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ORIGINAL ARTICLE

HIV POSITIVE MOTHERS; ISSUES AND CONCERNS: A QUALITATIVE STUDY

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ABSTRACT: OBJECTIVES: To get an insight into: 1. Perceived health needs and demands of positive mothers. 2. Constraints and barriers in accessing health services. 3. Impact of positive status on social and economic entitlements.4. Role of positive network in educating and empowering mothers. **METHODOLOGY:** Type of study; Qualitative research using focus group discussions (FGD). Study Setting; "AnandaJoythi Network of People Living with HIV/AIDS®"- A positive network at Mysore. Period of study; September- October, 2008. Study participants: positive mothers from in and around Mysore city attending AnandaJoythi Network of People Living with HIV/AIDS. Inclusion Criteria; Mother of at least one child irrespective of: Her age. Duration of the positive status/ stage of disease. Age of the child-live/dead. On ART or not. And were willing to participate in the study. **EXCLUSION CRITERIA:** Those not willing to participate in the study. **RESULTS: Health Needs and Demands**: The positive women felt the need for regular screening tests for side effects of ART free of cost, nutrition supplementation programmes, more health centres and health education. **Barriers to treatment:** Poverty is the main barrier to accessing treatment. This is the amount of money required by clients for the government health services before being put on the ART programme and individuals have to pay for a CD4 count, a full hemogram and a liver function test. Poverty also means that people experience difficulty in paying for transport to get to services, especially when travelling from rural areas where distances to the nearest clinic or hospital are further and infrastructure poorer. **Social and economic impact of positive status:** It becomes difficult to look after their children when they are thrown out of their house. Even though they are mentally harassed by their family members they find it difficult to come out of their house because of their children are too young and need a family support. They face discrimination in getting admission to schools for their children because of their positive status (especially when thrown out of the school).They find it difficult to get their daughters married as the bride groom may reject her after coming to know that her parents are HIV positives, even though she is negative. **Positive network and mothers:** The positive women find this network as a source of confidence, information and education regarding their rights, duties and the disease itself. By becoming members of this network they have rediscovered themselves and have developed a positive outlook towards life.

KEYWORDS: HIV positive mothers, focus group, positive network, felt needs.

INTRODUCTION: HIV/AIDS epidemic is a worldwide reality and it is one of the most serious public health problems. Globally, with an estimated 33 million [30.3 million—36.1 million] people living with HIV in 2007, this epidemic shows no signs of abating. In India, 2, 300, 000**:** Estimated number of people living with HIV/AIDS and 38%: Estimated percentage of HIV cases that occurred among women (ages 15-49) by the end of2007.[1]

Although these figures are concerning, they do not reflect well the devastating effect of this disease in the life of seropositive people. HIV/AIDS diagnosis is an event of personal impact, and it is

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an event in the story of families and in their experience with the disease. Another important marker is the fact that AIDS imposes new habits such as: frequent visits to doctors, undergoing long treatment, medication intake, undergoing several examinations, difficulty in dealing with the disease, as well as changes in family life.[2]

In India majority of HIV positive females represent the innocent population who has contracted the infection from their husbands, accounting for more than 85% of women living with HIV/AIDS[3]. They form a unique section having various challenges to be addressed. Women living with HIV/AIDS do not only face medical problem, but also face psychological problem, i.e.: the pregnancy issue; having a baby; gender inequality; to be single-parent; economic problems and lack of health access. Evidence shows that women with HIV are at risk of unintended pregnancy, unsafe abortion and delivery in India because they are not able to access the reproductive health information and services they need.

In their family, WLHA face rejection, eviction, physical/social isolation, physical/emotional violence, and denial of property. In the health care settings, PLHA faced sub optimal care or denial of services, verbal/emotional abuse, physical isolation, and breaching of confidentiality of their HIV status. In the work place, they were evicted and shunned by colleagues.

As mothers when they are entrusted with the motherhood, they need to meet the endless demands of care, love, affection, patience and mental & physical health for their children. Mothers with their positive children tend to face new challenges with regards to their children [4] such as: the diagnoses, the start and follow-up of school, adherence to a long-term complex treatment, the arrival of puberty and the start of sex life of children.

The study will throw light on the various dimensions (physical, mental, social) of health of positive mothers. Extent and impact of self-stigma and societal stigma can be understood and remedial measures (positive networks) can be developed.

Women's health has a key role to play in the child's health & development as they are aptly chosen as the indicators of National development. Thus relevance of THIS WORK is justified because of the need for greater knowledge on the psychological and social aspects that affect this group of seropositive people to structure care models geared to meet their essentials for the full and multidisciplinary attention in HIV/AIDS.

The study was done to assess the**,** Perceived health needs and demands of positive mothers, Constraints and barriers in accessing health services, Impact of positive status on social and economic entitlements and Role of positive network in educating and empowering mothers.

METHODOLOGY: Type of study; Qualitative research using focus group discussions (FGD).

Study Setting: "AnandaJoythi Network of People Living with HIV/AIDS®"- A positive network at Mysore.

Period of study: September- October, 2009.

Study Participants: Positive mothers from in and around Mysore city attending AnandaJoythi Network of People Living with HIV/AIDS.

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Inclusion Criteria: Mother of at least one child irrespective of:

a. Her age.
b. Duration of the positive status/ stage of disease.
c. Age of the child-live/dead.
d. On ART or not.

And were willing to participate in the study.

Exclusion Criteria: Those not willing to participate in the study.

Coordinators of the positive network were approached and they agreed to co-operate for conducting focus groups. Guidelines for FGD were prepared after consulting a sociologist. The research was carried out in the community setup (positive network) to elicit valid information from the study subjects:

- 7 focus group discussions were held during the study period.
- In depth interviews of coordinators of network and few participants of the focus groups was held.
- Each focus group had eight to ten participants, a moderator and an observer.
- Each focus group discussion was of approximately 45-60 minute duration.
- The group was introduced to the topic and guided by the moderator. Every group member was encouraged to be actively involved in the discussion by being free and open.
- Individual informed consent was taken from each participant.
- Informed consent of the group for audio taping the discussion was taken and the confidentiality of the same was maintained.
- Each topic was presented to them as an open question and was guided in the direction of the topic concerned.
- Group members were encouraged to share their experiences/opinions on the topic.
- The discussions were recorded using an audiotape.

The following areas were covered in Focus Groups: Episodes of ill health since the time of diagnosis and pattern of health seeking behavior.

Perception about health care delivery services in the context of availability, accessibility and acceptability issues including quality of care.

Challenges faced as a positive mother:

- Social
- Psychological
- Economical
- Vocational

Knowledge, Attitude, Practice with respect to:

- Breast feeding and child care
- Reproductive health including contraceptives

Care and support received at/through positive network.

At the end, the discussion was summarized by the moderator and the group was asked for necessary inclusions and to clarify their doubts.[5]

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The transcripts (debriefing reports) written during the discussion was supplemented from the audiotapes.[6] The translations and interpretations were carried out with group consensus. The transcripts thus developed were analyzed using ethnograph software.[7]

OBSERVATIONS AND RESULTS:

Profile of Participants: 61 mothers participated in 7 focus groups held during September-October 2009. The age of the participants ranged between 25-45 years with median of 33 years. Majority (41) belonged to class 4 socio economic group according to kuppuswamy/B.G. Prasad classification depending on urban or rural. All others belonged to class 3 and no one was from class 1 and 2. Only 6 women were engaged in some occupation.

FINDINGS:

1. INFORMATION AND KNOWLEDGE OF HEALTH NEEDS AND DEMANDS: The women living with HIV felt that they did not get adequate information on the following areas: treatment for opportunistic infections, adherence, treatment for side effects, planning for conception, pregnancy, ante-natal care, post-partum care for mother and child, sexual health issues and services, abortion, violence against women (VAW).

Women and young people appear to be more active in campaigning and raising awareness on issues around HIV and AIDS than men, including consciousness rising around transmission, through activities, home and community based care.

Some women wanted to know how their participation in this mapping would benefit them.

Needs and Demands:

Health Services such as: Regular Screening Tests for the side effects of anti-retro viral treatment (ART) should be available at the Govt. Hospital free of cost. Screening Test for the predisposed diseases/ Cancer such as PAP smear for cervical cancer should be done regularly free of cost.

Nutrition powder should be given for those who are on ART and also those who are unable to earn their bread because of their illness or as a result of the side effects of ART.

There should be more health centers so that they can easily access them.

There is a need of a center for the source of information like facilities available for them by the various NGOs. Through their outreach programme directed in educating the factory worker and school & college students they found that there was a great demand & need for mobile diagnostic kits. Thus they could use them to screen the people they meet.

Other Social Needs such as: Should be provided a short stay home as a shelter when they are thrown out of their homes. Some also requested for creating a housing board thus they could lead their life independently. Providing job (which they are able to do) to earn their bread when they are thrown out of their jobs by their employer or when they are no more able to continue their work because of their illness/ side effects of ART. They should be provided with Bus Pass as they need to give frequent visits for regular follow up and take ART tablets.

Children should be given scholarships so that they can pursue their studies even when their parents are not in a stage to bare their requirements.

DOI: 10.14260/jemds/2014/2451

2. HEALTH SEEKING BEHAVIOUR: They prefer private hospitals over Govt. hospitals as need to wait for a long time at Govt. Hospital or it may be too far from their place. They feel that they should reveal their positive status as it helps the Doctor to take precautions and also guides him towards proper prescription thus preventing drug reactions. But because of the fear of discrimination they will not reveal to them. They requested to have a health insurance from which they could draw money when they have reached a terminal stage and no more able to work for their bread.

The discussions revealed a greater tendency for women to test and disclose earlier than men. One consequence of this is that the general health of HIV positive women is better than that of positive men as they are able to seek treatment earlier. There would seem to be a higher mortality rate among men, who may not test or seek treatment until they are already very sick. All the FGD participants felt aware of how HIV is transmitted and were not overly concerned with the possibility of infection or re-infection. Most of the service providers felt fully aware of how the disease is transmitted, and did not feel that contact with clients was a cause for concern.

Most of the positive women present in the discussion were not really afraid of re-infection since most of them use condoms or they have abstained. Among the FGD participants were widows who have refused to be inherited by their in-laws. The majority of women do not have a sustainable source of income; the levels of poverty are higher in the rural areas, and even in urban areas among persons who do not have consistent income. Most members of the FGDs feel that a balanced diet is an expensive diet and they feel they are not eating well.

Availability: All are aware of the Govt. Services as ART, ICTC and PPTCT. Some are also aware of AshaKiran and Swami Vivekananda Hospital at Sargur which are lending help for positives. They were aware about these only through the positive network (AnandJyothi) .They are provided ART free of cost at Govt. ART Center which is not available outside. They are counseled and get support at ART Center.

Access to Treatment: Treatment is provided free of charge by government hospitals. While anti-retrovirals are free in government hospitals, most treatments for opportunistic infections (OIs) and other diagnostic tests are not. There was a perception among participants that the government hospitals were under strain, and that this resulted in delaying tactics on the part of medics when treatment uptake was sought, and that there was a question over the sustainability of treatment services. Some were on ARVs. Most of these were on 1st line treatment; one was on 2nd line. There was little knowledge about what 1st and 2nd line treatment means.

There are no clinics that deal specifically with sexual health, and treatment for STIs takes place in general hospitals and clinics. In the rural areas there are no such clinics available. Women had experienced more problems in accessing services as their partners often refused them permission to seek treatment for fear that health providers would want them to go for treatment as well.

They find it difficult to avail the health services available to them as it is far off from their places. To give regular visits they have to waste time, money, energy and also have to be absent to their jobs. They often find it difficult to come out of their homes for half/a day as they may not have revealed the truth because of the fear of rejection.

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Barriers to Treatment: Poverty is the main barrier to accessing treatment. This is the amount of money required by clients for the government health services before being put on the ART programme and individuals have to pay for a CD4 count, a full hemogram and a liver function test. Poverty also means that people experience difficulty in paying for transport to get to services, especially when travelling from rural areas where distances to the nearest clinic or hospital are further and infrastructure poorer.

People residing in slum areas and rural areas experienced the greatest difficulties in accessing treatment. Poverty also impacts on people's ability to access good nutrition, which can also be a major barrier to treatment compliance. There were concerns among the participants too about the sustainability of supply. One client who required 2nd line medication was told that it could not be supplied to her local hospital due to lack of demand for the drug.

A further barrier to treatment is (mis-)information regarding the rights of people living with HIV, medical advice and guidelines, and the services available to them.

Issues with health care delivery System: There is a lot of discrimination to them by certain doctors, nurses and Group-D workers. Certain doctors hesitate and refuse to treat or operate on them. There are doctors do not conduct the caesarean section even when needed and allow the lady for vaginal delivery.

SEXUAL AND REPRODUCTIVE HEALTH: Sexual health services tend to be combined with general health services rather than being allocated separate resources. Most of the following services could be accessed (if at all) within an hour's travelling time from clients' home. Other than family planning and pap smears, however, few participants reported having accessed any of the services that are available (see table). Some participants, however, were not aware of needing to have regular pap smears, and weren't aware where to go to have one.

STIs and other sexual health services	No specialized STI clinics. Treatment for STIs available at normal government clinics and hospitals
Abortion	Illegal (though illegal abortions can be accessed). Women seeking advice on unwanted pregnancies probably would not reveal their HIV status and would be counseled to have the child.
Sterilization	Did not arise as a specific issue.
Prevention of mother-to-child transmission (PMTCT)	PMTCT services were experienced differently by urban and rural women – those in urban areas reported good services with all those who had used them having had HIV-negative children; in rural areas women found the service harder to access; it was perceived as something only for women who discovered their seropositive status once they had become pregnant.
Assisted conception	Participants had not heard of assisted conception services being available
Family planning	Services are available and accessible though participants lacked adequate information regarding family planning, especially when on ARV treatment.

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	Participants were not clear whether they could take the pill at the same time as ARVs; some believed that other forms of contraception were recommended, such as the coil, or Norplant. The majority of participants either used condoms or abstained from sex.
Healthy motherhood	Services not generally offered
Pap smears/ breast examination	Few women have heard of pap smears and breast examinations and consequently many do not access them at all. However in rural areas there are poster campaigns to try to raise awareness of the importance of breast- and cervical cancer screening

Women are largely unaware of their sexual and reproductive health rights as women living with HIV and AIDS, and therefore are unlikely to seek out or demand services. This situation is compounded by negative attitudes within the health service sector. In government hospitals, treatment for opportunistic infections has to be paid for by the client.

4. CHALLENGES FACED AS A POSITIVE MOTHER:

Social: It becomes difficult to look after their children when they are thrown out of their house. Even though they are mentally harassed by their family members they find it difficult to come out of their house because of their children are too young and need a family support. They face discrimination in getting admission to schools for their children because of their positive status (especially when thrown out of the school)In certain cases positive children are not given due interest while teaching in the class rooms. Other children are told not to play or eat or sit with them.

Teachers ask for the doctor's certificate when the child is recurrently getting ill which they find it difficult to get every time. Certain teachers even ask to get checked for HIV when the child is becoming thin. They find it difficult to answer to every one when they ask as to why the child is becoming weak. They find it difficult to get their daughters married as the bride groom may reject her after coming to know that her parents are HIV positives, even though she is negative. They have a fear of uncertainty regarding the future of their children in this society which is so much filled with prejudices and discrimination.

Psychological: When they look at their children they gain strength to live at least for the future of their children. They take it as a challenge to give a better future for their children. They are extremely pained to see their children (Positives) suffering from the illnesses every now for the no mistake they have done. They find it difficult to convince their children to take regular ART tablets when they question as to how long are these tablets for. They find their children depressed and not having food because of the discrimination they face in the school.

Economical: Burdened because unable fulfill the basic needs of their children as they are withheld from work by their illness. As the children are not able understand their circumstances they find it difficult to meet all their children ask for.

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5. CARE AND SUPPORT RECEIVED AT/THROUGH POSITIVE NETWORK: The peer group meeting held at the network has given them a lot of confidence. It has provided a platform where they can share circumstances with each other as many don't have one to share with at their home. They can share thoughts as they all have same difficulties to pass through. This is the reason that they talk more freely in the peer group than with the counselors at the centers. They get psychological strength and hope when they see their fellow person leading healthy long life.

They are thought as to how to be healthy, prepare healthy nutritious foods, keeping clean and to be happy coming out of their worries. They get information regarding the benefits that are available to them by other organizations. Some people are trained to be peer group worker where they are taught about HIV/AIDS, how to prepare nutrition food, etc. They go to factories and schools & colleges conveying the message to them regarding HIV/AIDS.

DISCUSSION: The knowledge of study participants with respect to the disease, complications and health care availability is inadequate. This is in similar to the latin American mothers.[8] The awareness about the health facilities is adequate but they have financial and social constrains and barriers in accessing the same. This is similar to the findings of the study conducted by Lee et al.[9] Sexual and reproductive health is an area of concern and their demands are not met. This is similar to the study conducted at Malawi by Elen G and Piwoz[10] and a Canadian study in 2007.[11] The social stigma found in this study is universal.

Most of the countries have different levels of stigma even after all these years.[12-15]Discrimination at schools, work places and humiliation is very common in most of the places across the world.[16-21] In this study the positive network has given the suffering woman, knowledge, hope and support. A study conducted by Michael Robbins also gives similar findings.[22] Indian study conducted by Shankaran et al also gives similar results.[23]

CONCLUSIONS:

- HIV positive mothers constitute a vulnerable section of the society. The positive status has far reaching implications on the social, economical and medical dimensions.
- Provision of medical care/ART constitutes only one part of a comprehensive care and support mechanism for these mothers.
- Opportunity costs involved in accessing medical care and negative/hostile attitude among health care providers are major concerns.
- Stigma plays a major role and at times displaces the positive mothers from the mainstream of the society. There are instances of these women being thrown out of their homes and being fired from their jobs on account of their positive status.
- Positive networks play an important role in empowering the positive mothers with information about all aspects of the disease. The network has succeeded in infusing positive outlook on life.
- Just numbers do not tell the whole story always. Hence a qualitative approach to the subject was employed to get a feel of the issues pertaining to positive mothers.

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