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Barriers and Challenges in facilitating HIV Testing and Disclosure in Children and Adolescents in Manipur: Mothers' Perceptions

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Abstract:
The present study documents the experiences of 180 women having children and living with HIV/AIDS in four districts viz., Imphal East, Imphal West, Churachandpur and Ukhrul of Manipur, one of the north-eastern states of India bordering Myanmar. This study examined mothers' perception on the barriers and challenges faced in facilitating HIV testing of children and adolescents and in disclosure of their and their children's HIV status. The study has been conducted eight Focus Group Discussions (FGDs) in the four districts – two in each district, twenty Case Studies were undertaken in the four districts – five in each district and another individual interviews were conducted among eighty (80) infected women having children, in the four districts – twenty (20) in each district using standardized schedule. Key findings of the study have highlighted several factors that prevent parents from taking their children for HIV testing across all age groups. The probability of the child being detected positive creates in them the psychological fear of facing discrimination in society. The stigma and discrimination associated with HIV/AIDS was reported to be the most common barrier. Another key findings from the study have highlighted several issues, particularly in relation to disclosure of HIV status to children aged 9 and above. Some respondent's children know of their and their parents HIV status by overhearing and suspicion – by observing some activities around the time when their parents fell sick that created suspicion in them and the parent's conversations with peer groups/relatives at home and doctors/nurses at hospital, and also with the passages of years and their gaining awareness on about their condition. They knew the purpose of taking ART drugs. Some children were disappointed and some were accepted the situation. There is therefore, an urgent need to encourage parents to disclose their child's HIV status early and to other siblings who are likely to empathize with him/her and help him/her in coping.

Keywords: *Human Immuno-deficiency Virus; Acquired Immuno Deficiency Syndrome; testing; disclosure; Manipur*

1. Introduction

Globally, paediatric HIV infection continues to be a major problem. The issue of HIV status disclosure-whether, when and how to inform HIV-infected children about their HIV status-has gained increased attention in recent year (American Academy of Pediatrics, 1999 Vreeman et al.,2013).

Disclosure of HIV status is one of the most complex challenges facing individuals who live with HIV/AIDS. Again disclosure of the diagnosis of HIV to HIV-infected children is challenging for parents. It entails communication about a highly stigmatized, life-threatening, transmissible and currently still incurable infection. It is usually approached with much anxiety and fear of negative consequences, notably stigmatization and discrimination, and is often avoided altogether (Pinzon-Iregui et al. 2013).

The reviews of literatures suggest that during different stages in a child's life, the issues of testing and disclosure are different and that they offer varying challenges to parents.

The American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children. Disclosure should optimally be conducted in a controlled situation with parent(s) and knowledgeable professionals (American Academy of Pediatrics, 1999). A study by Havens et al., (2005) reveals that some parents are reluctant to inform children about their HIV infection status because the majority of HIV infected children acquired the virus from their mothers and the ensuing parental guilt about transmission distinguishes this disease from other life threatening pediatric illnesses. A study undertaken by Tindyebwa et al., (2006) highlights the controversy about the age of disclosure, with some people advocating for disclosure as early as the age of five to seven years, assuming that the older adolescents may not be able to deal with it. According to the study by Wiener et al., (2007), disclosing the diagnosis of HIV or AIDS to a child is a controversial and emotionally charged issue among both the health care communities and parents and caregivers of these children. Another study undertaken by Eneh AU et al., (2011) shows that although most mothers with HIV infected children are willing to disclose the diagnosis to their children, they would do it rather late – during the late adolescent period because they feel the child will be better able to understand and cope with the diagnosis then. They also fear that the child may be unable to keep the diagnosis a secret if told earlier and as such expose himself/herself to stigmatization.

The crucial barrier in treating children living with HIV (CLHIV) is confirming whether they are positive. In the absence of timely testing and diagnosis, many of them are lost before appropriate treatment could have been initiated. Understanding mother's perceptions regarding barriers and challenges in testing and disclosure are important to improve pediatric HIV treatment. A little study has been done on barriers and challenges in HIV testing and disclosure in children in Manipur. In this context an initiative was undertaken to document the experiences of 180 HIV-positive women in Imphal East, Imphal West, Churachandpur and Ukhrul Districts of Manipur. Manipur's geographic position is to some extent responsible for the high prevalence of HIV/AIDS in the state located as it is bounded on the east by Upper Myanmar, on the west by Cachar District of Assam, on the north by Nagaland and on the south by the Chin Hills of Myanmar and Mizoram. Manipur is geographically very close to the notorious "Golden Triangle", which geographically composed of northern Thailand, northern and eastern Myanmar and Western Laos. This study aims to explore Mother's own perceptions of their experiences on the challenges and factors that prevent the community from seeking HIV testing of their children and to understand the issues related to disclosure of HIV status, their motivation towards or away from disclosure, and their short and long term intentions for disclosure to their HIV infected children.

2. Methodology

The research study is an exploratory in nature and has used a mix of qualitative and quantitative methods. The study has been conducted eight Focus Group Discussions (FGDs) in the four districts (Imphal East, Imphal West, Churachandpur and Ukhrul) – two in each district, among the infected mother having children. The number of participants in each group was 10 women having similar age group of their children. Another 20 Case Studies were undertaken in the four districts (Imphal East, Imphal West, Churachandpur and Ukhrul) – five in each district, from the infected mother having infected children to understand their peculiar and significant problems. Again another individual interviews were conducted among eighty (80) infected women having children, in the four districts – twenty (20) in each district using standardized schedule. Informed consent was obtained from every participant in the research. The field work for the study took place between March 2010 and March 2011.

For the collection of the study population, different Drug abuse and HIV/AIDS epidemic relevant NGOs / CBOs / FBOs (Non Governmental Organizations / Community Based Organizations / Faith Based Organizations) in the study areas (Imphal East, Imphal West, Churachandpur and Ukhrul) are selected purposively. The study participants were selected through convenient sampling method as detail database of women living with HIV/AIDS was not available for random selection. The Focus Group Discussions and Case studies were recorded on tape with due informed consent obtained from the respondent and later transcribed for analysis. Mainly, the data was collected at the office of HIV/AIDS related organisations and few were collected at the place of convenience of the participants.

2.1. Study limitations

Mobilizing the individual respondents for focus group discussions were quite difficult, especially in the difficult tracts of Churachandpur and Ukhrul districts.

3. Result

3.1. Characteristics of Study Participants

A summary of the main characteristics of the participants is presented in Table 1, 2 and 3. From tables it is seen that the age group 30-39 years is the worst affected by the disease i.e. 52.50% in Focus Group Discussions, 75% in Case Studies and 76.25% in Individual Interview. Their marriage profile shows that out of 180 respondents 89 were currently married, 86 were widow and remaining 5 were separated/divorced. It is also observed that majority 73/180 of the respondents have 2 children followed by 44/180 who have 3 children. Their health profile shows that 116 out of 180 participants were undergoing ART treatment. Prevention of Parent to Child Transmission (PPTCT) treatment was taken by few participants. Only 32 out of 180 respondents had undergone PPTCT treatment. Except one all the women (179/180) reported that their husbands (former or current) had transmitted the infection to them. Most women (150/180) were generally infected from their husbands who were injected drug users. Some women (29/180) reported that their husbands had pre-marital or extra-marital relationships, and linked their husbands' sexual relationships outside marriage to their current positive status. One woman reported that she had got the infection as a result of blood transfusion.

In all cases, women had found out about their status only inadvertently, when they had been advised to take an HIV test after their husbands had been diagnosed with HIV or even as late as the death of their husband due to recent disease, or in some cases when they had sought care for general health or reproductive health problems for themselves, or in fewer cases they tested after their children got tested positive with the manifestation of symptoms of the disease.

3.2. Key Themes

Two major themes were identified. 1) Factors preventing HIV testing for children and adolescents, 2) Issues related to disclosure of HIV status to children and adolescents

3.2.1. Factors Preventing HIV Testing for Children and Adolescents

Key findings of the study have highlighted several factors that prevent parents from taking their children for HIV testing across all age groups. The factors are as follows,

(i) Testing technology: For children aged 0 to 18 months the challenge of testing is non-availability of testing technology, Polymerase Chain Reaction (PCR) test as well as child's health status such as underweight and anaemic condition.

"…. My last child is not tested; the reason is that my child is too young to test and I also used PPTCT treatment". (FGD Imphal West)

"…. My last son is not tested because he is only 12 months old and anaemic condition". (Widow, 39yrs, 3 children, Individual Interview, Churachandpur)

"…. My child is not tested because he is underweight and only one year old". (FGD Churachandpur)

(ii) Fear of stigma and discrimination: The stigma and discrimination associated with HIV and AIDS was reported to be the most common barrier. A frequently cited reason for this is that parents hesitate in getting their children tested simply because of the fear of the children's status turning out to be positive and hurdles in future prospects like marriage. It creates psychological fear and prevents many children and adolescents from getting tested. For children in 9 to 17 age groups, while availability of testing technology is not a problem but disclosure of HIV status to children, coping mechanisms and access to psychosocial support for children become critical determinants of the child's overall well-being. Therefore, access to testing and meeting the information needs of an adolescent age group are crucial issues.

"…. I have fully grown enough three (3) sons. None of the sons have been tested. I did not disclose my status to my sons. How can I tell them for blood test"? (FGD Imphal East)

"…. When our (my and my husband) status is known, our first two children are fully grown enough, so I was unable to asked for HIV test". (Widow, 42yr, 3 children, Individual Interview, Imphal West)

"…. When I became known my status my only child (son) attained 15yr. old, so I was unable to ask him for HIV test". (Widow, 36yr., 1 child, Individual Interview, Churachandpur)

"…. When my status is known my children (2 sons and 1 daughter) are fully grown enough so I was unable to ask them for HIV test. Above all I did not disclose my status also". (Widow, 50yr, 3 children, Individual Interview, Ukhrul)

(iii) Lack of awareness about HIV and AIDS: Lack of awareness on the part of parents makes it difficult for them to explain to their children (in the 9 to above age group). Almost all children were not told the reason for taking them for an HIV test. Most of their children were allured to go with them to ICTC without knowing why they were getting tested. Most of their children in 10 to above were in 3 to 8 age when they were tested.

"…. My first daughter is not tested because when our status is known she was fully grown enough and no sign of risks and symptoms". (Widow, 39yr, 3 children, Individual Interview, Imphal West)

"….When our (my and my husband) status is known our first two children are grown enough and no sign of risks and symptoms so we unable to test our first two children". (FGD Imphal West)

(iv) Low motivation level: Reasons which demotivate parents from getting their children HIV test done are parents inability to overcome the shock/grief/disillusionment of their own positive status, fear of finding their children also positive, fear of confronting stigma and discrimination and the disillusionment that if found positive Anti-Retroviral Treatment (ART) will just extend life but will not cure HIV.

"…. My first three children were not tested; the reason is that my status is recently known by ante-natal HIV testing". (FGD Imphal East)

"…. Only my last child tested and the result was non-reactive and the remaining five (5) children were grown enough and no sign of risks and symptoms and we believed that they also might non-reactive so we did not test others". (FGD Imphal East)

"…. My children were not tested due to I became HIV infection after all the child birth by blood transfusion". (FGD Imphal West)

"…. I have four children but only my last two children tested and the results were non-reactive and remaining two children were grown enough and quite healthy so I felt that visiting ICTC was not necessary for them". (FGD Ukhrul)

(v) Financial constraints: The time and travel costs involved in visiting the testing centre and fear of losing a day's wage have been reported by a few women from Churachandpur and Ukhrul.

"…. My children did not test because I am from distant village, it usually takes away a whole day to reach there (testing centre) and come back. We (I and my husband) work in a stone quarry as a day labourer. If we go there we likely loss one day of work for visiting the centre and have to spend around Rs.300/- for travel fare". (Currently married, 38yr, 2 children, Individual Interview, Churachandpur)

"…. My last child is not tested; the reason is that I along with my first two children tested at RIMS Hospital (Imphal West) at the time of my husband was hospitalized. We (I and my husband) work as a day labourer. We mostly wage loss for 2 day's work for visiting RIMS Hospital because we need to spend one night at Imphal and have to spend above Rs.1000/- for travel costs and lodging". (Currently married, 27yr, 3 children, Individual Interview, Ukhrul)

3.2.2. Issues Related to Disclosure of HIV Status to Children and Adolescents

The challenges and dilemmas of disclosure found in the study are put forth here. The following reasons have emerged as the causes of fear which inhibit parents to disclosure.

For parents of children in 0 to 8 age group, disclosure is ruled out as it is an age where children are too young to comprehend the meaning and significance of their own and their parents HIV status. Therefore most of them were of the view that they would let their children know when they gradually grow up their age. In fact, these parents reel under psychological turmoil as a result of not being able to disclose and for suppressing the knowledge of their children's status.

"…. I did not disclose my children about our (parent) being HIV positive status and child herself because my eldest daughter is disabled and mentally retarded and another child is too young to know about the knowledge of HIV/AIDS". (FGD Imphal West)

"…. Disclosing a positive status to one's children is especially difficult for me so I did not inform them about our (parent) and children themselves status after confirming the result. Both children were allured to take the ART drug by saying it is the medicine for rapid growth". (Case 1)

"…. Disclosing a HIV positive status to one's children is especially difficult for all mothers due to concerns about possible negative or fearful reactions, so we did not disclose our children about our (parent) HIV positive status as well as the children themselves status after confirming the result. Sometimes children asked why we take medicine every day. I responded that it helps for their rapid growth". (Case 6)

"…. I did not disclose my children about our (parent) HIV positive status as well as the child herself status after confirming the result because my daughter is too young to know about the knowledge of HIV/AIDS. My concerned doctor also advice me not to disclose the status of the child before completion of 15 years of my child's age. When she reaches the appropriate age to be told of HIV/AIDS I will tell her. Now my child was allured to take the ART medicine by saying it is the vitamin tablet for rapid growth". (Case 11)

"…. I did not disclose my children about our (parent) HIV positive status as well as the child himself status after confirming the result because my son is too young to know about the knowledge of HIV/AIDS, above all he is stunted and mentally retarded so I think it is futile to tell his status". (Case 20)

For the parents of children in 9 to 17 age groups it was dilemma in the first place to decide whether to disclose or not and the right time of disclosure. The fears of parents of children in 9 to 17 age groups were compounded by the difficulties involved in explaining or discussing the modes of transmission. Children may undergo enormous stress and pain and the information may spread in neighbours and then locality/community.

Parents of children, who had already disclosed their status to their children, reported their inability to deal with issues that came up during and after the process of disclosing.

"…. We informed our children systematically about our positive status. Initially our children were disappointed on hearing the news but later on they got well appointed with the situation". (FGD Imphal East)

"…. We informed our children systematically about our positive status. But we did not disclose the HIV positive status of the second child himself after confirming the result. But with the passages of years and his gaining awareness on about his condition, the son knew himself about his HIV positive status. He knew the purpose of taking ART drugs. He was disappointed with us over the matter he thought that he could have prevented it, if proper cares were taken in time". (Case 4)

"…. I disclosed my children about my being HIV positive status and the child herself status after confirming the result. Sometimes my daughter asked question as "am I not allow to marriage". (Case 10)

"…. We informed our-children systematically about our positive status. My eldest son understood about these disease but the last two children did not have much knowledge about it. My daughter who is infected knows the timing of taking her medicine and everyday she is asking the medicine but she does not know the medicine is for HIV/AIDS". (Case 14)

"…. We informed our children in gradual basis about our positive status. The eldest three daughters understood about this disease but the last five children did not have much knowledge about it. Initially my eldest three daughters were aggrieved on hearing the news but later on they got well appointed with the situation. My infected daughter has been started taking ART medicine from October, 2007 but she does not know the medicine is for HIV/AIDS". (Case 16)

Few parents of children said that their children themselves came to know the status of their parents by overhearing and suspicion – by observing some activities around the time when their parents fell sick that created suspicion in them and the parent's conversations with peer groups/relatives at home and doctors/nurses at hospital.

"…. My eldest son knew my and child himself positive status because my husband had died after prolonged illness due to HIV/AIDS infection, due to drug addiction. At the time of hospitalization of my husband my son aware about my and himself status from the conversations with doctors". (FGD Imphal West)

"…. I did not inform (disclose) my children about my being HIV positive status and the daughter herself status after confirming the result. I could not express it for the fear of possible negative impact to my daughter. With the passages of years and her (daughter) gaining on awareness about her condition, the daughter knew herself about her HIV positive status. She knew the purpose of taking ART drugs. My daughter was disappointed with me over the matter thought that she could have prevented it, if proper care like avoiding breast feeding were taken timely after her birth". (Case 15)

"…. I did not disclose my children about my being HIV positive status and the daughter herself status after confirming the result. I could not express it for the fear of possible negative impact to my daughter. With the passages of years and her (daughter) gaining on awareness about her condition, the daughter knew herself about her HIV positive status. She knew the purpose of taking ART drugs. My daughter was disappointed with me over the matter". (Case 17)

4. Discussion

Since the worst affected age group is the most productive part of life, the impact of the disease in the socioeconomic condition of the individual and the society is devastating. It could change the age and sex composition within the family – the family may lose an earning member or the child could become orphans if both husband and wife are HIV-positive. In the absence of timely testing and diagnosis, many of the children are lost before appropriate treatment could have been initiated.

Key findings of the study have highlighted several factors that prevent parents from taking their children for HIV testing across all age groups. The probability of the child being detected positive creates in them the psychological fear of facing discrimination in society. The stigma and discrimination associated with HIV and AIDS was reported to be the most common barrier. For parents of children in 0 to 8 age group, disclosure is ruled out as it is an age where children are too young to comprehend the meaning and significance of

their own and their parents HIV status. Therefore most of them were of the view that they would let their children know when they gradually grow up their age. In fact, these parents reel under psychological turmoil as a result of not being able to disclose and for suppressing the knowledge of their children's status. Another key findings from the study have highlighted several issues, particularly in relation to disclosure of HIV status to children aged 9 and above. Parents desired to personally conduct the disclosure, however, most reported being over-whelmed with fear of negative outcomes and revealed a lack of self-efficacy towards managing the disclosure process. Some respondent's children know of their and their parents HIV status by overhearing and suspicion – by observing some activities around the time when their parents fell sick that created suspicion in them and the parent's conversations with peer groups/relatives at home and doctors/nurses at hospital, and also with the passages of years and their gaining awareness on about their condition. They knew the purpose of taking ART drugs. Some children were disappointed and some were accepted the situation. Parents, however need to be empowered with practical skills to recognize opportunities to initiate the disclosure process early, as well as supported to manage it in a phased, developmentally appropriate manner.

5. Conclusion

This report summarizes the experiences of 180 women having children and living with HIV in four districts viz., Imphal East, Imphal West, Churachandpur and Ukhrul of Manipur. This study examined mothers' perception on the barriers and challenges faced in facilitating HIV testing of children and adolescents and in disclosure of their and their children's HIV status.

Key findings of the study have highlighted several factors that prevent parents from taking their children for HIV testing across all age groups. The probability of the child being detected positive creates in them the psychological fear of facing discrimination in society. The stigma and discrimination associated with HIV and AIDS was reported to be the most common barrier. Another key findings from the study have highlighted several issues, particularly in relation to disclosure of HIV status to children aged 9 and above. Some respondent's children know of their parents and children themselves HIV status by overhearing and suspicion – by observing some activities around the time when their parents fell sick that created suspicion in them and the parent's conversations with peer groups/relatives at home and doctors/nurses at hospital, and also with the passages of years and their gaining awareness on about their condition. Some children were disappointed and some were accepted the situation.

The study concludes with recommendations for policy responses and improvements in the pediatric HIV testing and disclosure.

Maximum numbers of HIV testing centre should be established to reach out nook and corner. If necessary, mobile testing team/units should be arranged to reach out to the people of far flung and remote villages round the clock to make testing easily available and affordable.

There is an urgent need for providing PCR for the District Hospitals. There is in need and demand to increase CD4 count machine for provision of Viral Load Testing and CD4 counting facilities in every Districts Hospitals.

There is therefore, an urgent need to encourage parents to disclose their child's HIV status early and to other siblings who are likely to empathize with him/her and help him/her in coping.

We hope the present report will be useful to all the concerned people, including decision makers, policy framers, donors, government organizations, non government organizations, voluntary organizations, research scholars, academicians and interested individuals.

Characteristics	Number	Percentage
Age (years):		
20-24	3	3.75
25-29	13	16.25
30-34	17	21.25
35-39	25	31.25
40-44	15	18.75
45-above	7	8.75
Marital status:		
Currently married/Remarried	38	47.50
Separated/Divorced	4	5.00
Widow	38	47.50
Number of surviving children		
1	15	18.75
2	38	47.50
3	15	18.75
4	8	10.00
5-above	4	5.00
Number of undergoing ART treatment	45	56.25
Number of ever used PPTCT treatment	11	13.75
Source of HIV infection		
Women who indicated husbands as the source of infection:		
a) Husband injected drug user	68	85.00
b) Husband had extramarital affair	11	13.75
Blood transfusion:	1	1.25

Table 1: Profile of focus group discussion's women participants (N=80)

Characteristics	Number	Percentage
Age (years):		
25-29	1	5
30-34	8	40
35-39	7	35
40-44	4	20
Marital status:		
Currently married/Remarried	13	65
Separated/Divorced	-	-
Widow	7	35
Number of surviving children		
1	2	10
2	9	45
3	7	35
4	1	5
5-above	1	5
Number of undergoing ART treatment	14	70
Number of ever used PPTCT treatment	5	25
Sources of HIV infection		
Women who indicated husbands as the source of infection:		
a) Husband injected drug user	15	75
b) Husband had extramarital affair	3	15
c) Husband had premarital sex	2	10

Table 2: Demographic profile of case studies women respondents (N=20)

Characteristics	Number	Percentage
Age (years):		
25-29	08	10
30-34	28	35
35-39	33	41.25
40-44	07	8.75
45-above	04	5
Marital status:		
Currently married/Remarried	38	47.50
Separated/Divorced	01	1.25
Widow	41	51.25
Number of surviving children		
1	25	31.25
2	26	32.50
3	22	27.50
4	04	5
5-above	03	3.75
Number of undergoing ART treatment	57	71.25
Number of ever used PPTCT treatment	16	20
Sources of HIV infection		
Women who indicated husbands as the source of infection:		
a) Husband injected drug user	67	83.75
b) Husband had extramarital affair	13	16.25

Table 3: Demographic profile of individual interview's women respondents (N=80)

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