

Establishing support groups for HIV-infected women: Using experiences to develop guiding principles for project implementation

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Abstract

HIV-infected women need support to deal with their diagnosis as well as with the stigma attached to HIV. As part of their practical training, Master's-level psychology students negotiated with the staff of four clinics in townships in Tshwane, South Africa, to establish support groups for HIV+ women and offered to assist them in facilitating the groups. This study aimed to understand why the implementation of groups was successful in one clinic and not other clinics. The student reports on their experiences and interaction with clinic staff and clients were used as sources of data. Using qualitative data analysis, different dynamics and factors that could affect project implementation were identified in each clinic. The socio-ecological and systems theories were used to understand implementation processes and obstacles in implementation. The metaphor of building a bridge over a gorge was used to describe the different phases in and obstacles to the implementation of the intervention. Valuable lessons were learnt, resulting in the development of guiding principles for the implementation of support groups in community settings.

Keywords: Support groups, HIV+ women, project implementation strategies, change in systems, socio-ecological theory.

Résumé

Les femmes séropositives ont besoin du soutien afin de faire face à leur diagnostic ainsi qu'avec la stigmatisation liée au VIH. Faisant partie du programme pratique de formation, les étudiants de maîtrise en psychologie ont négocié avec le personnel de quatre cliniques des *townships* (quartiers pour les Noirs) à Tshwane en Afrique du Sud. Le but fut d'établir des groupes de soutien pour des femmes séropositives. Ces étudiants ont également offert leur aide en animant les groupes. Le but de cette étude est de comprendre pourquoi l'exécution de groupes fut un succès dans une seule clinique et pas dans les autres. Les rapports des étudiants sur leurs expériences et leurs interactions avec le personnel et les malades ont été utilisés comme sources de données. En utilisant l'analyse qualitative des données, les dynamiques et les facteurs différents qui pourraient affecter l'exécution du projet furent identifiés dans chacune des cliniques. Les théories de systèmes socio-écologiques ont été utilisées afin de comprendre le processus de l'exécution ainsi que les obstacles à celle-ci. On a fait référence à la métaphore de bâtir un pont au dessus d'une gorge pour décrire les différentes phases du processus d'exécution et les obstacles face à l'exécution de l'intervention. On a appris des leçons importantes qui ont, par la suite, favorisé l'aménagement des principes directeurs des groupes de soutien dans un milieu communautaire.

Mots clés : Groupes de soutien, femmes séropositives, stratégies de l'exécution d'un projet, changement de systèmes, théorie socio-écologique.

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Introduction

It is estimated that between 5.7 and 6.2 million South Africans are infected with HIV (Department of Health, 2006) – 12.8% of women and 9.5% of men between the ages of 2 and 49 years (Shisana & Simbayi, 2002). Due to stigmatising attitudes in the community (Visser, De Villiers, Makin *et al.*, 2005), people are reluctant to test for HIV and those who test positive are scared to disclose their status. This obviously has a negative effect on care-seeking behaviour (Bond, Chase & Aggleton, 2002; Gebrekristos, Abdool Karim & Lurie, 2003; Skinner & Mfecane, 2004).

Being diagnosed HIV positive constitutes a serious life crisis that requires considerable coping resources. When receiving an HIV diagnosis, a person has to deal not only with a life-threatening disease and issues such as death and HIV-related symptoms, but also with a change in life expectancy, change in body image, decisions about disclosure, mistrust in relationships, stigma and possible social isolation and rejection (Hudson, Lee, Miramontes & Portillo, 2001; Skinner & Mfecane, 2004). The emotional experiences of women with HIV are largely affected by the stigma related to HIV/AIDS and the social support they receive from significant others (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003; Serovich, Kimberley, Mosack & Lewis, 2001; Silver, Bauman, Camacho & Hudis, 2003; Turner-Cobb, Gore-Felton, Marouf *et al.*, 2002). Various studies indicate that people with HIV experience lower levels of social support after the diagnosis than before, and less support than people with other chronic diseases and those non-infected (Klein, Armistead, Devine *et al.*, 2000; Turner-Cobb *et al.*, 2002). In a study in Tshwane (South Africa) where 150 HIV-positive women were interviewed, it was confirmed that women needed support to deal with their diagnosis, to disclose their status to significant others, and to deal with the stigma they perceive in their communities (Visser & Makin, 2004).

The need for support and the lack of professional services have led to the idea of establishing support groups as a form of intervention (Beckett & Rutan, 1990; Spirig, 1998). In this community a few informally organised support groups developed spontaneously, but there is no network of support groups to which newly diagnosed HIV-positive women can be referred. This project intended to address this need by establishing more and accessible support groups as part of the public health infrastructure. Support groups are groups of people with some pressing common concern coming together on a regular basis, often face-to-face, to contribute personal experiences and engage in the development of a cohesive, supportive system (Schopler & Galinsky, 1993). Support groups involve relationships on an equal level. A mutual supportive

environment is created where each person receives and provides support to deal with his/her specific situation. The emphasis is on sharing personal experiences of the problem and taking responsibility to help one another (Riessman, 1990).

Support groups in the HIV/AIDS context can be a valuable tool to help individuals adjust to the consequences of living with HIV in the absence of support from family and friends (Brashers, Haas, Klinge & Neidig, 2000). Groups can provide HIV-infected individuals with a non-stigmatising atmosphere in which to gain information, share experiences and learn from others. They can also offer sympathetic understanding and establish social networks that can challenge loneliness, give a sense of belonging, and supply mutual aid. Groups can help individuals to renew their hope and confidence in the face of devastating losses (Adamsen, 2002; Drower, 2005; Lyttleton, 2004; Summers, Robinson, Capps *et al.*, 2000). Drower (2005) advocates the empowerment of women in groups to disclose their status and negotiate their relationships with their partners, as this can contribute to social re-integration and a sense of taking control over their lives.

Support groups for people living with HIV/AIDS can be heterogeneous in both structure and format. Groups can have a limited number of sessions or go on for an indefinite period (Foster, Stevens & Hall, 1994), they can be open or closed to new members (Coleman & Harris, 1989), and they can be facilitated by professionals or by peers (Ribble, 1989). The success of a support group often depends on the extent that the fears and expectations of group members are taken into account and the degree of adherence to group rules agreed upon to protect members (Bor & Tilling, 1991). Confidentiality in HIV support groups is extremely important to ensure that the members feel free to express their feelings and experiences.

Research results show that HIV+ women who attended support groups were less depressed (El-Sadr, 2001), as well as more likely to disclose their HIV status and gain access to treatment (Kalichman, Sikkema & Somlai, 1996). A high correlation was found between the experience of social support and the slower progression of HIV (Moskowitz, 2003; Summers *et al.*, 2000). An HIV support group is therefore a place where individuals who spend much of their time preparing for death can work together in trying to learn how to live again (Beckett & Rutan, 1990).

Because of HIV+ women's need for support, students at the University of Pretoria attempted to establish support groups for HIV+ women at primary health clinics in Tshwane as part of their practical training. However, most of these attempts of the students failed. In this paper, the students' reports on their

attempts to establish groups, presented in the form of four case studies, are analysed in terms of existing theories to understand why some of their efforts were successful and others failed. This learning experience resulted in valuable lessons learned regarding project implementation that could pave the way for implementing support groups in community settings in the future.

Methodology

Eight Master's-level psychology students (two black and six white) explored ways of establishing and facilitating support groups for HIV+ women at clinics in Tshwane as an assignment for their practical training. Negotiations were conducted with local government health services authorities to obtain the necessary permission and support for the project. Four clinics that provide voluntary counselling and testing (VCT) services in townships in Tshwane agreed to participate in the project. These clinics provide medical services to a mainly black urban population in the very low to middle socio-economic class. Nurses in the clinics perform HIV testing, while volunteer HIV counsellors offer pre- and post-test counselling. Two students were assigned to each clinic for weekly sessions over a period of 6 months, with the aim of establishing and assisting in facilitating support groups. The students negotiated the development of groups with the clinic staff and HIV counsellors, who had themselves observed the need for support, but did not have the resources to start support groups. The HIV counsellors agreed to participate in establishing support groups by referring recently diagnosed HIV+ women, who consented to participate on a voluntarily basis, to the groups and to co-facilitate the groups. The goal of the groups was to assist HIV+ women to deal with the psychological consequences of their diagnosis. Group participation was to be voluntary with no cost involved for the participants, except for their own travel costs to the clinic. The two students working at each clinic kept a weekly diary of their experiences, interactions with clinic staff and clients, as well as progress made in the implementation of support groups.

After being involved in the clinics for 3 months the students met with their supervisor to report back on their practical work. The students discussed, interpreted and compared their experiences. Using a qualitative data analysis paradigm (Miles & Huberman, 1994), the students analysed their diaries in terms of the process of implementation, strategies that were successful, and obstacles they experienced. Their accounts of their attempts to establish groups are presented in the form of four case studies below. The socio-ecological and systems theory seemed to be appropriate to understand the processes taking place in the clinics. Students then interpreted their experiences according

to these theories. From these discussions guiding principles for project implementation were developed that could be used in future endeavours.

This is therefore a descriptive study using qualitative research methods to analyse the implementation strategies used to establish support groups in clinics. The students were the primary participants in this study and their reports of experiences, interaction with clinic staff and clients, and progress of implementation were the main sources of data used in the analysis. As in all qualitative studies (Miles & Huberman, 1994) the data obtained are of a subjective nature, being experiences and perceptions of the process of implementation. The analysis of the data is also a subjective process of making sense of the observed data in relation to their understanding of existing theories. The validity of the analysis was enhanced through discussions of the interpretations.

The experiential learning of students reported on in this paper was part of a larger project that was ethically approved by the University of Pretoria Faculty of Humanities' Ethics Committee. Students gave consent that their reports and discussions be used in this format.

The process of establishing support groups in four clinics

Initially, the formation of support groups seemed a simple answer to the needs of HIV+ women in underserved communities. However, the experience gained in attempting to establish groups has shown that this involves much more than mere good intentions. The four case studies that follow represent the students' account of their attempts to establish support groups. Each case study represents the experiences of the two students assigned to a specific clinic. The interventions took place independently, yet simultaneously. In each clinic different obstacles were encountered, resulting in the termination of efforts in two clinics and various degrees of success at the other two.

Clinic 1

In the first meeting between the students and the HIV counsellors and nurses at the clinic, the students tried to establish a climate of collaboration. The counsellors admitted the need for support groups. They undertook to inform newly diagnosed HIV+ women about the establishment of a support group and to hand out pamphlets on the value of support groups and the planned dates for meetings. The first meeting was scheduled 3 weeks in advance. No participants attended this first meeting. The students then realised that the HIV counsellors had not been handing out the pamphlets. When this was discussed

with them, the counsellors contended that they felt that HIV+ women would not be interested in joining support groups. By attending such a group, an HIV+ woman would have to admit her status to others and perhaps feel stigmatised if other people knew she was HIV+. The counsellors also argued that the clinic, which is part of a provincial hospital, was far from the township where the women lived. Transport and lack of money would therefore be further obstacles to the women's attendance of a support group. The students took note of their reservations, but strongly re-emphasised the benefits of support groups. Thus the counsellors agreed once more to refer the women diagnosed at their clinic to start a group.

After another 3 weeks of no response, the students were convinced of the unwillingness of the HIV counsellors to assist them. They consulted with the social worker at the hospital, who informed them that the clinic staff would actually act unethically if they were to refer the HIV+ women to the groups, because this would mean that they were indirectly disclosing the patients' status. The working relationship between the clinic staff and the students was clearly not established well enough to foster trust and collaboration. The students were seen as outsiders and not as part of the professional team at the clinic. This resulted in the students withdrawing from the clinic.

Clinic 2

At this clinic, negotiations with HIV counsellors resulted in the latter being eager to assist in establishing a support group, since they were well aware of the women's need for more support. The counsellors recommended that support groups be conducted in the nearby community centre, since the venue was available during the day and there were no vacant rooms in the clinic. At each weekly visit of the students, the counsellors reported how many women they had referred to the support group. However, for 4 weeks the students waited in an empty room for the women to attend the group. The students then started questioning the appropriateness of the venue, since it was in a public place where many people gathered. In this highly stigmatising community, they guessed that the women were afraid to come to the meetings for fear of being identified by others. The clinic staff subsequently suggested that a room in the clinic, which was a less public venue, be used for the group. Again, however, the room stayed empty at the times scheduled for the support group.

After many discussions with the clinic staff and other community members, the students learnt that a number of HIV-infected individuals had taken the initiative of starting a support group close by and that some of the recently diagnosed

women referred to the support group, had joined that group instead. The students then wondered if they should perhaps assist that group in establishing itself, but the clinic staff insisted that it would benefit the clinic to have its own support group. They again undertook to refer women to the clinic group. After another 6 weeks of no response the students eventually decided to terminate their efforts.

Clinic 3

At this clinic the nurses and HIV counsellors were eager to support the students in establishing a support group. They provided a private venue and referred women diagnosed with HIV. After 3 weeks there were 8 women in the group, 4 of whom were committed members who attended regularly. In assessing the needs of the HIV+ women, the students identified the most important to be information on HIV and healthy living, as well as support to cope with their diagnosis. In the first few sessions information about HIV was discussed. After 6 sessions the students started enquiring why the group was not growing and why all the women did not attend the sessions regularly. The women all came from a very poor socio-economic background and had no sources of income. Although not identified in the needs assessment, the students realised that the women's main concern was their need for financial resources to support their health, to afford medication and provide a future for their children. In trying to address the women's lack of basic resources for survival, a vegetable garden was started at the clinic with the permission of the clinic staff. The aim of the garden was to provide nutritious food and possibly a small income. On a therapeutic level the garden could also function as a metaphor for healing and growing together. The group worked in the garden for 3 weeks and shared fears, loneliness and disappointments in an informal way. However, membership started to dwindle, despite the fact that the garden was the group's own idea and they enjoyed participating in the endeavour. Not understanding what was happening, the students called a meeting with the clinic staff. It was established that one of the counsellors had referred some of the women to a nearby community-based organisation for financial support. The students realised that the immediate needs of the women were not talking about their fears, hopes and dreams, but to find a place to stay, to be able to feed their children and to pay school fees. The garden could provide means, but it would take too long for desperate people to benefit.

Clinic 4

In the fourth clinic the counsellors referred HIV+ women to the support group. At first only a few women attended, but they

were scared of sharing their HIV status, and needed assurance that the discussions would be confidential and in a private venue. They mistrusted one another until they agreed on ground rules in the group, *inter alia* to commit to the confidentiality of discussions. After 4 weeks there were 12 women who regularly attended the group sessions. For the next 12 weeks the students facilitated weekly group discussions on themes such as emotional reactions after the diagnosis, a healthy lifestyle, nutritious food, stress management and disclosure of status. The group afterwards continued to meet at the clinic and the HIV counsellors facilitated sessions. This proceeded for at least another 3 months of which we are aware. They also started an exercise group separate from the support group to stay healthy. Three group members who had to travel far to attend the sessions (some travelled 40 km) eventually dropped out of the group because of the high transport costs, but they started a new group closer to their homes.

The students reported that the group interaction assisted HIV-infected women to build positive relationships, to share their experiences and to build confidence. This empowered them to feel stronger in their interaction with others, despite existing stigmatising attitudes in their community.

At clinic 4 a number of factors contributed to the successful establishment of the group. The HIV counsellors and nurses had good relationships with the HIV+ women whom they referred to the group. The counsellors attended every session, co-facilitated discussions and provided the group members with information and support. The presence of the HIV counsellors as co-facilitators allowed for the group to converse in their mother tongue, as most of the members were Tswana- and Sotho-speaking while the students spoke English. The counsellors translated highlights of the discussions, allowing the students to facilitate but not to take control of the group process. The advantage was that the responsibility for running the group was shared by all its members. Group sessions were conducted in an unstructured and informal way. Group members could suggest topics for and participated in open discussion. This allowed members to interact with each other in an almost natural social milieu. It encouraged the development of personal relationships between members and fostered the sustainability of the group.

Discussion of implementation processes from a theoretical perspective

In the discussion of students' experiences in implementing the intervention, the socio-ecological theory (Goodman, Speers, Mc Leroy *et al.*, 1998; Goodman, 2000; Sarason, 1996) and the systems theory (Capra, 1997; Hanson, 1995) were especially relevant. According to these theories, all parts of a system are

interrelated and keep a system in balance. Interventions are challenges to alter the current context, which generally resists change. The way in which an intervention is introduced into a particular context will play a crucial role in its acceptance and implementation. The change agent therefore needs to understand the dynamics of the context (such as relationships, climate and ability to influence the current structure) to be able to establish a fit between the context and the intervention, and to mobilise people in the context to bring about change (Edwards, Jumper-Thurman, Plested, Oetting & Swanson, 2000; Goodman *et al.*, 1998). Sarason (1996, p.11) wrote in this regard: *'The more sensitive you become to this complicated embeddedness, the more you realise how many different systems have to change if the change you seek ... can be successfully introduced and maintained.'*

Systems theory provides us with concepts to understand change. Change can take place when the balance in a system is disrupted, which activates self-regulatory mechanisms to restore balance or to reach another balance (Capra, 1997). The balance in a system can be disrupted by changing components of the system, changing feedback patterns, or creating awareness that the current situation is different from the ideal. Imbalance in a social system may mobilise people to activate change by extending the system's capacity or by restructuring the resources within the system (Ford & Lerner, 1992; Levine, Van Sell & Rubin, 1992). Because of unique internal processes, each system reacts in a unique way to interventions; therefore the impact of an intervention cannot be predicted beforehand (Hanson, 1995). Another key concept in systems theory is that change can only take place from within a system (Capra, 1997). External change agents therefore need to mobilise people who are inside the system to activate change (Scheirer, 1990).

In terms of the theoretical framework, the goal of the intervention was to link students, as external change agents, to township clinics to create an awareness of HIV+ women's need for support and to provide the skills and capacity required for establishing and facilitating support groups in the clinics. The strategy was to mobilise HIV counsellors and nurses in the clinics (as gate keepers and possible internal change agents) to refer and motivate recently diagnosed HIV+ women to join the support groups for psychological assistance. This could mobilise resources from within the clinic to support change in dealing with HIV+ women. Although the same strategy was followed in all four clinics, the students reported different dynamics and factors that could affect the implementation of the intervention.

In clinic 1 the students (as external change agents) did not succeed in joining with the clinic team and establishing a

relationship that would enable them to initiate change. They could not mobilise the clinic staff (as gate keepers and internal change agents) to motivate women to attend the groups. This may be attributed to the fact that the students did not understand the dynamics of the context in the clinic (such as the relationships and the procedures) and therefore could not establish a fit between the context and the planned intervention (Edwards *et al.*, 2000; Goodman *et al.*, 1998). Another problem could have been that the HIV counsellors (as internal change agents) who were supposed to recruit the women did not hold influential positions in the clinics that allowed them to change the existing patterns of dealing with HIV+ women. The concept of support groups had also not been introduced to the counsellors in such a way that they were convinced of its value. It was their perception that HIV-infected women would not like to be identified or to meet with other HIV+ women, which may be indicative of their own perception of HIV rather than of the infected women's needs. The relationships within the clinic and with the students (as external change agents) did not promote mobilisation of the counsellors towards the establishment of support groups.

In clinic 2 the students succeeded in involving clinic staff in the effort to establish groups. As outsiders, the students were not familiar with the infrastructure and resources in this community and relied on the clinic staff for referrals and advice. As they gained more knowledge about the community, they questioned the appropriateness of the venue and learnt about the existence of another group. It was easier for women to join a support group of familiar people within their community, where perhaps there were existing relationships of trust, than to join a group led by outsiders with whom they had no relationship. However, the positive impact that the students had in this clinic was to raise awareness of the possibility of joining a group to access support. This assisted HIV+ women in general, but did not contribute to the goal of the project to establish a support group in this clinic.

Experiences in clinic 3 showed that although students succeeded in establishing a group of women who met regularly, the group interaction was not sustainable because the primary needs of the women were not addressed. Their needs were on a concrete and survival level, confirming Maslow's (1970) theory that basic needs should be satisfied in order for higher needs to be fulfilled. Therefore, when given the option, the women chose to turn to an organisation where they could get food for their families, and in so doing, address their immediate needs. The support group sessions that the women attended could have given them the support and courage to attempt to address their most pressing needs.

In clinic 4, the enthusiasm and commitment of the HIV counsellors (internal change agents) clearly mobilised change from within the system (Capra, 1997). The relationship between the counsellors and the HIV+ women was used as a link into the support group. In the group, women took the lead to initiate discussion themes and to support each other. The group leaders also initiated new ways of relating to one another, such as forming an exercise group to stay healthy. The role of the students (as external change agents) was to mobilise the HIV counsellors to recruit women, and to lay the foundation for group interaction and confidentiality. Their acceptance of the women could have contributed to the accepting climate in the group. Although the students as facilitators brought information about HIV, nutrition and coping styles, the group members took the responsibility for the functioning of the group. Being part of the support group as co-facilitators gave the HIV counsellors the opportunity to develop facilitation skills that enabled them to continue running the groups after the student facilitators were not available any more. In this group, change was initiated in such a way that new behaviour patterns developed, which contributed to sustainability of the group.

Developing guiding principles

In the discussion of the case studies the students suggested that the process of implementing support groups could be compared with building a bridge over a gorge. A bridge is defined as a structure spanning and providing passage over the gorge. The process of building a bridge can be complicated and multifaceted, as it involves planning, collaboration among project team members, organising building material and resources, securing a foundation, constructing the bridge from both sides to meet somewhere towards the middle, and finally crossing over the bridge. All of these processes require cooperation among various stakeholders. In the case studies referred to, the bridge needed to connect students who were not HIV-infected and women who were infected to travel together towards better wellbeing. Other differences that had to be overcome in connecting the two groups were differences in socio-economic status, level of education, cultural background and language, as well as different perceptions of HIV-related stigma.

In each clinic a different stage of building this metaphorical bridge was accomplished and different obstacles were encountered. In the first clinic discussed, the builders could not round up a committed construction team that could work together towards a common goal. The students remained outsiders and did not succeed in mobilising the HIV counsellors to address the need for support. Other issues such as the HIV counsellors' own perception of stigmatising attitudes (internal processes) inhibited them from taking action. The balance in

the system was therefore not disrupted and the procedures in the system remained as they were.

In the second clinic attempts were made at laying a foundation for the bridge by recruiting women for the groups, although it was found that the bridge was planned on the wrong construction site – HIV+ women started to build their own bridge on another more appropriate site. In this case resources were available, but research to identify an appropriate construction site was limited. Without knowledge of the community structures and relationships it was not possible to fit an intervention into existing structures. This was the only clinic where the background of the students could have played a role in the unsuccessful implementation, since the women obviously wanted to join a group, but rather joined a group led by people from within their own community.

In the third clinic the construction of the bridge was initiated as a connection between the two sides of the gorge. Yet, after initial connection, the bridge broke down because building blocks were slowly falling away – this bridge did not connect women with resources to meet their most pressing needs. Change was therefore not sustainable.

In the last clinic the metaphorical building site was prepared through good relationships between the students, HIV counsellors and HIV-infected women attending the clinic. The counsellors from within the clinic anchored the bridge, rendering support and information, and cultivating a positive relationship with the HIV+ women whom they had referred to the group. Together the bridge could be secured from both sides of the divide, enabling the construction of a crossing. The strength of this bridge eventually lay in the sharing of experiences between group members. The gorge was spanned successfully, as the whole team worked together to construct a strong bridge. Cultural and educational differences between the team members did not play a role, since they were overcome through collaboration and sharing of a vision and responsibility in the group.

Experiences of failure to implement the interventions highlighted a few valuable principles in project implementation. To mobilise change in an existing context, the metaphor of the bridge can be used again:

- A construction team is necessary to work towards a common goal – joining needs to take place between stakeholders, and a shared vision is needed to mobilise resources (Levine *et al.*, 1992; Scheirer, 1990).
- Thorough knowledge of the construction site is essential to decide on an appropriate site for laying the foundation – understanding the functioning and interaction within the context is needed for the intervention to fit into existing patterns (Goodman *et al.*, 1998; Goodman, 2000).
- Building of the bridge needs to take place from both sides of the gorge – change needs to take place from within the system and cannot be brought about by outsiders (Capra, 1997).
- If building blocks are not secured and they start falling apart, reconstruction of parts may be necessary to secure the bridge – feedback processes in a system should be used to understand what change actually took place and to overcome barriers by initiating new strategies to accomplish the goal (Capra, 1997; Levine *et al.*, 1992).
- To be a functional bridge, the bridge should assist travellers to get to their destination – the needs of the participants must be addressed to ensure the value and sustainability of change (Akerlund, 2000; Pentz, 2000).
- The bridge needs to be strong to assure a sustainable crossing – responsibility needs to be shared by all members and structural changes are needed in the setting to ensure sustainability (Akerlund, 2000; Ford & Lerner, 1992).

Stigmatising attitudes played a dominant role in the establishment of HIV support groups. Such attitudes in the community were the underlying reason for the need for support groups, since women did not get support from family and friends. Stigmatising attitudes also posed obstacles to HIV+ women's decision to join the groups, because these women actually disclosed their status by joining the groups. Once group rules of confidentiality were established and women could build trusting relationships, they gained confidence to face stigmatising attitudes outside of the support group.

In bridging the gap between non-infected students and HIV+ women, it seemed that differences in background regarding socio-economic status, level of education, cultural background and language did not play a decisive role. The two groups that were established successfully were facilitated by students who came from different racial groups than the participants. Differences in personal characteristics can therefore be overcome if appropriate implementation strategies are followed.

Another valuable lesson learnt was that women with HIV do experience obstacles because of their diagnosis, especially on an emotional and social level, but that their lives are not reduced to

dealing with HIV. Women in HIV support groups have a wide spectrum of needs that need to be taken into account in planning interventions. When women overcome the emotional and social barriers, they can be empowered to live constructively and contribute to the wellbeing of their families and communities.

Conclusion

In this study, students' reports on their experiences and interpretations of processes in primary health clinics that can affect attempts to establish support groups for HIV+ women, were analysed in terms of the ecological and system theory to derive principles to be considered in project implementation. It needs to be kept in mind that the subjective experiences and interpretations of 8 students doing practical work were used in the qualitative analysis. The perceptions of the other roleplayers such as the health care staff, counsellors and clients were not incorporated in this analysis. This is therefore one of many other possible interpretations of processes that could have played a role in the implementation of change in these clinics. The perspective of the students as both insider and outsider could also have played a role in their perceptions of the implementation process. Interesting though, is how well the experiences of the implementation process fitted into the theoretical framework that was used.

Although the establishment of support groups seemed to be the obvious intervention to provide psychological support for HIV+ women, students found that it involved much more than simply good intentions to establish sustainable groups in the clinics of Tshwane. The establishment of groups involved relationships with stakeholders, a shared vision, the mobilisation of resources and a grounded knowledge of relationships, culture and procedures in clinics, as well as community processes, to be able to fit an intervention into the current functioning of a clinic. A relationship of trust is needed to mobilise HIV+ women to take the step of joining a support group that will help them to deal with issues that result from an HIV+ diagnosis. The value and sustainability of groups are related, inter alia, to relationships within the group, the needs that are addressed and ownership of the group. Because of the complexity involved, the establishment of support groups in community settings can only be successful if clear theoretical guidelines are adhered to.

Acknowledgements

We acknowledge the contribution of Thembi Barnabas, Karen Bradford, Elizabeth Faria, Angelique Grigoratos, Ingrid Jonker, Tanya Meyburgh, David Thompson and Xandie van Dyk (Master's students in Counselling Psychology at UP), the staff

and HIV counsellors at the different clinics, as well as the HIV+ women who participated in the groups.

References

- Adamsen, L. (2002). 'From victim to agent': the clinical and social significance of self-help group participation for people with life threatening diseases. *Scandinavian Journal of Caring Sciences*, 16(3), 224-231.
- Akerlund, K.M. (2000). Prevention program sustainability: The state's perspective. *Journal of Community Psychology*, 28(3), 353-362.
- Beckett, A. & Rutan, J.S. (1990). Treating persons with ARC and AIDS in group psychotherapy. *International Journal of Group Psychotherapy*, 40, 19-29.
- Bond, V., Chase, E. & Aggleton, P. (2002). Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. *Evaluation and Program Planning*, 25(4), 347-356.
- Bor, R. & Tilling, J. (1991). Groups for people with HIV/AIDS. *Nursing Standard*, 6(12), 50-51.
- Brashers, D.E., Haas, S.M., Klingle, R.S. & Neidig, J.L. (2000). Collective AIDS activism and individuals' perceived self-advocacy in physician-patient communication. *Human Communication Research*, 26, 372-402.
- Capra, F. (1997). *The web of life, a new synthesis of mind and matter*. London: Flamingo.
- Coleman, V.E. & Harris, G.N. (1989). Clinical notes. A support group for individuals recently testing HIV positive: A Psycho-educational group model. *Journal of Sex Research*, 26(4), 539-548.
- Department of Health (2006). *National HIV and syphilis antenatal seroprevalence survey in South Africa, 2005*. Pretoria: Directorate Health Systems Research and Epidemiology, Department of Health.
- Drower, S.J. (2005). Groupwork to facilitate empowerment in the context of HIV/AIDS. In: L. Becker (Ed.). *Working with Groups* (pp. 101-119). Cape Town: Oxford University Press.
- Edwards, R.W., Jumper-Thurman, P., Plested, B.A., Oetting, E.R. & Swanson, L. (2000). Community readiness: Research to practice. *Journal of Community Psychology*, 28(3), 291-307.
- El-Sadr, W. (2001). *Challenges in providing treatment for woman*. Third International Conference on Global Strategies for the Prevention of HIV Transmission from Mothers to Infants, Uganda.
- Ford, D.H. & Lerner, R.M. (1992). *Developmental systems theory: An integrative approach*. Newbury Park: Sage.
- Foster, S.B., Stevens, P. & Hall, J. (1994). Offering support groups services for lesbians living with HIV. *Women and Therapy*, 15, 69-83.
- Gebrekrstos, H., Abdool Karim, Q. & Lurie, M. (2003). *Disclosure of HIV status for patients on HAART: Implications for treatment adherence and sexual behaviour*. Paper at the South African AIDS Conference, Durban, 3-6 August.
- Goodman, R.M. (2000). Bridging the gap in effective program implementation: From concept to application. *Journal of Community Psychology*, 28(3), 309-321.
- Goodman, R.M., Speers, M.A., Mc Leroy, K., Fawcett, S., Kegler, M., Parker, E., Smith, S., Sterling, T. & Wallerstein, N. (1998). An attempt to identify and define the dimensions of community capacity to provide a basis for measurement. *Health Education and Behavior*, 25, 248-278.
- Hanson, B.G. (1995). *General systems theory beginning with wholes*. Toronto: Taylor & Francis.
- Hudson, A.L., Lee, K.A., Miramontes, H. & Portillo, C.J. (2001). Social interactions, perceived support and level of distress in HIV-positive women. *Journal of the Association of Nurses in AIDS Care*, 12(4), 68-76.
- Kalichman, S.C., Sikkema, K.J. & Somlai, A. (1996). People living with HIV infection who attend and do not attend support groups: A pilot study of needs characteristics and experiences. *AIDS Care*, 8(5), 589-599.
- Kalichman, S.C., DiMarco, M., Austin, J., Luke, W. & DiFonzo, K. (2003). Stress, social support and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, 26(4), 315-332.
- Klein, K., Armistead, L., Devine, D., Kotchick, B., Forehand, R., Morse, E., Simon, P., Stock, M. & Clark, L. (2000). Socio-emotional support in African American families coping with maternal HIV: An examination of mothers' and children's psychosocial adjustment. *Behaviour Therapy*, 31, 1-26.
- Levine, R.L., Van Sell, M. & Rubin, B. (1992). System dynamics and the analysis of feedback processes in social and behavioral systems. In: R.L.

Levine & H.E. Fitzgerald (Eds). *Analysis of dynamic psychological systems (Vol 1): Basic approaches to general systems, dynamic systems and cybernetics* (pp. 145-261). New York: Plenum Press.

Lyttleton, C. (2004). Fleeing the fire: Transformation and gendered belonging in Thai HIV/AIDS support groups. *Medical Anthropology*, 23, 1-40.

Maslow, A.H. (1970). *Motivation and personality* (2nd edition). New York: Harper.

Miles, M.B. & Huberman, A.M. (1994). *Qualitative data analysis, an expanded sourcebook* (second edition). Thousand Oaks: Sage.

Moskowitz, J.T. (2003). Positive affect predicts lower risk of AIDS mortality. *Psychosomatic Medicine*, 65, 620-626.

Pentz, M.A. (2000). Institutionalizing community-based prevention through policy change. *Journal of Community Psychology*, 28(3), 257-270.

Ribble, D. (1989). Psychosocial support groups for people with HIV infection and AIDS. *Holistic Nursing Practice*, 3, 52-62.

Riessman, F. (1990). Restructuring help: A human services paradigm for the 1990's. *American Journal of Community Psychology*, 18, 221-230.

Sarason, S.B. (1996). *Revisiting "The culture of the school and the problem of change"*. New York: Teachers College Press, Columbia University.

Scheirer, M.A. (1990). The life cycle of an innovation: Adoption versus discontinuation of the fluoride mouth rinse program in schools. *Journal of Health and Social Behavior*, 31, 203-215.

Schopler, J.H. & Galinsky, M.J. (1993). Support groups as open systems: A model for practice and research. *Health and Social Work*, 18, 195-208.

Serovich, J.M., Kimberley, J.A., Mosack, K.E. & Lewis, T.L. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13(3), 335-341.

Shisana, O. & Simbayi, L. (2002). *Nelson Mandela/HSRC study of HIV/AIDS, South African National HIV prevalence, behavioural risks and mass media household survey*. Cape Town: Human Sciences Research Council.

Silver, E.J., Bauman, L.J., Camacho, S. & Hudis, J. (2003). Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS and Behavior*, 7(4), 421-431.

Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*, 1(3), 157-164.

Spirig, R.N. (1998). Support groups for people living with HIV/AIDS: A review of literature. *Journal of the Association of Nurses in AIDS Care*, 9(4), 43-55.

Summers, J., Robinson, R., Capps, L., Zisook, S., Atkinson, J.H., Mccutchan, E., Mccutchan, J.A., Deutsch, R., Patterson, T. & Grnat, I. (2000). The influence of HIV-related support groups on survival in women who lived with HIV. *Psychosomatics*, 41(3), 262-268.

Turner-Cobb, J.M., Gore-Felton, C., Marouf, F., Koopman, C., Kim, P., Israelski, D. & Spiegel, D. (2002). Coping, social support and attachment style as psychosocial correlates of adjustment in men and women with HIV/AIDS. *Journal of Behavioral Medicine*, 25(4), 337-353.

Visser, M.J. & Makin, J. (2004). *HIV+ women's experience of stigma and social support*. Paper presented at the 2nd African Conference on Social Aspects of HIV/AIDS Research, May, Cape Town.

Visser, M., De Villiers, A., Makin, J., Sikkema, K., Forsyth, B., Claassen, N., Vandormael, A. & Mundell, J. (2005). *The stigma the community attaches to HIV/AIDS*. Poster presentation at the 7th International AIDS Impact Conference, "The Moment is Now". Cape Town, 4-7 April.

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