Quality of Voluntary Counseling and Testing Services in Medical Colleges of Kerala - Perspectives of HIV Positive People: A Qualitative Study

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ABSTRACT

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Introduction: HIV counseling – and - testing services (VCT) are a major component of HIV and AIDS control programs in the industrialized as well as in the developing world. The scope and challenges of VCT has changed a lot over the past decade from the time and is now acknowledged within the international arena as an effective and pivotal strategy for both HIV/AIDS prevention and care. But the quality and benefits of VCT, in particular with regard to confidentiality, counseling and access to clinical and social support vary enormously as pointed by many researchers

Objectives: To understand the HIV positive peoples' perspectives of quality of voluntary counseling and testing service in the medical colleges of Kerala, and the factors that influences client satisfaction

Material and Methods: A Cross-sectional Descriptive study was done during June to August 2007 in Drop-in-centers in three districts in Kerala, and the VCTCs at three medical colleges.

Results: Only five percent of the clients in the survey came voluntarily to VCTC. Clients rated confidentiality and attitude of counselors as high while there were some issues with regards to accessibility and timeliness. The content of the counseling was poor as per standards set by the national program

Conclusion: Counselors need more on-the-job training and job-aids to support their work. The centres need to be renamed considering the fact that mostly the counseling is not voluntary as it is claimed

Keywords: HIV and AIDS, Counseling and testing, Quality, Positive people, Client satisfaction

*See End Note for complete author details

INTRODUCTION

Since the first cases were recorded in 1981, Acquired Immuno Deficiency Syndrome (AIDS) and its causative agent, the Human Immuno-deficiency Virus (HIV), have taken an enormous toll around the world. The Human Development Report 2005 rightly identified AIDS as having inflicted the single greatest reversal in human development.[1]

HIV counseling – and - testing services (VCT) are a major component of HIV and AIDS control programs in the industrialized as well as in the developing world.[2,3] VCT services include the provision of providing interactive, constructive information about HIV prevention and care, and one-to-one counseling by trained personnel.[4,5] These services are considered as a gateway to HIV prevention, care and treatment, by increasing the preparedness of the community as a whole for effective living with HIV.[5]

The scope and challenges of VCT has changed a lot over the past decade from the time when it was being primarily used to make a diagnosis of infection in symptomatic people to help medical management, and testing was often accompanied by minimal counseling. The cost effectiveness of VCT in reducing HIV transmission is also now recognized.[6] Cost- effectiveness analysis of VCT shows that the provision of VCT services fell well within the World Health Organization's (WHO) recommended threshold for the adoption of a public health intervention in developing countries. In fact, the cost per disability- adjusted- life –year saved was similar to the benefits achieved with basic immunizations and the improved management of sexually transmitted diseases.[7]

BACKGROUND

The HIV/AIDS figures in India have for a long time remained controversial, with high prevalence projections

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by international agencies and many academicians and program managers feeling that these projections over-estimated the extent of the problem. In July 2007, the National AIDS Control Organization (NACO) had put the prevalence at 0.36% of the population, which they attribute to a better methodology involving more sentinel sites. In September 2007, the third National Family Health Survey (NFHS-3),[8] which tested blood samples of 1,00,000 women and men in age group of 15-49 for HIV, put the prevalence rate at 0.28%. This was the second time such a large scale community-based survey to estimate HIV prevalence was carried out in the world. Till July 2007, it was estimated that the prevalence of HIV in the general population was 0.9%, the figure being 5.2 million. After NACO's announcement in July, India became the third worst affected country with the deadly disease after South Africa (5.5 million) and Nigeria (2.9 million). The infection rates varied from 1.13% in Manipur, 0.97% in Andhra, 0.34% in TN, and 0.07% in UP.[8]

NFHS-3 found that men have higher prevalence rate with 0.36% than women with a 0.22% prevalence rate. For both men and women, the prevalence was highest in the 30-34 year age group. Cities recorded 40% more HIV prevalence than rural areas. In Tamil Nadu, the prevalence rate is higher among women, while across the country it is higher among men than women.

Kerala is a low HIV prevalent state in India. As per the NACO figures[9] the prevalence rate was 0.25%. The first HIV positive case was identified in Kerala in 1987. Roughly 500 children are born with HIV every year in the state. It is likely that there are at least 3500 HIV positive children below 10 years in the State as of 2006[10]

VCT services are available in all the fourteen districts in Kerala and have also been expanded to 22 Taluks by 2007.[11] Totally 40 VCT Centres are functioning in Kerala now with two counselors each in place- one male and one female.

VCT is now acknowledged within the international arena as an effective and pivotal strategy for both HIV/AIDS prevention and care. But the quality and benefits of VCT, in particular with regard to confidentiality, counseling and access to clinical and social support vary enormously as pointed by many researchers.[12,13]

Now by the third phase of National AIDS Control Programme, India is expanding the VCT facility up to the Taluk (sub-district) level. Given that VCTCs are seen as an important component of the HIV/AIDS control strategy in India and the rapid increase in the number of VCTCs,[9] there is a major need for study of quality of services in these centers. There are only few published studies so far from India regarding the clients' perspective of quality of VCT services, their expectations and perceived benefits. Hence this study is undertaken.

OBJECTIVES OF THE STUDY

To understand the HIV positive peoples' perspectives of quality of voluntary counseling and testing service in the medical colleges of Kerala, and the factors that influences client satisfaction

MATERIAL AND METHODS

A Cross-sectional Descriptive study was done in Drop-in-centers in three districts in Kerala, and the VCTCs at three medical colleges. Drop-in-centers (DIC) are those centers run by the positive peoples' network in Kerala, under the auspicious of Kerala State AIDS Control Society (KSACS).

The data was collected during June 15 to August 31, 2007. Council of people living with HIV/AIDS in Kerala (CPK- PLUS), the network of HIV affected and infected people in Kerala, was approached and their consent to do the study at the DIC was obtained. The sampling frame consisted of all the HIV positives that came to the DIC during the study period. From them, only those above 18 years, who have visited the VCTC during the previous three weeks time were included in the study. Purposive sampling was done to accommodate both sexes and different age groups.

We expected about 100 interviews schedules and 30 in –depth interviews among the positives. We could get 91 interview schedules and 30 in-depth interviews. In addition we also interviewed a total of 6 counselors-two per VCTC. Non-participant observation was conducted on two consecutive days in three VCT centers.

DEFINITIONS

Quality of service is defined in this study; in terms of (a) the quality of the counseling as assessed by the contents of the counseling as understood and remembered by the client-assessed through the client interview, (b) accessibility and timely service as assessed by the client interview (c) the presence/ absence of the prescribed physical setting characteristics as laid

down in the NACO guidelines as assessed through the client interview and the non-participant observation and (d) clients' perceptions on behavior of the staff, (e) perceived confidentiality and privacy.

Client satisfaction is defined in terms of the (a) perceived confidentiality and privacy, (b) Behavior of the staff, (c) accessibility and timeliness of the service.

Data was collected from clients with the help of a pre-tested semi-structured questionnaire, by a single interviewer, after piloting. The questionnaire enquired about their socio-demographic details, the circumstance in which they reached VCTC, about the accessibility availability and timeliness of services, perceived confidentiality and privacy, behavior of staff and over all assessment of the quality of service. Non- participant Observation was carried out in all the three VCTC sites

Questionnaire data was coded and entered in Microsoft Excel and then analyzed using SPSS 15. All the in-depth interviews were entered into word document were coded around key themes. Analysis of the individual themes was done first. Then cross-analysis across various themes and identities were done to find out possible inter-linkages. The non-participant observation findings were analyzed and compared across the centers. Data collection, analysis and report writing took four months.

RESULTS

The study was done in three drop-in-centers, run by the positive peoples' network. One was in south Kerala (Center 1), one in central (Center 2) and the third one in north Kerala (Center 3). A total of 91 interview schedules were administered. There were 32 participants in center 1, 25 in center 2 and 34 in centre 3. Of the respondents, 53 were men (58% of the sample) and 38 were women. The mean age of the sample was 35 years and the age ranged from 22 to 55 years. Forty three percent of the sample was below 35 years.

Thirty in-depth interviews were conducted among a sub-sample of those who were administered the interview schedule. There were 18 men and 12 women. Mean age of the participants was 35 years and the range was 22-55 years. Forty three percent were below 35 years old. All together six counselors were interviewed. All of them were around 30 years old. All held a Master's degree in medical or psychiatric social work. One counselor had an additional Masters in psychology. None had any special/additional qualification on counseling. Two persons had previous experience of counseling, but that was not in HIV. Two of them had worked with research projects before joining VCTC.

Table 1. Socio-demographic characteristics of the whole sample of VCTC clients

Gender	Male 58% (N=53), Female 42% (N=38)		
Age Group	less than 35years - 42.9% (39) 35years and above - 57.1 (52)		
	Age group	Males	Females
	less than 35 years	17 (32.1%)	22 (57.9%)
	35and above	36 (67.9%)	16 (42.1%)
Employment status	Un employed or not engaged in paid work- 31% manual labour- 9% self employed -24% private salaried -20% paid domestic work- 15% government servant- 1%		

Circumstances in which clients reached VCTC

Among the 91 clients interviewed, it was found that only five people (5.5%) came voluntarily to VCTC. These five included three men and two women. About half (50.5%) came referred by doctors at government hospital or medical college hospital. Thus the voluntary nature of the voluntary counseling is itself questioned.

Among the 30 clients who were included in the in-depth interviews, twenty (67%) were tested for HIV even before they came to the VCTC, and all those twenty knew that they were HIV positive. There were four who have not tested before coming to VCTC, but were sure about their HIV status. The remaining six had not tested before and were unaware of their status till they were tested in VCTC.

There were two cases of compulsion- one in the case of a man whose wife died due to AIDS, who was compelled by his father, while the other was a woman whose husband and herself were compelled to attend VCTC by her brother-in-law.

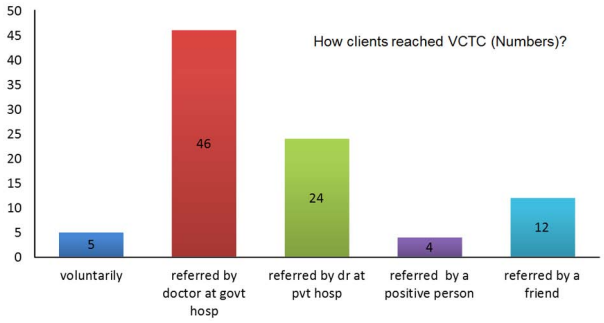

Figure 1. **Bar chart showing how clients reached VCTC?**

Accessibility of VCT Services

Of the 91 answering the interview schedules, the Majority of the clients (60.5%) travel more than 20 Kilometers. Of these 14% had to travel more than 50 kilometers. About 29% travelled between 5 and 20 kilometers and only11% travelled less than 5 kilometers. Fifty two percent of the clients have to travel between 1 to 2 hours to reach the VCTC from their house. Eleven percent had to travel more than 2 hours while 37.4% could reach the center within an hour

"Travelling more than 50 kilometers is very difficult for sick people like me" (43 year, Male, on anti-TB medicines now)

Of the total 91 clients, 67% found no difficulty in locating the center, while 14.3% found it somewhat difficult and 18.7% (N=17) found it very difficult to locate. It was clear from in-depth interviews that this led to some bitter experiences even on the way to the center.

"When the security man asked where I am going, I said I am going to VCTC. Hearing this he stared at me with contempt. He looked at me as if we lead a bad life and that is how we got this disease" (Woman, 35 year)

"When we were asking someone on the way, they wanted to know why we are going there... they stared at us…they looked as if all those who go there are HIV positives…" (Woman, 27 years)

Adequacy of infrastructural facilities and availability of services

Infrastructural facilities were assessed through non-participant observation by the researcher as well as through the client interview schedules and the in-depth interviews.

According to guidelines of the NACO, every center should have a male and a female counselor, separate cubicle with adequate privacy for male and female clients, a qualified laboratory technician, adequate waiting area, adequate IEC materials, and drinking water. Findings from non-participant observation are illustrated in the framework given below

In client interview, majority of the clients were satisfied with the availability of services and infrastructure. Almost ninety seven percent (N=88) were satisfied with the waiting area available. All of them could talk to the counselor on the first day itself. None of them were asked to come for another day for testing

Table 2. Findings from non-participant observations

Features	Center 1	Centre 2	Centre 3
Privacy and space for counseling	There is adequate space available. There is separate cubicle for male and female counselors	Same	Same
Waiting area	It is very good. There are benches in the corridor as well as chairs as we get in. There is drinking water source nearby.	Average. Only a bench. The area of the corridor is very narrow. Drinking water available	Good. There are two benches and few chairs outside. Drinking water available
Presence of counselor	Male counselor was absent on a day	Both counselors present on both days	Both counselors present on both days
Presence of laboratory technician	Laboratory technician was not available. Only laboratory technician students were there on both days	Technician was available on all the days	Technician available on all the days
Sign boards	All Signboards in English and one in Malayalam, seen near the center are done in durable materials. But the Malayalam (local language) versions seen on the way are written in a paper using a sketch pen and pasted on the walls	Sign boards are adequate nearer the centre, but the way to the centre doesn't have any sign board.	Sign boards are adequate, but mostly in English.
IEC materials	Adequate materials are pasted on the walls of the corridor. But there is no material on the waiting area, but some leaflets are seen on the counselors' table	Same	Same

Timeliness of VCT services

About seventy percent (N=64) of the clients could see the counselors within half an hour of their arrival at the centre, 18.7% could see in half to one hour time. Sixty one percent (N=55) clients could undergo testing within half an hour of pre-test counseling. Twelve percent took between ½ to 1 hour, 18% needed between 1 and 2 hours while 9% could undergo the test without delay as there was no pre-test counseling. Only 41.4% (N=37) could undergo post-test counseling within an half an hour of testing. While 34.4% needed to wait for half to one hour for post-test counseling, 17.8% and 6.7% waited for between 1 and 2 hours and more than 2 hours respectively before the counselor eventually gave the test result. This means 76.9% could collect the test results on the same visit.

Privacy and confidentiality

Privacy and confidentiality are two major indicators of good quality of counseling. Among the 91respondents,

Table 3. Content of counseling

Task to be performed	Total clients responded	Number of Times Task Was Omitted	Percentage of Times Task Was Omitted
Demonstrated how to use a condom	91	82	90.1
Explained about the Window period	91	63	69.2
Explained how the HIV Test is done	91	53	58.2
Enquired about financial status	91	53	58.2
Identified referral needs and gave guidance to what to do	91	43	47.3
Informed that ART is available free	91	42	47.1
Referred to positive peoples' network	89	41	46.1
Counsellor provided the name of agencies/ Institutions to seek help for treatment and support.	91	39	42.9
Talked about sharing the test result with the partner	87	37	42.5
Gave information on CD4 Count	91	36	39.6
Fixed the next appointment/ enquired about the willingness to come again	91	34	37.4
Interpreted the test results		91	33
Told about how to prevent further spread	91	27	29.7
Gave information about ART	91	27	29.7
Told about Condom use	91	26	28.6
Enquired about general health problems	91	16	17.6

82.4% (N=75) believed that no one else could see them during the counseling while 80.2% (N=73) believed that no one else could hear them during the counseling. 93.4% (N=85) believed that the information they have shared with the counselor will be kept confidential. Five persons (6.6%) were not sure about the confidentiality of the information. 96% of the clients were satisfied with the over all privacy during the counseling.

Behavior of the staff is one factor, which motivates clients to come for follow –up counseling and the overall rating was very good. The clients seemed to compare the behavior of the VCTC staff with their own previous experiences with government health system staffs. In-depth interviews gave more insights into why clients may have thought that the counselors' behavior was good:

"In govt. hospital settings you can't expect much... but this (VCTC) was a totally new experience... They behaved like a family member…." (Widow, 35 year old)

"… When we were discharged from the pay-ward where I was staying after my caesarian section, the nurses asked my mother to clean the room with bleaching powder…" (Woman, 37 years)

Content of the counselling

There is a list of tasks to be performed by the counsellors according to the NACO. The respondents were asked to recollect what all things were discussed with them in the counselling. They were not asked to differentiate whether it was told in the pre-test or post-test counselling as it may not be easy to recollect so. It was assumed that those things free-listed by clients and listed on probing by the researcher have been actually included in the counselling. The table given below lists the tasks and the percentage of clients in whom they were omitted during the counseling, for all the three centers together.

DISCUSSION

VCTCs are meant to be a starting point in the whole spectrum of prevention, diagnosis and treatment services related to HIV/AIDS.[4] Even though not everyone, at least majority of the clients coming to the VCTC is expected to come there voluntarily. But the findings from this study are not so encouraging. Only five percent of the clients in the survey came voluntarily to VCTC. In-fact 67 percent of them was tested positive even before coming to VCTC.

In terms of accessibility, we find that the most of the clients who come to VCTCs are coming from far off places as well. Accessibility is not just physical accessibility in terms of the distance from home or the time needed to reach from home. Twenty four clients said that it was somewhat or very difficult in locating the center in the campus. It was mainly because of somewhat remote location of the centers.

In the whole VCT procedure, most important component is counseling.[14] But in this present study it is found that nine percent of the clients didn't receive pre-test counseling. This is a serious flaw and whatever be the reasons cannot be justified.

Adequacy of infrastructural facilities was fairly good as per clients' perceptions and as revealed by observational study. Physical settings as stipulated in the NACO guidelines are almost followed in all the three centers. Counselors are available in all the centers, waiting area

and drinking water is available in all the three centers, and there as fairly good display of IEC materials. All the clients could see the counselors as well as undergo testing on day 1 itself, which shows that the quality of services in respect of availability of services is good. This may also indicates that the supply of test kits and re-agents are happening in a fairly good way.

Coming to timeliness of services, we found that 70% could undergo pre-test counseling within half an hour of arrival at the center, 61% could undergo testing within half an hour of pre-test counseling. Regarding privacy and confidentiality, 82.4% believed that there was visual privacy and 80.2% believed that auditory privacy during the counseling. Around 93 percent believed that the information they have shared with the counselor will be kept confidential. These figures show that quality of the service in ensuring privacy and confidentiality is fairly high.

Ninety seven percent clients said that the behavior of the staffs at the VCTC was either very good or good. Also from the in-depth interviews where in they have their expressed gratitude to the counselors for bringing them back to life, it is clear in this point of time that the satisfaction in respect of the behavior of staff is very high. Ninety percent have told that they have understood most or almost all the things counselors have told. Seventy three percent were happy with the time taken for the counseling.

The content of the counseling is a matter of great concern. In assessing the quality of counseling-the content of counseling in this study, it was found that even though 71.4% clients were told about condom use, only a bare 9.9% were demonstrated how to use the condom. This study also showed that when 29.7% were told about ART medicines, a significant 47.1% were not informed that ART is available free.

The in-depth interview showed that twelve out of thirty (40%) have not either used or heard that condom can prevent HIV until they came to VCTC. NFHS-3[8] finding shows that, in India women who know that consistent condom use can reduce the chances of getting HIV/AIDS is 34.7% and among men it is 68.1%. The corresponding figures for Kerala are 70.6% and 85.6% respectively, which goes with the present study findings. This is enough to say that the awareness about condom usage is far from acceptable levels even in a highly literate state like Kerala. The same NFHS III findings also showed that percentage of people using condom as a family planning method is 5.3% in India and 5.8% in Kerala. We have been promoting use of condom through more than one national program, the family planning program initially and now the AIDS control program. We are the largest makers of condom in the world.

CONCLUSION

Perceived quality of VCT depends on many factors. Most of the clients are satisfied with the services. But at the same time, we find that the content of the counseling has to improve a lot. There are also some problems with timeliness of services and accessibility to the center even though stipulated physical standards wise, the centers are fairly good.

Counselors are very enthusiastic and interested to deliver services to clients. But they are not adequately trained. There working atmosphere is not so conducive, as none of them are having any job security as they are all working on contract base.

This study has thrown light into many grey areas in literature related to HIV/AIDS prevention and control in India. We now know something about the expectations of the clients when they come to VCTC. Their fears are actually reflection of those people who are reluctant to come to VCTC. This should help us to modify our strategy regarding VCT so that more people come forward voluntarily to VCTC. We also got to know the perceived benefits of the VCT and the special issues regarding the ante-natal women and mothers.

RECOMMENDATIONS

There should be a strategy to provide counseling services to all those getting tested for HIV, at the nearest VCT centers. Alternatively the government should support recognized private labs by helping to set-up counseling services there itself.

Those ante-natal women attending the government hospitals are now getting group pre-test counseling and those who test positive there are given individual post-test counseling and then referred to VCTC, where there results are confirmed again by testing. This shuttling should be avoided. There should be provision at the ante-natal testing center, for confirming the result according to the national protocol, for those who are found positive in the rapid test.

Like other professionals, counselors need to have their

performance reviewed by skilled and experienced practitioners-both during their training and periodically thereafter to ensure that their performance remains acceptable. At present, no counselors have their field practice counseling sessions or their counseling performance reviewed. Simple job aids for counselors should be developed and distributed. They should list the tasks that need to be covered during each stage of counseling to help ensure that key issues are not overlooked.

We have been promoting condoms through the family welfare programs and the AIDS control programs. But still NFHS-3 report released in July 2007 shows that while at least 7 out of 10 men know each of the ABC prevention methods — abstinence, being faithful and condoms —among women it is only 4 in 10. From the present study also it is evident that many women have not heard that condoms can prevent HIV/AIDS. This point to the failure of or national programs aimed at condom promotion. We have to intensify our condom promotion activities, especially targeting the women.

It is high time to re-think even about the term "VCT". The voluntariness is barely visible. So it may be better re-named public health counseling centers and the services should not be just about HIV and STDs. Instead a wider menu services should be included including counseling on life style changes, dietary habits etc

Possible limitations of the study

Only those who are HIV positive and those who come to the DIC fell in the sample frame, which will raise the issue of limited generalizability of findings. Perceptions of those who tested negative and those HIV positives that are not part of the network will be left out.

END NOTE

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