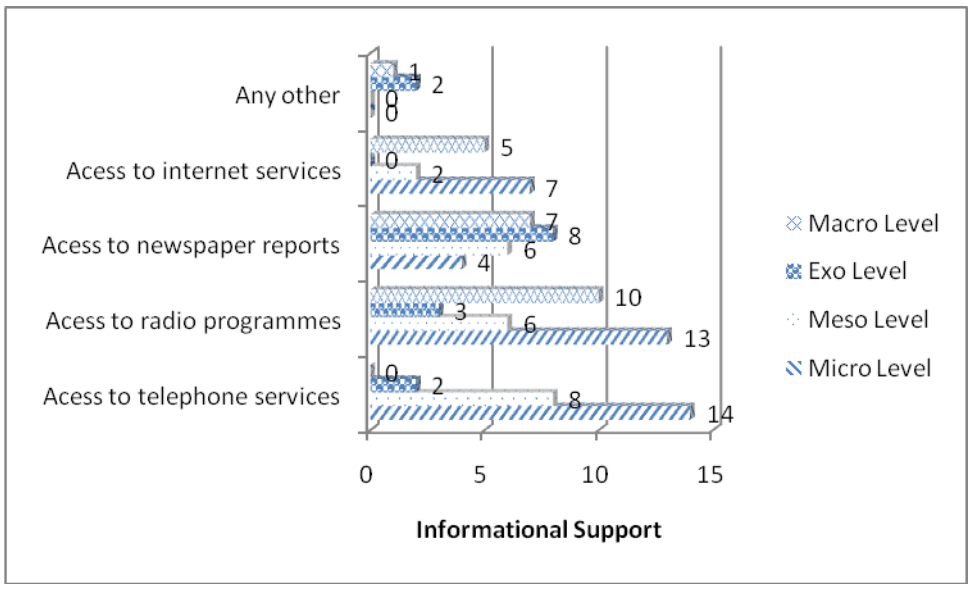

Figure 4.8 Types of informational support mothers receive at ecological levels(n = 30*)
*Participants were allowed to choose more than one type of instrumental support they thought the mother was getting at the four different levels.

4.8.3.1 Informational support atmicro-level

In the table below, the nature of informational support provided by people at the micro-level is presented.

Table 4.20 Informational support at micro-level: Family

Theme 3: Informationalsupport		
Sub-theme1	**Categories**	**Narratives**
Micro-level	Family	"It gives them *current information* on HIV nutrition and many other different factors that affect them." "Those that can access the internet especially on their phones can *research for information* about HIV virus and risk assessment behaviours." "They can use telephones to *communicate* with health service provider about side effects of their medication."

n = 30

At the micro-level, the family seems to be the provider of most informational support, as 14 (46.7%)participants said mothers get access to telephone services through the family, and 13 (43.3%) participants said they get access to radio programmes through the family. The bar really drops when it comes to newspaper access, as only four (13.3%) participants said they get newspapers from family and seven participants said they are able to access the internet through family provision.

The participants said the informational support that HIV-positive mothers living in the rural areas get from their families helps them because"*it gives them current*

information".According to Kalichman*et al*. (1996:590), informational support increases one's knowledge base. There is evidence that informational support does not only provide information, but also can assist mothers to deal with the impacts of HIV through communicating with others – it"*help[s] to communicate* with other family members when *feeling down and depressed*".

4.8.3.2 Informational support at meso-level

In the table below, the nature of informational support provided by people at the meso-level is presented.

Table 4.21 Informational support at meso-level: Friends and support groups

Theme 3: Informationalsupport		
Sub-theme2	**Categories**	**Narratives**
Meso-level	Friends	"Phones have internet and friends can *share useful information* with the mothers related to HIV." "At times friends can borrow each other's phones so the mother can be able to *communicate with health service provider*."
	Support group	"Help HIV-positive mothers *discuss information they get from radio programmes and newspapers*."

n = 30

At the meso-level, friends and support groups provide informational support. Eight(26.7%) participants said mothers get telephone support, and six (20%) participants said they get radio programmesupport as well as newspaper reports at the meso-level, while only two (6.7%) participants said they get internet support at the meso-level.

The participants said the informational support that HIV-positive mothers living in the rural areas get from their friends helps them in many different ways,such as that "[a]t times friends can *borrow each other's phones* so the mother can be able to *communicate with health service provider*". Support groups help in the discussion of important information regarding the mothers' health. There, people"*discuss information they get from radio programmes and newspapers*".According to Brashers, Neidig and Goldsmith (2009:312), support or peer groups have been shown to be particularly important sources of information for people with HIV, perhaps because of the high levels of uncertainty associated with the illness.

4.8.3.3 Informational support atexo-level

In the table below, the nature of informational support provided by people at the exo-level is presented.

Table 4.22 Informational support at exo-level: Hospitals, clinics and churches

Theme 3: Informationalsupport		
Sub-theme3	**Categories**	**Narratives**
Exo-level	Hospitals	"There are *readily available pamphlets* for mothers to access at health centres. Health professionals also give health talks to HIV-positive mothers where they are able to talk to ask questions on one-to-one basis." "Hospitals do *awareness relating to HIV* at villages."
	Clinics	"Rural clinics use *community gatherings (pitso) to disseminate information* about HIV." "It can also *help improve support from family* as family members can also *learn about HIV* from *newspapers or pamphlets* provided by the clinic."
	Churches	"At the church people *feel secure* and they are provided with *information and motivation* to build their *self-esteem*."

n = 30

At the exo-level, hospitals, clinics and churches offer informational support. According to two (6.7%) participants, mothers have access to telephone services at this level, while one(3.3%) participant said they have access to radio from this level. Only three (10%) participants said mothers get access to telephone services. Mothers seem to have better access to newspaper reports, as eight (26.7%) participants said they have access to them. None listed internet services, with other forms of information support selected by two (6.7%) participants. These were identified as informative gatherings (pitsos) done by hospitals, clinics or sermons done in churches.

According to Hage*et al*. (2013:2), community networks can be used for their ability to improve access to information, and particularly local information. Participants mentioned the importance of"*community gatherings (pitso) to disseminate information*".The participants said the informational support HIV-positive mothers living in the rural areas get from hospitals and clinics helps them in many different ways to get information by means of "*readily available pamphlets*". The churches also play a role by providing"*information and motivation to build their self-esteem*".

4.8.3.4 Informational support at macro-level

In the table below, the nature of informational support provided by people at the macro-level is presented.

Table 4.23 Informational support at macro-level: Government and social service providers

Theme 3: Informationalsupport		
Sub-theme4	**Categories**	**Narratives**
Macro-level	Government	"Has made it easy for its people to *access radio stations* everywhere in the country so almost every person is able to listen to the radio and get information." "*Government connects internet to health facilities* so that it can be *easy to access information on HIV*."
	Social service providers	(hard to reach areas within the mountains)

n = 30

At the macro-level,government and social service providers offer information. Ten(33.3%) participants said government and social services help mothers have accesses to radio programmes, while seven (23.3%) participants said mothers are assisted with access to newspaper reports, they*access radio station and get information*." Sixteen (16.7%) participants said the HIV-positive mothers are assisted with internet services, while one (3.3%) participant said they are assisted with other, which she said was gatherings (pitsos) they hold in communities.

The participants said the informational support HIV-positive mothers living in the rural areas get from the social service providers help in"linking*purposes*"and "*information dissemination*".Mothers can ask for help from health-care workers about the situationsin which they lack information; this can be considered to be of great help, as making a decision is better when one is properly informed.

4.8.4 APPRAISAL SUPPORT

Appraisal support involves the communication of information that is relevant for self-evaluation, rather than problemsolving. It can be seen as affirmation support, which encompasses expressions that affirm the appropriateness of acts or statements made by another (Langford, Bowsher, Maloney & Lillis, 97:1997).

The figure below shows the appraisal support available for HIV-positive mothers living in the rural areas of Lesotho at the micro-, meso-, exo- and macro-levels. This is followed by tables containing the theme, sub-theme, categories and narratives, which are discussed in conjunction with each other.

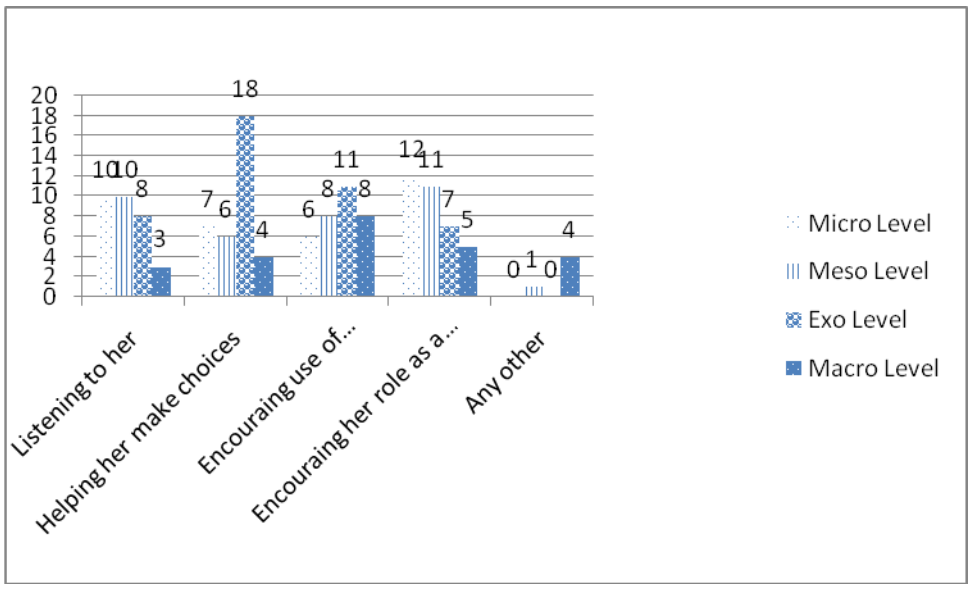

Figure 4.9 Types of appraisal support mothers receive at ecological level(n = 30*)

*Participants were allowed to choose more than one type of instrumental support they thought the mother was getting on all the four different levels.

4.8.4.1 Appraisal support at micro-level

In the table below, the nature of appraisal support provided by people at the micro-level is presented.

Table 4.24 Appraisal support at micro-level: Family

Theme 4: Appraisal support		
Sub-theme1	**Categories**	**Narratives**
Micro	Family	"Families are there to *support and encourage* these mothers." "The family has to listen to the mother and also try to help her to *make decisions and support* in implementing the decision, make her feel like a mother."

n = 30

At the micro-level, the family provides appraisal support. Ten(33.3%)participants said HIV-positive mothers living in the rural areas of Lesotho get listening to her as a form of appraisal support,six(20%) participants said the family encourages the mother to use medical care services, and encouraging her in her role of being a mother was selected by the most participants, at 12 (40%). According to Langford*et al*. (1997:97), appraisal support involves communication that is relevant to self-evaluation rather than to problem solving.

The participants said the appraisal support that HIV-positive mothers living in the rural areas get from their families assists them in different ways. They said families provide"*support and encouragement*",andseven (23.3%) participants said the family helps HIV-positive mothers in

making choices,"*supportingmother in her decision*." Support for decisions the mother takes, especially considering formula feeding, is very important, as it includes the finances of the family, as formula milk can be difficult to maintain if the mother does not get financial support.

4.8.4.2 Appraisal support atmeso-level

In the table below, the nature of appraisal support provided by people at the meso-level is presented.

Table 4.25 Appraisal support atmeso-level: Friends and support groups

Theme 4: Appraisal support		
Sub-theme2	**Categories**	**Narratives**
Meso	Friends	"Time is spend with friends so they *listen and motivate them*." "Some mothers *trust* their friends, they discuss their health status with them more than with family members, so *friends usually advise or encourage them to seek medical* help as early as they can encourage them."
	Support groups	"At support group they *listen to each other*, support one another and encourage each other to use medical services to better their lives, she feels understood and finds a *sense of belonging here*." "They motivate members to improve their state of mind, *encourage them to use medication* and offer them attention by listening to what they want to express."

n = 30

At themeso-level, friends and support groups provide appraisal support.Ten (33.3%) participants said HIV-positive mothers get the support of being listened to by friends and support group members who "*listen and motivate them*", while six (20%) participants said mothers get support from friends and support groups in making choices – they"*listening to each other, support one another and encourage eachother*".Eight (26.7%) participants said they get support and encouragement to use medical care services. According to Kalichman*et al*. (1996:596), support groups have become the most common social support services available to people living with HIV infection, and the aim of these groups is to improve individual quality of life. The participants said friends and support groups "*encourage them to use medication*".Eleven (36.7%) participants said mothers got appraisal support in encouragement in their role as a mother,while one (3.3%) participant selectedother kinds of support.

4.8.4.3 Appraisal support atexo-level

In the table below, the nature of appraisal support provided by people at the exo-level is presented.

Table 4.26 Appraisal support atexo-level: Hospitals, clinics and churches

Theme 4: Appraisal support		
Sub-theme3	**Categories**	**Narratives**
Exo	Hospitals	"The hospitals *assist them in making informed decision* without being judgmental or being discriminative." "There are qualified professionals who are there to *listen to their individual needs* and help them in making choices about their medication, social life, sex, parenting and more."
	Clinics	"*Support groups are formulated* at clinics and give *appraisal support* to the mothers." "Facilities offer HIV services in many ways. They do *adherence counselling and encourage*mothers to continuing being under medical care."
	Churches	"Some churches support mothers by *encouraging* them to use their medication." "Through spiritual counselling, they *encourage mothers in their roles of being a mother*."

n = 30

Hospitals, clinics and churches provide supportat the exo-level. Eight(26.7%) participants saidHIV-positive mothers getappraisal support of being listened to, while eighteen (60%) participants saidHIV-positive mothers get support in making choices, which seems to be the highest selected form of appraisal support at all the levels. Eleven (36.7%) participants said mothers get encouragement in using medical care services. Encouraging her in her role as a mother was selected by seven (23.3%) participants.

The participants said the appraisal support that HIV-positive mothers living in the rural areas get from the hospitals and clinics helps them meet their needsfor appraisal support by assisting "*in making informed decision*".According to Brasher*et al*. (2009:306), appraisal support motivates behavioural and psychological actions directed toward managing uncertainty. For example, people seek or avoid information to manipulate uncertainty to a comfortable level. Brasher*et al*. (2009) found that individuals with HIV or AIDS are likely to engage in active information seeking (e.g. by directly enquiring about their health and treatments from health-care providers, others with HIV and media sources).

"*Support groups* give *appraisal support* to the mothers" and churches provide appraisal support through encouragement – they"*encourage mothers in their roles of being a mother*."

4.8.4.4 Appraisal support at macro-level

In the table below, the nature of appraisal support provided by people at the macro-level is presented.

Table 4.27 Appraisal support at macro-level: Government and social service providers

Theme 4: Appraisal support		
Sub-theme 4	**Categories**	**Narratives**
Macro	Government	"Make *policies* and use various departments to implement them, for example police services have special units that deal with *family-related issues to ensure mothers are not abused* when carrying their motherly roles." "Mothers *are encouraged to use available services* to help themselves by all means."
	Social service providers	"They do on-going counselling and *encourage mothers to utilise health services and adhere to medication*." "*On-going counselling provided* with regard to infant feeding, treatment and management of the disease."

n = 30

At the macro-level, government and social service providers offer appraisal support. Three (10%) participants said mothers get appraisal support by being listened to and four (13.3%) participants said HIV-positive mothers get support in making choices. Encouragement on use of medical care services was selected by eight (26.7%) participants who"*utilise health services and adhere to medication*",and five(16.7%) participants said mothers get encouragement in their role as mothers:"*encourage mothers to utilise health services and adhere to medication.*" According to Glanz*et al*. (2008:190), appraisal support can be offered by helping a mother to develop confidence to carry out her decisions. This can be provided through ongoing counselling:"*Ongoing counselling provided*."The lastfour (13.3%) participants selected other kinds of support, which they explained to be donation of clothes and blankets.

4.9 EXTENT TO WHICH CULTURE, SOCIALISATION AND WORK AFFECT THE NEEDS OF MOTHERS LIVING WITH HIV/AIDS IN LESOTHO

4.9.1 CULTURAL EFFECTS

Participants were asked how culture affects the needs of mothers living with HIV/AIDS in Lesotho.

The participants said culture did seem to play a role within the nation of Basotho, as it seems to be there from the conception of the child to raising it. When analysing how it affects mothers living with HIV/AIDS in Lesotho, the findings show thatthe participants were concerned about the beliefs and practices of the culture and how they conflict with the medication and meeting the needs of these mothers.One claimed that they *interfere with the*

guidelines because some cultures say children should *breastfeed for two years*, while the guidelines says exposed babies should breastfeed for a *maximum of one year*, with the *first six months of exclusive breastfeeding*."

According to Giddens(2002:21), culture is about the aspects of human societies that are learned rather than inherited. They form the common context in which individuals in a society live their lives.In regard to how culture affects the needs of HIV-positive mothers, the health-care workers expressed the following concerns:"*respect your husband choices even when they put you in danger; such as not using condoms or taking medication*."

4.9.2 SOCIALISATION EFFECTS

Participants were asked how socialisation affects the needs of mothers living with HIV/AIDS in Lesotho.

According to Latkin and Knowlton (2005:104), behavioural settings can influence individuals' behaviour, as they provide a venue in which individuals may be linked by various forms of social interaction and meaning-imbued physical space and attendant behaviour norms. The participants said socialisation had a lot of influence on HIV prevention and treatment:"Basotho are *socialised in such a way that they are told to keep family secrets*."Or: "Most *do not disclose* HIV status, which results in them being *depressed*."

Mothers become "*anti-social* due to the *discrimination*".Furthermore, "some churches do not *recommend preventative measures* such as use of condoms and this causes re-infection."

These practices can put a lot of pressure on mothers, especially those who get most of their support from churches, as they would not want to disappoint those who are supporting them. However, this put their lives in danger as they could be re-infected with HIV or get sexually transmitted infections.

4.9.3 WORK EFFECTS

Participants were asked how work affects the needs of mothers living with HIV/AIDS in Lesotho.

According to Barger (2007:53), poverty affects women disproportionately. Women are more likely to be poorer than men, and poverty has a greater effect on women's health status the world over. Moreover, because many women are joint or sole providers for their families, a woman's own poor health can jeopardise the economic well-being of her entire family, for if

she gets to a point where she is bedridden, her children may have no one to rely on.The country has a problem of poverty and unemployment"*high unemployment rate*".Even though HIV-positive mothers in the rural areas are faced with the hardships of poverty, some manage to get work in the factories in town, but this becomes a problem if it is in non-friendly-HIV workplaces. One participant claimed that attendingofservices are sometimes *delayed or omitted* if the employer is strict and *not fully informed* about HIV and its management." They also have problems of "*discrimination* and *stigma* at work".

4.10 POLICY WITH REGARD TO HIV/AIDS

4.10.1 ASSESSMENT OF POLICIES AND SERVICES OFFERED BY THE GOVERNMENT OF LESOTHO TO SUPPORT PEOPLE LIVING WITH HIV/AIDS

4.10.1.1 Formulation of policies

The participants were asked to provide their assessment of policies and services offered by the government of Lesotho to support people living with HIV. The participants complained about the formulation of policies, arguing that"[t]he government sometimes *does not involve people living with HIV/AIDS* when *making policies* in regard to HIV/AIDS." According to Patterson (2006:138),AIDS can be framed in different ways as a health issue, human rights issue, a reflection of gender inequalities, a short-term humanitarian emergency, or a long-term development problem. These perspectives are not mutually exclusive, but the way the problem is framed leads to certain policy or programme outcomes. For example, those who those who view AIDS solely as a health issue will search for technical solutions, such as providing condoms for prevention and looking for funding and programme decisions in the ministry of Health(Patterson, 2006:138).

4.10.1.2 Implementation and evaluation of policies

The participants were asked to provide their assessment of policies and services offered by the government of Lesotho to support people living with HIV.The participants voiced their concerns aboutthe implementation and evaluation of policies, saying things such as:"The policies are good but there are *problems with implementation*." Or: "Guidelines on follow-ups of patients are *not well followed*."

According to Kusek and Rist (2004:12), evaluation is the systematic and objective assessment of an on-going or completed project, programme or policy, including its design,

implementation and results. An evaluation should provide information that is credible and useful, enabling the incorporation of lessons learned into the decision-making process of both recipients and donors.

There should be regular evaluation of implantation. This can be done through regular monitoring of how implementation is rolling out:"new policies are developed and government takes a long time to *evaluate these policies if they are effective or not*."Health services are usually very expensive, but the government of Lesotho has tried to make things easy by offering free services to those who are HIV positive:"*free access to treatment*".Even though the government may offer free services, it also has to make sure that the policies and guidelines that it draws up, such as that for free services, are being delivered with high standards and accordingly.

4.10.1.3 Support offered by government

The participants were asked to provide their assessment of policies and services offered by the government of Lesotho to support people living with HIV.The participants said they had a problem because patientswere seeking work in neighbouring countries and they usuallywere working there illegally and not able to go hospitals to get ARVs. Also, the government policy says a patient can only be provided with two months provision and they usually take six months, thus there is a"*lack of support* for those who *work outside the country*." Supporting illegal workers in another country would really be difficult for the government of Lesotho.

According tothe Social Work Encyclopaedia (1995:819),coping measures are special behaviours, often novel, that are devised to handle the demands posed by life stressors. Successful coping depends on various environmental and personal resources. Support is one of the biggest coping mechanisms that are needed to cope with HIV/AIDS. A community that is well mobilised, equipped and educated about HIV can contribute towards managing stressful encounters brought by it, but at times resources are needed to provide support.The government is doing its best by supporting all those who are HIV positive by the provision of free ARVsand all medical services around it:"Lesotho government is supporting since *ARVs are free*." The government needs to assist HIV-positive mothers more, not only with free treatment, but also support in living with the disease so that treatment can be as effective as it has to be.

4.11 CHALLENGES

4.11.1 SKILLS TO DEAL WITH HIV/AIDS

Participants were asked to give the main challenges they experienced in working with mothers living with HIV/AIDS and how they dealt with them. They raised their concerns about skills, as they sayHIV/AIDS evolves every day and it needs people who have skills to deal with it. Training and updating workers should be one of the priorities of an employee so as to improve quality of services, with"*trainings and campaigns* to be done at least strictly*quarterly*."

The hospital and its clinics only had one social worker serving them:"*during my leave days and offs no one is there to cater for clients*."If the whole hospital and its clinics rely on one social worker, this means when she is not available due to other duties or leave, services that need her specialty cannot be offered. This could affect the trust and confidence that mothers have in the facility, especially in cases where the social worker had set an appointment with a mother and now cannot attend it due to unforeseen circumstances.

4.11.2 INFORMATION TO DEAL WITH HIV/AIDS

The participants were asked to give the main challenges they experienced in working with mothers living with HIV/AIDS and how they dealt with them. They said lack of information or knowledge was one of the challenges that health-care service providers face with the mothers they work with." According to Bell et al. (2007:126), knowledge of health problems and rights can put HIV-positive women and men in a much stronger position for accessing the needed healthcare. However, it is unclear if it is lack of information and knowledge, or just fear and denial of the HIV/AIDS disease:"Most of *their partners come to clinic at late stages when HIV has already progressed and done a lot of damage* are *widows*.

Some mothers do not understand the value of keeping medical records, so they come with new medical record booksevery time: "*Use of new medical records* (bukana) every time they come to the facility."Health-care service providers saidthe keeping of records in the facilities assisted them:"We *record some information in our own books such as diagnosis and dates of attendance,* but this takes *a lot of time*, and if it's the first time the client is coming to our facility it means we will have *no information on her*."

Indeed, the way health-care service providers are trying to solve the issue of new medical records is very useful, but this can be a problem when a mother decides to change to a different facility where there are no records about her health.

4.11.3 DISCLOSURE OF HIV STATUS

The participants were asked to give the main challenges they experienced in working with mothers living with HIV/AIDS and how they dealt with them. They saiddisclosurewas one of the main challenges, as it bringswith it negative and positive impacts, as was mentioned in section 4.6, which discussed people whom the mother prefers to disclose to. The respondents said that health-care service providers address this problem through education("We address this during *health talks*".).

There are also cases where a couple may have two different statuses, with one being positive and the other being negative("in cases where *statuses are not the same (discontent),ongoing counselling* is provided"). Such results may hinder a couple from disclosing to other people for support due to fear of judgmental behaviour from not understanding why one partner has HIV and the other doesnot.

4.11.4 PSYCHOSOCIAL IMPACT OF HIV ON HIV-POSITIVE MOTHERS LIVING IN RURAL AREAS OF LESOTHO

The participants were asked to give the main challenges they experienced in working with mothers living with HIV/AIDS and how they dealt with them. They said the psychosocial impacts that HIV has on mothers was one of their daily challenges. They were concerned about "*stigma and discrimination*".According to the National Abandoned Infants Assistance Resource Centre (2012:9), stigma and discrimination contribute to women's vulnerability by inhibiting them from seeking help and support for their condition. The findings reveal that one of the reasons mothers feel these impacts is due to a "*lack of emotional support*", which health-care providers address through "*education* and*ongoing counselling*".

All of the above mentioned-impacts usually lead to denial, as the mothers fear being stigmatised or discriminated against("Some *deny* that they are HIV positive.").According to Cohen (2008:3), statements of denial are assertions that something did not happen, does not exist, is not true or is not known about.Mothers who are in denial"are *referred for counselling andsupport groups*"to help them deal with it.

4.12 CONCLUSION

The aim of this study was to investigate forms of social support available for HIV-positive mothers in the rural areas of Lesotho through an ecological perspective.

First, a general profile of the participants' professional category, years of service as a health-care worker, and experience of working with HIV-positive mothers was compiled. Then their workload and average cases of mothers living with HIV was looked into. Transmission from mother to child was explored, which led to looking at the extent to which the needs of mothers living with HIV/AIDS are met.

The psychological impacts experienced by mothers living with HIV were explored and ranked according to that experienced the most and the least. As the impacts vary due to the support system available to the mother, the people whom the mothers prefer to disclose to the most and get support from were also explored. This led to exploring the different support services available to mothers living in the rural areas of Lesotho from an ecological perspective, and all the levelswere discussed individually.

Culture, socialisation and work, being part of the ecological perspective, were also explored in terms of how they affect the needs of mothers living with HIV/AIDS in Lesotho. The policies with regard to HIV/AIDS were looked at, as well as challenges that the participants as health-service providers face in working with HIV-positive mothers.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The investigation of forms of social support available for HIV-positive mothers in the rural areas of Lesotho, through the views of health service providers, identified gapsin the literature and a lack of social support from an ecological perspective for HIV-positive mothers living in the rural areas of Lesotho. The exploration was achieved by presenting an overview of the phenomenon of HIV and describing the psychosocial needs and sociocultural circumstances of the HIV-positive mothers in the rural areas in Lesotho in Chapter 2. The second objective was met in Chapter 3, in which HIV-positive mothers' needs for support services from an ecological perspective were discussed.

The third objective was to conduct an empirical study to investigate forms of social support available for HIV-positive mothers in the rural areas of Lesotho through the views of health service providers. This chapter's aim is to meet the final objective of the study, todraw conclusions and make recommendations based on the study. These recommendations can be used as guidelines to design ecological social support for HIV-positive mothers living in the rural areas of Lesotho.

5.2 CONCLUSIONS AND RECOMMENDATIONS

Conclusions and recommendations of the study shall follow.

5.2.1 IDENTIFYING DETAILS OF RESPONDENTS

The participants in the study worked in different health-care service occupations, and comprised counsellors, nurses, doctors, community health workers and a social worker. They all had different professional experiences as well as different numbers of years working with HIV-positive mothers.

It was found that most of the doctors and the social worker had feweryears of experience working with HIV-positive mothers than the other service providers. A larger group, of nurses, counsellors and community workers, had the most years' experience. It can be

concluded that it is important for health-care service providers to work together in providing healthcare services to HIV-positive mothers by learning from each other's experiences and skills acquired in practice over different periods of time.

Recommendation

It is recommended that:

- There should be opportunities for open dialogue, at least quarterly, for all the health-care professionals providing health-care services to HIV-positive mother to share experiences, skills and frustrations related to their service rendering in this field.

5.2.2 WORKLOAD

It was found that the doctors had the highest number of patients to attend to, followed bycommunity health-care workers, counsellors, nursesand the social worker.

It can be concluded that there is a difference in the size of the workloads of health-care service providers.

Recommendation

It is recommended that:

- Managers should set norms for the size of the workload of health-care service providers to keep it manageable.

5.2.3 MODES OF TRANSMISSION OF HIV/AIDS

Most participants said mother-to-child transmission of HIV/AIDSwas the highest mode of transmission amongst the HIV-positive mothers they worked with, followed by breastfeeding,while only a few participants said labour was the highest mode of mother-to-child transmission of HIV/AIDS.

The conclusion can be reached that pregnancy is the highest mode of transmission amongst mothers living with HIV, because these mothers do not adhere to take their medication and probably do not go for regular check-ups. Consequently, this may result in mothers havinginfections that make it easier for them to transmit the virus to the baby. With regard to breastfeeding it can be concluded that different factors, such as poverty, ill health and culture, may contribute to this high mode of transmission of HIV/AIDS from mother to child, because most mothers use health facilities to deliver their babies or take the necessary precautions not

to infect the baby through delivery.It can be concluded that childbirth is the mode with the least transmission.

Recommendations

It is recommended that:

- Defaulter tracing should be strengthened through community health workers. The community health workers should get a monthly salary, unlike the current situation, where they get a stipend from government that is not consistent. This will motivate them and decrease defaulter rates, which will help to decrease infection rates during pregnancy, as the mothers would adhere to medication.
- Government and other stakeholders should invest in and expand stay-over facilities (mapulata) for HIV-positive mothers in health facilities.
- The government should consider copying the project run by MSF, which provided formula milk for children born from HIV-positive mothers and roll it out countrywide.

5.2.4 NEEDS OF HIV-POSITIVE MOTHERS IN THE RURAL AREAS

It was found that,in relation to the first three levels of Maslow's hierarchy of needs, most HIV-positivemothers are able to meet their physiological, safety, and love and belonging needs, but only a few mother were able to meet esteem and self-actualisation needs.

It can be concluded that HIV-positive mothers living in the rural areas of Lesotho mostly are able to meet their basic needs such as food, shelter and clothing, but struggle to meet higher needs such as self-esteem and reaching self-actualisation.

Recommendations

It is recommended that:

- Formal support structures such as support groups should be put in place by social workers and counsellors to provide mothers the opportunity to assist each other in meeting their basic needs.
- The government should consider creating 24-hour free call stations where mothers can get counselling.

5.2.5 PSYCHOSOCIAL IMPACT OF HIV/AIDS EXPERIENCED BY HIV-POSITIVE MOTHERS

It was found that the majority of mothers living with HIV in the rural areas of Lesotho face stress, depression, stigma and low self-esteem due to their HIV-positive status, and a few mothers faced discrimination, denial and bereavement as psychological impacts due to HIV.

It is concluded that HIV-positive mothers experience psychosocial stressors due to their HIV-positive status.

Recommendations

It is recommended that:

- Social workers should strengthenexisting support groups for mothers and should start such groups at community level and not only in facilities, as some mothers cannot afford transportation.
- Counsellors and social workers should reach out to communities and offer counselling to deal with the psychosocial impacts of HIV/AIDS and child care services for HIV-positive mothers.

5.2.6 DISCLOSURE

It was found that the majority of mothers living in the rural areas of Lesotho prefer to disclose to their partners or spouses. Some of the mothers also disclosed to family, friends and support groups, and very few mothers seemed to disclose to their children.

The conclusion can be drawn that mothers disclose to their partners due to the support they can get from them and also to protect their partner's health. It can be concluded that mothers who disclose to their friends, family and support groups and children disclose to them because they get different forms of social support,such as information on their health, instrumental support in the form of food, money and clothes, as well as emotional support such as counselling and appraisal support.

Recommendation

It is recommended that:

- Mothers should be encouraged by health-care service providers to disclose to support groups, as they provide information regarding healthcare and provide emotional and appraisal support.

5.2.7 SOCIAL SUPPORT AT MICRO-LEVEL

5.2.7.1 Emotional support

The findings show that, with regard to emotional support,most HIV-positive mothers get empathy, love and trust from their families.

It can be concluded that mothers do get emotional support from their family,which contributes to assisting them to deal with the psychological impacts of HIV and also assists in meeting their love and belonging needs.

Recommendation

It is recommended that:

- Mothers should be encouraged by health-care service providers to disclose to their families so that they can be able to provide them with emotional support

5.2.7.2 Instrumental support

With regard to instrumental support at the micro-level it was found that families mostly provide mothers with money for various things, such as transport, food and paying for medical bills.

It can be concluded that the family plays a major role in assisting mothers instrumentally in their daily lives.

Recommendation

- It is recommended that health-care service providers should commend the support families' offer to each other as support networks.

5.2.7.3 Informational support

Findings with regard to informational support at this level show that families help mothers with access to information through telephone services and radio programmes.

It can be concluded that not many mothers get informational support from their families.

Recommendations

It is recommended that:

- All parties involved in the fight against HIV, such as the government, NGOs, health-care facilities and others, should make information about HIV easily accessible for HIV-positive mothers living in the rural areas.

- Health-care service providers should emphasise the importance of being informed about HIV in every chance they get of communicating with individual clients, the family or the community at large.

5.2.7.4 Appraisal support

The findings show that, with regard to appraisal support, some mothers get encouragement for their role as a mother as well as for using medication, being listened to and support in decision making from their families.

It can be concluded that the family plays a major role in this kind of support, as mothers usually spend more time with their families. This contributes to meeting mothers' esteem and self-actualisation needs.

Recommendation

It is recommended that:

- Health-care service providers should make families aware of the importance of appraisal support in motivating mothers to live positively with HIV and carrying out their daily routines.

5.2.8 SOCIAL SUPPORT AT THEMESO-LEVEL

5.2.8.1 Emotional support

Findings with regard to emotional support at the meso-level show thatsome mothers get empathy, love and trust from friends and support groups, but very few mothers get spiritual support and counselling from friends and support groups.

It can be **concluded** that some mothers get emotional support from friends and support groups, which contributes to assist them to deal with the psychosocial impacts of HIV and contributes to meeting their love and belonging needs.

Recommendation

It is recommended that:

- The formation of support groups should be strengthened by health-care service providers andthey should alsoencourage mothers living with HIV to join the support groups.

5.2.8.2 Instrumental support

With regard to instrumental support at the meso-level it was found that a few mothers living with HIV in the rural areas get support in the form of transport, money and food from friends and support groups.

It can be concluded that friends and support groups do contribute to assisting mothers with instrumental support,which assists them to meet their physiological needs.

Recommendation

It is recommended that:

- Health-care service providers should support mothers with involvementin income-generating projects through support groups.

5.2.8.3 Informational support

Findings with regard to informational support at this level show that friends and support groups provide some mothers with access to information through telephone, radio programmes and newspaper reports. Very few mothers get assistance with access to the internet.

It can be concluded some mothers get some informational support from support groups and friends, which contributes to assisting them to meet their safety needs, as they can have access to knowledge on what is good for their health.

Recommendations

It is recommended that:

- Health-care service providers should encourage support groups to provide mothers with current information regarding their health.
- Health-care service providers should encourage mothers to make friends with other HIV-positive mothers and encourage reading about HIV.

5.2.8.4 Appraisal support

The findings show that, with regard to appraisal support, someHIV-positive mothers living in the rural areas get listening to, assistance in making choices, encouragementfor using medication and encouragement in role as a mother from friends and support groups.

It can be concluded that mothers do get appraisal from friends and support groups, but also they will only get appraisal support if they have disclosed their status. This means disclosure

plays a big role in order for one to get any form of support. This support contributes to assisting them to build their esteem needs and reach self-actualisation.

Recommendations

It is recommended that:

- Health-care service providers should encourage mothers to join support groups so as to be provided with appraisal support.
- Health-care service providers should encourage mothers to disclose their HIV status to friends so that they can be able to offer them appraisal support.

5.2.9 SOCIAL SUPPORT AT THEEXO-LEVEL

5.2.9.1 Emotional support

The findingsshow that, with regard to emotional support, most HIV-positive mothers get spiritual support, counselling and trust from thehospitals, clinics and churches.

It can be concluded that mostmothers get emotional support from hospitals, clinics and churches, which enables them to deal with the psychosocial impacts of HIV/AIDS. Very few mothers received trust at this level.

Recommendation

It is recommended that:

- Health-care service providers should strive to attain the trust of clients or patients by practising work principles such as individuality and confidentialityin order to provide emotional support to them.

5.2.9.2 Instrumental support

Findings with regard to instrumental support at this level show that very few mothers get support from churches, hospitals and clinics.

It can be concluded that not much instrumental support is provided by hospitals, clinics and churches. The little instrumental support HIV-positive mothers get at this level contributes to meeting their psychosocial needs.

Recommendations

It is recommended that:

- Health-care service providers shouldconsider developing income-generating projects or activities for HIV-positive mothers to enhance instrumental support.
- Healthcare service providers shouldconsider being involved in fundraising in order to assist HIV-positive mothers who may come to the hospital and are needy.

5.2.9.3 Informational support

Findings with regard toinformational support at this level show thatthe government and social service providers assist HIV-positive mothers with access to information through radio programmes and telephone services.

It can be concluded that some mothers get informational support from government and social service providers.

Recommendation

It is recommended that:

- Government and social service providers should plan constructively to provider informational support such asrunning web portals in communities where HIV-positive mothers can access information.

5.2.9.4 Appraisal support

Findings with regard to appraisal support at this level show that hospitals, clinics and churches provide mothers with appraisal support throughhelping them make informed choices regarding their health and that of their children, and encouraging mothers to use their medication.

It can be concluded that most mothers do get appraisal support at this level from hospitals, clinics and churches,which contributes to meeting mothers' esteem and self-actualisation needs.

Recommendations

It is recommended that:

- Health-care service providers should always provide all forms of appraisal support to HIV-positive mothers, as appraisal is important in mothers' adherence to medication and living a healthy, longer life.

5.2.10 SOCIAL SUPPORT AT THEMACRO-LEVEL

5.2.10.1 Emotional support

The findings show that, with regard to emotional support, most HIV-positive mothers get counselling,which includes emotional support,from government and social service providers.

It can be concluded that emotional support is provided at this level as part of counselling support that assists mothersto deal with the psychosocial impacts of HIV/AIDS.

Recommendation

It is recommended that:

- Government should provide a platform for HIV-positive mothers where they can get emotional support, such as government-run centres for counselling.

5.2.10.2 Instrumental support

The findings show that, with regard to instrumental support, most HIV-positive mothers get assistance for paying medical bills, cash assistance and food provision from government and social welfare service providers.

It can be concluded that mothers get instrumental support from government and social welfare service providersthat contributes to meeting the psychosocial needs of these HIV-positive mothers living in the rural areas of Lesotho.

Recommendations

It is recommended that:

- The government of Lesotho should copy Mexico's Progresa programmes and convert it more into the child support grant used by its neighbouring country South Africa (discussed in Chapter 3, section 3.4.1.2). By modifying it so that all children under the age of two years get a grant and formula milk regardless of the mother's HIV-status, children will be able to properly eat solid foods at the age of two years. This will assist in zero transmission from mother to child during breastfeeding and it can also act as a motive for mothers to come for antenatal care and help reduce mother-to-child transmission during pregnancy and breastfeeding.
- The government should consider making baby delivery free in all health-care facilities, not only in clinics as it is already doing.

5.2.10.3 Informational support

Thefindings show that, with regard to informational support at this level,government and social service providers assistmothers with access to information through radio programmes, newspaper reports and internet services.

It can be concluded that most mothers get informational support from government and social service providers. This can assist in meeting the safety needs of mothers by providing them with correct information regarding precautions to be followed when HIV positive.

Recommendations

It is recommended that:

- The government could consider exploring the expansion of e-health, especially in the rural areas. There are many technologies that could be put into place to make access to information easy. One that the government should consider trying is the introduction of public internet terminals (discussed in section 3.4.1.3 (i) in Chapter 3) in rural areas. These terminals could be designed to provide information on all HIV-related issues, as well as other health factors; they should be designed in a way that the information could be read out in the local language for those who are not able to read.
- Government should makethe use of technology in rural areas possible, so that doctors can Skype with nurses to discuss the condition of patients instead of a mother being referred to a hospital and end up not going due to a lack of funds to get there.
- All stakeholders involved in fighting HIV should try to invest in the development and running of a free HIV call centre or a general health call centre that mothers can call to ask for assistance regarding their health or everyday life situations.

5.2.10.4 Appraisal support

The findings with regard to appraisal support at this level show that a few HIV-positive mothers get encouragement for their role as a mother and medication use, assistance in making choices and being listened to from government and social service providers.

It can be concludedthat not much appraisal support is provided by government and social service providers to mothers at this level. The little appraisal support mothers get at this level contributes to the esteem and self-actualisation needs of mothers.

Recommendation

It is recommended that:

- Social service providers, as part of health service providers, should provide mothers with appraisal support.

5.2.11 EFFECTS OF CULTURE

It was found that cultural beliefs and practices, such as prolonged breastfeeding and taking of traditional medication with ARVs, can hinder the treatment and prevention of HIV.

It can be concluded that some cultural beliefs and practices contribute to spreading HIV. These cultural beliefs and practices also contribute to the psychological impacts that HIV/AIDS-positive mother go through.

Recommendation

It is recommended that:

- The government should involve traditional community leaders when formulating policies on HIV so that they can address the community and contributeto implementing such policies.

5.2.12 EFFECTS OF SOCIALISATION

It was found that socialisation is does not only happen in communities, but also in churches, and their sermons have an influence in decisions that people take in their daily lives.

It can be concluded that socialisation can play a big role in decreasing the transmission of HIV/AIDS. This can meet the mothers' safety needs in that their partners would understand HIV and not abuse them when disclosing their HIV status. Also, the community would not discriminate against or stigmatise HIV-positive mothers.

Recommendations

It is recommended that:

- The government should add HIV education to school curriculums.
- Churches should be encouraged to add condom use to their preventative teachings on HIV.

5.2.13 EFFECTS OF WORK

It was found that the majority of HIV-positive mothers in the rural areas are faced with poverty and high unemployment, thus those who manage to get jobs put it first before their health.

It can be concluded that, for those mothers who are able to work, value their jobs more than their healthdue to the high rates of unemployment. They jeopardise their lives to meet their most basic needs, such as food, shelter and clothing, which are purchased with money earned.Workplaces such as factories and security services allocate mothers only six weeks of maternity leave. They also earn low salaries and cannot afford to exclusively formula feed the baby. As a result, mothers end up mixed-feeding their children and infecting them with HIV.

Recommendation

It is recommended that:

- Work policies addressing HIV/AIDS should be revised,specifically those related tomaternity leave, as the Prevention of Mother-to-Child Transmission policy says a mother should exclusively breastfeed for six months and can only mix feed at six months.

5.2.14 POLICY WITH REGARD TO HIV

It was found that health-care service providers and HIV-positive mothers are not properly consulted by government in the formulation or changing of policies.

It can be concluded that non-consultation by government of those directly affected by policy formulation or changes will continue contributing to the failure of treating and curbing HIV/AIDS in Lesotho

Recommendations

It is recommended that:

- The government should involve people living with HIV/AIDS when making, changing or implementing policies. Surveys and studies should be done on how those that are going to be affected directly feel about it and make sure that they understand that the benefits outweigh the negatives.
- Health-care service providers should also be involved in the making and changing of policies through surveys so that they can understand the importance of doing so,

as they are the ones working hands-on with patients or clients and know how they feel about certain issues.

5.2.15 CHALLENGES

It was found that health-care service providers meet diverse challenges while providing services to HIV-positive mother from the rural areas of Lesotho,

It can be concluded that HIV/AIDS is not only a medical problem, but also a socio-economic problem that needs to be addressed from different perspectives.

Recommendation

It is recommended that:

- All healthcare service providersshould work hand in hand to defeat the HIV virus.

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ADDENDUM A

SEMI-STRUCTURED QUESTIONNAIRE

UNIVERSITY OF STELLENBOSCH

DEPARTMENT OF SOCIAL WORK

SEMI-STRUCTURED QUESTIONNAIRE

Views of health service providers on the need of support services for HIV positive mothers in the rural areas of Lesotho: An ecological perspective

Please Note:

• Participants' names will not be made known.

• All the information recorded in this questionnaire is confidential.

Instructions

There are four types of questions in this questionnaire:

1. Closed ended questions – yes/no questions. The respondent chooses between yes and no, but in some cases will be requested to explain his/her answer.

2. Scaling questions – the respondent indicates the level of his/her agreement with a particular statement.

3. Lists – the respondent is given a number of possible answers to a question and is requested to choose the answers that are applicable to the respondent's situation.

4. Open-ended questions – the respondent is asked to answer a question in his/her own words. Answers will vary from one word to a paragraph.

1. Identifying details

1.1. How long have you been a health care service provider?

1.2. Which category do you fall under?

Mark with X	Category
	Doctor
	Nurse
	Social worker
	Counselor
	Community health care worker

1.3. How long have been working with people with HIV/AIDS? …….. (No of years)

2. Work Load

2.1. How big is your average caseload per month?

Mark with "X" Size of caseload

Mark with X	Case load
	1 - 20
	21 - 40
	41 - 60
	61 - 80
	81 -100
	101 +

3. Modes of mother to child transmission

3.1 Which one ofthe following modes of mother to child transmission is the highest among mothers you work with?

Mark with X	Modes of mother to child Transmission

	Pregnancy
	Childbirth
	Breast feeding

3.2 What are the reasons for this mode of transmission?

……
……
……

4. Needs of HIV positive mothers and psychosocial impacts of HIV they experience

4.1 The following list consists of general human needs.

a) To what extend are the following needs of mothers living with HIV in the rural areas met? Mark the answer with an "X"

Types of needs	**Always**	**Sometimes**	**Never**
Physiological needs			
Safety needs			
Love and Belonging needs			
Esteem needs			
Self- actualization needs			

4.2 Motivate each of your answers above

a) Physiological needs……

……

……

b) Safety needs……

……

……

c) Love and belonging……

……

……

d) Esteem needs……

……

……

e)Self actualization……

……
……

5. Psychosocial impacts experienced by people living with HIV

5.1. The following list contains the psychosocial impacts that are experienced by people infected with HIV/AIDS.

a) Rank the highest psychological impact experienced by mothers living with HIV.

Rankings	**Psychosocial Impacts**
	Stress
	Stigma
	Discrimination
	Bereavement
	Denial
	Low self-esteem
	Depression

6. Disclosure and types of support mother living with HIV need and get

6.1 a) Which of the following people do mothers living with HIV prefer to disclose their status to?

Mark with an X	**Preferred person/group**
	Partner / spouse
	Children
	Family
	Friends
	Support group

b) What do you think are their reasons for choosing these people to disclose to?

Partner/Spouse……
……
……

Children……
……

Family……
……
……

Friends……
……
……

Support group……

……
……

c) What type of support do you think mothers need when disclosing and why?

……
……
……

7 Social support from an ecological perspective

7.1 a) From which of the following levels of the ecological perspective do you think mothers get emotional support?

Mark with an X

	Micro Level	Meso Level	Exo Level	Macro Level
Emotional Support	Family	Friends/ Support Groups	Hospitals/Clinics/ Churches	Government/ Social service providers
Empathy				
Love				
Trust				
Spiritual support				
Counseling				
Any other				

b) How do you think the emotional support they get from the above sub-systems at the different levels meet their needs? Motivate your answer

Micro level

(Family)……
…….....……
……

Meso level

(Friends)……
.....……
……

(Support groups)…….....

……
……

Exo level

(Hospitals)……..

……
……

(Clinics)……
……
……

(Churches)……
……
……

Macro level

(Government).....

……
……

(Social service providers).....

……
……

7.2 a) From which of the following levels of the ecological perspective do you think mothers get instrumental support?

Mark with an X

	Micro Level	Meso Level	Exo Level	Macro Level
Instrumental Support	Family	Friends/ Support Groups	Hospitals/Clinics/ Churches	Government/ Social service providers
Transport/transport money				
Provision in form of cash assistance				
Food provision				
Assistance in paying medical expenses				
Any other				

b) How do you think the instrumental support they get from the above sub-systems at the different levels meet their needs? Motivate your answer

Micro level

(Family)……

……
……

Meso level

(Friends)……
.....……
……

(Support groups)……

……
……

Exo level

(Hospitals)……..

……
……

(Clinics)……
……
……

(Churches)……
……
……

Macro level

(Government).....

……
……

(Social service providers).....

……
……

7.3 a) From the following levels of ecological perspective where do you think mothers get information support?

Mark with an X

	Micro Level	Meso Level	Exo Level	Macro Level
Information Support	Family	Friends/ Support Groups	Hospitals/Clinics/ Churches	Government/ Social services providers
Access to telephone services				
Access to radio programmes				
Access to newspaper reports				
Access to internet services				
Any other				

b) How do you think the informational support they get from the above sub-systems at the different levels meet their needs? Motivate your answer

Micro level

(Family)……
….....
.....

Meso

(Friends)……
……
……

(Support groups)…….....

……
……

Exo

(Hospitals)……..

……
……

(Clinics)……
……
……

(Churches)……
……
……

Macro

(Government).....

……
……

(Social service providers).....

……
……

7.4 a) From which of the following levels of ecological perspective do you think mothers get appraisal support?

Mark with an X

	Micro Level	Meso Level	Exo Level	Macro Level
Appraisal Support	Family	Friends/ Support Groups	Hospitals/ Clinics/Churches	Government/ Social services providers
Listening to her				
Helping her understand her choices with regards to taking care of her child (e.g choosing to breast feed or not to) and supporting her in making them				
Encouraging her to use medical care services				
Encouraging her in her role as a mother				
Any other				

b) How do you think the appraisal support they get from the above sub-systems at the different levels meet their needs? Motivate your answer

Micro level

(Family)……
…….....……
……

Meso level

(Friends)……
.......……
……
……

(Support groups)……

……
……

Exo level

(Hospitals)……..

……
……

(Clinics)……
……
……

(Churches)……
……
……

Macro level

(Government).....

……
……

(Social service providers).....

……
……

7.5 To what extend do you think the following factors affect the needs of mothers living with HIV/AIDS in Lesotho?

Cultural context.....

……
…..

Socialization……..

……
……

Work situation……

……
…..
.....

7.6 Policy with regards to HIV/AIDS

7.6 a) What is your assessment of policies and services offered by the government of Lesotho to support people living with HIV/AIDS?

……
……
……
……

8. CHALLENGES

8.1 What are the main challenges that you experience in working with mothers living with HIV/AIDS and how do you deal them?

……

……

……

THANK YOU VERY MUCH FOR YOUR TIME

ADDENDUM B

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

VIEWS OF HEALTH SERVICE PROVIDERS ON THE NEED FOR SUPPORT SERVICES FOR HIV POSITIVE MOTHERS IN THE RURAL OF LESOTHO: AN ECOLOGICAL PERSPECTIVE.

You are asked to participate in a research study conducted by (Shoeshoe Mofokeng) (M in Social Work), a student from the Social Work Department at the University of Stellenbosch. The results of this study will become part of a research report. You were selected as a possible participant in this study because you are a health service provider of HIV positive mothers in the rural area of Lesotho.

1. PURPOSE OF THE STUDY

The aim of the study is to gain a better understanding on the views of service providers on the need of support services for HIV positive mothers in the rural areas of Lesotho from an ecological perspective.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following:

A semi-structured interview will be utilized to gather information confidentially. You need not indicate your name or any particulars on the interview schedule. The schedule will be completed during an interview conducted by a student-researcher.

3. POTENTIAL RISKS AND DISCOMFORTS

Any uncertainties on any of the aspects of the schedule you may experience during the interview can be discussed and clarified at any time.

4. POTENTIAL BENEFITS TO SUBJECTS AND / OR TO SOCIETY

The results of this study can be used as information in improving service delivery in your facility as well as information in regard to policy making for service delivery for HIV positive mothers

5. PAYMENT FOR PARTICIPATION

No payment in any form will be received for participating in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding where each questionnaire is numbered. All questionnaires will be managed, analysed and processed by the student-researcher and will be kept in a safe place.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The student-researcher may withdraw you from this research if circumstances arise which warrant doing so, eg should you influence other participants in the completion of their questionnaires.

8. IDENTIFICATION OF STUDENT-RESEARCHER

If you have any questions or concerns about the research, please feel free to contact:

Professor Green (Supervisor), Department of Social Work, University of Stellenbosch,

Tel. 021-808 2074, E-Mail: sgreen@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms MaléneFouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me the participant by Shoeshoe Mofokeng in English. I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. A copy of this form was given to me.

_____

Name of Subject/Participant

_____

Name of legal representative (if applicable)

_____

_____

Signature of Subject/Participant or legal representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____[name of subject/participant]. [He / She] was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

_____ _____

Signature of Investigator **Date**

ADDENDUM C

SCOTT HOSPITAL
of the
Lesotho Evangelical Church

Comprehensive Health Care
Phone: 22360000/22360237
Fax: 22360237
E-mail: scotthospital@ilesotho.com

Private Bag
Morija, 190
Lesotho

07 July 2014

Ms. Shoeshoe Mofokeng
University of Stellenbosch
Western Cape Province

Dear Ms. Mofokeng,

RE: REQUEST OF PERMISSION TO DO RESEARCH AT SCOTT HOSPITAL

VIEWS OF HEALTH SERVICE PROVIDERS ON THE NEED OF SUPPORT SERVICES FOR HIV+ MOTHERS IN THE RURAL AREAS OF LESOTHO: AN ECOLOGICAL PERSPECTIVE

We received your letter dated 17 June 2014 in which you request permission to do research in our institution as stated above.

We find no problem in doing this and we would only like you to act in the best interests of the departments or personnel concerned.

Yours Sincerely,

DR. NGOY
Medical Superintendent