Mental Health and HIV/AIDS

Psychosocial Support Groups in Anti-retroviral (ARV) Therapy Programmes

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Mental health and HIV/AIDS series

This is module 4 in the Series 'Mental Health and HIV/AIDS'.

Other modules are:-

1. Organization and systems support for mental health interventions in anti-retroviral (ARV) therapy programmes
2. Basic counselling guidelines for anti-retroviral (ARV) therapy programmes
3. Psychiatric care in anti-retroviral (ARV) therapy (for second level care)
5. Psychotherapeutic interventions in anti-retroviral (ARV) therapy (for second level care)

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Preface

The AIDS epidemic is one of the most serious public health and social challenges the world has ever faced. It not only destroys individuals, but also families, communities and the whole societal fabric. Worst hit are communities least able to put in place appropriate measures for its containment and control. It is probably the biggest hurdle to the attainment of the Millenium Development Goals.

As a bold measure to counteract it, WHO has launched the 3 by 5 Initiative that, while primarily aimed at providing treatment to millions of people in need of it, also aims at building the elements of the health system that will be needed to deliver it.

Therefore, treating mental disorders of people living with HIV/AIDS has huge humanitarian, public health, and economic consequences; the same applies to providing people in need with appropriate psychosocial support. This is not an easy task, in view of the scarcity of human, technical and financial resources.

The present series is a contribution from the Department of Mental Health and Substance Dependence to the WHO 3 by 5 Initiative, but also goes beyond that. Its production brought together experts on mental disorders in people with HIV/AIDS from around the world. They graciously contributed their knowledge, expertise, energy and enthusiasm to this endeavour. We are profoundly indebted to them all, as well as to the agencies and organizations to which they are connected. The contributors' names are indicated in each of the modules in this series. A special thanks goes to Prof Melvyn Freeman, who steered this illustrious group, sometimes through uncharted waters, with patience and efficiency.

Now, we make this material available, not as a finalized product, but rather as a working tool, to be translated into local languages, adapted as needed, and improved along the way. A set of specific learning/training instruments, related to this series will soon be released, as another contribution to the mammoth task of improving the skills of the human resources available and needed, particularly where the 3 by 5 Initiative is being rolled out. Comments, suggestions and support are most welcome.

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Foreword

Among those affected by or at risk of acquiring HIV/AIDS are people with mental disorders. This happens primarily through-two mechanisms:

(i) some mental disorders make people more vulnerable to infection with the virus (e.g., intravenous drug use, alcohol abuse, major depression and psychotic disorders, developmental disabilities, and other mental disorders that impair judgement and decision-making) and more vulnerable to situations that increase the risk of passing the virus to others; and

(ii) some forms of HIV infection affect the brain thus creating clinical pictures that initially resemble several different mental disorders.

Unfortunately the interplay between HIV/AIDS and mental disorders goes beyond the mutual facilitation of occurrence. Perhaps the most relevant practical aspect of this interaction relates to adherence to treatment. It is well known that the presence of an untreated mental disorder – particularly depression, psychotic and substance use disorders – considerably decreases adherence to the treatment of any condition, including HIV/AIDS.

The failure of adhering to the proper regimen of anti-retroviral (ARV) treatment carries three major consequences. First, the expected benefit of the treatment does not take place, the clinical situation worsens and mortality increases. Second, the irregularity of the intake of the ARVs brings new resistant strains of the virus, thus complicating its future control. Third, the interrupted or incomplete course of treatment wastes money and other resources that could otherwise have produced more cost-effective results in adherent patients.

In addition, being HIV-positive, or having someone with HIV/AIDS in the family can be stressful for some people with HIV and for carers. In many countries where HIV prevalence is high it is not infrequent to find more than one person with HIV/AIDS in the same household, at the same time. The stress of living with a chronic illness or caring for an ill relative – even if it does not lead directly to a mental disorder such as major depression – may result in a chain of psychosocial reactions that cause considerable pain and dysfunction. Such dysfunction and

distress may decrease resistance and resilience to co-morbid conditions, and contribute to reduced adherence to medical regimens.

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Purpose of Support Groups

People facing similar life situations, especially adverse or unpleasant situations, often find comfort, support and strength in being together with other people in the same or similar situations. Support groups are places where people with common concerns and needs can share their experiences and help each other through difficult periods, and thereby achieve better health and well-being for all the members. Support groups have been referred to as 'places of healing' because they allow people to meet their needs and heal themselves, as well as assist others to do the same, in an environment that is understanding and caring.

Support groups help people cope with their lives and grow as human beings. Groups can work at various levels and, depending on the group objectives, may help people with emotional, spiritual, physical, psychological, and educational needs. Most groups decide for themselves, with the assistance of a facilitator, what their goals and objectives are and work towards achieving these.

People in groups usually share information, knowledge, ideas and experiences. Through the process of talking and listening, being supported and supporting others, people are often able to move forward with their lives with renewed strength and vigour. Groups are set up, and grow and survive on the key principle of **'mutual support'**.

Mutual Support

As will be explained later in this document, there are many kinds of support groups, each of which will be able to achieve different goals. While there are many different issues that determine the direction of a group and what it can achieve, two of the most important of these are what people in the group wish to get out of the group and the skill and experience of the facilitator or facilitators of the group.

It is very important that facilitators are fully aware of their levels of competence, training and experience and contain the group interaction within what they are able to manage. Otherwise, it is possible that the group interaction may be harmful, rather than beneficial. Some kinds of interaction, for example deeper exploration of emotions, or using interactions between group members to challenge fixed patterns of relating to others, require skilled facilitation, probably best handled by an experienced professional mental health practitioner, such as a psychiatrist, psychologist, social worker or psychiatric nurse.

Support groups for people living with HIV/AIDS

Groups for people living with HIV/AIDS may be very useful for different people at different points of the infection. Most People Living with HIV/AIDS (PLHA) experience emotional distress at some point, though the degree may differ substantially. Some PLHA may be somewhat distressed when they first hear that they are positive, while others may be overtly suicidal. Some people may be able to overcome their emotional distress with support from family and loved ones, while others may sink into deep depression. Some people may find that going onto anti-retroviral therapy and staying on it is easy, while others may find this difficult. Groups may be useful for all these people, sometimes mainly as receivers of support and sometimes mainly as providers, since providing support can often be as meaningful and important as receiving it.

Groups may be particularly useful because of social stigma, causing rejection and discrimination of PLHA by society. As a result of stigma, people may experience loneliness, isolation and depression, which could make them even more ill. The social network established in support groups may help to reduce these feelings of isolation and create a sense of social solidarity with others who are experiencing similar challenges in their lives. The very fact of being in a group can itself relieve emotional and psychological stress.

The decision of whether or not to start anti-retroviral therapy (ART) is not simple for most people. Groups can be helpful in creating a space in which PLHA can explore their questions and concerns regarding ART with other PLHA and make

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decisions regarding their own care. This is especially helpful when some members of the group are already on the medication. Sharing experiences in the groups and learning from others helps individuals to make more informed decisions about their lives and care.

People on ART may also find being in a support group very useful. Many PLHA find that some of the emotional difficulties they were experiencing before going onto ART, are replaced by new and different challenges, such as those related to adherence, social stigma, side effects, or depression. Often others in the group, who are also on ART, are likely to be experiencing similar kinds of issues, and exploration of the concerns and mutual support can be enormously helpful to all.

Support groups are for people to:

❖ Share common experiences, difficulties, and feelings;

❖ Gain a better understanding of side-effects and other negative consequences of the disease and/or treatment, and learn different ways of coping;

❖ Reduce feelings of fear, anxiety, guilt, and other negative emotions associated with the disease and/or treatment;

❖ Connect with other people who share similar problems and experiences;

❖ Gain insight into self and different issues discussed in the group;

❖ Improve one's ability to confront these and other adverse situations more effectively;

❖ Restore and improve one's family and social support networks;

❖ Obtain reliable information;

❖ Access referral systems; and

❖ Promote individuals' sense of social responsibility with regard to public health issues, such as preventing transmission of the virus or re-infection, combating stigma and raising awareness of HIV and AIDS.

Support groups are certainly not the only way for PLHA to deal with problems and to grow as people, and groups may not be the best option for all individuals. For example, some people may need medication to deal with mental distress or disorder, some people may prefer or require individual counselling or therapy, while for others, taking part in community activities promoting positive living for PLHA may be the most constructive way for them to deal with their situation. Nonetheless, for many people, groups offer a cost-efficient option to improve well-being.

Psychosocial support groups in developing countries

Whether psychosocial support groups are effective and appropriate in poor developing countries with vastly differing cultures may be of concern to some people. However, the following three examples, from different cultures, indicate that support groups can be highly successful in reducing mental health problems.

Example 1

Group Interpersonal Psychotherapy for depression in rural Uganda

Due to high rates of depression in the Rakai and Masaka provinces in Uganda, Group Interpersonal Psychotherapy (adapted to the local circumstances) was set up in 15 villages. The 107 people who participated in these groups were compared before and after the intervention with men and women who did not receive the therapy.

The groups met for 90 minutes over 16 weeks and were led by local people who had received two weeks of intensive training in Group Interpersonal Psychotherapy. During each session the group leader reviewed each participant's depressive symptoms and then asked them to link the events of the past week with his/her mood. The group leader facilitated support and used group members to suggest ways of change.

Results of the evaluation of the groups showed that those who participated in the groups had far less depression (statistically significant) following the intervention, than the control group. The researchers concluded that 'Group Interpersonal Psychotherapy was highly efficacious in reducing depression and dysfunction'.

Bolton P et al. (2003). Group Interpersonal Psychotherapy for Depression in Rural Uganda. A Randomized Controlled Trail. JAMA 289(23), 3117-3124

Example 2

Psychosocial Support Groups for patients with MDR-TB in Peru

In 1999 a Psychosocial Support Group intervention was introduced in Lima, Peru for individuals undergoing complicated long-term chemotherapy for

multidrug-resistant tuberculosis (MDR-TB). Achieving a cure from these drug-resistant strains of TB is possible, but requires strict adherence to difficult drug regimens for an extended period of time (18-36 months). Taking into consideration the difficult social and emotional experience associated with the disease and its treatment, the intervention was introduced as a means to strengthen adherence, as well as improve the quality of life of patients.

The rationale for the Support Group Intervention was to create a forum in which these otherwise socially isolated individuals could come together and face the disease and, through solidarity and mutual support, help one another to complete the difficult treatment. The broader result was the creation of a social support network, both formal and informal, as friendships were formed and group members sought each other outside the groups. This served to enable individuals to endure the difficult treatment, regain hope, draw inspiration, and provide mutual support to others undergoing similar difficulties.

The ongoing support groups convened twice a month for 90 minutes, and were co-facilitated by a team made up of a nurse and a psychiatrist. Participation included approximately 8 -12 patients in treatment, as well as several cured patients who were invited as guests to offer their testimonies and provide ongoing support. The membership in the groups changed over time as new members were integrated and other participants withdrew voluntarily. In addition to the therapy group sessions, periodic recreational excursions, informal celebrations, and family workshops were organised.

While it has not been possible to conduct a formal evaluation measuring the impact of this intervention, its observed impact has prompted broad replication of this strategy to new areas as treatment becomes available, including other parts of Lima, as well as several provinces of Peru.

Sweetland, A. Acha, J., & Guerra, D. (2002). Enhancing adherence: The role of group psychotherapy in the treatment of MDR-TB in urban Peru. In A. Cohen, A. Kleinman & B. Saraceno (Eds.), World mental health casebook: Social and mental health programs in low-income countries (pp. 57-85). New York: Kluwer Academic/Plenum Press.

Example 3

Peer-led Support Groups for people affected by HIV

Since 2001, HIVSA, an NGO operating in Soweto, South Africa, has been running support groups for people infected and affected by HIV. Group facilitators were selected from treatment programmes run by an associated research organisation and trained in group facilitation. Generally working in pairs, facilitators run support groups for clients recruited from treatment programmes, from VCT services and from the wider community. The facilitators have fortnightly consultation with a professional mental health worker and attend fortnightly debriefing sessions.

In a recent evaluation, involving primarily client-based measures, it emerged that the groups provided an opportunity for members to clarify misconceptions and obtain more individualised information in relation to their particular HIV-related concerns, including about ARV treatment. The groups also provided emotional support, mutual solidarity between HIV-positive members in the face of rejection and discrimination, as well as support for HIV-positive members in coming to terms with their status, dealing with disclosure, adopting a positive lifestyle and avoiding 'risk behaviour'. Finally, the groups provided a forum for problem-solving around treatment issues, the reactions of family members and community to HIV-positive people, as well as relationships with sexual partners, including questions of partner notification and negotiating safer sex practices.

Types of support groups

People working with PLHA or other affected individuals in a range of settings, such as, in clinics where patients receive their ART, in homes where they may visit as caregivers, or in advocacy non-governmental organisations (NGOs), are likely to come across individuals with various unmet needs. They are also very likely to find that many people have quite similar needs. For example, some people may need better knowledge of HIV/AIDS, others may need increased social support, while others may have developed deep depression, to the extent that they need extensive psycho-therapeutic intervention and, possibly, psychotropic medication. Furthermore, it is not only PLHA themselves who may have unmet needs; families of PLHA may also need additional support to continue their supportive role as volunteer caregivers. Starting a group and deciding who would be appropriate to be in it will depend on the greatest needs in a given community.

There are many different types of support groups for people living with HIV/AIDS. However, often there is overlap between different kinds of groups. For instance, people in a therapeutic group may at certain points need information and education, while people in an education group may, at times, share feelings and provide support for a member who may be struggling with a certain issue at a point in time.

The needs of individuals and communities affected by HIV/AIDS, or who are taking ART, may differ from place to place, and from person to person, so it is very important to identify the most common or pressing needs, then select the most appropriate format for services.

Three of the most common types of groups that can be used with PLHA or within ART programmes are:

❖ Educational groups;

❖ Peer-led support groups; and

❖ Therapeutic groups (led by professionals or paraprofessionals).

This chapter describes each of these types of groups, along with the benefits and limitations of each format.

Educational groups

Educational groups have as their main objective transmitting important information about a specific issue or common problem that affects group members' lives. Often these groups can have a 'workshop' format, with a series of group activities that all focus on the issue at hand. At other times, they will be in the format of a lecture, followed by a question and answer session. Examples of educational groups would be ones that are focused on:

❖ ARVs and side effects;
❖ HIV and pregnancy;
❖ Adherence;
❖ HIV and the family;
❖ Opportunistic infections;
❖ HIV/AIDS transmission; and
❖ Other relevant topics.
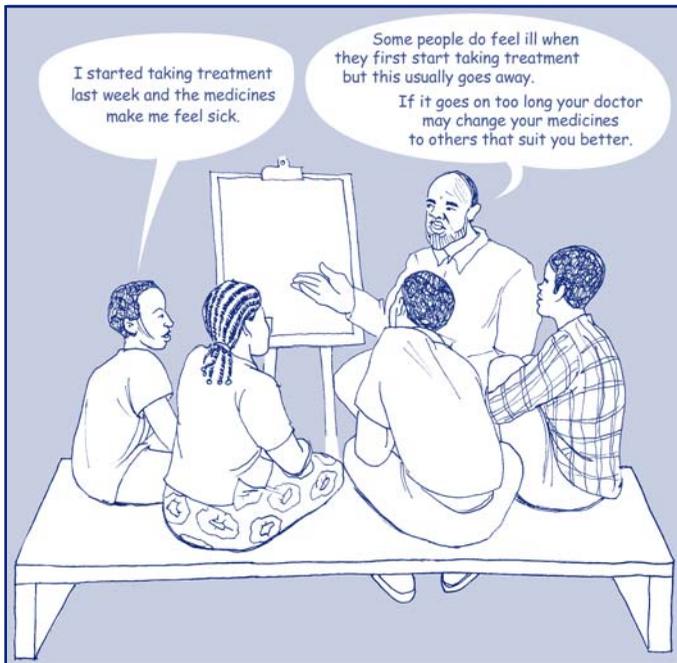
Educational groups

Benefits of educational groups:

❖ It is common for individuals to have many questions regarding their disease and/or treatment, and the group format can be useful in terms of maximising limited human resources (one or two facilitators for a group of individuals). The group format for delivering information is adequate for the majority of individuals, reducing the number of people who may require supplementary individual attention;

❖ This type of group can be very helpful in addressing specific issues of concern to individuals in greater depth than would be possible on an individual basis due to time and resource constraints;

❖ Some individuals may be shy or embarrassed to ask questions of their doctor/ nurse, and may feel more comfortable in a situation where many people are asking questions. Also, others in the group may ask questions (and get answers for the whole group) that individuals may have been too scared to ask;

❖ The information that group members provide, based on their own experiences, may be particularly helpful to others in the group, since it reflects 'real experience' rather than just 'expert opinion';

❖ Group members meet others with similar experiences in an emotionally neutral setting, and receive informal support from others; and

❖ Participants should leave the session with a specific set of skills and information that will improve their ability to live well with HIV.

Limitations of educational groups:

❖ Since these groups generally have specific learning goals, it may not be possible to address other issues or concerns that arise in the session that do not fall within the stated goals of the session; and

❖ Generally this format does not include a therapeutic component that will help group members to maximise their ability to act on the information they receive in these sessions.

Peer-led support groups

The second type of support group is organised by individuals affected by HIV/ AIDS, the primary purpose of which is to provide mutual support. This type of group does not replace similar professionally led services, but may serve as a useful complement.

Peer-led support groups

Benefits of peer-led support groups:

❖ Individuals with the same disease and treatment can be especially suited to support others in the same situation, based on their own experiences;

❖ It may be possible to organise this type of group with very limited resources;

❖ Peer-led support groups require considerable initiative from some individuals who assume leadership roles among their peers and, through their model, encourage other members to assume a more pro-active stance with regard to their own health and lives;

❖ Peer-led initiatives may complement services available through health institutions; and

❖ This type of group can provide a forum that enables mutual support among HIV-infected individuals, as well as create a means for community organising, which may or may not take on an additional mobilising purpose.

Limitations of peer-led support groups:

❖ Peer-leaders may not have as much experience in troubleshooting complicated issues that may arise in this type of group;

❖ Peers may not necessarily have the same level of technical information about the disease and/or treatment and may inadvertently contribute to the perpetuation of common myths and misconceptions about the disease; and

❖ Because peer-led support groups are often dependent on one or two individuals as leaders and organisers of the group, if their motivation declines, or they are no longer available (because of other commitments, leaving the area, or illness), the support group may collapse.

Therapeutic groups

A therapeutic group is essentially a conversation among a group of people with something in common, that is facilitated by another person (the facilitator) and has a therapeutic objective or purpose. In order for it to be 'therapeutic', it is necessary for the conversation to help bring about changes in the ways in which the participants think, feel and act. The desired outcome is to reduce their suffering and to increase their possibilities of living happily and healthily.

At times, PLHA may feel overwhelmed by the emotional burden of the disease, including depression, grief, frustration or anxiety. For these individuals, a therapeutic group may be the most appropriate type of intervention. However, even within the broad category of therapeutic groups there are different kinds of groups with different goals and objectives. They may also go about achieving their objectives in different ways, determined by the expressed needs of the group, as well as the qualities, skills and experience of the facilitator. All therapeutic support groups must have at least one constant person who leads the group, often referred to as the *facilitator*.

Therapeutic support groups

The facilitator for a therapeutic group could be a:

❖ Mental health professional (psychiatrist, psychologist, social worker, or psychiatric nurse); and

❖ Para-professional (health professionals from another discipline or others who are specially trained for this function, such as a nurse, an experienced community health worker or PLHA)

Therapeutic support groups may be run differently by mental health professionals or para-professionals. For example, mental health professionals will probably have more advanced skills and abilities to offer than para-professionals with more limited training in running groups. On the other hand, para-professionals may be closer to group members in terms of background, life circumstances, and sometimes, language.

Depending on the needs of the group, one type of group leader may be more appropriate for the group than others. In most countries there is also a legal regulatory body, which determines what qualifications a person needs to deal with different kinds of mental health problems, and it is advisable to check with this body regarding who is allowed to do what kind of interventions in the country where you are working.

Therapeutic support groups run by professionals

A psychiatrist, psychologist, social worker, or psychiatric nurse who has special training in running groups should be able to assist group members not only to share their experiences and find ways to deal with problems, but also to explore emotionally charged issues in greater depth.

Benefits of professionally facilitated groups:

❖ Group facilitation can be challenging and requires a special set of skills. When available, professionals may be more able to fulfil this role;

❖ Professionals are generally more comfortable and skilled at managing emotional crises that may arise in sessions;

❖ Mental health professionals may be more skilled at recognising individuals who may require additional individual attention; and

❖ Mental health professionals will know how to assess and deal with group members with more serious mental or emotional problems.

In all support groups, part of the function of the group is to allow members to share their feelings about what is happening in their lives and to have members of the group recognise those feelings and offer support. However, if the function of the group is to explore people's emotions and the reasons underlying those feelings in depth, or to use interactions between group members to challenge fixed ways of thinking or patterns of relating to others, then it is best to ensure that it is run by an experienced professional. Also, if these kinds of issues come up in a group with other objectives, then it is best to consult with a professional about how to proceed.

However, it is not always possible to find professionals able to fulfil this role due to resource constraints, and professionals may not be best suited for all situations.

Limitations of professionally facilitated groups:

❖ Social stigma may be attached to attending a professionally led therapeutic group and therefore some members may be reluctant to participate; and

❖ Where professionals are in short supply it may not always be the most effective use of their time, especially if there are trained paraprofessionals or other appropriate people to facilitate the group.

Therapeutic support groups led by paraprofessionals

In settings with resource constraints, the best option may be to train several paraprofessionals in group facilitation. These individuals may be professionals of other disciplines (for example, a nurse), or other individuals who are motivated to fulfil this role. In some circumstances it may be possible to provide intensive training to PLHA who can then run therapeutic support groups. Such groups would provide a forum for members to share experiences and feelings and gain support, but would generally not encourage in-depth exploration of emotions.

Benefits of paraprofessional-led groups:

❖ In low-resource settings with limited access to trained mental health professionals, training group facilitators may be a more economically viable option;

❖ In many support groups, the mere gathering of many individuals with similar life experiences and challenges can have a therapeutic benefit, irrespective of the group leader;

❖ Group members are less likely to see themselves as sick or even 'crazy' if the group is not run by a mental health professional. This can have distinct advantages for people in sharing with the group and opening up emotionally; and

❖ If the paraprofessional is HIV-positive, he or she may have a deeper understanding of the issues being addressed. He or she may also be more trusted by the group members.

Limitations of paraprofessional-led groups:

❖ Inexperienced group facilitators may have more difficulty addressing crises or emotionally charged topics, such as suicide and death, which may have significant therapeutic implications;

❖ If a paraprofessional is HIV-positive, the group may look to him or her to provide answers to a range of issues that are best worked through in the group process. A less skilled facilitator may attempt to give advice rather than allowing people to decide for themselves what is best. (This is not referring to factual information, for example on side effects of ART or what a CD4 count is, which a facilitator should provide if able to do so). For facilitators who are HIV-positive, it is also possible that some issues or problems of group members may hit "too close to home," that is, they may be difficulties that the facilitator faces with his/her own illness, and this may compromise his/her ability to deal with these issues effectively in the group; and

❖ It may sometimes happen that a group member gets into an emotional state that the facilitator is not skilled and experienced to deal with, for example, if a member of the group feels suicidal. It is essential that the facilitator refer the person concerned immediately rather than attempting to handle a situation beyond his or her competency, which may be detrimental not just to one individual but to all members of the group.

Group structure and membership

Once it has been decided what kind of group is going to be organised, based on the needs of potential group members and the availability of an appropriate facilitator, a number of other important decision need to be made. These include whether the group is going to be an open or a closed group, whether the group is going to be time-limited or ongoing, and whether the group will be 'mixed' or target specific people. These choices will need to be made whether one is running an education group, a peer-led support group, or a therapeutic group.

Open vs closed groups

Open groups

An open group is a group that allows members to join or to leave the group in any session. A person wishing to join the group may do so even if the group has been running for some time. Moreover there is no agreement or 'contract' to stay in the group and members may come and go as they please.

Benefits of open groups:
- ❖ People needing immediate support can join the group at any time rather than having to wait for a new group to start;
- ❖ It may be easier to accommodate PLHA whose physical, emotional or practical situation prevents them from being able to attend regularly; and
- ❖ A number of people may not want or need on-going support, but could receive help through an open group if and when they require it.

Limitations of open groups:
- ❖ It may be difficult for group members to make deep bonds with each other and to come to fully trust each other sufficiently to open up and share feelings or hurtful and embarrassing experiences, since membership may be changing over time;
- ❖ Group members may be more concerned about confidentiality if people are moving in and out of the group;
- ❖ The outcomes are likely to be slightly more limited than in a closed group; and

❖ New people coming in may want to discuss things that have already been covered and this may lead to boredom for certain members.

This format might therefore be appropriate for a group intended to offer limited support for its members or where the facilitator is not skilled to deal with in-depth emotions. Nonetheless it is not easy for a facilitator to run a group with people coming and going and having to deal with new people all the time, many of whom may join with pressing needs. Therefore people running open groups also need to have developed skills and experience, though of a slightly different kind from those needed for running a closed group, specifically flexibility and adaptability in unexpected situations.

Closed groups

A closed group is a group that has a fixed membership. All members join the group when it is set up and no new members are allowed to join once it has started.

Benefits of closed groups:

❖ This format promotes consistency, continuity and a safe environment in which to deal with feelings and difficult situations;

❖ It is possible to achieve a higher level of trust and 'group identification' amongst the members;

❖ A closed group enhances the therapeutic potential of the group and facilitates mutual support;

❖ People are often able to develop greater closeness and respect for one another;

❖ It is much easier for the members to feel that their confidentiality will be maintained and they are therefore usually more able to share openly with the group;

❖ All members will have been responsible for determining the objectives and the 'ground rules' of the group and therefore more likely to support the attainment of the goals; and

❖ Closed groups may be able to work through a set plan of topics or themes more easily than an open group.

Time-limited vs ongoing support groups

Time-limited groups

Time-limited groups have a pre-determined number of sessions over a period of time, for example *8 sessions*, *or 6 months*, etc. Often, this type of group has a specific set of goals that has been identified, and the sessions are structured to achieve the desired outcomes within the set time. Many will have a guide that will outline activities or strategies for each session that move progressively towards the final stated goals. Generally, this type of group is designed to encourage development over time, in terms of both content and depth. The learning in each session builds on that of the previous. As a result, this type of group often has *closed membership*, and individuals who participate in the first session are expected to participate regularly throughout the set course.

Benefits of time-limited groups:

❖ Most participants can be expected to receive a common base of knowledge and/or therapeutic support over the course of sessions;

❖ They can be very useful to target specific issues and needs, and address them in a timely manner;

❖ Due to the set number of sessions, it may also be more feasible to project and anticipate costs and resources needed;

❖ Some individuals may prefer a more structured format to the extent that they feel a greater 'sense of purpose' and accomplishment after having dealt with key topics; and

❖ Members know exactly what commitment they have given and can plan around this.

Limitations of time-limited groups:

❖ It may not be as possible to address unanticipated needs or crises that present during the course of the sessions; and

❖ Due to personal difficulties or competing responsibilities of participants, it may be difficult for some members to attend the sessions with sufficient regularity to achieve the desired outcomes.

Ongoing support groups

Ongoing support groups are generally less structured than time-limited groups. They do not have a set duration and the agenda for each session is usually

determined by the needs of participants. It is more common for this type of group to have *open membership*. However, some ongoing groups may have *closed membership*.

Benefits of ongoing groups:

❖ The informal structure of ongoing groups enables members to have a more active role in shaping the sessions, by influencing what they talk about, and when. This makes ongoing groups particularly effective in addressing current crises or critical issues that may present in an individual's life (for instance, death of a loved one) promptly. Members are encouraged to introduce new topics as they become relevant in their daily lives;

❖ As members' needs change over time, the flexible format enables individuals to participate in accordance with their own needs, that is, participate as frequently or seldom as they may need or desire;

❖ Ongoing groups which have a closed membership allow the same people to explore deeper issues without threats of a break of trust or a worry that the group will end when they are particularly vulnerable and need the emotional support offered by the group; and

❖ Where groups are both open and ongoing, the membership will vary from session to session and individuals may participate in an 'as needed' fashion.

Limitations of an ongoing groups:

❖ Due to the informal structure of the sessions, this type of group may require a more experienced facilitator to assist in maintaining a sense of purpose for the group and to respond to critical situations or needs;

❖ Ongoing groups can be highly resource intensive. The same people may be involved for extended periods, thus not allowing others who could benefit from supports groups the opportunity to do so. This limitation is particularly relevant to closed ongoing groups, but to be successful even open groups must have some limitations on membership; and

❖ Where ongoing groups have open membership, the level of trust that is established among group members may be limited, and the changing membership may raise concerns for some members with regard to confidentiality.

Mixed vs specific target groups

Groups almost always have some criterion that defines membership. In the groups being described in this manual, this criterion could be that all members must be living with, or affected by HIV/AIDS. The criteria, however, may be more specific than this, and the group may be restricted to people who are taking ART, and so forth. Once this broad categorisation has been decided upon, further choices need to be made on whether to have specific targeted groups or groups with mixed membership.

Specific target groups

Groups can be organised for particular sub-populations of individuals affected by HIV/AIDS. For example, groups could be organised based on:

❖ Gender;

❖ Age or life-stage;

❖ Illness stage;

❖ Sexual orientation;

❖ Life experience (bereavement, domestic violence, pregnancy, parenting, etc.);

❖ Specific difficulties related to HIV/AIDS or treatment (side-effects, adherence, disclosure issues, etc.); and

❖ Geographical location.

Benefits of targeted groups:

❖ The content and structure can be tailored to the specific needs of these special groups, and these themes can be explored in greater depth; and

❖ Group members may be able to identify more readily with people with similar backgrounds or life experiences.

Limitations of targeted groups:

❖ Specialised groups sometimes require more resources and may hence not be feasible;

❖ These groups may be exclusive and preclude the participation of other individuals who do not meet the criteria but are in need of additional support; and

❖ The group may not be exposed to views and perspectives from people with different experiences, knowledge, and points of view. For example, in a

gender-specific group, men would not get the benefit of hearing a women's perspective. In an age-determined group, an adolescent may not be able to benefit from the perspective of a more mature person, and vice versa.

Mixed membership groups

Mixed groups are those that do not have specific qualifying criteria for membership other than the general criteria described above (e.g. people affected by HIV/AIDS). In other words, *mixed groups* can have as members people of different sexes, age, race, sexual orientation, stage of illness, etc. In some cases, it may be possible that HIV is the only thing that members have in common.

Benefits of mixed groups:

❖ Due to resource constraints it may not always be possible to organise support groups that target specific sub-groups, and mixed groups may be a viable alternative;

❖ The diversity in the groups can highlight the broad range of individuals who are affected by HIV/AIDS. People from different backgrounds are able to come together and make 'common cause' against the disease, forming a network of solidarity; and

❖ People with different life experiences and backgrounds may bring in new perspectives and alternative ways of interpreting difficult situations.

Limitations of mixed groups:

❖ Some issues may be difficult to discuss in depth in mixed groups, such as sexuality or other intimate issues; and

❖ Some members may feel inhibited in their ability to express themselves freely due to cultural norms or customs regarding expected behaviour of specific groups (for example, women with men, or adolescents with elders).

Who runs support groups?

Not everyone is suited to running a support group. Moreover, training to run a support group is essential. Depending on the type of group that a facilitator is intending to run, different training is needed. Training may range from fairly brief to being longer and highly intensive. Finally, some form of ongoing supervision, mentoring or peer support is crucial. Even the most highly qualified and skilled practitioners can benefit from discussing cases, group dynamics, and strategies.

Qualities of a group facilitator

Regardless of a group facilitator's level of training or the type of group he or she is running, there are several basic qualities that all effective facilitators should have:

❖ Warmth;

❖ The ability to put oneself in someone else's shoes and understand their emotions (empathy);

❖ The ability to communicate and facilitate communication between others;

❖ Involvement with and commitment to individuals affected by HIV/AIDS;

❖ Recognition and control of any fears or negative feelings associated with HIV/AIDS (for instance, blame, judgment, fear of infection, etc.);

❖ Patience;

❖ A positive attitude towards him or herself and group members;

❖ Reliability and dependability;

❖ Interest, comfort, and knowledge about the topic discussed;

❖ Flexibility; and

❖ Thorough knowledge of the bio-psycho-social aspects of HIV/AIDS.

Co-facilitation

While it is not essential to have more than one person running a group, there are often advantages in having a second person share the facilitation or to 'co-facilitate' a group. With less experienced group leaders, it can be particularly helpful to have support. Co-facilitation can also be used as a means of training.

By pairing less-experienced facilitators with more experienced ones, they can learn through modelling and observation. Facilitators may also sometimes find that they get 'sucked into' the dynamics of the group, and a co-facilitator can step in and help at such points. Moreover, co-facilitation may ensure more continuity in a group, since the group can continue even when one of the facilitators is unable to be present.

Communication among co-facilitators is crucial before and after each session. This strengthens their ability to work effectively as a therapeutic team. Preparation before the session enables more efficient teamwork during a session, and discussion following each session permits the co-facilitators to share observations from the session, identify individuals who may require follow-up, problem solve, and plan for subsequent sessions.

Outside assistance

It is sometimes useful to invite people who are not regular members of the group to assist at strategic points. For instance, if your support group is for individuals who are new to ARV treatment, it may be useful to invite one or more individuals who have been on ARV treatment for a long time and who can provide advice and support to individuals who are just starting. Similarly, if your group targets HIV-positive pregnant women, it may be useful to invite one or two HIV-positive mothers who have already given birth, and can share their experiences and insights.

Who participates in support groups?

Selecting participants for a group

Not all people may wish to join a group. Reasons for this could be practical, such as difficulties with transport, or it could be related to fear of what the group may bring out. However, there may be a variety of reasons, one being simply not enjoying being in groups of people. Some people may not be ready to join a group at a particular point, but may wish to join at a later stage. At times, an individual might benefit from a one-on-one intervention first, like individual counselling, before joining a group. In order to guide the group member selection process, it may be helpful to make a checklist of qualities that participants should and should not have, often referred to as *inclusion criteria* and *exclusion criteria*. The *inclusion criteria* are characteristics that the participant should have, and *exclusion criteria* are characteristics that the participants should NOT have.

For example, in organising a support group for adolescents with HIV, apart from age, it may make sense to target HIV-positive adolescents that meet one or more of the following additional criteria:

❖ Limited social support;

❖ Problems with adherence;

❖ AIDS orphans or other adolescents that have lost loved ones to HIV/AIDS;

❖ Victims of abuse (household or partner); and/or

❖ Sexually active.

In organising the same group, it should also be possible to come up with a list of characteristics that the participant should NOT have *(exclusion criteria)*, such as adolescents with the following:

❖ Severe behavioural or personality disorders;

❖ Severe substance addiction (alcohol or drugs);

❖ Active mental illness (however, once symptoms can be managed with psychiatric medication, this individual may be eligible to join the group); and

❖ Co-infection with a communicable disease in its infectious stage, such as tuberculosis or pneumonia (since they may put other group members at risk for infection).

Depending on the type of group that is being organised, it should be possible to create a list of inclusion and exclusion criteria in order to guide the recruitment of participants.

It is usually a good idea for the facilitator to have an individual interview with each person who has expressed an interest in joining a group. The facilitator would then be able to assess whether the person fits the inclusion/exclusion criteria, but will also be able to explain how a group works, the commitment for participants (for example that members are expected to attend regularly), as well as clarify any unrealistic expectations or misconceptions that the individual may have about the group. This interview then acts as a preparatory step towards each member of the group contracting to agree upon guidelines.

Organising a support group: logistics and other considerations

In organising a new support group there are several issues which must be clarified before the group meets. Several of these are very practical issues, but unless they are clearly worked out, they may seriously disrupt the group.

Objectives of the group

Knowing the objectives of the group is a crucial step towards deciding which type of group would be most useful. For example, the main objective may be to provide information, support, and/or explore emotional reactions experienced by participants. Only once the objective has been decided, is it possible to make further plans.

Duration of the group

How long the group is going to meet depends on the type of group that is being organised. For instance, time-limited groups tend to meet more frequently for a shorter period of time, such as, once-a-week for ten sessions. Ongoing support groups may meet less frequently, but over an indefinite period of time. In order to guarantee some continuity in the groups, the sessions should not be scheduled more than a month apart.

Meeting times

In order to decide when a group will meet it is helpful to consider the schedules of the prospective participants. For instance, if the majority of participants are unemployed, a meeting time could be made for during the day. However, if people are employed, evenings or week-ends may be better. Other factors such as transport and safety should also be considered. Regardless of how frequently the sessions are scheduled, it is important to try to ensure continuity. That is to say, if the meetings are scheduled to occur at an interval of two weeks, efforts should be made to stick to that pattern as closely as possible.

Meeting place

It will often not be possible to find the ideal place to meet and some compromises may need to be made. Often groups are held in places such as church halls, school classrooms, an office, or at health clinics. To the greatest extent possible, the organisers should try to ensure that the meeting space has the following characteristics:

❖ **Not too large nor too small.** If it is a very large room, if possible, a portion can be screened off or the chairs arranged in such a way that the group is defined within a smaller area.

❖ **Free from distractions**. These include preventing non-group members from passing through the room and/or loud noises.

❖ **Private.** Some group members may not feel comfortable meeting in a place that is associated with HIV/AIDS for fear that their HIV-status may be revealed involuntarily.

❖ **Access to restroom facilities.**

❖ **Available long-term.** The place should be available to the group over a period of time.

❖ **Accessible by public transport.**

❖ **Safe.** Members should feel safe travelling to and from the chosen meeting place.

Arranging the meeting space

Seating of group members is very important. Seats should be arranged in a circle so that people can see each other. Sitting in a circle helps people to talk with each other more than if they are sitting in rows. The facilitator should be seated in the circle with the rest of the group members.

Group size

The number of participants will depend on the type of group you are organising. If it is a therapeutic group, it may be difficult to have more than 15 participants. Most believe that 8-12 is an ideal number for this type of group. Educational groups may be somewhat larger. It is important to consider that skilled facilitators will be required to manage a larger group.

Transport costs

Depending on resource availability, it may be helpful to have funding to cover transport costs for members who would otherwise not be able to attend. However this will not always be possible. Once a decision has been made on this, group members need to be told, so as to avoid possible misunderstandings.

Providing food and drinks

It is common for support groups to provide some refreshments. If it is possible to provide a meal for members this can be helpful as food often acts as a 'binding agent' around which people naturally congregate. If refreshments are provided, it is important to avoid interruption or change in the arrangements to avoid this issue diverting attention from the main purpose of the group.

Child-care

In some groups it may be necessary to have child-care while the parents/ caregivers are in the support group.

Clarifying expectations

Sometimes people joining groups have wrong or unrealistic expectations of the group. In some instances the expectations are for material goods such as food parcels, jobs or money. Others may have expectations and hopes for magical 'cures', be they cures for HIV or cures for depression or other psychological symptoms. When these expectations are not met in the group people feel disappointed and leave the group. It is therefore necessary to explain very clearly to prospective group members what they can expect and what may realistically be achieved.

Dealing with possible stigma

Due to negative reactions from community members to people living with HIV/ AIDS, it is usually preferable not to identify the group as an HIV/AIDS group and not to meet in a place identified with HIV/AIDS. For people who have not disclosed their HIV status, a neutral meeting place is particularly important.

How groups progress over time

Groups develop and change over time in three basic phases:

❖ Getting started;
❖ Operational/working phase; and
❖ Ending.

Each of these stages will be outlined and described in this chapter.

Starting a group: The first session

Starting a group can be quite anxiety provoking for all present. If the facilitator feels confident and competent in what he or she is doing, this helps group members feel more relaxed and comfortable. There are four guiding steps that are common in the first session:

❖ Introducing the group;
❖ Establishing guidelines;
❖ Encouraging communication; and
❖ Clarifying the group's objectives.

Step 1 – Introducing the group

Group members need to know who else is in the group. This can be done while at the same time 'breaking the ice'. An exercise (nothing too intrusive), which helps people relax and get to know each other at the same time, is a good idea. An example would be to share basic identifying information (name, age, married or single, any children, work) with a partner, with partners then introducing each other to the rest of the group.

Step 2 – Establishing ground rules

Generally the best way to create a list of guidelines or rules is to have group members come up with the list themselves, rather than imposing a pre-determined list. This allows the participants to play an active role in the formation of the group and begin to feel like valuable members of the group. The following type of questions could be used to elicit group members' opinions:

Step 1: Introducing the group

"*Before we get started, let's set some guidelines or ground rules for the group. Rules are generally set not to limit people, but rather to ensure that this is a safe place for everyone. What kinds of rules or norms do you think we should set so that everyone will feel safe and comfortable in the group?*"

Sometimes, members can be apprehensive and less inclined to participate in an initial session, and it may be helpful to prompt some answers, for example:

"*Let's see. What do you think the rules about confidentiality should be? Would it be okay for people to share what we discuss here with others outside the group?*"

"*Okay, so we agree that one of the rules of the group is confidentiality. What is another rule we can set that will help this to be a safe place for everyone?*"

Often it is helpful to come in with a list of anticipated norms (such as mutual respect, confidentiality, listening to one another, etc.), that the facilitator can introduce if they do not surface naturally.

These guidelines become the 'group contract' throughout the duration of the group. From the very first session there is a mutually agreed upon set of norms and guidelines as to how the group is going to function. This helps all members feel safe, respected, and supported within the group.

Each group will have its own set of guidelines or contract, depending on the type of group, and these are likely to differ in certain respects. For example, rules around attendance would be different for an open or a closed group. There may also even be rules regarding the rules themselves. Some groups may decide that the rules set at the first session should never be altered, while other groups may write a rule that rules can only be changed with the full consensus of the group.

Example of a group contract:

Confidentiality

Everything that is shared in the group stays in the group. Members' private lives should not be discussed outside of the session.

Attendance

All members should attend sessions regularly.

Punctuality

Everyone should respect the starting time of each session.

Mutual respect

All members should respect the opinions of other members of the group, even if they are different than one's own.

Participation

All members should make an effort to participate in group discussions.

Listening to others

All members have the right to participate and contribute their ideas in a session. The rest of the participants should listen to the person who is talking. Only one person should speak at a time.

These group guidelines can be written up on newsprint as they are agreed by the group and the newsprint can be put up again at each group session as a reminder. The guidelines should be **revisited at the beginning** of each group meeting, especially when new members have joined the group. This will also serve to check whether there is still agreement amongst the members regarding the contract.
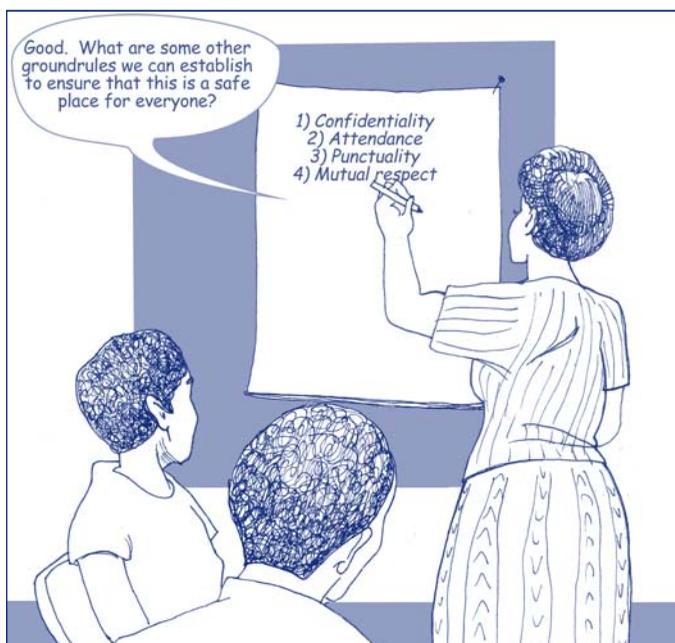
Step 2: Establishing ground rules

It is useful to discuss with group members how they will resolve things, if any of the guidelines are not followed. Referring to the group contract can be a useful strategy when the group is faced with challenging moments.

Finally, it can be helpful to mention the schedule of the sessions at this time. Depending on the anticipated structure, meeting times and place, you could say, for instance, "This group will meet every Saturday afternoon between 1-3pm. Each session will last about an hour and a half, and there will be a little extra time after each session to socialise with one another."

Step 3 – Encouraging communication

For an effective group (other than perhaps for some education groups), it is crucial that participants talk and interact with each other. This should be established in the first meeting and carried through for the duration of the group. Often in new groups, members tend to speak directly with the facilitator. It is the facilitator's role to find ways to encourage dialogue between group members, rather than between him or her and each member. This can be done with comments like:

"Who has experienced something similar?"

"That must have been difficult to share with the group."

"Who wants to comment on what has been said?"

"The group appreciates your sharing your feelings like that."

Step 3: Encouraging communication

Step 4 – Clarifying the group's objectives

It is important for members of the group to decide for themselves what they would like to discuss and what they want to get out of the group. This serves to provide some structure and the opportunity for group members to share their hopes and expectations regarding the support group.

However, often the group is not aware of all the possible themes and topics that could be covered, nor have they any idea of how therapeutic objectives can be reached. While the group members introduce the topics, the facilitator will guide the group towards themes that have more therapeutic or educational potential. Providing group members with a list of themes and topics that could be used in the subsequent meetings can also help them decide what they want to focus on. It is also possible for the support group to invite different speakers to provide additional information on the different topics.

It may be necessary to limit unrealistic or inappropriate expectations that any group member has. For example, if the group is an educational group, members should not expect to be able to talk about how to deal with discrimination in any

detail as part of the group (though they may do so during breaks or after the group). If the group is intent on discussing feelings about HIV status and being on ART, there will be limited opportunity to clarify information on HIV or ART.

The Operational/Working Phase

How to make best use of the operational or working phase of a group is described later. However, it is important to note that groups are not static and though some groups may be very structured, unpredictable things often occur in groups and facilitators should be prepared to deal with these situations.

Planning topics

Sometimes groups prefer to decide in advance the topics they wish to cover in the next meeting. Other groups may decide spontaneously which topics they would like to discuss in a given session. However, regardless of the anticipated structure of a session, especially in on-going meetings, it is very important for group members to have the opportunity to share with the group how they are doing and feeling on a particular day. If there are matters that require immediate attention it is usually best to be flexible and address such issues. This helps to ensure that the focus of the group is balanced between the needs of both the group as a whole and the needs of each member.

Step 4: Clarifying the group's objectives

Groups change over time

Groups change a lot from the initial session where people do not know each other, where trust has not yet been established, where people are unsure how the support group will work and how they may benefit from it. Groups develop differently depending, for example, on whether they are closed or open, whether they are more educational or therapeutic, and so forth. Nonetheless, as members become more familiar with each other, and as trust develops between them, the facilitator usually becomes less active in the group. Group members tend to take more responsibility and feel a sense of 'ownership' of the group. For example, members start drawing on other members for support more and more. Finally, in some situations, group members may look outside the group for ways to empower themselves. Many income-generating groups and other activities have resulted as by-products of support groups.

Despite the support that people get in groups, and depending on the type of group, there are likely to be times that will be difficult. Individuals within the group may go through difficult emotional times and these get brought into the group. Furthermore, sometimes the stress that people are under outside of the group may contribute to conflict within the group, or among members. Conflict can be difficult to manage but, when handled effectively, can lead to growth for individual members as well as the group as a whole.

Ending a support group

The process of how a group ends will be largely determined by whether it is a time-limited or open-ended group. However, so will the emotions of the people in the group.

In a time-limited group, the end date will have been agreed in the first session and members would generally have prepared themselves accordingly. If the group has been run effectively, members should experience a sense of closure as a chapter of their lives ends. Though some people may feel sad at the termination of the group, hopefully they will feel stronger having gone through the experience. Though most people will have built up fairly strong relationships with others in the group, it will have been understood that these relationships would end (at least, in the form that they took in the group) at a known point. Nonetheless some groups, or some people in groups, may decide that they would benefit from a longer period in a support group. They would then usually contract for another number of meetings, decide what their needs are, and plan for this.

If the support group is ongoing and is conducted in a way that people can join and leave periodically, termination occurs more at the individual level. People leave the group at different points, for different reasons. When withdrawal from a group is planned in advance, for instance, because a member is starting a new job and will not be able to continue participating, this can be acknowledged in a session, and the feelings of that member and the feelings of the group can be explored. Because loss is often an important issue for PLHA, it is essential that termination/ending is dealt with carefully and sensitively.

Where a closed group has been ongoing, the decision to terminate is often difficult. People have usually become quite dependent on each other and members may feel afraid of how they may cope without the group. Feelings of sadness or anxiety about the future are very common. The facilitator must prepare each member, and the group as a whole, to come to terms with the end of the group. However, when a group ends, people should be encouraged to develop support systems outside of the group.

What strategies are used to facilitate a therapeutic support group?

As discussed earlier, a therapeutic group is a conversation among a group of people who have something in common, and which aims to help bring about changes in the way participants think, feel and act.

What makes a conversation among peers 'therapeutic'?

The following are the keys to making a conversation 'therapeutic':

Participants are able to openly express their feelings, emotions, and thoughts

The open and unrestricted expression of emotions has two main benefits. First, it lets the participant unload feelings that have been kept locked up inside him or her. This can result in a feeling of relief, what is referred to as a cathartic effect. Second, talking about one's feelings makes it possible to look at them more objectively, to externalise or objectify them, and so to understand them differently. The expression of feelings by one participant may also set off emotions and thoughts in other participants which can help them to reflect differently on their own experiences.

Different points of view are shared and tolerated

Learning the thoughts, emotions, and feelings of other members may help the participants to recreate, reinterpret, or transform any beliefs and/or ideas they may have that contribute to suffering and unhelpful ways of coping and behaving.

What can the facilitator do to promote a therapeutic conversation among peers?

The facilitator can use a series of technical tools and resources in order to create conditions that favour an open, respectful, creative, tolerant, and safe dialogue. Among these tools are:

Create and maintain an environment based on mutual respect and trust

Trust emerges when individuals feel that they are going to be understood, and not judged or criticised for what they think or say. The therapeutic team is responsible for creating this climate of trust. To achieve this, the idea needs to be reinforced that all of the participants share something in common, 'we are a collective', and that each member is special and important. Actions such as mutual introduction, referring to others by name, listening to everyone (speaking one at a time) and not judging the behaviours or ideas of participants, all contribute to creating a trusting environment. Trust is the key to facilitating genuine dialogue, getting rid of negative or restrictive ideas or feelings, and opening up to thoughts and feelings that permit one to live more positively, even under adverse circumstances.

Encourage the expression of thoughts and emotions

For a new or inexperienced facilitator, it can be intimidating to try to work out how to initiate a group dialogue. Simply put, the goal of the facilitator is to get group members to share problems or concerns arising out of their daily experiences that would encourage group discussion. It is important to remember that there is not one correct way to do so, as there are many ways to begin a discussion. Below are several examples of common strategies used to initiate dialogue.

One option is to direct questions towards the group in general and wait for a member to share an experience:

"How are you doing? How have you all been during the last two weeks? Anything new? Has anyone felt happy or sad about something that has happened during the past two weeks? Would anyone like to share anything with the group?"

Alternatively, the facilitator can direct a question towards a specific group member so that he or she begins:

"How are you, Juana? What's new with you? How have you been during the past two weeks?"

Another option, a little more directive, is to give specific instructions to the group in order to commence the dialogue, for example:

"Let's introduce ourselves, one by one. We'll begin by stating our names, month of treatment, and some other information about

> *ourselves in order to get to know one another. Why don't we start with you, Juana."*
>
> *"Let's go in a circle and everyone can give a brief summary of how they have been during the past two weeks. After, as a group, we can decide which topic we'd like to discuss."*

Attempt to reconstruct, as objectively as possible, the situation presented by a participant

After a group member shares a testimony, there may be some details that are not clear. If an individual is very close to and tied up in his or her problem, it may be difficult for him or her to separate him or herself sufficiently in order to present the facts clearly and objectively. The function of the facilitator is to ask questions that will help to reconstruct the situation, as objectively as possible, in order to facilitate an intervention. It may help to ask specific questions in order to reconstruct the situation, for example, faced with a family-related problem it might help to know who else lives in the home, what the individual's role is in the family, and other relevant details. The following is an example of a brief testimony by a group member and some example of possible questions posed by the facilitator:

> **Juana:** *"I feel badly because I am not able to give more to my daughter. She's little and doesn't understand that her mother is sick. I would like to be able to do more for her, to work, give her things and help her with her homework, but sometimes I feel like I just can't. I tire easily, and have so many side-effects. I feel really badly."*

In this example, Juana's testimony highlights several difficulties she has with her daughter and some of the feelings they produce, mainly frustration and sadness. Depending on the therapeutic aspect on which the facilitator would like to focus, he or she could explore the situation asking questions like the following:

> *"How old is your daughter?"*

> *"Does your daughter say anything to you, does she complain at all? Or is it more the sense that you feel you are not taking care of her in the way that you'd like?"*

> *"Who else lives in the home? When you are unable to help your daughter, who helps her?"*

> *"Does your daughter's father live with you?"*

Explore different ways of thinking about and approaching a given situation

People have a tendency to form habits in the way they think and act, which may influence their interpretation of, or reaction to a given problem or situation. One tends to treat these habits or ways of thinking as if they were the only, and most legitimate ways of reacting to situations, and may come to use them time and time again, regardless of whether they are effective in confronting new problems. Most likely, these strategies were effective at one point in the person's life, but may fail to achieve favourable results in the current situation, or even contribute to increased suffering. Hearing the ways that others think and act when faced with similar situations may help one to break these habits, reformulate and expand the way one thinks about problems, and modify one's own attitudes or behaviours. This may be even more the case when these alternatives come from people one knows, likes, and respects.

In order to facilitate this change, the facilitator may encourage all participants to engage in the discussion of the problems of each member, as well as the free expression of emotions, experiences, and reflections on the situation. In addition, the facilitator can help the group to explore other ways of understanding and confronting problem situations.

One direct way of doing this would be to invite others to intervene:

"Would someone like to ask Juana something else about the difficulty she's having with her daughter?"

Another option would be to respond directly to her, highlighting the general problem and framing the situation from a different perspective, so that the group can reflect on it and help Juana:

"Thank you, Juana, for sharing this experience with the group. It is a very difficult situation. For many people, treatment brings limitations in their occupational and social activities, as well as their physical functioning and academic activities. However, we need to remember that these limitations are temporary. Your health comes first."

Since the group members are undergoing a similar treatment, it is very likely that other members of the group have similar difficulties and/or have overcome a situation similar to that of the group member. Thus, another strategy might be to use Juana's testimony as an example, and facilitate the intervention of other group members to help Juana:

"Juana tells us that she feels limited in her ability to take care of her daughter. Would anyone like to comment? What advice can we offer her regarding the situation with her daughter?"

Since it is possible that others have gone through similar situations and can advise her based on their own experiences, the facilitator could propose:

"Who else has children? Has anyone had similar difficulties? How can we overcome these problems with our children?"

Or, if the facilitator recognises a similarity between the experiences of one group member to that of another, he or she can bring these similarities to light in order to facilitate an intervention from the other group member. For example:

"Let's see, Maria, you have children, right? Perhaps you can share with the group how you've dealt with this issue. How have you managed to balance your role as both patient and mother?"

Finally, it may be possible to reframe the topic in a way that other participants feel more able to identify with, and reflect on, based on their own experiences. In this case, for example, instead of focusing on the topic of how to take care of one's children when one is sick, it could be useful to speak more generally about the different types of limitations that may be produced by treatment (occupational, social, academic, physical, etc.):

"Juana tells us that she feels limited in her ability to take care of her daughter because she's sick. Has anyone else felt limited in their activities due to treatment?"

Orient the discussion towards topics and/or problems that have the potential for therapeutic impact

Not all topics have the same impact on the ways in which the participants think, feel, and act. There are some topics that are more sensitive than others, and involve more emotional involvement of the subjects. However, often, these topics with more therapeutic potential, do not emerge naturally, and instead the groups may become distracted with topics of little relevance and emotional involvement. It is the responsibility of the facilitator to orient discussion towards these themes without pressuring or breaking the harmony and established trust in the group.

Some facilitators prefer to focus discussions towards the experiences or difficulties of one or more group members, and others prefer to focus on

general topics in order to seek solutions. Using Juana's example to illustrate, the main topic of the session could be her specific situation:

How does Juana live the experience? What are the main symptoms (side-effects) that restrict her activities? Who else lives in the home? How does her disease impact on family dynamics? Does she have other children? What advice can other group members give?

On the other hand, the main theme of the session could be:

How do we take care of our children when we, ourselves, are sick? Or, how does treatment impose limitations on our activities? How can we deal with this?

The facilitator can assess the level of interest and motivation in the group to focus on the problem of a specific group member, or gear the dialogue towards a more commonly shared topic.

Seek participation of strategic members

Several PLHA who are doing well on ART could be invited to sessions to serve as models for individuals in treatment and inspire them through their testimonies.

Seeking participation of strategic members

Their insights and experiences can be very valuable to group members faced with difficulties related to treatment, doubts about whether the treatment will be effective, or other situations. The advice of these more experienced group members has important therapeutic value, which differs from that of the facilitator, given that their advice comes from another person who has personally experienced the disease and treatment, and can orient group members based on his or her own experiences.

Other strategic participants are those 'veteran' members of the groups, who help to integrate new members. Since membership in the groups fluctuates over time and new members are constantly being integrated, the veteran group members can explain to new members, in their own words, the purpose of groups, what is done in the sessions, and the ground-rules of the group (particularly confidentiality). Through their explanations, they demonstrate the level of trust in the groups and facilitate the prompt integration of new members into the groups.

Correct distortions or generalisations in language

It is possible for people to increase their own suffering through the way in which they interpret their own experiences. These negative interpretations are reinforced by the way in which they are expressed. If we listen with attention, we can observe a series of messages from the group members that, without being totally true, generate suffering and limit their possibilities of taking action. Some examples would be:

"Nobody loves me."

"My children make me mad."

"I have to comply with my husband's wishes."

"I am useless."

"It is impossible to live with this disease."

"My wife left me."

"It is clear that that person hates me."

"I am sick of taking medicines." etc.

A careful analysis of these statements reveals that they may be out of proportion to the actual reality or experience of the group member. It is the task of the facilitator to try to link verbal expressions to real experiences through questions

that highlight the generalisations, replace omitted words, and correct verbal distortions (see table 1).

Table 1. How to correct language distortions or generalisations

Problem statement	What is the language distortion?	How can it be corrected?
"Nobody loves me."	Absolute terms such as *nobody, everyone, always, never,* are generally not true.	Seek some experience that contradicts the generalisation: *Absolutely nobody loves you?*
"My children make me mad."	While it is possible for emotions such as anger, happiness, or sadness to be triggered by the action of others, they are fundamentally internal processes, and thus the responsibility of each person.	Make the group member take responsibility for his or her emotions: *The only way to react to what your children did is with anger? In what way does your anger serve you?*
"I have to comply with my husband's wishes."	Statements like this imply powerlessness to respond to situations imposed by others, which limit one's possibilities for action. This limitation may be real or imagined.	Explore the reality of the situation: *Why do you have to do this? What would happen if you didn't?*
"It is impossible to live with this disease."	Many situations appear like absolutes, but few really are.	Make the connection between two related situations: *The only way to live is as a healthy person?*
"My wife left me."	There are situations that are the result of the inter-action between two or more people but are expressed as if one is active and the other is passive. In this type of situation, no one is totally active (victimiser) and no one is totally passive (victim).	Help the group member to assume responsibility and a more active role in the relationship: *In other words, you and your wife have separated from each other?*

Problem statement	What is the language distortion?	How can it be corrected?
"It is <u>clear</u> that that person hates me."	Sometimes a situation is presented as an absolute truth, without base or based on circumstantial evidence.	Seek evidence: *What makes you think that this person hates you?*
"I <u>am sick of</u> taking medicines."	Many current situations (ongoing) are presented as completed actions in the past, making it seem impossible to modify them.	Bring actions back to the present: *You mean you are <u>getting tired of</u> taking medicines?*

Encourage active participation during the session

There are different opinions regarding participation in the groups. Some argue that it is important for all group members to participate actively, by talking, expressing, listening actively, and reflecting on the topic being discussed in the session. Others argue that it is okay for some group members to talk while other members remain quiet and only listen.

There are advantages and disadvantages to both approaches. On the one hand, pressuring a very shy member to participate may make him or her so uncomfortable that they choose not to return to participate in future sessions. On the other hand, if one allows only those who wish to participate to contribute, it may be possible that only a few members dominate the dialogue and do not permit other more tentative members to intervene. Sometimes shy group members require a little help in order to feel comfortable in a group environment.

Reinforce participants' commitment and motivation to participate in future sessions

Generally, a good way to conclude a session is to summarise the topics of the day, including the problems that were discussed and the solutions that were offered, and agree on a date for the next session.

Some issues that commonly come up in support groups

This section uses five case examples to illustrate some of the issues that are commonly raised in support groups for PLHA. It then looks at some possible ways of responding to the needs of the people who raised the issues in a way that also allows the group to participate in and learn from the discussion. These examples include:

❖ Social rejection and discrimination;

❖ Disclosure: telling others one is HIV-positive;

❖ Living with antiretroviral therapy;

❖ Relationships with partners; and

❖ Death and dying.

No support group is quite like any other. This is because its members bring their own unique concerns, feelings, experiences, and backgrounds to the group. This is in part what makes the support group special for its members. All the same, there are certain issues that often come up in support groups. This is because people living with HIV/AIDS share in common the illness and the course it takes, the treatment, and especially the experience of dealing with the response of others to their HIV status.

Whatever the issue being raised by a group member, there are a series of questions the facilitator can ask him or herself in order to decide the best way to address it:

What are my personal views on this particular issue?

Awareness of one's own views will help the facilitator to check his/her own reactions and attempt to remain as neutral as possible in the group.

What do I know about the group?

For example, how long has the group been meeting? How familiar are people with each other? What kinds of relationships are there in the group? What similar issues have been raised in the past and how have these been addressed?

What do I know about the group member raising the issue?

For example, how long has the person been attending the group? How does he/she fit into the group? How confident or vulnerable is he/she? Does this problem fit a pattern of past issues raised by this individual? What are this individual's strengths?

What strategies can I use to open up communication between group members?

How can I help group members explore different ways of viewing the situation?

How can I manage the group process?

What are some problematic reactions that can emerge in the group process? In what ways can these problems be dealt with?

How can I ensure that the needs of the member or members who raised the issue are addressed in some way?

Always remember that there are usually a number of ways of responding to a particular issue. Therefore, when reading through the case examples, it may be a useful exercise to think about what other options there might be.

Social rejection and discrimination

People living with HIV/AIDS commonly experience rejection and discrimination, whether from partners, family, friends and the wider community. What is done and felt can be direct and obvious, or more subtle, as the quotes opposite show.

Direct experience of rejection and discrimination can eat away at the person's self-esteem, motivation to live a positive life, and capacity to stick to taking medication as they should. Even when someone has not personally experienced it, fear of rejection and discrimination can be an obstacle to positive living, to seeking treatment and to adherence.

Support groups provide a safe place where people can share their fears and pain and find ways to anticipate and respond to rejection and discrimination. To do this, it is important that the facilitator and group members understand what it is that leads to these kinds of experiences. For, while rejection and discrimination can never be justified, understanding why people behave in these negative ways can help in working to change those behaviours.

Stigma

The root cause of most rejection and discrimination towards people with HIV/AIDS is the stigma linked to this diagnosis. Stigma refers to negative beliefs and attitudes about individuals or groups who share a common characteristic, in this case HIV/AIDS. People who are subject to stigma are seen as 'others', who are different and separate. Stigma often involves stereotyping members of a particular group, in other words, assuming that because they share one thing in common (e.g. HIV/AIDS) they are also similar in a number of other ways (e.g. 'dirty', 'promiscuous', 'worthless').

Stigma can extend to people connected with a stigmatised group. This means not only those who are infected, but also those affected by HIV/AIDS, like partners or family members, may be subject to stigma. Perhaps most damaging, is that stigma is not only something that other people express. People with HIV/AIDS

may themselves accept the same attitudes and beliefs, feeling ashamed and guilty because of these negative views.

Stigma may be expressed through discrimination, in other words, people infected or affected by HIV/AIDS are treated in ways that are different from what is generally accepted in the community or society and which cannot be rationally justified. An example would be refusing to share household utensils with someone infected with HIV. Often, people affected by stigma may feel very alone or socially isolated.

Social isolation

What leads to stigma?

Lack of knowledge about HIV/AIDS: Many people do not know a great deal about HIV and AIDS, have confused ideas, or incorrect beliefs. For example, they may think that, in the same way that a child can catch measles by being with other children who are infected with measles, so HIV can be spread by being close to someone with HIV. They may believe that once you have HIV, you do not have long to live. There is also widespread misunderstanding that HIV is linked to homosexuality or promiscuous sex, that 'respectable' people do not get HIV infection. Confused ideas or incorrect beliefs of this kind can feed fears of being infected and may lead to negative attitudes towards people who are infected.

Fear: A second factor that feeds into stigma and discrimination is fear. The fact that so many people are infected and that, at present, there is no cure for AIDS makes people afraid of HIV/AIDS. The fact that most

people with HIV/AIDS have not been able to get treatment and have died in difficult circumstances, has probably reinforced the idea that HIV/AIDS means pain and death. Because people are afraid of getting HIV/AIDS, they try to avoid or reject those who are infected.

The link between HIV and taboos (death and sexual practices): Death is, in most societies, surrounded by taboos. That is, it is something that is not discussed openly and is dealt with through special rituals that help the community and society deal with something that is feared. In the case of HIV, the taboos are even stronger and deaths are often kept secret or hidden. HIV is also linked to sex, another taboo subject that is not openly discussed. It is considered private and carries its own set of expectations and moral judgments about what is, or is not, 'proper' behaviour.

These are all factors that should be kept in mind in helping group members to understand and deal with experiences of discrimination and rejection. While it may not always be possible to change the reactions of society towards PLHA, it may be possible to change the way in which individuals react to and interpret these situations and reduce suffering associated with them.
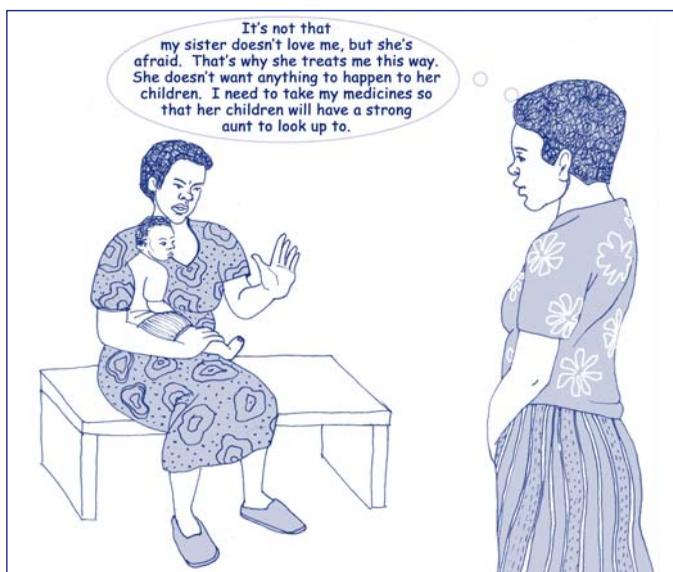
Understanding others can reduce suffering associated with stigma

Rejection and discrimination: Maria's experience

Maria recently joined the group. Today, she finally had enough courage to share her situation with the group. She said that she had heard about someone being beaten and thrown out of her home after her family found out that she was HIV-positive. Maria went on to say, "I still live with my family, but sometimes I feel that being thrown out of home couldn't be any worse. They try to avoid spending time with me, even being in the same room with me. My mother always liked the fact that I was willing to help around the house. Now, she won't let me help her with the cooking. My sister doesn't want me near her children. She calls them away if they happen to come into my room. It's hard to accept that your mother doesn't love you anymore and your sister doesn't want to have anything to do with you. Sometimes I feel so bad that I think it's not worth taking the drugs and then I maybe skip a dose or two. Maybe it would be better to die soon."

How can this situation be addressed?

The facilitator's own understanding of Maria's situation could be as follows:

Maria shared both how her family reacted to her and how she felt about those experiences. She compared her situation with that of others she had heard about. Her feelings of loss and despair seem to be affecting her adherence.

There are many possible explanations for Maria's family's reaction to her:

❖ Is it that they do not have accurate knowledge about the way in which HIV is transmitted and act this way because they are afraid of being infected?

❖ Are they influenced by the stigma associated with HIV/AIDS and therefore judge her and look down on her because of her HIV-positive status?

❖ Is this their way of coping with their anger and frustration of possibly losing her to the disease?

What the facilitator knows about the group and Maria's place in it:

The group is an open one and has been running for some time. There are some members who have been attending regularly for nearly a year, while others attend less often, but are accepted as members of the group. Maria is fairly new, this is her third session and she has participated very little in previous sessions. She sounded sad and had tears in her eyes as she ended her story. Others in the group have told similar stories before. Generally the group has been supportive, because many of them have had (or feared) similar experiences. But there have been times when some group members seemed to blame the HIV-positive person for not properly informing their family, while others have suggested a rather risky approach to confronting the family about their prejudice. In some cases, group members have been critical of people who have not been taking their medication regularly.

Some options for opening up discussion and addressing Maria's needs:

❖ Summarise Maria's story for the group. End by reflecting on her feelings of loss and despair, and noting that this is making it difficult for her to take her medication. Then get other group members to comment, by asking:

   "*Would anyone like to respond to what Maria has shared?*"

❖ Help Maria to see that she is not alone in what she is experiencing by asking other group members to share similar experiences with family members or others;

❖ Ask whether anyone could share how they dealt with a similar situation;

❖ Shift the focus to the family, by asking:

   "*How can we understand the way Maria's family is reacting and what can be done to change things?*"

Managing the group process:

Problematic reactions	Examples	Possible facilitator intervention
Blame	*"It's her fault that her family is reacting in that way. If she would just explain to them…"*	*"I'm sure we would all agree that no-one deserves to be treated as Maria has been. All the same, we can help Maria find other ways to educate her family. What ideas are there?"*
Setting unrealistic expectations	*"Why doesn't she just go to her partner and insist that…"*	*"Those sound like interesting ideas, perhaps Maria would like to think about them and we could go over them again next time."*
Pressuring to act	*"I'm telling you, the only way to get them to treat you better is to…"*	*"Let's remember that it takes time to work out how to do that. Perhaps Maria needs to take things one at a time."*
Judging	*"It's your fault you get sick if you don't take your medicines every day."*	*"Most people have difficulty taking medication from time to time. What kinds of things help them to stick to what they need to do, or get back on track?"*

Disclosure: Telling others one is HIV-positive

Fears about disclosure, advice on appropriate and inappropriate approaches to disclosure, experiences and consequences of disclosure and non-disclosure, are all issues likely to be raised at one time or another in support groups.

For people who are HIV-positive, making a decision about disclosure may be the most difficult, but also the most important decision of their lives. It can increase levels of practical and emotional support and promote better adherence to treatment. However, it can also result in rejection and discrimination, as well as material loss, and can negatively affect the person's ability to keep up a positive life-style and adhere to treatment. Not disclosing, on the other hand, while it can protect the person against possible negative effects, means the person continues to carry a burden of secrecy and is at constant risk of having others discover their HIV status.

What group members say:

"I am afraid that if I disclose I won't be accepted."

"What I think is you must be ready to disclose and not be pressured by someone else to do so."

"Some people say that it is better to disclose as soon as you get your result, but I think that you have to first accept your status and be sure you know a lot about HIV/AIDS, so that you can educate your family and if they ask questions, you are able to give answers to their worries."

"In some relationships, it is not wise to disclose, because if you tell the person, she or he runs away. It is better to get to know your partner and if you see that he loves you, that is when you should tell him or her."

"I don't have a job. If I tell my partner about my HIV status and he rejects me, how will I look after my kids with no income?"

"The reason some people don't stick to taking their drugs properly is because they haven't told anyone about their status and are afraid their partners will find out."
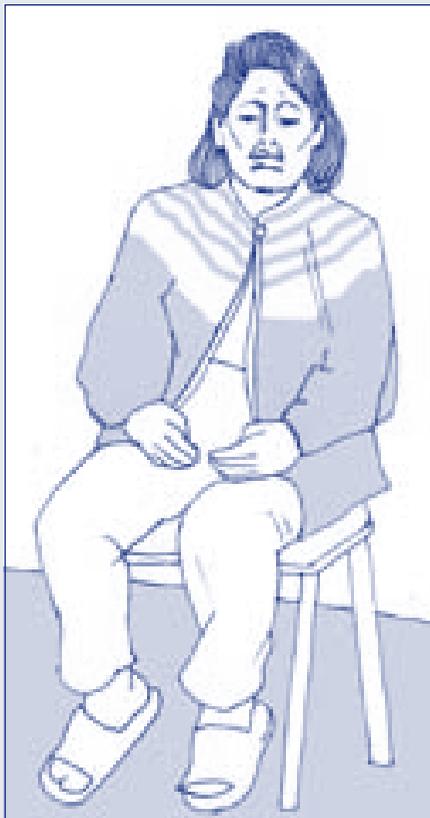
Because of the above, it is essential for the facilitator and group members to accept that making a decision about disclosure and how someone actually goes about disclosing can take weeks, months, or even years. It is a process, not a once-off event. It should not be rushed, but thought through carefully and systematically, so that the person makes an informed decision, taking into

account their particular life situation. There needs to be support *before*, *during*, and *after* someone attempts disclosure.

Questions that are helpful to keep in mind are:

❖ *To what extent has the group member accepted and come to terms with his or her own HIV status? Are there ways the group could help the group member to develop more positive attitudes and coping strategies?*

❖ *Who are the people to whom the group member could disclose?*

❖ *How much should be disclosed? Is some preparatory work necessary (e.g. first finding out about the knowledge and attitudes of those to whom the person might disclose)?*

❖ *When would be a good time, what should be said and how can it best be said?*

❖ *How is the person being told likely to react and what could the group member do then?*

and especially:

❖ *What is best for this group member at this time?*

Group members, drawing on their own experiences, can provide valuable input and support for a member thinking about or going through the process of disclosure. But there is also a danger that the group may pressure someone to disclose before they are ready. So it is essential that everyone in the group understands and accepts, and that the facilitator ensures, that the decision to disclose or not, remains that of the particular group member.

Disclosure: What should Petros do?

Petros had been attending the support group for a number of months. He previously told the group that he discovered his status when he was tested after his partner had tested positive during pregnancy. When the issue of disclosure came up, he said that, although his partner is aware of his status, he had no intention of disclosing to his parents or brothers or sisters. "It's none of their

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business. In any case, I take care of myself and I take my drugs regularly, so I'm fit and healthy, so why should I worry them?" he asked. Albert disagreed, "What if your partner leaves you, or dies before you? Who will look after you and your children, if you become ill?" Other group members took sides in this debate, some supporting Petros and others Albert.

How can this situation be addressed?

The facilitator's own understanding of Petros's situation could be as follows:

Despite being on ARVs, Petros does not seem to have fully accepted his HIV-positive status and seems to think he will remain healthy indefinitely, as long as he goes on taking the drugs. Disclosing to his family would mean his taking another step in coming to terms with his own status. There could also be risks as there is no indication of how his family might react if Petros does disclose. On the other hand, failure to disclose makes it difficult for him to begin to plan for the future, especially the care of his children.

What the facilitator knows about the group and Petros's place in it:

The group is a closed men's group and has been running for three months. Most members attend regularly and there are clear patterns of interaction amongst members. Petros and Albert both take leadership positions in the group. They have clashed on previous occasions and it has always been difficult to find a compromise.

Disclosure is something that has been discussed before and the disagreement between Petros and Albert reflects a wider disagreement in the group. It will be important to make sure that the group remains a safe space where everyone can share their thoughts and opinions without feeling they are being judged and that group members don't pressure Petros to disclose before he is ready and has a plan.

Some options for opening up discussion and addressing Petros's needs:

❖ Interrupt the discussion, summarise the different points of view, and ask whether group members agree with your summary. Point out that it is alright

if group members do not always agree on everything. The facilitator could say:

"Disclosure is a difficult issue. Not everyone will see or do things the same."

❖ Ask group members to list advantages and disadvantages of each position. Summarise again and highlight that there are advantages and disadvantages to each side;

❖ Remind the group that it is important for someone to have come to terms with their own status before disclosing to others. Ask whether anyone would like to share his/her experience of this;

❖ Ask whether a group member (anyone, or choose someone who has previously shared something about his disclosure experience) would share an experience of disclosure that had a positive or better than expected outcome. Ask the person to tell the group to whom he/she disclosed, why he/she decided on this person, whether he/she did anything to prepare for disclosure, when and where he/she disclosed, what he/she said, how the person responded, what he/she in turn then said or did, and how things progressed from there. Use this example to illustrate that disclosure is a process, not an event;

❖ Ask the group (not Petros specifically) whether anyone who has not yet disclosed would like to look at what he/she would need to do, in order to start the process of disclosure. Ask the group to help this person by making positive suggestions and pointing out any difficulties he/she should anticipate;

❖ If there is a volunteer, who agrees to start the process of disclosure, let the person and the group know that there may well be difficulties that were not anticipated and that this can be discussed in the next session. The facilitator could then ask:

"How did things work out? Tell us about what worked and what didn't."

❖ If there are no volunteers for starting the disclosure process, you may need to close the issue for this session and pick it up the following session by asking:

"Has anyone thought further about what we discussed last week about disclosure?"

Managing the group process:

Problematic reactions	Examples	Possible facilitator intervention
Argument between two members	Albert: *"You should tell your family."* Petros: *"It's none of their business."* Albert: *"They have a right to know."* Petros: *"I don't want to worry them."*	*"It is clear that Albert and Petros do not see eye to eye on this subject. What do others think some of the pros and cons are, of Petros telling his family about his HIV status?"*
Pressuring	*"You should go visit your family and find a way to tell them as soon as possible."*	*"Let's leave things there. Each of us needs to work out what's best in our particular situation."*
Taking sides	*"Petros is right. He's healthy, so why should he tell his family?"*	*"There is really no right answer in this situation. Each situation is different, and it is a personal decision to disclose or not."*

Living with antiretroviral therapy

In support groups, especially those that focus on adherence, there is a great deal of discussion to clarify misconceptions or questions about antiretroviral therapy (ART). The groups provide an opportunity for individuals to share any difficulties they are having in taking antiretroviral medication as required and to hear suggestions as to how to overcome these difficulties. Side-effects may also be discussed, along with strategies that can be used to overcome them. Finally, members may share concerns about changes in health status or treatment. While these discussions often seem to be about factual matters, feelings such as anxiety, fear, elation, disappointment and anger are never far away and may be the real reason why someone has raised a particular issue.

What group members say:

"I'm having so many side effects and they have lasted for more than a month, that's longer than the doctor said. Why is that? Does it mean the medicines are not working for me?"

"I've been on ARVs for three months now and I have much more energy, my appetite is good and I feel strong enough to do anything. My CD4 count is up and I feel sure that I'm going to be fine now!"

"I was sent to the clinic for ARVs because they said my CD4 count was less than 200. But I don't really see why I need to take ARVs because I'm not sick. In fact, sometimes I forget to take the drugs and it doesn't seem to make any difference."

"I've been on ARVs for three years. When I went for my check-up to-day, the doctor said that my CD4 count is down and my viral load is up, for the third visit in a row. He seems to think that I'm developing resistance to the drugs and I may have to change. I don't understand why, because I take my medicines exactly the way I was told."

Since ARVs have become more widely available, it has become possible to talk of AIDS as a chronic disease. In this sense, it is like other chronic diseases such as diabetes and hypertension, which are also life-threatening and also involve a lifelong commitment to adhering to a particular medication regime and adopting a specific lifestyle. Like these other diseases, being on treatment involves a number of critical points.

Critical points of treatment in HIV/AIDS:

❖ Assessing readiness to start treatment;

❖ Negotiating a suitable treatment plan and helping the person prepare to start treatment;

❖ Starting treatment and adjusting to treatment, including side-effects;

❖ Maintaining treatment when feeling well or in the face of opportunistic infections;

❖ Having to change treatment because of side-effects or resistance to the drugs; and

❖ Deteriorating health, suggesting that the treatment is no longer working.

At each of these points, a support group can help people through the process, offering both information and advice, based on the experience and emotional support of group members. On the other hand, whenever a group member encounters one of these points, his or her experience and reactions is likely to affect other group members, raising similar or related issues for them.

This is because there is also a sense in which AIDS is not yet 'just like any other chronic disease'. It still carries the stigma referred to above, treatment options are still new and relatively few and, although ARVs prolong life beyond what is possible without them, fear of death and dying are real and immediate concerns for people with HIV/AIDS. These differences add to the difficulties of people on ARVs in living with their treatment.

Living with ART: Jay's change in medication

Jay has been on ARVs for a number of years and seems to cope well. He is often a source of information, advice and support to newer members of the group, when they have questions about HIV/AIDS, side-effects of ARVs, healthy living, and the like. He has recently missed a few group sessions, which is unlike him, but to-day he turned up and had this to say, "Sorry I've missed a few sessions, but I've been losing weight and feeling more tired than usual lately, so I

> *decided to take it easy. When I went for a check-up, I told the doctor about this. I also have this cough that's been troubling me. The doctor sent me for tests and told me that I have TB. So now I have to take drugs for TB as well and they've had to change my ARVs because the two don't go together. Now I have to get used to a whole new set of drugs. I feel so upset about this because I really have been careful about looking after myself." At first the group was quiet, then a few members said they were sorry to hear about what was happening with Jay. One added, "I had TB before I started on ARVs and I had to have treatment for that before I could start on ARVs. Don't you have to stop your ARVs for a while?" Another person said, "I thought that taking Bactrim as well as the ARVs would prevent you getting TB. Does this mean any of us could get TB?"*

How can this situation be addressed?

The facilitator's own understanding of Jay's situation could be as follows:

It seems that Jay did not go to see the doctor as soon as he became aware of his symptoms, but waited until he was due for a check-up. This, together with the fact that he missed a few sessions, could mean that he had difficulty accepting that something could be wrong with him. Although he now seems to accept that there is a problem and that he has to take different drugs, he obviously has feelings about what is happening. His feeling 'upset' could mean various things, disappointment, depression, anger (toward himself, with the doctor, or about the unfairness of getting TB when he has been careful).

What the facilitator knows about the group and Jay's place in it:

Jay is a strong and self-confident member of the group. Both he and the group are used to his helping others, rather than needing help himself. His situation has raised questions and anxieties for other members. Their response is to touch only briefly on how Jay is feeling and to focus instead on factual matters, as a way of dealing with Jay's situation and their own concerns, without actually acknowledging the underlying feelings. This is a situation that calls for attention both to feelings and to providing information. The facilitator needs to ensure that both are addressed in a way that leaves Jay and the group strengthened.

Some options for opening up discussion and addressing Jay's needs:

❖ The facilitator could intervene by summarising what Jay and the other group members have said:

"Jay has told us something unexpected. It's been difficult for him to get this news. It's also difficult for other group members because it brings out fears that others could also become ill."

❖ The facilitator could go on to focus on Jay's feelings specifically:

"Jay, you said you felt upset because you have been careful. Tell us more about how you are feeling."

The facilitator could then ask whether any group members have had the same feelings at any time. Or the facilitator may choose to start with the group:

"How do other group members feel hearing about what has happened to Jay?"

and then ask Jay to comment.

❖ The facilitator may want to use this situation to draw group members into a broader discussion about their anxieties and fears.

❖ At some point, the factual issues should be addressed (can people taking ARVs get TB and how does this happen, does someone taking ARVs have to stop the drugs while taking TB treatment, is a change in ARVs always necessary when someone has to take TB treatment?)[1]. There may be group members (including Jay) who can answer these or related questions that come up, or the facilitator may do so, or there may be a need to investigate and report back to the group at another session.

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[1] Notes on medication queries (see *Living with ART*)
- *Bactrim (cotrimoxazole) does not prevent TB infection and people taking ARVs can get TB as an opportunistic infection as a result of a weakened immune system.*
- *Once someone has started on ARVs, it is not usually necessary to stop ARVs if they have to take TB treatment. This would only be considered, if there was great difficulty in tolerating the combination.*
- *It is only with some ARVs (nevirapine) that it is necessary to change to another drug when taking TB treatment. With many drugs, although it is not necessary to change to another drug, an increase in the dose or adding another drug may be necessary.*

Managing the group process:

Problematic reactions	Examples	Possible facilitator intervention
Focussing exclusively on information needs, avoiding deeper emotions.	*"I had TB before I started on ARVs and I had to have treatment for that before I could start on ARVs. Don't you have to stop your ARVs for a while?"* *"I thought that taking Bactrim as well as the ARVs would prevent you getting TB. Does this mean any of us could get TB?"*	*"Those are very important questions. But, before we try to find the answers, could we hear from other group members how they feel hearing about what has happened to Jay?"* *"Jay, could you tell us more about how you are feeling about what has happened?"*
Neglecting the needs of a strong or dominant member of the group.	*"Hearing about what has happened to Jay makes me feel scared. It could happen to me, too."*	*"What's happened to Jay makes everyone feel vulnerable. But Jay has a problem right now. Let's start by talking about that."* *"Jay, could you tell us more about what happened and how you are feeling?"*

Relationships with partners

In groups, people with HIV/AIDS often talk about relationships with their partners, including the ways partners help them in dealing with their illness and treatment, and how difficulties in the relationship add to their stress and affect their ability to adhere to treatment. Both men and women raise these issues, but, because women are more often dependent on men for material and financial support, women tend to raise these issues more often.

What group members say:

"When it's time to have sex, I don't know what to do because my husband doesn't want to use condoms. He says it's not the same. It's difficult to insist, but I worry about getting re-infected, so we end up not having sex."

"My boyfriend is unfaithful even though he knows the risks of re-infection. He takes advantage because he knows that I need him to support me and our children. It's very stressful and makes it harder for me to keep on taking the treatment."

"Sometimes I feel I don't want to keep on with the drugs, because they remind me that I will never be okay again. Then my partner sits with me to talk about it and helps me find ways to keep going."

"I realised that I can't blame HIV for all the problems in our relationship. If you don't talk with your partner, tell him when you are not happy about something, then he won't be aware that there is a problem, and be there to help you when you need him."
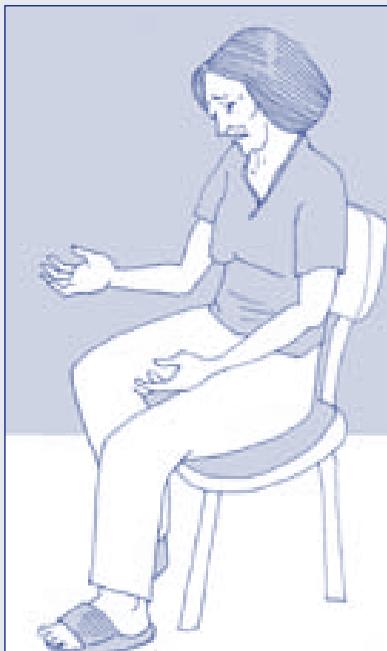
Gender role differences

In every society, there are differences in the ways men and women are expected to behave. There are also differences in power between men and women, with men generally having greater power to make decisions in a relationship.

These gender differences are reflected in the relationships between partners and their expectations of one another, including who should be dominant in the

relationship, who should be the breadwinner, who should be the one to make the first move in sex, who should look after the children, and so on. Usually none of these expectations is absolutely fixed and partners work around what is generally expected and end up with something that feels comfortable for them. But the background of gender role differences, especially in the differences in power between men and women, does affect how issues, including those to do with HIV and AIDS, are raised and resolved in relationships.

When group members talk about difficulties in their relationships, it is useful to keep these differences in mind, as they often lie behind what is presented. These differences also mean that group members, particularly in a mixed group of men and women, will often try to make sense of the problem through their own understanding of gender differences. As a facilitator, it is important to try to encourage the group to look at both sides, so that everyone has a better understanding of why each of the partners behaves as they do. This would include not only gender role differences, but also the specifics of each person and their background.

Relationships with partners: Sarita's difficulty

Sarita has two young children and is one of the regulars in an ongoing group with more women than men as members. She has previously talked about how difficult it was to disclose to her partner, Thomas, and how he threatened to throw her out of the house. Although that didn't happen and he does still provide for her and the children financially, things have not been good between them since then. Thomas refused to have an HIV test, saying that, if she was infected, he must be, too, so what was the point? For the same reason, he refuses to use condoms when they have sex. To-day Sarita brought up the problems again. "I went for my check-up this week and the doctor told me my CD4 count is down and my viral load is up. Because I'm taking my ARVs the way I'm supposed to, she said it could be something to do with re-infection because of having sex without using condoms. She understands my situation, but she says I really should think again about talking to Thomas about using condoms and about his coming in for a check-up. But every time I've tried to talk to him, he just gets very angry and tells me to go and take the children with me. I really don't know what to do".

How can this situation be addressed?

The facilitator's own understanding of Sarita's situation could be as follows:

Sarita has been doing well on ARVs and maintaining her health status until now. As far as Thomas is concerned, it seems that, whatever he says, he has not really faced up to the fact that he could be infected and this is probably the reason why he won't get tested. On the other hand, despite his threats, he has continued to provide for Sarita and the children, which suggests that at some level he is still committed to the relationship and the children. The group has previously made suggestions about ways Sarita could try to talk to Thomas about having a test, including pointing out that he could get ARVs if he is infected.

This is a very difficult situation for Sarita because Thomas clearly has the dominant role in the relationship (probably influenced by gender roles). It will be important to find some way forward in which Sarita is able to protect her health without running the risk of violence or being thrown out on the street with her children. The change in Sarita's health status and the implications for her children could provide new motivation for her to try again to talk to Thomas. However, it is important not to lose sight of her feelings about the change in her health status. If she is too demoralised by the news, it may be difficult for her to follow through on any plan.

What the facilitator knows about the group and Sarita's place in it:

Sarita regularly attends the group, but is generally rather quiet, not speaking much, unless the facilitator draws her into discussion. She easily backs down if others disagree with her. She seems to find it particularly difficult to stand up to men and to older members of the group. All the same, she seems to feel a sense of belonging in the group and to get emotional support from others. The group members are generally supportive of her and have tried to help her work out how to deal with Thomas.

However, group members have sometimes turned these kinds of issues into debates about men and women and who is to blame, or have become impatient when someone does not follow the 'advice' given by the group. It is important that the group remains a space where less confident members, like Sarita, can bring their specific problems and be given the chance to work out options that will suit her. Encouraging solidarity amongst group members who may have experienced or anticipate similar news could be a helpful way to start.

Some options for opening up discussion and addressing Sarita's need:

❖ Ask whether any group members would like to share how they have felt on hearing about a change in their health status, as has happened to Sarita. Encourage and reflect comments that would help Sarita understand that others share and understand her feelings of disappointment, anxiety, fear, hopelessness, anger, as well as renewed resolve;

❖ Comment that the problem of talking to Thomas is something that Sarita has shared before. Ask the group to discuss how things may be different for Sarita and Thomas now that there has been a change in her status (e.g. concern about deterioration in health status, need for greater caution, and increased urgency in thinking about future of children);

❖ What strengths do Sarita and Thomas have individually, and as a couple, to cope with the change (e.g., despite everything, Thomas continues to support Sarita and the children, and Sarita's concern for their children has kept her with Thomas)?;

❖ Do these factors suggest any new ways that Sarita could try in talking to Thomas?; and

❖ The facilitator could set up role-plays to try out the suggestions. Options would be to have Sarita playing the part of Thomas, while other group members play her role and then, perhaps, having Sarita play herself with one of the men as Thomas. Keep the role-plays fairly light-hearted and intervene, if necessary, to keep Sarita feeling supported.

Managing the group process:

Problematic reactions	Examples	Possible facilitator intervention
Blame	*"You should be more assertive with your husband."* *"Your husband should be more understanding."*	*"Before we talk about how Sarita could deal with this situation, it might be helpful to hear more from her about how she felt about what the doctor told her."* *"Sarita, how did you feel when you found out that your CD4 has been dropping, despite the fact that you've been taking your medicines"?*
Pressure	*"You should insist on using condoms with your husband."*	*"Sometimes that's easier said than done. Could others who have been in a similar situation share with us things they have done to start what is always a difficult task?"*
Taking sides on heated issues like gender	*"You have to understand, he's a man."* *"Women shouldn't have to put up with that kind of thing."*	*"Clearly there are strong feelings about this issue…."* *"Why is it that we have these feelings?"* *"But for now, what is important is to think of possible ways that would help Thomas and Sarita strengthen their relationship so they can support one another and care for their children."*

Death and dying

Death and dying are in the background of the lives of people living with HIV/AIDS. However, the emphasis on positive living and the real hope of a longer life that ART offers make this a difficult subject to raise and confront. Group discussion may offer a safe and supportive opportunity for members to speak about their feelings and to plan how to deal with failing health and preparation for death. In long-running groups, members may have to confront the issue quite directly when a fellow member dies.
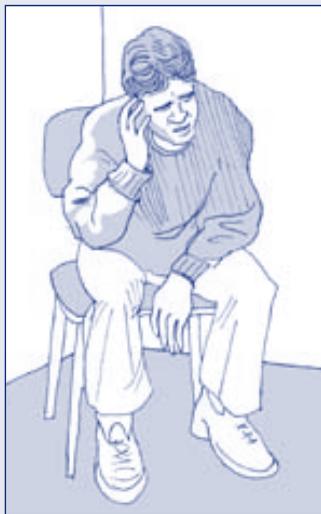
There are many different ways to understand the process a person goes through in thinking about and preparing for their death. One way is to think about death and dying as involving loss. Someone with HIV or AIDS will experience many kinds of loss. These are likely to include poorer health, being less able to work (or no longer able to work at all), having less income (or less to spend on things other than health care), being less able to manage ordinary daily tasks, together with loss of self-esteem in response to these changes, or to the reactions of others. Loss of family member or friends due to HIV/AIDS is also a common experience. These are actual losses.

But there is also a different kind of loss, which comes from anticipating these kinds of losses before they actually happen, or thinking about 'what might have been'. Examples would be following a decision not to have a child because of the transmission risks, thinking about not living to see a child go to school, worrying about being ill and dependent. These can be as real as actual losses.

It is important, too, to remember that people with HIV/AIDS usually face repeated losses. It is not just one of the above losses that happens, but usually many, possibly close together in time.

How do people respond to loss?

Although each person responds in a unique way, there are reactions that are common. At some time, most PLHA will feel depressed, sad and discouraged, and possibly become withdrawn and uncommunicative. Anger is another common reaction. This may be directed towards the person assumed to have infected them, something many people would find understandable. Anger towards others who are not infected or remain healthy, even towards those closest and most supportive of them may seem less understandable, but may reflect frustration, envy and resentment because of anticipated losses. Fear is also common. The fear may be about pain, losing control of bodily functions, dying alone, what will happen after death, and what will happen to family members left behind.

On the other hand, it is not unusual for someone with HIV/AIDS to seem unaffected by the seriousness of what is happening to them, even when there are signs that the stage of AIDS has been reached. Examples would be making plans for the future that have little chance of being carried out, or failing to make arrangements for the care of children, despite evidence of failing health. It is as if the person denies the reality of their illness and its outcome. In contrast, at some point, it may seem that the person has come to terms with their situation, and has started to prepare for what is to come.

However, although these reactions are common, not everyone will react in these ways and there is no predictable pattern to how different people will react. For example, after a period when a person seems to have come to terms with their situation, because of a change in their health or other circumstances, or for no apparent reason, anger, fear or depression may recur.

We have already mentioned that the subject of death is surrounded by taboos. These make it difficult for people to talk openly about their fears and concerns, to get support from others, or to find ways to prepare themselves and others

for their death. A support group, where members all face similar challenges and together have a wealth of experience in dealing with these challenges, can be one of the few places where it is safe to discuss death and dying. As always, though, it is important that the group does not impose its values and solutions on another member. If, for example, a group member is caught up in feelings of anger and cannot yet move past this, the facilitator may need to intervene to acknowledge and support *this person's* way of managing the situation at this time.

Dealing with death and dying: Nomsa's response to a friend's death

In the group today, the facilitator noticed that Nomsa was very quiet and withdrawn. The facilitator asked how she was feeling and she replied that she was 'feeling down'. The facilitator gently probed, asking her to share her feelings with the group. After a pause, Nomsa said she was feeling very sad because her best friend, also HIV-positive, had died over the weekend. She had become ill over the past few months and, although her drugs were changed, nothing seemed to help. At the end, she was hardly conscious, had no control over her bowels and seemed to be in pain. Nomsa ended by saying, "I know I shouldn't feel like that, but I really began to wish she would die. I couldn't bear to see her like that, especially because it made me think that that could happen to me."

How can this situation be addressed?

The facilitator's own understanding of Nomsa's situation could be as follows:

Nomsa is doing well on ARVs and is in good health. She has disclosed to her family and they are supportive of her. However, from what Nomsa has told the group, it seems that the family is not comfortable talking about sensitive matters. When Nomsa wanted to tell them about how she came to contract HIV, they said that was something in the past and all that mattered was to make sure that she took care of herself in the future. Nomsa has previously said that it is only in the group that she is able to share her feelings. On this occasion, it seems that

she has a range of feelings, fear for herself in the future, guilt about wishing her friend would die, maybe anger with her friend for how she died. Being able to share those feelings may allow Nomsa to put them behind her for the time being and prevent them from possibly affecting her good adherence record.

What the facilitator knows about the group and Nomsa's place in it:

Nomsa has been attending this open group for more than six months. The group has a shifting membership of about 20 people, but there is a core of about 10 who attend most sessions. Although Nomsa does not attend every session, she has a definite position in the group. She often raises or picks up on issues when others are more hesitant. In this situation, however, it is she who needs support from the group. However, it may not be easy for Nomsa to acknowledge to herself some of what she feels or to share this with the group. Group members may also have difficulty acknowledging that these are feelings anyone can have and that it is better to speak about them than to keep them locked up inside.

Some options for opening up discussion and addressing Nomsa's needs:

❖ Ask whether any group members would like to respond to Nomsa. Encourage and reflect comments that recognise that feelings of sadness, loss, anger, and fear are common and understandable in this situation;

❖ Ask how group members themselves react to hearing about Nomsa's friend. What thoughts and feelings does it raise for them;

❖ Ask group members to share ways of coping with these kinds of feelings;

❖ Comment on Nomsa's saying, "*that could happen to me*". Do others feel that way? Help the group to accept that feelings of fear and anticipated loss are common and to be expected; and

❖ Ask what can be done to prepare for one's death. If not suggested by group members, talk about ways to prepare e.g. putting together a memory box, making a will, making plans for children, telling family or friends one's wishes for a funeral. Suggest arranging practical sessions e.g. having a session to begin to make memory boxes and/or having someone come to talk about making a will.

Managing the group process:

Problematic reactions	Examples	Possible facilitator intervention
Shifting topic before Nomsa's emotional needs are met	*"That same thing happened to my neighbour who died a couple of years ago. He seemed to suffer so much in the end."*	*"So it seems that you are telling Nomsa that she should not feel alone in what has happened. We're so sorry, Nomsa, for your loss. We're here to support you."*
Starting a downward spiral of sadness and depression	*"Sometimes I feel so powerless, like there's nothing we can do."*	*"What are some ways we can keep ourselves strong in the face of such difficult situations?"*
Ignoring feelings and concerns of other group members	*"Sometimes it's better not to talk about these things."*	*"It **is** difficult to talk about this kind of situation, but sharing can help. Maria, you mentioned your neighbour. Would you like to tell us more about how you felt at the time? Or someone else perhaps?"*
Avoiding talk about fears of dying	*[as above]*	*"Perhaps what you are saying is that this is something that could happen to any of us and that it is hard to talk about. Would anyone like to share any thoughts or feelings they have about this? Are there things we can do to help us be better prepared if that should happen?"*

Overcoming problems that arise during the group process

All groups run into difficulties, even those organised by the most skilled facilitators and professionals. It is the role of the facilitator to recognise difficulties faced by the group and evaluate his or her role in attempting to resolve them. Importantly, solving problems is not the sole responsibility of the facilitator. Often, by acknowledging the issue in a session, the group itself can play an active role in finding ways to resolve the issue. Facilitators should not feel that they have to solve all problems by themselves.

While it would be impossible to anticipate all of the difficulties that might arise in running a support group, thinking through possible scenarios in advance can be helpful. This section looks at some of these difficult situations and outlines possible ways of dealing with them. Note that each group is unique and these guidelines should be adapted to the special circumstances of each group.

Confidentiality

Confidentiality is one of the most important components of a group as it creates the foundation for trust among group members. Feeling confident that what one shares in a group will not be divulged outside of the group is crucial to making members feel 'safe' to share very personal feelings or concerns. When confidentiality is broken to the point that a member no longer feels safe in a group, it is one of the most serious problems that can be faced by a group, as shown by the example below:

> Two group members, Adji and Marla, ran into each other on the street. Adji was with her husband, and Marla was alone. When Adji introduced the two, she added, "Remember? She's the one I told you about." Marla was horrified. While she did not know how much Adji had told her husband, Marla's confidence in the group was shattered. She questioned whether or not she would return to the group, and wondered if she'd ever feel comfortable enough to share one of her deepest concerns with the group, her husband's violence at home.

Possible strategies for addressing this situation

The most important way to address this kind of problem is prevention. Confidentiality should always be outlined as one of the ground rules for the support group, and it should be revisited at the beginning of each session. If all members agree as to the reason for the rule of confidentiality and its importance, they will be less likely to violate this rule. One strategy to achieve this is to ask the group members to explain its importance in their own words:

> *"Why is the rule of confidentiality so important?"*

When confidentiality has been broken, the member whose trust has been violated, like Marla, may be tempted to withdraw from the group. Before this happens, it may be possible to address the issue in the group, and allow the group to decide the appropriate action. Ideally, the group can help Adji and Marla to resolve the issue by talking. In an extreme situation, after discussing the issue in the group, the group may decide that Adji should stop participating. The important thing to remember is that the decision can be made by the group, and does not necessarily need to be made by the facilitator alone. Ultimately, any decision that is made should serve to protect the well-being of all members.

Differences of opinion and prejudice

When a group of people come together, not everyone will have the same opinions, nor will each person approach problems in the same way. Some individuals may even hold strong feelings about the 'right' way to approach certain situations or think about certain issues, with little tolerance for other alternatives. Further, some people may even have prejudices, or opinions (often negative) about certain issues that lead to making judgments about other people. Examples of issues about which some people have strong views are sexuality, disclosure, gender roles, or commercial sex work. One of the foundations of an effective support group is creating a safe environment of tolerance, in which no member feels like he or she will be judged or criticised for sharing what he or she thinks or feels. In a healthy support group, differences of opinions can be debated, but when it is not possible to reach agreement, the thoughts or feelings of each member are respected, no matter how different they are.

> Lindi shared with the group her frustration that her husband would not let her tell her teenage children about her illness. Most men in the group felt that the man is the head of the family and Lindi should do as her husband said. "He must have his reasons," said one. A number of women disagreed, saying that it was correct for Lindi to consult her husband, but that this should be her decision. "That is not the way things are done in our culture" said Jacob, "this thing of women making their own decisions is something that comes from outside, and it will kill us!"

Possible strategies for addressing this situation

Differences of opinion can lead to group members learning to see things in new ways and finding new ways of dealing with issues. However, this issue shows how differences of opinion and prejudices (in this case, about the roles of men and women) can split a group and make it difficult for the group to continue supporting its members. To keep the group focused, it is important to find ways to bridge the divide between members on this issue. It will be important to acknowledge differences, and at the same time, to avoid making any of the members feel that their opinion is being judged. It can be helpful to bring the discussion back to the problem being raised and to look for something in common between opposing points of view, or to shift the emphasis in how one or other point of view is being put forward. The facilitator could say:

> *"It is clear that there are different opinions about the roles of men and women in the family and that people feel strongly about this. But what we need to look at here is how to help Lindi with her situation. She is concerned about her children. Her husband, as the father of the children, must also be concerned for them. How could Lindi open a conversation about both their concerns?"*

Unacceptable behaviour

A group member may sometimes show behaviour that is unacceptable to some or all members of the group. Behaviour could be unacceptable because it breaks the ground rules or contract that the group made at the beginning of the group, or because it offends some members. Examples might be being aggressive or disrespectful to other group members, swearing, or being drunk.

> Dan often comes late to the group, and on one occasion arrived at the session drunk. During the session, he made several inappropriate comments, and was generally disruptive.

Possible strategies for addressing this situation

When a group member's behaviour becomes inappropriate, the facilitator first needs to look at the reasons for the behaviour. While it may be possible that the group member is simply being disrespectful, it is equally likely that there is some reasonable explanation for his or her behaviour:

> *Perhaps Dan lost his job? Is having trouble at home? Just found out that his partner is infected?*

The change in behaviour could be a negative way of dealing with his feelings of frustration, anger and depression. If this is the case, it may be possible for other group members to help him to come to terms with his reality and find more constructive ways to deal with his problems.

Particularly with this type of situation, it is important that the group as a whole makes a decision as to how the situation should be addressed. When it becomes clear that a group member's behaviour is unacceptable, the facilitator can pose the problem to the group and ask for ideas as to what should be done. If Dan is too drunk to be able to participate in a discussion, it may be better to postpone the discussion to another session. The group may decide to issue a warning to Dan, ask him to leave the session, or take some other measure.

Attendance

A common problem in support groups has to do with poor or irregular attendance. Alternately, individuals may arrive late and disrupt the session. This may be due to many different reasons, including health problems, side effects, financial difficulties, work, competing family responsibilities, or a loss of interest or commitment to the group. Depending on the reasons, different strategies can be used to address these difficulties:

> Since the beginning of the support group Rafael's attendance was fairly regular. He rarely missed a session. Then, at one point, Rafael stopped coming. When his absence came up in the group one day, several members said that they had not seen Rafael in a long time.

Possible strategies for addressing this situation

When a member suddenly withdraws from a group, if possible, either one of the group members or the facilitator should attempt to contact the person who has left to find out why. While it may not be possible to resolve all of the possible difficult situations, depending on the reason for withdrawal, there may be some possible solutions:

Health reasons

The group member could be assisted to obtain the necessary health services so that he or she can return to the group. Alternately, if the member has difficulty getting to a session due to physical limitations, perhaps a community health worker or another group member could help by accompanying him or her to a session.

Financial reasons

When funds are available, sometimes transportation costs can be covered. Alternately, it may be possible for the group to organise some fund raising activities that will help cover these expenses.

Lost interest or commitment to the group

Sometimes, an individual may feel that his/her needs are not being met in the group or that he/she is not an 'important member' of the group, and stop participating. In these cases, follow up contact may help to uncover unmet needs or make sure the member feels a sense of belonging in a group.

Unrealistic expectations

One type of unrealistic expectation is that one will miraculously get over their depression by attending a few sessions. When this does not happen, a member may grow frustrated and withdraw from the group. For instance, a member may ask, "why should I go to the sessions if it only makes me feel worse?" or "why should I listen to other people's problems if my own problems are hard enough?" Particularly in therapeutic groups, recalling and sharing painful experiences can be difficult, and participants may have this initial impression from a session. However, the goal of the support group is to reduce the suffering associated with these experiences, by processing them, reinterpreting them, and overcoming them with the help of the support group.

Attrition

Similar to the problem of attendance is that of attrition, or when, for various reasons, members who join support groups or have been attending for a substantial period of time, stop coming. A gradual reduction in members is a normal and natural part of a group's life cycle.

Group members might stop attending the group for a variety of reasons. Just a few examples of these are:

❖ A realisation that they do not belong in this particular group because their problems or needs are different to others in the group

❖ They feel that they do not have enough in common with other members of the group

❖ They might not yet be ready to acknowledge their difficulties and talk about them or

❖ They had different expectations of the group.

❖ Other practical reasons such as transport of child-care problems

> You started a closed ongoing group 10 months ago with 8 people, you now have only three people left!

Possible strategies for addressing this situation

It is possible that less experienced facilitators will take it personally when group numbers drop out. They may feel that they are to blame, that they are not liked by the members or that they are not doing a good enough job. While it is important to constantly evaluate one's performance as a facilitator, one needs to balance self-evaluation with an understanding that attrition is a natural part of the support group process.

Facilitators need to anticipate a drop in group numbers and plan accordingly. For example, a facilitator can enroll a slightly larger number of members during the planning stage than is ideal for the group. This way, the group will not seem too small once it has reached its state of equilibrium i.e. when those who are likely to fall out, have already left.

When group numbers fall the facilitator may discuss the future of the group with members and decide what they would like to do. For example even if the group started as a closed group, the group members may decide to change it into an

open group and invite new members. Alternatively they may decide to still keep the group closed but invite new people in at a particular time and then keep it closed again. Another option is for a facilitator who may be running more than one group where numbers have dropped, to suggest to the different groups that they merge.

Scapegoating

Scapegoating happens when one member of the group tends to bear the brunt of responsibility for different problems that might arise in the group.

> Joan has some difficulty relating to the other members. She often comes late to the sessions and every time something goes wrong in a session, it seems like all the group members 'gang up on her' and blame her for the problems in the group.

Possible strategies for addressing this situation

This is a common problem that can happen in any type of group. Blaming one member allows the rest of the members to continue relating in a harmonious way, at the expense of the targeted member. If this does happen, it is important for the facilitator to recognise this and to intervene. Because this is often a fairly unconscious act, it may be necessary for the facilitator to be quite direct in dealing with this problem, and at the same time remain as objective and neutral as possible.

For instance, the facilitator might point the problem out to the group and seek explanations:

> *"What do you think is going on here?"*

> *"Why does it seem that Joan takes the blame for most problems in the groups?"*

One member dominates the conversation

One problem that often emerges in groups is when one member dominates the conversation. It can be difficult to interrupt his or her story without making him or her feel badly. In order to know how to respond to this situation, the facilitator should ask him or herself, *"Why is this member talking so much?"* Some possibilities are that the person:

- ❖ Feels the need to talk?
- ❖ Finds it difficult to stop talking?
- ❖ Does not tolerate silence?
- ❖ Seeks attention?
- ❖ Wants to avoid more sensitive or risky topics?

The facilitator should also gauge the level of interest of other members of the group, and the therapeutic potential involved in the person's testimony. Once the facilitator has analysed the problem, identified the possible causes, and decides that it may be necessary to intervene, he or she can do this in several ways, depending on the situation and the person's response.

Possible strategies for addressing this situation:

"What you're saying is very interesting. What do the rest of you think about what he said?"

"Juan is telling us that … What do you all think of this idea?"

"Very good. Thank you for your testimony. Let's hear what others have to say. Perhaps we can listen to those members who have not yet participated…"

"It seems we've gotten a bit off topic. Let's return to the topic of…"

If these strategies do not work, it may be possible to appeal to the rules and norms of the group:

"In the rules of the group, we agreed that everyone should have the chance to speak. Let's see if any other members would like to intervene or share something with the group."

Other challenging situations

There is an emergency during the session

If a group member experiences an emergency situation during the session, for example, he or she feels very ill or has trouble breathing, a co-facilitator or one of the support-staff should attend to it. The emergency should be handled as discreetly as possible, without interrupting the group or allowing the incident to frighten the other members.

One of the co-facilitators is unable to attend the session

One advantage to having more than one facilitator in the group is that, if one cannot attend, the other may run the group in his or her absence. Continuity and regularity of sessions is extremely important.

One participant wants to bring his/her children

The participants may be of all ages, though it is preferable for young children not to participate in the session. They may serve as a distraction and/or interrupt the dynamic of the group. Furthermore, some themes are not appropriate for children and may impede the therapeutic process. However, this problem may be unavoidable in some groups, when alternate childcare is not available, and the group can make a collective decision as to how they would like to deal with this issue.

A member of the group dies

This situation is very difficult and may require a unique response in each instance. If a member of the group introduces the topic in a session, it is very important to discuss it. However, if the topic does not surface spontaneously in the group, it will be necessary for the co-facilitators to evaluate whether it would be productive to share the news and explore the person's reactions in the group. On the one hand, there is the risk that the news will frighten the other members and weaken their resolve to continue treatment. However, if the person who has died has been a regular member of the group, members are bound to notice his or her absence at some point or, if there is a good possibility that the other members will discover the news outside of the session, it may be helpful to explore feelings about the person's death in a safe and supportive environment to minimise the negative impact. Raising the issue may also provide a fruitful opportunity for members to share their fears and to talk about what can be done to prepare for their own eventual deaths. Each situation requires a careful analysis of the possible advantages and disadvantages of introducing or withholding the topic, to determine the most appropriate action. It is advisable that, when possible, the therapeutic team comes to an agreement before beginning the session.

A member falls ill with a contagious illness

In the instance that a group member becomes ill with a contagious illness, like tuberculosis, it will be necessary to suspend his or her participation temporarily. Due to compromised immune functioning, people with HIV are at greater risk of contracting and developing other illnesses and efforts should be made to protect

other members from unnecessary exposure to infectious illnesses. Once the individual is no longer contagious, he or she may be reintegrated into the support group. For instance, if the person has active tuberculosis, it may be necessary to wait for the individual to begin treatment for tuberculosis and obtain two consecutive negative culture results, and is no longer contagious, before he or she may rejoin the group.

A member of the group develops symptoms of severe mental illness

At some point during one's illness, it is possible for a member to experience symptoms that may require psychiatric medications. These symptoms could include becoming very withdrawn, confused thinking or speech, irrational fears or angry outbursts. Since a member with these sorts of symptoms may disturb how the group functions, it is better to suspend his or her participation until he or she is stabilised with psychiatric treatment. Once symptoms are controlled, the member may be reintegrated into the support group.

Two members of the same family (both HIV-positive) want to be in the same support group

It is possible to invite more than one person per family, especially if they have a supportive relationship. However, if there is a lot of conflict in their relationship, it may be necessary to include only one or the other in the group.

A member wants to bring family members or acquaintances to participate in an occasional support group

It will be necessary for the therapeutic team to decide whether or not it is appropriate for family members or others to participate in a session, depending on the situation. In some cases it may be helpful to the therapeutic process. However, as strangers to the group, their presence may also make it difficult for other members to feel free to discuss issues, and could weaken the capacity of the support group to work through issues.

Enhancing facilitator effectiveness

There are two important processes that help facilitators cope more effectively when leading a group. The first is to know one self as well as possible and not to allow one's own emotions, beliefs and prejudices to interfere with the group process. The second is to get ongoing support and supervision. This may take the form of having a more highly skilled person or mentor providing input and assisting with problems that arise or may involve peers providing support and supervision for each other.

Managing one's own reactions

> In one session, a person brought up the topic of marital separation when sharing some difficulties he was having with his spouse. By coincidence, one of the facilitators was going through a similar marital problem in his own personal life. Listening to the indivdual's testimony caused the facilitator to feel slightly anxious.

All people respond emotionally to situations. It is normal that group facilitators might feel moved by a person's experiences, and have some emotional reaction to their plights. In fact, it would be impossible to be totally objective, separating one's own personal reactions from the therapeutic interactions. However, to the extent that it is possible, the facilitator can try to be aware of his or her own feelings and prevent them from interfering in therapeutic interventions. In order to do this, it is necessary to be conscious of any changes is one's mood or feelings during the session, and also be aware how one's emotions or reactions may generate feelings in the indivdual.

Strategies to minimize the impact of our emotional reactions in the therapeutic environment

Take 'stock' of how one is feeling before the session begins
Before the session begins, it is important to assess one's emotional state. To do this, we need to conduct a self-introspection. As part of the introspection exercise, it is important to analyse one's emotional state, and identify any

potential causes for any emotional unrest. If we recognise that our emotional state is disturbed, we can try to do some relaxation exercises before initiating the session. If facilitators do not enjoy positive mental health, it will be difficult to assist and support other people.

What new emotions are experienced during the session?
It is important to be aware of any changes in our emotions during the session. Since we've already conducted a baseline self-introspection, it will be easier to note if and when there are any alterations.

Factors contributing to one's emotional reaction
A careful analysis of our emotional reactions is crucial in order to know how to proceed. New sensations that we may experience in the context of a therapeutic session, generally, are the reflection of what is happening with one or more people in the group. However, it is also possible that these emotions are triggered by some previous personal experiences of the facilitator, and it is important to be aware of this possiblity. It is necessary to ask oneself:

To what extent are my emotions the reflection of what is going on in the group, and to what extent are personal factors contributing to my emotional reaction?

For example, how can one interpret feelings of anxiety or fear in a session? Most likely, the anxiety is the reflection of a threatening or hostile attitude of one or more members of the group. Alternately, it could reflect the fear of confronting a difficult topic that puts our own therapeutic abilities to the test, and makes us feel nervous or anxious. Finally, it is possible that something happened in the session that has triggered latent anxiety, about which we are not fully conscious. Due to the variety of possible causes of our reactions, as facilitators, we have to be very aware of our reactions and the form in which it can influence the therapeutic interaction.

Expressing emotions in a therapeutic way
Once the facilitator has identified the cause of the emotion they're experiencing, it will necessary to make a decision about what to do with it, that is, how to express it in a therapeutic way. There are three options: disguise the emotion, express it openly, or emphasize the expression of the emotion.

For example, if during the course of the session, the facilitator feels a negative emotion, such as frustration, towards a member for dominating the dialogue, it

could be necessary to analyse this reaction. If the facilitator notes that this reaction is personal and is not necessarily the person's fault, the most therapeutic decision could be to disguise the emotion. On the other hand, if the testimony of the member provokes a reaction such as sadness, the facilitator needs to ask him or herself what the most adequate therapeutic reaction is, to disguise or express the emotion. Depending on the cause and implications of the response, the facilitator can elect the most appropriate action.

Avoiding becoming overwhelmed with the problems of group members

At the end of the session, the facilitator should do another introspection to evaluate how he or she is feeling emotionally. Do you feel altered? In this case it may be necessary to do a relaxation exercise or another activity of 'emotional cleansing' in order not to bring the member's problems or the problems of the group home with you. Taking good care of ourselves is an important measure to prevent emotional burnout and loss of therapeutic efficacy.

Getting input, support and supervision from others

Establish a network of experts

While it may not be possible in all situations, where it is possible, it is a good idea for a group facilitator to have a network of people to whom he or she can refer (for example for individual counselling or to get psychiatric medication), to get input when he or she is unsure of something, and even to invite to the group to give specialised input. For example, if a number of members of the group are on psychiatric medication but both the group members and the facilitator are unsure if these medicines can be taken together with ART, an expert may be called in to answer questions.

Ensure time for support and development

To remain effective, facilitators need emotional support, the opportunity to share successes and difficulties in working with groups, so that they continue to develop their skills. This is often referred to as 'supervision' or 'mentoring', and is usually conducted by someone who is more experienced. It is important that facilitators have structured, scheduled sessions to receive supervision/mentoring. Preferably this should occur on a regular and ongoing basis but for some facilitators such sessions may occur less regularly, even on an 'as needed' basis. Support and supervision/mentoring may be on an individual basis but may also be conducted by one supervisor/mentor in a single session, with a number of people who are running groups.

Some of the benefits of having support/supervision/mentoring are:

❖ Giving emotional support to the facilitator who may feel drained by always giving support to group members and getting little back;

❖ Helping the facilitator when they may be 'stuck' either with a member of the group or with the group as a whole;

❖ Providing the facilitator with new techniques and strategies;

❖ To make sure that the facilitator is on the right track and is being effective in their work;

❖ Providing expert information if the facilitator does not know the answers to certain things that have come up in the group; and

❖ Helping the facilitator deal with personal issues that may be interfering with his/her running the group effectively.

When a facilitator discusses issues with a supervisor/mentor, it is critical that the confidentiality of the group members is maintained. This can be done in part by not mentioning names. The facilitator should discuss with their group the fact that he/she will be discussing issues from the group with a supervisor/mentor. He/she should particularly emphasise the benefits of this for the group. However the group must be assured that all issues discussed will be kept confidential by the supervisor/mentor and others in a supervision/mentorship group if this format is used.

Conclusion

Joining a support group is a very important step for any individual who is HIV-positive. It may mean a complete reversal in the manner in which he or she is living with HIV/AIDS. In some cases, it could mean the difference between life and death. In most cases it will probably have considerable impact on the quality of life of the individual.

Thus it is very important that facilitators prepare carefully for a group, in terms of the type of group it will be, who the members will be, as well as setting realistic objectives for what the group can achieve. While the members should be involved in determining the 'rules' around which the groups should operate, the counsellor should be careful to encourage realistic expectations and counter any unrealistic expectations at the beginning of the group sessions.

Equally, it is important that the facilitator gets support and has the opportunity to 'debrief', as the emotional and psychological strength of the facilitator is critical. While each and every group will have its own particular dynamics, it is believed that the ideas and experiences outlined in this manual will give guidance on effective waysto conduct a support group.