

**Involvement of family/household members
of HIV positive women in family centered
PMTCT: A study of a level one hospital in
Limpopo province, South Africa**

by
Felix Okeroghene Idolor

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Supervisor: Prof. JCD Augustyn
Faculty of Economic and Management Sciences
Africa Centre for HIV/AIDS Management

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DECLARATION

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SUMMARY

Increasingly, HIV/AIDS is being viewed as a family disease. The underlying conditions that favour the transmission and spread of the epidemic are more often to be found in weaknesses, vulnerabilities and breakdowns of the family/household unit. The immediate impact of the epidemic is also seen within family/household units. Increasingly also, the family is being viewed as the immediate environment for combating the epidemic. Hence HIV/AIDS interventions are increasingly being designed and implemented in a family centred way. In family centred interventions, the needs of HIV affected families can be dealt with in a holistic way and not just attending to their health care needs alone.

Family centred prevention of mother to child transmission of HIV/AIDS exploits contact with the pregnant woman attending maternal services as an entry point to bring whole families and households including male partners into HIV/AIDS interventions.

This study carried out in Seshego Hospital, a level one district Hospital in Limpopo province was aimed at finding out to what extent health care workers providing maternal care engaged families/households including male partners of HIV positive women in prevention of mother to child transmission of HIV (PMTCT).

A survey of 34 HIV positive women from ages 19 to 43 years attending maternal care services was carried out using a structured questionnaire.

The study reveals that 52.9% of study participants reported disclosure of their HIV status to a member of the family while 47.1% had not disclosed

Admission of disclosure to male partners by the study population was 64.7% while 35.3% of denied disclosure of their HIV status to their male partners.

The study further revealed that 53% of the study participants admitted that their male partners had been invited to participate in PMTCT while 47% said that their male partner had not been invited participate.

An average of 23% of survey partners reported that their male partners participated in PMTCT either by taking an HIV test, being on antiretroviral medication themselves or by use of condoms for prevention of HIV transmission while in 77% of survey participants the male partners was reported not to be involved in any of these ways.

Overall participation of a member of the family/household other than male partner in PMTCT was reported to be 14% while in 86% of survey participants reported no involvement of a household/family member in PMTCT.

The low level of engagement of the families/households of HIV positive pregnant women including their male partners in PMTCT found in this study implies that this important entry

point into HIV prevention, treatment and care programmes is not being fully exploited.

OPSOMMING

MIV/ Vigs word toenemend as 'n familie-siekte beskou. Die onderliggende toestande wat die verspreiding van die siekte bevoordeel kan dikwels gevind word in 'n familie-struktuur wat onder druk is.

Hierdie studie is gedoen by die Seshego Hospitaal in Limpopo. Die doel van die studie was om te bepaal in watter mate die tussenkoms van en voorligting deur gesondheidsorgwerkers aan families of huishoudings die oordrag van moeder-na-kind MIV kan verminder.

'n Opname is onder 34 MIV-positiewe vrouens tussen die ouderdomme 19 en 43 jaar gedoen en 'n gestruktureerde vraelys is gebruik.

Die studie toon aan dat daar 'n baie klein invloed deur die inmenging van gesondheidsorgwerkers op moeder-na-kind oordraging van MIV is. Voorstelle word aan die hand gedoen om hierdie situasie aan te spreek.

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Chapter1: Introduction

1.1 Backbround

HIV/AIDS remains the foremost epidemic of the world. Its overall growth appears to have stabilised. However in spite of evidence of falling new infections worldwide and significant reductions in mortality due to HIV/AIDS the burden of infections worldwide remains significant.

According to the global report on HIV/AIDS by the Joint United Nations programme on HIV/AIDS (UNAIDS) in 2009, an estimated 2.6 million people who became infected with HIV. The majority of the new infections occurred in Sub-Saharan Africa. An estimated 370,000 children were newly infected with HIV according to the same report.

Worldwide there are an estimated 33.3 million people infected with HIV. Sub-Saharan Africa bears the greater burden with an estimated 22.5 million people infected with HIV. (UNAIDS, 2010).The vast majority of HIV infections in Sub-Saharan Africa are transmitted during heterosexual encounters with subsequent onward transmission from an infected pregnant woman to her child. Women according to UNAIDS,2010 represent 52% of those infected with HIV worldwide and in Sub-Saharan Africa 60% of those infected with HIV are women.

Women bear a greater burden of infection in Sub-Saharan Africa for biological and social reasons. In Heterosexual encounters women are more likely than men to be infected with HIV due to biological reasons. In Sub-Saharan Africa, women are more in a disempowered position to negotiate safe sex and are more likely to experience sexual violence.

Just as women represent a greater proportion of those infected with HIV both worldwide and especially in Sub-Saharan Africa they also bear disproportionately the consequences of HIV infection. In Severely affected countries HIV has become a leading cause of death among pregnant women. (McIntyre, cited in WHO, 2006).In many of these countries despite improvements in obstetric services, maternal mortality has been increasing over the past two decades. These increases have been attributed to HIV. (WHO 2006).The increase in number of women dying in pregnancy and after childbirth due to HIV /AIDS has been due in part to the emergence of Tuberculosis and Pneumonia as major causes of illness and subsequent death as reported by studies in South Africa and Zambia.(Krugger and Gwarjee, 2003).

Sub-Saharan Africa has the largest maternal mortality ratio (defined as the number of women dying from the time of conception to within 42 days after delivery per 100,000 live births over a defined period of time) of all regions of the world with an estimated maternal mortality ratio of 640 deaths per 100,000 live births. An estimated 9% of these deaths are due to HIV/AIDS. (WHO, 2010).

In South Africa the trend has been one of an increase in maternal mortality and due in large part to the epidemic of HIV. According to the confidential enquiries into maternal deaths in South Africa published in 2006, HIV/AIDS accounted for 20.19% of all maternal deaths in South Africa, (DOH, 2006)

In the face of the grim statistics due to the worldwide HIV/AIDS pandemic, advances in scientific understanding of the virus coupled with breakthroughs in ability to diagnose HIV rapidly and medications capable of controlling the replication of the virus in the human body have presented the world with the opportunity to turn the tide of HIV worldwide.

The introduction of antiretroviral medications in the form of highly active antiretroviral therapy (HAART) has significantly reduced morbidity and mortality due to HIV/AIDS making it a manageable chronic illness where these drugs are available and affordable especially in resource abundant countries of the western world.

With the emergence of highly active antiretroviral treatment (HAART) for HIV it has become possible to reduce remarkably, the load of the HIV virus in the infected individuals making it possible for them to have an immune system that can effectively combat opportunistic infections and thus allow them to lead an active and healthy life. Reduction in viral load as a result of antiretroviral therapy has also reduced the chances of transmitting the HIV virus from an infected individual to a non -infected individual.

With the availability of effective methods for prevention and treatment of HIV the goal of governments, multilateral institutions, non -governmental organisations and various other bodies in the forefront of the fight against HIV has been one of universal access to prevention, treatment and care.

Bringing HIV prevention, treatment and care programmes to scale will involve overcoming problems such as lack of financial and human resources, poor health care systems and infrastructure, poverty, stigma, discrimination and gender imbalance. These are problems mostly prevalent in low resourced countries especially in Sub óSaharan Africa.

The one area in which it has become feasible to virtually eliminate the spread of HIV is in its transmission from mother to children. This has become possible with the introduction of effective biomedical methods such as the use of highly active antiretroviral therapy (HAART) when combined with good obstetric practices, safe infant feeding practices and safe sex practices in pregnancy and beyond. This possibility has led to the call by UNAIDS for the virtual elimination of HIV transmission from mothers to their children by 2015 (UNAIDS, 2010).

Prevention of mother to child transmission of HIV (PMTCT) refers to interventions for the prevention of transmission of HIV from mothers to children during pregnancy, child birth and breastfeeding.

The world health organisation advocates a comprehensive approach for the prevention of mother to child transmission of HIV that addresses the broad range of HIV related prevention, care, treatment and supports the needs of pregnant women, their children and families. This comprehensive approach includes primary prevention of HIV infection especially among young women, prevention of unintended pregnancies, provision of specific interventions to reduce HIV transmission from HIV infected women to their infants and provision of treatment, care and support for HIV infected mothers, their infants and their families(WHO, 2007.)

Worldwide there has been a trend to integrate PMTCT services into maternal and child health services rather than stand-alone PMTCT services. The rationale for integrating PMTCT services into maternal and child health services takes into cognisance the fact that women of reproductive age are mostly at risk for HIV virus and when infected also place their unborn children at risk of being infected with the virus. Maternal and child health services therefore represent an entry point for these women into HIV prevention treatment and care.

Entry points are opportunities for identifying people who could benefit from HIV treatment. Entry points facilitate the link to HIV counselling and testing which is the gateway to all HIV prevention, treatment and care services (WHO, 2003).Maternal and child health services offer women and their families an important entry point to critical services because of their widespread availability and community acceptance(population council,2002)

In most countries maternal and child health services are well patronised. Integrating HIV interventions into such services therefore is expected to maximise the benefits for both

mothers and child health systems to be more responsive to the needs of women, children and their families (WHO, 2008)

Antenatal care attendance in South Africa has remained well above 90% since 1998 with an average of 5.2 visits per pregnant woman during their pregnancy and 83.7 of pregnant South African women delivering their babies in health care facilities (DOH, 2004). This represents a unique opportunity to expand HIV testing and therefore bring HIV prevention, treatment and care to scale.

Within the South African context PMTCT integrated within maternal and child health services offers a unique opportunity to further expand HIV testing and hence HIV prevention, treatment and care services to the families of pregnant women. It is however doubtful if this opportunity is being optimally exploited. A study of antenatal services in a rural district of Kwazulu Natal, found that the standard of care offered to pregnant women fell short of nationally required set standards. (Hogue, Hogue and Kader 2008)

The South African national strategic plan for HIV/AIDS, 2007- 2011 has as one of its two primary objectives, the reduction of the rate of new HIV infections by 50% by 2011 and reducing the impact of HIV/AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all HIV positive people and their families by 2011. High attendance of pregnant women at antenatal care and therefore their availability for PMTCT services offers a unique opportunity to move toward the realisation of this national objective as the pregnant woman is increasingly viewed as an access to take HIV testing, prevention, treatment and care to families and households and hence the community and society at large.

1.2 Research problem

High attendance of pregnant women in South Africa represents an opportunity to involve families in HIV/AIDS prevention, treatment and care programmes. However it is not known to what extent family or household members of HIV positive pregnant women are brought into HIV prevention treatment and care services through contact with the HIV positive pregnant women while providing PMTCT services within maternal health care settings.

1.3 Research question

To what extent do health care workers involve family or household members of HIV positive pregnant women in prevention, treatment and care through contact with the HIV positive pregnant women while providing PMTCT services in maternal health care.

1.4 Aim of study

The aim of was to contribute to a scientific evidence led process of organising prevention of mother to child transmission of HIV (PMTCT) services in Seshego Hospital and Limpopo province in such a way as to make it more family centred and therefore more effective.

1.5 Objectives of study

The objectives of the study were:

- To establish what a family centred prevention of mother to child transmission (PMTCT) service is.
- To find out what role family or household members of the HIV positive pregnant woman can play in a family centred PMTCT service.
- To find out to what extent family or household members of the HIV positive pregnant women attending maternal health services in Seshego hospital are engaged by health care providers in PMTCT services and through this means brought into HIV prevention, treatment and care programmes.
- To find out the extent to which health care providers in Seshego Hospital engage male partners of HIV positive women in PMTCT and other aspects of HIV prevention treatment and care.
- To make recommendations as how to better organise PMTCT services within the province to make them more family centred.

The first and second objective will be achieved by means of the literature review while the third and fourth objective will achieved by means the research process which will be carried out in Seshego Hospital.

The literature review and findings of this research will form the basis for recommendations made.

Chapter 2: Literature review

In the context of this study the literature review will seek to explore the concepts of HIV as a family disease looking at the family as the immediate environment within which HIV is spread and has its impacts. It also looks at the family as the immediate social unit within which to combat the infection of HIV. The concept of family centred care is looked into as it leads logically into family centred HIV interventions and hence family centred prevention of mother to child transmission of HIV (PMTCT). The role of men as fathers is also examined especially with a view of harnessing their influence to strengthen family centred PMTCT. Finally the place of provider initiated (routine) HIV counselling and testing will be discussed as a gateway to HIV prevention, treatment and care for the family and community at large.

2.1 Brief overview of prevention of mother to child transmission of HIV (PMTCT)

Prevention of mother to child transmission of HIV refers to scientifically proven interventions designed to prevent the vertical transmission of HIV from mothers to children. Primary prevention involves interventions to keep an HIV free woman of reproductive age from getting infected. Secondary prevention involves interventions designed to prevent an HIV infected pregnant woman from passing the virus onto an unborn child during pregnancy, during labour or during the period breastfeeding the baby. This is also referred to as the prevention of perinatal transmission of HIV from mothers to children. This strategy is based on the use of the appropriate combination of antiretroviral drugs, safe obstetric practices and safe infant feeding practices.

The field of prevention of mother to child transmission of HIV has rapidly evolved with continuously improving outcomes in preventing mother to child transmission of HIV. The breakthrough in this field began in 1994 in the United States of America when the paediatric Aids clinical trial group study (PACT 076) showed a 70% reduction in perinatal transmission of HIV from infected mothers who received a regimen of zidovudin from 14 weeks of pregnancy until 34 weeks and then intravenously during labour and six weeks orally for the children after birth.

With the effective use of combinations of antiretroviral drugs for the treatment of HIV infected pregnant women coupled with avoidance breastfeeding and safe obstetric practices in child birth, the transmission of HIV from mother to children in the United States and Europe has been reduced to less than 2% (NIH,2010). The dramatic success in reducing the

perinatal transmission of HIV from mothers to infants in America and Europe has been due in large parts to the rapid translation of research findings into practice (Fowler, Lampe, Tamieson, Kourtis, and Rogers, 2007).

Latest research reports indicates that South Africa may be heading in the same direction as the latest survey results by the South African medical research council presented in the 2011 HIV/AIDS conference in Durban, indicates that the rate of transmission of HIV from HIV infected mother to children is 3.5% (South African medical research council, cited in plusnews, 2010). Without the appropriate use of antiretroviral drugs by HIV positive pregnant women, safe infant feeding and obstetric practices, the rate of transmission of HIV from mothers to their children in pregnancy, child birth and breastfeeding would be about 25% (Fowler et al, 2007)

The world health organisation (WHO, 2007) recommends that combination antiretroviral treatment be offered to all pregnant who are eligible for treatment based on clinical staging of their illness or cd4 testing. This not only addresses the health needs of the women but also reduces significantly the transmission of HIV to the infant. WHO goes on to recommend appropriate prophylactic regimen of antiretroviral treatment for HIV positive women who do not need antiretroviral treatment. This includes use of zidovudine from 28 weeks of pregnancy or as soon as possible plus single dose nevirapine during labour and a seven day course of zidovudine. Appropriate safe infant feeding practices are then recommended based on the criteria of acceptability, feasibility, affordability, sustainability and safety. (The so called AFASS Criteria) It is important to note that WHO recommendations are tailored toward resource limited settings. In more resource abundant countries the standard approach of PMTCT is the use of appropriate combination antiretroviral medication for all HIV infected pregnant women with avoidance of breastfeeding and in some cases caesarean sections for the delivery of the baby.

2.2 HIV/AIDS and the family

Traditionally the family has been thought of in terms of those who are genetically related or in terms of the household. For example Webster's dictionary defines family in the following way: a group of individuals living under one roof usually under one head: a household. A group of persons of common ancestry: clan. A people or group of peoples regarded as

deriving from a common stock: a race. A group of people united by certain convictions or personal affiliations: fellowship. Thus according to Webster's dictionary a family may be household under one head, a clan, a race or a fellowship of individuals.

Webster's definition mostly conveys the traditional way of looking at the family in terms of genetic (blood) relationships or in terms of the household. However current demographic and social changes within societies appear to be prompting a shift away from the traditional view and definition of the families to one that is broader and more inclusive.

Family has been defined as a social network of biologically related members and socially (chosen) relationships (Van Empeden, 2005) The task force on young children and families, New Mexico legislature defines families in the following way: families are big, small, extended, nuclear, and multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, from a desire for mutual support. (Cited in Johnson, 2000). A family is a culture unto itself, with different values and unique ways of realising its dreams; together our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities, states and nations.

According to the world AIDS day newsletter, "any group of people linked by feelings of mutual trust, mutual support and common destiny may be seen as a family. The concept need not be limited to ties of blood, marriage, sexual partnership or adoption. In this light religious congregations, workers associations, support groups of people with HIV/AIDS, gangs of street children, circles of drug injectors, collectives of sex workers may be regarded as families, (WHO, 1994). Any definition of family should be broad enough to encompass a range of family structures, dynamics and functions. Therefore family can also be defined as "two or more people who are committed to each other, and who share intimacy, resources, decision making, responsibilities and values, (Olson and Defrain, 2006).

Given that the first population groups in which HIV/AIDS was first diagnosed was among men who have sex with men (MSMs) and injection drug users (IDUs) in the western world before being found among heterosexual sex partners it was customary to think of HIV in terms of the individual. However as the epidemic has evolved, increasingly HIV/AIDS is being thought of as a family disease. The reason for this being that HIV is a disease translated horizontally between partners in most cases within the family or households and vertically

from mothers to children also within the family or household. Another reason why HIV is being increasingly viewed as a family disease is that the immediate effects of HIV are felt within the family and the burden of care for HIV is borne mainly within the family.

The household (or the family) is the basic unit of most systems of immediate social support. (Barnett and Whiteside, 2000) and therefore the impact of HIV/AIDS on communities and societies as a whole ought to be analysed first and foremost through the lenses of the family. The full impact of AIDS including its social and economic effects is only appreciated when the family and not only the individual is the unit of analysis. (Bonuck cited in Richter et al, 2010)

The basic premise of looking at all the impact of HIV/AIDS on the family is the fact that it mostly affects the age group 25-50 years. This is the most sexually and reproductively active age group and also most economically productive. This is the age group that is working to raise and sustain families. Therefore when illness or death affects this age group on an epidemic scale as with the HIV pandemic, it affects the whole family structurally and functionally.

Illness or death of the male or female bread winner who is head of the family as a result of HIV/AIDS means there has to be shift to other members of the family or extended family for economic sustenance. Usually this is an elderly member within the family which is usually grandparents or other members of the extended family. In many cases it could mean that younger members of the families have to be called upon to head the household resulting in child headed households.

Illness from HIV/AIDS significantly increases the burden of care in the family. A survey of households affected by HIV/AIDS in several provinces in South Africa found that in more than two thirds of households, women or girls were the primary care givers. Similar scenarios have been found in Zimbabwe and other countries with a heavy burden of HIV/AIDS. A survey in Cote d'Ivoire found that care for people with HIV/AIDS was provided mainly in the home. In many cases urban based relatives often return home to their families in the rural areas when they become too sick to work or care for themselves as a result of HIV/AIDS (CHGA)

HIV/AIDS has psychosocial effects on the family as well, as families have to bear the brunt of social stigma and isolation resulting from the fact that one or more of theirs has

HIV/AIDS. The increased burden of care and social stigma of HIV/AIDS can result in increased stress levels in other members of the family. The psychosocial effects of one or more members of the family having HIV can result in poor communication between sexual partners; it could cause feelings of discomfort and anxiety among family members and between sexual partners. Denial about HIV sero-status among couples can lead to engagement in unprotected sexual intercourse and thereby putting others at risk of the virus. Sexual dysfunction among sexual partners with HIV/AIDS has also been reported. Children may experience emotional distress as a result of one or more parent being HIV positive (Van Empeden, 2005)

Families are important caregivers, providing social, (emotional and instrumental) support for members infected with HIV, with mothers and close friends being the most important caregivers. The benefits of emotional support are that it buffers stress, improves adherence to HIV treatments, results in fewer symptoms of depression and improves the quality of life. Emotional support may also help the family members infected with HIV to restore their reason for being and increase their self-esteem. Another aspect of instrumental social support involves practical help such as shopping, housekeeping and transportation. (Van Empeden, 2005)

2.3 Family centred care

Family centred care has been defined as an approach to health care based on mutually beneficial partnership among patients, families and the health care professionals (Johnson, 2000). The focus of family centred care is meeting and addressing the needs of the patient and the family.

The family centred model of health care has been growing out of the increasing recognition of the psychological and social components of health and the fact that the family is the basic and immediate unit of society that provides the individual with these components support for health. (Johnson, 2000). Family centred care according to McDaniel et al (cited in Wakheya, Dirks and Yeboa, 2008) is based on a bio-psychological systems approach where the primary focus is the client in the context of their family; and the client, family and clinician are partners in health care.

The key element of family centred model of care is the involvement of the patient and their families in the planning, implementation and evaluation of the health care services at all

levels: policy, programmatic and service delivery, (Johnson, 2000). In principle, within family centred care systems family members are full partners in defining needs and making decisions about the plan of care which in turn matches the family's needs and circumstances (Cook and Kilmar 2004)

Looked at from this perspective therefore, family centred PMTCT therefore is delivery of PMTCT services that seeks to include not only the HIV positive pregnant women but her family as well in the planning, implementing and evaluation of the service. In this way PMTCT services can be delivered in a way that takes into consideration the unique circumstances of every HIV positive pregnant woman including the prevailing psychosocial environment in which she lives within her immediate family household and taking advantage of her family strengths and addressing weaknesses and risk factors within the family.

The core concepts of family centred care were originally articulated in a publication entitled family centred care for children with special needs, (Shelton et al cited in Johnson, 2000). These core concepts are:

The recognition that systems and personnel may fluctuate but the family remains constant in the child's life.

Facilitation collaboration between family and health care professionals at all levels of care. Complete and unbiased information about children's care is shared with their parents continually in a supportive and appropriate manner.

Policies that are appropriate, comprehensive and provide for the emotional and financial needs of the family are implemented.

Strengths and individuality of families are recognised and the fact that different families may have different coping mechanisms is respected.

The needs and infants, children, adolescents and their families are understood and incorporated into the health care delivery systems.

Family to family support is encouraged and facilitated.

The health care system is designed in such a way as to make it flexible, accessible and responsive to family needs.

The conceptual framework of family centred care as applied in all areas of health care has grown out of these eight core principles.

The Nathan Cummings foundation in 1996 simplified these 8 principles to four core principles of family centred care as follows:

1. In family centred care health care people are treated with dignity and respect.
2. In family centred care health care providers communicate and share information with patients and families in ways that are affirming and useful.
3. In family centred care individuals and families build on their strengths by participating in experiences that enhance feelings of control and independence.
4. In family centred care collaboration among patients, families and providers occurs in policy, programme development and professional development as well as delivery of care.

Johnson, 2000 goes further to define the four tenets essential for the implementation of family centred care as follows:

1. The family is the constant in lives of the patients of all ages
2. The family is variously defined by the patients and families.
3. Family centred care must be comprehensive and integrated throughout the systems of care and embraced by all disciplines.
4. Patient and family involvement in policy and programmes development must be meaningful and widespread.

A focus on the family in no way excludes a focus on the health systems or disease specific strategies. What it does do however is include in programme design an understanding of how any health issue is firmly embedded within a context of the family (Tomlison, 2010)

Families can be a valuable source of support in planning, implementing and evaluating the health care plan of sick individuals. A family centred care approach emphasizes the relationships and recognises and builds on the strengths and interconnectedness of families. A family centred care approach also acknowledges that the potentially harmful effects of caregiving on family members in their own right requires and deserves the attention of health care professionals (McFarlane, 2011)

One of the important aspects and benefits of family centred care is that it links families with similar issues together within the community and in so doing enables them to form support networks within the community. This is can be very important within the context of HIV/AIDS intervention as linking families in which there are people infected with HIV can enable them to support each other against societal isolation, violence, stigma and discrimination. Such family support networks can also help with adherence with medications, support in times of illness and helping each to ensure regular attendance at clinics. When families are involved in health care planning, implementation and evaluation within a family centred health care paradigm, patient outcomes are better, health care cost decreases and health care provider and client satisfaction improves (the institute for family centred care)

Adopting a family centred care approach requires a shift in organisational practices and in the attitudes and behaviours of individual health care providers from a model in which care professionals are seen as the expert in possession of knowledge to a model that is based on knowledge exchange and partnerships(centre for addiction and family health,2004)

2.4 Family centred HIV/AIDS interventions

The concept of family centred HIV care began to evolve in the 1990s as HIV/AIDS emerged as a devastating epidemic threatening the health and wellbeing of children and mothers. Under a cooperative agreement with the maternal and child health board of the U.S, the institute of family cantered care carried out a four year study project to increase the implementation of family centred approaches to care for children, youth, women and families affected by HIV/AIDS(Johnson,2000)

Tomlison, 2010, argues that HIV is a highly stigmatised chronic condition with repercussions for the family members that go beyond the individuals and their illnesses. As a result a family focussed wellness perspective is likely to be more acceptable a method of intervention than a focus on any single condition.

Family centred HIV care has been defined as a comprehensive, coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs either directly or indirectly through strategic partnerships and/or linkages with other service providersø(Wakheya, et al, 2008)

Family centred HIV interventions recognise that in the first place, the risks factors that predispose the individuals to HIV infection and drive the spread of the infection tend to be

embedded within the families just as the factors that can be harnessed for the control of infection are also to be found largely within families.

There is therefore a growing evidence for a paradigm shift in HIV prevention, treatment and care programmes where attention is moved away from the individual and the disease process itself to a family centred approach. In this model of intervention, HIV infection, transmission, societal consequences, prevention, treatment and care are viewed through the lenses of families. It is not just important to provide antiretroviral drugs but it is just as important that the health care provider realise that the success or failure of any antiretroviral regimen depends to a larger extent on the family support systems within which the HIV positive individual lives. This is the logic for family centred HIV interventions.

Despite growing evidence in favour of the benefits of family centred HIV interventions, reforms in its favour have been slow to emerge (Richter, Bayrer, Kippax and Heidari, 2010). Levine argues that the impact of AIDS on families and the potential of families to be at the forefront of prevention, treatment and care have not been fully appreciated (Levine, 1990). Investing in programmes that target the entire family will undoubtedly have long term benefits for any response to HIV. Families are the primary sources of behavioural patterns, and interventions involving the entire family may positively influence risk reduction and health seeking behaviours and may help to overcome disparities in access to treatment and health care observed between men and women, (Richter et al, 2010).

Among the many benefits of this model of intervention is improved adherence to medications, sensitive monitoring of changes in the patient's state and extension of treatment and other services beyond the health facility (Dunst and Trivette, 2009)

Children living within households with one or more parent infected with HIV receive substantial indirect benefits when their infected parents are treated for HIV. The benefits include decrease in malaria, diarrhoea, hospitalisation, and mortality as well as improvements in children's nutritional status, school enrolment and decrease in child labour. This is irrespective of the HIV status of the children in the family (Ieper, Montague, Friedman and Flanigen, 2010)

Preliminary data from family centred care sites suggest that this model of care can be an effective tool for recruiting HIV positive women, preventing mother to child transmission of HIV, increasing paediatric and adult referrals, supporting patient adherence and clinic

attendance and improving clinical outcomes(leeper et al,2010).In the light of these findings and a growing body of research and practice, there is growing consensus among donors, health care professionals, and advocacy group that HIV/AIDS interventions be centred around the family.

2.5 Harnessing the role of men as fathers in family centred HIV/AIDS interventions

Fathers are intricately bound up in all aspects of family life. Yet in designing methods to combat the epidemic of HIV/AIDS it appears as if the role of men as fathers is understudied. HIV itself is a predominantly sexually transmitted infection closely intertwined with human reproduction and intimate relationships. Fathers and fathering therefore play a central role in the HIV epidemic. It follows that efforts to control the epidemic must seek effective ways of harnessing the role of men as fathers even though the reality on the ground seems to suggest that this process can prove difficult.

Fathers have inputs over life course from conception and birth attendance to child rearing. Psychological and sociological studies confirm the important and central role that fathers play within the family. Men as fathers occupy an important place in the structure, dynamic and function of the family particularly in decision making.

The growing body of evidence of the role men play as biological and social fathers is beginning to make researchers, policy makers, community and non-governmental organisations to explore how men might be engaged in family centred interventions (Hosegood and Madhaum 2010)

An ethnographic study of households in rural South Africa that had experienced adult AIDS illness or death found that men were positively involved with their families and households in a wide variety of ways including undertaking domestic activities and financially supporting immediate and extended family members, (Montgomery, Busza and Timaeus 2005).

The man fulfilling the role of father within a family may not necessarily be a biological father. It could be a social father: a term that includes step fathers, foster fathers, and adoptive fathers which is a common feature in sub-Saharan social and cultural contexts.

Although HIV testing has become almost a universal standard for pregnant women historically it has been focussed on women. However studies have shown that offering HIV testing to male partners of pregnant women is highly cost effective in recognising HIV status

discordancy and reducing the possibility of transmission of HIV during pregnancy. Testing women only has been found to be counterproductive, enhances stigma and leaves men out of the cycle of medical care (Postma, Beck, Mandalia, Sherr, Walters, Houweling and Jager, 1999).

Lack of male involvement in PMTCT and lack of disclosure by HIV positive pregnant women to their male partners has been identified as hindrances to use of proven, highly effective antiretroviral regimens for the preventing of mother to child transmission of HIV and also the use of such medications for their own treatment. (Fowler, et al, 2007)

Couple testing of females and their partners has been shown to be viable resulting in reduced stigma, enhanced treatment uptake and reduced risk of exposure in the event of discordancy (Sherr, 2010). Involving men as fathers in HIV/AIDS interventions has been shown to reduce risky behaviour through increased condom use, better adherence to medications, reduced domestic violence, promotion of exclusive breastfeeding and use of exclusive breast milk supplements by females in preventing vertical transmission of HIV.

Women whose male partners accompany them to antenatal care are more likely to utilize antiretroviral prophylaxis for preventing mother to child transmission (PMTCT) and are more likely to adhere to PMTCT feeding strategies and Infants of HIV infected women with male partner involvement have been found to have a significantly lower risk of HIV infection and a greater HIV free survival compared with infants born to HIV infected women without male partner involvement. (Alusio, Richardson, Bosire, John-Stewart, Mbori-Ngacha and Farguhar, 2011)

The development of culturally appropriate safe and acceptable family centred interventions that can successfully engage men in support of HIV and AIDS affected households requires detailed family data (Hosegood et al, 2010). However the enrolment of fathers or other male relatives may sometime be impossible or ill advised as in the case where these men are in prison or hospital or have problems related to mental health, drugs, or alcohol or have physically or sexually assaulted members of their family (Cabrera N et al, cited in Hosegood and Madhaum, 2010)

2.6 Components of family centred PMTCT

Family centred PMTCT is built on the underlying principles of family centred care which treats the patient and family members as partners in planning, implementing and evaluating health care delivery.

Betancourt, Abrams, McBain, Smith and Fawzi, 2010, in a study of various PMTCT services functioning according to family centred model lists the following as possible components of a family centred PMTCT service delivery model:

- Comprehensive package of medical care offered to all HIV positive adults and children.
- Early infant diagnosis of HIV
- Education and counselling of patients.
- Reproductive health and family planning services.
- Psychosocial support.
- Promotion of adherence and retention in long term care and treatment.
- Nutritional education and support as well as community outreach.

These services are supported by a multidisciplinary team that includes nurses, physicians, counsellors, social workers, pharmacists and community health workers.

Access to related services is encouraged; such as identification and treatment of tuberculosis and nutritional support, family planning and malaria prevention programmes.

2.7 Provider initiated HIV /AIDS testing of family members in PMTCT

HIV testing remains the gateway for all HIV treatment, care and prevention programmes and as such also remains the gateway to this model of HIV/AIDS care. Therefore contact with the HIV positive pregnant woman is to be viewed within the family centred HIV/AIDS care paradigm as an opportunity to bring the family into HIV care and treatment programmes respecting family members as partners in seeking agreed health outcomes. In this case the HIV positive pregnant woman in PMTCT settings is viewed as a gateway into her family.

The concept of voluntary counselling and testing for HIV (VCT) is gradually giving way to provider initiated HIV counselling and testing within the health care settings.

Voluntary counselling and testing is the process whereby an individual undergoes counselling, enabling him to make an informed choice about being tested for HIV (UNAIDS,2000). Voluntary counselling and testing is client driven as it depends on the client coming to health care worker and signifying an intention to know their HIV status. In the early days of the epidemic with no means of controlling the virus and serious concerns of stigma, discrimination and isolation directed toward people with HIV, voluntary counselling and testing appeared to be the only way to protect the individual rights and dignity of people with HIV while enabling them and the health care provider to know their HIV status.

With the discovery of effective antiretroviral medications there has been a change in perception of HIV from a death sentence to a chronic manageable disease. With this discovery coupled with increasing political will among nations with heavy burden of HIV, increasing financial and human resources committed to the fight against the disease, has come a convergence of opinion by governments, health care bodies, multilateral institutions, non-governmental organisations and advocacy groups, of the need to scale up access to treatment, care and prevention services making them universal. Therefore there has been a necessity to move toward provider initiated HIV testing as a way of recognising people with HIV in a timely manner and making available to them life sustaining antiretroviral medications, while the same time ensuring that transmission of the virus from them to others is prevented.

Provider initiated HIV counselling and testing began in the United States with discovery through the AIDS clinical trial group protocol 076 (PACT076 study) of 1994 that administration of Zidovudine during pregnancy, child birth and after child birth cut the transmission of perinatal transmission of HIV by about 70%. Based on this finding the U.S public health task force recommended that all pregnant women should be offered HIV testing as a means of identifying those infected with HIV and subsequently use of zidovudine by such women perinatally. (Fowler, Lampe, Tamieson, Kourtis and Rogers, 2007)

Provider initiated HIV testing is health care provider driven unlike voluntary counselling and testing. In this approach HIV counselling and testing is recommended by health care providers to persons attending health care facilities as a standard component of medical care. The major purpose of such testing is to make it possible to offer such persons the benefits of the range of prevention and care services for HIV/AIDS which would not be possible if their HIV status were not known.

The world health organisation recommends that in generalised HIV epidemic where HIV infection is firmly established in the general population, routine HIV counselling and testing also referred to as provider initiated HIV counselling and testing be offered to all clients attending health care facilities. Provider initiated HIV counselling and testing capitalises on all patients contact with the medical system using each as a potential opportunity for testing, diagnosing and linkage to care.

Routine HIV counselling and testing has been found to be acceptable in antenatal settings and can significantly increase HIV testing rates (chandisarewa et al, 2008).A study of Provider initiated HIV counselling and testing (routine HIV testing) found high acceptance among women and their partners and concluded that routine (provider initiated HIV counselling and testing) is acceptable and feasible to increase individual and couple participation in PMTCT interventions. (Humsey et al, 2006)

Provider initiated HIV counselling and testing practiced within the paradigm of family centred HIV PMTCT allows HIV positive members within the family of the pregnant woman to be identified and thus bringing them into HIV treatment while also ensuring that those within the family who are HIV negative can know their status and employ appropriate strategies to remain HIV negative.

Chapter 3: Methodology and data analysis.

3.1 Method and design:

A quantitative non -experimental research approach using a survey was employed for this research. The survey was carried out by way of structured interviews of study participants.

The research was carried out in Seshego Hospital. This hospital which is located in Seshego township of Limpopo province was selected for ease of access to study population due to constraints of time imposed by reason of the nature of the study. Permission to conduct the study was obtained from the ethical committee of the Limpopo department of health through the management of the Hospital. This was after obtaining ethical clearance from the research ethics committee of Stellenbosch University.

3.2 Participants:

A survey population of 34 HIV positive women attending maternal health services in the maternity department of Seshego Hospital in Limpopo was selected based on availability. These women were either on admission at the maternity ward, or in the postnatal ward or attending the antenatal antiretroviral clinic within the maternity department of the hospital. Only pregnant women from the age of 18 years and above were interviewed for reasons of the legal age of consent. The participants were selected based on the fact that they were HIV positive and pregnant or having been receiving maternal health care within the hospital or any of its feeder clinics have just delivered their babies and were still on admission within the postnatal ward of the hospital.

Potential research participants were identified using their hospital case record where the HIV status of all pregnant women is usually documented either as HIV positive written in a coded form(TP = tested positive) or HIV negative coded as TN(tested negative)

Potential research participants having been identified through their maternity case records were approached for the study. The nature of the research was explained to them using the participant's information sheet and the consent form. Consent to participate in the research was then obtained and the signatures of the participants requested as written record of consent to participate in the study.

3.3 Instruments and materials

A structured questionnaire was designed to cover the objectives of the study. The questionnaire consisted of 10 main questions numbered from 1 to 10. Question 8 consisted of three sub questions while question 10 of four sub-questions. (Please see addendum A for questionnaire)

A participant information sheet was made available for each study participant stating the study aims and objectives and it was translated into the local language of Sotho or Sepedi as necessary. (See addendum B). The University of Stellenbosch consent to participate in research document was used to obtain informed consent from study participants. This form was either read to study participants in English or translated in the local language of study participants which was Sotho or Sepedi. Interview of study participants was conducted in an office in the maternity ward of the hospital where adequate privacy was guaranteed for study participants one at a time.

3.4 Procedure

The research title, aims and objectives were explained to the study participants. The procedure of the research was also explained which was in the form of a structured questionnaire that required a yes or no answer from the study participants. Potential risk and discomforts of the research were also explained to the participants and measures in place to deal with these were also explained to the participants. Issues of potential benefits of the research, confidentiality and rights to withdraw from the study were also discussed. The language used was English and in some cases translation from English to the local language of Sotho or Sepedi if the participant was not comfortable communicating in English. Following this consent for the study was then obtained in a written form by asking each research participant to sign on the informed consent form.

The study questionnaire was administered to each study participants one at a time in an office where only the study participant was present with the investigator and a translator who was a nurse or midwife.

Each survey question was read to the participant in English and translated to the local language if the participant needed translation. An answer of yes or no was required for each question and in some cases a yes or no answer was not applicable.

Chapter 4: Results, analysis and discussion

4.1 Results and analysis.

Data collected about each study participant included age, booking status, number of visits to the local clinics for antenatal care, the number of visits to Seshego hospital antenatal antiretroviral clinic, and/or number of days stayed in the antenatal ward or post natal ward. This information was obtained from the maternity case record books or antenatal clinic cards. For survey questions asked please see survey questionnaire attached in addendum A. Survey data were analysed using Microsoft Excel 2010©. Survey data were analysed using percentages, averages and frequencies and illustrated with tables, pie and bar charts.

All but two of the study participants were booked at the local clinic before attendance at the hospital. The age of study participant ranged from 19 years to 43 years with an average age among study participants of 29 years. The least frequently occurring age groups within the study were the extremes of age on both sides: age groups 19 to 20 years and 41 and above. Most of the study participants were in the age groups 21 to 30 years and 31 to 40 years. (See Figure 4.1)

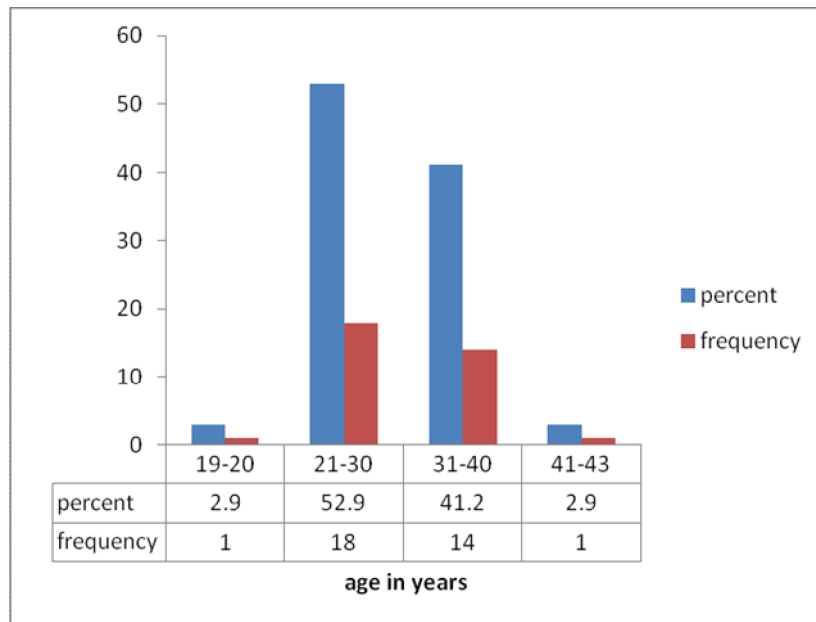


Figure 4.1: Age groups of survey participants

The survey participants had attended their local antenatal clinics from 1 to 5 times on the whole with an average of 3 clinic visits among survey participants.

Average number of days stayed in hospital ranged from 1 day to 24 days. One participant had been in the hospital for about 10 days while the other had been in the postnatal ward for about 24 days. In both cases they were there because their babies were premature and were in the neonatal unit.

Most of the study participants (76.5%) were drawn from the post natal ward of the hospital while 20.1% were from the antenatal antiretroviral clinic and 2.9% were in patients from the antenatal wards. (See Figure 4.2)

Most of the patients were from the post natal ward. This is because study participants were chosen based on availability and as such those who were readily available and met study criteria were chosen. High turnover of patients from the labour ward immediately after child birth meant that the post natal ward was the place for readily available study participants. (See Figure 4.2)

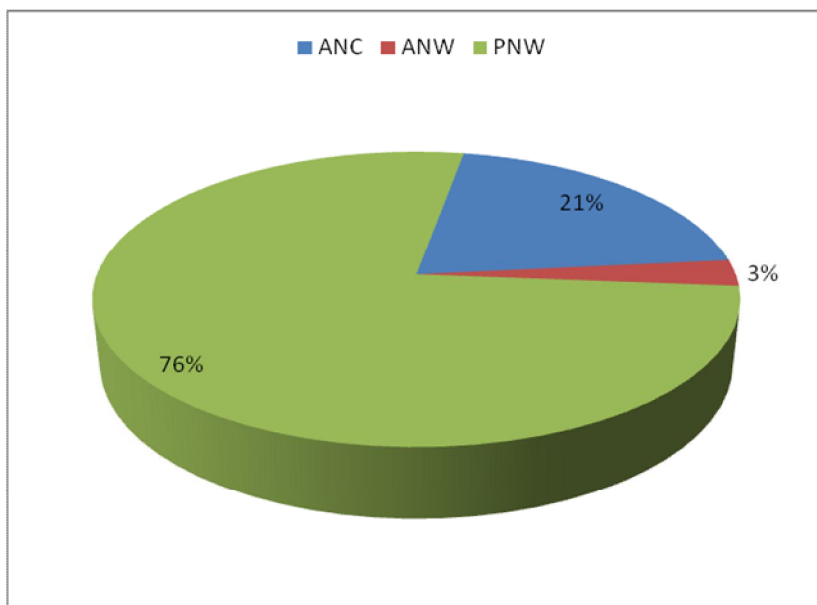


Figure 4.2 Sources of survey participants

Key to Figure 4.2

ANC= Antenatal clinic

ANW=Antenatal ward

PNW= Post Natal ward.

The responses of participants to questions asked were analysed using Microsoft Excel© computer software. Responses were codified as follows: yes codified as 1, No codified as 2 and then questions were a response of yes or no was not applicable was codified as 3. The questions asked were codified as Q1 TO Q10 with three questions under 8 codified as 8a 8b and 8c. Questions 10 was codified accordingly as 10a, b, c, and d (See Table 4.1, Figures 4.3 and 4.4)

The responses were then analysed by percentages, frequencies and averages and Charted accordingly using Microsoft Excel© software.

Table 4.1 Survey responses in frequencies and percentages

QUESTION ASKED	CODE1 FREQUENCY	CODE 1 %	CODE2 %	CODE 2 %	Code 3 %
Q1	23	67.6	11	32.4	
Q2	18	52.9	16	47.1	
Q3	6	17.6	12	35.3	47.1
Q4	25	73.5	9	26.5	
Q5	22	64.7	12	35.3	
Q6	4	11.8	8	23.5	64.7
Q7	18	52.9	16	47.1	
Q8A	11	32.4	8	23.5	44.1
Q8B	2	5.9	17	50	44.1
Q8C	10	29.4	9	26.5	44.1
Q9	12	35.3	22	64.7	
Q10A	5	14.7	4	11.8	73.2
Q10B	7	20.6	2	5.9	73.5
Q10C	3	8.8	6	17.6	73.5
Q10D	4	11.8	6	17.6	70.6

KEY:

Q1 to Q10: Questions asked in survey (See Addendum A)

Code 1: Yes

Code 2: No

Code 3: Not applicable

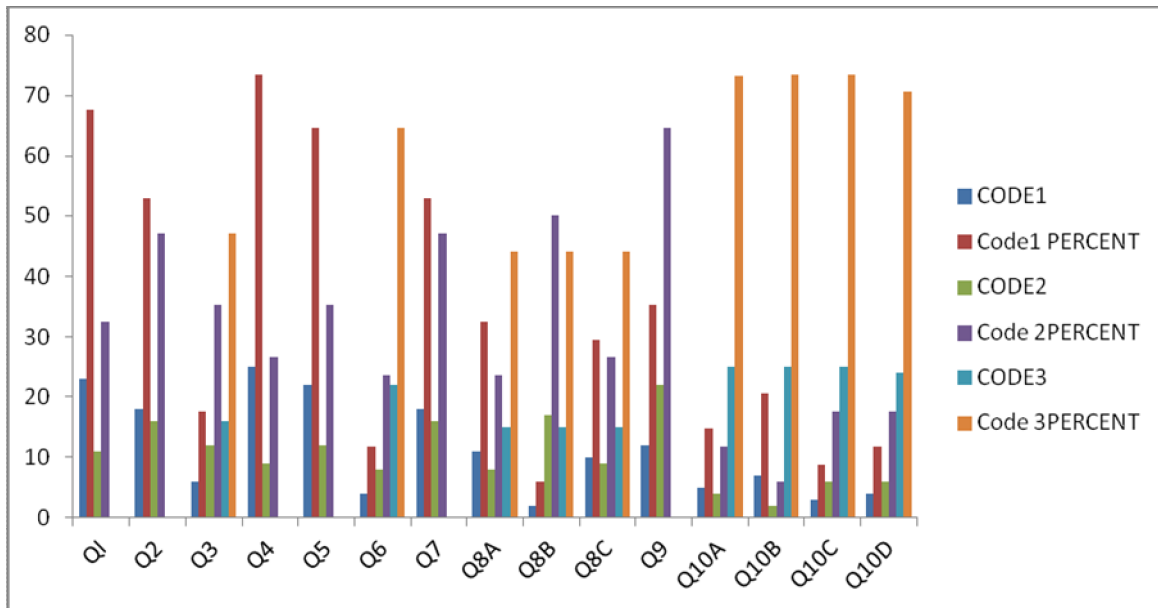


Figure 4.3 Questionnaire responses: frequencies and percentages

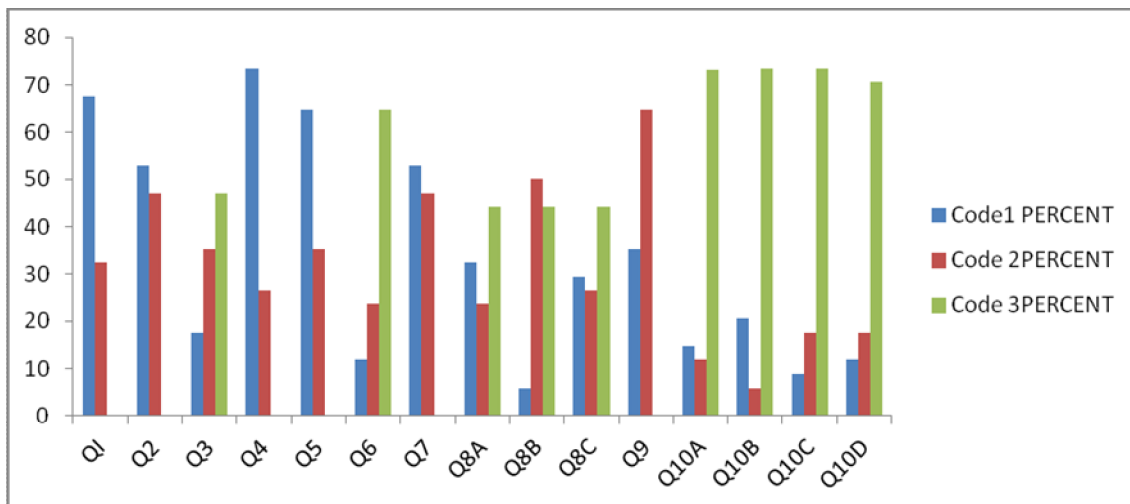


Figure 4.4 Questionnaire responses: percentages

Keys for Figures 4.3 and 4.4:

Q1 to q10 are codes for questions 1 to 10 (see questionnaire in addendum A)

4.1.1 Counselling on disclosure to a member of the family/household:

Survey participants were asked if during the course of attending maternal health services either in the clinic or the hospital a health care workers had discussed the disclosure of their HIV Status to any member of their household other than their male partners (Q1) and in Q2 if they had actually disclosed their status to any member of their family other than their male partners. Reported disclosure among the surveyed population was 67.6% while non-disclosure was 32.4%. Disclosure to family members other than their male partners was 52.9% while non-disclosure to family members other than male partners was 47.1%.

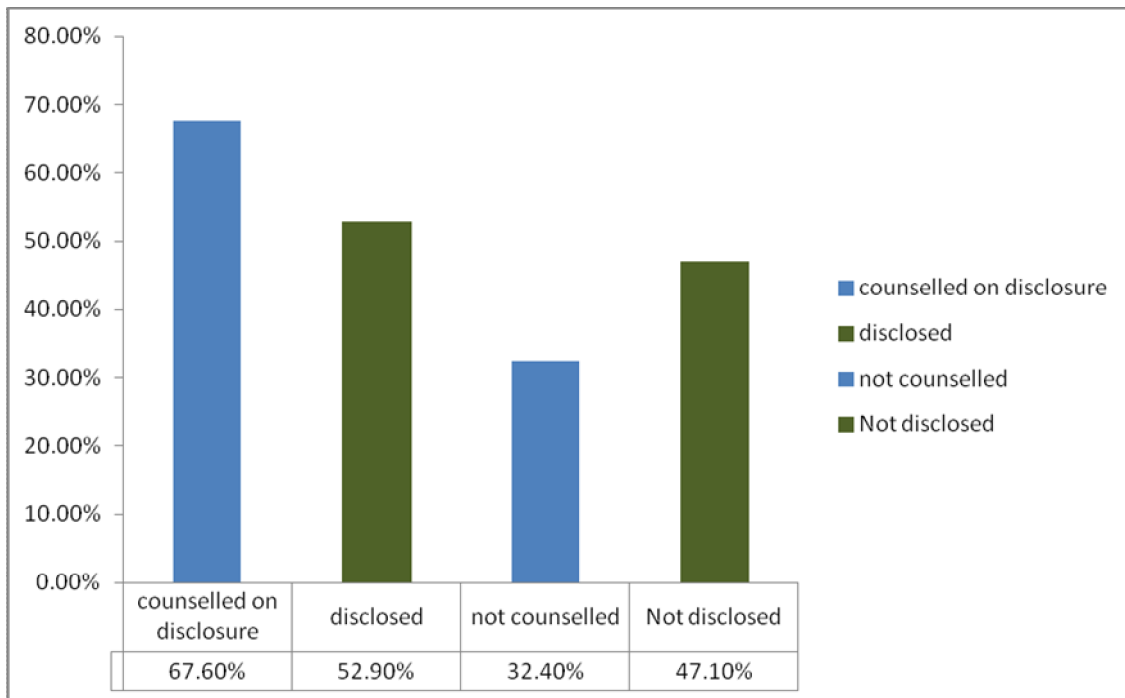


Figure 4.5 Counselling on disclosure to household/family members other than male partners compared with disclosure and non-disclosure

4.1.2 Counselling on disclosure to male partner and disclosure to male partner

In terms of counselling by health worker on disclosure of their HIV status to their male partners, 73.5% of the study participants admitted that they had been advised to do so by the health worker, while 26.5% said the subject had not been discussed. Admission of disclosure

to male partners among the survey partners was 64.7% while 35.3% said they had not disclosed their status to their male partners. (See Figure 4.6)

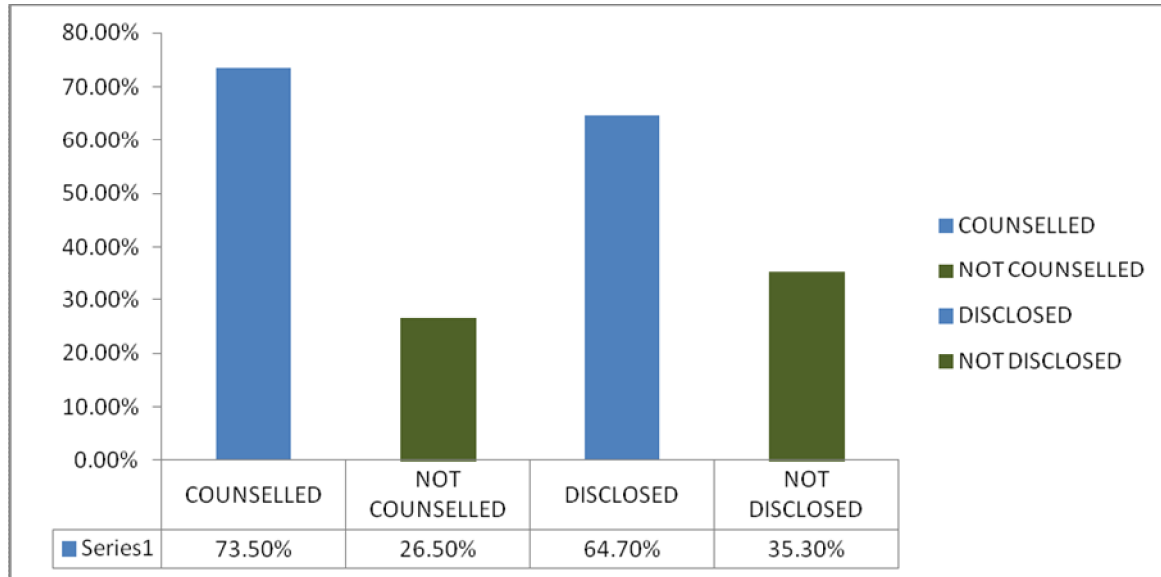


Figure 4.6 counselling on disclosure to male partners compared with reported disclosure to male partners.

4.1.3. Male partner involvement in PMTCT

Questions 7 and 8 was designed to find out to what extent health care worker tried to involve male partners in PMTCT and also in what way male partners were participating in

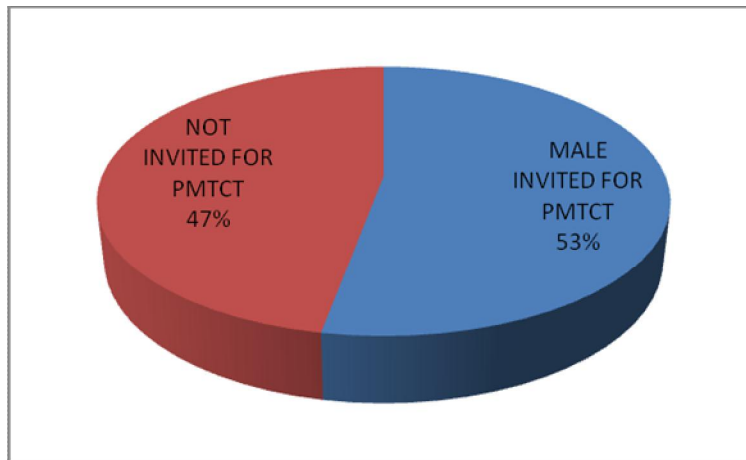


Figure 4.7 Invitation of male partners to participate in PMTCT

PMTCT. Invitation of male partner by health care worker to get involved in PMTCT was admitted by 52.9% of the survey respondents while 47.1% said their male partners had not been invited. (See figure 4.7)

In terms of male partner involvement in PMTCT 32.4% said their male partners had taken an HIV test while 5.9 % of survey participants said their male partners were on antiretroviral treatment and 29.4% said their partner used condoms during sex while being pregnant. (See Figure 4.7)

On the overall in terms of male partner involvement in PMTCT an average of 22.6% of survey respondents indicated that their partner was involved in PMTCT either by having taken an HIV test, being on antiretroviral therapy or use of condoms. On the contrary, 33.3% of the survey respondents said their male partners was not involved in PMTCT in any of the above forms despite disclosure and in 44.1% of the survey population the question of whether the husband was involved in PMTCT was not applicable mostly because disclosure had not been made to their male partner or an health worker had not invited the male partner to be involved in PMTCT. (See Figure 4.8)

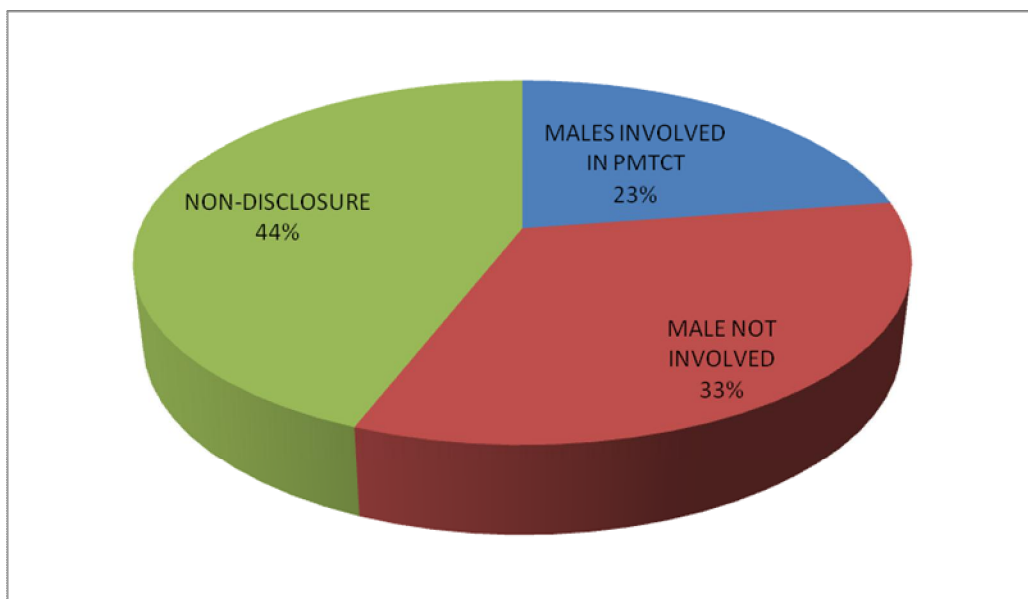


Figure 4.8 Male partner involvement and non-involvement in PMTCT.

The group depicted as green above (44%) represents those whose male partners were not involved in PMTCT because of non-disclosure of HIV status by the participants. Those depicted as 33% above are those whose male partners were reported not to be involved in PMTCT in spite of disclosure of HIV status by participants.

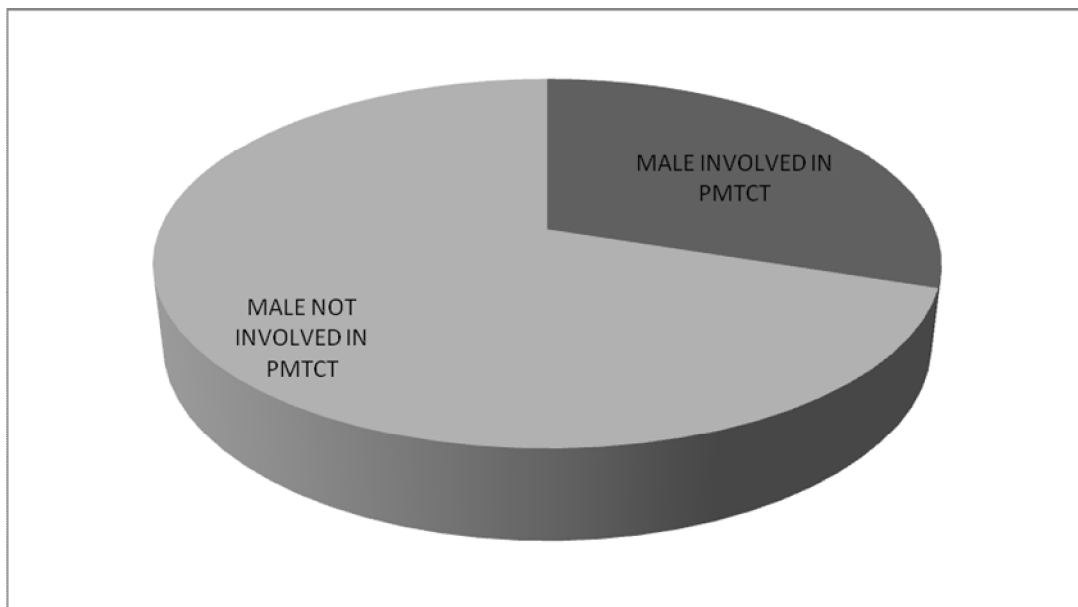


Figure 4.9 Male partner involvement and non-involvement in PMTCT compared.

Key to Figure 4.9

Male involved in PMTCT 33%

Males not involved in PMTCT 77%

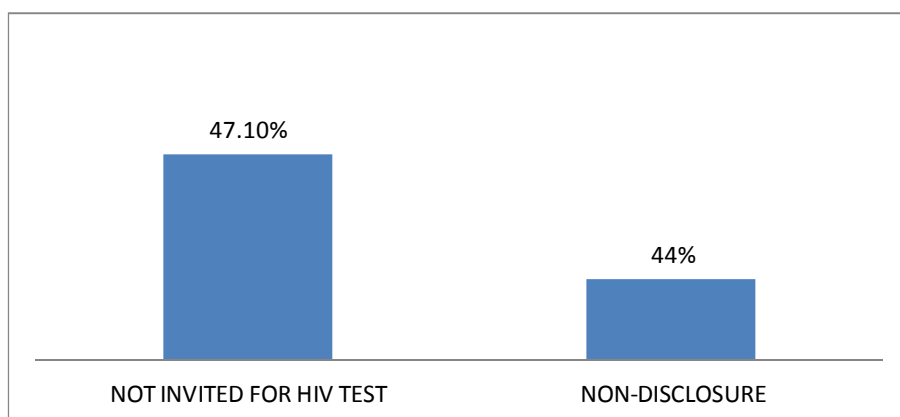


Figure 4.10 Comparison of Non- invitation of male partner for HIV test and Non- disclosure of HIV status.

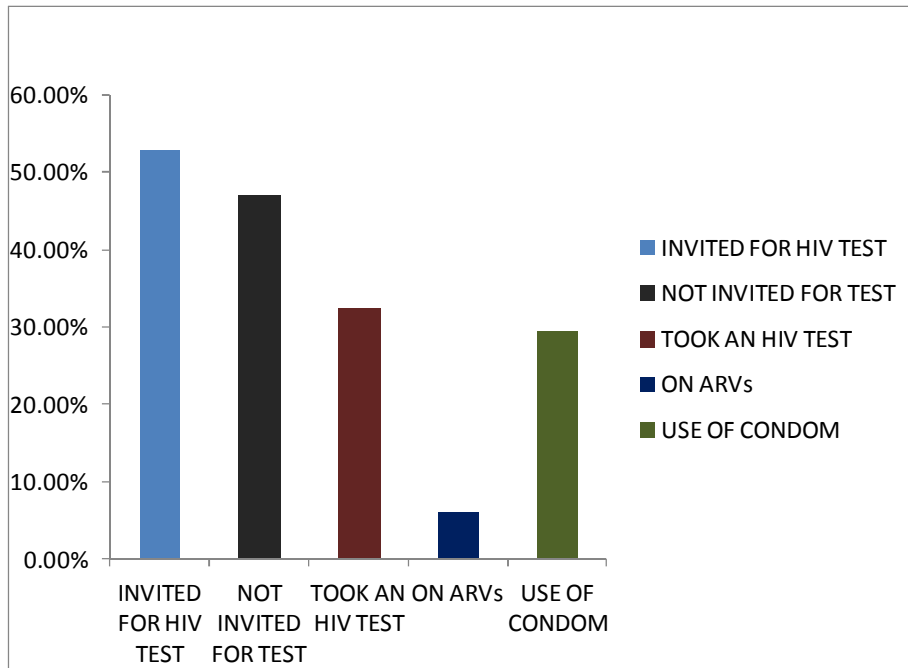


Figure 4.11 Breakdown of male partner involvement in PMTCT.

Involvement of family members other than male partner

On subject of health care worker counselling on involving members of family of HIV positive pregnant women PMTCT, 35.3% of survey respondents admitted that a health care worker had done so. However 64.7% said this had not been discussed in course of attending maternal care services. (See Figure 4.12)

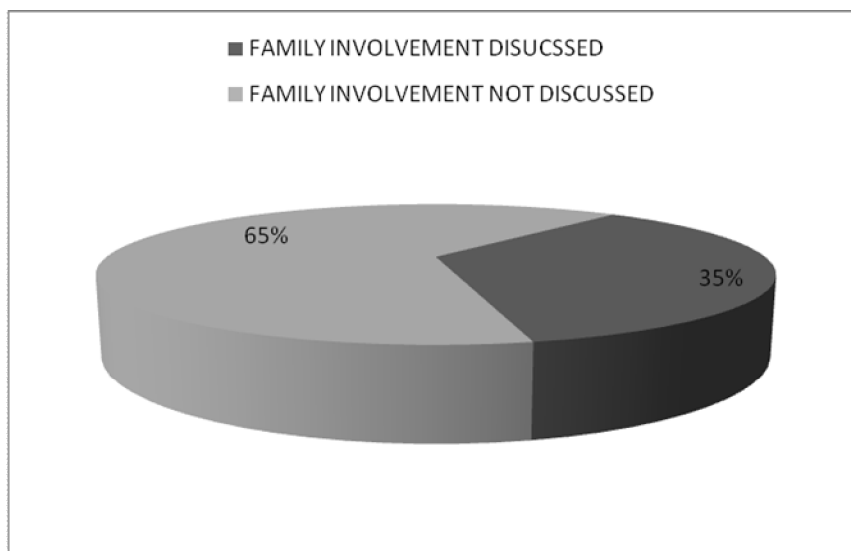


Figure 4.12 Discussion of involvement of family member other than male partner in PMTCT.

In terms of involvement of other family members in PMTCT, survey participants were asked if they were receiving assistance in any of four ways: financial assistance, reminder to take antiretroviral medications, assistance with collection of medication and attending clinics with them. To this question, 14.7% responded that they were being assisted financially, 20.6% said they were being reminded by a family member to take their antiretroviral medications regularly, 8.8% reported that they were assisted in collecting medications from the clinic and 11.8% indicated that they were accompanied to the clinic by some other member (see Figure 4.14)

On the average 13.9% of survey respondents said a family/household member was involved with them in PMTCT while 13.2% said no member of their family/household provided any form of assistance in the ways listed above. In 72.7% this question was not applicable either because the healthcare worker never discussed family member participation in issues of PMTCT or the patient had also not disclosed their HIV status to any member of their families or households. (See Figure 4.13)

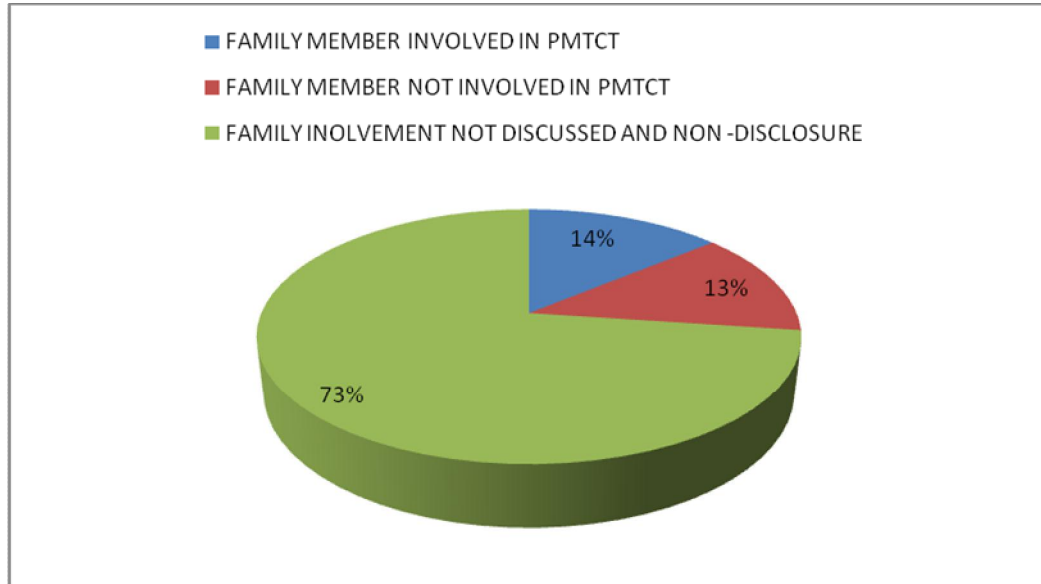


Figure 4.13 Family member involvement in PMTCT (other than male partner).

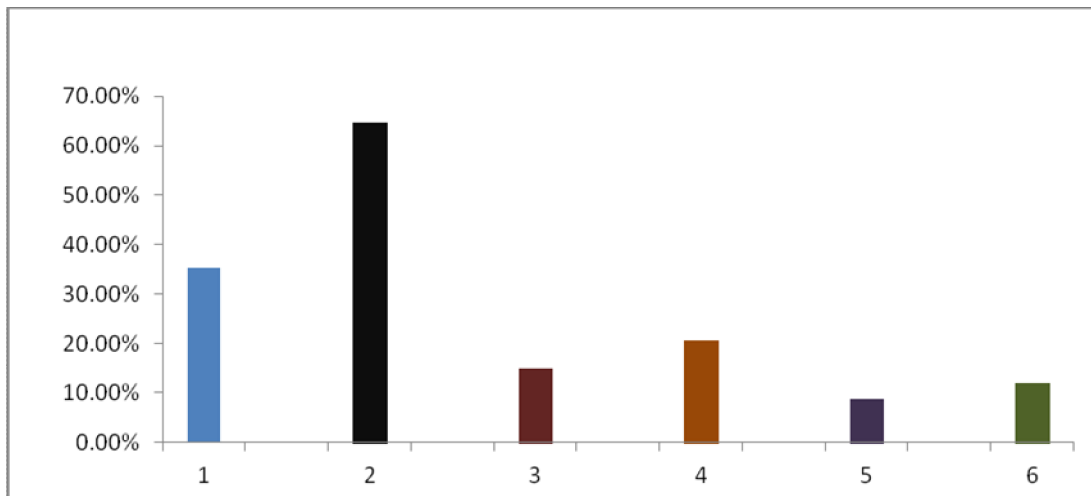


Figure 4.14 Discussion about involvement of family member and reported involvement of family members in PMTCT.

Key to figure 4.14

1= involvement of family member in PMTCT discussed

2= involvement of family member in PMTCT not discussed

3=family/household member assists financially

4=family/household member reminds on taking antiretroviral medications

5= family/ household member assist with collecting medication

6. =family household member attends clinic with client

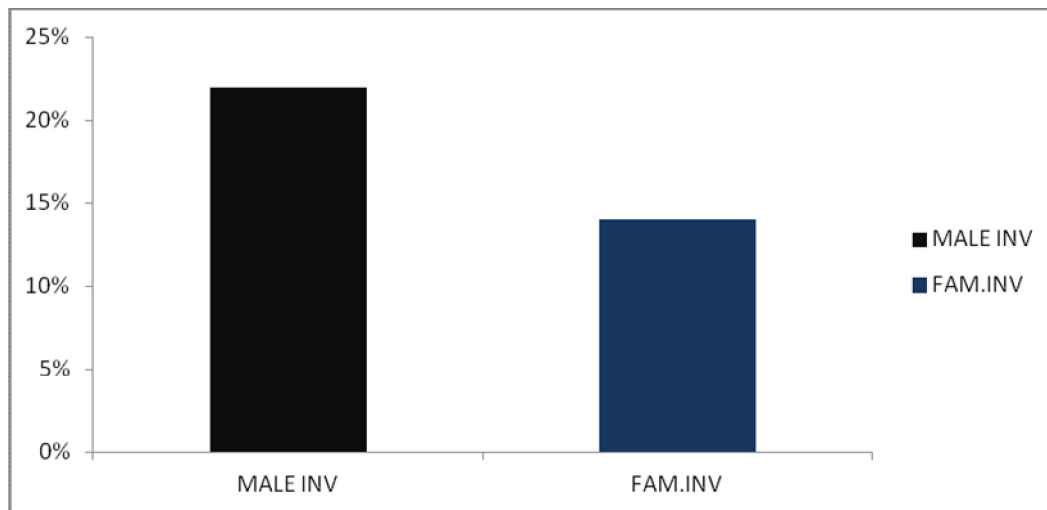


Figure 4.15 Comparison between reported involvement of male partner in PMTCT and involvement of other family members.

MALE INV= Male involvement in PMTCT

FAM. INV= another member of family /household other male partner involved

4.2 Discussion

A total of 34 participants were interviewed in this survey. All were HIV patients who were women of reproductive age seeking maternal services in Seshego hospital. All except for one of these women were booked for antenatal care in a local clinic before attending maternal care services at Seshego Hospital.

Booking means these women had attended one of the feeder clinics within the hospital's catchment area. Booking visits in antenatal care are the first visits in antenatal care. This is a very important visit in antenatal care as service providers use this occasion to collect and

document basic information that will form the basis to care for the pregnant woman throughout the duration of her pregnancy. A booking visit occurs when a woman suspects or has found that she is pregnant. During this visit her pregnancy is confirmed at the antenatal clinic. A pregnancy test is usually done and upon confirmation of her pregnancy the sister in charge proceeds to collect and document biographical data about her, including other important and relevant medical information. The patient is examined and presence or absence of risk factors evaluated to enable a decision to be made as to where she should continue to receive antenatal care and eventual delivery. During this visit also counselling and testing for HIV is usually done for all pregnant women according to South African guidelines for care of the pregnant woman. However apart from the booking visit to a local clinic all women attending health institutions for maternal health services are tested routinely for HIV in line with the department of health's policies upon first contact with them in a health care institution.

Patients who test positive are further counselled and further tests are done to determine their cd4 cell counts in order to initiate antiretroviral treatment or prophylaxis. Only one of the study participants was not booked; however this study participant not only delivered her baby in the hospital but had been in the hospital postnatal ward for at least one full day in which case she met the criteria to be included in the study.

The age group of the survey participants ranged from 19 to 43 years with the age groups 21 to 40 years constituting the bulk (94.1%) of the HIV positive participants of the study. Specifically the age group 21 years to 30 years made up 52.9% of the study population while the age group 31 to 40 years made up 41.2% of the study population. (See Figure 4. 1) This is in line with HIV prevalence in the general population in South Africa where the bulk of HIV infection among women is in the age group from 20 years to 39 years with prevalence peaking in the age groups 25 years to 29 years where there is an estimated prevalence of 32.7 % (Human research council, 2008)

4.2.1 Health worker counselling and disclosure of HIV status

Health care workers had counselled on disclosure of their HIV status according to 67.6% of the participants surveyed, while 32.4% reported that the issue had not been discussed with them by. Disclosure to at least a member of their family or households other than male partner was admitted by 52.9% of the study participants while 47.1% said they had not yet

disclosed their status to any member of their family. (See Figure 4.5) This indicates the need for on-going counselling, information and education during antenatal care visits, during admissions to antenatal wards, labour and after delivery. Of the study participants who had not yet disclosed their status to any member of their family 33.3% said they would need further health worker assistance for disclosure to their family members while 66.7% said they would do it in their own time and needed no help. This again indicates need for counselling and discussion about HIV disclosure not to be a once-off affair but should be a continuous dialogue between the health worker and the patient. A look at Figure 4.5 where response to counselling for disclosure and disclosure to a family member are compared there appears to be correspondence between the two percentages. Disclosure appears to be in proportion to counselling. Where there has been counselling for disclosure proportionately there has been disclosure and vice versa. However, it must be noted that since the proportion of those who said they had not been counselled on disclosure is similar to those who admitted not disclosing to any member of the families/households it could be that the actual problem is that they have not really disclosed to any member of their family despite being counselled on the issue. They could be blaming non-disclosure of their HIV status on not being counselled by the health care worker. However it could also indicate shortfalls in health care worker counselling of clients while they have been attending maternal health services. This study reveals a knowledge gap in this area which needs to be filled through further research and studies.

4.2.2 Disclosure to male partners

Survey participants admitted by proportion of 73.5% that in the course of attending maternal care services a health care worker had discussed the issue of disclosure of their HIV status to their male partners while 26.5% said this had not been discussed with them. In terms of disclosure 64.7% said they had disclosed to their male partners while 35.3% said they had not yet disclosed to their male partner. Again a similar pattern emerges here as above. (See figure 4.6) Counselling for disclosure is in proportion with disclosure. This indicates again that health care worker discussing disclosure both to male partners and other family members is effective as a tool for promoting disclosure and needs to be exploited further and made more effective as a tool for involving not only the male partners of pregnant females in PMTCT but also other members of the families/households of HIV positive pregnant women. This then becomes a gateway for involving the male partners and other family/household

members of the HIV positive woman in HIV prevention, treatment and care programmes. However an area of weakness with this study is that it relies on the verbal answers to questions about disclosure. There is need for further study in the way of documentary evidence to prove rates of disclosure between females in PMTCT programmes and their male partners.

4.2.3. Involvement of male partners in PMTCT

Invitation by health care workers of male partners of study participants to take an HIV test was admitted by 52.9% of the participants, while 47.1% said their male partners had not yet been invited for an HIV test. This indicates the need for invitation of male partners of pregnant HIV positive women for an HIV test to be made a routine part of health care protocol during maternal care and for there to be documentary evidence to that effect.

In exploring what extent health care workers were engaging male partners of HIV positive pregnant women in PMTCT 52.9% of the survey respondents said their male partners had been invited to participate in PMCT in ensuring their expected child could be HIV negative while 47.1% said their male partners had not been invited. (See Figure 4.7) This is difficult to verify in the absence of documentary evidence. (Being the major area of weakness of this study) This makes it necessary to incorporate the invitation of male partners of HIV positive women as a part of the standard PMTCT protocol and for there to be proper documentation in this regard.

Of the survey respondents who had disclosed their HIV status to their male partners, 23% said their partners were involved in PMTCT in one of the three ways: either by having taken an HIV test, taking antiretroviral medication or use of condoms. However, 33% of survey respondents said their male partners were not involved in PMTCT in any of the above ways in spite of having disclosed their HIV status to them while in 47% of survey respondents the question was not applicable because of non-disclosure of their status to their male partners as the main reason. (See Figure 4.8) Figure 4.10 shows that the percentage where male partners had not been invited to be involved in PMTCT corresponds to the percentage where there was no disclosure of HIV status as being the reason why the male partner could not participate in any way in PMTCT.

If the percentage of those who indicated that their male partners were not involved in PMCT is added to the non-disclosure group together they make up 77% of the study population

where it can be said the male partner is not involved in issues of PMTCT and consequently HIV prevention, treatment and care. (See Figure 4.9) There thus appears to be a low participation of male partners in PMTCT and therefore the opportunity offered by this important gateway for HIV prevention, treatment and care appears not to be fully exploited for men. Here again the central importance of involving the male partners in PMTCT and consequently HIV prevention, treatment and care is highlighted. Where disclosure has not taken place between the male and female partners in PMTCT the male partner cannot be engaged in PMTCT and hence his role as father cannot be effectively harnessed in HIV prevention, treatment and care programmed particularly in PMTCT. A very important gateway to HIV prevention, care and treatment will thus remain not fully exploited.

4.2.4. Engaging other family/household members in PMTCT

Survey respondents admitted in 35.3% of the cases that in the course of attending maternal health services the issue of involvement of other members of their household other than their male partners was discussed while 64.7% of the respondents said the issue was never discussed with them. This further highlights the need for the involvement of family members to be made a part of standard care protocol for in PMTCT and for proper document to that effect.

A breakdown of the ways in which families of the respondents participated in PMTCT revealed that 14.7% of survey respondents said a member of their family other than their male partners helped them financially in terms of attending clinics and receiving care for their condition; 20.6% said a member of the family assisted them as adherence reminders by reminding them to take their medication on time while 8.8% said a member of the family assisted with collection of medication and 11.8% said a member of the family other than their male partners accompanied them to the clinic. On the average 13.9% said a member of the family/household assisted in one of the four ways listed above while 13.2% said no member of their family/household provided any form of assistance, despite disclosure of their HIV status. In 72.7% of the respondent there was no assistance provided to them in terms of PMTCT because of non-disclosure or the issue was never discussed by the health care worker while they were attending maternal health services. On the average therefore 14% of the study participants reported that a member of their family/household was involved in some way with them in PMTCT while in 86% of the survey participants there was no member of the family/household involved.

This again highlights the central role the health care worker must play in driving the process of providing prevention, treatment and care services. As has been seen earlier where there has been health worker initiative in disclosure then disclosure has been proportionate in response. Where there is disclosure then other members of the family including the male partner can be engaged in PMTCT and other aspects of HIV prevention care and treatment programmes. This survey reveals a low level of family or household members' involvement in PMTCT for the two major reasons of inadequate disclosure of HIV status and apparent failure of health care workers to discuss the issue while clients are attending maternal health services either at the clinic level or hospital.

Chapter 5: Conclusion and recommendations

5.1 Conclusion

Increasingly HIV/AIDS is viewed as a family disease. The underlying conditions that favour the transmission and spread of the HIV are largely embedded within weaknesses, vulnerabilities and breakdown of the family and household units. The immediate medical economic and psychosocial effects of HIV/AIDS occur within the family/household units before being translated to communities at large. In the same way, increasingly the family is being viewed as the primary environment where interventions to curtail the spread of infection and curtail its effects are to be primarily focused. Family centred prevention of mother to child transmission of HIV (PMTCT) is based on this paradigm. Within this paradigm of PMTCT the expectant mother is not the primary focus of interventions to treat HIV/AIDS and prevent its spread but her immediate family or household becomes the centre of HIV/AIDS interventions. This approach is holistic addressing not only the health and social needs of the expectant mother but that of other adults and children with her family/ Household. In this way PMTCT becomes an entry point for the family/ household into HIV/AIDS prevention/ treatment and care programmes.

In this study in addition to establishing what a family centred PMTCT is and involves an attempt has been made to find out to what extent family/household members attending maternal health care services in Seshego hospital were engaged by health care workers. The study depended on answers given by participants who were requested to volunteer for the study in structured questionnaire. The major area of weakness with this study is that it was based on verbal answers by participants and there was paucity of documentary evidence to corroborate the answers given by study participants.

The study found that disclosure of HIV status by HIV positive women to male partner to family/household members was proportionate to counselling by health care workers for pregnant HIV positive females to disclose. However in terms of actual involvement of male partners and other family/household members there was found to be a low participation and engagement in PMTCT. Correspondingly the study found out that health care workers appear not to be taking the time and effort to engage male partners and other household and family members adequately in PMTCT. Consequently this important entry point of PMTCT for the

entire families/households to be brought into HIV/AIDS intervention programmes remains not fully exploited.

5.2 Recommendations

In order to address these shortfalls the following are recommended:

5.2.1 Greater emphasis on and recognition of the role of health care workers in providing leadership

There should be a greater recognition and reinforcement of the leadership role which health care providers play in driving PMTCT and other HIV/AIDS care, prevention and treatment programmes. Training programmes need to be more readily available in this regard and tailored toward making the health care workers leaders and drivers of the HIV/AIDS interventions.

5.2.2 Greater emphasis on a multidisciplinary approach to HIV/AIDS prevention, treatment and care

Family centred approach to PMTCT and other areas of care require a multidisciplinary approach which requires not just the input of the medical doctors, nurses, midwives and pharmacist but also inputs from other professions such as social workers, psychologists, community workers and counsellors are vital to be able to involve the entire families and households.

5.2.3 Expand current standard protocols of PMTCT

Standard protocols of HIV/AIDS intervention programmes such as PMTCT should include the involvement of the male partners. There is need for the formal invitation of the male partners of HIV positive pregnant through advisory slips and there should be adequate documentation to that effect.

5.2.3 Encourage better documentation

Adequate documentation by health care workers should be encouraged. For example the invitation and testing of male partners for HIV should be properly documented. Disclosure to male partner and other family members should be properly documentation. The involvement

and participation of other male members within the family/household should be properly documented.

5.2.4 Utilise informal avenues to involve family members

Informal avenues such as visiting hours when male partners and family members visit women receiving maternal care on hospital admission should be exploited to engage them more in PMTCT and other HIV/AIDS programmes.

5.2.5 Encourage couple counselling

Couple counselling and testing for HIV including counselling for initiation of antiretroviral therapy should be encouraged and reinforced.

5.2.6 Intensify public education on the role of the males and other members of the family/household in PMTCT

Information and education of the public on the role of the family and male partners in PMTCT should be intensified and given wider coverage

5.2.7 Build on the success of provider initiated HIV testing as seen in PMTCT

The success of provider initiated HIV counselling and testing also referred to as routine HIV testing should be extended to other areas of patient care such as contact with patients in the outpatient department, casualty and in the in-patient wards.

5.2.8 Suggestions for future research

Finally the study reveals the need for further research especially quantitative research, document study, clinic attendance exit interviews to further find out the degree to which male partners, family/household members are being engaged in PMTCT and hence HIV/AIDS programmes and to establish the effectiveness of these interventions. In this way the planning, implementation and management of HIV/AIDS interventions can be more family centred and evidence driven.

The procedure of obtaining institutional approval to carry out these researches should also be streamlined in order to make it easier for interested individuals to carry out research

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ADDENDUM A

INVOLVEMENT OF FAMILY/HOUSEHOLD MEMBERS OF HIV POSITIVE PREGNANT WOMEN IN FAMILY CENTRED PMTCT.

Interview questionnaire.

Q1. While receiving care in this clinic, have you been encouraged by the health care provider to disclose your status to any member of your family?

Yesí í í í í í í í noí í í í í í í í í í í í í í í ..

Q2. Have you disclosed you status to any member of your family/household as a result of discussion with the health care worker in this clinic?

Yesí í í í í í í í ..noí í í í í í í í í í í í í í .

Q3. Do feel like you need further assistance of your health care worker in disclosing your status to any member of your family

Yesí í í í í í í í .noí í í í í í í í í í í í í í .

Q4. Has your health care provider specifically discussed disclosure of your HIV status with your partner?

Yesí .noí .

Q5. Have you disclosed your HIV status to your male partner?

YESí .NOí .

Q6. Do you feel like you will need further assistance from your health care provider in disclosing your HIV status with your male partner?

Yesí noí .

Q7. Has you male partner been invited by the health care worker to be involved with you in helping to prevent transmission of HIV to your unborn baby?

ADDENDUM B

PARTICIPANT INFORMATION SHEET

Dear Respondent/Participant

Re: involvement of family/household members of HIV positive pregnant women in family centred prevention of mother to child transmission of HIV (PMTCT)

In partial fulfilment of the requirements for the award of a Master of Philosophy Degree in HIV/AIDS Management from the Africa Centre for the management of HIV/AIDS, Stellenbosch University, I am carrying out a study with the above title. The purpose of this study is to gather baseline information on the extent to which this hospital's programme for the prevention of mother to child transmission of HIV (PMTCT) enlists the support of families or household members of pregnant women who are HIV positive in ensuring that pregnant women do not transmit HIV to their unborn children. Through this questionnaire interview I intend to ask you a few questions in this regard. The information you will volunteer in will be treated with utmost confidence.

The aim of the study is to assist in the process of organizing prevention of mother to child transmission of HIV (PMTCT) services in this hospital and the province in such way as to make it more inclusive of the family and so make it more effective.

The study objectives are as follows-

1. To establish what a family centred prevention of mother to child transmission of HIV (PMTCT) service is.
2. To find out what role family or household members of the HIV positive pregnant woman can play in a family centred PMTCT service.
3. To find out to what extent family or household members of HIV positive pregnant women attending maternal health services in Seshego Hospital are brought into HIV prevention, treatment and care programs.
4. To make recommendations on appropriate strategies for organizing PMTCT services in Seshego and Limpopo province in such a way as to make them more family centred.

Please feel free to contact me phone number 0730119227 should you have any questions or you need clarification.

Thank you.

Yours sincerely

Dr. Felix O.Idolor