

THERAPEUTIC PROCESSES FOR SUPPORT GROUPS FOR PREGNANT WOMEN LIVING WITH HIV

BY

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This dissertation is dedicated to my daughter, Saphokazi, and my son, Lusapho. I love you guys.

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ACRONYMS

HIV – Human Immuno-Virus

AIDS – Acquired Immune Deficiency Syndrome

VCT – Voluntary Testing and Counselling

PMTCT – Prevention of Mother-to-Child Transmission

SUMMARY

As part of the Serithi project a longitudinal study of HIV positive women diagnosed during pregnancy, support groups for HIV-positive women were established in Mamelodi and Atteridgeville (Tshwane). Eighty-eight women participated in these groups during 2005, with the groups being facilitated by Masters Psychology students. This study explores therapeutic processes in these support groups.

Yalom's therapeutic factors were used as the underlying theory. These are factors that Yalom advances as therapeutic processes in understanding group psychotherapy. The process notes of the Masters Student facilitators, together with the interviews that were conducted with the women after the support group experience, were analysed to identify therapeutic processes that manifested themselves in the support group experience. Qualitative methods were used to collect data and thematic analysis was utilised to analyse the data.

The research results revealed that support groups are therapeutic, in the sense that ten of the twelve therapeutic factors advanced by Yalom proved to have been made manifest, or demonstrated, within these groups. These are: altruism, group cohesion, interpersonal learning input, interpersonal learning output, guidance, identification, family re-enactment, instillation of hope and existential factors. The women reported having felt a sense of relief from being part of a group of people who experienced similar issues. They also reported that they learnt from each other. This gave them hope and an understanding that, even though there may be people going through the same problems as they are, they still need to face life alone. The women reported feeling a sense of self-worth from helping others, which contributed to rebuilding their self-esteem.

These results indicate that support groups can be therapeutic for the people involved. They can be used to guide support group facilitators with regards to what to look for when facilitating groups. They can also assist policy makers in developing guidelines for the facilitation of support groups in order for the participants to obtain maximum benefit from their support group experience.



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CHAPTER I

ORIENTATION TO THE STUDY

1.1. Introduction

Since the first clinical HIV was diagnosed and reported in 1981, over thirty million people have been infected with HIV (Barnett & Whiteside, 2001). UNAIDS (2008) reports that, since 1990, the number of people living with HIV has continued to escalate, estimating it at 36 million by 2007. This report has also shown that deaths from HIV/AIDS are even more than are reported in the poorer nations, accounting for about 98% of the world's AIDS deaths. Within Sub-Saharan Africa, HIV initially flourished in East Africa, but the rates of HIV in countries such as Uganda and Kenya have started to decline. In Southern African countries such as Lesotho, Swaziland, Zimbabwe, Namibia and South Africa, the HIV infection rates are still persistent and prevalent, especially in South Africa (UNAIDS, 2008). According to the same UNAIDS (2008) statistics and reports, as well as the HSRC's South African National HIV Prevalence, Incidence, Behaviour and Communication Survey III (SABSSM III), South Africa is identified as having the highest HIV prevalence rate in the world, followed by India and Nigeria. Reports have estimated the rate of new infections in South Africa to be 1600 per day.

HIV / AIDS is one of the main challenges facing South Africa today. It is estimated that, of the 39,5 million people living with HIV worldwide in 2008, more than 63% are from sub-Saharan Africa. About 6 million people were estimated to be living with HIV in South Africa in 2008, with 18, 8% of the adult population (15-49 years) infected (UNAIDS, 2008). Women are disproportionately affected, accounting for approximately 55% of HIV positive people. Women in the age group 25-29 are the worst affected, with prevalence rates of up to 40% in certain areas. For men, the peak

prevalence is reached at older ages (+ 50). In the latest report (SABSSM III), it was found that HIV prevalence among younger women (15-24 years) has declined from 10,3 in the 2005 survey to 8,6 in the 2008 survey. This could be attributed to higher levels of awareness and to the effects of widespread condom distribution.

The impact of HIV/AIDS could have devastating consequences for the country's future economic and social planning. The epidemic is defeating the efforts of medical personnel (Peltzer, K., Phaswana-Mafuya, N., Ladzani, R., Ndabula, M., Davids, A., Dana, P., Metcalf, C. & Treger, L. 2008). That implies that additional support from other human and social science professionals is needed to synergise efforts to deliver health care services to HIV/AIDS clients. This is the reason that the Deputy President of South Africa, in conjunction with different government departments, has seen the need to call for a collaborative effort in fighting the disease (HIV and AIDS and STI strategic plan for South Africa, 2007-2011).

Based on the above, the South African government has recognised the need to re-evaluate the strategy that it has been applying in dealing with HIV/AIDS. This has prompted the Department of Health to devise a multi-sectoral strategy for dealing with HIV/AIDS. Big business, government departments, NGO's, CBO's, FBO's and research institutions have all been pulled in to help to deal with this pandemic (HIV and AIDS and STI strategic plan for South Africa, 2007-2011).

Essentially, it must be argued that, in as much as health personnel capacity is inadequate to cope with prevalent HIV infection rates in the country, clients and pregnant women who learn about their HIV status need more support than the

healthcare system can currently offer. Most women find out about their HIV status for the first time in antenatal clinics during their pregnancy, as part of the Prevention of mother-to-child transmission programme (PMTCT). The number of women who decide to take the HIV test during pregnancy is rising, which has actually helped in monitoring the extent of the pandemic (Dept of Health report).

When diagnosed with HIV during pregnancy, most often women are left in a particularly distressed state of mind. Depending on these women's level of sophistication and the availability of counselling resources in hospitals, most HIV positive diagnoses and candidates for healthcare assistance end up in clinics and hospitals. By way of illustration, VCT in South Africa is done by lay counsellors who have little or no psychological training (Peltzer, K., Phaswana-Mafuya, N., Ladzani, R., Ndabula, M., Davids, A., Dana, P., Metcalf, C. & Treger, L. 2008).

This study shows that, over and above the fact that the lay counsellors are not properly trained, there are problems with physical space for the actual counselling to take place in clinics. Because large numbers of women need counselling services, the help they receive is often inadequate, which can result in women having difficulty in making decisions - in terms of whether to breastfeed or not and whether to take ARV's during pregnancy or not. Women with HIV are often left at the mercy of their confusion, lack of knowledge, negative emotions, stress and hopelessness after hearing that they are HIV positive.

In its protocol on the implementation of the PMTCT programme, the Department of Health (2007) suggests that women should be encouraged to submit to testing for HIV on their first visit to the antenatal clinic. The document also suggests that pregnant

women should be encouraged to make their first ANC visit also within the first twenty weeks of pregnancy. The women who come to the clinic are then supposed to be tested and - if found to be HIV positive - they should become part of the PMTCT programme. This means that the women are supposed to have their CD4 count done and to be put on ARV's as soon as possible, if there is a need. This would seem to be happening, if one looks at the statistics on the uptake of VCT in the country. The HSRC national survey shows an increase on the uptake of VCT in South Africa (Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-Van Wyk, Mbelle, Van Zyl, Parker, Zungu, Pezi, 2009). HIV-positive women therefore have access to medication and information on ARV's in various centres across the country. The problems that still exist involve assisting them to accept their status, deciding on disclosure and mentoring them so that they are able to live responsibly with their status (Department of Health, 2007).

1.2. The psychological implications of an HIV-positive diagnosis

HIV is a chronic disease with a profound social impact owing to its strong ties with sexually and socially stigmatic behaviour, such as sexual promiscuity and illegal drug use . A diagnosis of HIV may lead to difficulties coping with illness-related problems, reduced self-esteem, social isolation and poor psychological well-being (Venable, Carey, Blair & Littlewood, 2006). Watstein and Chandler (1998) argue that not all people will experience all of the emotional responses or stages of being diagnosed with HIV. They argue that those who experience negative emotions may have to deal with feelings such as fear, loss, grief, guilt, denial, anger, anxiety, low self-esteem, depression, suicidal attempts and socio-economic issues. Some individuals face catastrophic challenges, not only in their personal and job relationships, but in their

health, self- esteem and social relationships. However, every HIV/AIDS situation remains unique.

Confronting HIV/AIDS involves a process of confronting fear and denial while maintaining hope (Bezuidenhout, Elago, Kalenga, Klazen, Nghipondoka & Ashton, 2005). Concurring, Vanable et al. (2006) claim that receiving emotional support from significant social network members such as partners, families, or friends may counteract the negative impact of HIV on psychological well-being.

1.3. Statement of the problem

In South Africa, living with HIV still carries stigma. . Stigma is described by Simbayi, Kalichman, Strebel, Cloete, Henda and Nqeketo (2007) as an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one. This is the classical description of stigma from the original work by Goffman (1963). Ngozi, Mbonu, van den Borne and de Vries (2009) did a review of research on stigma related to HIV/AIDS in Sub-Saharan Africa. They argue that stigma is a social construct that has significant impact on the infected and those affected by HIV/AIDS. They suggest that stigma can lead to active discrimination directed towards people either perceived to be, or who actually are, infected with HIV, as well as the social groups with whom they associate. Rankin, Brennan, Schell, Laviwa (2005) distinguish between external and internal stigma. External stigma refers to the actual experience of discrimination, while internal stigma refers to the shame of being diagnosed with HIV and the fear of being discriminated against.

Campbell, Nair, Maimane and Nicholson, (2007) argue that HIV stigma can have negative effects on the people, whether the stigma is actually experienced or expected to be experienced. Stigma, or the fear of being stigmatised, can result in lower VCT uptake, lower uptake of maternity or PMTCT services and lower disclosure levels for people who test positive. Stigma therefore contributes to the maintenance of risky sexual practices which can perpetuate the spread of HIV and thwart efforts to reverse the spread of the pandemic.

The Departments of Health and Social Development, in collaboration with CBO's and NGO's, are doing a great job of providing information on how one can contract the disease and how to live positively with the disease. It is through sustained media drives that there is information about the disease available in public places, on billboards and via media programmes. This has not, however, helped to dispel the misconceptions that people have about the disease. People live in communities, and the perspectives that dominate these communities naturally influence and affect them. In most cases, women have no support services to deal with the HIV crisis. Owing to a lack of mental health services in South Africa, HIV positive people often have to rely on social support from others in the same situation as themselves. This has resulted in support groups forming to provide psychological intervention for people living with HIV. As part of the Serithi project, a project following HIV-positive pregnant women after diagnosis for two years to investigate the medical and psychological experiences of HIV, support groups have been established for women living with HIV who consented to join the groups. About ninety women participated in ten groups during 2005. This study will use the process notes on the experiences in these groups to investigate the therapeutic processes within the groups.

From the ongoing discussion, it is clear that there is a lack of resources to assist women to cope with HIV and that support groups are needed to provide the necessary support. It is important to make sure that these women have knowledge of HIV, are able to cope with it in a positive way and they are able to negotiate safe sexual relationships. Since these are key areas that need to be addressed in support groups, it is against this background that this study has been undertaken.

1.4. Justification

Support groups are implemented widely in South Africa as a therapeutic means of helping people living with HIV (Dept of Social Development, 2007). Often they develop spontaneously with people starting groups with [their] peers. This research undertakes to investigate the therapeutic processes in groups that enhance the efficacy of those groups as a helping system. This research can provide the Department of Social Development with an understanding of why support groups are beneficial to participants. This can also be used to develop guidelines on how groups can be made more therapeutic and worthwhile for people living with HIV.

It is important to understand participant processes in the HIV positive support groups in order to be able to assess the therapeutic value thereof. In an article written by Lyttleton (2004) on support groups for women living with HIV in Thailand, he notes that support groups “increase the immune system both in their bodies and in their communities.” Lyttleton (2004, page 17) claims that support groups offer a sense of belonging to the members of the group. The author stresses the point that support groups are self-help organisations for people affected by stressful life circumstances whose need has been inadequately addressed by traditional healthcare interventions.

He further states that the characteristics of support groups are that they are participatory and that they involve the giving and receiving of help, learning self-help and sharing experiences and knowledge of common concerns. He discovered that there is increasing evidence that participation in support groups by patients with chronic or mental illness and/or their families has been shown to improve adjustments for the patients and their families.

This study is aimed at exploring the processes that take place in support groups for pregnant women living with HIV. Its aim is to find out what it is about those groups, or what takes place in them, that is actually therapeutic.

1.5. Overview of the study

This study consists of five chapters. In this chapter, a motivation for and overview of the study were given. CHAPTER II reviews literature written specifically about psychological issues related to HIV/AIDS, support groups and psychological processes taking place in groups. CHAPTER III gives a detailed description of the methods utilised to collect and analyse that information. CHAPTER IV presents the research results and a discussion of results. The last chapter will present conclusions, recommendations and open up avenues for further research.

CHAPTER II

OVERVIEW OF THE RELEVANT LITERATURE

2.1. Introduction

Undertaking research of this magnitude requires an in-depth review of multidisciplinary literature addressing the therapeutic elements of support strategies. In view of this, the literature review is set out using sub-titles for a more articulate, pragmatic and focused review. Yalom (1995) claims that there are many advantages of using group therapy to deliver an intervention. These advantages include: 1) the development of sense of universality, cohesion and social support among group members; 2) the opportunity for modelling and social learning from other group members and 3) the positive experience of sharing with and helping others. Based on the above findings, one can deduce that groups are viewed to be less stigmatising than individual interventions. These, together with more articulations, will be explored in this review. HIV/AIDS as a disease, its psychological impact on people infected and the benefits of group interventions will be discussed in this chapter.

2.2. HIV/AIDS

HIV (Human Immunodeficiency Virus) attacks the immune system, which is the body's defence against illnesses, of an infected person. This virus affects the body's CD4 cells, which are the cells that coordinate the immune system's response to infections. HIV attacks the CD4 cells and attaches itself to the cell's DNA in such a way that it cannot be isolated. Once it has done this, it begins to replicate and to produce millions of viruses. Eventually, the virus destroys almost all of the immune system and the person's

body becomes vulnerable to opportunistic infections. When a person's immune system has deteriorated, the person becomes sick with a combination of life-threatening diseases. They are then said to have AIDS (UNAIDS, 2005).

HIV is transmitted mostly through unprotected sexual encounters with infected partners. It can also be transmitted through blood-to-blood encounters and a mother can pass it on to her unborn child (UNAIDS, 2005).

2.3. The most vulnerable groups

Lau, Tsui, Choi and Su (2007) stress that vulnerability to HIV/AIDS is closely tied to the social marginalisation of people most affected by the virus. The people most vulnerable to HIV are women, the poor, adolescents, children, commercial sex workers, migrant labourers, men who have sex with men, drug injectors and prisoners (UNAIDS, 2006). Mentally ill persons are also regarded as being at high risk for HIV infection (Otto-Salaj, Kelly, Stevenson, Hoffmann & Kalichman, 1997). These authors advance the notion that practices such as sexual activity with multiple, casual or high-risk partners puts this population at high risk. They claim that there are also low levels of condom use and unprotected sex among the mentally ill population.

2.4. The vulnerability of women

As stated above, vulnerability to HIV/AIDS is closely tied to the social marginalisation of people most affected by the virus (Cremonesi, 2006; Drower, 2005). Factors such as gender inequality, economic disempowerment, lack of basic education, migrant husbands, ignorance and the stigma surrounding HIV/AIDS, child marriage and gender

violence put women at risk of contracting sexually transmitted infections including HIV (WHO, 2006).

Gender inequality refers to the notion that women are seen as second-class citizens in some parts of the world, which makes it difficult for them to have a voice, even with regard to their own bodies. Men's economic empowerment enables them to make decisions about sexual issues for women. The perceptions that women are unable to make decisions with regards to sex because they cannot take care of themselves financially - usually because they are not permitted to do so - are still prevalent. Ngozi et al. (2009) also argue that women failing to seek medical help with regards to sexuality issues is the result of 'inexperience', which means that such women are comparatively ignorant about sexual issues, which in turn is a 'good thing'. This is a manifestation of the victimisation of women by societal culture which promotes a misleading definition of sexual purity. Knowing less is regarded as proof that the women have not slept with a lot of men and that they are good women. Jewkes, Levin and Penn-Kekana (2002) note that economic disempowerment also forces women and young girls to have sex with older men in exchange for money and other liberties. These authors also argue that of the 121 million children in Sub-Saharan Africa who are not in school, 65 million are girls. This practice disempowers girls from effective future participation in the economy, as education is one of the tools that opens up opportunities for future positive development of a population. Girls also frequently pressurised to leave school early in order to take care of their sick relatives.

The problem of migrant husbands also puts women at risk of infection, as men engage in unprotected sex while away from home. In a study done in Cameroon, HIV prevalence in men who had been away from home was 7,6 % compared to 1,4 % for

men who had stayed at home (WHO, 2006). Ignorance and stigma surround this problem. Macleod-Downes, Albertyn and Mayers (2008) suggest that some women are ignorant of their vulnerability to HIV and the associated stigma makes it difficult for women to seek assistance, even when they need it. Women who are in monogamous relationships tend to think they are at low risk in terms of being infected, which in reality may not be the case at all.

In some cultures, girls are still marrying young. They often marry older men who are sexually experienced and who may already be infected by the time they marry them (WHO presentation, 2006). Gender violence is also common in South Africa. A woman who experiences sexual violence is physically at greater risk of infection. Research shows that physical violence, the threat of violence and the fear of abandonment act as significant barriers for women who have to negotiate condom use, discuss fidelity with their partners or leave relationships that they perceive to be risky (Mane, Rao Gupta & Weiss, 1994; Smith, 2002).

2.5. The implications of being diagnosed with HIV

Being diagnosed with HIV raises many issues for the infected person. Different people react differently to the information and this makes it difficult for there to be a standard format for dealing with people who are diagnosed with HIV. Hudson, Lee, Miramontes and Portillo (2001) suggest that people infected with HIV have to deal with issues such as family misunderstandings, financial burdens, stigma, discrimination, death, change in life expectancy, decisions about disclosure, mistrust in relationships, possible social isolation and social rejection, as well as various other emotional responses. These

issues can make it difficult for people to cope, because they all have strong potential for inducing stress.

2.6. Social support as a buffer for stressful events

Drower (2005) argues that the availability of a supportive social network can help people cope with various life stressors ranging from job loss through serious illness to marital disruption. Social support facilitates emotional adjustment to chronic illness, including HIV infection. Access to social support among people living with HIV/AIDS depends on the degree to which an individual has disclosed his or her HIV status to sources of social support, such as family members, friends and sex partners (Kimberly & Serovich, 1996). People living with HIV/AIDS who are unable to disclose their HIV status to family, friends, and others in their social networks have less social support and fewer coping resources and experience greater emotional distress than individuals who are able to disclose their status. While this social network becomes an invaluable tool for those people diagnosed with HIV, social support can mean different things for individuals. Hudson, Lee, Miramontes and Portillo (2001) define it as an exchange of resources between individuals perceived by either or both the provider and the recipient to be intended to enhance the well-being of the recipient. Tardy and House (1985) outline four broad types of supportive behaviours, namely: 1) emotional support; 2) instrumental support; 3) informational support and 4) appraisal support.

Emotional support encompasses empathy, caring, love, trust, esteem, concern and listening. Instrumental support refers to the provision of help in kind, or providing assistance via money, labour and time. Informational support refers to providing advice, suggestions, directives and information for use in coping with personal and

environmental problems, while appraisal concerns affirmation, feedback, social comparison and self-evaluation. Hudson et al. (2001) also distinguish between perceived and actual social support. Perceived social support refers to a person's subjective appraisal of the support that he/she receives and how appropriate that support is for that person. It may include considerations such as expectations, specific needs and personal experiences. It refers to the expectation of receiving social support should one need it, as well as to the perception that one is loved and esteemed by others, with the perception that being cared for can promote health being integral to the above.

Actual support, on the other hand, is the actual degree and kind of support given by others, whether or not it is perceived as adequate by the receiver. House (1981) also advances that social support is the perceived value that influences behaviour. A person who perceives that they will be able to get support, should they need, it will behave differently from a person who expects no support at all from their significant others. Those expecting support may be able to deal better with their conditions, which will lead to better adjustment, whilst those who do not may manifest self-destructive behaviours and may not adjust well to their conditions. Wethington and Kessler (1986) argue that the perception of one's network being ready to act in the event of something happening to them can be as important as - if not more important than - the actual supportive itself. The arguments above endorse the fact that social support is a critical need when one is dealing with life-threatening circumstances.

2.7. What are support groups?

Support groups can be defined as the “coming together, either face-to-face or over the telephone, of individuals with some pressing common concern who are willing to contribute personal experiences and engage in the development of a cohesive, supportive system” (Schopler & Galinsky, 1993, p.196). These authors further suggest that support groups are groups of people who share a common bond who come together or interact on a regular basis to discuss problems and experiences. These authors claim that, in support groups, members provide one another with various types of non-professional, non-material help for a particular shared burdensome characteristic. This help may take the form of providing relevant information, relating personal experiences, listening to others’ experiences, providing sympathetic understanding or establishing social networks.

Support groups provide their members with personal contact. Some members meet in person in groups small enough to allow conversational interaction. Membership in some of them is formally controlled, with admission requirements and membership fees. Some groups are open and allow anyone to drop in at an advertised meeting, or to participate in an online forum.

The definitions above demonstrate the fact that support groups are forums where people come to discuss common problems. They also help people deal with catastrophic events in their lives. HIV support groups are no different. People come together in these groups to discuss their experiences of the HIV. This includes sharing information, the provision of sympathetic networks and establishing social networks, which are important for a life with HIV (Schopler & Galinsky, 1993).

2.8. The difference between support groups, self-help groups and therapeutic groups

According to Schopler and Galinsky (1993), the underlying differences between these three groups relate to sponsorship, conceptions of participant roles, the basis of leadership, interventive methods or technology and the views of the groups. Treatment groups are run under the auspices of local treatment organisations or clinicians in private practice. Although there is wide variation among treatment modalities, these groups tend to be more leader-centred and there are clear distinctions between the roles of the leader and the members. The leader is a professional whose authority is based on specialised training and expertise. Members are selected for group membership because they share common concerns, but expectations regarding their behaviour in the group are dictated by the treatment modality. Leaders take responsibility for intervening, often playing an active role, and may prompt discussions of member-leader relationships or interpret member behaviour. Whatever their therapeutic orientation, they use complex treatment technologies involving assumptions about the cause and cure of problems and specialised therapeutic techniques. The group is viewed as a therapeutic entity that can become a significant force for individual change within the group.

Self-help groups are often initiated by professionals and are frequently affiliated to a national or regional sponsoring organisation. The control of the group activities lies with members, while leader and member roles may overlap somewhat. Experience with a focal life experience is the common denominator which provides the basis of shared authority. Professionals may help initiate the group and serve as consultants, make arrangements, and provide resources. Leaders, however, tend to rely on their personal experience with the members' shared concern to develop the emotional

understanding necessary to facilitate the group. The interventive technology often involves some standardised format with general procedures for sharing experiences and information that may have been developed by the sponsoring organisation. The emphasis is on self-help, mutual aid and peer support. The group is viewed as a supportive environment within which members can gain the strength to deal with life outside the group. In some cases, particularly in groups whose members have been stigmatised or discriminated against by society, the group may also become involved in political action.

Support groups lie midway between these two group forms. Sponsors may be national organisations, local associations and organisations or private practitioners. Frequently, these groups are member-centred, but there are some distinctions in participant roles. Leadership may be provided by professionals, volunteers, or at times by members. Because leaders serve as role models, their personal experience with the group's focal concern may be viewed as desirable but generally is not required for leadership. Rather, the leader's legitimacy tends to be based on training and expertise in group facilitation. Leaders share authority and are often on more or less equal terms with members. They do, however, carry the ultimate responsibility for facilitation. The leader's principal task is to promote the development of reciprocally supportive relationships among members. Members are usually expected to take active roles in sharing their experiences, providing information, giving advice and recruiting other members. Intervention technology tends to be varied, depending on leader orientation and training, and ranges from unstructured discussion and a few simple rules to more complex procedures related to developing emotional and cognitive understanding, coping skills and problem-solving. Leader interpretations of psychological factors are not likely to be a major focus of these groups. Furthermore, in support groups, the

group is likely to become both a supportive environment and a potential means for developing the coping abilities of the respective members. Although individuals may become empowered to take action outside the group, support groups typically do not take on advocacy functions (Schopler & Galinsky, 1993).

2.9. Support groups as social support in an HIV context

Support groups in the context of HIV/AIDS become an invaluable tool to help people cope with HIV. They provide people with HIV with a relaxed and informal place to share their experiences and build new friendships, as well as helping them to renew their faith and confidence in the face of devastating losses. They give couples (at least one of whom is HIV positive) an opportunity to discuss relational, legal, health, and other issues that concern them. Support groups provide specific groups of people with a context within which to discuss their HIV with a group of people in a similar situation. Usually people gain acceptance, support, nurture and intimacy from their birth families, close friendship groups, and/or religious groups, such as churches and synagogues. Too often, however, these groups reject individuals when their HIV positive status becomes known, especially if the person contracted AIDS from IV drug use or through sex.

Group work is, according to Toseland & Rivas (1984), a goal-directed activity with small groups of people aimed at meeting socio-emotional needs and accomplishing tasks. It is directed at individual members of the group and to the group as a whole - within a system of service delivery. This means that, in the context of the groups that are being explored here, group work is imperative in helping these women to meet their emotional needs and is a vital service delivered to them. Lyttleton (2004) argues

that joining a support group entails forms of self-transformation concomitant with one's publicly acknowledging their HIV status, even if it is to a limited public. Secondly, he claims that it entails in itself the act of appealing to different categories of people for assistance in coping with HIV without literally knocking on their doors.

Lyttleton (2004) also claims that joining a support group is an act of reversing the shame that is associated with living with HIV. He calls them 'identity coalitions' that offer substantial services that address a range of acute needs such as material and emotional assistance. He says support groups also challenge social discrimination and points out that the anxiety, fear, guilt, sadness, ignorance, blame and anger that these people confront can thus be dealt with positively. In this way, when a person joins a support group, she also enters a forum that offers an opportunity to reformulate a sense of self worth that has been categorically devalued by mainstream associations. These groups facilitate empowerment of women to negotiate their relationships with their partners. They help raise awareness about the nature and course of HIV. Interaction in groups may contribute to an increase in the self-esteem, social integration and sense of control for people living with HIV. Support groups also help in strengthening community networks in the face of the HIV/AIDS epidemic.

Drower (2005) continues to argue that groups help people in that they challenge loneliness, give a sense of belonging, are a source of mutual aid, create hope and can even be a source of social action. The above-named characteristics are all important for the well-being of a woman living with HIV. Because of the stigma and social rejection, a woman may find herself without friends, especially those she can talk to about her HIV status. A support group can be a forum where she is able to talk about her status without fear of discrimination. The groups also create hope that this is not

the end. In South Africa, there is an organisation called the Treatment Action Campaign (TAC) that started from a support group, so support groups can also help to organise resources for the assistance of individuals living with HIV.

2.10. Types of support groups

Williams (1992) identifies four general types of support groups. They are:

- Those that follow a suggested, often ritualistic format and have established written guidelines, but use rotating facilitators
- Those that follow either a loose regular format or are free form
- Those that are facilitated by trained volunteers. These groups usually have some kind of verbal or written agreement about the format of the meetings and the ground rules for the group
- Those that are facilitated by trained professionals. The format and guidelines of these groups vary with the professional's style of leadership and the purpose of the group.

The groups that will be studied in this research are facilitated by trained volunteers, together with professionals. They follow a written format and have ground rules which are agreed to by the group members, together with the facilitators.

2.11. Characteristics in group processes that may be therapeutic for group members

Group processes have the potential to assist the facilitator to see whether or not the group is progressing towards the resolution of issues. The facilitator needs to understand these and be observant of them in the group as it progresses. Most groups will show the following stages: 1) the initial stage, 2) the transitional stage and 3) the working stage.

2.12.1. The initial stage

In the initial stage of the group, members may be hesitant to participate and may be dependent on the leader (Yalom, 1995). Corey and Corey (1997) also claim that, at this stage, members may be resistant and have problems with self-focus as opposed to focussing on others. In other words, members may focus on outside things and on others, rather than focussing on themselves. This tends to make members shift their focus from themselves, which may be caused by the fact that members are not trusting at this stage and can delay the group's progress. . This may also be caused by the members' lack of understanding of the benefits they stand to gain from the group. The facilitator may help this process by making the goals of the group clear and having each individual see him/herself as an equal contributor to the group. The resolution of these internal conflicts may be very helpful to the individuals concerned, because they may be able to find their role within the group.

Yalom (1995) claims that members also tend to size each other up. This process helps members in their search for roles in the group with which they will be

comfortable. They also wonder whether they will be liked or rejected. This is what Corey and Corey (1997) refer to as resistance. This is an important process, in that it is at a time when members do not know how much of themselves they will be expected to disclose. The resolution of this stage may be helpful, in that it will mean that members are now free to disclose information about themselves and therefore be able to accept help from others.

There is also the issue of trust versus mistrust. This can be a very crucial element in group processes. People need to be able to feel that they can express their feelings, no matter what they are, without fear of censure, when they are willing to decide for themselves specific goals and personal areas to explore, when they focus on themselves and not on others, and when they are willing to risk disclosing personal aspects of themselves (Corey & Corey, 1997).

Establishing group norms together can also help the group members relax somewhat, knowing that whatever they talk about will be confidential, as well as giving each other a chance to talk or discuss the rules about attendance etc. They also feel a sense of ownership towards the group, which makes them want to make the group work. This can also be very therapeutic and liberating, because it becomes a safe space for people to explore their HIV infection. Group norms also need to ensure that the opinions and feelings of others are respected. The foundations for the development of group cohesion are always laid at the initial stage. In fact, group cohesion usually becomes evident after the group members have struggled with conflict, shared pain and committed themselves to taking significant risks. Some indicators for cohesion of the group are: cooperation among members, a willingness to show up for meetings and be punctual, an effort to make the group a safe place, support and caring etc.

(Corey & Corey, 1997). Yalom (1995) agrees with this process and claims that cohesive groups tend to develop things such as in-group cohesion, a common goal and group spirit, consensual group action, cooperation and a “we” consciousness. These are very good in helping members identify with one another and feel a sense of an identity within the group. He argues that there is an increase in morale, mutual trust and self-disclosure at a later stage, if this stage is passed through successfully. Attendance will improve and members will share secrets freely, as well as showing considerable concern about missing members.

2.12.2. The transition stage

The transition stage, according to Corey and Corey (1997), is characterised by feelings of anxiety and [the display of] defences in the form of various resistances. The members are now concerned about “playing it safe” versus “wanting to risk” getting involved. They may be experiencing some struggle for control and power and some conflict with other members or the facilitator.

The members may also be dealing with feelings of reluctance to get fully involved in working on their personal concerns because they are not sure others in the group will care for them. Members may be reluctant to ask some questions, for fear of being the ‘odd one out’ with such a problem. They are also engaged in observing the facilitator at this stage, to see if he/she is trustworthy. Learning to express themselves in such a way that others will listen may also be an issue on which some of them are working (Corey & Corey, 1997).

2.12.3. The working stage

The working stage, according to Corey and Corey (1997), is characterised by group cohesion and high levels of trust. Communication within the group is open and involves an accurate expression of what is being experienced. Leadership functions are likely to be shared by the group, in that members interact with one another freely and directly. There is willingness to risk sharing threatening material and to make themselves known to others. Members bring to the group personal topics that they want to discuss and understand better. Conflict among members is recognised and dealt with effectively. Feedback is given freely and accepted and considered non-defensively. Confrontation occurs in a way in which those doing the challenging avoid slapping labels on others. Participants feel supported in their attempt to change and are willing to risk new behaviour. Members feel hopeful about life and they take necessary actions, they do not feel helpless (Corey & Corey, 1997).

Problems that may arise with this stage include that members may relax and enjoy the comfort of familial relationships, thus avoiding challenging one another. This is both the most relaxing and the most challenging stage of group work for the facilitator. In the initial stages, the facilitator is mostly busy with trying to help the group's cohesiveness, enhance group participation and ensure that ground rules are understood and put into action. After that, the process of change needs to take place. This is a stage where one watches the group happening with minimal interference, to make sure the group does not go off course.

In the final stage, when the group is about to terminate, the following characteristics are evident: group members may be sad over the imminent separation; they are likely

to pull back, in terms of participation, because of the anxiety induced by the imminent separation. There may also be anxieties about carrying over into real life what has been learnt in the group. Accordingly, the final sessions may be partly devoted to preparing members to meet significant others in everyday life. Role playing and behavioural rehearsals for relating to others more effectively may happen. There could be an evaluation of the group process (Corey & Corey, 1997).

This stage is usually not easy for the facilitator as well. He/she has to prepare the members for termination. This means terminating another experience in his or her life as well. He/she has the responsibility of ensuring that members translate insight into action and of encouraging members to make sure that learnt information is applied outside the group. While he/she still has to make sure that group norms are adhered to, the facilitator also has to be aware of therapeutic factors that operate to produce change and to intervene in such a way as to help members make desired changes in feelings, thoughts and actions.

2.13. Some characteristics of effective facilitators

There are many characteristics needed for the group to be effective. Of the many that there are, only those applicable to this context will be discussed, namely:

- Courage to be vulnerable sometimes, to admit mistakes and take the same risks the facilitator expects the group members to take.
- Courage to be emotionally touched by another person is also an asset in which a facilitator may invest.

- Being present emotionally with group members, dealing with the emotions that the group elicits in the facilitator as well as his/her own emotional problems. This shows the group members that the facilitator is human too.
- Caring; this is the fundamental reason that support groups exist in the first place.
- Showing a sincere interest in the welfare of others.
- Demonstrating a belief in the group process, trusting the process after it has been introduced the activities and being observant.
- The facilitator does not need to be defensive in dealing with attacks, but must be frank in dealing with criticism.
- Being willing to seek new experiences enhances the facilitator's willingness to learn about his/her profession.
- Self awareness
- A sense of humour is also important.
- He/she has to be spontaneously creative (Corey & Corey, 1997).

2.14. Theoretical framework

This research will use Yalom's therapeutic factors as the theoretical framework to interpret the data. Yalom (1985) advances sixty therapeutic factors in his theory but these are categorised into eleven major categories. These factors were developed for therapeutic group contexts but they prove themselves helpful in support groups as well. He states that the following characteristics in groups contribute to the therapeutic value of groups. These are altruism, group cohesiveness, universality, interpersonal

learning -input, interpersonal learning-output, guidance, identification, family re-enactment, instillation of hope and existential factors.

Altruism is, according to the theory, helping others in the group. This includes putting other's needs ahead of the individual's, giving part of oneself to others and communicating feelings of their importance to others - because one is helping them.

Group cohesiveness refers to feelings of belonging and being accepted by the group. This includes feeling that an individual can reveal embarrassing things about themselves and still feel accepted by the group, as well as the sense of belonging to a group of people who understand and accept them.

Universality refers to feelings of not being alone, a feeling that others also have the same problems that the individual has. This also makes individuals feel that they are also part of the human race. **Interpersonal learning-input** means individuals get to learn about themselves and how they come across to others. Group members can help point out habits and mannerisms that can be irritating to others.

Interpersonal learning-output may help individuals to improve their interpersonal skills. Individuals may learn to trust other people and they may also learn to deal with conflicts with other people.

Guidance refers to how group members can advise one another on how individuals can deal with problems in their own lives. This may take the form of suggestions or advice from a member who has had the experience. Group members may even help each other in terms of shaping behavioural patterns

Identification means trying to be like someone in the group. This can also help members improve some behavioural trends that they feel are not desirable by emulating conduct that a group member feels is good.

Family re-enactment refers to the fact that group members react towards the other group members in ways similar to the manner in which they interact with family members. Here, members are empowered to understand old 'hang-ups' that they had with their own families. This includes understanding how they grew up and arriving at a better understanding of past relationships with friends and family. Members gain hope from the experience that other members have had similar problems overcome them in the past.

Existential factors refer to the fact that members learn to recognise that life is not fair and may seem to be fundamentally unjust. Members also learn to understand that ultimately there is no escape from some of life's pain, or from death. They may also learn that, no matter how close they may get to other people, they still need to face life alone.

The group manifestation of some or all of the above characteristics has the potential to assist group members to deal with the stressor concerned. Characteristics such as altruism, guidance, group cohesiveness, interpersonal learning–input, interpersonal learning–output and identification refer to the individual in relation to the group. This can help the individual to understand the disease and how it affects his/her relationships. Family re-enactment and instillation of hope may help the individual reflect on his/her own family and belief systems and how these relate to the fact that s/he finds her/himself living with HIV. These characteristics together can then assist the individual to look both inside her/himself and in her/his environment for ways to cope with the disease.

The next chapter discusses the methodology used in facilitating the groups and analysing the processes in the groups that may have been therapeutic for group members.

CHAPTER III

RESEARCH METHODOLOGY

3.1. Introduction

This chapter provides an overview of the research methodology. It outlines how data was collected and analysed using a qualitative research approach. Ethical considerations are also discussed in this chapter.

3.2. Study design

Qualitative research is defined as a method used by researchers to study human action from the perspective of the social actors themselves. The primary aim of this method is describing and understanding, rather than explaining, human behaviour. Qualitative research is conducted in the natural setting of the social actors being studied. The focus is on process rather than outcomes. The actor's perspective is emphasised and the primary aims are in-depth descriptions and arriving at an understanding of actions and events. The main concern is to understand social action in terms of its specific context, rather than attempting to generalise. The research process is often inductive, resulting in the generation of new hypotheses and theories. The researcher is seen as an instrument in the research process (Babbie & Mouton, 2001). Alvesson and Skoldberg (2000) argue that the researcher's influence is significant in the qualitative research process. It is the researcher who will be the one to judge how a specific respondent should be given voice or how understanding the context will be related to a respondent's remarks. The quantity of context presented in relation to specific respondents or situations will also be the researcher's choice. The

researcher also uses her/his personal knowledge and experiences as tools to make sense of the material (McCracken, 1988). This refers to the reflexivity of the researcher in the research process. It includes an acknowledgement of the impossibility of remaining 'outside of' one's subject matter while conducting research. The process of reflexivity therefore urges the researcher to explore ways in which a particular frame of mind influences the research process.

Flick (2002) describes four features of qualitative research methods. He insists that methods and theories have to be appropriate. Like Babbie and Mouton (2001), he says that the variety of perspectives of different participants is important and should always be taken into consideration. The researcher and the research are both reflective. Reflection entails engaging in critical appraisal of one's own practice: whether this be research or client work where the purpose of such reflection is to throw light on why we frame issues in particular ways and investigate them in particular ways, further to show how such approaches lead us to particular kinds of solutions and theories and not others. This process, in turn, leads to a more trustworthy interpretation of data.

This research uses qualitative methods based on the fact that the participants were studied in their context. It also analyses the participants' interpretations of what happened in the support groups. There are also the observations of the facilitators, which record their experiences of facilitating the support groups. The researcher therefore analyses people's perceptions of what happened in the group - and this analysis represents another interpretation of what happened. Because of the subjective nature of qualitative data, this analysis constitutes one interpretation -

where a different researcher may be able to see other aspects in the data as well (Babbie and Mouton, 2001).

Qualitative research appears to offer a sound methodological framework for developing an understanding of the implicit subjectivity that occurs in people's contexts. The process of documenting and interpreting information provides a fundamental basis for describing and interpreting the contextual variability of phenomena that surround the lives of human subjects. The utilisation of qualitative research methods provides access to the lived reality of individuals, facilitating the exploration of people's internal construction of their personal worldview. Such methods also assist in generating data that is rich in the subjectivity of actions, interactions, emotions, culture, symbols and rituals. Interaction between researcher and participant is recognised as a key component of data generation and valued as such, because it is a means of getting close to the experiences of participants so that phenomena can be viewed from their own perspective (Morgan & Drury, 2003).

3.3. Sampling

This research explores therapeutic growth processes in support groups that were conducted at two sites in Tshwane, namely Mamelodi-West Clinic and Kalafong Hospital. The target groups were women living with HIV who were willing to participate in support groups. Support groups were developed and managed and their impact assessed using a quasi-experimental design as part of the larger Serithi Project (a project funded by the National Institute of Health) (Mundell, 2006; Visser, Mundell, De Villiers, Sikkema & Jeffery, 2005). This research forms part of the evaluation of the outcome of support groups for women living with HIV.

HIV counsellors were trained to recruit women diagnosed with HIV during pregnancy to participate in the research. These women were invited to participate voluntarily in the support groups. Women who agreed to participate and signed a consent form were included in the groups. Although Yalom (1995) gives criteria for inclusion and exclusion of people from groups, the only selection criterion in this case was that they were to be pregnant women living with HIV willing to participate in the groups. There were no screening interviews to find out whether or not people were suitable for inclusion in the groups.

3.4. Procedure

Ten support groups were facilitated in 2005. The groups were composed of about eight to fifteen women at a time. Community Counselling Masters Students, together with facilitators who were people living with HIV, facilitated these groups. The Masters students were trained in group processes and in facilitating groups and were therefore able to observe progress in support groups. They also had weekly supervision sessions to discuss their observations and their process notes. Facilitators gave permission for researchers to use the process notes as part of their research. The co-facilitators were women living with HIV from the same community, who were trained in group facilitation. They were role models for the participants and provided them with practical advice. At times they also assisted the facilitators by interpreting discussions that were held in Sotho (the women's vernacular).

The group sessions were structured around the needs identified in interviews held with pregnant women living with HIV in the first phase of the Serithi project. The

development of the manual is discussed at great length in the paper written by Visser et al. (2005). The following themes were addressed:

Sessions 1-3 – Facts about HIV and pregnancy; prevention of mother-to-child-transmission.

Session 4 - 5 Emotions, experience and the meaning of being diagnosed with HIV.

This was done through drawing and discussing each participant's life map.

Session 6 - HIV, disclosure and stigma

Session 7 – Coping, problem solving and stress management

Session 8 – 9 HIV and relationships, human rights and stigma

Session 10 - Life planning and goal setting: socio-economic survival and decision making.

The groups were informal in style and the participants were given the opportunity to share their problems with and fears about HIV. Participation in all activities and by all those involved was highly encouraged. Even though every session had its own topic that needed to be addressed, facilitators understood that the most important thing was the voice of the participants. Participants were encouraged to be open with and to support one another. Three months after the termination of the support groups, the women who participated in these groups were followed up and interviewed. These research processes were part of the larger Serithi project. In the next section, data collection for this study will be outlined.

3.5. Method of data collection

The process notes of facilitators consisted of the facilitators' interpretation of what happened in the groups and how they, as facilitators, experienced each session. The process notes followed a format which required that they give the outline of the session, the content discussed in the session, the process of the session and what was learnt by the facilitator in that particular session. The facilitators were also given an opportunity to comment on the session and to highlight any outstanding occurrences or findings. Facilitators wrote their process notes immediately after every session and handed them to the co-ordinator at the weekly supervision meetings.

Individual interviews were conducted with the participants three months after completion of the groups. This study will analyse the responses of the eighty-eight women who participated in the support groups during 2005. Participants answered short open-ended questions about their experiences in the group sessions. The following questions were asked as part of the interview done by trained research assistants to gain understanding of the participants' experience of the group interaction:

- What did you expect, prior to your involvement in the group?
- What were your reasons for not attending all the sessions?
- What did you get from participating in the support group?
- Which sessions helped you the most, and why?
- Which sessions did you feel were boring, or did not address your needs?
- What else would you have liked to have seen as part of the programme?
- Did the facilitators understand the needs of the group?

- What specific situation that had an impact on you can you remember from the group?
- What was it like interacting with other HIV infected women?

3.6. Data analysis

Thematic analysis of data was used. Thematic analysis, according to Holloway and Todres (2003), should be seen as a foundational method for qualitative analysis. They identify thematising meanings as one of the few generic skills that cuts across qualitative analysis. Roulston (2001) claims that thematic analysis is compatible with both essentialist and constructionist paradigms. Braun and Clarke (2006) claim that thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data.

They further claim that it minimally organises and describes your data set in rich detail. These authors believe that, because thematic analysis does not need detailed theoretical and technological knowledge of approaches, it can offer a more accessible form of analysis, particularly for those early in a qualitative research career. They therefore claim that thematic analysis can be a method that works both to reflect reality and to unpick, or unravel, the surface of reality.

The data was read over and over again and then it was categorised (Spiggle, 1994). Categorisation is the process where data is labelled and classified according to themes. These themes were analysed according to what they mean for the process. According to Boyatzis (1998), the researcher in this process should be flexible and

open to the possibility of perceiving patterns. Furthermore, he claims that this openness must be sustainable, which requires long hours of being immersed in information processing and analysis before the data is even analysed.

In a discussion of what counts as a theme, Braun and Clarke (2006) argue that a theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set. They claim that it is not how many times a theme is repeated, both in terms of space within each data set and prevalence across all data sets, that determines whether or not a specific theme will count as a theme. It is its relevance and whether or not it captures something important in relation to the overall research question that will qualify a set of statements as a theme.

The interpretations of group process by the facilitators were analysed using the therapeutic characteristics of group therapy of Yalom (1995) described in Chapter 2. The participants' responses were read and themes were identified, as described by Braun and Clarke (2006). These were written down and coded according to the therapeutic characteristics derived from Yalom (1995). Data triangulation was also used in order to assure completeness of findings. It also assisted in describing how the findings occurred under different circumstances and therefore assisted to confirm the validity of the findings.

3.8. Ethical considerations

Participants recruited at the clinics were informed about the project and signed consent forms to participate voluntarily in the groups. They participated in the process

of setting ground rules for the group. Confidentiality, respect, and participation by all emerged as rules to be observed by all group members. Consent also included participating in personal interviews after the support groups. Confidentiality, i.e. making sure that the names of the participants were not to be divulged, was taken into consideration during the conducting of this research. This also included ensuring that the documents from the research process were locked up safely. Women were remunerated by providing them with transport money to be able to attend the sessions. They participated in the research voluntarily. The research processes of the larger Serithi project were approved by the Ethical committee of the Faculty of Health Sciences, University of Pretoria and this analysis was approved by the Ethical committee of the Faculty of Humanities, University of Pretoria.

The next chapter presents the results of the data analysis.

CHAPTER 4

PRESENTATION OF DATA AND ANALYSIS

4.1. Introduction

This chapter will present the research results of the qualitative data analysis process. The themes will be presented as they emerge from the process notes of the facilitators and interviews done with the participants after participating in the support groups. In this section, the responses of the women to the interviews will be given for each theme and the analysis of the facilitators' process notes will follow thereafter.

4.2. Participants' experiences of the support groups

The experiences of participants were obtained through the interviews after participating in the support groups. The women's responses were analysed in terms of criteria outlined by Yalom (1995). The women who participated in these groups ranged from twenty to thirty-five years of age. At the time of participation in the groups they resided in Mamelodi and Atteridgeville townships. Themes from the women's responses were the following:

4.2.1. Theme 1 – Altruism

Women indicated that they gave and received assistance in the support groups and that they benefitted from altruism as part of the group process. Examples of experiences of altruism are the following:

They (the other group members) were all equally helpful. I learnt a lot about HIV and living positively (woman from Atteridgeville)

I realised that some people had more problems than I did. I also realised that I had to enjoy my life and live positively but also help others (woman from Atteridgeville)

I learned about how I should live my life and also the group helped me to accept my status (woman from Atteridgeville)

The quotes above show that these women appreciated both the help they received and what they learnt from others, as well as their desire to help others. This theme - as part of group processes - seems to manifest itself as one of the therapeutic processes that assisted the women in the support group experience.

4.2.2. Theme 2 – Group cohesiveness

The participants showed strongly that this theme was prevalent in their groups. The quotations below are from the women themselves, illustrating how cohesive their group had become and the fact that group cohesion made it easy to disclose very personal information to each other.

At first it was difficult and as time went on we got used to each other and we became friends in the process (woman from Atteridgeville)

It felt like I was part of a new family (Woman from Atteridgeville)

After listening to their stories I was encouraged to disclose to at least one person when I got home (woman from Mamelodi)

I realised it was easy to talk about my status with other women who were in the same situation as me (woman from Atteridgeville)

4.2.3. Theme 3 –Universality

Universality - as discussed above - refers to the fact that members of the group come to realise that their problem is not unique and that there are other people going through similar circumstances. It emphasises the feelings of not being alone. The majority of the women felt that the realisation that others experience similar problems was therapeutic. Indeed, this is one of the most therapeutic processes observed in the support group experience.

I was strengthened because I could see that I was not alone (woman from Atteridgeville)

It was very good because I understood that I'm not alone in this (woman from Atteridgeville)

I initially thought that I was the only one, so finding others helped me to be able to share my experiences and we looked forward to attending support group and some of us knew each other, but didn't know our status My neighbour is also a Serithi client and I met her there in the support group (woman from Atteridgeville)

It felt good because I was with people who understood what I was going through (woman from Atteridgeville)

4.2.4. Theme 4 – interpersonal learning – input

Interpersonal learning as a theme also manifested itself in these groups. Through the experiences of others, they learnt how to disclose their status to significant others, how to live with HIV and how to deal with stress. Women also earned the acceptance and support of other women, which contributed to their regaining self-esteem and helped them to accept their HIV status. The session on life maps proved itself as the

session that helped women considerably in learning from each other. On a count of the number of women who made a comment on the mind maps, most of the women said that the mind maps session was very helpful in their learning from others. This theme featured very strongly in these groups and could be noted as an important therapeutic process that assisted the women. The following statements support the above:

I gained a lot of support that helped me cope and accept my status (woman from Atteridgeville)

I gained a lot of things (from others) that helped me to accept my status (woman from Atteridgeville)

Mind maps – This helped me realise who I am and celebrate my difference and that I’m special, being made different from others (woman from Atteridgeville)

I gathered that I should trust myself, believe in myself, not to look down on myself and how to live a positive life – live like any other person (woman from Atteridgeville)

A look back at my life when we made drawings of our past history gave me an idea of how I might have contracted the virus. Also disclosing helped to be free about the idea of disclosing or talking about HIV (woman from Atteridgeville)

It was good because one can always learn something from people who are in the same situation as me (woman from Atteridgeville)

4.2.5. Theme 5 –Interpersonal learning – output

This theme refers to individuals’ ability to improve their interpersonal skills. Individuals may learn to trust other people and they may also learn to deal with conflicts with other people. This theme did not often emerge from the women’s responses. A few statements illustrating this theme are given below:

*There was a lot of respect, loving and caring for each other, having a feeling of dignity
(woman from Atteridgeville)*

*I learned that a HIV+ person is a human being just like others. I also learned about
love, respect and understanding each other (woman from Atteridgeville)*

4.2.6. Theme 6 –Guidance

Guidance as a theme was also common to these groups. Guidance refers to how the group members are able to advise one another on dealing with problems in their own lives. This can be done in the form of suggestions or advice from a member who has had the experience. Women were able to advise each other on how to deal with HIV, which helped them in making valuable decisions such as whether to breastfeed or not. This helped them think less about HIV and it comforted them. They also made friends. Below are statements of the participants that illustrate this:

*I found it better because we were giving one another advice, comforting each other.
You always find yourself happy and thinking less about HIV (Woman from
Atteridgeville)*

*Disclosure – not being afraid to disclose. When I need help – I was given direction to
go. Information on CD4 count, Nevirapine (woman from Atteridgeville)*

*We would make friends, talk about our problems and give each other support and
advice (woman from Atteridgeville)*

I got comfort and advice (woman from Atteridgeville)

4.2.7. Theme 7 –Identification

This refers to the fact that individuals in the group may try to be like someone [else] in the group. This can help members to improve by emulating good mannerisms that a group member feels are good. Below is a statement from a participant supporting this theme:

*Some women in the support group were strong, so I felt like I wanted to be like them
(Woman from Atteridgeville)*

4.2.8. Theme 8- Family re-enactment

Family re-enactment refers to the fact that group members would express experiences that make them feel like they are with their own families in the group. This helps members to be able to help themselves understand some old “hang-ups” (problems etc) that they had with their own families. This theme did not show itself strongly in the support groups, since the groups did not focus on inter-personal dynamics, but rather on coping with current relationships. There is only one statement that shows something of this theme in the groups. It could be an indication that participants’ families were not as supportive as the support groups. Below is a statement from one of the group members illustrating that fact:

It was very good because we were joking and laughing together, we were always happy to attend. I was feeling like I’m having my own family (woman from Atteridgeville)

4.2.9. Theme 9 –Instillation of hope

This theme helps members to know that they have similar problems to other people who have solved these problems before. Women learnt from other participants who had been infected with the disease longer that it is supposedly possible to live. The future planning session also helped the women realise that they still needed to plan for the future, which gave them hope that they still had lives to live. Below are statements in support of this from the participants:

Future planning session; It helped me to plan for the future of my children, to look back and see how I got infected and most of all to move on with my life (woman from Atteridgeville)

Their experiences of living with HIV and how they got infected with the virus motivated me and gave me the strength to go on and stop worrying about my status (woman from Atteridgeville)

I realised that AIDS is not written on a person's face, I saw that people can live with AIDS and there are people more healthy than me (woman from Atteridgeville)

It was good, I felt that I am not alone, there are also others living with this virus and they are managing it fine and I realised that I can also live a long life (woman from Atteridgeville) .(role modelling, creating hope)

4.2.10. Theme 10 –Existential factors

Existential factors refer to the fact that members learn to understand that ultimately there is no escape from some of life's pain and from death. Members learn to understand as well that, no matter how close they may get to other people, they still

need to face life alone. It refers to the recognition that, ultimately, no matter how much guidance they may get from other people, they still need to take responsibility for themselves. Women came to realise that HIV is a reality in their lives with which they had to deal. They had to learn from it but, most importantly, they still had to move on. Below are statements that support this:

It was interesting because I realised that having HIV was not a mistake, many people are infected (woman from Atteridgeville)

It used to worry me as to why I was HIV+ and they explained that anybody can get infected and that everybody is at risk (woman from Atteridgeville)

Some of Yalom's therapeutic processes emerged frequently in these groups and some did not. The following themes were very prevalent in the groups: altruism, group cohesiveness, universality, interpersonal learning–input, guidance, identification, instillation of hope and existential factors. The process that did not show up much was family re-enactment. An in-depth discussion of these processes follows in the next chapter.

4.3. Analysis of the facilitators' process notes

The process notes of the four facilitators who conducted the ten support groups were analysed. Two of the facilitators facilitated three groups each, while the other two facilitated only two groups. Each group participated in ten sessions over a period of ten weeks. This results in process notes for ten groups and ten sessions per group for analysis. The facilitators of support groups wrote process notes after each group

session. The process notes presented an outline of the session, the content and the process of group interaction, as well as the difficulties and how they were handled.

Below is a discussion of the facilitators' impressions of the group interaction of the groups they facilitated. These will be discussed under the same themes that the participants' responses were discussed.

4.3.1. Altruism

In responding to how women helped each other, one facilitator made the observation that women helped one another with how to disclose their status to significant others:

In this process of helping each other with their stories, it also emerged that getting magazines and watching TV on issues regarding HIV helped them disclose to the people they wanted to disclose to (MA facilitator).

4.3.2. Group cohesiveness

Cohesiveness in the groups developed, especially after the fourth session, where the focus was on the sharing of the emotional experiences of having HIV. The facilitators described this session as a catalyst in the groups that paved the way for sharing of emotional experiences. The statements below attest to that:

The bond between the group is increasing as the women feel more reluctant to leave immediately and are still visiting after the meeting (Masters students facilitator)

The women really enjoyed this ice-breaker and it really facilitated the group's connection to each other (Masters Student facilitator).

I think this session was really productive in the sense that it allowed the women to really bond through sharing experiences (Masters student facilitator) (this comes from the session on life maps)

The women were all very active in the discussions. Even A who is usually not very talkative was very active and shared a very sensitive problem with the group. This is probably indicative of a sense of openness and trust that has been created within the group (Masters Student facilitator).

By talking about her problem and sharing it with the group, D had the opportunity to get the problem off her chest and the group offered her “advice” regarding how to deal with the situation and take care of herself (Masters student facilitator).

4.3.3. Universality

Universality refers to the realisation that there are other people with similar problems. The facilitators noted universality as an important theme. They observed that women got to feel that they were not alone in dealing with HIV. As a therapeutic process, this assisted women in dealing with HIV. Here are some of their observations:

Through talking to each other they knew that they are not alone. (HIV+ facilitator)

She said that she now feels that she is not the only person in the world with HIV (Masters Student facilitator.)

4.3.4. Interpersonal learning - Input

The facilitators commented on the interpersonal learning that they observed in the groups. The example of some of the women helping others to get the courage to disclose their status has already been given. Here are some of the observations:

On reflecting on the session, the new member S said that she now feels that she will disclose to her loved ones because she has not yet told anyone about her status. Thus, just by listening to the other women's stories, she felt empowered and motivated to share her status with those that she loves (Masters student facilitator)

Last week X said that she felt like she would be able to disclose to someone after hearing the other women's stories (MA student facilitator)

4.3.5. Interpersonal learning – output

This theme refers to the ability of individuals to improve their interpersonal skills. The facilitators observed that participants were able to trust one another with very personal information they would not share with just anyone. They have learnt to trust others, to accept others and to express their feelings in interpersonal relationships. A facilitator wrote:

E was now in a place where she could talk. It has been encouraging to see how E has transformed over the weeks from feeling insecure to becoming the centre of the group with her stories. The anger and distance which were there in the beginning have

slowly been replaced by confidence and a sense of worth. So many people comment on her experiences and this has helped her to blossom (Masters student facilitator)

The group's coping strategies were mainly problem focussed so, with D's example of her difficult neighbour, we explored what else she could do to prevent the woman from stressing her out. The group themselves came up with the idea of her ignoring her and for D to prevent herself from even thinking or caring about the lady's views towards her (Masters student facilitator)

4.3.6. Guidance

Guidance refers to how the group members were able to advise one another on dealing with problems in their own lives. The facilitators noted how members advised one another on various issues. One woman who had given birth the previous week advised the others who were still pregnant how to take their medication before childbirth to protect their babies. Women also advised one another on raising their children to change gender role perceptions in future generations:

Their solution was both boys and girls should be expected to perform similar tasks, e.g. cleaning, cooking, washing dishes etc. so that boys would be able to help their wives when they got married or just be able to take care of themselves when they grow up. The emphasis was on starting to change child rearing practices so that men and women are reared to accept flexible gender roles that allow for men and women to really be partners and share tasks and responsibilities (Masters student facilitator).

4.3.7. Identification

This refers to the fact that individuals in the group may try to be like someone in the group. This was observed in the group:

The group responded very well to J and they felt that she is a role model to other HIV positive women. In addition they felt that if she has been living with the virus for seven years now and she is still very healthy, they can live even longer (Masters student facilitator)

4.3.8. Family re-enactment

The facilitators did not observe or note how participants re-enact relationships with their own families. This is probably because their experiences in their families were very different from those of the support groups. This can be therapeutic in itself. It could also be that the facilitators did not observe such behaviour because there was no focus on this in the groups.

4.3.9. Instillation of hope

The facilitators noted the presence of this theme:

They felt inspired by the people who had discussed their life maps (Masters student facilitator).

4.3.10. Existential factors

Here the facilitators made an important observation, where participants were asking whether having HIV could be God's will for them.

Member asked at end of session if it was God's will for them (Masters student facilitator)

4.4. Summary

The facilitators thus observed aspects of many of the therapeutic principles in the groups. Most significantly, the facilitators noted the development of the processes as the groups progressed. The processes above show that the following, namely: altruism, group cohesiveness, universality, interpersonal learning (both input and output), guidance and identification were very prevalent in the groups. Instillation of hope and existential factors were also observed, but very minimally. Family re-enactment did not emerge at all - as far as the facilitators' process notes indicate. An in-depth discussion of these processes follows in the next chapter.

CHAPTER 5

DISCUSSION OF RESULTS

5.1. Introduction

In this chapter, the results presented in the previous chapter will be discussed. This study undertook to find out what is therapeutic in support groups of women living with HIV. As noted in the methodology chapter, the research identified to what extent the therapeutic factors of group therapy, identified by Yalom (1995) were present in the interaction in the support groups. Of the 11 factors, ten themes manifested themselves in the support groups being studied here, some to a greater degree than others. One of them did not really emerge from these support groups at all. The findings are discussed below.

These therapeutic processes started to become manifest in the groups mainly from the fourth session, when psychological content was introduced. As discussed in the methodology chapter, the group sessions were structured around the needs identified in interviews done with pregnant women living with HIV in the first phase of the project. A manual, which addressed the following themes, was developed based on the needs identified:

Sessions 1-3 – Facts about HIV and pregnancy; prevention of mother-to-child-transmission.

Session 4 - 5 Emotions, experience and the meaning of being diagnosed with HIV. This was done through drawing and discussing each participant's life map.

Session 6 - HIV, disclosure and stigma

Session 7 – Coping, problem solving and stress management

Session 8 – 9 HIV and relationships, human rights and stigma

Session 10 - Life planning and goal setting: socio-economic survival and decision making.

5.2 Prominent therapeutic processes in support groups

The following processes were prominent in the groups: altruism, group cohesiveness, universality, guidance, interpersonal learning–input, interpersonal learning–output, guidance and identification. Indeed, these themes started to appear interchangeably after the third session. The first three sessions dealt mainly with the factual information about HIV/AIDS, although women shared some experiences. Corey and Corey (1997) argued that the first few sessions form part of the initial stage, where members are often reluctant to participate. They may not trust other members in the group and may also be unable to demarcate their roles within the group. The fourth session may have proven to be the beginning of the working stage. According to Corey and Corey, (1997) the working stage is characterised by group cohesion and high levels of trust. There are also open communication and an accurate expression of emotions and experiences. The members are willing to risk threatening material and conflict is recognised and dealt with effectively.

This is the environment that encourages therapy within groups. The process notes started recording these processes from the fourth session. This was the session that dealt with emotions and the group members seemed to have started opening up from this session onwards. These processes, such as altruism, universality, interpersonal

learning, guidance and identification could have also been prevalent because they involve relating to one another.

5.2. 1. Altruism

In essence, altruism has the potential to restore one's self-esteem. Looking at these women's backgrounds, feeling important because one is helping others can be therapeutic in itself, since - as discussed above - HIV affects an infected person's self-esteem (Watstein & Chandler, 1998). Altruism was present in these groups and was one of the therapeutic aspects contributing to women developing a realistic perception of themselves and overcoming their focus on their own problems. This was noted in the participants' comments after the support group and the facilitators' notes.

5.2.2. Group cohesiveness

HIV is a highly stigmatised disease because of its mode of transmission and it generates fear because it is incurable. An HIV diagnosis often results in people feeling isolated and blaming themselves for getting the disease (UNAIDS, 2005). Being accepted in a group can therefore be a helping factor. The facilitators noted that group cohesion formed, especially after the session of emotional sharing. The growing cohesion encouraged women to share their feelings in a safe environment where everybody was understood. This proved to be therapeutic for the women, as they said it made them feel proud and less stressed. They also claimed to be able to make new friends.

5.2.3. Universality

The women in the support groups claimed to experience universality. They realised that they were not the only ones going through this experience. This strengthened them, gave them confidence to live and gave them hope.

5.2.4. Interpersonal learning – input

Modelling

Here the women learnt a great deal from each other and this helped them to cope better with the disease. It also helped them deal with their self-esteem issues and encouraged them to be able to live more positively.

There was no pointing out of mannerisms that were irritating to others. There could be numbers of explanations for this. It could be that nobody had irritating mannerisms, or that members were concentrating too closely on dealing with their HIV issues to care about things like that. There could also be cultural factors at play. In the nothing, it is an offence to tell people about their mannerisms to their face. One would have to further study this aspect further to find the explanation.

5.2.5. Interpersonal learning – output

This theme refers to the ability of individuals to improve their interpersonal skills. The women learnt to develop the trust in each other to be able to reveal sensitive information about themselves, resulting in personal growth experiences.

5.2.6. Guidance

The women gave each other advice on issues relating to HIV, childbirth and issues of breastfeeding, which is therapeutic, in that it helps women make decisions based on knowledge, thereby relieving stress on the pregnant women. This also helps them with regard to future planning, as they wanted to ensure that their children were safe.

5.2.7. Identification

Women looked up to some of the women who were strong. They identified with them and wanted to be like them.

5.3. Processes that appeared occasionally

Instillation of hope and existential factors are two processes that were occasionally but not extensively manifest. These also emerged after the groups had started in the working stage. The session of future planning assisted considerable in the manifestation of the instillation of hope process. Members shared how it made them understand that having something to live for and a plan of how you would accomplish it prolongs life. It also gave them hope for the future.

5.3.1. Instillation of hope

The women showed that they benefitted from the sessions and specifically from the future planning sessions. These sessions gave them hope that they were still going to live longer and that they had need to plan for the future. They also benefitted from

seeing women who had recently delivered their babies coming to the sessions with their babies and they could see they had a chance of delivering healthy babies. Also, the women who had lived with HIV longer helped instil hope in the newly diagnosed women. This in itself helps members, in that it shows that the fear of dying with which many of them live is a misleading distortion of the truth.

5.3.2. Existential factors

Participants came to understand that everybody is at risk as far as HIV is concerned. The life maps seemed to help them look back over their lives and learn to live with the disease. The facilitators also made a very valuable note here, in terms of the participants asking whether it was God's will for them to be infected.

5.4. Processes that did not take place

Family re-enactment did not emerge as an issue in these groups. This could have been because the groups were support groups focussing on support and information and did not use a psycho-dynamic frame of reference, which was not a feature of the group interaction.

5.4.1. Family re-enactment

As above, family re-enactment did not prove to be prevalent in these groups. This could be because the women felt more accepted in the groups than at home. This was also not the focus of the group and no-one was specifically trained to be aware of this.

The focus of the intervention was on providing information, psycho-education and support amongst women and not in intra-psycho processes.

5.5. Conclusion

The aim of the research was to uncover and identify the therapeutic elements in support groups. Process notes of support group sessions and the responses of participants were used to identify which of the therapeutic elements of group psychotherapy are present in these groups. The women who participated responded that they regarded the groups as being therapeutic for them. The facilitators also observed that the groups helped the women develop - from being in a state of shock to acceptance of their status - because of their diagnosis.

A process of growth was observed in these women through their participation in the groups. Some of them were able to disclose to other people because of the assistance they received in the groups. Some of them received information that helped them make valuable decisions for the benefit of their babies. Indeed, just to be able to talk about the disease with people who understood was therapeutic for them. The acceptance they received from fellow group members was most helpful.

Based on this study, one can safely say that support groups for women living with HIV are therapeutic and that people who participate in support groups stand to gain something positive for themselves. Participants in these support groups were able to rebuild lost self-esteem, gain information, deal with stress, disclose to people outside the support group, make friends, become motivated to move on with life, be strengthened and generally enhance their well-being. This was possible because of

the effects of therapeutic processes such as universality, group cohesion, altruism, interpersonal learning, guidance and instillation of hope being present in these groups.

5.6. Limitations to the study

Although information has been gained with regards to support groups for women living with HIV, this study had its own limitations. It focused on groups of African women living with HIV. These women were from lower socio-economic backgrounds and had low educational backgrounds. The results can therefore not be generalised as being applicable to other types of support groups or other members of the population as a whole. Another limitation is that these inferences are built on the interpretations of the group facilitators and the experiences of the participants. The facilitators wrote their process notes after each session. These notes represented their perception of what happened in the groups. There are obviously things they could have missed. They could also have emphasised things, based on their own experiences and expected outcomes.

In the analysis, the perceptions of facilitators and responses of the participants were interpreted according to the frame of reference of the researcher. Though steps were taken to assure validity of interpretation, the interpretation of qualitative data is a subjective process and could have been interpreted differently from another frame of reference (Babbie and Mouton, 2002).

5.7. Recommendations

It is recommended that, for future research, the study includes a wider spectrum of the populations in terms of race, economic background and educational background. The study can assist in the development of guidelines for support groups, since the provision and monitoring of such groups have proven to be effective in assisting people dealing with HIV. This research assists in the understanding of what happens in support groups and why they are effective in helping people. It can also be used to develop support groups further as a method of intervention.

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