Development of structured support groups for HIV-positive women in South Africa

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ABSTRACT

Women living with HIV in a stigmatising community need support to cope with their HIV status. In a process of action research, a structured support group programme was designed to meet the needs of women to cope with their diagnosis and interpersonal relationships. The emphasis was on identifying their needs and developing programme material to address those needs through group participation and interaction. The programme was pilot-tested at two sites located in two townships in Tshwane, South Africa. Feedback after each session made it possible to adjust the programme to the needs of the participants. In a formative evaluation, audio-taped sessions, process notes of facilitators, and experiences of the participants were used to identify therapeutic elements, the value of the groups and the problems in the implementation process. Women reported benefit from participation in the support groups. A 10-session structured programme to be used in support groups addressing the most important needs of HIV-positive women was developed.

Keywords: support groups, HIV-positive women, South Africa.

RÉSUMÉ

Les femmes vivant avec le VIH dans une communauté stigmatisante ont besoin de soutien afin de faire face à leur statut de VIH. Au cours du processus de la recherche active, un programme de groupe de soutien structuré a été conçu avec le but de répondre aux besoins de ces femmes pour qu'elles puissent faire face au diagnostic et aux relations personnelles. L'important était d'identifier les besoins et de développer le matériel nécessaire au programme afin d'aborder ces besoins à travers la participation et l'interaction du groupe. Des essais pilotes du programme ont été fait dans deux sites situés dans deux banlieues à Tshwane, Afrique du Sud. La réaction au bout de chacune des sessions a permis une adaptation du programme aux besoins des participants. Durant l'évaluation formative les enregistrements de sessions, les notes du processus des animateurs et les expériences personnelles des participants ont été employé dans le but de relever les éléments thérapeutiques, l'importance de groupes et les problèmes émergeant de l'exécution du processus. Les femmes ont signalé que la participation aux groupes de soutien a été rentable. Un programme structuré, ayant dix sessions, a été aménagé pour être utilisé dans les groupes de soutien avec le but d'aborder les besoins les plus importants des femmes séropositives.

Mots clés: groupes de soutien, femmes séropositives, Afrique du Sud.

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Introduction

Due to the stigma associated with HIV/AIDS, many newly diagnosed individuals are understandably fearful of disclosure and of seeking support and information about HIV. Stigma is now considered to be a major limiting factor in primary and secondary HIV/AIDS care and prevention (Holzemer & Uys, 2004; Skinner & Mfecane, 2004). At the United Nations General Assembly, Jonathan Mann asserted that an epidemic of discrimination was as central to the global AIDS challenge as the disease itself (Parker, Aggleton, Attawell, Pulerwits & Brown, 2002). The epidemic of stigma, discrimination, blame and collective denial makes it so much more difficult to effectively tackle the spread and impact of HIV/AIDS. For some people, living with the shame and guilt of contracting HIV outweighs the actual physical effects of the virus (Bond, Chase & Aggleton, 2002; UNAIDS/WHO, 2002). Many HIV-positive women are rejected by their families, abused by their partners and gossiped about by their friends and neighbours (Chase & Aggleton, 2001).

In South Africa where an estimated 12% of the population was HIV-infected at the end of 2004 (Department of Health, 2005), research to stem the tide of the epidemic has largely focused on prevention, development of a vaccine and the promotion of medical treatment. The assumption was that prevention efforts could be more cost-effective (Amon, 2002). In this process, important aspects of the provision of psychological support for people who are HIV-infected have received less attention. It was only recently that the overwhelming need for improved treatment and support services contributed to a re-evaluation of what constitutes effective AIDS programming. Evidence from integrated programmes has led to growing consensus that the expansion of care and support services can result in better control of the pandemic (Manning, 2000; WHO/UNAIDS, 2000; Zuniga, 1999).

People living with HIV/AIDS often suffer in silence because of their fear of rejection and discrimination (Bond et al., 2002; Jackson 1992; Jackson & Hunter, 1992; Lie & Biswalo, 1994; National Association of People with AIDS, 1992) – a silence that can contribute to the development of depression and hopelessness (Phillips, 1998), reduce the likelihood of one's seeking information and treatment, and increase the chances of transmitting the virus (Parker et al., 2002).

In a country where traditional and cultural beliefs have yet to overcome the barrier of gender stereotyping and inequality, women are often forced to live their lives feeling disempowered and inferior to their male counterparts. For a woman living in a traditional black community, an HIV diagnosis can mean much more than simply contracting the virus, as the psychological consequences can outweigh the physical effects of HIV. Many women discover their HIV status during pregnancy, and a positive diagnosis can seem like the end of the world, especially for an individual already burdened with the challenges of poverty, inequality and sometimes even violence (Blaney, Fernandez, Ethier, Wilson, Walker & Koenig, 2004; Skinner & Mfekane, 2004). The situation can be made worse by the lack of sources of psychological support.

The prevalence of depression and anxiety in HIV-positive individuals in the USA has been estimated to range from 2% to 21% higher than in the general population (Leserman, Petitto & Perkins, 1997; Lyketsos, Hoover, Guccione & Dew, 1996). Figures for the South African population are less known. HIV presents a multitude of sources of anxiety and depression, such as discrimination, fear of infecting others, concern about opportunistic infections, and the fear of death. Depression tends to occur more frequently at certain points in time, during which people are more vulnerable. Examples include periods of initial adjustment to HIV-positive status, experiencing rejection upon disclosure to family and friends, and learning of a significant drop in CD4 count. The experience of depression complicates the management of the disease by increasing the likelihood of non-adherence to treatment (Angelino & Treisman, 2001). Depression can also limit the energy needed to focus on staying healthy and may contribute to the acceleration of the progression of HIV to AIDS (Leserman et al., 1997; Page-Shafer, Delorenze & Satariano, 1996). In a study of the relationship between depressive symptoms and mortality in HIV-positive women, it was found that participants with depressive symptoms were nearly twice as likely to die as those without these symptoms (Ickovics, Hamburger, Vlahov, Schoenbaum, Schuman, Boland et al., 2001).

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Social support was one of the main themes identified by Coward (1995) and Forehand, Steele, Armistead, Morse, Simon & Clark (1998) as predictive of psychological adjustment in women diagnosed with HIV. It was found that it is *perceived* social support – the person's cognitive appraisal of the support received – and not the actual *availability* of support that plays an important role in a person's psychological well-being (Serovich, Kimberley, Mosack & Lewis, 2001; Turner-Cobb, Gore-Felton, Marouf, Koopman, Kim, Israelski *et al.*, 2002). Various researchers have found an inverse relationship between social support and measures of distress in women living with HIV (Hudson, Lee, Miramontes & Portillo, 2001), suggesting that low perceived social support is a significant predictor of emotional distress and depression among HIV+ persons (El-Sadr, 2001; Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003). Satisfaction with social support on the other hand is significantly related to more optimal functioning and a positive state of mind (Forehand *et al.*, 1998; Gielen, Mcdonnel, Wu, O'Campo & Faden, 2001; Mellins, Ehrhardt, Rapkin & Havens, 2000; Silver, Bauman, Camacho & Hudis, 2003; Turner-Cobb *et al.*, 2002). Individuals involved in social networks have been shown to live longer than their counterparts who have fewer types of social relationships (Miller & Cole 1998; Moskowitz 2003; Summers, Robinson, Zisook, Atkinson, McCutchan, Deutsch *et al.*, 2000). A possible reason for this is the impact of positive effect on the immune system and that positive effect may improve health-related behaviours (Moskowitz, 2003).

Various studies also indicate that people with HIV experience lower levels of social support after the diagnosis than before and less social support compared with people with other chronic diseases and non-infected women (Klein, Armistead, Devine, Kotchick, Forehand, Morse *et al.*, 1998; Turner-Cobb *et al.*, 2002). Hudson *et al.* (2001) found that HIV-positive women reported limited social interaction with family and friends and a low level of perceived social support.

One of the ways in which these challenges can be managed is through interaction with similar others (Roth & Nelson, 1997). This provides 'a less threatening comparison environment and allows those who are stigmatised the opportunity to be "off-duty" from the attribution ambiguity, stereotype threat, anxiety and mindfulness that are likely to accompany interactions with the non-stigmatised' (Crocker, Major & Steele, 1998, p.504). Often a listening ear, together with acceptance and reassurance, is exactly what is needed and is more therapeutic than any treatment protocol (Philips, 1998). In the absence of support of family and friends, support groups can provide recently diagnosed women a safe environment to talk about the virus, share their experiences, learn from the stories of other infected individuals and access information (Summers *et al.*, 2000). It has been shown that HIV+ women who attend support groups are more likely to disclose their HIV status to their family and friends (Kalichman & Sikkema, 1996) and to gain access to treatment (El-Sadr, 2001). The implementation of structured support groups takes the focus of providing support a step further, in providing coping skills and empowerment through knowledge. Although support groups are becoming a popular way of providing the needed support for people living with HIV in a resource-limited environment such as South Africa (Department of Social Development, 2002; Spirig, 1998), very few structured programmemes have been developed to be used in support groups, and even less evaluation has been done regarding the effectiveness of support groups as a psychological intervention in this context.

Based on interviews conducted with 317 pregnant HIV-positive women who are part of the Serithi project, it became evident that an intervention was needed to provide support to women to cope effectively with their HIV status, disclose their status to their partners and close family members, and deal with stigmatising attitudes. The Serithi project is research conducted by a multi-professional team investigating the medical, psychological and social impact of HIV on the lives of pregnant women, with the aim of developing interventions to help them cope and to empower them to take responsibility for their own health and that of their child. The purpose of this paper therefore is to describe the process of developing structured support groups for HIV-positive women at clinics in Tshwane, South Africa.

Methods

An action research approach (Mc Niff, 1988; Walker, 1998) was used in the development of the structured programme for the support group intervention. Action research is a generic term for a wide range of research methods aimed at the mobilisation of social change to

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address social issues in a specific context (Hollingsworth, Nofke, Walker & Winter, 1997). There are two main characteristics of action research:

- It involves a process of participation of community members in solving social issues (Bhana, 1999; Hollingworth *et al.*, 1997).
- It is a process involving a repeating cycle of planning, action, observation and reflecting. Action research is a circular process of feedback used in the planning of each next step of the research. This allows for continuous evaluation and sufficient flexibility to make changes as the process progresses (Hodgkinson & Maree, 1998; Hollingworth *et al.*, 1997; McNiff, 1988; Walker, 1998).

The development of the intervention started with a needs assessment, the development of programme material to address each topic, implementation of the programme, and gathering feedback from each session, to be used in revising the programme material (described below). The programme was implemented at two sites in Tshwane. A session was implemented in the first support group, audio-taped and discussed. The experiences and feedback of the participants and facilitators were then used to revise the session for the second support group and to plan for the next session. After the second presentation of each session, feedback was again considered in revising the programme material for evaluation in a research trial. The process of programme development is illustrated in Fig. 1.

Needs assessment

A focus group discussion was conducted with the eight field workers from the Serithi project. They were retired nurses and graduate students with extensive knowledge of the communities from which the women came. In the discussion they identified the needs they perceived in the group of 317 HIV+ pregnant women they had interviewed. The following perceived needs were identified:

- Information about treatment, protection and ways to stay healthy
- Ways to deal with stress, depression and anger
- How to disclose to partners, introduce condoms, convince them to test and how to deal with infidelity
- How to deal with HIV in a household where people are scared of getting infected
- How to deal with stigma and discrimination
- How to plan their lives to provide support for their children.

FIG. I. PRESENTATION OF ACTION RESEARCH PROCESS
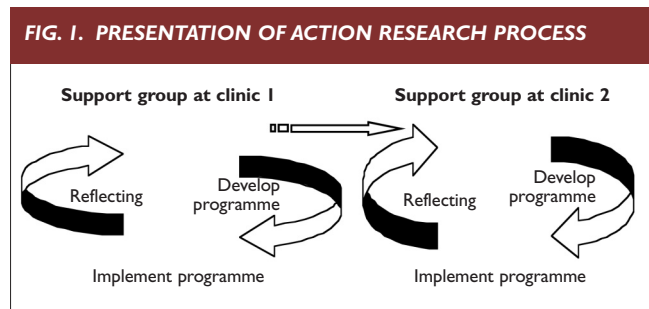
The data on the perceived needs were used to draw up a draft outline of possible topics to address in the support groups. During the first session of each support group the HIV+ women were asked to discuss what they would like to address in these sessions. Their suggestions were added to the draft outline of topics. The list of topics was then presented and discussed in the support groups.

Development of the programme material

A 14-session programme was designed based on the needs assessment. The sessions were semi-structured to the needs of the participants and encouraged group participation. Each session started with an 'icebreaker', feedback from the previous session, and sharing experiences of the week and then a focus on the theme of the day. Experiential learning was encouraged through participation in games, role-plays, exercises, story telling, case studies and sharing experiences.

A systems approach (Capra, 1997; Hanson, 1995) was used in developing the content of the programme. Various aspects of life with HIV were addressed as well as the broader systems within which HIV-infected persons interact:

- **Session 1:** The session started with explaining the goal of the support groups and asking women to give informed consent to participate in the groups. Then group members introduced themselves, shared expectations and the problems they dealt with as a needs assessment. They set the group climate by suggesting group norms to encourage confidentiality and group cohesion.

- **Sessions 2 and 3:** The next two sessions dealt with information about HIV. The effect of the virus on a person's health, the various stages of the illness, ways of transmission and protection were explained using metaphors of the body, soldiers and invaders. How to

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stay healthy through nutritious food, avoidance of re-infection and ARV treatment were explained, as well as the risks and prevention of mother-to-child transmission. The core message of these sessions was that HIV is a chronic disease that can be managed through healthy living.

- **Sessions 4 and 5:** The focus then shifted to the emotional experience of being HIV-infected. Participants had to draw and share their life maps – illustrating the role that HIV played in their lives. From each person's life story, problem areas and coping skills were identified. The stages in crisis management (Kubler-Ross, 1989) were used to explain the emotions they experienced.

- **Sessions 6 and 7:** With the focus on coping with various intrapersonal stressors, each participant was invited to share a positive way of coping with a difficult situation. Each member also was asked to discuss a situation that she had difficulty in dealing with. The coping model of Lazarus and Folkman (1984) was used to distinguish between problem-focused and emotion-focused situations. Problem-solving skills and stress management, rational thinking processes, use of social support and externalisation of emotions were introduced as coping skills and applied to the situations with which they had difficulty. Interpersonal relationships were dealt with in sessions on disclosure and stigma, intimate relationships, and HIV in the household.

- **Session 8:** Participants who had disclosed their HIV-status shared with the group how they had disclosed, and women who still wanted to disclose discussed their feelings about disclosure, planned strategies and participated in role-play exercises on how to disclose.

- **Session 9:** Participants shared their feelings about their intimate relationships in a discussion of the most valuable gift they had received and never received from their partners. The impact HIV had on a relationship with an infected or uninfected partner and the use of condoms was discussed, and in role-plays they negotiated condom use. Women's inferior position in the community and violence in intimate relationships were discussed with a focus on the improvement of relationships.

- **Session 10:** For this session women were invited to bring a family member to join in the group discussion. The aim of involving next of kin in the group was to support family members and strengthen their relationships. Safety in a household with HIV, relationships with family members and disclosure to children were discussed. The suggestion of making memory boxes (Smith, 2004) as an activity to share with their family members and children was made.

- **Session 11:** Thereafter, a broader community focus was introduced regarding how to deal with stigma and discrimination in the community, at the work-place and in medical settings. Human rights of HIV-positive people were introduced and discussed. By knowing their rights, women would be able to identify and deal with aspects of discrimination.

- **Sessions 12 and 13:** The last two formal sessions focused on goal setting and future planning, which included setting short- and long-term goals to give new meaning to their lives. It also included discussions on generating an income to provide for their families. The focus shifted away from HIV to ideals and hopes for the future.

- **Session 14:** During the last session a video of the experience of a woman with HIV in a South African context was shown and discussed. This session also included the evaluation of the intervention.

Implementation of the programme

Participants: Support groups for HIV-positive women were formed at two community clinics in two townships in Tshwane. The clinics provide medical services to a mainly black, very low to middle socio-economic class urban population. The HIV counsellors at the clinics recruited HIV-positive women to join the support groups and explained to them that the groups would form part of a research project. The two support groups consisted of 20 women between the ages of 17 and 42 years, with a mean age of 28 years. Five of the women were married, 10 were single with a partner and 5 single without a partner. Eighteen of the women had children of their own. Participants spoke various languages: 6 women were Zulu-speaking, 4 spoke Sepedi, 3 Indibele, 3 Setswana, 2 Sesotho and 1 woman

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Xhosa. They could understand each other, although women in the group sometimes had to translate words to help each other and the facilitators to understand the conversation. All the women had at least secondary school education, but the majority (15) were unemployed and the mean household income for the group was R2 194 per month (about $365). Most of the women were living in homes with extended family, as is common in black households in southern Africa, with a mean of 4.8 persons per household. Sixteen of the women had known their HIV status for at least 6 months, while 4 women were recently diagnosed. Fourteen of the participants had disclosed their HIV status to at least one other person, while the other 6 had not disclosed to anyone.

Facilitators: Masters-level psychology students facilitated the support groups. They were trained to facilitate the sessions through role-play group sessions. Group and individual processes related to group interaction were reviewed during the training (Yalom, 1995), and systems theory was used in order to better understand the experiences of the women in the context in which they lived. The project leaders supervised the facilitators during and after each session.

Ethical concerns: At the first meeting the women were informed about the project and were asked to sign the informed consent form if they were willing to participate in the groups. Confidentiality and respect for group members were important group rules of the support groups.

Participant and facilitator feedback
After each session, women provided feedback on what they experienced and gained from the session. This information was used in planning the next session and revising the session to be implemented in the second group. The sessions were tape-recorded with the permission of the participants and transcribed into English. The transcriptions and the process notes of facilitators were used in the formative evaluation of the programme to identify elements that enhanced participation and personal growth as well as problems in the implementation process.

After participating in the support group, a short semi-structured interview was conducted with each woman, regarding her experience of the support group. Interviews were conducted with 12 of the participants present at the last group session.

Seven open-ended questions were asked to evaluate the experiences and the value of the support groups. The questions will be used as a framework in the next section to discuss the feedback. The women also evaluated their experience of the therapeutic elements of group interaction (Yalom, 1995).

Data analysis
The sessions were transcribed in English and read through with the aim of identifying activities that were either successful or not successful in enhancing group interaction and personal growth. The qualitative feedback of the participants and the facilitators was interpreted by identifying themes in the responses to each question using the framework suggested by Miles and Huberman (1994). Three researchers interpreted the data to enhance the trustworthiness of the themes identified.

Results
The results are presented in the following sections:
- participant evaluation of the group sessions
- facilitator feedback in identifying therapeutic aspects of the group interaction and challenges in implementation
- the finalised version of the structured support group programme.

Participant evaluation of the support groups
The participants evaluated what they gained from the groups by answering seven open-ended questions in an interview situation. For each question, themes were identified and are reported below.

Expectations before the sessions started. Participants expected to meet and talk to other women with HIV, to share knowledge and experiences and to support others. They also expected to make friends who would help them to accept themselves. Most of these expectations were met in the support groups.

Group interaction. From the analysis of the participants' evaluation of the group interaction, it can be concluded that the women experienced the group interaction as very positive. All the women indicated that they felt group members listened to them, accepted and understood them. They felt they belonged in the group, could talk freely about their problems, helped each other and learnt from others' experience. The group helped them to experience

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hope for the future and to gain knowledge of HIV. Some of the women indicated that they wanted more social activities and active participation to be part of the programme.

What they gained from participating in the groups. The participants indicated that they primarily gained knowledge about HIV, healthy living and how to cope positively. Women felt free in the group to talk about their experiences and the problems they experienced, made friendships and gained support and self-acceptance. The following is what some of the women said about the support groups: *I felt free and safe and I felt at home and loved. I have enjoyed being in the group and I have learned to accept myself and to have self-confidence. I know now there is something I can do for other people.*

It was a shelter to hide away where I could talk freely. I can tell others now. Now I am stronger, I can stand on my own.

Feedback about specific sessions. The sessions that were perceived as the most beneficial were those that provided information about HIV and treatment (sessions 2 & 3), sharing emotional experiences (sessions 4 & 5), discussing disclosure and stigma (session 8), and intimate relationships (session 9). Through these sessions, women had to share experiences and could learn from each other. A few participants also mentioned the value of the future planning sessions (sessions 11& 12). The reactions of the women included the following:

The talks we had on disclosure (session 8) *helped me because I was able to talk about the pain and got rid of the anger.*

Drawing the life maps (session 4) *and talking about my experiences were difficult. I had to think about past experiences, my husband, my family. But it was helpful. I told you about the problem and you helped me. The group gave me ideas how to handle it.*

I learned to stand up for myself, learned that I'm an individual woman and I'm going to do things differently now. I'm not going to be dependant anymore. I learned that I can make my own work and can earn money doing that (sessions 12 & 13).

Suggestions to enhance the programme. To improve the programme, some of the participants suggested the addition of more social activities such as picnics and outings. Suggestions also included ideas about income-generating activities while conversations regarding their problems take place.

The experience of meeting other HIV-positive women. Participants experienced the interaction with other women in similar circumstances as very positive. They could share experiences and felt that others understood what they experienced. Contact with people who were coping well gave them hope. The following quotations indicate how the women felt:

It was very helpful, I am not alone anymore, there are other people in the same situation. When you find out about your status you feel very alone but when you join the support group you can talk to people and develop self-confidence and self-esteem.

I was surprised to see them. I knew some people from school. I saw them and they did not look as if they have HIV. It was a positive picture of HIV. I did not feel alone and embarrassed anymore.

Impact of the group on their lives. All the women indicated that the groups had made a difference in their lives. They did not feel alone anymore, they gained self-acceptance and confidence, learned to talk about their problems and how to cope with the diagnosis:

I was feeling alone and sad. In the group I was free to express myself, to feel that I belong. It helped to talk to others, to listen what they said. Now I feel OK, I can live life to the fullest. I have learnt to talk about problems and that has made me feel free.

One lady told a story about her problems and I learned that people deal with their problems and emotions differently. You can learn from other people's experiences. I learnt that I must not judge other people for the decisions they made.

Feedback from facilitators and transcripts
Transcriptions of sessions and facilitators' reports were used to reflect on the group process and interaction as well as the problems experienced in the groups.

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Therapeutic value of the group interaction. The facilitators reported that women disclosed their experience of being HIV-positive from the start of the first session – thus a climate of sharing, acceptance, and close interaction between the women was created. They openly shared their experiences, relationships with their partners and family, and the discrimination they anticipated or experienced. Sessions were very long, sometimes more than 3 hours, ending in drinking tea and informal interaction.

Informally, women gave one another advice on how to deal with problematic situations. The heterogeneous nature of the group (some women were recently diagnosed and others had known their status for almost a year, some had disclosed and others not) encouraged mutual help because they could learn from each other's experiences. They shared ways of coping and strategies of disclosing their HIV status. This can be illustrated by the following incident: A newly diagnosed woman joined the group in tears in the middle of a session. The group members introduced themselves and shared their experiences of HIV, they answered all her questions and offered to meet with her outside the group to comfort her. Her response was that this interaction gave her hope that she was not going to die and that it was possible to live a happy life with HIV. After that she became a regular participant in the group, disclosed her status to her boyfriend, coped well and started to encourage the other women.

The most successful sessions were those where active participation took place. Role-play situations were found to be very successful to create a reality in the room, much more than through discussions. Women could express their emotions in role-plays and had to deal with situations of discrimination and disclosure in the session, while having the support and suggestions of other HIV+ women. For example, in a role-play situation, one of the women expressed an intense fear of disclosing her status to her mother. After dealing with these feelings, she dared to disclose to her mother. She reported in the next session that her mother cried with her and assured her that she will always support her: '*You are my daughter and I love you*'.

The role of the facilitator centred around modelling acceptance and disclosure to the group. Participants were cautious when having to share their life stories. When the facilitator accepted the stories of the women without judgement, the group members did so as well. When she shared her emotions honestly with the group, they were more willing to share in the group. The facilitator modelled the initial role-play situation. Thereafter, the participants were willing to expose their feelings in the role-play situations. The facilitators occasionally confronted women who had difficulty in openly expressing their feelings in order to help them to deal with difficult situations.

The facilitators gave some feedback about the value of specific sessions:
- They reported that the participants experienced the sessions dealing with information about HIV and healthy living as informative. Participants asked many questions and were relieved that they would still be able to live a normal life. After those sessions, the participants were more confident in their interaction in the group.
- In session 4, which consisted of life maps and story telling, the intensity of the group deepened and women shared various issues in their lives. The exercise helped them to focus on their emotions.
- The women shared many stories of discrimination, in the work environment, in the health care setting and in their families. The introduction of human rights helped them to identify situations and realise that they were not at fault, but that other people discriminated unjustly against them.
- Only one woman in each group brought a family member to session 10. Other participants had various reasons for not inviting their family to the session, mainly because they were unsure how the family member would react. Group members did not feel uncomfortable with someone new entering the group, and in fact, the situation created an opportunity for group members to disclose their status to someone else without experiencing rejection.
- The goal setting and future planning sessions (sessions 11 & 12) were an eye-opener to some women. For many women, an HIV diagnosis meant they were going to die. In these sessions the focus was on setting goals for the future. They realised that they could make plans for life and not for death. The

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idea of possible income-generating activities to provide for their families also gave them hope for the future.

Challenges in the implementation
A few challenges were experienced in the implementation of the programme.

Attendance: Attendance in the support groups was problematic. The number of participants varied from 3 to 12 at a session, with only 2 women attending all the sessions and another 4 attending 12 of the 14 sessions. In interviews conducted with participants who had not attended regularly, it was found that some of them could not attend because they were working, and others had problems at home or were sick. None of them indicated that meeting other HIV-positive women or the content of the discussions were reasons for not attending.

Language: Women in the support groups were from various African language groups: Zulu, Sepedi, Indibele, Setswana, Sesotho and Xhosa. The facilitators were, with one exception, English speaking. Many of the women could understand English but some found it difficult to express their feelings in a second or third language. Group discussions were often conducted in the women's mother tongue and translated back and forth by the other women to enable the facilitator to understand. This improved the communication in the group to an extent, but contributed to a slower interaction process and gaps in understanding.

Finalised programme
Based on the action research approach, the intervention will be shortened to 10 sessions to encourage attendance and to rule out overlaps. The final programme, to be evaluated in a quasi-experimental design, consists of the following sessions:

Session 1: Introduction, needs assessment and setting the climate

Session 2: HIV information and access to treatment

Session 3: HIV, mother-to-child transmission, nutrition and healthy living

Sessions 4 and 5: The emotional experience of having HIV

Session 6: HIV, disclosure and stigma

Session 7: Coping skills, problem solving and stress management

Session 8: HIV and intimate relationships

Session 9: HIV, family relationships and human rights

Session 10: Life planning and goal setting.

Conclusion
In this research, an action research approach was used to develop a structured programme to be implemented in support group interventions for HIV+ women in a South African community. The content of the programme was focused on the women's needs and through continuous feedback the programme content was adapted to help women deal with the issues relating to HIV. The most important needs identified by the participants were:

- To understand the facts of HIV and how it would affect their lives
- Assistance in disclosing their HIV status to partners and family members
- Coping skills to deal with their emotional reactions such as depression, stress and anger and the stigma they experience in their communities
- To have supportive relationships and to share experiences
- To get their lives back on track.

All the women who participated in the support groups indicated that they gained from participation. The interaction with other HIV+ women was an important component in the success of the support groups, because they could share experiences and learn from others. The interactive exercises in stress management, coping skills and dealing with emotional experiences, and the role-plays were the catalysts to stimulate discussion and experimenting with new skills in a supportive environment. The women also indicated that they gained knowledge about HIV and healthy living and that participation in the group helped them to gain confidence and hope to plan their future. Through structured support groups, the value of peer group interaction can be combined with counselling skills of professional facilitators. The role of the facilitator was especially important in modelling sharing and coping and assisting women to express deep-felt emotions.

This research showed that the formation of support groups can be a source of valuable support for people

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living with HIV in a South African context, as suggested by research internationally (El–Sadr, 2001; Kalichman & Sikkema, 1996; Summers *et al.*, 2000).

To address some of the problems in the implemen–tation of the programme, it was decided to run support groups also on a Saturday to encourage and enable women who work to attend the sessions. The programme was also shortened to condense the content. To address the language issue it was decided to include African language speaking HIV+ women as co–facilitators in groups. They could then facilitate the groups in the women's mother tongue, enhance identification in the groups and they could model healthy behaviour.

A programme like this, developed according to the needs of HIV+ women, can be widely used, because support groups led by peers are currently being formed in many communities (Department of Social Services, 2002). This programme can provide them with a framework and activities to use in assisting group members to deal with issues about living with HIV.

This was a pilot study describing the process of action research in developing programme content to be used in support groups for HIV+ women. The emphasis was on identifying the needs and addressing those needs using programme content that enhanced group participation and interaction. The small sample of participants and the mainly qualitative results obtained in the form of self–report of participants and facilitators limit the conclusions that can be drawn from this research. More extensive research is required to assess the effectiveness of such an intervention in providing support to women and decreasing the adverse psychological effects of HIV infection.

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