

Original Article

Evaluation of the Needs of People Living with HIV/AIDS in Selected Districts of State of Madhya Pradesh, India: Findings from a Preliminary Study

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Abstract:

Introduction: Evaluating the needs of People Living with HIV / AIDS (PLHA) and providing them with adequate care and support is important in combating the Acquired Immunodeficiency Syndrome (AIDS) epidemic. **Objectives:** The study was conducted to ascertain the needs of PLHA, the support obtained and required, extent of involvement in programs related to HIV and evaluate the impact of Government programs as perceived by PLHA. **Methods:** A cross sectional study was conducted on 150 PLHA in the districts of Indore, Neemuch and Ujjain in the state of Madhya Pradesh (India) using semi-structured interview schedules. The data was analyzed using SPSS version 12.0. **Results:** The major support available to the patients is the free Anti-Retroviral Therapy (ART) available at Government health care centers. The other supports obtained from self help groups and NGOs were medicines for opportunistic infections, nutritional supplements, traveling allowance to ART center for monthly doses, free monthly ration and school fees for one child in the family. The major support required were an educational plan for children, free investigations at hospitals, decentralization of ART centers and adequate employment opportunities. Involvement of PLHA in health programs was minimal: the reasons for non-involvement being unwillingness, fear of disclosure and lack of opportunity. The respondents stated that Government policies have had a positive impact and changed the perception of the society towards HIV patients. **Conclusion:** PLHA have a number of unmet needs and a collaborative attempt from the government and support groups is needed to meet the needs of PLHA.

Key Words: ART center, Needs, PLHA

Introduction:

Evaluating the immediate and long term needs of People Living with HIV / AIDS (PLHA) and providing them with adequate care and support has a special significance in combating the Acquired Immunodeficiency Syndrome (AIDS) epidemic. Mainstreaming PLHA is also needed to effectively evaluate their needs. The fact has been envisaged by Policy makers around the world. In 1994, leaders of 42 countries signed the Paris AIDS Summit Declaration acknowledging the central role of positive people in the formulation and implementation of national and international policies and programmes (1). This declaration was then adopted by the Joint United Nations Programme for HIV / AIDS (UNAIDS) as the Greater Involvement of People Living with HIV / AIDS (GIPA) principle (2). Even the National AIDS Control Program (NACP) Phase III of Government of India, goes a long way in addressing the issue. It has been clearly stated in the guiding principles of the programme that “Particular focus is on the Fundamental rights of PLHA and their active involvement in prevention, care, support and treatment initiatives” (3). In spite of all the existing guidelines and policies not much research has been carried out to know the felt needs of PLHA and even their involvement in policy making remains mere tokenistic in both governmental and non-governmental organizations. The findings reported here are a part of a bigger study which was done to evaluate such needs of PLHA along with their perception towards HIV and the Stigma and Discrimination faced by them. The findings try to evaluate gaps concerning various issues related to PLHA and suggest measures to rectify them.

Aims and Objectives:

1. To ascertain the immediate and long term needs of PLHA.
2. To study the support received by PLHA from various governmental and non-governmental sources.
3. To study the extent of involvement of PLHA in community work related to HIV/AIDS
4. To ascertain the impact of Government programs on prevailing situation concerning HIV in the community.

Methodology:

The infection in the state of M.P shows a preferential geographical distribution with it being concentrated in some select districts. As per the official data for the state Indore reports the maximum number of AIDS cases. It is essentially the HIV Capital of Madhya Pradesh. The neighbouring districts of Dewas and Ujjain are close seconds. A second peak is witnessed in the border districts of Neemuch, Mandasaur and Burhanpur. The state has presently 3 functional ART centers at Indore, Jabalpur and Bhopal. A cross sectional study was conducted on 150 PLHA in the districts of Indore, Neemuch and Ujjain in the state of Madhya Pradesh during the months of February- March 2008 in collaboration with Madhya Pradesh Voluntary Health Association (MPVHA), a Non Governmental Organization (NGO) working on HIV in the state of Madhya Pradesh (Figure 1).

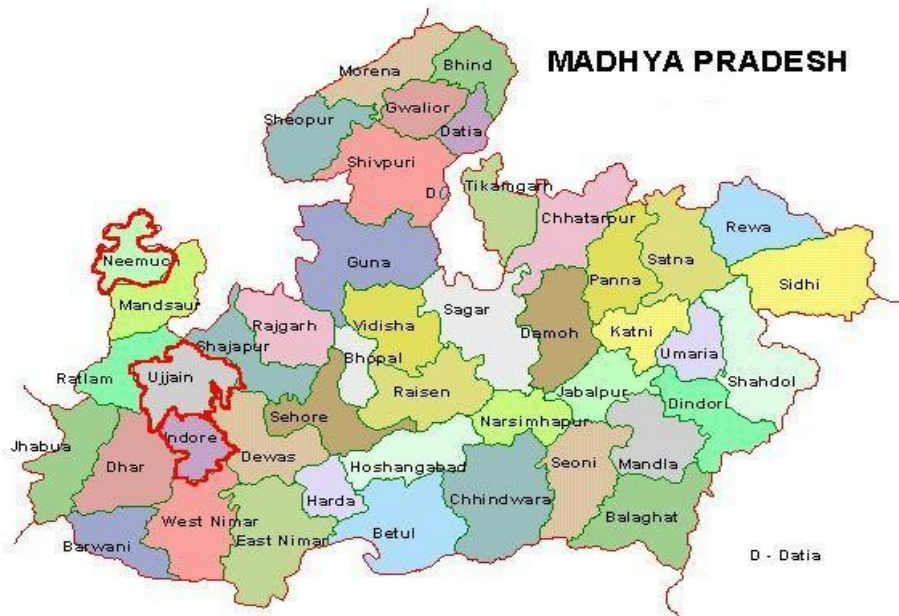


Figure 1: Map of Madhya Pradesh showing the districts under study

50 PLHA in each district, pre-identified by the health workers of MPVHA were selected for the study purpose. Six health workers who had been working in the field of HIV and presently employed by MPVHA and its partner NGOs were recruited for the study purpose. A one day orientation and training programme was conducted for the health workers by the authors and two workers were assigned one district each for data collection. One to one interviews using predesigned and pretested semi-structured interview schedules were conducted with the study group after obtaining written informed consent from the participants. If both partners were HIV positive then only one was included in the study. Data was collected and analyzed using SPSS version 12. The findings from this particular study will be utilized to conduct a more thorough and detailed research in the area. The authors intend to carry out a similar study at the ART center of MGM Medical College Indore to ascertain the felt needs of PLHA in the area. The ART center in the above college serves as a treatment center for patients from 10-15 districts in the state of Madhya Pradesh, and this future research will provide a better insight into the above mentioned issues.

Results

Socio-demographic profile of respondents:

Of the 150 respondents 73 (48.66%) were males while 77 (51.33%) were females. All the respondents in the study were in the age group of 15-60 years, 52 respondents (34.7%) were illiterates while graduates formed 5.3% of the study sample. 132 subjects (88%) had a monthly family income of less than Rs 5000. 53% informants were employed as labourers, farmers or servicemen while 11(7.33%) respondents were presently employed in various Non Governmental Organizations working in the field of HIV / AIDS. In Neemuch 16 (32%) informants were working as Commercial Sex Workers (CSWs), all of them still involved in the trade inspite of being seropositive. 130 out of 150 interviewed (86.67%) in the study had been diagnosed as positive, in the last 5 years with 50% cases in Neemuch testing positive within the last 1 year.

123 (82%) respondents were ever married, out of 77 (51.33%) presently married patients 58 (75%) were using condoms regularly, 10.40% did not use condoms regularly while the rest 15.6% of patients didn't use condoms during sexual intercourse with their spouses. 41 respondents were widowed at the time of the study, 35(85.37%) of widowed patients were females while 6 (14.63%) were males. At least one child was positive in 10.60% of families studied.

Supports presently received:

The major support available to the patients is the free Anti-Retroviral Therapy (ART) which is available at Government health care centers. According to them this has helped them a lot, earlier they used to spend anywhere from Rs 2000-5000 per month on ART. 101 respondents in the study (67.33%) were getting support from various organizations. This support system was best established at Ujjain were 42 (84%) informants are being benefited. (Table 1)The support available is in various forms as follows:

Table 1: Support Obtained					
Type	Indore	Neemuch	Ujjain	Total	Percent
Support regarding health					
Medicines (excluding ART)	1	4	36	41	27.33%
Nutritional Supplements	27	---	1	28	18.67%
TA for ART	---	19	2	21	14.00%
General health check up	3	3	5	11	7.33%
None	22	27	10	59	39.33%
Support regarding livelihood					
Ration	---	---	24	24	16.00%
Job	3	1	2	6	4.00%
Monetary help	2	---	---	2	1.33%
None	45	49	24	118	78.67%
Help for children					
School fees	23	1	24	48	32.00%
Books	1	---	2	3	2.00%
None	27	49	26	102	68.00%

Support regarding health:

Other than free ART, the study subjects were being provided free medicines for opportunistic infections, free nutritional supplements and traveling allowance for coming to Indore to collect ART. At Indore the major help was in the form of free nutritional supplements, 28 (54%) of those interviewed were getting nutritional supplements on a regular basis from NGOs / help groups. 19 (38%) respondents at Neemuch used to get traveling allowance to come down to Indore for their monthly dose of ART, at Ujjain 36 (72%) respondents were getting free medicinal support.

Other supports:

24 (48%) study subjects at Ujjain were getting free ration every month from support groups. 24% patients at Indore and Ujjain were getting school fees from help groups. However this help was usually restricted to one child in the family.

Support required:

The major concern for the respondents is the future of the children, 70 (46.67%) of them need a separate educational plan for their children. They want their children to be able to pursue higher studies and that this help should continue even after the death of the parents. The second major need was free investigations and free medicinal help for opportunistic infections at all hospitals other than the free ART currently available. 4% patients wanted second line drugs to be made available at ART centers in Madhya Pradesh. (Table 2) District wise support required is as follows:

Type	Indore	Neemuch	Ujjain	Total	Percent
Educational help for children	34	16	20	70	46.67%
Job opportunities	8	23	17	48	32.00%
Free medicines	10	17	20	47	31.33%
Emergency helpline	31	---	1	32	21.33%
Household help	24	7	1	32	21.33%
Free investigations	5	15	6	26	17.33%
Pension	2	12	12	26	17.33%
Local availability of ART	---	26	---	26	17.33%
Blood facilities	12	---	---	12	8.00%
No discrimination at hospitals	9	1	---	10	6.67%
Free nutritional supplements	4	2	1	7	4.67%
Second line ART	2	1	3	6	4.00%
Separate hospitals	5	1	---	6	4.00%
Facility of households	2	---	1	3	2.00%

Indore: The major need felt here was that of an Emergency helpline: immediate help available at health care facilities. 30 (60%) informants at Indore want this sort of system to be put in place. Separate educational plan for children was deemed necessary by 35 (70%) of them. 25 (50%) wanted help in form of employment opportunities which can be pursued at the household level. 12 (24%) respondents want facilities of Blood to be made available to patients at all times. Other felt needs were decreased discrimination at hospitals, free medicines for opportunistic infections other than ART and free nutritional supplements.

Neemuch: 32 (64%) respondents wanted free Medicines for opportunistic infections and free investigations available to them at health care institutions, while 26 (52%) emphasized establishing an ART center at Neemuch. 23 (46%) felt adequate job opportunities to be made available in different organizations according to the capacity of the patients. Respondents expressed the need for establishing a system of pension for the family members of HIV patients. Availability of second line medicines for HIV from government set up, free health supplements and separate hospitals for treatment of HIV patients were stated as the other needs.

Ujjain: 25 (50%) patients were in favour of free medicines for opportunistic infections and investigations particularly at government set ups, 20 (40%) needed educational help for children with special provisions for higher education. 17 (34%) want proper job opportunities and 12 (24%) patients' establishment of a pension scheme. Emergency helpline and household employment help were also stated as needs.

Involvement in Community programmes connected to HIV:

12% i.e. 18 respondents were actively involved in community work associated with HIV, they were involved in providing health education regarding the infection. 11 of them were involved with different NGOs and 5 of them were being paid by the organizations in which they were employed. The major reasons stated by others for non involvement in community work were lack of time (25.33%) and lack of opportunity (14%), while 11% stated that they didn't want to be involved in awareness programmes citing fear of disclosure of their serostatus. Other reasons for non involvement were illiteracy and poor physical condition. 29% patients did not state any reason for non involvement in community work. (Table 3)

Type	Indore	Neemuch	Ujjain	Total	Percent
Yes (health education)	6	1	10	18	12.00%
Not involved:					
Don't get the time	6	17	15	38	25.33%
No opportunity	4	17	---	21	14.00%
Unwilling	5	10	2	17	11.33%
Illiteracy	---	3	7	10	6.67%
Physical condition poor	---	1	4	5	3.33%
No specific reason	26	3	14	43	28.67%

Assist in measures to prevent further spread:

More than 127 (85%) respondents were ready to assist in programmes focusing on increasing awareness regarding HIV / AIDS in the community, the major source of information concerned with imparting health education to the people. Other possible measures included assisting in self referral of patients, helping in their daily needs and increasing awareness in schools.

Impact of government programmes:

Informants replied to this question in the affirmative. 79 (52.67%) of those interviewed believed that the awareness drives had a positive impact and there was much reduced discrimination now as compared to the situation some years ago. 54 (36%) respondents were of the opinion that the people were much aware about the disease, there was more self referral and doctors too had become more cooperative. 44 (29%) of the study subjects thought the programmes had not had much impact and the situation was more or less the same.

Suggestions to HIV positive people:

Self care and importance of a positive attitude along with a regular intake of medicines especially ART was stressed upon by the informants. 72 (48%) informants emphasized that self care in terms of adequate nutritional intake and regular health checkups were most necessary, 65 (43.33%) stated the importance of having a positive frame of mind. 53 (35.33%) patients believed that timely and regular intake of medicine is very essential and according to 12 (8%) respondents HIV positive people should take all possible steps to prevent spread of infection from them to others. (Table 4)

Type	Indore	Neemuch	Ujjain	Total	Percent
Proper self care	30	27	15	72	48.00%
Positive attitude	33	13	19	65	43.33%
Regular ART	15	28	10	53	35.33%
Prevent spread from self to others	1	6	5	12	8.00%
Avoid substance abuse	3	2	4	9	6.00%
Regular use of condoms	2	1	3	6	4.00%

Discussion:

The major support available to the study subjects is the free ART available at Government Health Care Centers. 19 (38%) respondents at Neemuch used to get Traveling allowance for coming to Indore to get their monthly doses of ART. Neemuch is situated around 250 kms from Indore and a round trip costs between Rs 300-400. This sort of innovative help is highly commendable and indirectly helps in improving the compliance rates for ART. Consequently establishment of an ART Center at Neemuch itself was one of the foremost requirements stated by the interviewees. Routine traveling to a specified place on specified dates might lead to concerns being raised by the patient's relatives and neigh-

bors, eventually leading to disclosure of serostatus of the patient: hence the need for decentralization of ART Centers. Link ART Centers (LAC) have been proposed in the state of Madhya Pradesh under NACP-III and efforts should be undertaken to operationalize LACs in high prevalence districts as early as possible.(4)

101 (67.33%) respondents in the study were receiving support from various NGOs and self help groups. Initial support is very essential; the reaction following diagnosis of HIV infection is generally of depression and this is the time when support is most required. PLHA should be educated about the support groups operational in their area and counseled to get registered with these networks. Capacity building of PLHA should be encouraged. Developing counselling skills in PLHA and employing them as peer educators at care centers and NGOs will definitely have a positive impact on newly diagnosed patients referred to these set-ups.

The major forms of support required were social, medical, nutritional and financial i.e. adequate employment opportunities. Similar findings were observed in a study done to evaluate the palliative care needs of PLHA in Rwanda. (5) Though the support required varied among the three districts: the major concern for PLHA was the future of their children. Providing adequate employment opportunities to the PLHA and setting up an insurance fund for PLHA at support groups from pooling a part of their income can be taken up. This fund can then be used to provide help for their family members and children. Providing vocational training to the children of PLHA while the parents are still alive should be definitely undertaken.

Adequate and quality nutritional supplementation is extremely necessary for PLHA. This has been envisaged by the Addis Ababa study.(6) 28 (18.67%) of study subjects were receiving free nutritional supplements from support groups. 132 (88%) participants in the study had a monthly income less than Rs 5000. The importance of a balance and nutritious diet for PLHA is well established. PLHA from lower socio-economic groups can't obtain the required diet further compounding their problems. The quality of supplements being provided to patients from support groups is also to be monitored. Appointing a dietician at support groups and ART centers and provision of free nutritional supplements at the ART centers itself is a viable option. This will also ensure the quality of supplements being provided.

Generating home based employment opportunities for unemployed PLHA and extending them monetary support in the initial phases can be taken up. Home based employment not only provides income but also prevents unforeseen and unwanted disclosure.

Often HIV positive patients have to deal with discriminatory attitudes at health care centers. Establishing a network of HIV positive volunteers at major health care settings to care for admitted PLHA can result in reducing the extent of the problem. PLHA undergo a variety of laboratory investigations during the course of their illness. Though facilities of routine investigations are available at majority of health care centers, specialized investigations pose a problem. Linking functional support groups or NGOs with private laboratories and providing PLHA with free or laboratory investigations at subsidized rates can be undertaken.

The study findings reflect minimal involvement of respondents in community programmes concerned with HIV / AIDS. The major reasons outlined were unwillingness, fear of disclosure of HIV positive status, lack of opportunity or lack of time. "Nobody supports me, so why should I be involved in community work." "I don't want to be recognized by my peers so I am not involved in social work." The findings are similar to studies conducted elsewhere.(7,8) Involvement of PLHA is essential; their personal experiences can help in better framing of health policies. Also involvement of PLHA is directly associated with the issues of disclosure and discrimination prevailing in the society and effectively addressing such issues will have a positive impact on the contribution made by PLHA to policy making processes. Furthermore mere tokenistic involvement wouldn't prove to be effective, PLHA should be provided with decision making authority in both governmental and nongovernmental organizations. 85% respondents were ready to assist in future programmes related to HIV / AIDS. Involving PLHA in providing health education in schools and colleges will not only improve the perception of adolescents towards HIV but also help indirectly in tackling stigma and discrimination in the society.

Majority of the respondents were of the view that Government health programmes in the country have proved to be effective. "The customers now themselves bring condoms."—CSW in Neemuch "Because of Television people now know a lot about the disease." This shows that the policies framed have had a positive impact and enhanced involvement of PLHA in them will make them more beneficial and worthwhile.

Conclusions:

The study findings reflect that PLHA have a number of unmet needs. A collaborative attempt from the government, support groups working in the field of HIV/ AIDS is needed to meet the needs of PLHA. Effectively addressing the issues concerning PLHA will improve the Quality of Life of PLHA and also provide them with an opportunity to make their own contributions in tackling the HIV / AIDS epidemic.

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