SELINUS UNIVERSITY
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THE EXPERIENCE OF WOMEN WHO ARE HIV/AIDS POSITIVE ON EXCLUSIVE BREASTFEEDING LIVING IN THE SLUMS OF KENYA

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ABSTRACT

Background: Breastfeeding is a deeply rooted and valued practice in many societies in developing countries, with the obvious importance to the child's optimal growth. The emergence of Human Immune-deficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and the realization that the virus can be transmitted to the child through breast milk has given breastfeeding a different focus.

Objective: To explore the experiences and perspectives of Kenyan women living in resource limiting areas who are HIV positive and were instructed to exclusively breastfeed their babies. The aim was to broaden the aspects of the care given to the HIV/AIDS positive women whose health seems to have been compromised. The anticipated new knowledge generated by the study would be used to improve healthcare services given to HIV/AIDS positive women and their babies.

Methodology and design: A qualitative methodology was used that enabled a holistic, humanistic, intense and systematic examination of a complex social phenomenon. An ethnographic study design gave a detailed examination of individuals within a real lived context using multiple data collection methods. Individual in-depth interviews were conducted using semi-structured interviews with open-ended questions, and unstructured observations were maintained as field notes to enrich data.

Setting: The research setting area was in Mukuru slums, in Nairobi. Five (5) HIV positive mothers visiting The Mater Hospital (MCCC) department for healthcare services represented the population living in resource limiting areas in Kenya.

Findings: From this study, it emerged that all the five participants (100 percent) representing the population of HIV positive women living in the slums of Nairobi, Kenya, had given birth and opted to exclusively breastfeed their infants were aware of the advantages of breastfeeding. They all embraced exclusive breastfeeding and all their infants (100 percent) survived, remained free of the HIV virus and to date they are thriving well. However, all the participants acknowledged that the issue of breastfeeding is complicated for HIV-positive childbearing women not only because of the risk of transmission of the HIV virus to the baby, but due to many issues pecked on several factors and societal cultural expectations.

Conclusion: The population under study expressed their experiences and perspectives of being HIV positive, a mother living in the resource limiting area. All the women were aware of breastfeeding and the risks of MTCT. They lacked knowledge of the recommended proper teaching on breastfeeding in HIV as a result of inappropriate counselling before getting pregnant, inadequate education and support during pregnancy and beyond. Although they were happy with the choice of exclusive breastfeeding following the instructions, the success of their choice was actualized through the support provided by the MCCC in terms of food to ensure enough milk production for their infants. But the many issues grounded on the reality of their living conditions complicated by poverty compromised their good intentions to withstand the option. It emerged that the skilled midwives, who are mostly with the women, should help the HIV positive mothers in their efforts to make the best decisions within their circumstances, and enhance positive living. This could only be actualized through a proper a designed Woman Centred Education Model.

Key words: - Exclusive Breastfeeding, HIV/AIDS, MTCT, Decision-making, Education model

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
CHW	Community Health Worker
C/S	Caesarean Section
DTG	Dolutegravir
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immune-deficiency Virus
IgG	Immunoglobulin-Gamma
MCCC	Mater Comprehensive Care Clinic
PLWA	People Living With Aids
PMTCT	Prevention of Mother To Child Transmission
MTCT	Mother To Child Transmission
RNA	Ribonucleic acid
SVD	Spontaneous Vaginal Delivery
UNAIDS	United Nation's Acquired Immuno-Deficiency Syndrome
UNICEF	United nation International Children Education Fund
VCT	Voluntary Counseling Test
WHO	World Health Organization

DECLARATION

"I do hereby attest that I am the sole author of this thesis and that its contents are only the result of readings and research that I have done". Permission was obtained from persons and intuitions mentioned in the form of direct interactions and interviews.

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Mary Syokau Ngui.

DEDICATION

This thesis is dedicated to the memory of my late mother, Anna Mbula Ngui whose inspirations still linger on. *"Mwaitu, your wise counsel is cherished by many who treasure your many gifts of motherhood. May these gifts be manifested in this thesis; and may all who read it benefit from the inherited gifts as they pass them to the future generation"*

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"I look up to the mountain…Where does my help come from? My help comes from God…"
(Psalm 121)

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To the faithful mentor mother June Atieno, many thanks for the untiring efforts and support during the home visits. To Mr. Mulei, the ever-faithful community health worker, who acted as my guide and zigzagged through the densely populated slums with no landmarks to the clients' homes. Your help and guidance are highly appreciated. *To both of you, keep up the good work!*

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Finally, to my family, you are the centre of my life. *You always take delight in my success. I would love to shine for you.*

CONTENTS

CHAPTER ONE

1.0 Introduction

The scenario in one of the informal settlements hereby referred as "slums" in Nairobi, Kenya is a mesmerising one. Walking through, one is met by a bee-hive of activities. Children kicking balls made from old used tins and newspapers tied neatly to resemble modern balls. Others playing with toy cars made of used metal wires, wood, carton boxes, and rubber materials. Talk of creativity! Women appear busy cooking all sorts of dishes; some washing utensils and clothes, while others carry out their business of selling food stuff, household items, and second-hand clothes. Men are not left behind either. They seem busy doing what men do best; idling talking about current news; while others engage in entertainment such as playing darts with bottle tops. Amidst all these are shanty houses made of mud, iron sheets, cartons, plastic papers and wood that they call homes. There is garbage all over, open sewage running through the crowded shanty houses. One is reminded of where they are by the stench from the surroundings, and the many hops, steps and jumps over the running and pools of sewage water. Animals have their part too, as they strive to look for something to feed on. It is amazing how happy these people appear despite their surroundings. The scenario is characterized by a lot of movements as the residents go about minding their own business. One is met with welcoming smiling faces and warm greetings. Yet, inside this community, there are women who are HIV positive and have been rewarded with their "bundles of joy". These women have to fulfil their expected social role of breastfeeding their babies as well as adhere to the WHO guidelines on how to protect these babies from acquiring the dreaded HIV virus. The scenario in this community is a representation of many other communities in Kenya where HIV positive women face dilemmas in decision-making pertaining to the best feeding option for the optimal well - being of their infants amidst the environmental and economic situations.

Mary S. Ngui

The following scenario drew the attention of the researcher to explore how the HIV positive women and their new-born babies survive in such circumstances.

Pictorial presentation 1

Source: -http://int.search.myway.com/search/AJimage.jhtml?n=7857a7cf&p2= percent 5EBBQ percent 5Expu359 percent 5ETTAB02 percent 5Eke&pg=AJimage&pn=1&ptb=4E446096-BE0F-41AA-803C-0C328DA5F5CC&qs=&searchfor=pictures+of+slums+of+mukuru+in+Nairobi&si=93-912878632&ss=sub&st=hp&tpr=hst&trs=wtt&ots=1546791634633

The World Health Organization (WHO) recommends that mothers practice exclusive breastfeeding of their infants for at least six (6) months because breast milk as a natural resource has a major impact on a child's health, growth and development (Lokare & Hippargi, 2015). Exclusive breastfeeding is suggested to continue for at least the first two years of a child's life (Muchina, 2010). The reason being breast milk contains the nutrients that are needed and in the right quantity; and these nutrients are quickly and easily digested making them available for the growing infant as stated by the United Nation International Children Education Fund (UNICEF, 2018). This study focused on the experience of Exclusive Breastfeeding in HIV positive women living in resource limiting areas.

1.1 Background of the study

The definition of health provides its broad sense, as being not only the absence of disease but also general mental, physical, and social well-being (Misselbrook, 2014). However in this definition, the environment in which people live including access to nutritious food, safe water, sanitation, education and social cohesion also determines the state of health (Denis, 2014). Early start of good health influences the future of individuals and breastfeeding plays a major role in nutrition and well-being in children since human milk is the ideal nourishment for infants' survival, growth and development and to maintain this, various breastfeeding support interventions have been developed to encourage mothers to maintain breastfeeding practices (Kim et al., 2018). When the infants are exclusively breastfed for the first six months of life, there is stimulation of the immune system that gives protection from diseases like diarrhoea and acute respiratory infections, which are two of the major causes of infant mortality in the developing world (Access, 2015). Hence,

exclusive breastfeeding for the first six months after delivery is an important public health tool for the primary prevention of child morbidity and mortality (Seidu & Stade, 2013). Furthermore, and important to note, breastfeeding provides pride to the mother as well as aiding in the physiological changes during puerperium such as the involution of the uterus (Henshaw et al., 2015). Hence there are duo benefits to both mother and the baby.

Despite the recognized benefits of breastfeeding for mothers and children, breastfeeding practices in Africa remain sub-optimal and enmeshed with issues around the current Human Immune-deficiency Virus (HIV) epidemic and prevention of mother to child transmission (PMTCT). Oiye et al., (2017) study highlighted the risk of transmission of the HIV through breast milk that has over the years presented a challenge on how HIV positive women from resource limited settings should feed their infants. Moreover, another study carried out by Maryam et al., (2016) in Kigali, Rwanda showed that adherence to six months of exclusive breastfeeding rapidly declined after three months postpartum. This challenged the adherence to the WHO guidelines on exclusive breastfeeding for the first six months and beyond.

The alternative mode of completely avoiding breastfeeding in African countries where cultural beliefs and gender dynamics that involve men in decision making is not a feasible option for the many HIV positive women in resource poor areas. In other words, despite the circumstances, there is a strong cultural imperative to breast feed, especially as African women coming from cultures where breastfeeding is highly valued as stated by Amendah et al., (2014). Although commercial infant formula is the recommended infant feeding option for some of the HIV positive women in developed countries, mothers in the poor

countries face many issues such as the expense of infant formula, lack of access to safe water for the preparation, unsanitary living conditions, increased risks to their children from common childhood illnesses, inadequate healthcare, and socio-cultural factors (Nankumbi & Muliira, 2015 ; Gizaw et al., 2017). There is a recommended compliance to Highly Active Antiretroviral Therapy (HAART) and exclusive breastfeeding for all positive women that goes with ensuring good nutritional status for the women. However, this was challenged by earlier studies carried out by Coutsoudis, (2005), who argued that women in resource constrained settings such as Sub - Saharan Africa carry a double burden of HIV and food insecurity and are therefore prone to nutritional deficiencies that affect breastfeeding. Therefore, attention should be paid to ensure individual client-centred support and counselling that improve the effectiveness of nutritional interventions (E. L. Fox et al., 2019). Thus, promote the health of both the mother and the baby. This study therefore explored the experience of HIV positive women living in informal settlements, who had opted for exclusive breastfeeding of their babies. A midwifery education model would address issues faced by this vulnerable child-bearing population.

1.2 Statement of the problem

The recognition that Human Immunodeficiency Virus could be transmitted through breastfeeding precipitated a public health dilemma, because breastfeeding posed a potential health hazard to the new born babies (Bakthavatchalu et al., 2013)**.** Research conducted by Sirengo et al., (2016) found that although the proportion of women who reported being screened for HIV at the prenatal clinic had risen substantially since 2007, there remained a substantial burden of HIV among women of child bearing age. About 40 percent of HIV

infected women and 45 percent of exposed infants did not receive antiretroviral prophylaxis, highlighting current challenges in the prevention of mother to child transmission. These studies were supported by an earlier research carried out in one of Level five hospitals in Kenya by Gitonga Betty Makena (2014) that indicated that exclusive breastfeeding rate of 28 percent is below the level recommended by WHO of 90 percent and below the national level of 32 percent. From the study, socio-cultural factors greatly influenced the practice especially the perception of having insufficient milk production by the mothers.

1.3 Rationale and purpose of the study

According to Issaka et al., (2017), promoting the practice of exclusive breastfeeding has the potential of making a key impact in reducing neonatal deaths. It is important therefore to implement intervention programmes to promote breastfeeding that place emphasis on the practice of exclusive breastfeeding especially relevant to countries in Sub - Saharan Africa, particularly in Kenya where there are high rates of neonatal and infant mortality. The purpose of this study was to explore the experience of exclusive breastfeeding in HIV positive mothers living in informal settlements that are resource limiting areas. This study sought to broaden the aspects of the care given to the HIV/AIDS positive women whose health as implied by Sugandhi et al., (2013) seems to have been compromised The anticipated new knowledge generated by the study would be used to improve care given to HIV/AIDS positive women and their babies. The researcher came up with a woman-centred midwifery education model to address issues that affect child-bearing women globally.

In this research, qualitative ethnography methodology approach was deemed to be ideal to understand the natural settings, attitudes and the social pressures. Hence, enabling factors that influence the decisions to breastfeeding and the ability of HIV positive pregnant women and their families to utilize available safe birthing processes within their settings, and make informed decision regarding the feeding options. In so doing, a holistic humanistic, intense and systematic examination of a complex phenomenon was used to achieve an understanding of other persons' perspectives, experiences and the interpretations and meanings they bring to specific events and situations as indicated by Astin & Long, (2009a). Using interviews and participant observations as the mode of data collection, the social-cultural aspect was addressed.

The study was carried out in the Mukuru slums, targeting specific clients who receive HIV/AIDS related services from the Mater Hospital Comprehensive Care Clinic. The participants provided the reality of the real lived experiences within their world. It is important for international policy makers to be informed and made to understand what influences HIV positive mothers to exclusively breastfeed, or formula feed; and adhere to antiretroviral medication while breastfeeding before they make comprehensive policies and recommendations that are as culturally sensitive and be practical as possible.

1.4 Research Questions

According to Do & Formulate, (2014), a clear and appropriate research question, or set of interrelated questions forms the foundation of good qualitative research because researchers

see a question as a beginning point for their study. The following questions were used accompanied by participant observations to collect enriched data.

Interview questions

1. Could you please tell me what you know about feeding of your baby?
2. How were you involved in the decision making about the feeding of your baby?
3. What is your understanding of Exclusive Breastfeeding?
4. What other methods are you aware of for feeding your baby?
5. What concerns do you have about any of the feeding methods?
6. Given the reality of mother to child transmission of the HIV virus, what do you think healthcare professionals can do to help childbearing women who are HIV positive in making choices about their method of infant feeding?

1.5 General Objective

The objective of clinical nursing and midwifery research is to contribute scientific information to change and improve clinical practice (Kleinpell, 2008). Hence, the results of clinical research should be applied to clinical practice and used to influence clinical change and provide the best evidence based nursing and midwifery care. Therefore, the main objective for this study was to explore the experiences and perspectives of Kenyan women living in resource limiting areas who are HIV positive and were instructed to exclusively breastfeed their babies. The aim was to come up with a midwifery education model that would be implemented to improve the care given to not only the population under study, but to all childbearing women. In order to get an understanding of their

motherhood experiences within their reality, the following specific objectives were considered:

- Establish the health education in HIV and breastfeeding options and develop a modality on how best to deliver it
- Explore the understanding of Exclusive breastfeeding in HIV positive women.
- Identify the need for teaching on alternative artificial feeding methods
- Identify the need for more education on breastfeeding, HIV and MTCT, embracing family approach for support
- Determine the preparation, understanding and support before and after diagnosis, including support with the baby, and home follow-ups
- Optimize the key role played by understanding, acceptance and support of people with HIV/AIDS to help them live positively and to avoid stigmatization
- Define need for more involvement in the decisions, to include other decision - makers from the family and significant others with better preparation and timing
- Pose a challenge to researchers to find alternative methods to avoid MTCT of the HIV virus and the international guidelines to address those living in resource limiting areas
- Maintain the need for better services and care (evidence-based) for childbearing women who are HIV positive.

1.6 Chapter summary

This chapter introduced the study, giving the background that looked broadly at breastfeeding and its beneficial factors to both mother and baby. The emergence of HIV/AIDS in the world, Africa, and Kenya, and the cultural influence on the spread of HIV among Kenyan women and children was discussed. The current HIV/AIDS statistical figures from the WHO and UNICEF were highlighted, and the controversial MTCT was outlined. The purpose, problem statement and the research methodology approach were defined. The next chapter reviewed the literature from several resources regarding breastfeeding and HIV/AIDS, addressing the many issues of breastfeeding in relation to HIV/AIDS. The focus was on the current research, and exposed the gaps that justified a need for research on the experience of women who are HIV positive, living in resource limiting areas and have opted to exclusive breastfeed their infants.

CHAPTER TWO

Literature review

2.0 Introduction

A review of the literature was conducted using various sources that included articles from electronic journals available on the World Wide Web, HINARI, Mendeley, WHO and UNICEF fact sheets, published thesis documents, printed journals, printed books, magazine articles, clients' records, conference papers and newspaper articles. The main purpose was to review issues related to breastfeeding, HIV infection, Mother to Child Transmission, use of the antiretroviral drugs and use of formula feeding as an alternative feeding method. The focus was on what has been investigated by other researchers in order to unearth more insights into the study, identify gaps and suggest possible means of addressing these gaps without duplicating the work already done in this area.

2.1 Breastfeeding

Breastfeeding is the normal way of providing young infants with the nutrients they need for healthy growth and development. It is considered as the most single effective way of saving the lives of millions of young children, and a deeply rooted and valued practice in many societies, especially those of developing countries (Gemma, 2012 ; Balogun et al., 2017). It is known to provide life-term health, economic and environmental advantages to children, women and the society at large (Nabulsi et al., 2014; Rollins et al., 2016). Furthermore, breastfeeding method in developing countries is the socio-culturally acceptable way of feeding infants during the first year of life and a key determinant of child survival and

development as stated by Aishat et al., (2015). As a result of breastfeeding, new-borns survive, children thrive and grow, and well-nourished women have healthy pregnancies and live more productive lives.

Exclusive breastfeeding is defined as feeding an infant only on breast milk in contrast to mixed breastfeeding, defined as the feeding of breast milk along with complementary foods, other milks, and/or infant formula (E. L. Fox et al., 2018). In most societies in the Sub – Saharan African, it is the only acceptable method for feeding infants and an affirmation of motherhood. This was further supported by studies carried out in eight developing countries in Africa that indicated that exclusive breastfeeding for six months, followed by the timely introduction of safe and nutritionally adequate complementary foods to prevent malnutrition and reduce morbidity in the first five years of life (Patil et al., 2015; Tessema, n.d). Unfortunately, this has remained far from being actualized in most of the developing countries like Kenya. Factors influencing breastfeeding such as mother's occupation, health facility for delivery and longer maternity leave for those employed to improve exclusive breastfeeding practice have been widely acknowledged as deterrents to exclusive breastfeeding adherence (Hunegnaw et al., 2017). Unfortunately, in low income and middle-income countries, only 37 percent of children younger than 6 months of age are exclusively breastfed (Mnyani et al., 2017). However, studies carried out in Uganda by Dunkley et al., (2018), showed that infant feeding can be complex with many challenges, especially in the context of HIV due to vertical transmission from mother to child. There is need therefore, to balance between the many recommendations that emerge from the scientific evidence and the reality of women's health status, social, economic, cultural and emotional circumstances.

In many African countries, due to the important contribution of breastfeeding to the child's optimal growth, and the unavailability of the alternative formula milk or its cost implications, it is crucial to recognize that efforts by healthcare professionals that are geared towards its successful implementation with emphasis on the cultural importance and the social pressure to breast feed (Tariq et al., 2016). Although in most cases decline in breastfeeding is associated with women's involvement in work force, there is lack of knowledge on the benefits of the practice and the management of lactation problems (Muchina, 2010). Failure to breast feed or use of formula for those who can afford would signify women's HIV positive status with an outcome of stigma. Additionally, there are concerns regarding physical and psychological effects on the development of children with some women feeling that their identity as good mothers would be compromised by not breastfeeding. Factors that influence successful exclusive breastfeeding include family support, social context and backing from the healthcare professionals (Thepha et al., 2017). Therefore, since the choice of maternal infant feeding practices could be complicated, it can only be analysed though the lens that reveals the mothers' experiences in their living environment.

From many theorists, breastfeeding is the natural, efficient way of using the readily available reserve for feeding babies and unequalled to no other way of providing ideal nutrition for the healthy growth and development of infants (Nicoll & Williams, 2002 ; Lanktree et al., 2011; Victora et al., 2016). Moreover, there is clear evidence that exclusively breastfeeding for the first six months of life helps to achieve optimal growth because it protects children against malnutrition, and reduces infant morbidity and mortality in both developed and

developing countries (Njeri, 2012). According to UNICEF (2018), the optimal nutrition practices for childhood include early initiation of exclusive breastfeeding for the first six months of life, followed by the addition of nutritionally adequate, safe, and appropriate complementary foods with continuation of breastfeeding for at least one year or beyond. However, exclusive breastfeeding rates have remained low as evidenced by studies carried out in South Africa, whereby, some states are classified among the low resource setting areas indicated that the actual practice of exclusive breastfeeding is uncommon, with estimated rate of 10.4 percent of infants younger than four (4) months being weaned off early (Mnyani et al., 2017). This is significantly low in Sub-Saharan Africa, where breastfeeding is highly valued. Furthermore, there are approximately 35 percent to 50 percent of lactating women who discontinue breastfeeding before three months postpartum and commonly introduce complementary foods sometimes as early as six weeks of age (Sibeko, et al., 2005). Therefore, understanding the determinants of breastfeeding behaviour is a critical step toward the prevention of breastfeeding erosion and thus an essential public health measure. More evidence of some barriers to breastfeeding includes inconsistent advice from relatives, friends, partners, and needless to say from some healthcare professionals; unacceptability of breastfeeding in public places and therefore opting for the acceptable bottle-feeding; inexperience, especially for first time mothers; and returning to work (Jama et al., 2017). Nevertheless, in order to enhance self-efficacy, parents would need to be taught about challenges that may arise during early breastfeeding and know how to manage them.

It is also important to encourage support by partners in addition to healthcare providers and other designated members of the family especially the grandmothers whose role in infants feeding is crucial, even though some are known to practice traditional remedies that could be harmful to the child's health (Aubel, 2012). To accelerate this, the WHO and UNICEF issued new guidance and steps that underpin the baby friendly healthcare facility initiative to promote breastfeeding globally. Thus, emphasizing the key role played by the partner, the employer and conducive working conditions in the contribution to successful breastfeeding (Tsai, 2014). It is imperative therefore, to breastfeed all babies, unless contraindicated for the first two years to save their lives to ensure lifelong health, and reduce costs for health facilities, families, and governments. Ways of combating any challenges that oppose this healthy position, especially in resource limiting areas must be addressed to safeguard quality life of the future generation, especially in African countries. The joys of breastfeeding in an African woman are equal to none other. However, healthcare providers play a significant role through education, counselling and support especially during the postnatal period as implied by Sciences et al., (2012).

The benefits of breast feeding outweigh all other forms of infant feeding. The obvious healthy-looking fulfilled happy baby portrays an image of contentment, satisfaction and reward to the mother giving her the pride of motherhood.

Pictorial Presentation 2

Source : - http://www.mumsworldafrica.com/

2.1.1 Benefits of breastfeeding

The many benefits associated with breastfeeding include its naturalness, emotional bonding, infant's health and potential optimum growth; as well as protection against many early infant killer diseases such as gastroenteritis (UNICEF, 2018). Studies carried out by Pottinger, (2015) and Lampe & Lampe, (2016) indicated that exclusive breastfeeding provides many benefits that can be life saving for the infant; plays a crucial role for a child's health and cognitive development especially in low resource settings where vulnerable infants' access to proper nutrition is unavailable. Furthermore, the significance of exclusive breastfeeding from zero to six months of age and continuation thereafter with introduction to complementary foods up to a period of two years has been widely acknowledged as a contributory factor to the health of infants and children, that lead to a healthy nation (Hansen et al., 2011). There is also evidence from researchers that exclusive breastfeeding during the first six months of postpartum provide many nutritional, immunological and psychosocial benefits, including protection of the infant against infectious diseases, improved child spacing due to lactational amenorrhea, and enhanced maternal health as well as improving infant to mother relationship (Chowdhury et al., 2015; Sankar et al., 2015). In addition, Mogre et al., (2016) and Ogbo et al., (2017) put an emphasis on strategies for reducing infant morbidity and mortality as a result of diarrhoea related diseases in resource limited settings through breastfeeding. Nonetheless, exclusive breastfeeding practices has remained low because mothers are faced with multiple challenges (Agunbiade & Ogunleye, 2012). However, for effective exclusive breastfeeding, community-based peer support to enable mothers increase the duration of exclusive breastfeeding for infants in low and middle-income countries was underscored by Shakya et al., (2017).

Breastfeeding is therefore a pivotal factor between life and death for the vast majority of children in developing countries (Brand et al., 2011). Although the potential effects of breastfeeding appear large, exclusive breastfeeding rates remain low in the world, and are even lower among the HIV positive population. This is evidenced by studies carried out by Thet et al., (2016) that showed that even though the levels of knowledge about exclusive breastfeeding were reasonably high, there was low adherence because mothers, husbands and grandparents believed that exclusive breastfeeding was not sufficient for the babies and that solid foods and water were necessary. Additionally, studies carried out by Babakazo et al., (2015) in Democratic Republic of the Congo indicated that the percentage of breastfeeding remained low because some mothers lacked confidence in the ability to breastfeed; while others had no intention to exclusively breastfeed. There are circumstances, like HIV positive mothers with high viral load where clients are instructed by healthcare providers to completely avoid breastfeeding, and commercial infant formula is the recommended infant feeding option (Myer et al., 2017). But this may not be a safe or feasible option for many HIV positive mothers in resource poor areas (Zehner, 2016). Mothers in poor countries face issues such as poverty, lack of their own food to produce breast milk, the expense of infant formula, lack of access to safe clean water, unsanitary living conditions, increased risks to their children from common childhood illnesses, inadequate healthcare facilities, all complicated by the socio-cultural factors (Agambire, 2013).

Given that these benefits are essential to infant's foundation, healthcare professionals, especially the nurses and midwives have a paramount duty to achieve a high percentage

through extensive education to parents and close family members regarding the benefits of breastfeeding. An important factor to successful breastfeeding is the role played by the partner (Lowe, 2011). Unfortunately, some partners perceived their wives as suffering and struggling to breastfeed and viewed breastfeeding as a potentially harmful practice because they lacked the knowledge, understanding and skills since they were excluded in the breastfeeding education and support sessions (Brown & Davies, 2014). Their account demonstrated that breastfeeding problems affect families, which would lead to decline in the breastfeeding adherence. Therefore, as much as exclusive breastfeeding has been advocated for with its immense benefits, there are some limitations to its successful implementation especially among the HIV positive mothers in resource limiting areas like the slums. To counteract these limitations, the lactating mothers' knowledge of and attitudes towards exclusive breastfeeding such as mothers' misconceptions and misunderstanding, their role in determining the choice of breastfeeding and the level of education should be addressed. It is recommended therefore, that education on breastfeeding be commenced as early as when a woman plans to become pregnant and continue during pregnancy and postnatal period. Furthermore, immediately and during the postnatal period, mothers require a lot of support on how to initiate breastfeeding, especially if they are first-timers. This includes the practical support in showing the correct breastfeeding positioning and attachment, and how to manage the minor disorders breastfeeding should they occur.

A study carried out in two slums in Nairobi, Kenya by Wanjohi et al., (2017) indicated that cultural and social beliefs influence breastfeeding practices. It is important that people involved in promoting breastfeeding understand the socio-cultural and environmental

circumstances regarding breastfeeding; and that messages need to be tailored to specific groups to maximize the chances of success in optimal breastfeeding practices and improved infant nutrition outcomes. Hence, the need to place oneself amidst the community of HIV positive women living in the slums, who have opted to exclusively breastfeed their infants and get familiarized with their real lived experiences; seeing things from their worldview before sharing the recommended guidelines or giving instructions on feeding options to the HIV infected and affected families.

2.2 HIV infection and breastfeeding

HIV is a microscopic virus that comes from the sphere of molecular biology belonging to the family Retroviridae which have Ribonucleic acid (RNA) genomes and according to the theory of retroviruses, an additional step in their replication cycle is the reverse transcription of their genome (Horton, 2017). This virus is made up of a cylindrical core that contains the viral RNA, and the enzymes reverse transcriptase, protease and integrase, which the HIV virus uses for infection and replication. The result of HIV infection is relentless destruction of the immune system leading to onset of the acquired immunodeficiency syndrome. The HIV/AIDS pandemic resulted in many deaths of victims (Edward C. Klatt, 2017). Globally, there are efforts to ensure that advances in treatment and care of HIV/AIDS clients are available, but the pandemic continues to spread throughout due to structural inequalities and lack of resources (Denis, 2014). This makes HIV infection remain increasingly concentrated in the poorest and most marginalized sectors of society in all countries. Further studies on HIV virus that causes AIDS indicated that the condition is characterized by vigorous viral replication, Cluster of Differentiation 4 (CD4), which is a glycoprotein found on the surface of immune

cells such as T helper cells, monocytes, macrophages, and dendritic cells; plus lymphocyte depletion and profound immune deficiency making the infected individual highly susceptible to all manner of infections which the individual up to then could resist (Nwaozuzu & Dozie, 2014). The HIV attacks the immune system making it difficult to fight infections and diseases (Wahl et al., 2012).

Unfortunately, the HIV that causes AIDS is one of the world's most serious public health challenges, despite the numerous efforts put to control the situation. Consequently, HIV and AIDS continue to be a global phenomenon that is rapidly killing people without discrimination in terms of race, sexual preference, age or socio-economic background (Hinckley, 2011). Worldwide there is 1 percent of pregnant women are HIV positive, with, Sub - Saharan Africa being most affected with 95 percent of HIV positive women (Hampanda, 2013). Exclusive breastfeeding is the cornerstone of any society and the main indicator of the health status especially in the infants who are exclusively breastfed because they have a much better chance of survival as opposed to those infants who are mixed fed (Sawe, 2010). Therefore, there is an urgent need to create a workable relationship between HIV/AIDS, social and economic development that should become a central point in policy discussions about the most effective responses to the epidemic.

Although mothers were reported to have adequate knowledge on breastfeeding benefits and had received health messages on infant feeding and could all access healthcare services, unfortunately mixed feeding was reported to be the practice. However, prediction by World Health Organization (2007) was that between 2010 and 2018 around 1.4 million HIV

infections among children would be prevented due to PMTCT programmes. Although this expectation has not been realized, it is important to acknowledge efforts made towards the prevention of mother to child-transmission programmes that reported substantially lower rates of perinatal transmission through use of ARVs, breastfeeding infants and lactating mothers (Coovadia, 2009). Evidently, although both HIV testing programmes and antiretroviral prophylaxis are available, regrettably many infants become infected through breastfeeding in resource poor countries. Studies carried out by Sama et al., (2017) showed a gap in the current intervention strategies including scaling up of PMTCT measures; implying the need to strengthen the overall prevalence of maternal HIV prevention strategies that in turn would curb the growing burden of paediatric HIV. Nevertheless, Since the scale-up for PMTCT services, rates of HIV infection among exposed infants have significantly declined (Wudineh & Damtew, 2016). This is supported by a randomized clinical trial study carried out in Uganda by Cohan et al., (2015) to establish the efficacy and safety of combination of the antiretroviral therapy and provided evidence to support current WHO guidelines that recommend efavirenz as a first-line regimen and lopinavir/ritonavir as an alternative as the global standard for HIV-infected pregnant and breastfeeding women at all CD4 cell counts.

Kenya ARV guidelines 2018 were released for the healthcare providers to support and strengthen strategies that ensure good health for the breastfeeding mothers and their children. These include provision of a comprehensive package of fully integrated, routine antenatal care interventions, ignition of lifelong antiretroviral therapy in all pregnant and breastfeeding women living with HIV, regardless of gestational age, WHO clinical stage

and at any CD4 count. Emphasis has also been placed on the need to have all infants irrespective of HIV status exclusively breastfed for the first six months of life, with timely introduction of appropriate complementary foods after six months, and continued breastfeeding up to 24 months or beyond. According to Kindra et al.,(2011) effective antiretroviral prophylaxis to the mother or infant during breastfeeding can reduce vertical transmission to as low as 1 percent. However, to help maximize HIV free survival of infants', longer breastfeeding period with prophylaxis as well as the timely start of ART for the mothers was recommended.

According to Kates, (2015) fact sheet, the latest statistics were that global prevalence among adults aged 15 to 49 who are infected has levelled since 2001 and was projected to be 0.8 percent in 2017. Further, there were 36.9 million up from 32.4 million people living with HIV in 2010 indicating continuation of new infections. Although there was decline since 1990, there were still about 1.8 million new infections in 2017, with new infections of about 5,000 per day. These statistics are alarming despite the global efforts, and show that HIV remains a major concern that seems to have been side-lined, especially in the Sub – Saharan African countries that are most affected. According the WHO, breastfeeding by HIV infected mothers carries a risk of HIV transmission from mother to child, and that risk decreases from 45 percent to less than 5 percent with the practice of exclusive breastfeeding and appropriate antiretroviral therapy. Fortunately, in some HIV infected women, the virus does not cross the placenta from mother to foetus during pregnancy, as long as the mother remains relatively healthy, because the placenta helps to protect the foetus from infection. But, HIV-1 in breast milk originates as a blood cell free virus released into breast milk; it is

produced by local replication in macrophages and in ductal and alveolar mammary epithelial cells. It is also detected in both cellular compartment of breast milk (Kevin Clark, n.d.).

There is evidence that in resource limited settings, exclusive breastfeeding among HIV infected mothers reduces infant morbidity and mortality from all causes including HIV (Tuthill, 2015). However, exclusive breastfeeding rates remain low. Further studies by Hazemba et al., (2016) suggested that as much as a broader health promotion campaign supporting all mothers to exclusively breastfeed has been advocated; more efforts are needed to improve communication skills among Community Health Workers (CHWs), who are the main caregivers in the community. Unfortunately, a qualitative study carried out in Kenya showed that there was stigma associated with HIV and exclusive breastfeeding in HIV endemic regions because women who adhered to this practice were perceived to have HIV infection (Odeny et al., 2019). This poses a big challenge to widely educate the communities to support women who opt for exclusive breastfeeding. It is also important to target all women and equip them with information and support on exclusive breastfeeding practices regardless of maternal HIV status in order to improve acceptance and hence, children survival rate. This will ensure the provision of objective infant feeding counselling regardless of the method of feeding promoted for HIV positive mothers to avoid mother to child transmission, especially those living in the slums and have opted for exclusive breastfeeding. Therefore, there is great need to create a midwifery education model that would address this important aspect that will widen the scope of healthcare services provided to the child-bearing women.

2. 3 Mother to mother transmission

The emergence of HIV/AIDS epidemic and the recognition that HIV positive mothers can transmit the virus to their babies during pregnancy, childbirth and through breast milk precipitated a terrible public health dilemma in countries with a high incidence of HIV (B, Allen, & Ph, 2012). Evidence of HIV and MTCT has surfaced from various research findings (Mandala & Dirks, 2012; Bekere et al., 2014; Sama et al., 2017). This situation continues to be a major concern in poor Sub- Saharan African countries like Kenya where breastfeeding is the norm and essential for child's survival. In these countries, Mother to child Transmission of the virus is the primary way that causes infection to the children; and without prevention, over 40 percent of the children born to HIV positive mothers are affected.

According to a renowned Professor researcher in HIV and breastfeeding, Anna Coutsoudis, of the Department of Paediatrics and Child Health at the University of the KwaZulu-Natal, Durban, until recently, the World Health Organization advised HIV positive mothers to avoid breastfeeding if they were able to afford, prepare and store formula milk safely. But evidence from research has since emerged that shows that a combination of exclusive breastfeeding and the use of antiretroviral treatment for both mothers and babies can significantly reduce the risk of transmitting HIV virus to infants ("WHO | Breast is always best, even for HIV-positive mothers," 2011a). This was supported by Kemp, (2018) and Umeobieri et al., (2018) who maintained that the reduction of HIV infection rates and the growing evidence of breast milk's benefits have convinced some experts that it is appropriate for many HIV positive mothers to breastfeed their infants. Hence, advocating

the factor of exclusive breastfeeding as an option that aims at protecting the infant from the HIV virus. This new approach brought relieve to many HIV positive mothers and breastfeeding advocators in Africa as cited in Infant, (2011) as evidenced by the following:-

> *"I am proud that our nation came to a decision that protects and supports breastfeeding. With the high level of malnutrition among children under five and the low rate of exclusive breastfeeding, we need to promote consistent messages about infant feeding and ensure that optimal breastfeeding is the norm in Nigerian society."*
>
> ***Prince Wasiu Afolabi, Former IYCN Country Coordinator***

However, this factor is strengthened by a mother's belief that the breast milk is enough for the infant depending on her nutritional status, support from significant others, mother's own decision on infant breastfeeding; plus, the knowledge and belief in breast milk properties. The role played by healthcare workers' influence on exclusive breastfeeding through effective breastfeeding education, and the facilitation in immediate initiation of breast milk is fundamental (Access, 2015). Nevertheless, according to Koima's (2013) study, implementing exclusive breastfeeding as part of efforts to prevent mother to child transmission of HIV was still a challenge in resource poor settings because the HIV positive mothers did not adhere to exclusive breastfeeding. This was due to several factors such as lack of a breadwinner and unavailability of sufficient food in the household, failure to disclose HIV status to husband and relatives and the inability to attend the required prenatal clinic visits for education and support.

In countries where culture dictates breastfeeding as the only acceptable method, with women attuned to such, and with little choice of alternatives, these women are put under undue pressure. According to Fox et al., (2018), mothers share a common cognitive understanding of infant feeding messages. Unfortunately, studies carried out in Cameroon by Njom et al., (2018) showed that alongside PMTCT interventions using ARVs, the practice of mixed feeding was common and appeared as a contributing factor to HIV 1 transmission to children that contribute on mortality among children. There is need to embrace continuous counselling on best feeding practices throughout the PMTCT especially in the resource limiting settings to help further eliminating new MTCT while improving the life expectancy of children within PMTCT high in priority countries. The woman's psychological health, client centred counselling and context sensitive support ought to be sustained to meet the individual's needs because responses to diagnosis and the realization of not being able to breastfeed are received differently by women. The culture, socio-economic, family, and now the medical profession all influence their decision-making abilities and processes.

The World Health Organization promotes a comprehensive approach to PMTCT programmes by providing appropriate treatment (WHO, 2010). Earlier guidelines recommended that all pregnant women living with HIV be immediately provided with lifelong treatment, regardless of CD4 count with 91 percent of the 1.1 million women receiving antiretroviral drugs as part of PMTCT services receiving lifelong ART (Siegfried, et al., 2011). Later, WHO released further guidelines recommending a 'treat all' approach, meaning all people diagnosed with HIV should be offered immediate treatment. This

increased the number of women of reproductive age who are taking ART, regardless of whether they are pregnant or not. Many countries have implemented these World Health Organization guidelines (World Health Organization [WHO], 2007). This is not withstanding that these guidelines continue to confuse not only healthcare providers, but also the HIV positive women who have to make difficult decisions about the best options for themselves and their babies. Nonetheless, from optimistic point of view, and according to Chi et al., (2013), with an ever-growing awareness of highly effective PMTCT interventions and unprecedented resources available to implement new interventions across the continent, it is now possible to envision the virtual elimination of paediatric HIV in Sub - Saharan Africa. This is supported by further studies carried out in South Africa suggesting that PMTCT in Africa is optimized when interventions engage and empower community members, including male partners, to support program implementation and confront the social, cultural and economic barriers that facilitate continued vertical transmission of HIV (Dunlap et al., 2014).

Unfortunately, for the women who are HIV positive, other factors such as low Cluster Differential 4 count, high viral load, and breast pathology increase the risk of a mother transmitting HIV during breastfeeding (Srinivasula et al., 2011). In addition, the urban poor informal settlements or slums present unique challenges with regard to infants and children health and survival, where death rates are as high as four times before the age of five than those from a privileged background. Slums in Sub - Saharan Africa are expanding at a fast rate, and many urban residents live in slum settlements with their families endangering the health of children (Fink et al., 2014). These slums are characterized by poor environmental

sanitation and livelihood conditions that are made worse by the lack of employment opportunities and the rapid population growth. Moreover, HIV positive mothers from such settings are faced with challenges in complying with optimal breastfeeding practices owing to lack of community support complicated by fear of self- disclosure of their HIV status (Marinda et al., 2017). Hence, it is important to explore the real lived experience of HIV positive mothers living in the resource limiting areas especially those living in the slums. Thus, assist healthcare providers in their efforts to prevent transmission of the virus to children who form part of the future workforce in any nation. Despite the quality work done around the topic of HIV and breastfeeding, and many clients embracing the recommended guidelines like use of ARVs to minimize spread of the virus especially from mother to child, obvious gaps have emerged from these studies that need to be addressed by deepening the understanding regarding what informs the choices to breastfeed and the challenges faced.

2.4 Use of the antiretroviral drugs

Globally, there has been scale up of antiretroviral therapy that is associated with the primary contributor to a 48 percent decline in deaths from AIDS related causes from a peak of 1.9 million in 2005 to 1.0 million in 2016 according to the Joint United Nations Programme on HIV/AIDS (UNAIDS., 2017). Out of these, 51 percent of people living with HIV in the world are female who are likely to get pregnant and transmit the virus to their babies. But the good news is that there is a higher treatment coverage and better adherence to treatment among women that has driven more rapid declines in AIDS related deaths among females and obvious better outcomes for those who get pregnant. According to Lundgren et al., (2013), there is a global consensus that the benefits and the risk ratio favour use of ART in

any HIV positive person with moderate HIV induced immunodeficiency; whereas current evidence makes it uncertain whether this ratio is also favourable if ART is initiated earlier on the course of HIV infection. Although there was no definite conclusion from this particular study, the WHO guidelines of 2013 made a strong recommendation to start ART based on individual's CD4, which is a glycoprotein found on the surface of immune cells such as T helper cells, monocytes, macrophages, and dendritic cells. Further studies by Siegfried et al., (2010), indicated that there is evidence that initiating ART at CD4 levels higher than 200 or 250 cells/microL reduces mortality rates in HIV infected people, recommending that practitioners and policy makers may consider initiating ART at levels </= 350 cells/microL for patients who present to healthcare facilities and are diagnosed with HIV infection. Hence, CD4 count played an important role in early HIV epidemic as a concrete, biological clinical surrogate marker with which to rationally distribute medications.

It is worth noting that studies carried out by Chikhungu et al., (2016) indicated that the availability of antiretroviral treatment for HIV positive mothers has decreased the rate of new infections by 58 percent from 520,000 to 220,000 between 2000 and 2014. This provided evidence of substantially reduced postnatal HIV transmission risk under the cover of maternal ART. However, transmission risk increased once ART stopped at six months, which supports the current WHO recommendations of life long ART for all (Bispo et al., 2017). When ARV drugs are not immediately available, the WHO guidelines still recommend mothers exclusively breastfeed for the first six months of an infant's life and continue, unless environmental and social circumstances are safe for and supportive of

replacement feeding. This decision is based on international recommendations, but other considerations such as the socioeconomic and cultural contexts of the population groups served by maternal and child health services, the availability and quality of health services, the local epidemiology including HIV prevalence among pregnant women, the main causes of under-nutrition among mothers and children and infant and child mortality as recommended by the World Health Organization beckon for attention (WHO, 2007).

However, according to Hyun et al., (2015), a universal, highly potent and safe ART regimen for all individuals living with HIV, regardless of their CD4 count especially those from low income communities, including pregnant women is clearly the most beneficial strategy to keep mothers alive and healthy and to prevent transmission of HIV to their children. These studies were challenged by Yagi & Ton, (2011), earlier study who had argued that there was discordance in global ART initiation guidelines based on CD4 count, suggesting that CD4 count may not be a reliable surrogate marker for ART initiation. This created more confusion in healthcare providers who guide clients based on current evidence based information. Nevertheless, since evidence is now strong that antiretroviral drugs used during lactation prevent transmission of infection from a seropositive mother, strategies that promote exclusive breastfeeding can now be recommended for enhancing the health of mothers and infants (Kuhn, 2012). Further studies carried out in Zimbabwe by Chadambuka et al., (2017) on acceptability of lifelong treatment among HIV positive pregnant and breastfeeding women revealed that, although most women accepted lifelong ART, there was fear of commitment to taking lifelong medication because they were afraid of defaulting, especially after cessation of breastfeeding, confusion around dosage and fear of side effects;

not having enough food required to take alongside with the drugs, and the lack of opportunities to ask questions in counselling sessions.

It is also important to note that research conducted by Boateng et al., (2013) indicated that adherence to antiretroviral drugs is necessary to prevent drug resistance and MTCT among HIV positive women. However, a gap in clients' knowledge, attitudes and perceptions of antiretroviral therapy and Prevention of Mother-To-Child Transmission was identified as a major concern that influences decision to ART compliance. Notably, for many of these studies, the use of antiretroviral drugs was combined with other interventions such as the Caesarean Section (C/S) mode of delivery and the exclusive use of formula milk instead of breastfeeding. Regrettably, these options were only proven to be successful in the richer developed countries like the United States and Western Europe. In the Sub - Saharan African countries where the prevalence of HIV/AIDS has remained high, there is little access to such options. Unfortunately, there seems to be confusion around the use of ARVs based on CD4 count (Di Mascio et al., 2011); putting healthcare providers and the clients in a dilemma. Consequently, HIV positive mothers living in resource limiting areas are faced with challenges of adherence to ARVs that should accompany exclusive breastfeeding or choosing the alternative feeding method.

According to an article written by Angela Oketch and Pauline Kairu 2019 ("WHO recommends once feared drug to treat HIV - Daily Nation," n.d.) the WHO has recommended Dolutegravir (DTG) which was a once feared drug to treat HIV as it was associated with severe side effects such as defects in the brain, spine or spinal cord that were

higher for babies born of women on the drug. The WHO has opted to update the HIV therapy guidelines to strengthen recommendation for DTG drug as the first-line treatment because of its efficacy, tolerability and a high genetic barrier to resistance. This news was well received by the HIV positive child bearing women because the drug has been shown to have better outcomes. However, it is hoped that it will be made available to the people of Sub-Saharan Africa especially those living in resource limiting areas such as the slums, who opt to breast feed their infants and have challenges accessing the recommended choice of alternative feeding of formula milk.

2.5 Formula milk as an alternative method

In many societies**,** bottle-feeding using formula products is perceived as the modern way, while breastfeeding is perceived as old fashioned and inconvenient method, and associated with poverty (Keraka & Wamicha, 2014). Researchers such as Ramara et al., (2010) confirmed that a substantial percentage of 80 percent of mothers opted to formula feed their infants, while those who opted for breastfeeding were only 20 percent and they also practiced mixed feeding. It was clear that most of the mothers lacked appropriate facilities to sustain availability of the milk formula and basic sanitation. According to Lakshman et al., (2009), inadequate information and support for mothers who decide to bottle-feed may put the health of their babies at risk. Notwithstanding the importance to promote breastfeeding, it is also necessary to ensure that the needs of the mothers who choose to bottle-feed are met. Therefore, decisions about feeding options should be based on adequate and unbiased information rather than ignorance because this is what informs choices.

Mothers who are HIV positive have the right to detailed information when they are making decisions about infant feeding.

Studies conducted by Smith et al., (2016) showed that there is an existing dilemma on the type of formula feed to choose associated with parents' perception of infant satiety and lack of healthcare advice. As a result, within the first twelve months, there is changing from one type of feed to the other which could result to intolerance and affect the baby's health. Further claims from studies carried out by Gizaw et al., (2017) showed that the developing countries had increased mortality risks due to infectious diseases among non-breast feeders, particularly the very young infants of two to three months of age whose incidence of diarrhoea and pneumonia was high. Cost implications were also identified as inhibiting factors (Thi & Hong, 2015). Evidence from several studies has implied that there was a substantial mortality associated with not breastfeeding especially in poor settings areas like the slums (Nduati et al., 2012; Wildeman et al., 2016).

The emphasis should be placed on the importance of developing feeding policies that are appropriate and relevant to child-bearing women especially those living in resource limiting areas, and thus assist them in their efforts to improve infant health. In return, this will be successfully supported by healthcare service providers and guide individual mothers in their feeding choices. A cohort study carried out in India on the effect of formula feeding and breastfeeding on child's growth, infant mortality, and HIV Transmission in children born to HIV infected women who received triple Antiretroviral Therapy in a resource limited setting concluded that the use of formula feeding was associated with increased risk of mortality

and lower HIV free survival compared to breastfeeding (Alvarez-Uria et al., 2012). Furthermore, although breastfeeding was found to increase the rate of HIV transmission, formula feeding was found to be associated with malnutrition during the first months of life, increasing mortality and, therefore, has lower HIV free survival compared to breastfeeding. The results of this study confirmed the WHO 2015 guidelines recommending that all pregnant persons living with HIV be immediately provided with lifelong treatment, regardless of CD4 count (Bigna et al., 2016). This is more applicable in Sub - Saharan Africa whereby, supporting the implementation of universal ART regardless of CD4 count to all HIV infected pregnant women and breastfeeding for all HIV exposed children in order to achieve WHO goals of elimination of paediatric HIV without increasing infant mortality in developing countries that are associated with high levels of malnutrition.

Global trend of having a universal, highly potent and safe ART regimen for all individuals living with HIV including pregnant and breastfeeding women is clearly the most beneficial strategy to keep mothers alive and healthy and to prevent transmission of HIV to their children (Hyun et al., 2015). Nevertheless, a randomized clinical trial study conducted by Nduati et al., (2012) focused on breastfeeding and formula feeding to identify the frequency of breast milk transmission of HIV 1 to infants; and to examine the effect of breastfeeding on maternal death rates during two years after delivery, concluded that the mortality among mothers was higher in the breastfeeding group than in the formula group. Thus, creating more confusion on how to balance the best feeding options that could result to favourable outcomes for both mothers' and infants' health. It is obvious from various studies that decisions to forego the benefits of breastfeeding do not compare well with the associated

risks of using formula milk. This is most relevant in the poor countries like those in Sub – Saharan Africa, Kenya included and in particular in the slums where formula milk is too expensive or unavailable, and there is little access to clean water for preparing it.

Bottle feeding is also discouraged in areas where there is improper sanitation, especially in the slums where sewage water surrounds the slum houses that are overcrowded with poor ventilation. This is because with formula preparation and non-adherence to hygiene, bottle feeding can introduce pathogens to the infant, putting the child at a greater risk of illness and malnutrition (Lokare & Hippargi, 2015). Therefore, formula milk although recommended as an alternative feeding method of babies born of HIV positive mothers may not be an option in resource limiting areas, especially in the slums of Nairobi, Kenya, where income, sanitation, water and living conditions remain opposing factors. Unfortunately, from many studies, the feeding method options seem to have unique challenges which place the healthcare providers in an awkward position when trying to support the HIV positive mothers in their breastfeeding choices. Since research often unearths the hidden treasures, it is hoped that this study will equip the healthcare providers with relevant knowledge distinctive to this population whose health seem to have been compromised. Thus, empower them to make informed decision regarding breastfeeding.

2.6 Decision-making in breastfeeding

There are various factors that inform the choices women make pertaining to breastfeeding options. It is important therefore to understand women's specific reasons for the choice of feeding their infants, why they stop breastfeeding and the choice of breastfeeding duration.

In the low and middle income countries, especially in Africa, significant 'others' like grandmothers and other relatives play a central role in various aspects of pregnancy and child rearing decision-making within the family unit (Negin et al., 2016; Chaponda et al., 2017). This is pecked on the fact that there are perceived as owners of traditional wisdom, and this leaves no room for the HIV positive women, especially those who do not wish to disclose their HIV status. It is critical that infant feeding choices be influenced by the nursing and midwifery personnel who should marry the influential authority given to them with correct information to those concerned with decision-making in order to change feeding behaviours that seem to be affected by family dynamics. Further study carried out in Kenya by Nabwera et al., (2017) indicated that infant feeding decision-making by mothers living with HIV is constrained by a lack of autonomy, stigma and poverty. It is important thus, to develop approaches that foster empowerment and psycho-social support of mothers, and increase the involvement of influential family members such as husbands, mothers in law and aunts in infant feeding counselling sessions that would serve to optimize their infant feeding choices. This study strengthened an earlier research by Laar & Govender, (2011) in Southern Ghana that emphasized on the role of breastfeeding played by fathers, and significant others such as grandmothers, friends and even the community members. Consequently, there should be enhancement in understanding women's breastfeeding experience and providing women with emotional support (Brown et al., 2016). This awareness provides an opportunity to healthcare providers to not only address the issues of pain, physical discomforts of breastfeeding, postnatal depression but more importantly the psychosocial reasons highlighting the importance of spending time with mothers and providing the necessary support, especially in the HIV positive women living in resource

limiting areas. The socio-cultural factors greatly influenced by poor nutrition and the pre-determined practice especially the perception of having insufficient milk production by the mothers, that is often associated with lack of the recommended lactational nutrition play a key role in breastfeeding choices (Kimani-Murage et al., 2017).

It is worth noting that among the population of HIV positive mothers are the teenagers who find themselves pregnant. Findings from a study on teenage mothers' knowledge about recommended feeding practices showed that they had no role in infant feeding decision-making process because this role was mainly played by the older mothers in the family (Jama et al., 2018). This was also associated with their age and financial dependency that diminished their autonomy and ability to influence feeding practices or challenge incorrect advice; returning to school and fear of breastfeeding in public were also barriers to exclusive breastfeeding for these teenage mothers (Shakya et al., 2017). This study highlighted the need for the healthcare workers to ensure that knowledge about infant feeding is shared with the teenage mother's family, where feeding choices are made. Hence, improving support for this category of mothers and positively impact on the nutritional status of the children. Therefore, HIV service providers should seek to embed themselves in other child health service promoters like those dealing with youth to normalize infant feeding strategies in the context of HIV.

Although the whole aspect of breastfeeding and HIV appears to be a complex one, with proper approach from the clients, healthcare providers, institutional administrators and policy makers, best choices can be made to maintain the health of the mothers and their

babies. It is clear from these reviews that with the era of HIV/AIDS, ensuring safe breastfeeding cannot be as easy as a quick conversation at the clinics. Although the recommendations imply that HIV-positive mothers should exclusively breastfeed their infants, it should be recognized that a careful balance between the risks of HIV transmission and elaborated education on the well-known nutritional benefits of breastfeeding should be maintained to convince the women on the choice they have made.

2.7 Chapter Summary

This chapter covered the literature relevant to the study. The different studies generated good knowledge on the issues of breastfeeding and HIV infection mainly in the developing countries of the Sub-Saharan Africa, MTCT, and the recommended preventive measures. The alternative feeding method for HIV positive women was also reviewed. The issues, gaps of knowledge and practice inherent in these studies were identified, especially pertaining to HIV/AIDS positive mothers, who choose to exclusive breastfeed their infants and are living in resource limiting areas. Therefore, there was need to explore this aspect of women's experiences and perspectives by carrying out a research with a methodology approach that enabled the researcher to enter into women's world and allowed them to narrate their real lived experiences, bring meanings into their lives in the natural settings. This enabled the researcher to gain more insights to the study, suggested possible ways to address the gaps and help the HIV positive women enjoy their motherhood as well as safeguarding the health of the infants. The following chapter described the most appropriate methodology for the study that included the design, methods and the techniques used for data collection.

CHAPTER THREE

Methodology

3.0 Introduction

Research is based on some underlying philosophical assumptions about what constitutes to a valid study and which methodology approach guided by the researcher's paradigm is appropriate for the generation of the envisioned knowledge (Spector et al., 2014). Furthermore, a paradigm is a perspective undertaken in research where the researchers summarize their beliefs about efforts to create new knowledge to be shared by a scientific community that provide guidance about inquiry and a specific way of viewing reality (Bruin, 2014). Hence, for this study, the researcher's paradigm guided her in the selection of the methodology that would create evidence based on nursing and midwifery knowledge to help better the services rendered to the HIV positive women living in resource limiting areas. Given that different paradigms provide an approach to understanding how social phenomena are guided by certain philosophical underpinnings (Addae, 2015; Shannon-baker, 2016), it was important for the researcher to stay within the paradigm stemming from the field of work that is informed by her experience, belief systems, philosophy, efficiency and effectiveness. Therefore, the researcher focused on a paradigm that directed her to the connected assumptions about the social phenomena of HIV and breastfeeding, providing the philosophical and notional frame for studying them pecked on values, beliefs, convictions and assumptions that broadened the whole system of thinking and explained how the world is perceived by the HIV positive breastfeeding women living in resource limiting areas.

Furthermore, the researcher acknowledged that there is a relationship between paradigm and methodology chosen because the methodological implications of paradigm choice direct the researcher to the research questions, selection of the participants, data collection method and analysis (Kivunja et al., 2017). Additionally, the philosophical underpinnings of the appropriate methodology are vital to choices of design and knowing the importance of what the researcher stands ontologically and epistemologically (Devetak et al., 2010; Wahyuni, 2012; Young & Hren, 2017). Since the researcher's aim was to scrutinize the social phenomena in the context of experiences of breastfeeding in the HIV positive mothers living in the slums, the research paradigm led to the choice of the relevant research methodology.

3.1 Qualitative Methodology

The important role played by qualitative approach and its usefulness is appreciated in many fields including healthcare, where use of the various styles in exploring and describing complex phenomena provides textual accounts of individuals' life worlds (Teherani et al., 2015). Furthermore, a collectively qualitative research is a group of methodologies, with each approach offering a different lens through which is used to explore, understand, interpret or explain phenomena in real word contexts and settings as well as addressing the social and behavioural issues related to public health that are not achievable with quantitative methods (Moen & Middelthon, 2015). Hence, the choice of the qualitative methodology as the most appropriate approach for this study was deemed necessary to give a voice to the HIV positive women who represent the vulnerable population from many healthcare settings (Erlingsson & Brysiewicz, 2017). This was based on the fact that the qualitative approach attempts to uncover meanings via analysis of non-numerical data

obtained from multiple sources of information such as words, images, impressions, gestures and tones. According to Isaacs, (2017), qualitative research methodology is useful when the research focuses on complex issues such as human behaviour and felt needs because it looks at the significance of both personal role and social construction of reality within the paradigm. The focus turns to understanding human beings' richly textured experiences and reflections about those encounters and brings about the understanding of human beings' experiences in a humanistic, interpretive way. Furthermore, critical qualitative methodology offers an approach to scrutinize the human experience and its relationship to power and reality bringing out meaning and experience dimensions of humans' lives and social worlds as the researcher aims to get the whole picture. Thus, the aim was to bring in a holistic humanistic, intense and systematic examination of breastfeeding in HIV positive women, which is a complex phenomenon that need to be addressed by understanding the women's perspectives, experiences, interpretations and meanings they bring to their complex situations (Astin & Long, 2009).

Using qualitative research methodology situated the activities, located and placed the observer researcher in the world of a set of revealing material practices that make the world visible and transformative (Matsumoto & Domae, 2018). This approach also provides a systematic inquiry into social phenomena and events in natural settings, often interpreting them in terms of the subjective implications attached to the individuals under study, and allowing more detailed investigations of the issues (Carolyn et al., 2011). Hence, answering the questions of meanings as understood by the HIV positive in women living in the slums. This phenomenon included, but was not limited to how the HIV positive women who had

given birth and are exclusively breastfeeding their infants experienced their lives, how they behaved and how interactions shaped their relationships. Cultural safety is a concept that has been applied to nursing and midwifery practice as it refers to interactions that recognize and respect the unique cultural background of clients (Harrowing & Mill, n.d.).Therefore, the use of qualitative research in this study was relevant because of its characteristics of relating to understanding some aspect of social life as noted by B. et al., (2011). In addition, the design and methods which generated words rather than numbers and data analysis that was aimed at determining health concerns of the participants, family members and community residents developed a creative intervention approaches for addressing the concerns of the HIV positive women living in the slums.

3. 2 Research design

According to Creswell John, a renowned professor associated with mixed methods research, the research design process in qualitative methodology begins with philosophical assumptions that the inquirers make in deciding to undertake a study. In this way, the approach help in the examination of the design method and technique of data collection; analysis and interpretation (Creswell, 2014; HU, HU, & CHANG, 2017). Further, issues of validity and reliability play an important role that underpin the quality of the study (Approaches, 2017). From the researcher's paradigm and aim of the study, it was important therefore to opt for the best design to direct a meaningful and relevant means for the study to be carried out. The process of this research involved immersion in the everyday life of the natural settings of the HIV positive women, their families and community that enabled

the researcher to enter the women's world within their context, giving a direction towards to the most appropriate study design.

3.2.1 Ethnography

Ethnography as a research design goals include describing a particular cultural context and offering interpretation of places, people and other meaningful things within that context, as well as people's behaviour studied in everyday environments (Jones & Smith, 2017). Additionally, as stated by Sangasubana, (2009), ethnographers seek to unearth the predictable patterns in the lived human experiences by carefully observing and participating in the lives of those under study because it is conducted on-site in a naturalistic setting in which people live; addressing areas where understanding is inadequate and making sense of complex situations and social processes. Hence, in this study, the researcher was able to learn from the participants' lived experiences, beliefs, motivations and options as implied by Wall, (2015).

This type of research design invited the researcher to simultaneously immerse into a culture and become a participant observer providing an opportunity to see and understand the cultural means pertaining to breast feeding from the perspective of the HIV positive women and their families within the natural settings. This provided an opportunity to understand the big picture through exploring their needs as well as understanding their language, concepts and beliefs (Aug, 2017). There was full engagement by the researcher in the day to day lives and cultural norms of the families under study with the main focus on HIV positive women and breastfeeding practices. Central to ethnography study is the process scrutiny of

specific social phenomena, a tendency to elicit unstructured data, and even though the sample size tend to be small, the product of analysis is narrative description that includes an unequivocal, acknowledgement of interpretation of the significance and purpose of human behaviours (Higginbottom, n.d.). Therefore, although the participants' sample chosen for this study was small, data obtained was thick, comprising of written notes; as well as artefacts that were analysed to understand how women living with HIV/AIDS, who had given birth lived their lives within their social-cultural aspect, and what they valued.

Specifically, in this study, the researcher was able to observe and interact with the HIV positive women who had opted to breastfeed exclusively, their partners, significant family members like the grandmothers and in rare circumstances the community members in their real-living environment. This was important because the researcher was concerned with learning from the broader perspectives of life (Simmons, 2011; Jones & Smith, 2017). Thus, by using the ethnographic research design that stemmed from the researcher's paradigm and the qualitative methodology, it was possible to unearth the realities through the social interaction, observations and behaviours that occurred in the HIV positive women who had opted to exclusively breastfeed their infants by obtaining rich, holistic insights into their views and actions as cited by Reeves et al., (2013). The defining characteristics highlighted by Nwaozuzu & Dozie, (2014), that focus on natural settings, intimate face-to-face interaction; presentation of an accurate reflection of participants' viewpoints and behaviours; interactive data collection to build local cultural theories and using the concept of culture as a lens through which to interpret study were all employed to attain adequate enriched data.

3.3 Research setting area

The purpose of this research was carefully considered in order to align its relevance to the field under review and improve nursing and midwifery healthcare services provided to the HIV positive childbearing women both in the hospital and the community settings. In addition, the benefits to the research participants who were the main focus of the study were also taken into consideration, with an overall aim to influence decision and policy-making processes that guide the delivery of wholistic healthcare services in many healthcare institutions (Burchett, et., 2013). Therefore, the research setting area was in Mukuru slums, in Nairobi capital city of Kenya. Mukuru is one of the many informal settlements that have mushroomed within the city in past few decades. It is made up of several slum areas covering an area of 525 acre, hosting approximately 100,561 households, and has a population of 492,000 (Thiong'o 2017). The living conditions in these slums are deplorable characterised by overcrowding with poor housing, limited toilets facilities, inadequate water supply and unhygienic environmental surroundings symbolised by heaps of garbage and sewage water running along the foot pathways and in-between the shanty houses.

The Mater hospital is a faith based institution that has a longstanding history of excellent healthcare services, especially midwifery care since its inception in 1962. Although the patients and clients who seek medical services in this hospital come from high to middle income category, it is situated near the Mukuru informal settlement area where the majority of the residents have no source of income and cannot afford the healthcare services offered in this institution. Nevertheless, as part of the hospital corporate social responsibility, and in keeping to its mission of the Sisters of Mercy to improve living standards of the less

fortunate, the hospital has a well-established department hereby referred to as Mater Comprehensive Care Clinic (MCCC) whose focus is to offer free healthcare services to the poor people living with HIV/AIDS from the nearby Mukuru slums and its environs. Among the beneficiaries of these services are the pregnant HIV positive women who receive comprehensive prenatal care, intra-partum care as well as post-partum care that include close follow ups in the community through home visits with emphasis on the support in breastfeeding options and provision of care to both the mothers and the new-borns. Specific services are also rendered to the families and the community at large, with the aim of improving and uplifting standards of living of this population, whose health seem to have been comprised because of their economic challenges. The clients who visit the MCCC refer to it as their second home, where their needs are met.

3.4 Research question

According to Do & Formulate, (2014), a clear and appropriate research question or set of interrelated questions forms the foundation of good qualitative research that gives the researchers a perspective to see a question as a beginning point for their area of study. The research questions must be clear, open-ended, developed for the specific discipline and researchable. In addition, the reflective and interrogative processes required for developing research questions can give shape and direction to a study in ways that are often underestimated, and as such unearth useful information for the specific study area (Agee, 2009). Hence, it was imperative for the researcher to define a clear open-ended research question based on her creativity, experience and knowledge of the field of inquiry, which was HIV and breastfeeding to guide the types of data to be collected in the study (Flynn et

al., 2010; Baškarada, 2014). The specificity of a well-developed research question helped the researcher to work towards supporting an arguable thesis on the experience of the HIV positive women and exclusive breastfeeding. The researcher's good insight, intuition, analytical thinking and reflection skills played a key role in this study that addressed some aspects of the HIV phenomenon that is often presumed but poorly understood. This enabled the researcher to develop a rich comprehensive and context-bound understanding of the area under review (Ennis, n.d.).

Therefore, in the formulation of a research question, thorough and structured search of existing evidence was deemed important in enhancing understanding to ensure that the proposed question remained relevant to the study (Wiggins, 2017). With the link between cultural values placing such importance on exclusive breastfeeding regardless of the individual women status, it was assumed that the healthcare recommendations on exclusive breastfeeding produce undue pressure on childbearing women who are HIV positive and are living in resource limiting areas such as the slums. The experience could only be understood from these women's perspective by answering the following question: -

"What it is like being HIV positive, a mother living in the slums with instructions of exclusive breastfeeding?"

3.5 Sampling

The complexity of sampling in qualitative research has been acknowledged by researchers (Higginbottom, n.d; Roy et al., 2015). However, choosing a suitable sampling is key in ensuring that the researchers gain greater insight into the area of study. Purposeful sampling is

widely used in qualitative research for the identification and selection of the participants who provide rich information related to the phenomenon of interest (Palinkas et al., 2015). Additionally, the principles of sampling offer purposeful variety based on the intimate relationship between the people and the phenomena interrelatedness of data collection and ongoing sampling decisions. Therefore, for this study, the researcher selected purposeful sampling because she had prior information of the HIV positive pregnant women who were at term and had opted to exclusively breastfeed their babies. However, saturation of data has been acknowledged by many researchers as evidence of rigor in qualitative research, and it is used in qualitative research as a criterion for continuing or discontinuing data collection (Saunders et al., 2018). Thus, allowing the continuity of sampling until theoretical saturation occurs. The researcher interacted with many HIV positive women whose gestation ranged from thirty-eight to forty weeks and were attending the prenatal clinic in the MCCC. From these, five (5) were identified as potential participants for this study; keeping in mind that this number could be more or less depending on data saturation, whereby, the decision was made relating to a need for further sampling and the determinant of adequate sampling that could develop a theoretical category in the process of analysis to improve the quality of data, enhancing richness and depth of the study as indicated by Roy et al., (2015). However, the sample size proved to be enough for this study and provided adequate data that was used to meet the main purpose of the study.

3.6 Methods of data collection

The qualitative ethnographic methods of collection data used by interpretive researchers attempt to derive their data through direct interaction with the phenomenon being studied (Jamshed, 2014; Bradshaw et al., 2017). An important aspect of data analysis is the search

for meaning through direct interpretation of what is observed by researchers as participant observers; as well as what is experienced and reported by the subjects through interview and careful documentation following thoughtful analysis of people's words, actions and records (Ejimabo, 2015). By choosing a qualitative ethnography approach for this study, the researcher ensured that oral narration was gained through a direct encounter with the participants. Additionally, the methods used answered questions about experiences, meanings and perspectives from the standpoint of the participants by providing the researcher with views of the phenomenon under review and cultural aspects within their social world. Thus, the direct relationship between the researcher and participants played an important role. The researcher developed unstructured interview questionnaires to be used to collect data from the key participants. This was enriched by observations and documentation of field notes as the researcher got involved with study participants, who were the HIV positive women; had given birth to live babies and had opted to exclusively breastfeed.

3.6.1 Interviews

Qualitative research deepens understanding of phenomena such as health, illness and healthcare encounters. The most common format data collection in qualitative research used in healthcare is the interviews and observations because data collection is by words and expressions to convey the information gathered to answer particular research questions (Al-Yateem, 2012). Importantly, interviews are particularly useful for gaining the story behind a participants' experience, and also pursuing in-depth information around a topic. Individual in-depth interviews were conducted using semi-structured interviews with open-ended

questions that allowed the respondents to formulate their own responses. Semi-structured interviews were carefully designed to elicit the interviewee's ideas and opinions on the topic of breastfeeding in HIV positive mothers (**Appendix i**).

Privacy and comfort were ensured before the commencement of interview sessions to avoid interruptions. This tool relied on the interviewer following up with probes to get in-depth information on topic under review (Zorn, 2008). Thus, any new situations during the interview process became an opportunity to add to the data, and the researcher had an opportunity to ask questions that were conversational and free-wheeling. This enabled the researcher to adjust questions according to how interviewees were responding rather than rigidly adhere to an interview scheduled. Having explained to the participants what the study entailed, consent to take part in the study was requested from the HIV positive women who had opted to exclusively breastfeed their infants. The researcher provided the vital information to potential participants, that included: - a statement of the research purpose, description of potential benefits, how confidentiality policy would be upheld; and a statement that participation was voluntary and participants were free to withdraw at any time from the study **(Appendix ii).** After establishing rapport, permission to take notes of the interviews was sought from the participants. Following each interview, the recorded notes were checked immediately, messages obtained through non-verbal communication such as gestures, vocal tones were added to the recorded data and any additional information noted. The recorded data in form of notes was transcribed in English by the researcher and those in Swahili were translated into English.

3.6.2 Observations

The unstructured observational method is recommended in the interpretive or inquiry paradigms (Knox & Burkard, 2009). Therefore, along with the interviews, the researcher used unstructured observations that were later recorded as field notes. The researcher played a role as an active participant observer during the scheduled weekly prenatal health talks paying keen attention to how messages on breastfeeding options were given to the pregnant HIV positive women by the healthcare providers. This active participant role was further enhanced during home visits as well as during the interview sessions, where the researcher was able to pick up the unspoken themes.

Bias in unstructured observations has a potential to influence human perceptual errors and inadequacies that are a continuous threat to the quality of obtained information (Denise & Tatano, 2010). However, the researcher felt that during the interviews, there were essential themes emerging from her interaction with participants that could not be captured by spoken and recorded words. The researcher tried to maintain objectivity as she interpreted what was being observed. Condensed field notes that focused on observable actions such as gestures, vocal tones and expressive emotions; the environment and any other observable things that could add value to data were made soon after the observations and the interviews. The themes that emerged were incorporated with those that emerged from the interview sessions and these provided enriched data.

3. 7. Data analysis

The purpose of qualitative data analysis is to use the data in ways that will facilitate the continuing unfolding of the inquiry and lead to a maximum understanding of the phenomena being studied in its context (Bradley et al., 2007; Noble & Smith, 2014). Since data collection is done in the natural settings such as participants' home, the qualitative modes of data analysis provide ways of discerning, examining and interpreting meaningful patterns and themes enhanced by exploration and understanding of the phenomena under review. Rich information was generated about healthcare pertaining to breastfeeding preferences in HIV positive mothers focusing on decision-making**,** culturally determining factors, values and health beliefs.

Coding and categorizing of themes is a key process that serves to organize the copious notes and documents that have been collected (Hedlund, n.d. ; Gibbs, 2007; Maguire & Delahunt, 2017). Open coding was done soon after data collection, and words and phrases used by the participants to describe the phenomena were underscored. By reading and identifying the responses to the questions from the transcripts, the researcher was able to draw out and categorize major themes, issues, ideas and patterns that surfaced from the HIV positive mothers who had opted to exclusively breastfeed their infants. Any other information obtained from non-key participants was considered as it added value to what the selected participants provided. This was done manually rather than by use of a computer package to ensure that the researcher was not distanced from the data.

3.8 Establishing rigour

The social nature of inquiry in qualitative research is an ongoing challenge to the production of good quality work with reliable pool of knowledge (Social, 2011). This stems from the trustworthiness, validity and credibility of the research. It also relates to the extent to which the data provides insights, knowledge and understanding of meanings of the people under study. Additionally, the research users are confident that the knowledge and claims contained within the research are transferable to their area of practice and can be defended when challenged (Bashir & Azeem, 2015**;** Roberts et al., 2019). This study was thus, conducted within the criteria using the standards set by positivists and naturalists that ensure that the researchers adhere to the standards of reliability and validity (Lewis, 2009 ; Barusch et al., 2011; Leung, 2015; Noble & Smith, 2015). The researcher remained faithful to the principles of truthfulness, values, constituency and maintained a neutral stance during the whole research period because the end result would have direct implications for the legitimacy of evidence-based healthcare with the advancement of good clinical nursing and midwifery practices (Ammouri et al., 2014). The aspect of reflexivity as a process that challenges the researchers to explicitly examine themselves in relationship to the research agenda; paying attention to the assumptions, subject locations, personal beliefs, and emotions that enter into their research was embraced through keeping a reflexive journal (Attia & Edge, 2017; Hsiung, n.d.). By practicing reflexivity, transformative insights were adhered to through critical self-examination believed to be an important aspect of qualitative researchers (Mccreaddie & Payne, 2010). In this case, the researcher was able to identify and understand her biases to ensure that there was no influence on the research results.

Furthermore, keeping a reflexive journal helped me, as the researcher, to identify myself in the study. In actuality the demands of an ethnographic research on one's intellect, ego and emotions are far greater than those of any other strategy because it is not possible to predict the way the study will progress or what kind of relationships will be established with the research participants (Jansson & Nikolaidou, 2013). However, to some extent, this approach empowers the participants because they actively partake in the whole research process. Moreover, the researcher acted as an empathetic effective listener and could only ask open-ended questions related to the study area. At the same time, she adhered to flexibility and adaptability to any new situations, which became a source of enriched data. Importantly, the researcher remained impartial and had no preconceived notions about the participants or study outcome. Cautiousness, sensitivity and responsiveness to possible contradictory evidence were welcome as a call for the researcher to be more aware because it was assumed that these women would be in a vulnerable state. All these led to the collection of faithful descriptive and sufficient information from the HIV positive mothers who had opted to exclusively breastfeed their infants. Hence, rigour was well established.

3.9 Ethical considerations

There are specific ethical issues generated by qualitative research stemming from the close relationship between the researcher and subjects. Given that research ethics deals primarily with the interaction between researchers and the people they study as indicated by B, Allen, & Ph, (2012), it was important to be guided by the ethical principles in the course of collecting data from the HIV positive women who had opted to exclusively breastfeed their infants**.** The main ethical issues in nursing and midwifery that include conflicting values

and uncertainty in decision making as noted by Marianna & Paraskevi, (2011) were taken into consideration. This was regarded as important because once the researcher gained access to the HIV positive women's life-world, she entered their personal, private life. The research process could therefore, lead to some extend to disempowering the individuals who often rely on the nurses and midwives for information and guidance. Hence, the vulnerability and feelings of powerlessness experienced by the women who are HIV positive was acknowledged and protected.

The general principle of respect for persons and beneficence led to the consideration of obtaining an informed consent from the participants before commencing the interviews **(Appendix iii).** Additionally, the risk and benefit assessment and the process under which human research participants were selected were also taken into consideration (Angeles & Copy, 2011). It is of paramount importance that researchers must have the welfare of their participants and the betterment of society at the forefront of their minds when planning, conducting, analysing and disseminating their research (Mccarron, 2013). Therefore, a detailed and meaningful informed consent process that follows the cardinal principles of ethics including autonomy, beneficence and non-maleficence was observed (Collste, 2015; Artal & Rubenfeld, 2017). This guaranteed the treatment of research participants with respect and dignity ensuring that they were not harmed physically or psychologically in any way. These principles were strictly applied to protect the rights of HIV positive mothers and their families. The researcher forwarded her application and preliminary research proposal to the Mater Misericordiae Hospital Standards and Ethics Committee and approval and

permission to carry out the research in the Mater Misericordiae Hospital, MCCC department that renders services to the Mukuru slums was granted **(Appendix iv).**

3.10 Chapter summary

This chapter demonstrated the study paradigm, which included the methodology, study design, research setting area and question; sampling and methods of data collection. It also outlined how the establishment of the rigor and ethical considerations were maintained. The next chapter covered data presentation and the findings.

CHAPTER FOUR

Presentation and the findings

4.0 Introduction

The previous three chapters covered the contextual framework, highlighting the significance of the study, and a focused review of the literature that identified sufficient gaps to warrant the current research. From the researcher's paradigm, the study methodology and design used for this study were clearly outlined putting into consideration the ethical issues. The interpretative paradigm approach gave subjective relationships, interpretations and sharing of experiences' substance because as stated by Polit & Beck (2004) and Jeanfreau et al., (2010), findings are based on the creation of interactive processes. The approach used for data generation enabled the researcher to interact with the participants to explore their real experiences, and describe the ambiguities and complexities of extracting meanings from equivocal and complex data (Carolyn et al., 2011; Lukenchuk & Kolich, 2013; MOON & BLACKMAN, 2014). Therefore, the researcher was forced to use theory from the studies in several ways that included a broad explanation for behaviour, culture and attitudes of the study population. Furthermore, as a researcher in nursing and midwifery the content was used to analysis and provide evidence for the sensitive phenomena under review that Elo & Kyngäs, (2008) talk about. Consequently, it was anticipated that the study would generate important scientific knowledge and thus, contribute to the profession and ensure the use of the best clinical evidence in making decisions on mothers' and babies' care pertaining to breastfeeding. Hence, an opportunity to employ cultural themes and aspects of philosophy that were picked in course of interactions with the clients to understand the emerged specific

concerns such as social control, beliefs, attitudes, practices and family dynamics that influence breastfeeding practices.

The purpose of this chapter was therefore to present the data collected as evidence to support the argument developed in the previous chapters. The major themes were identified from conversational interviews as well as participative observations and reflexive journaling. However, where appropriate, the researcher used quantifiable measures to present data such as counting techniques that were theoretically derived and ideally based on participants' own categories. This provided a means to survey the whole body of data that is ordinarily lost in intensive qualitative research. The ethnography design approach gathered information from observations, interviews and documented data in form of field notes that produced detailed and comprehensive accounts of the social phenomena under review as indicated by Reeves et al., (2013). The combination of direct observations as a participant observer and interviews to collect data was employed to ensure collection of relevant enriched data. This was recorded in notebooks over the course of the period of twelve months where the researcher was fully engaged with the participants during clinic visits, home visits; telephones conversations and from Community Health Workers' interactions. It is important to acknowledge the role played by the latter who acted as the gatekeepers.

In this study, the use of qualitative research methodology in breastfeeding, HIV/AIDS, Prevention to Mother and Child produced a number of insightful accounts into the population under review. This approach enabled the women to narrate their unique experiences, interpretations and meanings as perceived in their own world. The ethnography

study design offered the 'how' question on breastfeeding and the experience of being a HIV positive childbearing woman based on social-cultural aspect. Through the methods use of in-depth interviews and observations, the researcher placed the participants in a position they could make sense of their own world. According to Johnson et al., (2008), cited in Care et al., (2010) patients and families are the focal points of health care delivery and as such should be clearly recognized as central to the design of healthcare facilities, care processes, and new ways and technologies to support self-care; communication and coordination. Hence, in addition to the selected participants, the researcher involved significant family members such as husbands and the mothers in law who also provided vital information based on the fact that they too play a key role in service delivery.

It was acknowledged that a lot of evidence from previous studies established MTCT of the HIV virus through breast milk. Therefore, the main aim in this particular study was to specifically explore the perspectives and experiences of Kenyan HIV positive women who had opted for exclusive breastfeeding, were visiting a private faith based hospital for comprehensive care and were living in resource limiting areas hereby referred to as "the slums" of Nairobi. By responding to the interview questions listed in chapter one, the participants were able to address the following research question.

> ***"What is it like being HIV positive, a mother living in the slums with instructions of exclusive breastfeeding?"***

4.1 General information

The study was carried out in Mukuru slums situated in Nairobi, the capital city of Kenya in East Africa. The participants were picked during their prenatal clinic visits in the Mater Hospital Comprehensive Care Clinic. In addition to interacting with the participants during the clinic visits, the methodology and design used was qualitative ethnography that allowed the researcher to visit all the clients in their homes where she immersed in their day to day activities, and this provided rich data in the natural settings. Although the researcher interacted with many HIV positive women during the research period, only five (5) who were at gestation ranging from thirty-eight (38) to forty (40) weeks were selected for this specific study during their prenatal visit at the MCCC. The age range was from 23 to 37 years. Their parity was from one (1) child to six (6) children. Unfortunately, some women indicated that some of their children were dead and the assumption was probably due to the HIV/AIDS. The mode of delivery was by Cesarean Section 60 percent (n=3), and normal spontaneous vaginal delivery 40 percent (n=2). The participants' main occupation was housewife, with no source of income, 80 percent (n=4). One participant 20 percent was a college student, also with no source of income. All the women 100 percent (n=5) came from the slums indicating the poor background settings, and were relying on support from their husbands and parents who were all casual workers receiving very little income. Pseudonym names were used to conceal the clients' identity.

4.1.1 Personal information

Name	Age	Parity	Mode of Delivery	Occupation	Source of income
Mil	34	6	SVD	Housewife	Husband-Casual jobs
Bem	24	2	C/S	Housewife	Husband-Casual jobs
Mam	35	2	C/S	Housewife	Husband-Casual jobs
Ram	23	1	SVD	Student	Parents-Casual jobs
Nao	37	4	C/S	Housewife	Husband-Casual jobs

The main themes described in this chapter emerged from the scheduled interview questions, conversations during prenatal and postnatal clinics as well as well-baby clinic attendances; home visits and through the telephone conversations. Key aspect employed by the researcher for getting themes was through direct interaction with the participants, active participative observations and occasional interactions with significant others. The whole idea was to broaden the participants' views on their experiences of being HIV positive and a mother with instructions to exclusively breastfeed their infants; and living in resource limiting area, especially in the slums of Nairobi. In process, the following specific thematic areas emerged: -

- Breastfeeding education
- Decision-making process
- Exclusive breastfeeding
- Alternative feeding methods
- Concerns from breastfeeding options and education
- Expectations from the healthcare professionals to assist HIV positive women in making decisions given the reality of MTCT.
- Other issues

4.2 Breastfeeding Education

As discussed in Chapter two, the HIV positive mothers can transmit the virus to their babies during pregnancy, childbirth and through breast milk (B, Allen, & Ph, 2012; Mandala & Dirks, 2012; Bekere et al., 2014; Sama et al., 2017). It is deemed important therefore, that childbearing women be made aware of MTCT of the HIV virus before getting pregnant to

enable them to make informed choices for feeding their babies. Various data collection methods were used at different times to suit the participants. **To the question about the knowledge of breastfeeding their babies**, all the women interviewed (100 percent, n=5) stated that they were aware of the reason for breastfeeding their babies. This was given as due to the fact that they knew that they were HIV-positive, and the awareness that they could pass the HIV virus to their babies through their breast milk. Additionally, the participants narrated that they were cognizant of the many advantages and benefits of breastfeeding as stated by Lampe & Lampe, (2016) in chapter two. However, all the participants (100 percent, n= 5) indicated that they were following what they were told about breastfeeding by the healthcare providers during prenatal clinic visits to avoid passing the virus to the baby. None of the participant indicated that they were aware of their HIV status before becoming pregnant. They become aware of their HIV status following the routine HIV testing during the prenatal visit. This was contrary to the WHO and UNICEF statements guidelines and policies on proper counselling, education and adequate support to make the HIV-positive; and to allow them ample time to make decisions on the breastfeeding options as stated in chapter two ("HIV and Infant Feeding | Nutrition | UNICEF," n.d.; "WHO | Breast is always best, even for HIV-positive mothers," 2011b). This statement was further supported by Access, (2015) who argued that the role played by healthcare workers' influence on breastfeeding through effective education on breastfeeding and the facilitation in immediate initiation of breast milk was fundamental regardless of their HIV status. Further reinforcement regarding education HIV and breastfeeding was highlighted by Ramoshaba & Sithole, (2017) whose study indicated that the clients must receive knowledge and awareness of HIV/AIDs and PMTCT. All the women interviewed clearly indicated the

lack of adequate education and preparation before pregnancy as evidenced by their statements.

> *"I was diagnosed with HIV when I attended the prenatal clinic. I was warned that if I don't breastfeed for six months and strictly adhere to taking my ARV drugs, I will pass the virus to my baby. But I am also supposed to give my baby the prescribed Nevirapine... My mother in law will be wondering why I am giving him the syrup and he is not sick…. Anyway, I will do my best to follow instructions given in the clinic to protect my baby".*
>
> *Mam*

> *"I know I am HIV positive and at risk of passing the virus to my baby. I have not told my husband about it. We were told in the clinic that we must breastfeed if we don't want our babies infected with the virus and die…So I am doing it".*
>
> *Mil*

> *"Well… I tested HIV positive during prenatal booking clinic and was told to exclusively breastfeed my baby. My husband does not know my status. I don't know his either. I have given birth to six children and only one is alive… I don't want this one to die… So, I must do as I was told to save him. The only problem is that I have no source of income and I don't have enough milk because I had caesarean section. I do not have enough milk for the baby".*
>
> *Nao*

"I was instructed to breastfeed without giving anything else for six months. I am HIV positive and my husband is negative. But he understands and supports me. So, we just have to follow the instructions. I am grateful for the food received from the clinic because now I have enough milk for my baby".

Bem

"I was informed to breastfeed although I am a student and I don't know how I will manage. I intend to go back to college and take the baby to my mother in the rural village after the six months. You have to support me with food if I have to breastfeed. I am not working and my parents are both HIV positive and have no income. I don't know about my boyfriend's status… and he has no work…"

Ram

It was clear from these statements that even though all women in this study were aware of breastfeeding and the risks of MTCT, to some extent a lack of the recommended proper teaching on breastfeeding in HIV pecked on inappropriate counselling before getting pregnant, inadequate education and support during pregnant and beyond were evident. All the participants were either instructed, told, warned, advised or informed during their prenatal clinic visits. Such situation showed submissiveness from the women's perspective. Obviously, there was lack of adequate preparation on exclusive breastfeed that should have involved more than giving instructions to the participants. According to Partridge, (2009), counselling especially in HIV positive clients involves more than the giving of information because this population face numerous challenges secondary to poverty, psychological or

emotional effects and social alienation. Additionally, Dietrich Leurer & Misskey (2015), maintains that ways to ensure proper lactation support should be reinforced by provision of critical information and seeking feedback to ascertain that mothers have clearly understood the information offered.

Ensuring mothers received and understood key breastfeeding information through broad planned education sessions could have been a modifiable factor in efforts to increase breastfeeding efficiency. Hence, as much as information sharing and counselling was done to these HIV positive women, there should have been a careful holistic assessment of each individual woman to improve their ability not only to cope and lead to better outcomes despite their HIV positive status, but more importantly understand their role with the added responsibility of being breastfeeding HIV positive mothers. As maintained by Hazemba et al., (2016) in chapter two a broader health promotion campaigns supporting all mothers to exclusively breastfeed should be advocated and more efforts put to improve communication skills among healthcare providers and the community health workers, who are the main caregivers within the community settings. These campaigns should start at the community level.

From being an active participant observer, it was noted that mothers did not adhere to some of the simple practices for effective breastfeeding that include hygiene measures, breastfeeding fixing techniques, proper latching and burping the baby ("WHO | Breastfeeding," 2018a). The researcher observed that 100 percent (n=5) did not observe breast hygiene. Given the environmental surrounding of their houses, there was risk of

infections to the infants. Sixty percent (n=3) had poor latching technique leading to complaints of inadequate breast milk and babies crying a lot. However, as an active participant, and for the sake of the infants' health, the researcher got involved in the demonstrations and there was improvement. The remaining forty percent (n=2) mothers did not know about the minor disorders of the new-born like vomiting, skin rashes, engorged breasts, physiological jaundice, causing a lot of anxiety that in turn affected breast milk production. This too was addressed by the researcher through health talks on these minor disorders and how to manage them when they occur. This posed a big challenge on how health messages are shared by the healthcare providers since they only focused on giving instructions to exclusively breastfeed, forgetting other necessary health education messages to make it work and assist the mothers cope better. Thus, need to broaden health education on breastfeeding in HIV positive women and enhance decision-making process.

4.3 Decision-making process

As discussed in chapter two, several studies revealed factors that inform the choices women make pertaining to breastfeeding options; and the central role played by the significant others in decision-making within the family unit (Laar & Govender, 2011; Negin et al., 2016 ; Chaponda et al., 2017; Nabwera et al., 2017;)). Enquiring on **how the participants were involved in the decision-making process regarding the feeding of their babies**, the majority of the participants 80 percent (n= 4) implied that they were not involved in the decision making, rather they followed the instructions provided by the healthcare providers to ensure they do not pass the virus to their new-born infants. The women narrated that they depended on the information given to them by the healthcare providers who knew what was

good for them and their babies. Although this might be viewed as a positive aspect of healthcare service delivery, at the other hand it could be dis-empowering the HIV positive women who are vulnerable because of their HIV status, poverty, stigma, reinforced by the obvious lack of autonomy in decision-making. Consequently, the women felt that they were not involved in the decisions made citing lack of preparation and support before and after diagnosis; lack of support with the baby and no home follow-ups which were seen as crucial if they were to succeed in the efforts to exclusively breastfeed their babies. There was an urgent need to address these challenges through scaling up psycho-social and gender empowerment strategies for women, and introducing initiatives that promote the integration of HIV infant feeding strategies into other child health services as stated in chapter two (Nabwera et al., 2017b).

The researcher acting as an active participant observer also witnessed this reality during the prenatal health and home visits education sessions, where health messages were delivered to the HIV positive women, who though appeared attentive, did not contribute to the session, but rather remained passive. It could have been important to involve them in the decision-making process, even by asking them questions to ascertain what they knew because this could have given them a voice and hence, ownership of the option chosen. Furthermore, leaving the decision-making process to the women could have facilitated them in involving significant others like the partners and mothers in law who play key roles in breastfeeding practices. Hence, guarantee of support in the breastfeeding process. The importance of giving more information and time before decision making was emphasized by one (20 percent) participant.

"I will not say that I was involved because I was just informed of the dangers of not exclusively breastfeeding my baby. I had to make the decision because I did not want my baby to get the virus … I was not even given time to discuss with my friend since I did not want my husband to know. Well, I went with the instructions because I wanted what was good for my baby. I think there could have been a better way of discussing the whole issue of exclusive breastfeeding and other options. There are other factors especially when you have no source of income and no food to eat well…"

Nao

Fortunately, one participant (20 percent) indicated that she was very much involved in the decision-making process because she was a student and fully dependent on her parents to guide and support her financially. As stated by Shakya et al., (2017) in chapter two, for the young mothers, the role of breastfeeding practices was played by the older women in the family, who were perceived as the experts in the area of breastfeeding. It was clear from this participant that her age and financial dependency diminished the autonomy and ability to influence decisions pertaining to feeding practice choice and as such she was forced by the circumstances to make a decision. So, when asked about her involvement in the choice she opted for, she happily replied: -

"I was provided with all information and the breastfeeding options, and I choose to exclusively breastfeed my baby for the first six months. You see, this is my first baby and I do not know anything about breastfeeding. I have no income to buy formula milk. My boyfriend is not responsible because he is young like me and

has no job. He doesn't know that I am HIV positive. My mother will guide me since she has the experience. After the six months, I will go back to college and do some course so that I can support myself and the baby. I have informed my parents and they have agreed to take care of my baby…"

Ram

This was commendable since this young lady participated in the decision-making process. Nevertheless, it would have been better if the healthcare workers involved the said significant family members in the sessions where feeding choices were made to ensure that they understood their role and guarantee support to this young mother especially upon return to college. This in turn would have improved communication and ensure positive impact on the nutritional status of the infant.

Although the aspect of HIV and breastfeeding appears complex, it is believed that with proper approach to decision-making process by the healthcare providers that involve the clients, best choices can be made to empower the HIV positive women and maintain their health and that of their babies. Mothers want the best for their infants. Realizing one's inability to make the right decision about feeding their infant as expected by culture and society could imply blame that she is responsible for the transmission of the virus that often leads to the infant's death. Furthermore, the impact of learning of one's HIV status and limited feeding options could leave most women vulnerable. Therefore, since the nurses and midwives who provide services to women are already a trusted source of information, building on this foundation of relationship can be an important source of caring and

providing supportive HIV/AIDS counselling (Domenica Cappellini & Motta, 2015). Hence, enhancing this relationship by embracing inclusion criteria of the clients in the decision-making process regarding exclusive breastfeeding.

4.4 Exclusive breastfeeding

Studies carried out by Patil et al., (2015) in eight African developing countries highlighted the importance of exclusive breastfeeding for six months. This should be followed by the timely introduction of safe and nutritionally adequate complementary foods to prevent malnutrition and reduce morbidity in the first five years of life. Furthermore, it was alluded that breastfeeding within the first hour of birth protects infants from infections and saves lives, improves intelligence quotient (IQ), school readiness and attendance and is associated with higher performance in adult life (Jaafar et al., 2016; Moore et al., 2016; "WHO | Early initiation of breastfeeding to promote exclusive breastfeeding," 2019). Infants are at greater risk of death due to diarrhoea and other infections when they are partially breastfed or not breastfed at all (Yotebieng et al., 2015; Duff, 2018). The WHO recommendations on breastfeeding for two years and beyond demonstrated the influence breast milk has on the infants' milestones ("WHO | Breastfeeding," 2018b). However, study by Kimani-Murage et al., (2017) indicated poor adherence to these recommendations on breastfeeding and infant feeding practices. Nevertheless, the aspects of breastfeeding are appreciated more in countries where the water supply is unsafe and the cost of formula milk prohibitive; while artificial feeding option is applicable in developed countries with less risk of poor sanitation related ailments (Agunbiade & Ogunleye, 2012). It is imperative therefore, that further research and interventions should pay attention to factors such as sanitation, clean water

availability, cultural practices, access to and utilization of healthcare facilities; child feeding education including decision makers in matters pertaining to feeding options. Regardless of the settings, healthcare providers education and support is crucial in successful exclusive breastfeeding (Jarrett, 2017). Additionally, women encounter barriers to breastfeeding across all socioeconomic, racial, marital, and demographic lines. Poverty being the worst of them all (Boyd et al., 2013), as was evident in this study. All these factors hinder women from continuation of exclusive breastfeeding for the recommended long time.

To the question on the understanding of Exclusive Breastfeeding by the participants, surprisingly, only one (20 percent) was able to explain correctly that exclusive breastfeeding means that the infant receives only breast milk directly from the mother's breast; no other liquids or solids are given, not even water; with the exception of oral rehydration solution, or drops/syrups of vitamins, minerals or medicines according to WHO 2019 ("WHO | Early initiation of breastfeeding to promote exclusive breastfeeding," 2019). The rest of the mothers, 80 percent (n=4) believed that they should give water because they perceived that the infant needed it. One woman (20 percent) believed that she could express the breast milk and feed the baby using a bottle. While this is still considered as exclusive breastfeeding, concerns were raised pertaining the hygienic standards given the area of study that was characterized by unhygienic environmental surroundings and lack of clean water. Three (60 percent) were influenced by cultural beliefs that breast milk was not enough as stated in chapter two where significant 'others' like grandmothers and other relatives played a central role in breastfeeding options and provision of ideas pertaining to culture within the family unit since they are perceived as owners of traditional wisdom (Negin et al., 2016 ; Chaponda

et al., 2017). In addition, it emerged out that instructions and orders were issued by significant others to the mothers to give their infants water and solid food. This was complicated by the fact that these HIV positive women did not wish to disclose their HIV status to the relatives for fear of social stigma and possible blame. Being an active participant observer, the researcher noted that the healthcare providers did not elaborate on exclusive breastfeeding meaning, rather pointed out to the women that they must opt for exclusive breastfeeding, assuming that they understood what it was. This is notwithstanding that these women were from a vulnerable population living in low income setting area, with low levels of education and limited resources such as internet where they could search the meaning of the terms used by the healthcare providers. It was noted that information sharing sessions excluded the alternate feeding method.

4.5 Alternative feeding methods

A substantial percentage especially from developed countries and high income category opt for formula feeding method for their infants according to Ramara et al., (2010) in chapter two. **When the participants were asked what other feeding methods they were aware of,** all the mothers 100 percent (n=5) stated that they were aware of the alternative formula feeding option. However, many issues concerning this method were expressed such as being culturally unacceptable 40 percent (n=2), while the remaining 60 percent (n=3) gave other deterring factors such as cost-inhibitive, less nutritional values, source of infections and the effects on the child's growth and development as cited by Thi & Hong, (2015) in chapter two. One mother clearly stated how impossible it was to imagine of the formula feeding method.

"The biggest concern is the inconvenience and off course the financial constraint. The Nan formula milk costs about six hundred…that is a lot of money and I have no income. It really becomes very difficult to maintain. It takes somebody who is financially stable…. and now am aware of the breast milk which is free of charge. Even though one needs to eat well…."

Mil

This was strengthened by what the researcher observed during the home visits and the basic data that implied that all the participants had no source of income. Additionally, from many researchers, there is evidence showing that the developing countries has increased mortality rate risks due to infectious diseases among non-breast feeders, particularly the very young infants of two to three months of age whose incidence of diarrhoea and pneumonia remains high as stated in chapter two (Gizaw et al., 2017). For this study, the situation is complicated by the poor living conditions where overcrowding in shanty unventilated houses surrounded by heaps of garbage and sewage water running all over contribute to infectious diseases that increase the mortality rates, rendering the infants born of HIV positive mothers at greater risks. Hence, it would seem from these studies that decisions to forego the benefits of breastfeeding do not compare well with the associated risks of using formula milk as indicated in chapter two (Nduati et al., 2012; Keraka & Wamicha, 2014; Wildeman et al., 2016). Hence, need to address the concerns of feeding methods.

4. 6 Concerns about feeding methods options

When it comes to any of the feeding method option, there are various factors such as cultural, level of education, income, marital status, mother's confidence and the obvious advantages of bonding and close relationship with the mother of breastfeeding as stated in chapter two by several researchers (Sankar et al., 2015; Chowdhury et al., 2015; Pottinger, 2015; Lampe & Lampe, 2016). Denying the baby of the latter could lead to self-blame. Some of these factors lead to some anxieties from many mothers at some point in making a decision about whether to breastfeed or use formula feed (Radzyminski & Callister, 2016). However, whichever method chosen, there are some challenges as indicated by the participants when they were asked to cite **the concerns regarding the feeding methods.** All the women under study 100 percent (n=5) recounted different concerns. Majority of the mothers had no source of income and their nutritional status was compromised. 80 percent (n=4) did not have means of getting the recommended balanced diet to aid in breast milk production. This was supported by Agambire, (2013) in chapter two, who argued that mothers in poor countries face issues such as poverty, lack of their own diet to produce breast milk; the expense of infant formula, lack of access to safe clean water, unsanitary living conditions, increased risks to their children from common childhood illnesses, inadequate healthcare facilities; all complicated by the socio-cultural factors that dictate that women must breastfeed their infants.

It is worth noting that all the participants (100 percent) in this study were supported by the nutrition department of the MCCC that supplied them with food to maintain their nutritional status and hence ensure adequate milk-production for their babies. However, on home visits,

it was noted that this food meant for the lactating mother was used by the whole family. Hence, the problem was not solved because the food was used within a very short time and the women did not have the courage to return to the clinic for more food for fear of being reprimanded by the food store staff. On several occasions, the researcher had to intervene for the women to be supplied with more food for the sake of the new-born infants. Two (40 percent) stated that by choosing to exclusively breastfeed and giving the babies Nevirapine drug would raise suspension among some family members since they had not disclosed their HIV status to them. These mothers were encouraged to consider the benefits of exclusive breastfeeding and adherence to the ARVs and ignore what others say since the evidence is now strong that antiretroviral drugs used during lactation prevent transmission of infection from a seropositive mother as recommended by Kuhn, (2012) and WHO 2013 in chapter two. One (20 percent) of the women stated that it did not matter since she had full support from her husband.

> *"My husband is very pleased about the choice to exclusively breastfed our baby because he wants our baby to grow well without HIV infection. He is so supportive in continuing with exclusive breastfeeding until the six months elapse because he does not want our baby to be HIV positive. His mother is against exclusive breastfeeding but she doesn't know why I opted for it. It is best I consider what is best for my baby…"*
>
> *Mam*

This couples approach to exclusive breastfeeding was supported by Denis, (2013) study that emphasized on exclusive breastfeeding because it was found to be protecting the babies

against killer diseases such as AIDS, diarrhoea and respiratory infections which are common in African countries especially those from resource limiting settings like the slums.

One (20 percent) brave participant indicated that the alternative artificial method of feeding was totally culturally unacceptable because an African woman is expected to breastfeed her baby. However, this reality was contradicted by Odeny et al., (2019) qualitative study in Kenya in Chapter two, where stigma was said to be associated with HIV and exclusive breastfeeding in HIV endemic regions since women who adhered to this practice were perceived to have HIV infection.

> *"Well, I am happy that I choose to fully breastfeed my baby because it is expected that all African women must breastfeed as the only acceptable way by the society. Even if people talk about my breastfeeding and guess of my being HIV positive, it is okay because I want what is best for my baby".*
>
> *Bem*

The many issues concerning breastfeeding in the HIV positive women were stemming from poverty, cultural expectations, environmental sanitation and social stigma. These were disturbing to the researcher, who at many times felt helpless and wondered what the government was doing to alleviate the living conditions of people living in resource limiting areas with no source of income; are faced with all sorts of challenges and now the HIV pandemic, and now with the mother to child transmission of the virus to the newborn.

4.7 The reality of MTCT

There is evidence of mother to child transmission from various research findings (Mandala & Dirks, 2012; Bekere et al., 2014; Sama et al., 2017). This situation continues to be a major concern in poor Sub- Saharan African countries like Kenya where breastfeeding is the norm and essential for child's survival. Given the reality of MTCT, the participants were asked to outline **what they thought the healthcare professionals could do to help childbearing women who are HIV positive in making choices about infant feeding method.** All the women 100 percent (n=5) expressed gratitude for the support given by the MCCC department of the Mater Hospital. The fact that they were all from the slums with no source of income at all, 80 percent (n=4) requested for more support in terms of employment to enable them take care of their families. One (20 percent) requested support to further her education that will enable her get work and support herself and the baby. From being an active participant observer, the clients showed a lot of positivity and it was felt that with facilitated support and empowerment, they could lead a more productive life that will move them from just occupying the role of being HIV positive to responsible and fecund citizens.

It was acknowledged that several studies concluded that women have initial reaction of shock and denial when given a diagnosis of HIV in the prenatal clinic as implied by B, Allen, & Ph, (2012) in chapter two. This was further emphasized by Lingen-Stallard et al., (2016), who indicated that the emergence phenomenon of being women and acceptance of HIV status as part of their lives could be overwhelming. This also applied to this population but with support from the MCCC, they were able to deal with these reactions and accept their reality. It is obvious that the situation becomes worse in pregnancy with all the

physiological changes and disorders of pregnancy. From participative observations, the researcher admired the participants' resilience. One participant (20 percent) felt that more education on HIV/AIDS with emphasize on exclusive breastfeeding of the infants could be done through media such as radios and televisions using different native languages to enable the message to reach many infected and affected families, even in the remote areas. This calls for the healthcare providers especially the nurses and midwives attending to these women to embrace a unique understanding of the complexities and major implications for women who test positive for HIV and employ different modalities of delivering HIV/AIDS health messages. Consequently, they all requested for more teaching, education and support upon HIV diagnosis to enable them cope and live positively.

From the researcher's perspective, there was a big challenge to the obvious assumption that women are aware and comfortable with their HIV/AIDS status, and as such, it was like any other disease. However, this is a life-long condition that is not given the attention it warrants. Therefore, this assumption should be replaced by proper continuous education that goes beyond passing information; and support to ensure adequate preparation before the actual screening of HIV is done and constant follow ups all through, even after delivery. Two (40 percent) of the participants implied the inappropriateness of HIV screening that was done during the first prenatal clinic visit because they were unprepared, and their views were not sought. This is despite a well-established Voluntary Counselling Testing (VCT) programme that encourages clients to freely walk in for the services. Freedom to participate in HIV counselling was seen as important to avoid what the participants termed as routinized sending of all prenatal mothers for pre-test and post-test counselling without adequate

teaching and providing ample time to ponder, react and respond. The importance of allowing them more time to absorb the news, discuss with their husbands or significant other was seen as crucial before carrying out the HIV tests and more importantly, before giving the feedback. There were fears and anxieties that needed to be addressed before breaking the news. This was clearly stated by one of the women as she narrated…

> *"How can anybody make a decision about feeding of the new-born after coming to the clinic for the first time? After I learned of my HIV status, I was too shocked to make a decision regarding the breastfeeding option. I needed to understand and accept myself first. It is not easy to make a decision just like that. I needed time for the news to sink and come to terms with the reality. I wasn't given time even to discus with my friend…"*
>
> Nao

However, from being an active participation observer, the researcher noted that the WHO guidelines on VCT and HIV testing, passing information and support were adhered to by the healthcare staff. Nevertheless, as the saying goes "clients are always right", it is important to re-evaluate the whole process of information sharing, teaching and education methods in the prenatal clinic to determine the gaps.

In many sub-Saharan settings, early infant feeding practices have been influenced by a variety of less favourable habits based on cultural beliefs and practices such as cleansing rituals of the mother before initiation of breastfeeding ; giving solid feeds as part of religious ceremonies, with some of tribes giving herbs as protective measures and others delaying breastfeeding (Engebretsen et al., 2007; Mgongo et al., 2013 ;Gallegos et al., 2015; Bee et al., 2018; Mgongo et al., 2019). Additionally, some common practices in most of the

African countries like Kenya is to visit the grandmothers of the new-born and bring the baby to the rural homes for some rituals as dictated by specific tribes and cultural practices. This was clearly given top priority by one woman (20 percent) who stated:

> *"I have opted to exclusively breastfeed. But I have to respect our culture because my mother-in-law has insisted that she must perform some rituals that will include giving the baby some herbs to provide protection against some diseases and bad omen …You see, she does not know that we are both positive and I don't want her to know because I will be blamed that I brought the disease to her son… I will make sure that I hide the Nevirapine so that she does not ask why I am giving the baby modern medicine…"*
>
> *Mam*

The recommendations regarding breastfeeding as suggested by many researchers and international bodies are geared towards protecting the future generation from the fatal virus that causes AIDS. Unfortunately, they may be applicable only in countries where women and individual families have control over their way of life, and where the views of women are respected. In the Sub-Saharan African countries, like Kenya, where significant others like mothers in law, community and cultural norms affect women's role in decision-making, the recommendations are not effective. This leaves the HIV positive in an awkward place since she has to deal with the conflicting instructions. The courage of *Mam* in this study was admirable because she was able to adhere strictly to the healthcare instructions in order to protect her baby. It is important to address other issues affecting breastfeeding within cultural and individual settings.

4.8 Other Issues

Erlingsson & Brysiewicz, (2013), upheld that qualitative research especially ethnography approach explores reality as constructed by individuals embracing the ontological of multiple truths. Consequently, this results to textual accounts of the individual's world as well as reflecting the diversity and variation of lived experiences. The interview method in this study employed a free response approach that enabled the researcher to move according to the informants' drives. Other issues though not part of the main objective of this study but strongly and indirectly affected the broader aspects of HIV and breastfeeding emerged. This was associated to the fact that the researcher had an opportunity to ask questions that were conversational and free-wheeling as stated in chapter three, hence, enabling the researcher to adjust and acceptance issues raised by the participants.

It materialised that the poor living conditions, lack of income pecked on unemployment, extreme poverty as well as low levels of education are the main reasons that have contributed to the rapid spread of HIV/AIDS in the slums of African countries leading to lack of security and sexual violence (K, 2011 ; Arora et al., 2017). In these slums, where the inhabitants call home, the area is characterized by heavy population, substandard living conditions in shanty houses with no ventilation, inadequate access to clean water and extremely poor sanitation. There was also evidence of a constantly movement of the residents from one area to another in search of better living conditions. The latter made it difficult for the researcher to keep a close follow up to of some of the clients. The reality of such poor living conditions affect everything about a community: - from lifestyle, education to natural disasters like flooding when it rains and frequent fires that leave total destructions rendering the residents homeless

(Bolay, 2006; Manuscript, 2016). Yet, despite, the reality of the slums and its challenges; and the emergence of HIV/AIDS, the natural law of life apply to this population where people grow, embrace marriage life and babies are born. Nonetheless, the process of bringing up a delicate vulnerable baby in such situation could be overwhelming for many families because they too have rights to procreation like any other population in the world. The researcher's imaginative mind lured her to this study to understand how the HIV positive women managed to bring up their little "bundles of joy" in the midst of such circumstances.

It is worth noting that the researcher found the experience wonderful and rewarding. It was a blessing to observe the women as they happily enjoyed their roles of motherhood despite their harsh surroundings. Hence, a challenge to people from rich nations who have so much and yet, appear unhappy (Deaton, 2008; Marczyk, 2017). Contrary to this, all the participants and their families portrayed great sense of contentment, that left many questions for the researcher as one wondered what was there to make these people happy in such poor living conditions with barely nothing for survival. It was observed that all the participants, hundred percent (n=5) live in a small shanty crowed houses, with no ventilation. The main cooking method employed by all the participants was paraffin stove that polluted the whole house, causing difficulty in breathing that could easily lead to suffocation to all including the new-borns. This posed a great challenge about how the infants with delicate respiratory systems managed to breathe.

It also surfaced that there was unequal share of the government resources among the citizens and the gap between the rich and the poor is very wide citing how corruption has been embraced by the politicians and government officials to rob the country of its resources, and subsequently affecting the voiceless poor. The country has 16.9 percent of its population living below the poverty line. The severe poverty is mainly caused by an undiversified economy, social inequality, government corruption, health problems, and a water crisis (Hope, 2014; Bigsten et al., 2016 ; Shifa & Leibbrandt, 2017). This has led to deprivation of the people living in the slums who appear to be totally ignored and struggle to survive. The most affected are the HIV positive women who are the homemakers and struggle to endure the hardships. This was expressed by one participant (20 percent).

> *"The government does not recognize us… only the rich can manage to live because they have everything while we have none. We have no source of income, no jobs, no food and look at where we live… so crowded, dirt all over…and when it rains, it becomes impossible to walk because the sewage pipes burst and surround our houses. This is a source of infection for all of us and especially for this new-born. We don't even have access to healthcare facilities, and even in the small clinics, healthcare is very experience. If it were not for the MCCC, we will be dead long time… but I thank God that you people take care of our needs…"*
>
> *Nao*

The above narration concurred with the reality in Kenya and the researcher's active observation findings. According to Madise et al., (2012) study carried out in the Kenyan slums, it was concluded that there was high urban HIV occurrence in Kenya that was largely

driven by very high prevalence among slum dwellers. Therefore, addressing the lack of security and sexual violence in the slums could confer protection among young girls and women who are targeted because of carrying the responsibility of procreation. In addition, given the circumstances this vulnerable population find themselves in, the participants in this study indicated that one of the compelling reasons to exclusively breastfeed was because the formula milk was unavailable due to its cost. With the option of the alternative feeding mode, they wanted help on how to get formula milk for the baby, and the possibility of government intervention was suggested. The women also felt the need for help with other children with food and essentials, posing more challenges on the nation to provide these basic needs to the poor, disadvantaged women and children. Hence, an urge for the government to put more efforts to improve the living standards of slum dwellers who are mostly at danger of infectious diseases including HIV/AIDS. A suggestion to create job opportunities was deemed important because the population under study were all young people who believed that if they had jobs, life could have been different. Problems among the poor come with some complexity posing many health challenges. There seems to be chain that entwine and envelope the affected poor. Unfortunately, the cycle is vicious and enslaving making it difficult for the clients to free themselves. Hence, clients find themselves in such situations that are likely to continue unless there is outside intervention (Berry, 2006 ; Creedy & Kalb, 2006; Curtis, 2006; Marger, 2008). It was clear that these women found themselves in such circumstances and were yearning for a better life amidst their HIV/AIDS status with the added responsibility of breastfeeding their infants.

With HIV/AIDS being a global issue, there was a general feeling of lack of understanding, acceptance and support of people living with HIV/AIDS to help them live positively and productively. Hence, an urge for more resources from the government, healthcare facilities, non-governmental organizations, faith based intuitions and any other avenues directed towards the education and support towards winning the battle of HIV pandemic.

Despite the joys of motherhood displays by the women in the slums, the scenario in the informal settlement areas is a shameful reality in a country that has wealth of recourses, which is limited to a few leaving the future generation at a great risk.

Pictorial presentation 3

Source:-https://www.google.com/search?client=firefox-b-d&biw=1342&bih=619&tbm=isch&sa=1&ei=oav9XMiiNLCblwTcg45I&q=Pictures+of+a+woman+breasfeeding+in+the+typical+slums+areas+in+Nairobi&oq=Pictures+of+a+woman+breasfeeding+in+the+typical+slums+areas+in+Nairobi&gs_l=img.3...1718206.1729266..1729928...0.0..0.259.5917.0j4j24.....0....1..gws-wiz-img.aNOq902YL2c#imgrc=zrhW-L3QUOx0fM:

Entering into the precious lived world of five women who were HIV-positive living in the slums of Nairobi, had given birth and opted to exclusively breastfeed their infants due to their HIV status was a blessing; but yet a big challenging for the researcher. This is not withstanding that although the objectives of the study were clear, at times, the women's agenda took precedence over the researcher's focus, forcing adjustment to fit into the situation as it arose. This included the daily schedules, preferences especially when it came to the convenient times for the home visits; and to some extent what they felt needed to be said. As shown through pictorial presentations in this study, the weather was also another determinant factor that drove the researcher to the planned events, because whenever it rained, most of the homes were inaccessible. In other words, the interviewees set the agenda for the interview, giving the additional benefit of ensuring each participant's relevance was taken into consideration as well as adhering to research validity (Bashir & Azeem, 2015). Nevertheless, it was a worthwhile and enriching experience, as the researcher tried to maintain objectivity and present a valid interpretation of what was observed and heard amidst the many issues that surfaced. This is notwithstanding the reality of subjectivity that the researcher experienced through the sharing of emotions as the researcher got immersed into the reality of real lived experiences amidst extreme poverty and the lack of the very basic necessities for life. Many tears were shed as the researcher listened and empathized with some of the women who freely narrated their ordeal. From the researcher's perspective, it was clear that this unfortunate population is faced with many battles in order to survive. As such, they did not seem to see their being HIV positive as an issue because they had major pressing issues for survival.

It was hard to discourage the participants from talking about other issues in their lives because they anticipated the possibility of being relieved from their current situation. Therefore, the mothers were encouraged to share and talk about anything they felt was important. Every woman had several issues to express, and the researcher remained open to whatever transpired. Though these were not included in the interview questions, it was deemed that they influenced the study. As discussed in chapter three, reality in qualitative studies is internally experienced and socially constructed through interactions and interpretations, and the emphasis is on looking at the holistic description of events, procedures, experiences and philosophies in natural settings (Carolyn et al., 2011). Hence, this study opened up more issues related to individual participants, birth practices, the family, community, society and the government. Such issues were pecked on extreme poverty, poor living conditions, and lack of health insurance for the poor sick; social stigma, dependency syndrome and expectations from significant family members. Most of these issues were evident during the home visits and often overwhelming for the researcher who remained as objective as possible. Nevertheless, all the mothers (100 percent) expressed their gratitude for having participated in the research, for the support given during the research period through health education and material items that were channelled through the MCCC. Referrals were made to the manager of the MCCC, different heads of sections such as food, clothings, gender violence, social workers, counsellors and community health workers for appropriate action and follow-ups.

Towards the end of the research period, it was very unfortunate for one participant (20 percent) who ended up losing her husband to another woman. All through the home visits

and various interactions forums, this woman put up a brave face, and to the researcher she was doing well. But things were totally opposite in her real life. As stated in chapter two, cultural and social beliefs influence breastfeeding practices in Kenya (Wanjohi et al., 2017). Upon delivery, this participant was supposed to travel to the rural village and stay with mother-in-law who was expected to perform some traditional cultural remedies for minor disorders in new-born that involved cuttings on the gums and applying herbs. But knowing her HIV status which was unknown to the mother in- law, she declined and continued staying in her shanty house in the city. This was taken as being disrespectable to the culture. In addition, she was expected to fulfil her marital role through sexual intercourse. But due to her caesarean section wound she needed more time for healing. Little did she know that her husband who appeared to be very supportive had gotten another woman with the approval of his mother and migrated to unknown location. Consequently, she found herself alone with her fragile new-born.

> *"Life has been hard… I refused to accept the traditional remedies, but that cost me my marriage. …My mother in-law wanted to practice magic that involves cutting the gums of my baby and applying herbs. I refused because we were taught in the clinic the dangers of inflicting cuts on the baby. Following caesarean section, my husband demanded sexual relationship. I was in pain…and requested for more time to heal… My husband disappeared with another woman…I do not know where he is. But I thank God that my baby is healthy. My own parents have accepted to take care of me and my children and the MCCC is there to offer me the support I need".*
>
> *Mam*

Interestingly, one woman (20 percent) felt that she should not be counselled against giving birth to more children just because she was HIV-positive. But instead, she should be encouraged to get pregnant and reassurance given by healthcare providers that they would do everything to reduce the MTCT of the HIV virus to the infant.

> *"My mother-in-law will look at me and see that these children are not enough; they are only two. So, there is this pressure that we have more children. It is true that I am positive and my husband is negative and he doesn't mind. So, we should be encouraged by the healthcare personnel that when pregnancy comes, we try to be positive about it. There should also be reassurance from the healthcare personnel that they are going to do everything possible to prevent the transmission of the virus from me to my baby …"*
>
> Bem

The importance of understanding and supporting families infected and affected by HIV/AIDS was seen as pivotal to the health of women to enable them to avoid social stigmatization. The role played by the government was expressed as crucial especially now that Universal Health Coverage has been identified as one of the Big Four agendas highlighted by the Kenyan President in order to improve the living standards in Kenya ("Uhuru's Big Four Agenda supported : The Standard," n.d.).

According to Ramlagan et al., (2018), disclosure of HIV status remains one of the major challenges to the effectiveness of the prevention of mother to child transmission of HIV in rural areas in Africa. Sixty percent (= 3) of the participants had not disclosed their status to

their partners. As a result, they were taking their ARVs secretly which added an extra burden of developing tactics that ensure that their partners did not see the drugs. One of these mothers did not wish to be visited by many people especially the "Wazungus" (white people) citing that the neighbours would suspect that she was HIV positive.

> *"You are welcome to my house but … please do not come as a group especially the Wazungus…You see when neighbours see so many people, it will be obvious that I am HIV positive because you people are known to take care of the poor people living with HIV and live in the slums…so, you can come but not more than 2 people…"*
>
> *Nao*

This was narrated with a lot of emotions. However, as much as the researcher wished to remain objective and respect this participant's request not to have many people visiting her; a caring, empathetic and compassionate approach was employed to guide her towards acceptance to be followed up by the MCCC staff for counselling so that she could move away from self-stigmatization. Eventually, *Nao* agreed to be visited and the encounter unearthed a lot of social issues that were handled by the counselling staff of MCCC. This scenario was a clear indication of the seriousness of the social stigma that seems to be hindering the efforts made by government and healthcare facilities in the control of HIV/AIDs. The researcher was faced with a big dilemma regarding respect for the participant's wish and had to employ a balancing act in order to accommodate the need for more education on the HIV/AIDS to eliminate the social stigma. This gap seems to be widening and calls for more efforts towards its elimination. Consequently, there is still a strong implication of self-social stigma that has remained a main concern in the management

of HIV/AIDs in African countries. It is recommended that more efforts should be made to address this aspect of tackling HIV/AIDs pandemic and help clients to accept their status positively.

In an effort to provide a general experience of what it is like being HIV positive, a mother with an option of exclusive breastfeeding from the women's perspective, many issues surfaced. As stated in chapter three, and according to Hedlund, n.d. ; Gibbs, (2007), and according to Maguire & Delahunt, (2017) coding and categorizing of themes as a key process that serves to organize the copious notes and documents collected was followed. From this, words and phrases used by the participants to describe the phenomena were underscored. By reading several times and identifying the responses to the questions from the transcripts, the researcher was able to draw out and categorize major themes, issues, ideas and patterns that surfaced from the HIV positive mothers who had opted to exclusively breastfeed their infants. Hence, the following sum up the participants' perspectives and gaps that surfaced and need to be addressed in order to fully understand the women's experience of being HIV positive, a mother with an option of exclusive breastfeeding living in a resource limiting area.

- Extensive education on breastfeeding and MTCT of the HIV
- Influence of culture and poverty on breastfeeding
- Alternative applicable to all methods of feeding to avoid MTCT
- Involvement in the decision-making process, especially of significant others
- Evidence-based healthcare services for childbearing women who are HIV-positive

- Understanding, acceptance and support of people living with HIV/AIDS to help them live positively and to avoid stigmatization
- The government to address the slum dwellers healthcare needs as part of the Big Four agenda as per President's dream
- The need to narrow the gap between the rich and the poor, since the latter are the ones mostly affected by HIV/AIDS
- Ways of availing equal opportunities to all regardless of their backgrounds.

These formed the basis for discussion in chapter five of the thesis and directed the way forward.

4.9 Chapter summary

This chapter presented the study findings as narrated by the informants in response to the interview questions. The question of how it is to be HIV/AIDS positive, a mother with instructions to exclusively breastfeed was addressed from the women's own perspectives. This was also enriched by the researcher's active participation. Other issues raised by the participants were also taken into considerations as they provided a wider scope to the whole area of the study. The main issues from the women's worldview were summarized using thematic coding. The following chapter presented a discussion of the findings and addressed the issues raised by the participants that emerged following thematic coding and the researcher's active participant observations by identifying the gaps and the possible recommendations to bridge or minimize these gaps. The chapter also accentuated the limitations of the study, posed more questions for future research and drew conclusions to the whole study.

CHAPTER FIVE

Discussion and conclusion

5. 0 Introduction

This chapter provided the overall discussion of the results obtained from the research as they emerged in the previous chapter in relation to the research questions and following thematic coding of the main issues. Other issues that transpired during the research, even though they were not related to the research questions, were discussed because it was felt that they indirectly affect breastfeeding in HIV positive women living in the slums of Nairobi. The literature review and research findings were used as points of reference to provide the evidence for discussion of the issues raised by the participants and the basis of the researcher's argument. Objectivity on the sensitive issues was observed as the researcher critiqued some controversial issues. The limitations to the study and the conclusion to the whole study were both underscored, with suggestions for further research areas.

There is an ascertained obvious necessity for the healthcare providers to be adequately trained, motivated and resourced to face the many HIV/AIDS challenges. This will provide a guarantee for the global implementation of HIV care strategies that will ensure provision of the level of care required especially in developing countries. Some of the many barriers directly affecting the HIV positive clients comprise the difficulty of clients in disclosing their HIV status and low partner engagement in healthcare facilities (Jaiantilal et al., 2015). This reality exists despite the efforts made by the international healthcare bodies like WHO, UNSAID, and other AIDS experts in providing evidence-based guidelines for HIV care in developing countries. Consequently, clients who are often women have difficulties

disclosing their status to their partners because they are afraid of rejection, divorce, and abandonment; and to their families and communities fear of stigma and discrimination. These hinder the numerous efforts in HIV control measures. Due to interaction with the women in this study, many issues surfaced that affect their lives in general. Using thematic coding the following were seen as important in relation to the study topic.

5.1 Breastfeeding education and MTCT

As stated in chapter two, the benefits of breastfeeding for both mothers and infants are well known. However, from some studies, it surfaced that despite generally undisputed advantages, many women either do not breastfeed or breastfeed for only a short period of time due to several reasons ("ABM Clinical Protocol #7: Model Breastfeeding Policy (Revision 2010)," 2010). There are several factors that affect how women feed their infants and the length of time they breastfeed. Some of these factors are influenced by urban or rural residence, socioeconomic status, maternal education, women's employment status and market pressures for using formula milk; knowledge about and the availability of breast milk substitutes (Canicali Primo et al., 2016). However, regardless of all these, breastfeeding promotion remains a priority for the improvement of the health and quality of life of children and a guaranteed well-being of the future generation as stated by many theorists in chapter two (Brand et al., 2011; Hansen et al., 2011; Pottinger, 2015; Lampe & Lampe, 2016; UNICEF, 2018). There is evidence that despite the various difficulties and barriers experienced by breastfeeding mothers such as lack of enough milk, breast complications like mastitis, sore nipples among others, there is a general willingness to embrace this noble mode of infant feeding. Regrettably, the women voiced that they felt left

alone and exposed to unnecessary suffering; associated with the struggles they face with the infants and also lack of caring behaviour from the healthcare providers who were termed as indifferent (Palmer et al., 2012). This research uncovered serious gaps that are crucial in supporting clients during the early period of a baby's life. Healthcare professionals need to understand how fragile the breastfeeding mothers' confidence could be. This self-confidence is vital for the mothers in making decisions to continue with breastfeeding, and respond to the physiological and psychological processes of milk production.

The aim of this study was to explore the experiences of HIV-positive Kenyan childbearing women living in the slums of Nairobi who had given birth and were instructed to exclusively breastfeed their babies in order to protect them from the HIV infection. Evidence from several studies has shown that breastfeeding is perceived as the only acceptable method of feeding young babies in most of the developing societies in Africa especially those with limited resources. Important to note from some studies is the fact that it was reassuring that breastfeeding by women infected with HIV was not perceived as a risk, but was highly protective against the mortality among their infants irrespective of the child's initial HIV infection status (Nicoll & Williams, 2002; Taha et al., 2006 ; Lanktree et al., 2011; Victora et al., 2016) . However, the study findings revealed that exclusive breastfeeding practices in HIV/AIDS women in Kenya are far from meeting the World Health Organization promotion towards a comprehensive approach to PMTCT programmes by providing appropriate treatment (WHO, 2010). In this study, women identified great need to address issues in dealing with their HIV status, which were affecting the choices they made about feeding their infants. It is worth noting that the WHO has continued to update the guidelines

pertaining to breastfeeding in HIV positive mothers, and as a result there has been a substantial reduction of the transmission rate. However, the researcher had a major concern regarding how the WHO guidelines are cascaded down to reach the marginalized of the society, especially those living in the slums.

As highlighted in chapter one of this thesis, barriers to the practice of exclusive breastfeeding among HIV positive mothers in Sub - Saharan Africa included personal biases, inadequate counselling skills and guidelines, lack of knowledge; a culture of mixed feeding norms, and maternal lack of decision-making powers as well as fears of vertical transmission (Maryam et al., 2016). Subsequently, the need to disseminate community wide messages on infant feeding and stigma reduction ideally facilitated by sensitized community gatekeepers, traditional leaders, and peer counsellors, and in turn reinforce appropriate infant feeding guidelines was emphasized. In addition, it was deemed important for the health community workers to receive structured training on counselling skills with standardized messages on quantified risk of postnatal transmission of HIV through breastfeeding that ensures that all women are supported to breastfeed regardless of HIV status. Unfortunately, adherence to the recommendations and good practice was found lacking. Hence, the participants underlined the need for more extensive **education on breastfeeding and MTCT of the HIV virus**.

Education on breastfeeding would address the many complex factors surrounding the question on whether women who are HIV-positive should breastfeed or not. More specifically, the issues of decisions that are influenced by the economic, cultural,

environmental and educational status of each individual woman would be tackled. These women need unlimited support and follow-ups to ensure successful implementation of the choices they make because breastfeeding is unequalled to no other feeding method. Additionally, when it comes to its ability to promote infant growth and development, the crucial benefits of breast milk are best placed to provide optimal nutrition and protection against common childhood infections (S. L. Young et al., 2010). The role played by significant others, especially mothers-in-law and husbands in the decisions regarding the feeding methods of newborn babies remain central. The seriousness of this complex situation was highlighted during the international AIDS day held annually in December 2018 that revealed that there are approximately 36.9 million people worldwide living with HIV/AIDS ("World AIDS Day — December 1, 2018," 2018). Of these, 1.8 million were children aged less than 15 years, with an estimated 1.8 million people having become newly infected with HIV and about 5,000 new infections per day. This includes 180,000 children aged less than 15 years. Unfortunately, most of these children live in Sub - Saharan Africa and were infected by their HIV positive mothers during pregnancy, childbirth or breastfeeding.

The African region remains most severely affected, with nearly 1 in every 25 adults (4.1 percent) living with HIV and accounting for nearly two-thirds of the people living with HIV worldwide, where HIV affects all aspects of life including politics, culture, social relations, material life as well as religion (Denis, 2013). As stated above, MTCT occurs during pregnancy, labour, delivery or breastfeeding and in the absence of any intervention that primarily involve ART for the mother and a short course of antiretroviral drugs for the baby,

transmission rates range from 15 percent to 45 percent, while those on ART and other interventions can reduce this risk to below 5 percent. Therefore, despite the evidence from many researchers citing education as being carried out in the clinics, healthcare settings and in the community, the women in this study indicated that there was deficient as far as education on HIV/AIDS is concerned. Thus, the researcher established that there exists a big gap pertaining to education on breastfeeding, HIV/AIDS, and MTCT seen from the women's perspectives and their lived reality. This posed many challenges to healthcare providers, leaving many questions unanswered: - Is it the way the messages are delivered? Are the clients actively involved during the education sessions? Could there be communication barriers? Are clients tired of hearing "the same old all?" How else could this education be done to be effective? Nonetheless, the researcher being an active participant, observed teaching sessions during the prenatal clinic and home visits. From this, it was concluded that there is an obvious need to urge the healthcare team to be more aggressive on the area of education and HIV. Maybe develop different teaching methods that will make education more effective, especially in the communities stricken by the poverty in the slums. Hence, the researcher found if necessary to come up with a woman centred midwifery education model.

5.1.1 Poverty and breastfeeding

Apart from breastfeeding being deeply rooted and valued in many societies, especially in the poverty-stricken developing countries, it is an affirmation of motherhood and an integral part of strategy to promote child survival (Tiwari et al., 2007). Furthermore, breast milk has been known to contribute greatly to optimal child growth as well as offering immunological

benefits and is associated with decreased risk of infectious disease hospitalization (Ásbjörnsdóttir et al., 2016). The research findings confirmed the societal expectations of motherhood regardless of their social-economical state, where they come from, and the awareness of the benefits of breastfeeding. This was evidenced by many mothers' concerns of what other people especially the mothers-in-law, husbands and relatives would say if they were seen not breastfeeding. Although the WHO recommends six months of exclusive breastfeeding and many healthcare facilities have put good strategies in place to reinforce this, the practice of exclusive breastfeeding especially from slum settlements has remained quite low (Khan & Islam, 2017). As pointed out in chapter two of this study by Agambire, (2013), mothers in poor countries face issues such as poverty, lack of their own food for nutritional status required to produce enough breast milk for the baby, the expense of infant formula, lack of access to safe clean water, unsanitary living conditions, increased risks to their children from common childhood illnesses, inadequate healthcare facilities; all complicated by the socio-cultural, and environmental factors.

This reality was evident during the home visits, interactions with the participants and significant others as well as through active participative observations, where poverty seemed to dictate the way of life among this population situated in the worst living conditions of any human being. This was also verbalized by the participants as they requested the researcher to explore and **employ new ways of addressing the many issues crippled by the poverty in the slums and improve standards of living.** Therefore, by yielding to the participants' request, the gaps arising from the consequences of poverty and poor breastfeeding practices in the slums will be addressed through implementing the

interventions suggested in this study; hence, embracing the tool of education and ensuring the importance of breastfeeding to mothers and their families. This in turn will help reduce the gap between breastfeeding recommendations and reality in the practices. Despite all these, the challenge of poverty remains disturbing and until it is addressed, the newborn infants born by HIV positive women living in the slums have limited chances of survival and becoming tomorrow's productive citizens. The option of the alternative feeding methods poses unique challenges depending on the population.

5.1.2 Alternative feeding methods

The recommended alternative artificial method of feeding has been identified as culturally unacceptable in most of the developing countries in Africa because an African woman is expected to breastfeed her newborn. This was also underscored in this study by some participants and significant others. Other concerns raised included sterility and nutritional values, source of infections, the effects it has on a child's growth and development and being cost-prohibitive as implied in chapter two (Thi & Hong, 2015; Gizaw et al., 2017). From the above, it is understandable that anxiety over relationships and social standing is a hard-stumbling block. The recommended artificial feed and taking of drugs are both foreign concepts in most African societies. Hence, for a Kenyan woman to be seen using infant formula instead of breastfeeding, or taking a daily regimen of pills is tantamount to publicly announcing her HIV-positive status to her family and community. This could be followed by social stigmatization, abandonment or domestic violence as indicated in chapter two (Lakshman et al., 2009). Therefore, the many questions and dilemmas faced by these women

give them no other options than to remain silent and suffer quietly as they ponder their unfortunate situation.

Issues of caesarean section as the recommended mode of delivery and constant use of ARVs were not deemed as an option in Kenyan women who are expected to bravely face the whole process of labour. By enduring labour pains and to deliver normally is deemed as proof of good womanhood (Beigi et al., 2010; Akadri & Odelola, 2018). This was despite many studies showing a substantial maternal viral reduction and very low MTCT rate in HIV positive women who opted for C/S and use of ARVs (Panburana et al., 2004; Read & Newell, 2005). But transmission was not completely preventable, implying that these recommendations are not completely reliable; and so posing further challenges on the reliability of the evidence from research. In countries where culture dictates breastfeeding as the only acceptable method, with women attuned to such, and with little choice of alternatives, it is obvious these women are put under undue pressure, and as such need a lot of support to maintain the feeding choice they make.

There seemed to be a state of desperation from the participants as they are faced with many challenges and conflicting information regarding the choices they make. This then posed a challenge to **the researcher to find alternative applicable to all methods of feeding to avoid MTCT**. Unfortunately, as much as a lot has been done to find the best feeding option, confusions and contradictory messages continue to be a source of anxiety and stress to many childbearing women who are faced with many dilemmas instead of the expected joys of motherhood. With some conflicting recommendations from some studies around this area,

the researcher found herself caught up in this confusion and at times, was lost for words to convince the participants on the best evidence based option. This creates a gap for researchers to be consistent in the delivery of information to the HIV positive population and help them cope with the challenges. It is worth noting that with easy access to the internet, many people can access information on the subject of HIV/AIDS. However, some of this information is not reliable. For the HIV, positive people living in resource limiting areas, and might not have access to internet; and who seem to have placed total trust in the healthcare providers, especially the nurses and midwives, concrete support through the most effective and reliable option is mandatory. Conversely, their participation in decision-making process is of paramount importance to guarantee success.

5.2 Decision-making and breastfeeding

Several factors influence decision-making process regarding breastfeeding as accentuated by many researchers in the previous chapters (Negin et al., 2016 ; Chaponda et al., 2017; Nabwera et al., 2017; Laar & Govender, 2011). The main contributing factors are, but not limited to personal issues, cultural, poverty, social and environmental. However, the mother's knowledge and attitudes, followed by the husband's and mother-in-law support were identified as quite significant in influencing the choices they make. Consequently, from the participants point of view, it was deemed important for the healthcare workers to play a key role and ensure that there is **more involvement in the decision-making process and involvement of significant others.** In the population under review in this thesis, it was assumed that the women were already depressed from being HIV-positive and therefore the extra burden on decision-making process complicated by cultural pressure could no doubt

make their condition worse. To mask this, it was noted that the women sat quietly and attentively listening to health talks on the importance of exclusive breastfeeding. This was well supported by the researcher, who being an active participant observer noted that the healthcare professionals were giving instructions during the clinic health talks and home visits without involving the participants. It was also observed that the significant others like husbands were absent during these sessions. A study carried out by Nabwera et al.,(2017) in rural Kenya indicated that infant feeding decision-making by women living with HIV is constrained by a lack of autonomy, stigma and poverty. From this stand, decision making is a process that should involve both parties, and that clients must be guided and given ample time and support to make informed decisions.

Under condition of utter poverty and poor hygiene, the risks of death from replacement feeding exceed the risks of MTCT through breastfeeding during the first months of life; while exclusive breastfeeding and efforts to treat breast problems make breastfeeding safer (Coetzee et al., 2017)**.** Therefore, adequate information should be provided to HIV-positive mothers living under such conditions so that they can make informed infant feeding decisions. Unfortunately, in this study, the researcher noted that the focus of decision making involvement was directed to giving the women instructions. But, it is important to appreciate that including the male partner in HIV/AIDS counselling during a woman's pregnancy increases the adoption of specific strategies to prevent mother-to-child transmission of the disease as well as providing the necessary support (Natchu et al., 2012). Therefore, husbands or partners should be part of the journey and should be encouraged to undertake the HIV testing along with their wives. They should be urged and enabled to

accompany their wives during the prenatal clinics and counselling sessions and invited to participate in communication and decision-making processes. Furthermore, education programs for the mothers-in-law should be available because they too play a major role in breastfeeding decisions. Subsequently, this would encourage them to accept the interventions recommended for preventing MTCT. But nonetheless, the need for better teaching and education about HIV/AIDS, other options of delivery and other methods of feeding was expressed before all involved are expected to make decisions. This could prepare the women before HIV testing and give them ample time to discuss the issues with their husbands or significant others; hence, placing them in a position to make informed decisions and choices. Notably, there is an obvious gap that limits the scope of the expected decision makers' participation. This can only be filled by research to provide the best practiced based on evidence.

5.3 Evidenced based healthcare services

Reproductive rights are legal rights and freedom relating to reproduction and reproductive health that vary amongst countries around the world (Pillai et al., 2017). Individuals, including those living with HIV have the right to make informed, autonomous decisions about whether to bear a child and for women, the appropriate care during pregnancy and childbirth ("GFMER Sexual and Reproductive Rights Country Information - Kenya - Karim Abawi, Marloes Schoonheim, Anne Khisa," n.d.). For people with HIV, reproductive decisions can be more complex, involving medical decisions that can drastically reduce the risk of transmission during pregnancy, childbirth, and feeding ("Reproductive Health and Rights | The Center for HIV Law and Policy," n.d.). As advocated by Hazemba et al., (2016)

in chapter two, exclusive breastfeeding has the potential to reduce infant and under-five mortality rates. But unfortunately, further research showed that the practice is not widespread in resource-poor settings of sub-Saharan Africa. From this study, it emerged out that people living with HIV/AIDS are yearning for **better evidence-based healthcare services for childbearing women who are HIV-positive.** The researcher found this interesting because despite good knowledge of the benefits of exclusive breastfeeding, gaps in understanding and embracing the practice remained obvious and of main concern. This was associated with the fact that information promoting exclusive breastfeeding may have been understood by mothers as instructions from the healthcare professionals indicating how to feed their HIV- exposed babies rather than as an option for the mothers' own informed-decision based on the evidence provided by the healthcare providers. It is important therefore, to employ better strategies to the understanding influenced by mother's perceptions of breast milk safety while on ARV medicine from the available evidence.

This study bought out the evidence from several researchers that children who fed with formula products are prone to recurrent childhood illnesses leading to poor growth or even death (Nduati et al., 2012; Keraka & Wamicha, 2014; Wildeman et al., 2016 ; Gizaw et al., 2017). However, it is worth noting that infant feeding decisions are influenced by various factors such as financial considerations, socio-cultural factors, education and support given to the mothers; as well as the availability of safe replacement foods. However, it emerged that regardless of the circumstances, exclusive breastfeeding is indeed a safe and effective practice that substantially protects infants of HIV positive women from many childhood diseases. Unfortunately, there is evidence that without appropriate management, the HIV

virus can be passed from mother to baby during breastfeeding. Further, the studies highlighted the importance of encouraging support by partners in addition to healthcare providers and other designated members of the family especially the grandmothers whose role in infants feeding is crucial; even though some grandmothers practice traditional remedies that could be harmful to the child's health as alluded by Aubel, (2012).

Studies carried out by Gitobu et al., (2018) showed that Kenya has some of the highest rates of maternal and neonatal mortality rates in the world at 360/100,000 and 22/1,000 live births respectively. Translated into numbers – this equates to about 7000 maternal deaths and 29,000 neonatal deaths per year. Although the findings suggested that cost is a deterrent to healthcare facility delivery service utilization in Kenya, free delivery services are an important strategy to promote utilization of healthcare facility delivery services. However, there is a need to simultaneously address other factors that contribute to pregnancy-related and neonatal deaths. From this study, it is obvious that among the many other childhood infections, HIV/AIDS contribute to these alarming numbers. Therefore, to enhance feeding practices for HIV- exposed infants, it is mandatory to encompass a broader health campaign supporting not only mothers to exclusively breastfeed, but all those infected and affected by the HIV virus through evidence from research.

5.4 Support of people living with HIV/AIDS

There are many challenges faced by people living with HIV/AIDS in the Sub-Saharan African countries. One of the leading reason is dread of HIV/AIDS-related stigma that has remained pervasive in local communities. Consequently, there are difficulties of disclosure

of individual HIV status for fear of rejection. Also notable was the role of risky behaviours such as lack of condoms or refusal to use them. Important point to note is that people living with HIV/AIDs (PLWHA) considered their HIV/AIDS status as secondary to daily life stressors like poverty, unemployment, and gender-based violence (Cloete et al., 2010). There is therefore, a strong need for HIV risk reduction interventions with those who know that they are living with HIV/AIDS; identify issues which need urgent consideration as well as developing a locally relevant intervention for PLWHA suggesting some specific areas of focus that ensure support towards this vulnerable population. During the interactions in the clinic, home visits and from the interviews, it emerged from the participants that despite all that was being done to them, there is still a need to embrace more proactive ways to enhance understanding, acceptance and **support of people with HIV/AIDS** to help them live positively and to avoid stigmatization. The key issues in participants' descriptions of their lives as HIV positive women and mothers living with HIV were narrated as characterized by living with fear, distress, stigma and isolation. The women in this study spoke openly regarding the need to be able live openly like other people in the community with hope, emotional support, non-judgmental, acceptance and caring relationships. The role of re-creating the lost family network as indicated by McLeish & Redshaw,(2016) was seen as fundamental.

From active participative point of view, the Mater hospital, MCCC department through the support from donors from overseas was doing a lot to support the poor and marginalized living in the slums. But new approach to people living with HIV/AIDS is imperative to holistically address the whole issue. Thus, empowering them to ownership and

responsibility over their health and lives instead of making them dependant all the time on the support given. The researcher was left wondering what happens to the so many poor HIV positive people who do not have support projects like the MCCC. How much has the government done to take care of its citizens who have equal rights to healthcare like the rest? In the events of the donor world withdrawing their funds in the future, what will happen to these many clients who have made the MCCC their second home? The state of utter poverty remains pathetic and beckons for attention.

5.5 Poverty in the slums

In the efforts to improve the quality of living in Kenya, the Big Four agenda was adopted as a good strategic direction. It is importance to extend the driving forces towards achieving the goals of the strategy to the slum dwellers, whose lives are exposed to many risks. The President of the republic of Kenya outlined the Big Four Agenda during his tenure of office to include Expansion of Manufacturing Sector, Affordable Housing, Affordable Healthcare and Food Security according to report cited by Jael Keya, (2018). ("4 Pillars Uhuru Announced in His Jamhuri Day Speech - Kenyans.co.ke," n.d.). This approach is welcome especially for the population living in limited resources areas like the slums, where this study was carried out. However, from the researcher's objective perspective, though wishing to remain open and hopeful, this approach is far from reaching the population in this study. The reality was voiced by one participant in chapter four *(Nao)*, who felt that the government does not recognize the poor people living in the slums. The slums scenario is characterized by utter poverty with no income, poor housing, garbage cluttered environment; no food, no healthcare facilities as revealed by pictorial presentation 1 and 3 in chapters one and three.

The marginalized people are left to the mercy of well-wishers mainly non-governmental organizations and faith based institutions like the Mater hospital where MCCC carries out many activities geared towards improving the living conditions of the slum dwellers. Nevertheless, the President has remained optimistic towards achieving his dream during his term of office. The focus on these Big Four Agenda that are also underlined by the Vision 2030 are meant to provide decent work for people, ensure that people remain healthy, ensure educated society and that everybody is given a guarantee to affordable decent housing. But from this study, the participant expressed wish to be part of the plan put in place by **the government to address the slum dwellers healthcare needs as part of the big four agenda as per President's dream.** If anything, to go by, the situation gets worse by day as per researcher's observations during the many trips made through open running sewage water in between the pathways and surrounding the shanty houses the occupants call home.

As for affordable healthcare, this too is far from being realized. According to Article 43 (1) (a) of the Kenyan Constitution 2010, "Every person has the right—to the highest attainable standard of health, which includes the right to healthcare services, including reproductive health care. ("Healthcare, a right that is not : The Standard," n.d.). The healthcare charter dictates that all citizens have right to the highest attainable care, but needless to say this is only applicable to the wealthy citizens who can afford medical care in private or private faith based healthcare institutions, where payments must be done before receiving treatment. Given the circumstances the HIV positive mothers and their newborn infants find themselves in, the Big Four Agenda should have included other attainable strategies to reach

this vulnerable population. The obvious gap between the rich and the poor, especially those living with the HIV virus is wide.

5.6 The rich and the poor gap

There is a big gap between the well to do citizens and the poor living in resource limiting areas like the slums. The reality of being HIV-positive, a mother, living in the slums with no income and poor living conditions has affected many childbearing women in Africa as it emerged in chapter four (Mandala & Dirks, 2012; Bekere et al., 2014; Sama et al., 2017). This was confirmed by the research findings where women described their reactions to this reality. For some women, when they learned of their status, the reality of being HIV positive was narrated as "hard, impossible and unacceptable; unbelievable, difficult; like a dream, did not sink well, wished it was not true". Some expressed feelings of guilt, self-blame because of the possibility of passing the virus to the baby, and "it felt like committing a crime". Fears of the reactions from other people especially husbands and mothers-in-law, compiled with societal expectations were stated as "haunting". All these reactions were complicated by the state of utter poverty these women found themselves in. For them the reality surfaced as being hard enough to be poor without acquiring the HIV virus that made the situation worse. The participants' reaction to their situation concurred with Madise et al., (2012) study carried out in one of the Kenyan slums in chapter four, that concluded that there was high urban HIV prevalence that was largely driven by very high occurrence among slum dwellers. Moreover, Mbirimtengerenji, (2007) and Fox, (2010) concluded that HIV is an important consequence of poverty, with sexual trade, migration, polygamy, and teenage marriages as its predictors in the Sub Saharan region. This was associated with the fact that

poverty acts as an underlying driver of human immunodeficiency virus infection in sub-Saharan Africa. Additionally, poverty includes deprivation, constrained choices, and unfulfilled capabilities and refers to interrelated features of well-being that impact upon the standard of living and the quality of life.

An interesting article featured in the Standard newspapers by Dominic Omondi, (2018) ("Kenya, rich nation but home to many poor : The Standard," n.d.), showed that Kenya was ranked rich, but key indicators showed it is a poor nation. This is because, despite many efforts put by the government, the gap between the "haves" and the "have nots" has remained high. Report by BERNARDINE MUTANU 2018 ("Gap between Kenya's rich and the poor widens despite economic gain - Business Daily," n.d.) in Daily Nation and another one by ADONIJAH OCHIENG in Business Daily in January 2019 ("Gap between rich and poor 'keeps growing', new study shows - Daily Nation," n.d.), both showed the gap between the rich and poor in Kenya is widening with a 0.1 per cent of the country's population or 8,300 people holding the bulk of wealth, limiting equal access to opportunities.

Unfortunately, the poor continue to be poor compared to other groups of people whose income levels continue to improve. This reality was highlighted during the interactions with the participants. Regrettably, the poor are the ones at risk of contracting the HIV virus because of the above realities; and with women getting pregnant and passing the HIV virus to their infants, puts the future generation at a high risk. Therefore, there is **the need to narrow the gap between the rich and the poor,** since the latter are the ones mostly affected by HIV/AIDS. The researcher wishes to remain objective in this reality by acknowledging

the immense efforts the government has put to alleviate the poor living conditions in the slums; and hopefully the Big Four Agenda will extend to these vulnerable citizens and find **ways of availing equal opportunities to all** regardless of their backgrounds. **Important to note is that** the situation remains pathetic and warrants serious considerations and top priority to save the innocent newborn infants and their families.

6.0 Limitations of the study

It is usual and acceptable that any research will have some limitations and that is normal (Desmond & Meaney, 2016). However, it is critically important for the researcher to be a striving force to minimize the range of scope of limitations throughout the research process. Also, as a researcher, one needs to honestly provide the acknowledgement of the research limitations in conclusions chapter. This gives unbiased and frank discussion of study limitations by authors and represents a crucial part of the scientific discourse and progress (Puhan et al., 2012). The following were the limitations encountered during this study and how each one of them was overcame or minimized.

6.1 Subjectivity

As discussed in Chapter three by Aug, (2017), an ethnographic study strategy provides an opportunity to understand the big picture through exploring subjects' needs as well as understanding their language, concepts and beliefs. In the process of actualizing this reality, the demands on the researcher's emotions and intellect were high as objectivity was aimed at. Getting into the real lived world of five women and their families as required by the qualitative methodology placed the researcher in a world of subjectivity. This was found to

be emotionally draining because the women's experiences and the tragedy of their lives' stories affected the researcher. However, strict adherence to principles of reliability and credibility were embraced to reduce bias that typifies qualitative research. To minimize all these, a reflexive journal was maintained throughout the study, and periods of rest taken in between data collection.

6.2 Setting

According to Burchett et al., (2013), research setting is useful because it highlights the understanding perceptions of the applicability and transferability of the study. Additionally, for healthcare sector, a well-conducted research focused on the settings is vital to the success of global heath endeavours. Based on the research methodology and design, ideally, interviews for this study should have been carried out in the participants' households. But, clients were interviewed in a hospital setting because of the limiting space in the overcrowded shanty houses; and also following request by the participants not to carry out interviews in the homes because they feared that family members or neighbours might get to hear the conversations. Notably, during the home visits, the participants spoke in whispers and made sure that the doors were shut in fear of other people passing hearing the dialogues. However, this was justified by the fact that the participants spent most of their time in the hospital settings, which they gladly referred to as their *"home"*. This limitation was compensated by the researcher's open and free informal interactions during the home visits and jotting down any key information shared during the visits. Additionally, her active observations and noticing any observable messages during the home and visits were used to enrich data.

The reality in the slums is that once it rained, it remained a no go zone because of the muddy pathways and the burst sewage water that surrounds the shanty houses. Therefore, this affected the planned visits that had to be rescheduled several times. However, the researcher availed herself and made use of the possible days that allowed accessibility to the houses, and employing active participatory methods gathered most of the information through indirect conversations and observations. Nevertheless, the entire scenario above was limiting because the practicability of qualitative ethnographic research demands that activities that include interviews and observations are carried out in the community setting where issues of cultural and societal expectations affect lived reality. Furthermore, the researcher is called to live full time in the dwellings of the participants to enable accessibility of a comprehensive picture of real lived life around the clock. However, the nature of the housing settings did not allow the researcher to stay over nights because when night came, it was survival for the fittest as family members searched for a corner to put their heads down for the night. As such, there was no corner left for the researcher's head and these circumstances forced the researcher to return to her abode. To counteract this limitation, the researcher made many home visits during different specific times of the day including late at night when most members where present; and in so doing, was able to gather enough data at different times to describe the real life in the slums.

6.3 Time constraint

As discussed in Chapter three, interviews are particularly useful for gaining the story behind the participants' experience (Al-Yateem, 2012) . Therefore, ample time is required to pursue in-depth information around a topic. Time factor was a constraint, because interviews were

scheduled for specific days and times. Some women, having managed to open up on a considered 'hidden area' of their sexuality, social life and family issues felt that they needed more time with the researcher. This made it hard to terminate the well-established relationship during the sessions. However, although the researcher had to remind herself of the boundaries, and adhere to ethical guiding principles, flexibility was embraced to cater for the participants' needs. The frequent encounters with the participants during clinic visits and home follow ups at different times of the day that were dictated by participants availability provided ample time for discussions that addressed the women's concerns. In some circumstances reassurance was given that the MCCC counsellors could make follow-ups to ensure that their issues were fully addressed. The researcher made herself reachable through the phone and any urgent issues were handled through this mode of communication. The termination process took longer than planned to ensure that the women were not left in a vulnerable state.

6.4 Sample and subject selection

As stated in chapter three, it is important to consider sampling and the determinant of adequate numbers that could develop a theoretical category in the process of analysis to improve the quality of data, enhancing richness and depth of the study as indicated by Roy et al., (2015). Several clients qualified to be part of this study and were selected during their prenatal clinic visits. Following explanation on what the research entailed, many accepted to participate. This was followed by home visits by the researcher to get familiarized with the home settings. Unfortunately, the clients' houses were so hard to trace that the researcher needed assistance from the community health workers. This was not appreciated by some

of the participants because visiting their homes with the community health workers, who were residents of their area could be interpreted by the neighbours that they were HIV positive. The researcher was able to objectively convince the participants the important of these primary caretakers who work as the mediators between them and healthcare institutions.

The residents living in informal settlements areas have general characteristics of frequent change of residence (Ma, An, & Park, n.d.). This was actualized as some participants kept on changing their houses making it difficult for the researcher to trace them in the midst of the thickly populated slums of Mukuru that have no roads or landmarks. It was hard to interpret the reason behind this migration, although, it became clear that the clients expected some enumeration for participating in the study. Additionally, upon discovering some unacceptable warranting domestic issues such as gender violence, that needed immediate intervention, one participant opted to decline from taking part in this study, and moved to undisclosed area. Another woman was staying with three men and was having sexual relationships with them all as a way of income. This was risking re-infecting herself despite being on ARVS. Efforts from the MCCC to provide her with safe accommodation were met with negativity; and she too changed the house. The whole issue of selection of subject size was compensated by initial inclusion of many potential participants and the researcher was able to stay with a sizeable number that provided enriched data for this study.

6.5 Other issues

As discussed in chapter three, reality in qualitative studies is internally experienced and socially constructed through interactions and interpretations. The emphasis is on looking at the holistic description of events, procedures, experiences and philosophies in natural settings (Carolyn et al., 2011). Thus, this study opened up more areas for discussion that had nothing to do with their HIV status and breastfeeding, though to some extent influenced the practice. Such issues related to the society expectations, unemployment leading to lack of income and inadequate food; need for food support especially for the infants to make sure that they grow well; the importance of MCCC staff to continue with home visits after delivery and beyond; government inability to take care of the less fortunate members of the society, myth about birth practices and the crippling poverty. One (20 percent) participant clearly stated that, although she appreciated the support offered by the MCCC, sometimes it is not possible to avail for such services because to get airtime to call when issues occur or bus fare to visit the clinic was a big challenge. Thank God, the clinic has a well-established community services department, and this was utilized to take the drugs, baby clothes and food to this client the home setting.

A good number of the participants had great expectations from the researcher hoping that they would get preferential treatment, material and financial assistance. But, this being against the principle of ethics in research and good practice, the participants were explained about its impossibility. These issues were very overwhelming for the researcher who through active participation observed the state of desperation of the clients. Keeping the reflexive journal and taking breaks from the situation provided an opportunity to rejuvenate.

Nevertheless, referrals were made to the relevant experts like the social workers and counsellors within the department for appropriate action and follow-ups. Another unique limitation to this study was that all the participants declined to keep the documents that included the interview questions, information sheet and the signed consent. The reason given by all being that they were afraid their children or any of their relatives might come across such documents and hence know their HIV status leading to many questions and social stigma. Additionally, despite clear explanation and reassurance, they refused to be recorded for fear that this would be used to disclose their status. This was against the stated intention in chapter three of the methodology indicating that the participants would be keep these records to show that they freely participated in the study and were not coerced in any way. To address this, and to respects the clients wishes, all the documents were kept in a safe custody by the researcher.

7.0 Conclusion and recommendations

From this study, it emerged that all the five participants (100 percent) representing the population of HIV positive women living in the slums of Nairobi, Kenya, had given birth and opted to exclusively breastfeed their infants were aware of the advantages of breastfeeding. Further, they all acknowledged that the benefits of breast feeding have undoubtbly far reaching rewards compared to the other mode of feeding. Similarly, all recognized that breast milk has many health benefits for infants, such as essential nutrients and immunological agents that protect against early infections; and help the infant to develop stronger immune systems as they grow and develop. It also materialized that the breastfeeding mode should not be ignored regardless of the circumstances the woman finds

herself in. Additionally, breast milk was stated as less expensive than formula milk, and therefore more applicable to the population living in resource limited areas. More importantly, although they all did not know what exclusive breastfeeding meant and entailed, they gladly accepted the instructions provided by the healthcare professionals based on the trust relationship they had established. Subsequently, all the participants (100 percent) embraced exclusive breastfeeding and all their infants (100 percent) survived, remained free of the HIV virus and to date they are thriving well. However, all the participants (100 percent) acknowledged that the issue of breastfeeding is complicated for HIV-positive childbearing women not only because of the risk of transmission of the HIV to the baby, but due to many issues pecked on several factors and societal cultural expectations as highlighted all through this thesis. However, from this study, it was obvious that the issues of breastfeeding are secondary compared to the circumstances these women find themselves; and that the utter state of poverty seemed to have hindered many good intention towards healthy style and good living standards.

With the emergence of HIV/AIDS, the concept of breastfeeding especially in the African countries, where the cultural norm is that every woman must breast feed the newborn, is perceived from different viewpoints. Whether or not the risk of transmitting justifies using formula depends on the specific factors stemming from cultural, economic, educational, and environmental conditions, and the support provided by the healthcare providers. Unfortunately, there are many areas in the world Kenya included, with limited resources and poor environmental conditions where the recommended formula feeding may not be the best solution. However, in areas where the economy is strong, there is access to clean water

and people have high levels of education, mothers who are HIV-positive could formula feed their babies following adequate information and counselling. It was also noted that despite the health talks provided to the women, not all were aware of meaning of exclusive breastfeeding as the normal way of providing young infants with nutrients they need direct from the mother's breasts for healthy growth and development ("WHO | Breastfeeding," 2018c). Additionally, it was clear that the majority were not involved in the decision-making process, but rather were instructed. This raises concerns regarding the practicability of not involving the implementers of recommendations who are the women themselves. Virtually all mothers can breastfeed, provided they have accurate information, and the support from their families, the healthcare systems and society at large. In addition, the study revealed that the population under study being vulnerable tended to be submissive in following the instructions given to them since they considered the healthcare providers as "the holders" of expertise and knowledge.

The participants posed many challenges stemming from utter poverty characterized by the poor living conditions that pose great risks of infections to the newborns; lack of source of income leading to no food on the table for the breastfeeding woman who is expected to exclusive breast feed. Unfortunately, it surfaced that with no food for the other members of the family, the obvious result was for them to indulge in the food provided by the MCCC as part of the support system to help the women have enough milk for their infants. Hence, the situation was not adequately addressed, but posed further challenges on the care of the other members of the family from wholistic perspective. From the researcher's angle, there was an urgent need to address the challenges highlighted by the participants through scaling up

psycho-social and gender empowerment strategies for women, and introducing initiatives that promote the integration of HIV infant feeding strategies into other child health services as stated in chapter two (Nabwera et al., 2017b).

Education programs that equip nurses and midwives with more evidence-based knowledge and skills to effectively manage services such as teaching on breastfeeding and HIV, how to avoid re-infections, good diet, the preparation of formula milk for those who wish to embrace this mode of feeding and other related health topics should be implemented. Importantly, the skilled midwives, who are mostly with childbearing women should help the HIV-positive mothers make the best decisions for their circumstances. The bottom line is that HIV- positive mothers who live in developing countries, with no income and living in informal settlements with poor living sanitation need increased access to more information and resources that could simplify their difficult decision-making process. International bodies like WHO, UNAIDS and UNICEF need to consider several factors based on individual state, values, living conditions, environmental and cultural factors; and level of education that influence successful implementation of suggested recommendations. Issuing of blanket recommendations must be stopped and instead embrace the concept of acceptability, feasibility, affordability, sustainability and safety pecked on the specific population with their unique challenges. Recommendations made in developed countries where basic needs are obviously available and accessible are unlikely to be applicable in developing countries where most people struggle daily for their basic needs.

It should be acknowledged that while policies are being debated on the matters of breastfeeding in the era of HIV/AIDS, cultural practices continue to be the driving force in their applicability. In addition, decision-making needs to reside within the hands of those who own the problems. The obvious lack of voice of African women in decision-making processes demands attention. Nevertheless, the efforts by the international bodies to assist Africa in the fight of HIV/AIDS are timely and highly appreciated. But nonetheless, it is cruel to offer mothers advice, with no provision of ways and means to accompany that advice. Worse still, it is vindictive to allow children in this generation to needlessly acquire the fatal virus that causes AIDS and subsequent death, leaving a gap of our potential future citizens and leaders. The HIV epidemic is a major concern for all of us, and we can contribute to change the situation.

The unfortunate slum dwellers continue to occupy the poor persons' role and appear to be the forgotten citizens because the government does not seem to recognize them with their multiple and complex specific needs. This was evidenced by the living poor conditions that do not qualify for any human being or animal habitation. However, the role played by non-governmental organizations and faith based organizations has no doubt contributed immensely in trying to improve the living standards of the slum dwellers. From this study, it was revealed that strategies and some concrete small steps have been put into place to empower the clients who visit the MCCC with some means of income generating activities such as self-help groups with specific activities such as basket weaving and cooking of snacks in the efforts towards sustainability. However, as much as this is highly acknowledged, the initiative is far from providing the basic needs to the population living

in the slums of Mukuru in Nairobi. There are gaps warranting urgent attention that include but not limited to dependency syndrome, lack of government initiatives to take care of its citizens and provide the basics, the gap between the rich and poor being too wide, the numbers of the slums mushrooming in the urban areas; lack of employment even for the university graduates and rapid population growth rate. The article in Kenyan Sunday Nation by Oketch Angela 2019 ("AOketch@ke.nationmedia.com - Google Search," n.d.), highlighting the long overdue step by the Ministry of Health initiative to start assigning healthcare professionals to the communities is appropriate and provides hope to this population under study.

In Conclusion, the research's objectives were sufficiently met because the population under study expressed their experiences and perspectives of being HIV positive, a mother living in the resource limiting area were narrated from real lived reality which was the focus of the research. Although they were happy with the choice of exclusive breastfeeding, the success of their choice was actualized through the support provided by the MCCC in terms of food to ensure enough milk production for their infants. But the many issues grounded on the reality of their living conditions complicated by poverty compromised their good intentions to withstand the option. The willingness to stay with the choice of exclusively breastfeed was pecked on the promise that the clinic would continue with food supply, with the researcher frequently acting as a mediator to ensure constant supply. Hence, reinforcing the dependency syndrome, but this was inevitable because the infants needed to be protected from acquiring the virus.

It is worth noting that it was hard to stay within the scope of the study given that this was a qualitative methodology with ethnographic design approach which opened areas of free-wheeling discussions that went beyond the limits of the study. Interesting, the researcher felt that the participants did not view HIV/AIDS as a major issue from their stance, but rather other far pressing issues stemming from their lived world. There were also doubts regarding the role played by creating dependency syndrome and how to wean the clients off by empowering them to be more independent and productive. A major concern from the researcher was what happens to thousands of HIV positive childbearing women who do not have any access to the support services like those provided in MCCC and the many non-government and church organizations who seem to have taken over the role of the government.

Based on the many issues and factors surrounding HIV/AIDS and exclusive breastfeeding, the following recommendations are deemed important for further research:

- The fate of slum dwellers in Kenya
- What drives people to migrate from their rural homes and choose to live in such poor urban conditions?
- Why people living in the slums appear "happy" despite the living situations; are they really happy?
- Why HIV/AIDS is not being given top priority as part of the Big Four Agenda
- What policies and recommendations may work for people living in resource limiting areas?

It is evident from this study that the era of HIV/AIDS has not only placed a burden on childbearing women, healthcare professionals and governments but has also created a big

dilemma on international policy makers as they ponder on the critical decisions about breastfeeding policies that are applicable to all. Nevertheless, it is believed that by unearthing some hidden factors related to the above recommended research area topics; the whole issue of HIV/AIDS especially in childbearing women living in resource limiting areas will be holistically addressed. Then, researchers and healthcare professionals will gain better understanding and perceptions of: -

"How is it like to be HIV positive, a mother with instructions to exclusively breastfeed her infant; and living in resource limiting areas called the slums"

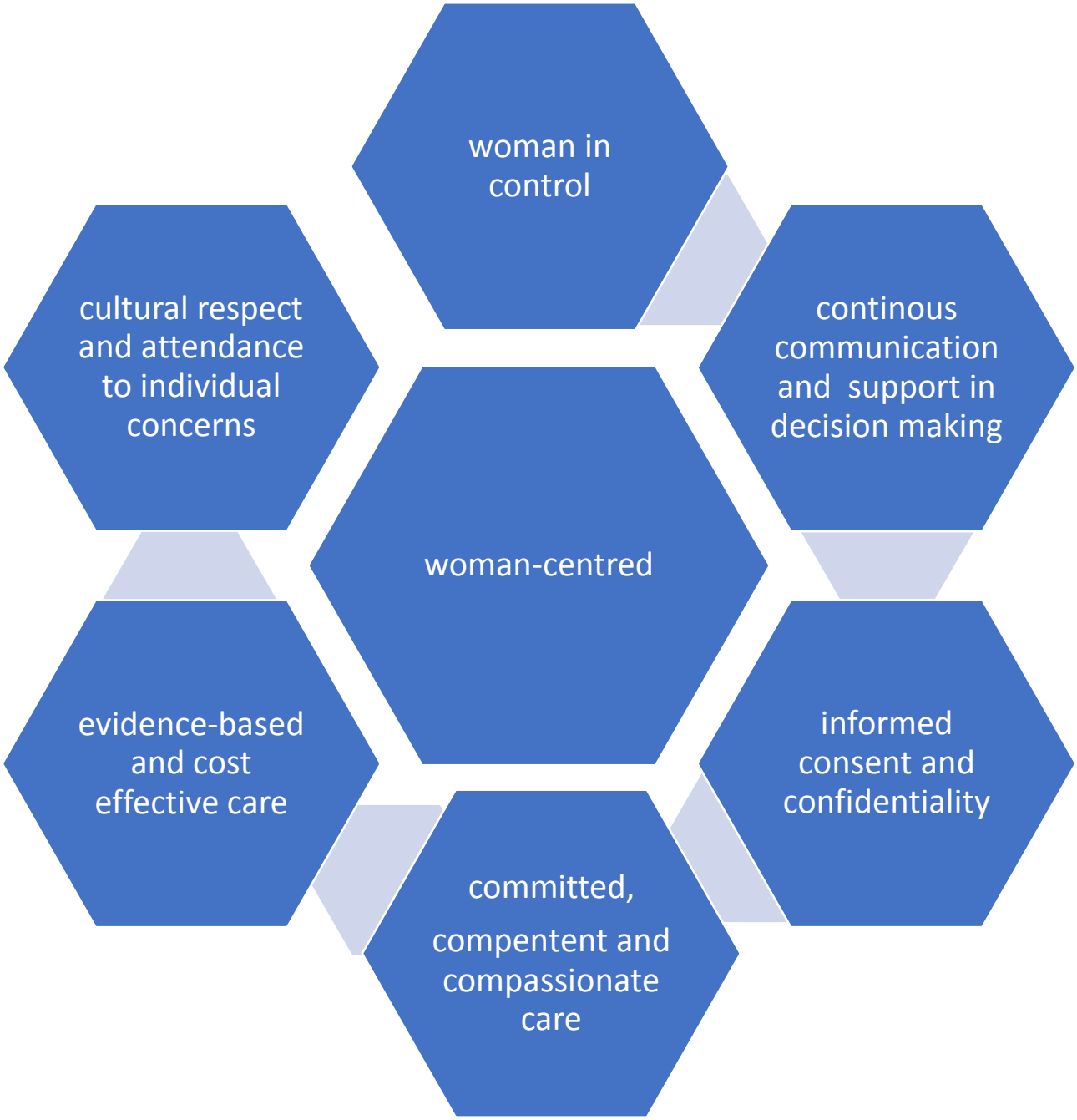
The evidence based on the above recommended areas of study will help in the provision of better healthcare services to Kenyan citizens, people living with HIV/AIDs especially to the slum dwellers who have the same rights to healthcare like any other citizen as dictated by the Kenyan Constitution 2010. More importantly, the new born babies will be accorded an opportunity to grow and develop normally and become future responsible citizens and potential leaders of tomorrow.

7.1 Recommendation

Apart from areas for further research, the researcher wishes to recommend a midwifery education model that would address the issues that surfaced from this study. The philosophy of midwifery education is based on the 'Women-centred care' model, which provides holistic care to women. In this model, continuity of care is integral to the concept of holistic women-centred care and fundamental to midwifery practice (Yanti, Claramita, Emilia, & Hakimi, 2015). In addition, International Confederation of Midwives in the efforts of strengthening midwifery globally, maintain a woman centred model of care (Document,

n.d.). The Childbirth being a unique experience, with cultural, social and psychological effects, it is believed that the mothers should be the main focus of maternity services; where the midwife becomes a partner in the care providing education, guidance and support. Further, the approach to care should enable the woman to feel in control, encouraging her to make informed choices about pregnancy, childbirth and parenthood. It is important therefore to recognize the fundamental importance of appropriate communication and liaison with other members of the multidisciplinary team; as well as provide an environment that encourages teaching, innovation and learning. The following education model is recommended for effective midwifery services not only for this vulnerable population but to the child-bearing women to provide a positive birthing experience. The education model below will be commenced in the all healthcare institutions offering maternal services to the child-bearing women and, hence empower the women to own the part in procreation and the responsibility that accompany their protagonist.

7.1.1 Midwifery Education Model



APPENDICES

Appendix i

INTERVIEW QUESTIONS

1. Could you please tell me what you know about feeding of your baby?
2. How were you involved in the decision making about the feeding of your baby?
3. What is your understanding of Exclusive Breastfeeding?
4. What other methods are you aware for feeding your baby?
5. What concerns do you have about any of the feeding methods?
6. Given the reality of mother to child transmission of HIV, what do you think healthcare professionals can do to help childbearing women who are HIV positive in making choices about their method of infant feeding?

Appendix ii

INFORMATION SHEET FOR PARTICIPANTS

The research is based on exploring the experience of women who are living with HIV/AIDS, have delivered, and have been instructed to exclusively breastfeed their infants because of the high risk of mother to child transmission of the HIV virus.

The research will lead to writing of a thesis in fulfilling one of the requirements for Doctor in Philosophy.

The following areas of breastfeeding and HIV will be addressed during the interviews:

- The of concept breastfeeding
- Implications of breastfeeding based on cultural aspects
- HIV/AIDS and the Medical recommendations on breastfeeding
- Other methods of feeding and concerns regarding these
- Decision-making regarding breastfeeding and women involvement
- Experience of exclusive breastfeeding as mandatory for HIV positive childbearing women

The results of the study will be used to make recommendations to policy makers both locally and internationally. These recommendations will pertain to the importance of women involvement in decision making as well as the need to support these women in whichever choices they make.

The researcher will obtain an informed consent from each participant. Participants are free to participate, or even withdraw from the interviews. There are simple questions provided by the researcher, and participants are free to answer these in either English or Swahili.

Thank you for taking time to read this.

Appendix iii

CONSENT FORM FOR PARTICIPATION IN RESEARCH

I ….....**.....**

being over the age of 18 years hereby consent to participate as requested in the interview for the research project on: The experience of women who are HIV/AIDS positive and have opted to exclusively breastfeed their infants.

1. I have read the information provided.
2. I agree to my information and participation being recorded.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
4. I understand that:
    - I may not directly benefit from taking part in this research
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage
5. I agree / do not agree to the tape being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……Date……...

I certify that I have explained the study to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name: - Mary Ngui

Researcher's signature……Date……

Appendix iv

Mater Misericordiae Hospital
Under the Sisters of Mercy

P. O. Box 30325 - 00100
Dunga Road, Nairobi, Kenya
Telephone: (254) (020) 6903000
Mobile Lines: 0719 - 073000, 0732 - 163000
Fax: (254) (020) 6534289
Email:inform@materkenya.com
Website: www.materkenya.com

5th March 2019

Sr. Maria Ngui
Catherine McAuley Nursing School
P.O. Box 30325-00100
Nairobi
Our Ref: MMH/DMS/VOL.2019/05

RE: PERMISSION TO CONDUCT A STUDY IN MCCC-TO SELECT PRENATAL MOTHERS WHO ARE TERM AND DOING A FOLLOW UP IN THE SLUMS AFTER DELIVERY TO EXPLORE THEIR EXPERIRNCE IN EXCLUSIVE BREASTFEEDING

We acknowledge receipt of your request for permission and assistance to conduct a research study in MCCC 'To select prenatal mothers who are term and doing a follow up in the slums after delivery to explore their experience in exclusive breastfeeding.'

Standards & Ethics Sub-Committee of The Mater Misericordiae Hospital, has reviewed your request as entitled above, and found it acceptable.

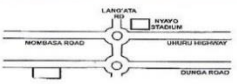
You are hereby allowed to proceed with your research but **MUST** submit a copy of findings for inclusion in our inventory.

I wish you well.

Thank you.

Yours faithfully,
FOR: THE MATER HOSPITAL

Dr. Andrew Ndonga
CHAIR, STANDARDS AND ETHICS SUB COMMITTEE



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