

CHAPTER VII

SUMMARY, CONCLUSION AND POLICY RECOMMENDATIONS

7.1. Introduction

The final chapter gives summary, conclusion and policy implications based on the findings of the present work. It also highlights limitations of the research work and scope for future research for strengthening the PPTCT programme in India

7.2. Background

Epidemiological evidence indicates that sexual contact continues to be the major mode of spread of HIV transmission in developing countries, leading to high prevalence of HIV infection in women of child-bearing age (Schmid et al., 2004). World-wide one in seven of those who become newly infected with HIV are children under the age of 15 years (UNICEF, 2008; UNAIDS, 2008). It is estimated that 2.3 million of the 33 million (30.3 million —36.1) people currently living with HIV worldwide are children under the age of 15 years. There are an estimated 20.9 lakh People Living with HIV (PLHIV) in India, with national adult HIV prevalence of 0.27 per cent (NACO, 2012). Of these, women constitute 39 per cent of all PLHIV, while children of less than 15 years of age constitute 7 per cent of all infections (1.45 lakh) and 14,500 children are newly infected annually (NACO, 2012). As in March 2013, 0.1 million HIV positive children had been registered under the antiretroviral therapy (ART) programme and 38,579 received free ART (NACO, 2013). In the absence of any intervention, a substantial proportion of children born to women living with HIV acquire HIV infection from their mothers either during pregnancy, labour/delivery or during breast feeding. Without any intervention, the risk of transmission of HIV from infected pregnant women to their children is estimated to be around 20-45 per cent. Use of ART and sd NVP/Sy NVP to mother-baby pairs is shown to be effective in reducing this transmission to as low as 10 per cent. Use of single dose Nevirapine (sd-NVP) at the onset of labour significantly reduces pre-partum HIV transmission.

Mother-to-child-transmission of HIV is a major route of HIV infection in children. It is estimated that 27 million deliveries take place in India annually, and 97,200 of these occur in HIV positive pregnant women resulting in a yearly cohort of 21,000 HIV positive children (NACO, 2007). Breast feeding is culturally normative and it is one of the most serious public health dilemmas today. Until recently, there was no means of preventing parent to child transmission for those HIV-positive women who wished to give birth. Though two interventions using antiretroviral (Nevirapine) are available to reduce the mother to child transmission, successful implementation of the programme is dependent on

the choice and effective implementation of an appropriate feeding regimen. To date there is no published data that examines knowledge, attitude of PPTCT and infant feeding choices of HIV positive women. Hence, it is important to understand these of HIV positive mothers and the factors affecting these practices.

7.3. Rationale for the study and its objectives

This study is an attempt to understand the knowledge and attitude of HIV/AIDS, PPTCT, infant feeding methods and factors determining the infant feeding practice among HIV positive women. It also explores the knowledge and attitude of infant feeding methods by health care providers and challenges involved in different infant feeding methods by such women. Its findings would be useful to provide an appropriate choice of infant feeding practices to prevent the parent to child transmission, improve the quality of PPTCT services and growth of infants. Its specific objectives are: 1) To examine the socio-economic, demographic and behavioural characteristics of HIV positive women, 2) To assess the knowledge of HIV/AIDS and prevention of parent to child transmission among HIV positive women in selected health facilities, 3) To measure the knowledge, attitude and perceptions of infant feeding and its relation to HIV transmission among HIV positive women and health care providers in selected health facilities, 4) To assess the infant feeding practices and associated factors which determine feeding practices among HIV positive women.

7.4. Profile and study design

The study has been carried out in the resource limited setting of Odisha. It has been undertaken in high HIV prevalence 'A' category and medium prevalence 'B' and low prevalence 'C' category districts of Odisha as per the National AIDS Control Programme Phase-III categorization. Three centres have been selected purposively where PPTCT centres have been integrated with ART centres and have a number of ANC women. One centre has been selected for each district. The selected centres are Govt. Medical colleges and served as centre of excellence in the selected districts.

A cross sectional and explorative analysis using both quantitative and qualitative methods has been done in this study. The basic data used to fulfill its objectives have been collected both from the primary and secondary sources. Primary data have been collected through questionnaire method from the women diagnosed as HIV infected who came to the hospital during the antenatal stage and delivery care. In-depth interviews have been

conducted with HIV positive women to know the infant feeding practices. Information was also collected from health care providers such as doctors and counsellors in PPTCT programme to understand the knowledge of infant feeding practices and recommendations. On the other hand, secondary information was gathered from HIV positive women line list, ANC registration form, ANC check-up and follow-up form, infant follow-up form, monthly summary report, and ICTC/PPTCT registers. Treatment records, medical information and child growth data have been collected from selected ART centres in these hospitals. All necessary ethical principles like ethical clearance from the Institutional Review Board (IRB) from the institute, Department of AIDS Control and informed consent of the study participants have been taken into consideration during data collection. Scientific software package SPSS was used for analysis. Univariate, bivariate and multivariate techniques were employed to analyse data. Univariate analysis has been used for the computation of frequency and number of cases that determines the variation between or among different categories of a given variable. The Chi-square test was used to measure the strength of associations between variables, a p-value and significant level of <0.05 was considered to be statistically significant. Multivariate analyses were carried out using binary logistic regression methods. Logistic regression method was used to understand the level of effect of different background factors on outcome variable. Adjusted Odds Ratios (ORs) were calculated to understand the factors affecting the infant feeding practices.

The study measures the knowledge and attitude of HIV/AIDS, PPTCT and infant feeding of HIV positive women in the stud setting. For assessment of knowledge, Modified Bloom's cut off points were used. Scores of 75 – 100 per cent, 50 – 74 per cent and less than 50 per cent placed the respondents in good, moderate and poor basic HIV/AIDS and PPTCT knowledge respectively. Attitude was assessed by eight questions. These were put on Likert's scale and respondents were provided with statements to indicate the extent to which they agree with them as to whether they strongly agreed, agreed, had no opinion, disagreed or strongly disagreed with what they were asked.

7.5. Profile of studied population

The study has captured information of HIV positive women who were identified as HIV positive in selected hospitals. In all 152 such HIV positive women were interviewed. An almost equal proportion of them (39 per cent) was found to be in the age group of 20-24 years and 25-29 years. About 16 per cent of them were below 20 years and only 5.3 per cent were in the age group of 30-34 years. The mean age of HIV positive women in the study was 28 years. A majority of the respondents were Hindus (84 per cent). Two-thirds of HIV positive women were from either general class or other backward classes. A considerable proportion of HIV positive women (18.4 per cent) were found to be scheduled castes and the remaining 13 per cent of Scheduled Tribes. About one-fifth of HIV positive women were illiterate and 50 per cent of them had completed primary school. Occupation of the HIV positive women indicates that majority of the HIV positive women are housewife (72 per cent). With regard to occupation of the husband of HIV positive women, nearly 33 per cent of them worked as daily labourers, followed by migrant workers (30 per cent). About two-thirds (63 per cent) of the respondents' family income was from Rs. 2000 to Rs. 5000 per month. Thus, most HIV positive women belonged to low economic and educational strata of the society.

7.6. Knowledge of HIV/AIDS and PPTCT

In this study the knowledge of HIV/AIDS, PPTCT, modes of transmission of PPTCT, prevention method and association between demographic characteristics and PPTCT strategies were identified. Two-fourths of HIV positive women had moderate knowledge, followed by two-sixths of them having good knowledge and about one-fifth having poor knowledge of HIV. The educational and occupational status of the HIV positive women and their husbands, and income of the family had positive association with the knowledge of PPTCT. The study revealed that 68 per cent of HIV positive women were aware that HIV could be transmitted during delivery, followed by breast feeding (50 per cent) and pregnancy (47 per cent). Education, occupation and income of the family have positive impact on the modes of transmission of PPTCT. An anti-retroviral drug to the new born baby was the most chosen method to prevent HIV transmission (81 per cent). Lack of knowledge about HIV/AIDS and PPTCT is a major weak point among the HIV positive women. Therefore, attention needs to be focused on awareness of HIV/AIDS and PPTCT in the studied setting.

7.7. Knowledge and attitude for infant feeding methods among HIV positive women

The study throws light on the knowledge and attitude of HIV positive women and health care providers towards infant feeding methods and PPTCT. One-fourth of HIV positive women received HIV counselling during ANC visit at the health facility and 53 per cent of them received infant feeding counselling. Regarding knowledge of infant feeding methods, 52 per cent of HIV positive women thought that breast feeding was adequate for the babies in the first six months of life for it prevented childhood illness. Feeding formula food/other food was found to be expensive. Regarding colostrums, half of the HIV positive women did not have sufficient knowledge of their benefit, whereas only 24 per cent of them reported about nutritional completeness, strengthening of immunity (14 per cent) and so on. Attitude of women towards PPTCT and breast feeding suggests that 63 per cent of them agreed that every pregnant woman should get tested for HIV. The study exposed that stigma and fear of disclosing results were barriers to implement PPTCT intervention in the community. More than 60 per cent of the women believed that breast feeding beyond six months was due to fear of stigma and 73 per cent reported due to the fear of disclosure of HIV condition. This appears to be similar to a study done in Uganda and Temeke district hospital in Dar es Salaam in 2010 which showed that HIV positive women were breast feeding beyond six months due to fear of stigma and disclosure. Most of the HIV positive women supported PPTCT strategies which is a positive attitude towards PPTCT intervention.

Attitude towards MTCT, breast feeding and formula feeding is reflected in the findings. Though 80 per cent of HIV positive women agreed that exclusive breast feeding was an appropriate option for feeding the exposed children, 70 per cent of them consider the use of formula as the best option. Attitude towards breast feeding and formula feeding was presented in Likert type scale. More than 80 per cent of such women strongly agreed or agreed that breast feeding is healthy, hygienic and it satisfies the infant. Most of HIV positive women (78 per cent) reported that breast feeding was nutritionally complete. Further, 44 per cent of them received post-test counseling and 78 per cent received Sd of NVP for baby and for their own health.

7.8. Knowledge of PPTCT, infant feeding and experience among health care providers

The study has found that 60 per cent of health care providers received training on PPTCT and 50 per cent of them on infant feeding counselling. Very few health care providers (20 per cent) received training on new WHO guidelines. With regard to experience by health care providers on PPTCT and infant feeding, health care providers provided appropriate infant feeding options to HIV positive women and advised them to choose better options according to their personal circumstances. A PPTCT counsellor stated, *“Most of the women offering services here come from rural areas and are very poor. Very few people afford the formula/replacement feeding.”* Another counsellor explained, *We receive the HIV positive women from different parts of the district and some times we get them from outside from the district. We provide information on all the methods so that HIV positive women are able to choose infant feeds for themselves according to their own personal circumstances.”* PPTCT counsellors at the health facility emphasized exclusive breast feeding during counselling and post-test counselling. Promotion of formula/replacement feeding (satisfying the AFASS criteria) was observed in the study. A counsellor at the *Hospital-1* explained, *“ Since I started counselling in 2009, I am mentioning infant feeding options to all the HIV infected and HIV negative women. My experience has shown that a majority of the HIV positive mothers choose exclusive breast feeding and a small minority will go for formula feed. In the end, the message we emphasize is, therefore, about exclusive breast feeding and formula/replacement feeding”.* A counsellor at the hospital of Khordha district observed that lack of training in PPTCT and infant feeding counselling presented major obstacles on how messages on infant feeding for HIV infected mothers were provided. She observed, *“I have had no training in PMTCT infant feeding counselling. I was just given an infant feeding training manual to study- but you know, self study is not the same thing as being trained. I am sure my messages to HIV infected mothers will improve after training”.*

The study found that a majority of health service providers lacked basic knowledge of infant feeding counselling in the context of HIV and AIDS. There are essential nutrition interventions necessary for promoting children and maternal nutrition and this signifies the need for capacity building of health service providers in the studied area. They can support mothers to adopt recommended practices that are necessary to prevent MTCT of HIV and increase the likelihood of HIV-free survival of HIV exposed children.

7.9. Intention of infant feeding practices among HIV positive women

In this study, the intention of infant feeding practices and challenges of infant feeding practices experienced by the HIV positive women has been investigated. Among all the HIV positive women, 51 per cent women favoured exclusive breast feeding and 36 per cent exclusive replacement feeding. About 9 per cent reported giving some solid food and formula feeding along with breast feeding which is mixed feeding. The reason most commonly agreed to by these women for exclusive breastfeeding was expenses involved in formula feeding (82 per cent), followed by advised by health care professional (65 per cent). Intention of breast feeding and formula feeding was assessed with background characteristics. Association of feeding practices with monthly family income was found to be statistically significant. HIV positive women staying in joint families were prone to practise breast feeding. This was found to be statistically significant. HIV positive women who did not disclose their HIV positive status to their husbands or in-laws were less likely to opt for breast feeding. Concurrently, HIV positive women who received infant feeding counselling, also received ARV prophylaxis and those women who disclosed their HIV positive status were more likely to opt for formula/replacement feeding.

7.10. Factors affecting infant feeding practices among HIV positive women

Factors associated with exclusive breast feeding and exclusive replacement feeding were elaborated in the study. It concluded with the impact of socio-demographic characteristics on recommended (exclusive breast feeding and exclusive replacement feeding) and non-recommended (mixed feeding) feeding practices. Educational status of HIV positive women, family income and disclosure of HIV status to her husband and in-laws were associated with exclusive replacement feeding [ERF ($p < 0.05$)]. Similarly, education, place of residence and knowledge of PPTCT were associated with exclusive breast feeding [EBF ($p < 0.05$)]. The exclusive breast feeding and exclusive replacement feeding are the recommended feeding practices in the study where-as mixed feeding (breast feeding with solid food and others and replacement feeding with breast milk and other foods) is not recommended in the study. In logistic regression, it is found that residential status, disclosure of HIV status to their husbands and family members were found to have association with ($p < 0.05$) for those who intended recommended way of infant feeding practices. The HIV positive women who disclosed their HIV status to their husband and in-laws were 7.7 times more likely to have recommended way of infant feeding practice.

Those women who were educated were 14.6 times more likely to have the recommended way of infant feeding practices than illiterate HIV positive women.

7.11. Challenges of infant feeding practices for HIV positive women

The challenges of infant feeding practices were observed among HIV positive women who experienced feeding practices. Cases of exclusive breast feeding for six months, exclusive replacement feeding, feeding of cow milk and mixed feeding practices are elaborated in the study. It proves that decision making on infant feeding is not only based on knowledge about medical risks, but also on social risks regarding disclosure, rejection and stigma. It found difficulties of practising exclusive formula/replacement feeding as the stigma and fear of disclosure prevailed in the studied setting. HIV positive women who practiced replacement feeding were not satisfying the AFASS criteria as they did not have proper drinking/water facilities in their household premises. A quote by HIV positive woman, *“We don’t have drinking water facilities in our household compartment. I need to go far to bring water”* (*Ama ghare pieba pani ra thik se subidha nahi, mote pani aniba ku bahut bata jibaku hue*). The study also found the difficulties to purchase the formula feeding and that prolonged breast feeding existed in the community. A HIV positive woman quoted that she can’t afford formula feeding (*“Ame ta dhanighar nuha, ame kemiti Amul kemiti piaybu”, epariki ame ta khati mazuria loka, kama kale khaibu, ta pare ete paisa kuade anibu”*).

The cases identified in the study reflect that exclusive breast feeding for the first six months is the best method for infant feeding. The basic principle of ‘informed choice’, promoted through the international guidelines on HIV and infant feeding, requires that an HIV positive woman be provided with adequate information about the recommended feeding options to make her choice (WHO, 2003). To achieve success in exclusivity of feeding options, a mother’s decision should be respected and pressuring her by the family/neighbours to introduce other food to the infant should stop. Furthermore, the risks involved in each infant feeding option should be communicated to the parents (mother/father) during PPTCT to enable them to make informed choices. Continuing work on the options of feeding and involving spouses in every health and nutrition education session to help mothers choose safer infant feeding options is important.

7.12 Policy implications

Paediatric AIDS remains a major contributor to child mortality in resource poor countries. Thus, interventions that seek to significantly reduce MTCT of HIV have the potential to contribute towards achievement of the Millennium Development Goal of reducing child mortality by two-thirds by 2015 from the 1990 level. The finding that a majority of the participants did not receive the recommended counselling on infant feeding underscores the need for PPTCT programmes in a resource poor setting to take proper care to understand global and national recommendations on infant feeding in the context of HIV and to find appropriate ways to communicate research evidence to HIV-infected women so that they can make informed choices regarding the infant feeding options. It was evident from the study that though the HIV positive women intended exclusive breast feeding, in practice they practised prolonged mixed feeding. It was also learnt that formula/replacement feeding was not feasible as most of the rural positive women were not satisfying the AFASS criteria. Breast feeding was only the acceptable way to feed the infants. Taking into account the present situation of HIV/AIDS and risk of MTCT, a need is recognized to strengthen the counselling for infant feeding in PPTCT services. The major recommendation springing out of the present work is that infant feeding counselling should recommend exclusive breast feeding as the first choice of HIV-positive mothers and those substantial efforts should be put into strengthening breast feeding practices. This might be more effective when combined with other on-going interventions like use of common mass media like radio and television to disseminate information about safe infant feeding practices and benefits of exclusive breastfeeding. Further, women's empowerment through education, improvement of ANC follow-up status and male involvement may significantly associate with PPTCT knowledge, attitude and uptake of the services.

In additional, health workers need to be given continuous job training and refresher courses in areas of updated knowledge on infant feeding practices in regard to national and international guidelines to equip them with the latest knowledge. Outreach activities should be expanded to follow-up HIV positive women and their infants to provide the advise on health, nutrition and better feeding practices.

7.13. Limitation of the study

The study has been conducted at the facility level with limited sample size. Its cross sectional design does not allow drawing conclusion regarding actual infant feeding practices of all the HIV positive mothers as there has been no follow-up. The sample size has been chosen purposively as it is difficult to select them. Due to small sample size, we should be cautious in our interpretation of the results and generalization of results for a larger population. As the study has conducted at the facility level, respondents have been chosen who have been identified as HIV positive. The study does not cover HIV positive women identified as such at private health clinics and other such health facilities. The HIV positive women who did not visit the health facilities may have different characteristics as those who visited the latter. Difficulty was also faced in doing the follow-up of HIV positive women. The HIV positive women were asked about intention of feeding practices during the in depth interviews, but their responses may not have reflected the actual practices. The study has covered the actual feeding practices among HIV positive women with few case studies as it is very difficult to follow up them. In addition, there is a possibility of recall bias from HIV positive mothers for the simple reason that they might have forgotten what happened in the past. The study has also not verified the environmental factors of all HIV positive women as most of the information was collected at the post-natal clinics. Infant morbidity and status of HIV exposed children are not elaborated in the study due to the time factor.

7.14. Scope for future research

Several research questions have emerged from the present study which would benefit significantly from further investigation within the same or other settings with similar socio-cultural and economic characteristics. Based on the findings of the study, the following recommendations emerge:

1. The study was conducted with a small sample size with cross-sectional design. It is recommended that a study may be conducted with a bigger sample size having cohort study. This is to ensure that the sample of the respondents can be followed subsequently.
2. This study presents self-reported infant feeding practices of HIV positive women. Further research based on bio-medical research would give a better picture of its intensity and proactive nutrition and treatment seeking behavior.

3. It assessed the factors that influence infant feeding practices from the HIV positive women's perspectives due to time constraints. Therefore, further research is needed to assess related factors in order to aid policy formulation and foster promotion of exclusive breast feeding.
4. In order to promote EBF there is a need to further explore characteristics of HIV positive women who have succeeded in maintaining it and their surroundings that may provide an opportunity to promote it in the state. At the same time, experience of maintaining the ERF/EFF of HIV positive women may be required. It will help health care providers to furnish adequate examples to the HIV positive women in order to promote particular feeding practices.
5. The study does not provide the picture for transmission of HIV from different infant feeding options, i.e., exclusive breast feeding, exclusive formula/replacement feeding and mixed feeding. It requires clinical trials to determine the impact of different feeding options.
6. There is also a need to explore more ways of involving men and family members of HIV positive women in PPTCT which are the providers of care and support as well as decision-makers on infant feeding.