A Descriptive Study on the Users and Utility of HIV/AIDS Helpline in Karnataka, India

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ABSTRACT

Background: Globally, Telephone help-lines have proved their utility in several crisis situations. They were introduced in India for helping persons in need of counseling or emergency care such as victims of suicide, cardiac arrests, etc. The utility of such help-lines in HIV/AIDS has not been established. Hence this study done in ASHA Foundation, Bangalore. Objectives: To determine the characteristics of persons who access the HIV/AIDS helpline. To determine the reasons for calling the helpline. To identify the gaps in the provision of this service. Materials and Methods: Details on all calls received on ASHA Foundation’s HIV/AIDS help line during the period January 2007 to December 2008, were entered on MS excel worksheet and analyzed using the SPSS software. Results: Majority of callers are male, are in the age group of 20-39 years and educated. The most common reasons for calling the helpline were for HIV testing, information about HIV/AIDS, care and support services and referrals to other services not linked to HIV/AIDS. Reasons for calling were linked to risk (HIV testing, condom use etc) in younger persons, and to avail of care and support services in the older age-group. Conclusions: The main users of the HIV/AIDS helpline are urban, young, educated males.

Keywords: Helpline, HIV/AIDS, India, telephone

Introduction

Global statistics reveal that at 2.5 million, India has the third highest HIV/AIDS population in the world after South Africa and Nigeria. Dealing with HIV/AIDS means focusing on issues that center around sexuality and behavior, and are therefore considered taboo to be talked about openly in Indian society. Over the years, however, Government agencies and non-governmental organizations working in the field of HIV/AIDS have learnt to address these issues frankly, but at the personal level, individuals still hesitate to discuss their problems openly, and would rather use an anonymous and private forum to get their queries answered and their doubts clarified with regard to HIV/AIDS.

Telephone helplines have been used as effective tools in health care in the past, especially in the context of diabetes,(6) heart disease(7) and other conditions. With the entry of mobile technology, the telephone is a medium of communication, which helps individuals to access information at their convenience and to be in touch with experts without too much effort. Since the late 1990s, telephone helplines have been used to impart information on HIV/AIDS. The advantage of HIV/AIDS helplines lies in the fact that as the counselor and counselee interact only on the phone, confidentiality and anonymity are maintained. Moreover, the call is completely under the control of the caller and can be discontinued at his will.

The ASHA Foundation in Bangalore established a manual telephone helpline for HIV/AIDS in the year 2000. This article describes the profile of the callers, the nature of their queries, the gaps in this service and the overall effectiveness of such helplines.

Materials and Methods

The present study was conducted at ASHA Foundation,
located in Bangalore urban district in the state of Karnataka. Karnataka is one of the states that has a high prevalence of HIV/AIDS.

The HIV/AIDS helpline was established in 2000 and functions on all days of the week from 9.30 am to 4.30 pm and for half a day on Saturdays. It is manned by three trained and qualified counselors. The availability of this service was advertised through public announcements in newspapers, radio, yellow pages and stickers. Initially we had an automated interactive voice response system on toll-free number 1097, but we found that people preferred talking to a person rather than an automated machine.

All the calls received on our manual helpline during the period of 2 years from January 2007 to December 2008, were included in this study. Each call varied in length from a few minutes to almost 40 minutes depending on the need of the caller. Once a rapport was established, general details such as age and occupation of the caller were noted. Details of each call were recorded and entered on MS excel worksheet and finally analyzed using the SPSS software package.

**Results**

A total of 2835 calls were received during this period. Of these, 2101 (74.1%) were first-time callers and 734 (25.9%) were repeat callers. The gender of the new and repeat callers is given in Table 1.

Of the 2101 first time callers, 87.8% were male and only 12.2% were female. Among the 734 repeat callers, 80.6% were male and 19.4% were female. Thus overall, less than 15% of the callers were female.

Almost two-thirds of the callers used English as the medium of communication and only one-third used the local language.

A vast majority of the callers (nearly 90%) were in the age-group of 20-39 years as presented in Table 2.

Callers in the age groups of below 20 years and between 40-49 years jointly account for 10% of all calls and there are hardly any calls from persons above 50 years of age.

The reasons for using the helpline-first time or repeat-are listed in Tables 3 and 4 and are classified by age of caller.

The reasons for calling the helpline vary and includes information on HIV/AIDS, HIV testing, condom usage, care and support services, sex and sexuality, window period, emotional support while waiting for testing, details on testing, queries that are not linked to HIV/AIDS, details on helplines for other services such as elders helpline, services for prevention of mother to child transmission of HIV, etc.

For those below 20 years the most common reasons for calling the helpline in decreasing order of importance were for HIV testing, information about HIV/AIDS, care and support services and referrals to other services not linked to HIV/AIDS. For those between 20 and 29 years testing, information, modes of transmission and condom use were the common reasons for calling. Between 30 and 39 years, care and support services available and then testing were the main reasons for calling and beyond 40 years, information on care and support services was the main reason. Although testing was an universal reason for calling the helpline across all ages, its importance decreased with age.

For those below 30 years the reasons for calling were mainly linked to risk (HIV testing, condom use, etc) and for those above 30 years the reasons for calling were to avail of care and support services.

With regard to repeat callers, most of the callers called repeatedly for further information on testing, probably as they neared the completion of the window period. Another reason for calling repeatedly was for emotional support while they waited for the HIV testing. Other reasons included care and support services and this again was the most common reason for calling for those above 30 years.

With regard to occupation, 68.8% of the callers were skilled, 8.9% were unskilled, 12.8% were students and in 9.4% occupation was not known. Among the unskilled callers almost one-third were repeat callers, probably for greater understanding.

Finally, 16.4% of all calls resulted in a drop in visit to the center, and most of these visits were for counseling and testing for HIV infection.
Table 3: First-time callers-reasons for calling according to age

| For the first-time callers-reasons for calling | <20 (160) | % | 20-29 (1264) | % | 30-39 (577) | % | 40-49 (80) | % | >50 (20) | % |
|-----------------------------------------------|-----------|---|--------------|---|------------|---|------------|---|----------|---|
| Information about HIV/AIDS                    | 36        | 22.5 | 341          | 27.0 | 80         | 13.9 | 6          | 7.5 | 0        | 0.0 |
| Transmission                                   | 9         | 5.6  | 268          | 21.2 | 58         | 10.1 | 3          | 3.8 | 0        | 0.0 |
| Symptoms                                       | 7         | 4.4  | 112          | 8.9  | 53         | 9.2  | 2          | 2.5 | 1        | 5.0 |
| Window period                                  | 9         | 5.6  | 78           | 6.2  | 4          | 0.7  | 7          | 8.8 | 1        | 5.0 |
| Testing                                        | 46        | 28.8 | 507          | 40.1 | 115        | 19.9 | 6          | 7.5 | 1        | 5.0 |
| Retest                                         | 2         | 1.3  | 64           | 5.1  | 30         | 5.2  | 5          | 6.3 | 2        | 10.0 |
| Condom use                                     | 12        | 7.5  | 215          | 17.0 | 79         | 13.7 | 13         | 16.3 |3       | 15.0 |
| Incorrect use of condoms                       | 4         | 2.5  | 67           | 5.3  | 31         | 5.4  | 6          | 7.5 | 1        | 5.0 |
| Care and support                               | 24        | 15.0 | 136          | 10.8 | 204        | 35.4 | 33         | 41.3 |8       | 40.0 |
| Prevention                                     | 15        | 9.4  | 150          | 11.9 | 71         | 12.3 | 16         | 20.0 |3       | 15.0 |
| PMTCT                                          | 0         | 0.0  | 10           | 0.8  | 5          | 0.9  | 1          | 1.3  |0        | 0.0  |
| STIs                                           | 3         | 1.9  | 40           | 3.2  | 21         | 3.6  | 5          | 6.3  |0        | 0.0  |
| Fear of pregnancy                              | 0         | 0.0  | 7            | 0.6  | 2          | 0.3  | 0          | 0.0  |0        | 0.0  |
| Personal queries not related to HIV            | 10        | 6.3  | 169          | 13.4 | 100        | 17.3 | 11         | 13.8 |2       | 10.0 |
| Referrals                                      | 32        | 20.0 | 97           | 7.7  | 67         | 11.6 | 6          | 7.5  |1        | 5.0  |
| Post-exposure prophylaxis                      | 0         | 0.0  | 3            | 0.2  | 5          | 0.9  | 0          | 0.0  |0        | 0.0  |
| Redressal of guilt feelings                    | 1         | 0.6  | 15           | 1.2  | 8          | 1.4  | 0          | 0.0  |0        | 0.0  |
| Support for counselees in the window period, expecting their results | 1 | 0.6 | 24 | 1.9 | 15 | 2.6 | 3 | 3.8 | 0 | 0.0 |
| Sex and sexuality                              | 28        | 17.5 | 87           | 6.9  | 41         | 7.1  | 9          | 11.3 |0        | 0.0  |

PMTCT: Prevention of mother to child transmission; STIs: Sexually transmitted infections

Table 4: Repeat callers-reasons for calling according to age

| Repeat callers-reasons for calling | <20 (8) | % | 20-29 (478) | % | 30-39 (200) | % | 40-49 (38) | % | >50 (10) | % |
|-----------------------------------|---------|---|-------------|---|------------|---|------------|---|----------|---|
| Information about HIV/AIDS        | 0       | 0.0 | 24          | 5.0 | 14         | 7.0 | 0          | 0.0 |1        | 10.0 |
| Transmission                      | 0       | 0.0 | 41          | 8.6 | 14         | 7.0 | 7          | 18.4 |1       | 10.0 |
| Symptoms                          | 0       | 0.0 | 24          | 5.0 | 4          | 2.0 | 7          | 18.4 |0        | 0.0  |
| Window period                     | 1       | 12.5 | 15          | 3.1 | 1          | 0.5 | 0          | 0.0  |0        | 0.0  |
| Testing                           | 4       | 50.0 | 181         | 37.9 | 32         | 16.0 | 6          | 15.8 |2       | 20.0 |
| Retest                            | 0       | 0.0 | 4           | 0.8 | 2          | 1.0 | 0          | 0.0  |0        | 0.0  |
| Condom use                        | 0       | 0.0 | 1           | 0.2 | 0          | 0.0 | 0          | 0.0  |0        | 0.0  |
| Incorrect use of condoms          | 0       | 0.0 | 0           | 0.0 | 0          | 0.0 | 0          | 0.0  |0        | 0.0  |
| Care and support                  | 2       | 25.0 | 102         | 21.3 | 122        | 61.0 | 23         | 60.5 |7       | 70.0 |
| Prevention                        | 0       | 0.0 | 14          | 2.9 | 2          | 1.0 | 0          | 0.0  |0        | 0.0  |
| PMTCT                             | 0       | 0.0 | 4           | 0.8 | 1          | 0.5 | 0          | 0.0  |0        | 0.0  |
| STIs                              | 0       | 0.0 | 6           | 1.3 | 1          | 0.5 | 0          | 0.0  |0        | 0.0  |
| Fear of pregnancy                 | 0       | 0.0 | 1           | 0.2 | 0          | 0.0 | 0          | 0.0  |0        | 0.0  |
| Personal queries                  | 1       | 12.5 | 59          | 12.3 | 17         | 8.5 | 10         | 26.3 |4       | 40.0 |
| Referrals                         | 0       | 0.0 | 17          | 3.6 | 3          | 1.5 | 3          | 7.9  |0        | 0.0  |
| Post-exposure prophylaxis         | 0       | 0.0 | 0           | 0.0 | 0          | 0.0 | 0          | 0.0  |0        | 0.0  |
| Redressal of guilt feelings       | 1       | 12.5 | 9           | 1.9 | 3          | 1.5 | 0          | 0.0  |0        | 0.0  |
| Support for counselees in the window period, expecting their results | 3 | 37.5 | 193 | 40.4 | 28 | 14.0 | 14 | 36.8 | 0 | 0.0 |
| Sex and sexuality                 | 1       | 12.5 | 6           | 1.3 | 0          | 0.0 | 0          | 0.0  |0        | 0.0  |

PMTCT: Prevention of mother to child transmission; STIs: Sexually transmitted infections

Discussion

In the western world, telephone helplines have been used as a screening method for case finding through anonymous telephone interviews asking details of sexual practices to enable screening for HIV-related risk. In the context of HIV/AIDS, telephone helplines can be even more useful because of the stigma and secrecy associated with HIV/AIDS and one would expect individuals to rather communicate on a telephone than make an actual visit to the center. Moreover, the whole process is under the caller’s control and can...
be discontinued at his will. Given this background, the response to the helpline has not been as great or encouraging as one expected, at the rate of about 4-5 calls per average day. It is possible that the availability and potential of such helplines have not been understood by the public at large, nor have they appreciated the value of such helplines to help them. It is also possible that the gravity of the encounter has not been understood nor the fact that effective help is possible through a telephone call. In any case, much more publicity and motivational measures may be required to sensitize the public to HIV/AIDS helplines.

The fact that women account for only 14% of all callers depicts a wide gap in helpline services reaching out to women and this gap needs to be narrowed considering that women are a vulnerable group with regard to HIV/AIDS in our country. Greater efforts need to be made to reach out to women through publicity efforts targeting women, using women counselors so that women callers are comfortable and creating an enabling environment for women to utilize this service.

That predominantly males have used the helplines is therefore disappointing although this has been the experience in other helplines at Pune and Delhi. This is probably because males play a dominant role in HIV transmission and are more likely to be concerned with the dangers. On the other hand, males might have easier access to phones within and outside the house and are more likely to voice their concerns with regard to risk in their lives. Women on the other hand, may not even know that they are at risk leave alone accessing a helpline. However, where they are aware of the dangers involved, one would have expected them to seek advice and help, given the fact that mobile phones are quite widely used regardless of the gender of the user. Even when they did call the helpline it was mainly to determine the care and support services available for a positive husband, a positive child or a positive relative, clarify doubts regarding symptoms that these relatives had or whether the medications they were on were being taken correctly.

Although the helplines are offered in both English and Kannada, the local vernacular, more callers communicated in English. This probably implies that the helpline may be accessing only a particular segment of the society, which may or may not be the most vulnerable segment in the AIDS scenario.

Conclusions

The HIV/AIDS helpline appears to be an important tool of communication for the young, educated, urban, male who wants his concerns addressed but at the same time wants to maintain anonymity. Women and youth in rural areas, however, need to access this facility too and efforts need to be made enable this to happen. HIV/AIDS is moving from the urban to the rural areas and in this era of mobile technology, reaching out to youth—both men and women in rural areas should not be too difficult a task.

The fact that 26% of all callers were repeat callers indicates that the helpline was useful to these callers especially during the window period and for emotional support while they waited for testing. Further, 16.4% of all calls translated into drop-in visits to the counseling center of our foundation, indicating that helplines complement prevention efforts and care and support services.

The scope for telephone helplines in the context of HIV/AIDS appears limitless.

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How cite this article: Alexander G, Kanth C, Thomas R. A descriptive study on the users and utility of HIV/AIDS helpline in Karnataka, India. Indian J Community Med 2011;36:17-20.

Source of Support: Nil, Conflict of Interest: None declared.