

Assessing PLHA Expectations Regarding Care and Support Services with a view to Strengthen Networks of PLHA



POPULATION FOUNDATION OF INDIA

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Prelude

Population Foundation of India is implementing the project “Access to Care and Treatment” in six HIV high prevalence states in India funded by The Global Fund To Fight AIDS, Tuberculosis and Malaria under Round 4 grant. On the basis of programme needs and experiences, PFI identifies issues that need attention and conduct special studies to provide possible solutions. These special studies are seen as integral elements of the programme and the results are expected to feed the programme to improve coverage, effectiveness and ultimately profit the beneficiaries.

The study entitled “Assessing PLHA Expectations Regarding Care and Support Services with a View to Strengthen Networks of PLHA” is one such study that PFI had conducted during the phase 1 programme. Hope the findings and conclusions of the study presented in this report would be of significant use to managers implementing care and support programmes for the benefit of people living with HIV/AIDS.

Context

PFI led NGO/private sector initiative committed to provide care and support services to 160,000 People Living With HIV/AIDS (PLHA) across six HIV high prevalence states over a five year period starting from April, 2005 under the Access to Care and Treatment (ACT) project supported by The Global Fund (Round 4),

The Indian Network for People Living With HIV/AIDS (INP+) is one of the partners in the project and has its affiliated state level and district level networks. The District Level Network (DLN) is set up by PLHA and for PLHA. Therefore, the networks of PLHA have been identified as one of the strategies to ensure that this commitment is achieved effectively and thereby improve the quality of life of PLHA. However, the ground reality is that many PLHA are not and do not want to be a part of these networks. Anecdotal evidence suggest that several PLHA prefer to seek treatment, care and support services independent of the network. As a result of this, one was not sure whether or not they receive appropriate follow up and counselling that they may need at various stages of disease progression. This tendency of PLHA not to seek services at DLN may have implications of its utilisation and its long-term sustainability. No systematic information exists on why many PLHA do not wish to become part of the networks and if there is any other model of providing treatment, care and support, services within the larger networking system.

Several people in the field of HIV/AIDS feel that the profile of many PLHA who do not seek services through the network has a direct bearing on the nature and type of services that are relevant and acceptable to them. For example, it is likely that some PLHA due to their social, economic and demographic status may be more sensitive to the need for greater anonymity than others and may not want to be part of DLN. It is also likely that there may be varying expectations about the quality of care and support services due to the attitudes

to life, psychological conditions and life style of PLHA. It is hypothesised that the expectations of PLHA already enrolled at the networks are different from that of non-enrolled.

In view of this, a special study was initiated to explore the nature and range of expectations of the PLHA with regard to the treatment, care and support services with a view to strengthening the capacity of DLN to meet these expectations and accordingly enable DLNs to make an action plan.

For meeting these goals, PFI conducted a study among PLHA, local service providers and DLN staff in Tamil Nadu, Karnataka and Andhra Pradesh.

Purpose

- Provide a strategic direction to the networks of PLHA in providing quality care and support services to PLHA.

Objectives

- Explore the nature and range of expectations of PLHA with regard to treatment, care and support services.
- Assess the magnitude of the expectations of PLHA and prioritise them for possible implementation.

The findings of the study would help INP +/PFI in designing strategies for strengthening the capacity of DLNs and effectively addressing the expectations of PLHA regarding treatment, care and support services.

Research questions

Are there differences in the expectations of PLHA (enrolled and non-enrolled) with regard to treatment, care and support services? If yes

- How can the service system (DLNs) meet these expectations?
- Whether alternative ways to provide care and support services to PLHA are needed?

Methodology

The study was carried out in two phases, namely, Qualitative phase (Phase I), and Quantitative phase (Phase II).

Phase I: Qualitative phase — In-depth interviews

This phase was intended to explore the expectations of PLHA with regard to care, treatment and support services. An attempt was made to search for patterns that can

be programmatically responded to. This phase was also expected to throw light on the expectations, perceived benefits and experiences of enrolling PLHA. In-depth interviews were conducted at various levels involving PLHA (both enrolled and not enrolled), DLNs/INP+ functionaries/board members and local service providers, including NGOs.

Study area, PLHA and coverage

The consultations with INP+ revealed that amongst DLNs set up in the ACT project, as in September 2006, the districts of Prakasam and Vishakhapatnam in Andhra Pradesh, Belgaum and Dharwad in Karnataka, and Chennai and Madurai in Tamil Nadu have higher number of non-enrolled PLHA. Geographical location of DLNs was also a criterion in selecting the districts for study. Accordingly, the study was carried out in these six districts.

PLHA included:

- PLHA, both enrolled and non-enrolled;
- PLHA on ART and not on ART;
- Functionaries of DLNs;
- Functionaries of INP+ Secretariat;
- Health care providers, both government and private, and NGO functionaries working on HIV/AIDS.

A total of 84 PLHA were contacted, 28 from each state, equally divided between those enrolled and not enrolled. Both males and females and PLHA on ART/not on ART were covered, by and large equally. In addition, 22 in-depth interviews with DLN/INP+ functionaries and 24 in-depth interviews with local service providers in the districts selected were conducted.

Phase II: Quantitative phase

Using the insights from Phase I of the study, a survey was carried out among the PLHA to assess the magnitude and patterns of expectations and differentials in these expectations with respect to gender, ART status and enrollment status. The survey also sought to quantify the perception of PLHA towards DLN as a channel of meeting their expectations.

Specifically, the aim of the survey was to understand:

- What is the magnitude of each expectation explored during phase I?
- Where does DLN stand as a channel of meeting these expectations in the overall support system?

- Do these expectations significantly vary by gender, ART status and enrollment status?
- What could be priority areas that DLNs can act upon?

Community-based surveys cannot focus on PLHA given the fact that many do not easily disclose their HIV status in the community. Hence, structured interviews were conducted with PLHA coming to five ART centres in the three states of Andhra Pradesh, Tamil Nadu and Karnataka. The ART Centres covered during phase II are: Guntur, Vishakhapatnam, Madurai, Namakkal and Hubli. These ART centres selected in phase-II caters to DLNs covered in phase-I. At each ART Centre, 80 PLHA were interviewed.

Limitation of the study

As the PLHA were interviewed at ART centres, it is very likely that they are symptomatic and the expectations stated in this study would reflect their perspective.

To minimise this limitation, the study asked a question — *“When did you first detect that you are HIV positive?”* — and tested whether expectations of PLHA recently infected vary from the expectations of those PLHA suffering since a long time.

Findings - Phase I

INP +/DLN perspective

Key tasks identified by INP+ and DLNs for strengthening DLNs include raising awareness about networks, networking with NGOs/ICTC/ART centres, linkages with government schemes, programmes for reducing stigma and discrimination, extending treatment, care and support facilities at primary level, etc. Barriers faced by the networks, both structural and functional, as revealed during in-depth interviews include:

- Administrative and functional problems due to the presence of many peewee networks and overlapping of jurisdiction;
- Lack of funds for creating awareness about the networks;
- Social stigma deterring PLHA from joining DLN;
- Lack of support from NGOs and healthcare facilities.

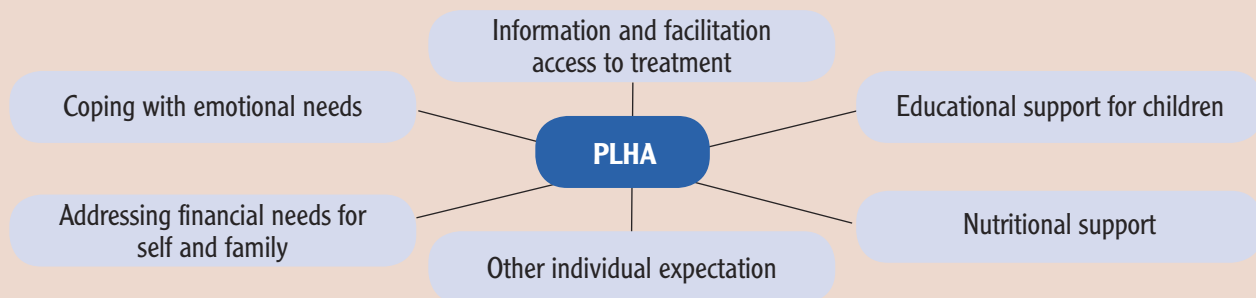
Service providers’ perspective

Suggestions from service providers indicate the need for increasing awareness, networking with other stakeholders, ensuring confidence of PLHA, etc. in DLN as an important link for PLHA and others.

PLHA perspective

Both enrolled and non-enrolled PLHA have a range of expectations presented in Fig 1.

Fig. 1 – Expectations of PLHA with regard to care and support services



Information and facilitating access to treatment

1. Increasing access to treatment for both ART and OI;
2. Facilitation in undergoing tests;
3. Facilitation in procuring medicines;
4. Free or subsidised medication for OI.
 - The expectations of non-enrolled PLHA related to availability and information provision for ART/OI, while enrolled PLHA are concerned more about regular supply of ART.
 - Enrolled PLHA identify the need for care and support and treatment for their children too. Non-enrolled PLHA limit their expectations to accessing treatment for self only.

Coping with emotional needs

1. Counselling to improve confidence and courage to live positively;
2. Opportunity to share experience and suffering;
3. Psychological support.

Enrolled PLHA were observed to be more articulate than non-enrolled.

- DLN to stand by even when the family deserts;
- DLN to instill confidence in the family through counselling;
- Solving problems arising in the family.

For non-enrolled PLHA, psychological support was limited to the self. Enrolled members view DLN as a support structure. Non-enrolled members are unsure from where to obtain such a support structure.

Addressing financial needs for self and family

Expectations relating to economic and financial needs include:

1. Need for a job;
2. Monetary help (from government or elsewhere);
3. Job/loan from DLN;
4. Better job than the present one.

Expectations for addressing financial needs of self and family are similar for both enrolled and non-enrolled. In essence, they want to be helped to remain financially sound. Enrolled members specifically identified DLN for facilitating meeting of these expectations, while the non-enrolled primarily expected government to help them. While the enrolled wanted a job for financial sustenance, the non-enrolled wanted a loan.

Educational support for children

1. Children's education should be funded;
2. DLN should help admit the child in a hostel.

The expectations of enrolled PLHA are more specific than those of non-enrolled. Both men and women are equally emphatic in expressing the need for education for better future of their children. However, the emphasis on the need for education for children was more among widow PLHA who are not supported by other family members.

Nutritional support

1. Nutrition for basic food need;
2. Nutrition to support ART.

The need for nutritional support was more amongst PLHA who are on ART but did not differ much by their enrollment status.

Overall, both enrolled and non-enrolled members have expectations relating to a broader set of needs arising as a result of their HIV status — family issues, reducing stigma, social acceptance, access to basic amenities, and psychological

support. However, while enrolled PLHA appear to have accepted their HIV status and identify needs associated with family, positive living, and treatment, the non-enrolled have needs that relate to all aspects of life, reflecting an ambiguity in what to expect and from where.

Channels identified to meet expectations

Both enrolled and non-enrolled PLHA identified the following channels to meet their expectations:

- Government hospitals;
- DLNs;
- NGOs/CBOs;
- Family;
- Others (private sector, etc.).

Government organisations and NGOs are repeatedly mentioned as the main channels. DLN also featured as an important channel, especially amongst enrolled PLHA. Channels like family were identified more for psychological support.

Reasons for not enrolling

Question: *In general, what according to you are the reasons for PLHA in general not enrolling in networks?*

Enrolled	Non-enrolled
• Lack of awareness about DLN	• Home visits or regular contacts by network
• Fear of disclosure of status	• Lack of monetary benefit
• Stigma attached to DLN.	• Not being able to meet travel expenses, and other family issues.

From the preceding, the following issues emerge:

- Some PLHA prefer to seek services anonymously rather than through the network;
- PLHA do not think that network of PLHA can maintain confidentiality;
- PLHA do not expect to benefit through DLN;
- PLHA would not like DLN staff visiting their home or making regular contacts.

Findings - Phase II

The series of specific expectations that came up in Phase I were rearranged in 15 mutually independent categories, to facilitate data collection and capture PLHA

perspective better. The PLHA were interviewed at ART centres. At any ART centre and on any given day 65 to 70% of the visiting PLHA are on ART (including follow-up cases). In the present study 63% of PLHA interviewed are on ART.

Awareness and level of enrollment

Table 1: Distribution of PLHA according to various parameters

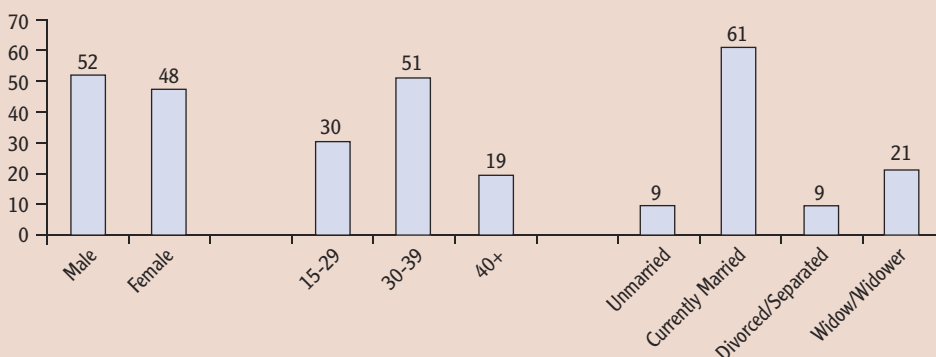
Parameter	N	%
Number of PLHA on ART	253	63
Number of PLHA not on ART	151	37
Number of PLHA heard about network	252	62
Number of PLHA not heard about network	152	38
Number of PLHA enrolled in network	199	49
Number of PLHA not enrolled in network	205	51

Total number of PLHA interviewed (N) = 404

Majority of PLHA are on ART and heard about networks. Almost half of PLHA interviewed are enrolled in networks. This is possible as networks of PLHA usually work/coordinate with ART Centres by referring PLHA for ART services. Also, many times, network staff is present at ART Centre helping PLHA who are coming for the first time and for follow-up services.

Profile of PLHA

Fig. 2 – Profile of Respondents (N=404)



Out of 404 PLHA, 17% are illiterate, 49% had some education, and 34% had studied up to SSC and above. The mean age was 34 years for those on ART and 33 years for those not on ART.

Enrollment status

Table 2 – Characteristics of enrolled vs not enrolled PLHA

Characteristics	Enrolled in any network %	Not enrolled in any network			Total % (N)
		Not heard about network %	Heard about network %	Total	
Sex					
Male	45	40	15	55	52 (209)
Female	54	35	11	46	48 (195)
ART status					
On ART	60	27	13	40	63 (253)
Not on ART	31	56	13	69	37 (151)

The table shows that there exists a sizeable number of PLHA (both males and females) who heard about networks but not yet enrolled. At the same time, around 13% of PLHA, regardless of their ART status, had heard about networks but not enrolled.

Median duration and HIV status of children and spouse: The median duration of exposure to HIV amongst PLHA was 29 months. Around 9% of their children were HIV positive. A majority (57%) reported that their spouse is also HIV positive.

Association with network: The data show that PLHA who have longer association with networks are more likely to be on ART as compared to PLHA who have lesser association with network. However, as the data were retrospective, it is not certain whether they got enrolled first and then started ART or vice versa.

Around 13% of PLHA, regardless of their ART status, had heard about networks but not enrolled.

Magnitude of expectations

The expectations expressed by PLHA regarding care and support services fall into:

Expectations of PLHA regarding care and support services

- Emotional support for positive living
- Expects someone to stand by when the family deserts
- Solving problems arising in the family
- Need for counselling on regular basis
- Need to provide counselling to family members
- Information about antiretroviral treatment
- ART medicines to be made locally available
- Medicines to be made locally available for opportunistic infections
- Free testing facility for CD4 and to start ART
- Financial support to help families
- Financial help for children's education
- Helping children seek admission in good schools
- Help admit affected/infected child in a hostel
- Provide regular job
- Provide food/ration

Though PLHA view these expectations as immediate, there are some statistically significant differences between males/females, ART/non-ART and enrolled/non-enrolled PLHA regarding these expectations.

Variations of expectations by ART status and gender

Females expressed greater need for support than males on issues related to family, such as support when family deserts ($p \leq 0.01$), solving problems in the family ($p \leq 0.01$) and counselling to family members ($p \leq 0.01$). Treatment-related needs such as information on ART and its availability at local level are expressed more by PLHA who are already on ART than those who are not ($p \leq 0.001$). However, both males and females have equally expressed the need for information on ART and its availability at local level.

Similarly, availability of medicines for Opportunistic Infections locally and free testing facility for CD4 are most immediately sought by PLHA on ART (98%), while financial support for family or self (91% vs 86%, $p=0.000$) and help for children for school admission was expressed more by females than males (88% vs 77%, $p=0.000$). Enrolled PLHA are also equally in need of this support. No differences between enrolled and non-enrolled exist, possibly because many of these expectations have not been met by DLN for enrolled PLHA.

PLHA see government as a channel to setting up the systems for treatment related issues, while DLNs are seen to be for information provision and as a facilitator too.

Overall, females require support on family issues; PLHA on ART require support on treatment related to ART and OI management.

Channels identified for meeting expectations¹

Government emerged as the single largest channel in case of information about Antiretroviral Treatment (81%), availability of ART medicines in proximity (82%), availability of medicines for Opportunistic Infections in proximity (81%) and free testing facility for CD4 and to start ART (85%). Following the government, networks of PLHA was also identified as an important channel for meeting expectations related to treatment, especially in case of information about Antiretroviral Treatment. PLHA see government as a channel to setting up the systems for treatment related issues, while DLNs are seen to be for information provision and as a facilitator too. For issues related to family/self (such as emotional support, to stand by when family deserts, solving problems of family and counselling), however, networks of PLHA is the preferred channel.

Gender differentials

More females than males prefer DLN to provide regular counselling to self/family (63% vs 57%), information on ART (62% vs 54%), support for free testing facility for CD4/ART (51% vs 38%), employment opportunity (50% vs 42%), and provision of ration (53% vs 42%). Expectations of females increased when they identified DLN as a channel, to support on free testing for CD4 and initiate ART, employment opportunity and provision of ration.

Differentials by ART status

PLHA on ART prefer DLN to make sure that ART medicines and medicines for opportunistic infections are locally available (at district, village level) than PLHA not on ART (51% vs 44%). Also, interestingly, as females preferred DLNs to solve problems arising out of HIV positive status, PLHA on ART also prefer DLN to come

¹ Percent values are calculated amongst males and amongst females separately for sex to look at the differentials. Similarly for ART status and enrollment status.

Enrolled PLHA want DLNs to facilitate loan from the government while non-enrolled want money to clear their debt.

forward and solve family problems arising out of HIV status (52% vs 44%). This has an implication for DLNs on what to focus when they deal with females as well as PLHA on ART. On issues related to treatment/medicines, DLNs are seen more as facilitator.

Differentials by enrollment status

While enrolled PLHA would want DLNs to meet their expressed requirements, they seem to have understood the limitations of DLNs but lack clarity about what expectations DLNs can meet (children’s admission in good schools and help admit in a hostel) and what they cannot (provide job, food/ration).

While enrolled PLHA thought the DLN’s capacity is limited on certain issues (job, food, support to children), they would like DLN to stand by when their family deserts and solve problems at family level. Enrolled PLHA still expect DLN to support them on family issues and counselling to family members. Non-enrolled PLHA want DLNs to help them admit children in good schools/hostel, offer job and food/ration. Enrolled PLHA want DLNs to facilitate loan from the government while non-enrolled want money to clear their debt. Males or females, ART or not on ART or enrolled or not enrolled, the requirement of financial support is equally felt.

Since the expectations vary according to their enrollment status, DLNs need proper planning to meet these needs in order to retain enrolled PLHA in the networks and further to make the entry easier for those who are not yet enrolled.

Addressing the limitation of the study

To minimise this limitation stated earlier, the analysis was done taking into account the duration of the infection. The study asked: When did you first detect that you are HIV positive? — and tested whether expectations vary by PLHA recently infected (six months) vs PLHA suffering since long (more than six months).

PLHA with recent status of HIV expressed greater need for support for self when the family deserts and help for children’s admission in a hostel, whereas those

suffering from long have greater need for information on ART and free testing facility. In other respects, the expectations of the two categories appeared to be similar. To ascertain this condition, a logistic regression analysis was carried out considering the expectations (those expectations that were found significant in bivariate analysis) as dependent variables and effects are controlled using age, sex, education, income, marital status, spouse's HIV status and children's HIV status.

The logistic regression results (for someone to stand by even when the family deserts as a dependent variable) show that PLHA who had exposure to HIV for more than six months were three times more likely than their counterparts to seek support when their family deserts them. Except for this variable, no other expectation was observed to have varying expectations significantly according to symptomatic or asymptomatic stage.

Discussion

This section lists the findings about expectations of PLHA and identifies the implications for DLNs' planning and programming.

During phase I, the expectations were found to vary according to the enrollment status of PLHA in the networks (enrolled vs not enrolled) and also with respect to ART status (ART vs non-ART). For example, in relation to information and facilitating access to treatment, expectations of non-enrolled PLHA are related to information provision and availability of ART and OI, while enrolled PLHA felt a greater need of treatment and regular supply of ART. Furthermore, enrolled PLHA identified treatment needs related to their children as well, while non-enrolled PLHA limit their expectations for self only.

In phase II, a majority of PLHA are on ART, have heard about networks and nearly half of them are enrolled in networks. Since the interviewed PLHA were those visiting ART centres, the findings — 49% enrollment, 63% PLHA on ART and 62% PLHA heard about networks — need to be seen with caution.

The mean age of PLHA was 34 years, with equal proportion of males and females; majority were currently married, and also majority studied above primary level of education. The bivariate analysis showed that age factor does not predict the likelihood of enrolling in network. The likelihood of enrolling is more among females, and also where the spouse and children are HIV positive.

Since the stigma attached to PLHA discourages enrollment there is a need to make it clear that without the consent of those enrolling, their status will not be made public.

Many PLHA (79%) are willing to join the network. Local service providers (Doctors, VCTC, NGOs) suggested a media campaign (documentary films, street plays, hoardings and advertisements) to generate awareness. The stigma and confidentiality issues should be addressed while using these media. It should be noted that DLNs were reminiscing not enough cooperation from either NGOs or the private sector in providing information about DLNs.

Since the stigma attached to PLHA discourages enrollment there is a need to make it clear that without the consent of those enrolling, their status will not be made public (both at the time of enrolling and during the outdoor activities). How to mitigate the stigma attached to networks is in itself a challenge.

The majority of the enrolled have been suffering from the disease for more than two years. The fact that as many as 80% of PLHA waited for two years to enter into care supportive system after they were detected with HIV also highlights that DLNs need to strive to approach PLHA in the initial stages. One way is to coordinate with VCTCs and explain the need to contact such PLHA and create awareness.

The treatment related needs such as information on ART and its availability locally was expressed by PLHA who are already taking ART than those who are not. Also, availability of medicines for OI locally and free testing facility for CD4 are preferred by PLHA on ART. The financial support for families/self and children for school admission was expressed more by females than males. Also, females prefer to have someone to stand by when their family deserts and expect some one to solve the problems arising out of their HIV status. This has implications for DLN — when

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dealing with females, the focus needs to be on family level issues, children's education and financial support. Similarly, when dealing with PLHA on ART, the focus needs to be on treatment issues including ART and OI management. With regard to economic support, although the difference between enrolled and not enrolled PLHA is not statistically significant, it is important to find that half of the PLHA contacted expressed this need. The qualitative phase highlights that enrolled PLHA prefer economic support in the form of loan, while not enrolled PLHA want it for clearing their debt.

For the majority of expectations, NGOs and family are least preferred. The majority depended on government and DLNs. DLN is the preferred channel for regular counselling to self and family members. DLN should continue to provide emotional support to PLHA, extend counselling support to families, and solve family problems arising out of HIV status. DLN is seen as a facilitator particularly for treatment i.e., getting the CD4 test done, help obtain a loan etc. which some DLNs are already providing. The data suggest the enhancement of the activity will yield better results. This can help in increasing the coverage.

The analysis on comparison of PLHA who have less period of association with PLHA having longer association with DLN revealed that it takes time to receive support from networks upto the satisfaction of PLHA. The data clearly shows that over a period of time, the PLHA who express less or lack of satisfaction now, will have encouraging attitude in the coming period. Meanwhile, one thing to remember is that if networks do not address the issue of anonymity, many PLHA may drop out of the system. This observation is supported by another fact that several PLHA do not think DLN can maintain confidentiality. Always, DLN has to ensure the sensitive nature of PLHA is protected and respected. There exists another opportunity to DLN — in spite of the fact that enrolled PLHA do not think networks can maintain confidentiality, 88% would be willing to continue in the networks. This is largely due to the experience or strong belief that DLNs stand by when family deserts and it solves family problems arising out of HIV. DLNs should capitalise this opportunity to use these PLHA to widen their reach. As enrolled members are having positive

DLN should continue to provide emotional support to PLHA, extend counselling support to families, and solve family problems arising out of HIV status.

attitude towards continuing in the networks, it is useful that DLNs seek support from these people to reach and convince others who have not yet enrolled.

Implications for Programme Managers

The following actions can improve coverage by the networks and help to meet the varying expectations of PLHA:

- Prepare documentary films to raise awareness and benefits that it offers, street plays, hoardings and advertisements. Nevertheless, the present data suggests addressing the stigma issue while using these media. This would be an attempt towards increasing the awareness and coverage.
- DLN is indispensable to make sure that they approach PLHA in the initial stages of infection to avoid disease burden in future and clear their myths/misconceptions. One of the ways is to coordinate with VCTCs and explain them the need of contacting such PLHA. At the same time, DLNs can take an opportunity to show documentary films (as discussed above) regarding networks so as to make it voluntary yet informed decision of PLHA. The coordination with VCTC and government hospital is vital in improving the coverage.
- On confidentiality issue, it is suggested that at the time of enrolling a PLHA and during the outdoor activities, DLNs must make it clear that without the consent of PLHA, their HIV status will not be made public. Also, it should be made sure that PLHA's sensitive nature is protected and respected.
- When dealing with females, the focus needs to be on family level issues, children's education and financial support. Similarly, when dealing with PLHA on ART, the focus needs to be on treatment issues including ART and OI management. This helps spread word of mouth about the flexible nature of DLNs and accordingly contribute to increase coverage.
- DLN should continue to provide emotional support to PLHA, extend the counselling support to the families of PLHA and try to solve family problems arising out of HIV status.
- Facilitate for CD4 test, in the process of ART initiation. Since providing job may not be possible to DLNs, efforts need to be concentrated around linking them with schemes that benefit PLHA. Wherever possible, facilitate the process of PLHA seeking loans.
- Linkages needed with other stakeholders. However, as seen earlier, some of the stakeholders are not supportive of DLNs. Therefore, this requires care and proper planning.
- PLHA already enrolled have strong belief or experience that DLNs stand by when family deserts and it facilitates solving family problems arising out of HIV. DLNs should capitalise this opportunity to use these PLHA to widen their spectrum of activities and reach.



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