

# Understanding participation in a hospital-based HIV support group in Limpopo Province, South Africa

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## Abstract

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**Background:** Support groups are an appropriate way of delivering psychosocial support to people living with HIV/AIDS, especially in low-resource countries. The aim of the study was to understand why people with HIV attended psychosocial support groups.

**Methods:** This was a qualitative study design using focus-group discussions in which support-group members volunteered to participate. Five focus groups were involved in the study.

**Results:** The participants attended because they were referred by a health-care worker, wanted information, wanted emotional support, accompanied an ill relative or knew about the support group. Perceived benefits included receiving psychological support, accepting one's HIV status, reducing stigma and isolation, increasing hope, forging new friendships, helping others, obtaining HIV-related information, developing strategies to change behaviour, gaining access to medical care at the adjoining HIV clinic and receiving food donations. Negative aspects of attending the support group included the large size of the support group, long queues at the HIV clinic, concerns about confidentiality and negative staff attitudes towards the participants. Leaders were concerned about conflict, burn-out and impractical protocols. Access to disability grants was also a concern.

**Conclusions:** Support groups can assist members to cope with the various challenges associated with living with HIV/AIDS through offering structured emotional, informational, instrumental and material support. Support group sizes should be limited. A structured curriculum containing up-to-date information about ART should also be offered to support groups. Social workers should furthermore be involved to facilitate access to appropriate social grants. Finally, support group leaders should receive appropriate training and regular debriefing.

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## Introduction

People living with HIV/AIDS (PLWHA) face significant physical and psychological challenges. To begin with, an HIV diagnosis may bring about a psychological crisis in a person's life. The person's view of life and sense of purpose, of control and of self-worth may be shattered and she or he may experience symptoms of anxiety, depression, shame and a disruption of social relations.<sup>1-5</sup> Psychosocial support, however, can help a person to adjust to an illness and to improve psychological well-being, the quality of life and general health.<sup>2,5-7</sup> One way of offering psychological support is through support groups. These vary in characteristics and activities but they are generally organised around a theme and assist their members with pragmatic approaches to deal with certain life challenges and needs.<sup>8</sup> In low-resource

countries, support groups for HIV have been shown to be an appropriate, acceptable, equitable and cost-effective solution to providing psychosocial support.<sup>9-11</sup>

Benefits of attending support groups include emotional, informational and instrumental benefits. Participants can benefit emotionally through receiving psychosocial support from other people, through forming new friendships, through companionship, through isolation being reduced, through networking and through increased self-confidence.<sup>12-16</sup> They can also benefit through receiving information, such as up-to-date information about medication and treatment for HIV/AIDS, coping skills, women's health issues, safe sex, sleep, hygiene, communication skills, nutrition, exercise, relaxation, daily living and legal issues.<sup>14</sup> Support groups furthermore provide instrumental benefits through teaching

skills and through supporting behavioural change. Cognitive behavioural interventions offered in support groups have been shown to reduce depression,<sup>17</sup> to improve coping skills,<sup>18</sup> emotional well-being, quality of life<sup>19-21</sup> and emotion-regulation strategies,<sup>22</sup> to enhance perceptions of control, medication compliance and hope<sup>1,2,15,23,24</sup> and to reduce stigma.<sup>25</sup> Behavioural interventions can improve self-efficacy,<sup>26,27</sup> antiretroviral therapy (ART) adherence,<sup>28</sup> abstinence from alcohol and drugs<sup>29,30</sup> and the disclosure of HIV sero-positive status<sup>31,32</sup> and reduce unprotected sex and sexually transmitted diseases.<sup>33,34</sup>

Potential negative experiences of attending support groups are concerns around confidentiality and open communication in groups, worsening depression when groups focus on illness, witnessing the decline of fellow members or experiencing members leaving, negative group dynamics and the presence and influence of disruptive members.<sup>7,14,35</sup>

This study was performed at a hospital-based HIV clinic involving an HIV/AIDS peer support group in rural Limpopo Province, South Africa. At the time of the study, a general HIV support-group service was offered twice a week and ART literacy and adherence support were offered on two other days. ART was not yet available through the government's ART programme but the clinic had a few patients on self-funded or donor ART. The general support group was open to anyone living with HIV/AIDS. Participants attended the general support group while waiting for clinical services at the HIV clinic. Between 30 and 40 individuals visited the general support group on any given day and were mixed in terms of age and gender, with approximately two-thirds being female. Services were offered by trained peer facilitators, with educational input provided by primary health-care nurses.

The aim of the study was to understand why people with HIV attended psychosocial support groups.

The objectives of the study were

- to identify factors that motivated HIV-positive people to attend support groups;
- to determine how participants perceived the benefits of attending support groups;
- to identify activities or aspects that participants did or did not enjoy; and
- to determine changes that participants wanted to see in support groups.

## Methods

A qualitative study design using focus-group discussions was used. Support-group members were asked to volunteer for the study. Each focus group consisted of between five and seven participants.

Five categories of participants were selected:

- New support-group attendees – men (who had attended fewer than three times)
- New support-group attendees – women (who had attended fewer than three times)
- Regular support-group attendees – men (who had attended three or more times)
- Regular support-group attendees – women (who had attended three or more times)
- Support-group facilitators and leaders – men and women

A focus-group discussion was piloted, transcribed and submitted to all the authors for review and comment. The interviewer subsequently received additional training and held two additional practice sessions.

One focus-group interview was held with each of the above categories in the local languages (Tsonga or Sesotho). A single exploratory question – “What is your experience of support groups?” – was posed to each focus group and facilitatory techniques were used to explore this until saturation was achieved. The discussions were audio-taped, translated into English and transcribed by an independent person. The transcribed interviews were then verified by the interviewer. Data analysis was done using the software package QSR N6, designed for qualitative-data analysis. A framework approach was used. Themes were defined deductively early in the analysis process based on information obtained from literature and from themes identified in the interviews. The themes were indexed, charted and interpreted according to this framework.<sup>36</sup>

**Ethical considerations:** Support-group members were told about the study and asked to volunteer to participate. An information leaflet and an informed-consent form were given and read to the participants in their first language (Tsonga or Sotho). Questions were answered and written-consent forms were signed prior to the focus-group interviews. Ethics clearance was obtained from the Medunsa Research, Ethics and Publications Committee (clearance-certificate number: MP 83/2004). Permission to conduct the study was also obtained from the Limpopo Provincial Research Committee, the hospital and the clinic managers.

## Results

### Demographics

A total of five focus groups were used in the analysis, one focus group for each of the subgroups of participants. Each focus group had between five and seven participants. All the participants were from villages surrounding the hospital. The majority of the participants' first language was Tsonga, while a few Sotho-speaking individuals also participated. The focus groups were therefore conducted in Tsonga, with an occasional repetition of questions in Sotho. Most of

the regular participants had been members of the support group for more than two years. The new members had attended fewer than three times. The leaders consisted of the support-group facilitator, of lay counsellors in the Voluntary Counselling and Testing and Prevention of Mother to Child Transmission (PMTCT) programmes in the hospital and of HIV-clinic assistants and translators. All the leaders were also living with HIV.

### Themes

Six themes were identified. The themes and sub-themes, with supporting quotes from the transcripts, are presented in Table I.

### Theme 1: Reasons for attending the support group

The participants from all the focus groups mentioned that they first attended the HIV support group because they were referred by a health-care worker while they were ill. Many did not know what to expect and came simply because they were told to do so. Gaining information about HIV and about how to remain healthy was an important reason for participants to continue attending the support group. This reason was mentioned by new male and female participants and by regular female participants.

**Table I: Themes and sub-themes (with supporting quotes in italics)**

Themes and sub-themes	Supporting quotes
<b>Theme: Reasons for attending</b>	
Referral by a health-care worker	<i>"The main thing that made me come here is because I was very sick and then I decided to go to the clinic and . . . I arrived here and they showed me the place where I can come for a support group."</i>
Referral via the PMTCT programme	<i>"And the time I was pregnant I used to go for check-ups and when you are there they do blood tests . . . after giving birth I stayed for three weeks and then I started to become sick and then I started attending the support group."</i>
<b>Theme: Emotional benefits</b>	
Psychological support	<i>"The support group helps because, even if you feel unhappy about your situation, when you get into the support group you see other people who are in the same situation as you . . ."</i>
Social friendships	<i>"When I am in the support group I do not feel lost; I really feel like it is where I belong because we share our pain with each other and we suffer from the same thing."</i>
Meeting potential new partners	<i>"You find that we do not have wives . . . I think if you want a girlfriend from the support group you just need to stand and say 'I want a wife' and then the person who also wants a husband from the support group will stand and say 'I will be your girlfriend if you want me'."</i>
Providing hope	<i>"The thing that makes me feel better I think is the messages that I get from other people who are also in the support group . . . it makes me feel like it is not the end of the world because what other people are saying in the support group really gives me hope for my life."</i>
<b>Theme: Information benefits</b>	
Basic information on HIV/AIDS	<i>"The reason for me to go to the support group was that I wanted to know how to look after yourself if you are living with the virus . . . I can say that the support group makes you know what to do with your situation."</i>
Information on condom use	<i>"They teach us about how to look after ourselves; like now I am HIV-positive . . . I am protecting my life and his life by using a condom. It is not him only who is going to be infected – I will also be more infected . . ."</i>
Information on nutrition	<i>"They say we must eat vegetables and not eat fatty food. The other thing is that they teach us to eat something that has vitamins."</i>
<b>Theme: Instrumental benefits</b>	
Disclosure	<i>"When I started to attend the support group, and when I arrived at my sister's home I was not scared to tell all of them . . . I told them that they need to know their status just like me – I know my status."</i>
Adherence	<i>"You will run out of options of drugs and there will be no treatment for you to take."</i>
Alcohol and smoking	<i>"They advise us to stop drinking alcohol because when you are HIV-positive it is not healthy to drink alcohol."</i>
<b>Theme: Material benefits</b>	
Access to medical care	<i>"The support group helped us by getting the pills."</i>
Food	<i>"I think they enjoy getting food parcels and sharing their problems with other people."</i>
<b>Theme: Concerns</b>	
Support-group size	<i>"Now the protocol says they want 10 people per support group but we attend being 80, which means it is not a support group anymore, it is a public meeting." Leader</i>

### Theme 2: Emotional benefits

The most common perceived emotional benefit that the participants mentioned was the psychological support that they received through sharing their experiences. This was mentioned in all the focus groups. The participants appreciated the freedom with which they could talk about their problems, they could identify with other peoples' experiences and benefit from advice and they appreciated the love and encouragement that they received from others. The participants also reported a sense of belonging in the support group. Friendships were not limited only to the support-group environment and regular male participants suggested that support groups could also serve as a place where one could meet future partners. The support group furthermore reduced feelings of stress, anxiety, stigmatisation and isolation, increased hope and helped patients to accept their status.

The most commonly cited concerns of the participants were the care of children during the patient's illness and after death and sexual concerns (the need to use condoms and dealing with a spouse who refused to use them).

### Theme 3: Information benefits

Participants in all the focus groups mentioned that they benefited from information received in the support group. They felt that the knowledge gained about nutrition and the detrimental effects of smoking and alcohol use helped them to maintain their health. They also felt less anxious because they understood the virus better and they knew what to do, what to avoid and when to access health care. Information on condom use was mentioned by new and regular males and females but not by the leaders. New females, regular males and leaders mentioned that they benefited from information about general medication use. Information around ART focused on adherence to ART.

Regular females discussed the use of traditional herbal medication and that they were taught not to use traditional medication or to combine it with Western medication. One participant's opinion was that most patients did not agree with this view and that they continued using traditional herbal medication.

### Theme 4: Instrumental benefits

All the focus groups except the group comprising the facilitators and leaders mentioned concerns around the need to change sexual behaviour and that the support group provided an environment where participants could exchange ideas and experiences in an attempt to solve problems. One of the main sexual concerns for female participants was the issue of asking their partners to use condoms and dealing with husbands who refused to do

so. Husbands refused because they did not believe that they were ill, they did not want to be tested or they did not believe that HIV existed. This behaviour was exacerbated by alcohol use. Male participants recognised the difficulty that women faced when trying to persuade their husbands to use condoms. They also mentioned that the support group encouraged them to abstain or be faithful and to use condoms.

Some participants mentioned that the support group gave them the courage to disclose or assisted with the disclosure of their HIV status to someone at home. Participants also mentioned that the support group encouraged them to adhere to their medication. Smoking, alcohol use and strategies to reduce consumption were discussed in the male groups.

### Theme 5: Material benefits

The support group and the HIV clinic's services complemented each other. The leaders mentioned that members of the support group benefited from food that was distributed but also mentioned difficulty with food preparation.

### Theme 6: Concerns about the support group

Participants mentioned that the support group was large and that this affected confidentiality; this inhibited free discussion, especially about sensitive topics. Support-group leaders felt overwhelmed and burnt-out, which caused them to lose hope, to become less sympathetic and to quarrel with each other. Male participants were concerned about the long queues at the HIV clinic and about the fact that some of the clinic staff did not treat them well.

Another major concern was the need to gain access to social grants. New members expected the support group to assist them with accessing grants and were disappointed when their needs were not met. Leaders were concerned that group members did not understand the criteria for qualifying for social grants and that people might engage in dangerous activities to enable access to grants.

## Discussion

The main reason that the participants decided to attend the support group was that they were referred or told to come by a health-care worker. The male participants mentioned that they wanted information from the support group. This corresponds with findings by Barg,<sup>37</sup> who found that one of the reasons that men participated in support groups was the need for information.

The participants mentioned that they benefited emotionally through sharing their experiences, through identifying with other peoples' experiences and through forming

new friendships in the support group. These findings are consistent with those from other studies indicating that the psychological benefits of support groups arise mainly from the groups universalising problems,<sup>15</sup> preventing loneliness and enabling friendships to be developed.<sup>12-16,38</sup> Some studies have found that support groups assist patients in finding new meaning in life and to regard an HIV diagnosis, paradoxically, as a positive part of a new identity.<sup>1,4,5</sup> None of the participants in this study mentioned these as benefits.

The participants in all the focus groups benefited from basic information about HIV/AIDS, HIV prevention strategies and general health maintenance. This finding is similar to a previous qualitative study in Limpopo Province, South Africa, where participants reported that they learned about HIV, basic facts, transmission, prevention and treatment in support-group meetings and had not had accurate or adequate knowledge about HIV before they joined the support group.<sup>16</sup>

In this study, few comments were made about ART. The reason for this could be that no specific questions were asked about ART during the focus-group meetings and because few patients were on ART at the time. Traditional (herbal) medication was mentioned more frequently than Western medication. The general feeling amongst the participants was that the majority of people in the support group used traditional medication. Similarly, in a US study of an African-American church-based support group, members mentioned self-treatment with herbs and colonic cleansing as recommended by friends or relatives rather than taking chemotherapy.<sup>37</sup>

Previous studies have found that support-group participation assists with disclosure<sup>31,32</sup> and that cognitive-behavioural interventions could improve adherence in low-adherent patients.<sup>28</sup> The participants in this study mentioned that the support group assisted them in changing their behaviour. This study was not, however, designed to assess whether there was actual behavioural change.

In this study, concerns about confidentiality, large support-group size and the open nature of the support group prevented people from opening up and sharing their experiences. Previous studies have recommended that groups limit their size to a maximum of 12 members,<sup>39</sup> since closed groups allow people to build up trust and warmth, although this would exclude others who could also benefit.<sup>40</sup> Negative group dynamics, disruptive members, open communication in the group and concerns about confidentiality can deter patients from visiting support groups.<sup>35</sup> Other major concerns amongst the participants were poverty, food, access to disability grants and unsympathetic health-care providers, which have also been identified by previous authors in South Africa.<sup>41</sup>

## Study limitations

Firstly, the support-group members were asked to volunteer for the focus-group discussions. This could have caused selection bias, since people who did not attend or enjoy the support group were excluded. Secondly, a staff member of the HIV clinic facilitated the focus-group discussions. Although she was not directly involved in patient contact, this could have caused inhibition amongst participants who may not have wanted to criticise the service that they regularly used. To reduce inhibition amongst the research participants, the principal researcher did not attend the discussions and the groups were kept small and homogenous. Thirdly, the qualitative study design was appropriate to explore the subjective experiences of the participants in the support group but it did not allow the researchers to assess the accuracy of the information given or to measure behavioural change.

## Conclusions and recommendations

Support groups can assist members in coping with the various challenges associated with living with HIV/AIDS through offering structured emotional, informational, instrumental and material support. Support-group sizes should, however, be limited to allow confidentiality and open discussions in the groups. A structured curriculum containing up-to-date information about ART should also be offered to support groups. Since one of the main concerns of the patients was access to social grants, social workers should furthermore be involved in facilitating access to appropriate social grants. Lastly, support-group leaders should receive appropriate training, support and regular debriefing to reduce burn-out.

## Declarations

There is no conflict of interest.

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