

# Understanding Support Group Meetings of People Living with HIV/AIDS



**POPULATION  
FOUNDATION  
OF INDIA**

## Background

*P*opulation Foundation of India (PFI) is managing the program "Access to Care and Treatment—ACT" in the six high HIV prevalence states of India supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). Indian Network for People Living With HIV/AIDS (INP+) plays a key role in providing care and support services to PLHAs. One of the activities of this program is strengthening and actively engaging district level networks of people living with HIV. Besides other activities, every month district level networks (DLNs) organize support group meetings for PLHA. The support group meetings (SGM) are attended by PLHAs who may or may not be on antiretroviral treatment. A typical support group meeting usually takes about 4 hours and about 25 to 30 PLHAs attend. The meeting provides an opportunity for people living with HIV to share their life experiences, and discuss about various issues related to living with HIV.

This study was conducted to assist DLNs to better organize support group meetings and maximize the benefits available to PLHAs through these meetings.

In spite of the fact that support group meeting is an important component of the services provided for and by PLHAs, there is paucity of published material on understanding why and how these support group meetings are conducted; what are the experiences of PLHA attending these meetings; and how useful these meetings are. There is no dearth of relevant material on the support group meetings for cancer patients and alcohol/injecting drug users in western literature. However, no systematic documentation exists on support group meetings conducted by and for PLHAs. In the program, Access to Care and Treatment, DLNs are organizing support group meetings in different ways. It was not clear how DLNs plan and conduct support group meetings and how the agenda/content of the meetings are decided. Thus, it was important to know these details and whether the variations in the content

and process of meetings affected the expected outcomes of support group meetings.

Although, in general, support group meetings are considered to be useful, there is almost no systematic documentation from India on the effectiveness of support group meetings for PLHAs. For example, it is generally believed that these support group meetings provide a platform for PLHAs to share their experiences; combat their loneliness; and improve their self-esteem. Hence it was decided to explore the various benefits of support groups meetings and document how PLHAs perceive the usefulness of participating in these support group meetings. Thus, this study was conducted to assist DLNs to better organize support group meetings and maximize the benefits available to PLHAs through these meetings.

## Goal, Purpose and Research Questions

**Goal:** To assist district level networks to better plan and organize support group meetings; and to assist PLHAs in maximizing the benefits of participating in the support group meetings.

**Purpose:** To describe the various ways in which support group meetings are being conducted by district level networks of INP+ and to explore critical influences these meetings have on the lives of PLHA.

The study also intended to understand the usefulness of these support group meetings as perceived by PLHAs who participated in them. This was not an intervention or evaluation study and, although the quality of life of some proportion of PLHAs might have been improved by participating in support group meetings, measuring effectiveness of the support group meetings was not the focus of the study. However, findings from this study are found to be useful to improve the effectiveness of the support group meetings.

**Research questions:** The key research questions were:

1. How the support group meetings for PLHA in DLNs are planned and conducted?
2. What are the perceptions of PLHA on the usefulness of the support group meetings they had participated in?
3. How the support group meetings have influenced the lives of PLHA who participated in them?

## Methodology

The study design was prospective, exploratory and descriptive. The study population included PLHAs who participated in SGM, staff of DLN responsible for planning and organizing SGM, board members of networks and some of the experts with relevant expertise/experience. Among six states of ACT project, networks from three states viz., Andhra Pradesh, Tamil Nadu and Maharashtra were selected to take into account if any regional variation were studied. One PLHA network from the Union Territory of Pondicherry was also included for the study. Out of the 10 networks chosen, four DLNs are relatively older and are functioning prior to ACT project so that the study could document differences in planning and conducting the support group meetings if there were any.

The qualitative research methods used were: key informant in-depth interviews, group interviews, in-depth interviews with PLHAs who participated in the

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support group meetings and non-participant observation of SGMs. Informed oral consent was obtained from all the study participants. The table below shows the extent of interviews carried out:

Methods	Final sample size	Purpose
In-depth interviews with participants	24 PLHAs participated in SGMs (on ART and non-ART)	To understand experiences and usefulness of meetings
Group interviews with DLN staff	10 groups each with 3 to 4 DLN staff (in charge of SGMs)	To find out why and how the support group meetings for PLHA in DLNs are planned and conducted
Key-informant interviews	8 board members of the district/state level networks having extensive experience of working at grassroots level and having sound insight of the issues for conducting SGMs.	To find out how and why the support group meetings for PLHAs in DLNs are planned and conducted To understand what support board members/state level networks are providing in organizing SGM
Support Group Meetings observed	Six	Observations to see what kind of people participated, their level of participation

## Salient Findings

### How support group meetings of PLHA are planned and organized?

#### Planning for SGM

Prior to conducting an SGM, the staff of DLN organise a 'planning meeting' to decide about the content of the meeting and the way to conduct it. The content is usually decided based on the areas suggested by the PLHAs attending the meeting or the issues raised during the last SGM. The draft agenda is discussed with the board members and their inputs are sought before finalizing the agenda. The usual venue of SGM is DLN office, but sometimes it is organized at government community health centers or partner-NGO-run hospitals etc. Most of the DLNs conduct SGMs on specific days in a month. The duration can be anywhere from 3 hours to 6 hours—sometimes a day-long meeting. Both old members and new PLHAs are invited to participate in the SGMs.

#### Comfort for new PLHAs in the SGM

DLN staff orients new PLHAs about the functions and concept of DLN and SGM. A brief counseling is also provided before they join the SGM. In SGM, they are introduced to jovial older members and seated in between them or they are seated next to the staff of the DLN so that they feel welcomed. Some DLNs give the option of just observing the proceedings of SGM and not introduced to the group unless the new PLHA is comfortable. Usually basic information about HIV/AIDS is provided in almost all meetings for the benefit of new members.

#### Range of topics included in SGMs

Most of the time support group meetings start with a prayer or welcome address, which generally follows introduction of DLN and participants and experience sharing. External resource persons (like Doctors, Lawyers, Social Welfare department from District Collectorate, Nutritionists etc.) are also invited in the SGMs to give detailed information on nutrition, treatment issues, gender, government schemes, legal issues etc.

Following topics are covered in most of the SGMs regularly. The extent of information shared is decided according to the need of group:

- Importance of joining network
- Why we need to attend SGM
- Basics of HIV/AIDS (transmission modes, difference between HIV and AIDS, etc.)
- Antiretroviral therapy (ART)
- Importance of taking proper and adequate nutrition
- Importance of maintaining self-hygiene
- Nutrition

DLN staff maintains a register for documenting the minutes of the meeting. These minutes are referred while developing the agenda for the next SGM. Some DLNs also take photographs of the meetings.

#### Socio-economic status of PLHAs

PLHAs who attend the SGMs are usually from the lower or lower-middle socio-economic status. PLHA from all religions and castes could be seen attending SGM.

A limited number of female sex workers, men who have sex with men (MSM) and *Hijras* may also be attending the SGM. Even among the HIV-positive, MSM and female sex workers do not reveal their sexual orientation to their fellow group members because of fear of discrimination.

While the support groups are primarily for PLHAs, sometimes family members of PLHAs who are not HIV-positive are also allowed to be present in SGM. If PLHA could not come for SGM because of some reasons, their family members (parents, siblings) attend SGM to know about any new information and to clarify their queries. Spouses may come together or alone.

The older members and the staff usually encourage new members to share their experiences. New PLHAs may be quiet for the first few meetings but usually 'open up' in the subsequent meetings.

## Participation of PLHAs in SGM

Most of the support group meetings are observed to have active participation of attendees with the help of good facilitators. PLHAs are given equal opportunities to communicate about their experiences. They are encouraged to discuss sensitive issues in separate informal discussions like women health issues or issues related to relationships. The facilitators give a chance to each member to talk; encouraging newcomers and other PLHAs to give their perspectives or opinions about particular issue; and in making the newcomers feel comfortable. However, in some meetings, some members (not necessarily older members) dominate the discussions. Sometimes PLHAs contact the staff/counselor after the meeting to discuss about their personal issues.

## Barriers in attending SGM

Most of the PLHAs have pre-conceived notions about SGM in terms of fear of the unknown or fear of discrimination; however, after attending it once, the perceptions are changed. Other barriers in attending the SGMs are: fear of disclosure, no one to take care of children at home, timing and/or duration clashes with other duties/priorities, sometimes self or spouse falls ill etc.

## Issues to be addressed for conducting SGM

The facilitators of the SGM are usually the staff in-charge for organizing the meeting and most of them are PLHAs. PLHA facilitators feel that their open status actually helps in building rapport with the new participants and instilling confidence in them. But these facilitators had no formal training on conducting/organizing SGM or in facilitation skills. They expressed need for training for facilitation skills, communication skills, HIV/AIDS treatment updates, materials to read and distribute and also guidelines and training for conducting SGM. Some of the participants requested compensation for the daily wages lost due to attending the meeting.

## Articulated and unarticulated benefits of attending support group meeting: perspectives of PLHA regarding usefulness of SGM

Some of the articulated benefits listed by PLHA are:

### *End of sense of isolation*

"I was not sure about what others will do in such meetings. But I was surprised to see so many people like me. I knew I was not the only one..."

### *Alleviates depression*

"I forget that I have HIV while I attend the meetings." Initial suicidal ideation and tendencies changed after I started attending SGMs.

### *Helps in letting down emotions*

The experience sharing sessions in the SGM act as effective channels to let down their emotions and helping them in decreasing their mental burden.

### *'Rationalizing' as a mechanism to get psychological comfort*

PLHA feels that they are not alone in suffering from the various problems but there are many others like them.

### *Learning from others' experiences*

"As I came to know how he handled that difficult situation of disclosing his HIV status to his wife I also came to know how I can do that to my wife. It helped me."

### *Comparing one's situation to other's and getting a sense of comfort*

"At least I'm better than them—some satisfaction that I am not suffering to the extent some do."

Some get consoled that "Fortunately that did not happen to me."

### *Safe space to share feeling and emotions*

"It is based on mutual trust. I need not hide my [HIV] status [in this group] and hence I need not hide my feelings too."

"But I was surprised to see so many people like me. I knew I was not the only one..."

### ***Social support system ("The third network") -***

PLHAs develop friendship, bond with one another and ultimately developing strong social ties with other PLHAs.

"This relation is not blood-based [meaning it is not through traditional family system] but because we have one thing common with us. There are no caste or religious differences. Everyone likes everyone. This relation is better than our [biological family] relationships."

### ***Information from SGM***

Before attending SGMs they did not have much information about even the basic issues of HIV/AIDS as the healthcare providers did not have sufficient time to explain to them or because they were not explained in an easily understandable manner.

### ***Building self-confidence and self-esteem***

"...willpower, because of HIV I should not always be worried but work like any other person."

"I enjoy living each day" and "now that I know about HIV/AIDS I also go back and tell four other persons about how in spite of HIV we can live like anybody else."

"Now I no longer have guilty feelings. I was feeling bad about myself and blaming myself for the situation and continuously worried about that."

### ***Changing perspectives on having HIV***

"I feel this is like any other disease. We have ART now. Don't the people with Diabetes and BP [hypertension] take medications and live for a long time."

"This is a small insect in your blood, should we keep worrying about that always."

"If I did not have HIV, I would not be planning for the future. But now, we know we are going to die sometime or another and I take care of my family better; plan for my children and stopped bad habits (meaning quit smoking and drinking alcohol)."

Below is the list of benefits of attending the SGM which were not often articulated by PLHA but they

came out during the interviews with the participants and key informants:

- Monetary help by means of education of their children, groceries for needy PLHA, small-scale self-employment (buying goats, setting up petty shops), development of self-help groups, etc.
- Knowledge on government and bank schemes. DLNs are also doing advocacy with such organisations so that PLHAs can avail maximum benefits from the schemes.
- Resolving family conflicts. When family members attend SGM they accept PLHAs in the family. Sometimes network leaders also play "mediator" or "matchmaker" role for PLHAs when conflicts arise between family members and PLHAs.
- Increasing self-esteem and decreasing self-stigma. Sometimes SGMs also help them in developing leadership qualities.
- Health benefits as SGMs enhance knowledge of PLHAs in
  - PLHA-sensitive healthcare providers or clinics providing quality services
  - Availability of free CD4 testing
  - Enabling them to take informed decisions about starting ART
  - Giving awareness about not getting involved with quacks for wrong treatment
- Sexual and reproductive health and rights—In SGMs safer sex practices are discussed and condom demonstration is performed with a special emphasis to sero-discordant couples. DLNs also refer needy PLHAs to VCTC and PPTCT programs, gynecologists and STI specialists. However, other than condom no contraceptive method is being discussed.
- Motivates women who are unaware of their status to undergo HIV testing and also helps with mediating conflicts with their husbands.

## How the support group meetings have influenced the lives of PLHAs who participated in them?

SGM or DLN per se enables PLHAs to have information on a range of issues on a single platform, while other sources may not be catering to all the needs of PLHA at one go. For instance, doctors usually do not have time to talk in detail about the basics of HIV/AIDS, no proper and systematic follow-up counseling is practiced for addressing the needs of PLHA, their family members do not get adequate information on treatment issues etc. On the other hand, the network through its various activities provides tailored information and client-oriented counseling. SGM as one of its activities helps PLHA to discuss sensitive issues like disclosure of positive status, not infecting others, sexual health etc. SGMs, especially for PLHAs on ART, help in promoting adherence as in this forum they get to understand the importance of ART and the effects of missing a dose.

The results of the study show that support group offers the individuals various direct and indirect benefits and also leads to having new perspectives in life. The participation assists the individual in understanding the self and others. Also, this study describes that through support groups, PLHA participants are better aware and capable of dealing with the situations that are commonly encountered by other participants. It is also understood that support groups assume great significance as they provide opportunities through which social support is available to the participants. Social support is provided in the form of mutual guidance, providing monetary and emotional support, and providing feedback. As discussed earlier, support groups are regarded as the 'third network', the primary network being kinship and neighbour relations, and the secondary network being various professional support systems like the relief offered by social-welfare and health-care settings. It has been found that the information and psychological support they get from the support group members are complementary to the psychological support they get from their families, friends and spouses. The group helps them in coping up with the problems they face; help them prepared for anticipated challenges; remove the feeling of abnormality and make them more capable of dealing with potentially traumatic experiences.

Support group meetings serve multiple purposes. They are useful in socializing; sharing and getting information; getting peer and professional counseling; and getting psychological and emotional support. As seen under the previous section, SGM benefits PLHAs who attend as well as who do not attend SGM. For example: the advocacy activity of the networks that resulted in age relaxation for widows living with HIV (or who lost their husbands to HIV) will be useful for even those PLHAs who had never been to SGMs. In addition to the unique benefits of attending SGM, it serves as one of the many entry points for PLHAs to get various services from the networks and other agencies (linkages and referrals). SGM is closely linked with community mobilization and organizing for rights.

There is still scope of improving SGMs at different levels by different stakeholders.

The networks involved in conducting SGM need to:

- Document success stories and lessons learnt out of the advocacy activities carried out on the issues identified in SGM
- Initiate bereavement support meetings for spouses and negative family members
- Train the SGM staff on facilitation skills
- Ask one of the network staff to co-facilitate the SGM
- Not use certain English terms and jargons which may not be understood by all PLHA
- Link up with community organizations working with various marginalized groups like MSM, FSW, and IDU so that there can be cross-referrals.

Other stakeholders need to have great role to play in making SGM more effective through:

- Preparing operational guidelines for conducting various types of SGM effectively
- Preparing a training manual for training facilitators and co-facilitators of SGM
- Conducting training programs on organizing SGM for facilitators and co-facilitators of SGM
- Capacity-building in documentation of the lessons learnt in conducting SGM
- Conducting training on how to be sensitive to the needs of PLHA from various subpopulations (MSM, *Hijras*, IDU, FSW) in SGM and how to mobilize these subpopulations of PLHA

## Various methodologies in support group meetings

### 1. Mini-dramas

Some DLNs organize mini-dramas to convey messages—providing information about HIV disease/treatment; showing discrimination in health-care settings; conveying that network is there to support them (Drama titled 'Even if your relations leave you network will not').

### 2. Debates ('Pattimandram')

Some DLNs in Tamil Nadu organize structured debates, which are called 'Pattimandrams' (in line with the local culture to talk for and against a particular issue and then trying to come to a consensus).

Some examples of debate topics:

- "Whether taking ARVs is beneficial to PLHA?"
- "Whether HIV-positive mother can breastfeed her child?"

### 3. Dance and songs (cultural programs)

Once in a while some DLNs organize 'cultural programs'—especially on certain days like World AIDS Day—in which PLHA and people from marginalized groups also perform.

### 4. Songs by participants during SGM

To break the monotony in SGM, the participants are encouraged to sing their favourite songs—songs can be religious, classical or from cinemas.

### 5. Food recipes demonstration

In addition to telling what to eat and how to cook nutritious food, some DLNs may even demonstrate cooking some nutritious and tasty foods. Some of the recipes that had been taught in a DLN include 'Egg bajji' and "Murungaikai Kootu" (Drumstick sidedish).

### 6. Games

Various games are also used in some DLNs as 'warm-up' exercises or as energizers. In one DLN, a 'laughing session' is held routinely in which the participants have to just laugh without any reason (based on the local tradition of having 'laughter clubs'). Through some games, messages are also conveyed. For example, in the 'clapping hands' game, the participants are asked to start with clapping with one finger first, then two fingers and so on. They will be explained that as more fingers join the sound becomes louder. This is used to demonstrate the strength of joining forces and joining hands to achieve common goal.