

Women Living with HIV

A Group Encounter

Robyn Berman

A short-term support group for women with HIV-infection was run by the author and a co-therapist, at the Community AIDS Information and Support Centre in Hillbrow. The group met for six one-hourly sessions on a weekly basis. Most referrals were made from the HIV Clinic at the Johannesburg Hospital, although one member was referred from Rietfontein Hospital in Edenvale.

The group consisted of three black women, a white and an Indian woman. All the women could speak and understand English. They were aged between their early twenties and late forties. Group members came from both stable and chaotic backgrounds. Some of them were single parents, and others were in stable marriages. One member was pregnant and another had recently terminated a pregnancy. Another member was recovering from tuberculosis. The group included women who had left school early or had done matric.

The goals of the support group included helping women to cope with their situation and explore feelings arising from being HIV positive. It was also intended to help them realise that their situation and experience was universal.

Getting to Know Each Other

During the first two sessions the members introduced themselves and described when and under what circumstances they had been diagnosed. The HIV status of all the members appeared to create a sense of communality. The phrase "me too" was often heard, as one or another member spoke about a painful experience. Over the first sessions the group appeared to become a cohesive unit.

Initially it was difficult to end sessions, as members kept on talking after the hour had ended. It thus became obvious that the group experience was the first opportunity for members to speak openly about the disease without fear of rejection. Three members had not told their parents and children about their diagnoses. Their greatest fear was that people would not understand and would isolate them. There was almost no-one, outside the group, to turn to for support.

The reactions of hospital staff towards women with HIV-infection was a further area of concern for members, who often experienced a great deal of insensitivity from them. For example, a member found that after telling a nurse she was HIV-positive, the nurse suddenly put on two pairs of gloves in her presence.

During the second session, the group membership changed when a white woman entered the group and a previous member was absent. The co-therapist was also absent on that day. Instead of working with the issue of HIV/AIDS, the group focused on the process arising out of their absence. This illustrates to what extent cohesion had already occurred during the first session.

The new member also affected the group content and process in important ways. For example, her presence temporarily interrupted the flow and perceived self-identity of 'the group'. Members began to separate themselves into 'racial' sub-groupings, with comments such as "we blacks look at things differently". Boundaries had, therefore, to be expanded to include the new member.

The new member also required more attention from the other members and from the therapists, as she had just terminated a pregnancy. Initially, this seemed to confirm that new members should not be included in a group once



HIV positive mother and child. The child has a slim chance of living beyond the age of five. Photo: Ismail Vawda

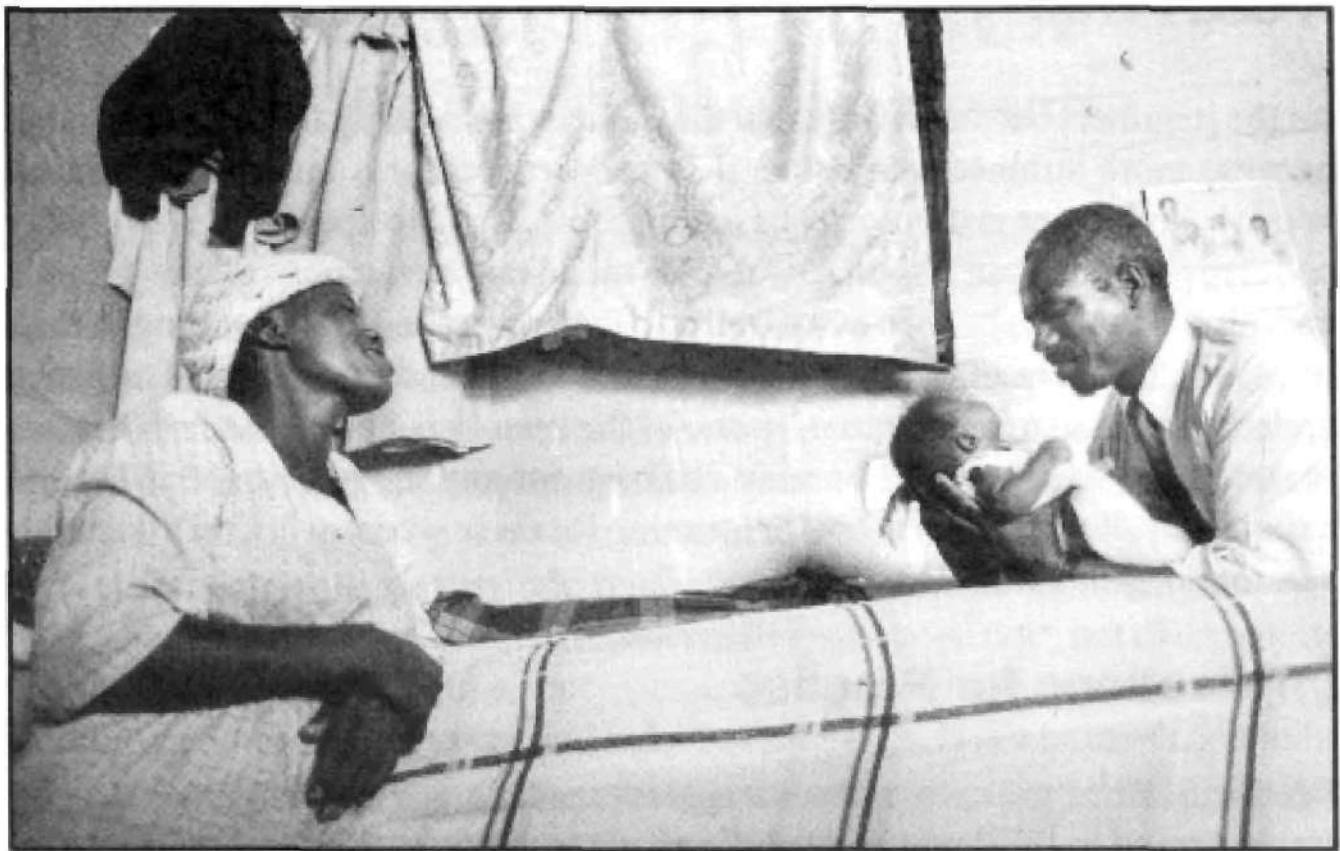
cohesion had progressed significantly. It later emerged that instead of becoming an obstacle to the development of the group process, adjustment to the new member contributed to the realisation of a communality, in that people of different race groups experience the same feelings and reactions from others when diagnosed with HIV.

Becoming Friends

At this point the catastrophic nature of the illness was recognised and members began to feel comfortable enough with each other to reveal deeper and very personal feelings of helplessness, fear and frustration concerning the illness. Most of the participants felt frustrated at not knowing when they would develop symptoms and how long it would take before they died. Members also spoke about the possibility of a cure. They discussed the frustration of feeling well and being asymptomatic, but simultaneously living with the thought that they could become ill and die at any time. They also expressed frustration at the medical staff for not being more exact about the onset of symptoms. It was apparent that group members lacked basic knowledge about HIV/AIDS and its transmission. Basic AIDS education had to be incorporated into the sessions, although it was initially intended that the group would primarily work on an emotional/supportive level.

Members discussed the suicidal feelings they experienced when they first heard about their diagnosis. One of the members was still dealing with suicidal feelings. This had a powerful effect on the other members. Members supported her and tried to suggest ways in which she could alleviate these feelings. For example, members suggested that it was helpful to keep busy, rather than think continually about the disease. The member who constantly experienced suicidal feelings was also the only pregnant member. In view of the extra responsibility she had assumed through her pregnancy, her feelings were understandable. It should be noted that a woman has a 25-40% chance of passing on HIV to a child in the womb or at birth. Children born already infected by the AIDS virus have a 25% chance of dying before the age of one, and an 80% chance of dying before the age of five.

All members wrestled with an intense awareness of the fragility of life. Members tended to rationalise their fears of dying early in life by saying that everyone is vulnerable and can die at any time. In addition, the group sessions became a context for re-enactments of current and historic conflicts. For example, members re-enacted with anger and rage their feelings towards other people who acted negatively towards them, because they were HIV-positive.



She needs her husband to understand that he has to take precautions so that he may survive and care for their children. Photo: Afrapix

The effect of this 'acting out behaviour' was of very real value to members. There were also periods of great laughter, as members were able to see the *absurdity and even humour of other people's reactions towards them on finding out that they were HIV positive.*

During the fourth session, once members felt safe and accepted each other, they were able to discuss sexual issues. Members discussed how a diagnosis of HIV had affected their sex lives. Married members mentioned that their husbands' reactions to condoms was a problem, exemplified by one husband who consistently refused to wear a condom and wants to catch the virus and die with his wife. This member was very upset due to the increased burden, responsibility, fear and feelings of helplessness this placed on her.

The group, with the assistance of the therapists, reached out to this member and helped her to work through her feelings. Group members reacted *with anger towards her husband's attitude and encouraged her to speak to him again and to try to encourage him to wear a condom.* They also suggested that she make her husband understand that one of them needs to remain healthy in order to look after their three year old child.

A Sad Farewell

As the members became aware that the group was reaching its end, interaction became more strained, almost as if in preparation for a farewell. Members appeared reluctant to divulge their feelings and began to speak about everyday concerns, rather than about AIDS. The members' awareness of the group's ending can perhaps be seen as a parallel to their awareness of the ending of their lives and their fear of confronting this sense of impending finality. The group ended on a poignant statement by one of the members during the last session. A statement which would be very ordinary for anyone to say about her life expectancy, but was charged with meaning for these women: "I don't want this session to end, I want it to take long..."

Implications for Practice

Feedback from group members suggests that the greatest need the support group served to fulfil was in providing a place to reveal to others - without the fear of being ostracised or judged, that they had HIV/AIDS.

The support group also provided an opportunity for members to express anger about social and personal issues and provided opportunities for empowerment through suggestions as to how to channel anger into positive action.

The fact that the group was non-racial and served the special needs of women is unique. For instance, in this group, the process of inter-action implied that women were able to confront, explore and, in a sense, transcend several issues concerning patriarchy and racial hegemony.

In South Africa, there are very few organisations which specifically address the needs of women with HIV (*see resource list*). As women often do not receive the information and support which would assist them take responsibility for their own lives and health, a women's organisation addressing the needs of HIV-infected could fill this gap. There is a need to develop a campaign to ensure that HIV-infected women are visible, and that the services and support needed by women are provided. Women infected with HIV can also play a crucial role in these organisations, in terms of counselling other infected women and thereby developing their skill at helping others.

Robyn Berman incorporated the above material in her Masters thesis in Clinical Psychology. She is a practicing psychologist.