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Guidelines for Establishing and Operating Successful Support Groups for People Living with HIV

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OVERVIEW

What is a support group?

A support group is a group of people who come together to talk about a challenge, experience and/or role that they have in common without being judged, blamed, stigmatised or isolated. By joining support groups, people realise that they are not alone in their situation. The group is a forum in which members can share problems and concerns, brainstorm solutions, give each other advice and form friendships.

Support groups are effective because members receive firsthand advice and the approaches that they learn come from peers who are coping with very similar circumstances. This means that the guidance is not theoretical, but practical, personal and relevant.

In addition, support groups often advocate for members' mutual goals and create awareness about shared challenges. This joint action leads to policies that better serve people living with HIV (PLHIV) and fosters supportive community environments in which group members can thrive.

Why do People Living With HIV form support groups?

PLHIV form support groups to give and receive emotional, social and spiritual support. They also form support groups to develop and sustain positive strategies for living with the virus and to strengthen their knowledge about HIV and AIDS. The

group is a place where PLHIV can share experiences confidentially, gain self-confidence, make friends and develop a public voice. When PLHIV form support groups, the groups typically address the following broad topics:

- **Living positively with HIV.** Group members talk about how to accept their diagnosis and live positively. They discuss the health and psychosocial challenges they've experienced and how best to deal with these challenges. For example, members might share ideas about attaining good nutrition and maintaining adherence to anti-retroviral therapy (ART), or exchange practical advice about overcoming anxiety, dealing with feelings of powerlessness, and coping with stress. Sharing experiences is especially helpful for members who have recently learnt of their HIV-positive status.

- **Disclosure.** Support group members can help each other think through how to disclose their HIV-positive status to friends, family members, spouses, partners and co-workers. Disclosing an HIV-positive status can be very stressful, and members can share ideas about what to say, when to disclose and who to disclose to.

- **Relationships.** Members can offer each other advice and guidance, and can share knowledge about re-infection. Peer commitment to prevention helps make these practices more socially acceptable, appealing and sustainable. Although HIV is now a treatable chronic illness, support groups may also address bereavement issues. In

particular, members may discuss how to talk with friends and family about death and dying and may introduce activities such as memory boxes and succession planning.

- **Stigma.** Support groups provide an important refuge from the stigma that PLHIV and their families may experience. Groups can also collectively develop ways of addressing stigma in their communities. For example, children living with HIV or caring for sick parents often feel excluded from activities at school or miss classes due to their caring role. Adult support groups can find ways of helping children in these situations by, for instance, encouraging schools to establish support groups for pupils.

- **“Buddies”.** The “buddy” system is a method of providing one-on-one support over a long-term period, and is especially effective for people who have recently learnt their HIV-positive status or have commenced ART. PLHIV support groups are often a hub for “buddies”; members both serve as buddies and identify buddies who can support them. Buddies’ key role is to offer personal and frequent support to their peer PLHIV by, for example, reminding them to take their ARV drugs on time and accompanying them to the clinic for check-ups.

GUIDELINES

Catholic Relief Services (CRS) conducted research with more than 10 organisations in Zimbabwe to understand the basic guidelines that underpin the formation and operation of

successful support groups. This booklet articulates these basic guidelines. The audience is PLHIV who belong to support groups or who want to form support groups, as well as the non-governmental organisations (NGOs), community-based organisations (CBOs) and health facilities that help to initiate and assist support groups.

The guidelines are grouped under five main headings:

- **General**
- **Forming Support Groups**
- **Operations and Logistics**
- **Activities**
- **Groups for Specific Populations of PLHIV**

General

1) PLHIV must meaningfully participate in all aspects of support group formation and operation.

Although NGOs, CBOs and health facilities often play a role in forming, nurturing and facilitating support groups, the primary drivers and decision-makers should be the PLHIV who belong to the group. Meaningful participation by PLHIV ensures that decisions are made by the people closest to the situation; that PLHIV have ownership over the group; and that PLHIV know the group's vitality is dependent upon their own needs, interests and participation.

2) Group members must uphold confidentiality at all times.

Each member must be certain that any information he or she shares with the group will not be discussed outside group boundaries without his or her consent. Support groups only work when members trust each other and can have free, open discussions. One way to promote confidentiality is for members to sign a “contract” that commits them to upholding confidentiality.

Forming Support Groups

1) Every support group should have a constitution, developed by its members, that clearly outlines how the support group will function.

Constitutions provide clear guidance about what is allowed and is not allowed within the group, and they establish the framework for the group’s norms and values. The constitution should address, at minimum:

- Overall vision and mission of the group,
- Membership (e.g., how new members will be recruited; maximum number of members; membership fee, if any),
- Rights and responsibilities of group members,
- Confidentiality,
- Conflict resolution and grievance procedures (e.g., what happens if one member violates confidentiality),
- Leadership (positions, selection, term length and succession),
- Meeting frequency, and
- Life span of the group.

Having a constitution that all group members are aware of and believe in provides the foundation for teamwork and smooth operations and reduces the potential for confusion and conflict.

2) Groups members must share a common vision and mission.

If members do not share a common vision and mission, there is bound to be conflict within the group. PLHIV should seek out support groups that have a vision and mission they believe in.

3) Membership in support groups should be voluntary.

Once individuals understand the purpose of a particular support group, they decide whether or not they want to join. PLHIV can join as many support groups as they want, as long as they actively participate in each group and the groups meet their needs. Before joining a group, PLHIV should not only consider how they might benefit from the group, but also how they will be able to contribute to the group.

4) Support groups for PLHIV should only contain PLHIV.

However, there are many ways that people who are HIV-negative can support PLHIV. For example, in some communities people have formed ART peer support groups comprised of people who are HIV-positive, people who are HIV-negative, those that are receiving ART and those who are not. These groups help PLHIV on ART adhere to their treatment regimens and live positively. Similarly, individual community members may serve as “treatment buddies” for PLHIV who belong to support groups.

Families of PLHIV, caregivers of orphans and vulnerable children, and other specific groups affected by the HIV/AIDS pandemic should consider forming their own support groups in which they share mutual problems and concerns, brainstorm solutions, give each other advice and form friendships.

5) Group leadership must be selected through a process that is transparent and fair, as articulated in the group constitution.

There are many different methods of determining which members will comprise the group's leadership. Some support groups use a system of "rotational leadership", whereby members move through leadership positions on a regular basis. Other groups use secret ballot elections to choose their leaders. Each method has its own strengths and weaknesses, which group members should carefully weigh.

One way NGOs and CBOs can assist support groups is by serving as objective observers during leadership elections. For example, Tariro Support Group's constitution says its leaders will be elected annually by secret ballot. The Centre, a Harare-based NGO with close ties to Tariro, assists during the process to ensure free and fair elections.

6) The roles of group leadership should be clearly defined.

Support group leaders do not undertake unilateral decisions, rather, they build consensus and act as coordinators. Leaders' roles should involve:

- Ensuring all members actively participate,
- Upholding the group constitution,
- Organising effective group meetings, and
- Overseeing the group’s schedule of activities.

7) A support group cannot meet all of the emotional, social, spiritual and health needs of PLHIV. What a group can do and cannot do should be clear to all members.

Individual counselling, medical assistance and family support are all important types of support that are not typically offered by support groups. Support groups are just one type of support that can help PLHIV live positively.

8) There must be a clear distinction between support groups and groups that work together on income-generating activities (IGAs).

Due to the economic burdens that PLHIV face, such as the cost of healthcare and transport to medical appointments, support group members sometimes decide to collaborate on IGAs. But when support groups engage in IGAs, their support focus can be compromised. In addition, people who are not HIV-positive may begin asking to join the group. As one support group member said, *“Support groups are not about money issues; they are about giving each other emotional support to cope and about having a place where we are free to discuss our illness in a safe, non-judgmental atmosphere”*.

One option is for interested members to form separate groups that pursue particular IGAs. Membership can overlap, but the

support group and the IGA groups should keep their own identities, including their own vision and mission.

Operations and Logistics

1) The meeting venue needs to be accessible, affordable, safe and agreeable to group members.

When selecting a venue, members should consider the cost of transport fares to and from the location for all members, while at the same time recognising that some members purposely decide to attend a support group in another neighbourhood because of concerns about stigma and discrimination in their own neighbourhood. In rural areas, groups often meet at people's homes. In urban areas, meetings are often conducted in churches, schools, municipal halls or members' houses. All members should agree upon the meeting time.

2) Members should come to a consensus about whether to have refreshments at meetings.

PLHIV have greater calorific requirements than people who are HIV-negative and, especially in rural areas, members may travel a significant distance to attend meetings and may arrive hungry. If members decide to have refreshments, they must determine how these refreshments will be provided. In rural areas, members may prepare food using produce from nutrition gardens run by home-based care programs. In urban areas, members may bring packed meals for themselves or to share. Groups may decide to collect modest membership fees to support refreshment purchases. Or, they could ask an affiliated

NGO, CBO or health facility to provide refreshments. Such organisations could use this opportunity to share information with the group about good nutrition and careful cooking.

3) Meeting facilitators can come from inside or outside the group; outside facilitators should have an excellent understanding of the group's purpose and ground rules and must uphold confidentiality.

The group should identify meeting facilitators when developing the master diary of activities (see below). Each member should be tasked with facilitating at least one meeting on a topic that he/she feels comfortable with. If the group wants to explore a topic and no member has the required expertise, the group should look for qualified facilitators within other PLHIV support groups or identify qualified outside facilitators.

4) The group should establish meeting ground rules.

These rules are more specific than the constitution and include things such as agreeing to listen when others are speaking, respecting time, and supporting the participation of all members.

5) Home-based care should be an entry point into support groups.

Volunteer caregivers should know about support groups in their area so that they can refer patients to these groups, and group members should be well-connected to home-based care programs so that they can refer members to these programs, if

necessary. NGOs, CBOs and health facilities can look to support groups when recruiting volunteer caregivers.

Activities

1) On a regular basis, group members should work together to develop a diary of events and activities.

At a set period – usually once or twice a year – groups members should work together to prioritise events and activities for the next period. This “master” diary should be circulated to all members. Creating a diary helps ensure that members’ expectations, needs and desires will be addressed during the period. Some successful groups establish a topical theme for each month of the year, such as nutrition or adherence, and then organize speakers, activities and events that support this theme. Maintaining a varied, relevant, dynamic schedule is critical to retaining members.

Here are three examples of activities currently engaging support groups in Zimbabwe:

- Training in peer and group counselling.
- Keeping up-to-date on the latest research on HIV and AIDS. This may be done using knowledge within the support group and/or through partnerships with health centres, the Ministry of Health, NGOs and CBOs. Topics could include prevention, nutrition and treatment literacy.
- Sport. Sport improves people’s health while also building trust and camaraderie among group members.

2) Groups should document their work for institutional memory and reference, and to enable them to share best practices and lessons learned with other groups.

Exchange visits can be an effective way of promoting learning and sharing amongst support groups.

3) Strategic partnerships with NGOs, CBOs and health facilities are critical to maintaining vibrant, active support groups over the long-term.

Strategic partners can keep groups updated on the services available for PLHIV and advise them of new opportunities for access to resources.

Support Groups for Specific Populations of PLHIV

PLHIV may form support groups for specific populations, such as children, youth, women, men, the elderly or pregnant women.

1) Parents or guardians must give their informed consent for children under the age of 18 to participate in support groups.

NGOs, CBOs and health centres that facilitate support groups for children must specifically seek the informed consent of parents and guardians. Parents/guardians need to understand the group's goals and objectives and be aware of the meeting location and time. Informed consent also provides the organisation with some measure of legal protection in case anything happens to a child on the way to or from a group meeting. Organisations can use the informed consent process to begin developing relationships with parents/guardians. These

relationships are important because the organisation may need to discuss significant issues affecting a child with a parent/guardian, or vice versa.

2) Children's groups should have adult facilitator.

The adult facilitator moderates discussions, links children with relevant community resources, and identifies children that need one-on-one counselling or a home visit. Adult facilitators should have experience working with children and a solid understanding of the tenets of child protection and the issues faced by children living with HIV. He/she must know how to skilfully increase children's role in group management as they develop their capacities and become more mature.

3) Adult facilitators of children's support groups must sign a confidentiality "contract".

This contract should explain the specific occasions when information shared within the group will be brought to the attention of people outside of the group – for example, if children report that they are being sexually abused. Children and their parents/guardians need to fully understand this confidentiality contract.

4) Children's support groups should undertake activities chosen, to the greatest extent possible, by children themselves.

Just like adults, children should be in charge of determining what they want their support groups to accomplish.

5) The adult facilitator must prepare children and youth ahead of time for their transition to a youth or adult support group.

It is difficult for a child or youth to leave a group they have come to depend upon once they reach a certain age. However, to ensure that support groups meet the specific needs of children and youth, there must be a time when members “age-out”. The earlier children and youth are prepared for this transition, the better.

6) PLHIV should have the option of joining support groups just for women, just for men, or for both men and women.

Female-only support groups can empower women to become more self-confident and assertive, especially in the area of advocacy. However, a challenge to creating vibrant female support groups, especially in rural areas, is that women may be reluctant to undertake activities without seeking men’s permission. When this issue arises, one strategy is for group leaders to give the woman small responsibilities, and then to slowly increase her opportunities for decision-making as she becomes more comfortable and confident.

7) Members should consider the strengths and weakness of having groups with a diverse membership.

Having diverse membership in terms of educational background, nationality, income level and profession has both advantages and disadvantages. The advantages are that a diverse membership can bring with it a broad range of networking opportunities and a variety of resources. The disadvantages are that social and professional differences can make members’

experiences less relevant to one another and that social tensions can become exacerbated in group settings.

CREDITS

CRS is the official relief and development agency of the U.S. Catholic community. The agency has worked in Zimbabwe since 1989, with the goal of mitigating the effects of HIV and AIDS on the people it serves. CRS partners with more than 20 community-based organisations across Zimbabwe, several of which nurture and facilitate support groups for children, youth and adults living with HIV.

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