

Client satisfaction in relation to HIV/AIDS care counselling services in Maharashtra, India: A gender focused approach

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INTRODUCTION

Though, the number of annual new HIV infections has declined by more than 50 percent during the last decade, but approximately 2.4 million people still living with HIV in India (NIMS & NACO, 2010). In India, the main mode of HIV transmission is heterosexual contact (Lakhashe, et al., 2008) and HIV prevalence is higher among the high risk group populations like, injecting drug users (9.19%), men having sex with men (7.3%), female sex workers (4.94%) and STI clinic attendees (2.46%) and lower among the attendees of antenatal clinics (0.48%) (NACO, 2010). The National AIDS Control Programme (NACP), launched in 1992, aims to prevent and control the HIV / AIDS epidemic in India. Under NACP III (2007 - 2012), services were provided to 106 lakh persons including 45.9 lakh pregnant women through 5,233 stand-alone ICTCs, 1,632 facilities integrated ICTCs at 24x7 PHCs and 668 ICTCs under a Public Private Partnership model from April to December 2010. Out of 12,429 pregnant women who tested HIV positive, 8,492 mother-baby pairs received Nevirapine prophylaxis to prevent the mother to child transmission of HIV (NACO, 2010). However, the evidence is there that men and women tested for HIV reported inadequate counselling and sought treatment from traditional healers in India (Pallikadavath *et al.*, 2005).

To deal with this challenge of universal access to HIV/AIDS care services requires strengthening of the health services. The main barriers to health care utilization in India are long waiting times, lack of affordability, poor quality of care, distance, and attitude of health workers (Banerjee et al., 2012). Client satisfaction is one of the indirect measures of any health care service delivery mechanisms.

A study in India found that access to health care for self-reported long-term ailments is affected by gender role (Iyer, Sen and George, 2007). Lack of autonomy in terms of control over finances, decision making power and freedom of movement could be the reasons for such variation (Bloom, Wypij, and Das Gupta, 2001). Gender relations in the family and society play an important role in mediating the social impact of HIV infection. When a husband contracted HIV infection, the family typically used all the economic resources to treat him, eventually leaving very little for the treatment of HIV infected wife and children; while women face the threat of divorce or separation from (discordant) husbands if they are found to be HIV-positive (Pallikadavath et al. 2005).

The needs and satisfaction of the clients of different genders could be different. However, information on this aspect is very scanty. Therefore, the present paper aims to explore the gender perspectives of HIV/AIDS client satisfaction.

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METHODOLOGY

The present paper is based on the qualitative findings of a study that aimed to develop a client satisfaction scale related to the HIV/AIDS counselling services in India. The study was conducted by Saksham -Tata Institute of Social Sciences and was funded by GFATM, round-7, counselling component programme.

Study sites

The present paper is based on the qualitative data collected from six districts of the state of Maharashtra (one of the high HIV prevalence state in the country).

Study respondents

Seven focus group discussions (FGDs) with women (n=3), men (n=3) and transgender people (n=2) as well as twenty two in depth interviews with HIV/AIDS counsellors were conducted. Counsellors were from ICTC, ART and CCC centers. Total number of counsellors interviewed in the study are twenty two. Half of the counsellors were male. The median age of the counselors was 26.5 years and median years of counselling experience was around two years.

Seven FGDs were conducted among the HIV/AIDS clients at different targeted intervention (TI) sites. Participants at FGDs were spread across the reproductive age group, literacy level, employment and marital status. All total 30 women, 38 men and eight transgender people participated in FGDs.

Data collection

Field workers trained in qualitative research methods conducted the FGDs and in depth interviews in local languages. With participants' permission all FGDs and in-depth interviews were tape recorded. Interviews were then transcribed verbatim, translated into English, and back translated for accuracy. Study instruments were piloted after one FGD with HIV positive women to ensure language appropriateness and understanding. Interviews and FGDs were conducted in Marathi and Hindi languages.

Ethical considerations

Saksham - Project Advisory Committee (PAC) reviewed and approved the method and the research tools. No monetary incentive was offered to any participants of the study. Participants signed informed consent form prior to being interviewed or taking part of the FGDs.

Analysis

The analysis involved coding and classification of the data by reviewing the transcriptions for potential conceptual categories, using the guideline questions as initial categories. To understand the gender dimension both clients' and counsellors' perspectives were studied under the three themes – male clients' satisfaction, female clients' satisfaction and the satisfaction of the transgender clients. Under each theme, data were classified into different categories – needs, concerns and satisfaction.

Findings

The study finds that almost all counsellors agreed that distinct difference existed between male and female clients in relation to their needs, concerns and satisfaction with the counselling services.

Male clients

Needs:

(1) Information need

Across all the counselling centers, the most demanded counselling service by the male clients (irrespective of their HIV serostatus) was information on HIV/AIDS. The main reason for visiting a counselling center was to clear doubts and confusion for many of the male clients. Information on - CD4 testing, STDs/STIs and their relation to HIV/AIDS, safe sex practices ARV treatment, referral services and family planning methods – was most needed.

(2) Needs for counselling services

Counsellors' support and interference was most needed by male clients to disclose HIV serostatus to the immediate family members and to resolve the family tensions. Single male clients sought counsellors' support to find suitable female partner for marriage. They needed supportive counsellors of their own gender. The reason for visiting a counselling center was to receive positive messages from a counsellor to many of the clients. They felt satisfied if the counsellor listen them attentively.

(3) Readiness of the facility

Getting - test report quickly, medicines prescribed and condoms -- are the most common requirements for the male clients reported by the counsellors as well as the clients. ART counsellors reported that male clients were keen to get medical treatment instead of counselling services. As visiting a health facility many a time leads to loss of wages for that day, so many male clients needed integration of all the services (HIV testing, CD4 count, counselling services and getting ARV drugs or other medicines) from a same counselling center.

Concerns:

(1) Maintaining confidentiality of the HIV sero status.

(2) Privacy in the counselling room

(3) Judgemental attitude of the counsellors

Counsellors found that male clients felt difficulty in admitting their socially disapproved sexual behaviour in front of the counsellors at the initial counselling sessions. Clients were more concerned about the counsellors' reactions while discussing their sexual history.

(4) Future of the children

Married male had shown their concern for the future of their infected or affected children. Some clients needed counsellors' interference to stop the school authorities (at rural areas) from throwing out their infected children from the schools.

Satisfaction:

(1) Health status

After receiving treatment, if health status got improved (i.e., either CD4 counts got increased or they gained weight) then male clients appeared to be very much satisfied. During the post test if the HIV test result was found to be seronegative then the clients become extremely satisfied irrespective of the quality of the services they received from the center

Female clients

Needs:

(1) Information needs

The need for information about HIV was pervasive among the female clients. Information on the ARV drugs' side effects, condom demonstration and safe sex practices – were major counselling needs expressed by the female clients at ICTCs.

(2) Readiness of the center

Female clients mainly looked for “actual” treatment (medical services) than the counselling services. They were keen to receive free ARV treatment; free medicines; and nutritional support.

(3) Counselling services

Female clients seemed to be very satisfied after the follow up counselling sessions, as well as after doctor consultation. They preferred counsellors to accompany while consulting with the doctors. They need counsellors' interference to resolve their family conflict. The specific counselling needs of female clients were – nutritional counselling and counselling on sexuality, safe sex and STI protection. Commercial sex worker (CSW) clients were keen to receive good quality condoms from the counselling centers. Pregnant female needed counselling on “dos” and “dons” to keep their unborn child out of the infection.

(4) Psychological support

Female clients looked for psychological support from the counsellors -- to decrease their anxiety, to feel good about themselves, to improve hope, and to increase confidence.

(5) Training

Female clients used to feel very useful in attending any vocational training programmes (like, tailoring, handicraft, etc) arranged by CCCs.

Concerns:

The future of the children - Female clients were concerned for their children's future, so they felt satisfied if HIV test results found negative for their children.

Satisfaction:

Female clients felt extremely satisfied when counsellors referred them to NGOs who offered social services (e.g., small loans from the income generation scheme; free education for HIV infected or affected children) to HIV seropositive people.

Transgender clients

Needs:

(1) Acceptance - Acceptance of their sexual identity by the counsellors.

(2) Treatment - STI was the most prevalent disease among them and they needed treatment of STIs.

(3) Condom demonstration - Transgender clients also needed were condom demonstration and sex education.

(4) Readiness of the facility - They looked for getting HIV test report as quickly as possible.

(5) Economic support – They look for economic supports while visiting an HIV/AIDS counselling center.

Concerns:

Most transgender people, especially youth, faced great challenges in disclosing their gender identities in front of the counsellors. The fear of rejection, disclosure and stigma used to impose barriers in accessing health care facilities.

Satisfaction:

They usually felt discouraged the counselling sessions, as most of the counsellors not from their own community were unable to understand transgender clients' feeling, anxiety and sexual life. So, they felt highly satisfied if the counsellors were from their own community (transgender counsellor).

Discussions & conclusions

The study found that the needs for information on HIV related issue was common among the clients of all genders. Readiness of the facility was needed by most of the clients. Both male and female clients were concerned for the future of their children. However, significant differences were noted in relation to the needs, concern and satisfaction among the clients from different genders. In India, male are mainly responsible for managing their family reputation. Our study has found that male clients were more concerned about their family reputations so they were worried about the confidentiality of HIV sero status. Transgender clients were concerned about the reaction of the counsellors after disclosing of their sexual identities. Female clients were comparatively less concerned about the confidentiality issues as the spread of HIV epidemic was mainly from male partner to female partner. Other studies have shown that the continued treatment costs associated with HIV/AIDS can progressively deplete the savings and increase the indebtedness of households. In India, while a male member becomes ill, the other family members generally take responsibility to provide care to them but when female members become sick on a prolong basis hardly any care to them. This fact has reflected in our study too, where female clients used to become satisfied if they are referred to NGOs provided economic support / nutritional support. Similarly, transgender clients also mentioned that receiving economic support used to make them satisfied as in many cases they do not live with their biological families.

Finally, the study suggests that to meet the HIV/AIDS clients' expectations and needs, counsellors should practice gender specific counselling. Further, curriculum on gender issues should get proper importance at any HIV/AIDS Counselling training.

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