IMPLEMENTING A PROGRAMME FOR COPING WITH STIGMA FOR WOMEN WHOSE PARTNERS DIED OF AIDS: A CASE STUDY

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ABSTRACT

The purpose of this research was to develop a programme to help women whose partners died of AIDS to cope with stigma. Having experienced severe stigmatisation these women used mostly ineffective problem-focused strategies and limited emotion-focused strategies. Due to their difficulty in coping there was a need to develop a programme to assist them to cope with the stigma of having lost a partner to AIDS, as well as being HIV positive themselves. The programme was developed, implemented and evaluated by means of a holistic multiple case design with a sample of four women. Data were collected by means of multiple sources from transcripts of the eight sessions, naïve sketches by participants, as well as field notes from observations of individuals and of the group. Data analysis was done according to the case record method. The conclusions about the impact of the programme were that it had a positive impact based on the fact that these women grew from being lonely, reserved, having negative self perceptions, to being open about their HIV status, sharing their problems related to stigma, seeking support, being altruistic by advocating for assistance of other women in the same situation, as well as suggesting the establishment of a home-based care facility where they can assist in caring for others.

KEYWORDS: Coping, living with HIV/AIDS, HIV/AIDS, HIV/AIDS supporting group, programme, stigma.

INTRODUCTION AND PROBLEM STATEMENT

At the end of 2007 it was reported that 5.7 of the 46.4 million South Africans were living with HIV/AIDS (Dube & Nkosi, 2008:13). The escalating number of people living with HIV/AIDS coupled with a high death rate of the infected people, causes concern in

the prevention and treatment measures of this pandemic. Contributing to this threat is the degree of stigmatisation and discrimination of people living with HIV/AIDS. The stigma of HIV/AIDS nullifies efforts of preventing and treating the infected or to deal confidently with the pandemic (Ogden & Nyblade, 2005:34). The difficulty of dealing with HIV/AIDS is due to the fact that the stigma makes it difficult if not impossible for sufferers to go for voluntary confidential counselling and testing (VCCT), to disclose their status when already diagnosed, as well as to access the available treatment or resources (Siyam'kela, 2003). The findings from their experiences of stigmatisation reflected that these women experienced severe stigmatisation from various sources such as their families, the community as well as health workers (Mayers, Naples & Nilsen, 2005:100). In 1998 the worst scenario of gender and stigma occurred when Gugu Dlamini, a female AIDS activist was killed in the KwaZulu-Natal Province of South Africa, following her public disclosure of her HIV positive status (Brown, Macintyre & Trujillo, 2003:51).

A study by Olley, Gxamza, Seedat, Theron, Stein, Taljaard, Reid and Reuter (2004:23) found that both effective and ineffective coping strategies are used in coping with HIV/AIDS. In the study that led to this programme development, women whose partners had died of AIDS also used a range of effective and ineffective strategies to cope with the stigma. A need was then realised to develop a programme for these women to strengthen their coping skills and/or to develop more effective coping skills. Brown et al. (2003:62) are of the opinion that because the problem of stigma is a serious concern, something should be done in the form of programmes targeted at the stigmatised. They reviewed 22 stigma intervention studies, one of which was done in South Africa. These studies yielded unsatisfactory results regarding coping with stigma, hence they recommended an approach that would include contact and information given to people living with HIV/AIDS (Brown et al., 2003:640). Ogden and Nyblade (2005:42), supported by Parker, Aggleton, Attawel, Pulerwitz and Brown (2002:15), concur with the view that these programmes could reduce HIV/AIDS stigma.

The question that arose was how these women could be assisted to cope with the stigma associated with having had a relationship with a PLWA.

Objectives

The objective was to develop, implement and evaluate a programme to assist women whose partners had died of AIDS to cope with the stigma associated with having had a relationship with a PLWA.

Literature Study of Programmes and Interventions to Deal with the Stigma of HIV/AIDS

Prior to the formulation of the programme various sources in the literature were consulted in order to study the types of programmes that were available. The focus of most programmes in the literature that was consulted was information/fact-based, skills

acquisition, counselling, resource provision, contact with affected groups, as well as multiple intervention programmes. Information-based approaches are those that provide information to the target group either for preventive purposes or to provide facts. ThIs information could be written, in the form of pamphlets, booklets, videos/compact discs, presented factually in a class-room set-up, peer education, games as well as guided group discussions (Brown et al., 2003:53; Siyam'kela, 2003:3). A school-based HIV prevention programme failed (Reddy, James & McCauley, 2005:6) because of inadequate preparation and lack of evaluation mechanisms. Uys (2003:10) maintained that information may be used to change attitudes, increase coping, and decrease stigma.

An information-based programme aimed at increasing tolerance for people living with HIV/AIDS could not change negative attitudes of people towards HIV/AIDS (Brown et al., 2003:63; Yang, Li, Stanton, Fang, Lin, & Naar-King, 2006:23; Baker, Sartsara, Rumakom, Guest, Schenk, Pramualratana, Suksakulwat, Panakitsuwan & Moonmeung, 2004:22). Some authors refer to information only as a fact-based programme, which could also include life skills teaching (Reddy et al., 2005:1). This information based approach was used as a basis for most interventions because in most communities, knowledge about HIV/AIDS issues might still be lacking (Yang et al., 2006:722). Most stigma intervention programmes utilise the skills acquisition approach to empower people with skills to train PLWA on coping strategies (Ogden & Nyblade, 2005:10). Material support, providing resources, are necessary in impoverished communities.

Contact sessions aimed at creating an environment where people living with HIV/AIDS could interact with other stigmatised groups (Brown et al., 2003:62). This approach advocates a more personal relationship that involved PLWA at all levels of the community (Siyam'kela, 2003:2), district and national levels (Khan & Loewenson, 2005:5). A combination approach is one that combines information about stigma, coping skills acquisition or empowering, prevention, counselling as well as support (Mahendra, Gilborn, Luke, George, Samson, Mudoi, Jadav, Gupta, Bharat & Daly, 2006:6;) Parker et al.; 2002:14; Siyam'kela, 2003:13; Uys, 2003:28; Hadjipateras, 2004:38; Ogden & Nyblade, 2005:38). This programme focused on the empowerment of these women to develop their internal strength to cope with the stigma, so that they could reach out to support others.

RESEARCH DESIGN AND METHOD

A holistic multiple case study type one design as described by Yin (2003:43), was chosen for this programme. It is a rich design with the advantage of allowing for the replication of cases. Therefore, when conclusions are drawn they result from the analysis of more than one case (Yin, 2003:53). The fact that the context of each case differs also adds to the richness of the data, hence the choice of the holistic multiple case design (Yin, 2003:40).

Sampling

For the purpose of this programme development a purposive voluntary sample as described by Babbie & Mouton (1998:166) was selected. Four women were selected according to these specific inclusion criteria. Firstly, the women had lost their partners to AIDS within a two year period. Secondly, they had been through voluntary counselling and testing and were aware that they were HIV positive. Thirdly, they resided in the Central Region of the North West Province of South Africa. And lastly, they spoke and understood the Setswana and Sesotho languages.

These women experienced stigmatisation after their partners died of AIDS. Had there been a programme to help them with coping skills, they would have benefitted. The women were visited at their homes to inform them about the intended programme and to motivate them to participate. The aims, objectives, benefits and risks of participating were explained to them in the language of their choice. On having agreed to participate, they were promised to be contacted again to be informed about the definite date, time and venue of the first meeting where they would meet their group mates and commence with the programme. Of the four women, two had three children staying with them, the third one had two children of whom one was staying with relatives in another town, and the fourth one had one child also staying in another town. Only one of them was employed while the rest lived on government allowances. Three of them were HIV positive and were already on Anti Retroviral Therapy (ART). One was awaiting consent from her family member to use ART.

DATA COLLECTION

Permission to undertake this programme was obtained from the directorate of epidemiology, and from the sub-directorate of HIV/AIDS in the Department of Health (DoH) of the North West Province. Ethical approval was obtained from the Research Committee of the School of Nursing Science, as well as from the Ethics Committee of the North-West University, Potchefstroom Campus. Participants gave permission to participate in the programme as well as to the recording of sessions on audio-tape by signing consent. Prior to implementing the programme the home-based care volunteers, acting as mediators, assisted the facilitator in organising the venue. When the venue was ready the facilitator notified participants about the date of the first meeting as well as the venue. Data were collected by means of multiple sources of evidence namely, individual notes of participants from tape recordings during the sessions, naïve sketches written by each participant at the end of each session as well as field notes recorded by the researcher as described by Yin (2003:4) and Babbie and Mouton (1998:282). The process was guided by the objectives of each session.

PROGRAMME DEVELOPMENT, IMPLEMENTATION AND EVALUATION

The purpose of this programme development was to assist women whose partners had died of AIDS to cope with the stigma associated with having had a relationship with a PLWA.

Session one: Orientation and introduction of participants

This session involved informing the participants about the aims and objectives of the programme, the number and duration of sessions, agreeing on the days and times of meetings as well as setting ground rules.

Session two: HIV/AIDS and voluntary confidential counselling and testing (VCCT) knowledge

The session involved the playing of card games on HIV/AIDS facts and knowledge about the mode of transmission. Their experiences of VCCT were shared.

Session three: Stigma, its manifestations and effects

The session involved watching a DVD about stigma and its manifestations. They also did an exercise on how stigma is experienced, how to react to the effects of stigma and how to identify support mechanisms for stigmatised individuals.

Table 1: Case record of programme implementation

	SESSION 2	SESSION 3	SESSION 4	SESSION 5	SESSION 6	SESSION 7	SESSION 8
	HIV/AIDS knowledge	Stigma manifestations and effects	Coping awareness	Coping with internal stigma	Dealing with disclosure	Coping with received and associated stigma	Evaluation of the participants' internalisation of the programme
OBJECT-IVES	Recall facts about HIV and AIDS, its trans-mission and VCT	Identify stigma manifestations and its effects.	Realise coping and own coping strategies.	Acquire internal stigma coping skills.	Share views on disclosure and acquire strategies of successful disclosure.	Identify received and associated stigma and coping.	Evaluate the programme; identify shortcomings and recommendations.
Group Growth	They had some basic knowledge about HIV and AIDS though superficial.	Discussion empowered them to understand the context of stigma as referring to the 'others' experiences, and then moving closer, to the more realistic 'me' experience	Became aware of their ineffective coping.	Having moved from the discussion of stigma on the general perspective, and applying it to the "me" experience enabled them to realise and share their feelings about their HIV status.	Sessions four and five made them feel stronger.	They established, evaluated and spoke about their coping.	The group experience as well as the layout of sessions had assisted them during the month break, to actually take full control of their own coping.
	The information was an opportunity to clarify their uncertainties especially about the mode of infection.	Having developed trust and safety, they moved from the 'other' to the 'me' experience; they got empowered to take more control.	Participants learned about coping from the general perspective as relating to others.	Trust improved to their feeling safer to share personal experiences	A broadened strength of coping strategies, led to deciding and making an informed decision of disclosure	Observed other group members' coping and applied the experience at the level of internal stigma, having considered possible disclosure or non-disclosure, were now looking at how people re-acted to them as evidence of received stigma	They moved from rationalising, denying and used more positive acknowledgement of their illness

Strengthened relationship and meaningful trust, evidenced by their sharing of their experience.	Started to loosen and relax and contributed meaningfully to discussions.	Acknowledged that they needed to learn more positive emotional coping	They could realise that they were doing something that was effective, and some strategies that were not effective.	The decision of disclosure was also supported by gaining strength from the group member who had publicly disclosed her HIV status.	They had to decide whether they were going to confirm the received stigma that they experienced.	Degree of growth enabled them from being concerned about selves to expanding to being altruistic, having concern for others.
Having learnt these facts, they gained insight into their symptoms, thus overcoming the fear associated with misconceptions that are discussed in the community		They observed what strategies worked for others	Group context assisted them to learn and benefit from each other	By then they were free to share incidents of received and associated stigma	Participation at its highest. Focus began on one member with a personal problem	They learnt to be strong and brave in dealing with stigma.
They could then move ahead as their paralysis was resolved and were empowered with knowledge	Some of them said the church conducts prayers for HIV/AIDS people to give them a chance to heal your heart	They realised how the people's behaviors and attitudes impact on them and could take control of own coping..				
Excited to learn new facts and knowledge	Had not joined any support group before this one.	They were free to show stigmatisation				
Appreciated learning acronyms and their meaning. When VCCT was discussed they believed that testing was good		Perceiving the programme as "school" which meant that they were learning.				

Starting to show congruence. Learnt and discussed new HIV transmission modes	Group members staying far from the venue (about 10km) were the first to arrive as a sign of commitment. Their commitment and willingness to attend were associated with the need to cope	Showed commitment by waiting while the facilitator looked for the keys. Bond and trust were growing. Degree of acceptance of their status evident. They were being discriminated against. Taught about their rights such as the right to live, treatment as well and be treated by the per-son of their choice. Complied with their treatment regimen. Three were on ART and one awaiting consent from her family.	Already familiar to the environment, came early, dusted chairs and arranged the seating. They were free to talk about disclosure and shared painful experiences. They felt free to realise that their concerns were understood. Three of them disclosed partially and one publicly. They were excited about the types be-cause they did not know that there were types. They believed that disclosing felt like removing the burden.	. They noticed stigmatisation from others. Coping strategies used were ignoring, confronting and avoiding. Made aware that their coping was superficial; that they had to deal with their emotions. Had to explore different coping strategies. Spirituality through prayer seemed to be the preferred strategy. They promised to join support group.	Share the information they were taught with others. Concern for those who were not exposed to the programme. Their fear had disappeared due to supporting each other. Were worried about HIV positive pregnant mothers and other widows. Now free to talk to any-body. Have developed into a strong support group. Learnt that taking care of them is part of coping. Closure meaningful; se-pa-ration anxiety allayed.

Session four: Creating awareness on coping

The aim of this session was to enable participants to understand what coping implies so that they could identify their own coping styles. Participants did an exercise on identifying positive and negative coping styles, followed by a discussion about the effectiveness of these styles and how they could be improved.

Session five: Coping with internal stigma

It was designed to empower them to deal with feelings of self-stigmatisation. They carried out an activity on the sharing of feelings and perceptions about being HIV positive themselves, followed by a discussion of these feelings and perceptions.

Session six: Dealing with disclosure

Disclosure being a difficult process, the aim was to equip these women with skills used for disclosure. They discussed understanding disclosure, shared personal views on how they personally felt about disclosure, and were provided with information strategies leading to successful disclosure.

Session seven: Coping with received and associated stigma

Participants identified the types of stigma that affected them and they were assisted to identify strategies of coping and asking for family support. They did role play on incidents of stigmatisation and identified strategies to cope with community behaviours and attitudes.

Session eight: Evaluation of the participants' internalisation of the programme

This session was conducted a month after the seventh session in order to evaluate the participants' internalisation of the programme, as well as the effectiveness of the preceding seven sessions. The benefits, shortcomings as well as future suggestions were also evaluated.

Physical Setting

Sessions for the implementation of the programme were held at the church hall which served as a venue for church meetings. It was well equipped with tables, chairs and notice boards. It was private, comfortable and quiet. All sessions proceeded without any disturbances or interruptions. They sat in a circle to maintain eye contact and create an environment of being equal so that free participation was enhanced. A small bench was placed in the middle for a tape recorder, laptop computer, posters, charts and pamphlets. Ventilation was conducive throughout.

Multiple Sources of Data

Multiple sources of data namely, transcripts, naïve sketches as well as field notes served as evidence for the case study as suggested by Yin (2003:97). All the sessions were

audio-taped, transcribed and analysed using the case record. Each participant recounted her experiences at the end of each session, by writing naïve sketches. At the end of each session, field notes of individuals, as well as group experiences were written using observational, theoretical and methodological notes as suggested by Cook and Campbell, in Babbie and Mouton (1998:282). The observational notes reflected and accounted what happened during sessions, without attempting to interpret the events. These included the who, what, when, where and how of the circumstances. Theoretical notes were the researcher's self-conscious and systematic interpretation of her observations during the sessions. These were described in relation to the observational notes, reflecting the meaning, conceptualising and linking the present to the previous session. Methodological notes created the researcher's awareness about the appropriateness of the methodology that was followed. The researcher reflected on her own process of facilitating sessions within the selected methodology. These were done following Schatzman and Strauss' descriptions in De Vos (1998:286).

DATA ANALYSIS

Data obtained from transcripts, naïve sketches, as well as field notes of the individual and group experience were ordered according to the case record discussed under the findings (See table 1).

Findings of the Impact of the programme on women whose partners died of AIDS

The case record reflected a summary of the eight sessions' objectives, a summary of each participant's naïve sketches for each session, followed by the researcher's observational field notes, each individual participant's as well as the group's growth during each session. The participants' naïve sketches were superficial due to their literacy level but observational field notes reflected a richer description of the experiences of the impact of the programme as described in table 1.

CONCLUSIONS REGARDING THE IMPACT OF THE PROGRAMME FOR COPING WITH STIGMA FOR WOMEN WHOSE PARTNERS DIED OF AIDS

The programme was successful and had an impact due to the following evidence:

• The programme sessions were structured and presented in such a way that it had a positive effect on the participants. Each session intended to prepare them for the next session in such a way that the sessions followed each other in a consecutive order, with each adding more value. The orientation allowed them to get to know each other, as well as introducing the programme and establishing a working relationship. The systematic order according to which the themes of the programme

were structured contributed to the sustained personal growth of always starting from the external others' experience which is less risky, to the internal 'my' experience, which was more risky.

- The group size and context also provided the opportunity for intimacy and to see how other participants were dealing with issues or managing their experiences in comparison with how they were personally dealing with issues. Sharing the same background enabled them to learn from one another and adopt positive coping strategies in a supportive and trusting environment.

- As the sessions progressed trust developed and the intensity of honest sharing of their genuine experiences increased. The intensity of their sharing was so intensive that the planned two hour sessions became too short and were extended.

Limitations of the Study

Limitations regarding the development, implementation and evaluation of the programme are described as follows.

- Two participants absented themselves more than once, despite the fact that they signed consent forms and committed themselves to regular attendance. This delayed the group's progress due to the postponement of sessions to allow the absent members to catch up with an individual session as well as compromised the richness and sharing of experiences.

- A small group of four participants could be a disadvantage due to limiting the group's strength thus depriving participants from the opportunity to learn from a wider variety of others persons' coping skills.

- The duration of two hours, when considering the intensity of emotional discussions that these women had to undertake, needed to be longer. Their level of understanding also differed so adequate time was needed for games and exercises in each session so that the slowest one could be accommodated.

- Posters, pamphlets and videos were mostly available in English and as a result it created a language barrier for those participants who were not fluent in English. The researcher had to interpret thus increasing each session's time.

RECOMMENDATIONS

Recommendations are made for nursing practice, for nursing education as well as for nursing research.

Recommendations for nursing practice

- The programme should be facilitated by a professional person who is experienced and effective in facilitating people who experience emotional trauma, and who

is able to observe group dynamics, as well as working with people from various educational, socio-economic and religious backgrounds.

- The size of the group should be between six to eight participants in order to enhance opportunities for growth from a variety of coping strategies of the other members.

- As the programme progresses the facilitator should adjust the length of the session to accommodate the needs of the participants when the intensity of sharing increases and more support is needed.

- The sessions should be presented once a week to allow for the internalisation of learned coping skills between sessions. Participants should have the opportunity to apply their new skills in reality.

Recommendations for nursing education

The programme should be offered as an in-service education programme for nurses who are working within the HIV and AIDS context. They should be experienced in group facilitating skills, counselling, as well as in handling group dynamics.

Recommendations for nursing research

Further research could be done on the long term effectiveness of the programme for women whose partners died of AIDS to determine whether the effectiveness of the programme is sustainable.

SUMMARY

The structure of the programme contributed to the meaningfulness in the manner in which the participants interacted, the effectiveness of coping strategies, as well as the emotional growth enhanced by sessions that encouraged sharing of experiences by the participants. The content of the programme was developed to make an impact on assisting women whose partners died of AIDS to cope with stigma. The participants' widowhood status, literacy level, socio-economic background as well as their sero-positive status have contributed to the success of the programme due to the homogeneity of the group that led to their cohesion, thus strengthening their coping experiences. The program would, therefore, provide a useful tool for assisting women whose partners died of AIDS to cope with the stigma associated with their having had a partner who was infected and died of AIDS.

REFERENCES

Babbie, E. & Mouton, J. 2001. *The practice of social research*. Oxford: Oxford University Press.

Baker, S., Sartsara, S., Rumakom, P., Guest, P., Schenk, K., Pramualratana, A., Suksakulwat, S., Panakitsuwan, S. & Moonmeung, S. 2004. Using incentives to encourage AIDS programs and policies in the workplace: A study of feasibility and impact in Thailand. *Horizons*. Washington, DC: Population Council.

Brown, L., Macintyre, K. & Trujillo, L. 2001. Interventions to reduce HIV/AIDS stigma: what have we learned? *Horizons*. Washington, DC: Population Council.

Brown, L., Macintyre, K. & Trujillo, L. 2003. Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Education and Prevention*, 15(1):49-69.

De Vos, AS. 1998. *Research at grass roots: a primer for the caring profession.* Pretoria: Van Schaik.

Dube, FN. & Nkosi, ZZ. 2008. The acceptability, knowledge and perceptions of pregnant women toward HIV testing in pregnancy at Ilembe District. *Curationis*, 31(3):12-20.

Hadjipateras, A. 2004. *Unravelling the dynamics of HIV/AIDS-related stigma and discrimination: the role of community-based research. Case study of Northern Uganda and Burundi*. Kampala: Hasap.

Khan, N. & Loewenson, R. 2005. *Guidelines for reducing stigma and discrimination and enhancing care and support for people living with HIV and AIDS.* Harare: Training and Research Support Centre.

Mahendra, V., Gilborn, L., Luke, S., George, R., Samson, L., Mudoi, R., Jadav, S., Gupta, I., Bharat, S. & Daly, C. 2006. Reducing stigma and discrimination in hospitals: positive findings from India. *Horizons*. Washington DC: Population Council.

Mayers, A.M., Naples, N.A. & Nilsen, R.D. 2005. Existential issues and coping: a qualitative study of low-income women with HIV. *Psychology and Health*, 20(1): 93-113.

Nyblade, L., Pande, R., Mathur, S., Macquarrie, K., Kidd, R., Banteyerga, H., Kidanu, A., Kilonzo, G., Mbwambo, J. & Bond, V. 2003. Disentangling stigma in Ethiopia, Tanzania and Zambia. *Horizons*. Washington DC: International Center for Research on Women.

Olley, B.O., Gxamza, F., Seedat, S., Theron, H., Stein, D.J., Taljaard, J., Reid, E. & Reuter, H. 2004. Psychopathology and coping in recently diagnosed HIV/AIDS patients: the role of gender. *South African Journal of Psychiatry*, 10(1):21-24.

Ogden, J. & Nyblade, L. 2005. *Common at its core: HIV-related stigma across contexts*. Washington DC: International Center for Research on Women.

Parker, R., Aggleton, P.A., Attawel, K., Pulerwitz, J. & rown, L. 2002. HIV/AIDS related stigma and discrimination: a conceptual framework and an agenda for action *Horizons*. Washington, DC: Population Council.

Reddy, P., James, S. & Mccauley, A. 2005. Programming for HIV prevention in South African schools: a report on programme implementation. *Horizons* Program. Cape Town: Medical Research Council.

Siyam'kela. 2003. *A report on the fieldwork leading to the development HIV/AIDS stigma indicators and guidelines.* (Policy Project, South Africa: Centre for the Study of AIDS, University of Pretoria; United States Agency for International Development; Chief Directorate: HIV, AIDS, TB, Department of Health.

Uys, LR. 2003. *Combating HIV/AIDS stigma: a workshop manual for nurses*. Pretoria: SANNAM.

Yang, H., Li, X., Stanton, B., Fang, X., Lin, D. & Naar-King, S. 2006. HIV-related knowledge, stigma, and willingness to disclose: a mediation analysis. *AIDS Care*, 18(7):717-724.

Yin, R.K. 2003. *Case study research: design and methods*. 3rd edition. Thousand Oaks, Calif.: Sage.