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Research Article

Socio-demographic profile and health needs of HIV patients: a study at a tertiary care teaching hospital

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ABSTRACT

Background: AIDS the acquired immune deficiency syndrome is a fatal illness caused by a retrovirus known as the human immune deficiency virus (HIV) which breaks the body's immune system, leaving the victim vulnerable to a host of life. It is essential to understand the priority needs of PLHIV. So that medical and non-medical, social, cultural and economical interventions can be planned to bring them in the mainstream of the society. Objective was to study the socioeconomic and demographic profile of the HIV positive patients registered at an ART clinic and to enlist and prioritize their health and other needs.
Methods: The study was carried out at an ART clinic in a tertiary care centre in Mumbai. Only HIV positive patients registered at ART clinic and willing to participate in study and HIV positive patient above 18 years of age were included in the study while HIV positive patient not willing to participate in study were excluded from the study. The study was carried out during the period of April 2013 to December 2013. The statistical analysis was performed using Microsoft Excel.
Results: Total number of respondents was 180. The mean age of study group is 35.49 years. Majority of the respondents had acquired at least primary or secondary education in schools, 18 (10%) respondents were graduates and only 3 (1.67%) with a post graduate degree. The priority needs as perceived by the subjects were classified as immediate, intermediate and long term needs.
Conclusions: The study showed that the demographic and socioeconomic profile of the respondents reflects the same trend as at national level. The published data by 'NACO' corroborates these findings. A substantial proportion of the total HIV +ve cases reported are living below poverty line (31.6%). This could require special interventions to ensure that they were treated for opportunistic infections and for reducing the viral load.

Keywords: Antiretroviral therapy clinic, HIV infection, Health needs

INTRODUCTION

AIDS, the acquired immune deficiency Syndrome is a fatal illness caused by a retrovirus known as the human immune deficiency virus (HIV) which breaks the body's immune system, leaving the victim vulnerable to a host of life - threatening opportunistic infections, neurological disorders or unusual malignancies. Among the special feature of HIV infection is that once infected, it is probable that a person will be infected for life. In comparison with the rates of HIV infection in Africa, those in the general populations of Asia are low. The prevalence among 15-49 year-olds exceeds 1% in only three countries-Cambodia, Myanmar and Thailand. China

and India between them account for around 36% of the world's population. With such huge populations, even low HIV prevalence rates mean that huge number of people live with the virus.[1]

Maharashtra is the 2nd largest state in India with population of 100 million and area of 3.08 lakhs Sq.mt. The Maharashtra State AIDS Control Society (MSACS) and Mumbai Districts AIDS Control Societies (MDACS) were established in 1999 and 1998 respectively to expedite the programme of Phase II which involved various programmes such as: motivating low risk behaviour groups to practice safe sex, strengthening and operationalizing STI clinics, ensuring blood safety strengthening and modernizing blood banks, strengthening database for better planning, emphasizing integration with RCH and TB control programme.[2]

It is essential to understand the priority needs of PLHIV. So that medical and non-medical, social, cultural and economical interventions can be planned to bring them in the mainstream of the society. It is only when a needs assessment study is done prior to implementation of the care and support activity, that focused and need-based programme can be developed. Objectives of the study was to study the socioeconomic and demographic profile of the HIV positive patients registered at an ART clinic, enlist and prioritize their health and other needs.

METHODS

The study was carried out at an ART clinic in a tertiary care centre in Mumbai. Only HIV positive patients registered at ART clinic and willing to participate in study and HIV positive patient above 18 years of age were included in the study while HIV positive patient not willing to participate in study were excluded from the study. The study was carried out during the period of April 2013 to December 2013. An interview schedule was prepared in local language to obtain the desired information based on the objectives of study. A pilot study involving 20 HIV positive people was first conducted for rapid assessment of their needs by one-to-one interview technique. This led to formulating a suitable hypothesis and also contributed in structuring the interview schedule. The sampling was done by 'period sampling' method, where the newly registered HIV positive patients attending the ART Clinic were selected during the study period of three months and subjected to interviews based on the interview schedule. This was a sample of 180, considering the number of new registrations every month at the ART Clinic which was about 60-70. The informed consent of the patients was obtained prior to the interview and the purpose of the interview was explained to them. A well designed pretested proforma was used for interview. Ethical committee approval was sought before commencement of the study. No any conflict of interest was directly or indirectly associated with the study conduction. The assistance of the coordinator and counsellor of ART clinic was taken to establish rapport with the patients. Participants were classified as per their occupation as unskilled, semiskilled, skilled, professionals and self-employed.[3] The information obtained through the interview schedule did not have the name of the patient hence; appropriate confidentiality was maintained. Data Analysis was carried out by simple Frequency and Percentages as a descriptive analysis with the help of Microsoft excel. The information was presented in tabular and graphical forms and appropriate conclusions were drawn based on the data analysis.

RESULTS

Table 1 depicts that the mean age of study group is 35.49 years, mean age among males is 35.65 years (range 26 to 55 years) and that of female is 35.15 years (range 26 to 53 years). Maximum respondents belong to the age group 26 to 45 years of age 162 (90%), reflecting congruence with the national data on HIV/AIDS, whereas there were only 18 (10%) in the age group 46-55 years and only 6 (3.33%) were in the age group 46-55 years.

Table 2 shows that Majority of the respondents had acquired at least primary or secondary education in schools, 18 (10%) respondents were graduates and only 3 (1.67%) with a post graduate degree. There were were 6 (3.3%) illiterate persons. About income (mean per capita income is 1147.55±881.95 with minimum amount of Rs 300 and maximum Rs 4500).

Table 1: Distribution of study subjects by age and marital status.

Age Group	Male		Female	
	Frequency	Percentage	Frequency	Percentage
26 - 35	70	38.88	32	17.78
36 - 45	41	22.78	19	10.56
46 - 55	12	6.67	6	3.33
Total	123	68.33	57	31.67
Marital Status				
Married	102	82.93	57	100.00
Unmarried	21	17.07	0	0
Total	123	100.00	57	100.00

Table 2: Distribution of study subjects by education, income and occupation.

Sr. no	Education	Number	Percentage
1	illiterate	6	3.33
2	primary	45	25
3	secondary	81	45
4	higher secondary	27	15
5	graduate	18	10
6	post graduate	3	1.67
Total		180	100
Sr.no	**Income per capita**	**Number**	**Percentage**
1	< 500	57	31.67
2	501-1000	51	28.33
3	1001-1500	24	13.33
4	1501-2000	27	15.00
5	2001-2500	-	-
6	2501 and above	21	11.67
Total		180	100
Sr.no	**Occupation**	**Number**	**Percentage**
1	Unskilled	66	36.67
2	semi skilled	30	16.67
3	skilled	54	30
4	professional	6	3.33
5	self employed	24	13.33
Total		180	100

Table 3: showing profile of present complaint & duration of Illness.

Sr. No	Complaints	Number	Percentage
1	Central Nervous System	21	11.67
2	Cardio Vascular System	3	1.67
3	Respiratory System	21	11.67
4	Gastro Intestinal	24	13.33
5	Skin	15	8.33
6	Others*	69	38.33
Sr.No	Duration of Illness (in years)	Number	Percentage
1	> 10 years	3	1.67
2	5 – 10 years	30	16.67
3	1 – 5 years	99	55
4	< 1 years	48	26.67
	Total	180	100

51 (28.33 %) respondents had per capita income between 501 and 1000, but 57 (31.67%) had per capita income less than Rs.5000 about 40% of respondents had per capita income exceeding Rs. 1000. As per Table 3, the other category consists of others - (weakness, fever, pain generalized / local, edema, weight loss.) The morbidity profile is seen to be manifested as generalized common symptoms of discomfort perceived as weakness, fever, weight loss, loss of appetite etc. (38.3%). The commonest morbidity was with reference to gastro intestinal system followed by respiratory system and central nervous system. (13.33%, 11.67%, 11.67% respectively) the table 4, the priority needs as perceived by the subjects were classified as immediate, intermediate and long term needs. Immediate Needs: Desire for free ART drugs was cited by 43.3% as the commonest need followed by availability of medical treatment during illness (41.67%).

Table 4: Profile of priority needs.

Profile of Needs	Immediate needs		Intermediate needs		Long term needs	
	No	%	No	%	No	%
Employment	27	15	45	25	3	1.67
House	12	6.67	12	6.67	6	3.33
Children's education	9	5	39	21.67	21	11.67
Children's economic security	3	1.67	21	11.67	48	26.67
Support by family friends	6	3.33	3	1.67	0	0
Medical treatment	75	41.67	9	5	30	16.67
Financial assistance	63	35	9	5	9	5
Overcoming stigma discrimination	6	3.33	3	1.67	3	1.67
Free ART (Anti Retroviral Therapy)	78	43.33	3	1.67	18	10
ART at concessional rate	3	1.67	0	0	0	0
Spouse economic security	0	0	0	0	18	18

DISCUSSION

The study setting was ART Centre in tertiary care hospital. The study period was from April 2013 to December 2013. Total number of respondents was 180. Total male respondents were 123. Total number of female respondents was 57. Number of married individuals identified was 159. Total new HIV positive cases reported during study period were 821. Total study subjects were 180. Average time per interview was 30 minutes. Table 1 depicts that the mean age of study group is 35.49 years, mean age among males is 35.65 years (range 26 to 55 years) and that of female is 35.15 years (range 26 to 53 years). Maximum respondents belong to the age group 26 to 45 years of age 162 (90%), reflecting congruence with the national data on HIV/AIDS, whereas there were only 18 (10%) in the age group 46-55 years and only 6 (3.33%) were in the age group 46-55 years. "PLHIV Satisfaction Survey" shows that the mean age of the participants was 36.3 which are similar to above data.[4] Amongst the respondents 88% were married. The prevalence of infection is equally in between 26 to 45 years age group, hence those females who are unmarried have still not utilized the care and support service. While "PLHIV Satisfaction Survey" data shows that about 62% respondents were married this is a large proportion and support above findings.[4] Table 2 shows that Majority of the respondents had acquired at least primary or secondary education in schools, 18 (10%) respondents were graduates and only 3 (1.67%) with a post graduate degree. There were were 6 (3.3%) illiterate persons. The data reflects that the facilities available in HIV/AIDS programme are probably still beyond the reach of those who are illiterate. Most of the participants of PLHIV Satisfaction Survey are educated up to primary or secondary level. About income (The mean per capita income is 1147.55±881.95 with minimum amount of Rs 300 and maximum Rs 4500). 51 (28.33 %) respondents had per capita income between 501 and 1000, but 57 (31.67%) had per capita income less than Rs.5000 about 40% of respondents had per capita income exceeding Rs. 1000. The income profile indicates that a substantial number of HIV+ people are living below poverty line. According to data of "PLHIV Satisfaction Survey" approximately two third of the participants had monthly income less than Rs. 5000 which is similar to above data and 14% with income between 5000 to 10,000 per month and 6% with income exceeding Rs.10,000 per month.[4]

As per Table 3, the other category consists of others - (weakness, fever, pain generalized / local, edema, weight loss.) The morbidity profile is seen to be manifested as generalized common symptoms of discomfort perceived as weakness, fever, weight loss, loss of appetite etc. (38.3%). The commonest morbidity was with reference to gastro intestinal system followed by respiratory system and central nervous system. (13.33%, 11.67%, and 11.67% respectively). This information indicates the type of services that would be required by them. Amongst those who reported to the care and support centre, 48 (26.67%) had acquired the infection since less than 1 year. However, 99 (55%) of the respondents had acquired the infection between 1 to 5 years. The finding indicates that the motivation to utilize the facilities at the care support centre is maximum amongst those who have acquired HIV infection recently. However, it is possible that those living with HIV infection for more than 5 years are not aware of the present available facilities or they might be utilizing the facilities at other centres in the city. In any case it indicates that the infection is not focused on any geographical location and the recent awareness campaigns have contributed in reporting of cases of less than 5 years duration.

As per the table 4, the priority needs as perceived by the subjects were classified as immediate, intermediate and long term needs. Immediate needs: desire for free ART drugs was cited by 43.3% as the commonest need followed by availability of medical treatment during illness (41.67%). The majority of families affected by HIV are also affected by poverty.[5] The other needs were desire for financial assistance, sustaining employment,

children's education, family support and availability of house as they feared being evicted by their families out of the house. Caregivers, who are mainly spouses/partners, may have reduced life satisfaction or even feel burnout in the course of taking care of their loved ones.[6] The above priority needs have been effectively addressed in the National AIDS control programme especially with reference to ART. The other needs were amenable to counselling and advocacy support from the HIV/AIDS supportive units. Intermediate needs- the prime concern was completing children's education and ensuring their economic security. However sustainable employment was indispensable for the respondents followed by redressal of the issues of overcoming stigma and discrimination. It is important to note that HIV-related social stigmas have never disappeared.[7] Research in Hong Kong had previously reported that physical health and social discrimination were the most "difficult aspects" of the life of HIV-infected individuals.[8] Long term- most respondents indicated children's economic security and availability of affordable medical treatment during illness as their long term needs, followed by economic security of their spouses. The profile of priority needs is seen to be focused on "Survival to fulfil commitments" rather than vested selfish interests. Similar needs are found by Arns PG and others in study titled "Psychosocial needs of HIV-positive individuals seeking workforce re-entry" which states that, in addition to help with training and job placement, participants indicated a need for assistance with finances, money management, housing access and access to health care, as well as with alcohol or drug problems, legal problems and social relationships.[9] The status of being HIV positive has certainly led to introspection regarding life amongst the respondents. The needs reflect their struggle to maintain minimal standards of quality life. It may be noted here the respondents have not compromised their self-esteem while expressing their needs. They have also not demanded sympathy, compassion, donation, or special attention from others. It is possible to address all their needs if appropriate resources are mobilized and supportive policies are resolved at government level.

CONCLUSION

The demographic and socioeconomic profile of the respondents reflects the same trend as at national level. The published data by 'NACO' corroborates these findings. A substantial proportion of the total HIV+ve cases reported are living below poverty line (31.6%). This could require special interventions to ensure that they were treated for opportunistic infections and for reducing the viral load. Total 88% of the respondents were married but those unmarried and HIV+ve are not yet registered in large numbers to utilize the facilities in the National AIDS Control Programme. Illiterate HIV+ve people constituted 3.3% of the total study group. Hence, strategies to ensure accessibility, affordability of care, support and treatment of the illiterate HIV +ve people need to be developed. Care and support services form a common platform for advocacy in the interests of unorganized work force amongst HIV +ve people. The commonest morbidity symptoms were weakness, fever, weight loss, loss of appetite, predominantly involving the gastro-intestinal system followed by the respiratory system are the common findings.

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