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# The Effect of Support Groups on AIDS Patients

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THE EFFECT OF SUPPORT GROUPS  
ON AIDS PATIENTS

By

Karen Bouwman

A Thesis

Submitted to Grand Valley State University

in partial fulfillment of the requirements

for the degree of

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## ABSTRACT

### The Effect Of Support Groups On AIDS Patients

By

Karen J. Bouwman

The purpose of this study was to answer the following question: Will individuals with HIV/AIDS have the same or decreased levels of anxiety and hopelessness after participating in a support group? A one-group pretest-posttest design was used. A convenience sample consisted of 40 persons with HIV/AIDS attending a large support group which met on a weekly basis. Spielberger's State Anxiety Inventory (SAI) and Beck's Hopelessness Scale (HS) were administered to the participants. Six weeks later, the HS and SAI were repeated. A Social Support Inventory was also given to assess the subject's perceived satisfaction with the support group. Based on House's stress paradigm, it was hypothesized that levels of anxiety and hopelessness would not increase after participating in the support group. Fifty percent of the subjects were satisfied to totally satisfied with the support from the group. Anxiety levels remained stable while hopelessness scores decreased (paired  $t = 2.13$ ,  $p = .04$ ).

## Dedication

This thesis is dedicated to my husband Nick, whose continued love, support and encouragement were essential to the completion of this project

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## CHAPTER 1

### INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) is a life threatening condition characterized by severe and irreversible damage to the cell-mediated branch of the immune system. Human immune deficiency virus (HIV) is the virus which causes AIDS. The HIV virus infects the T4 lymphocyte. The T4 lymphocyte has the major role in the immune system of inducing every other immune function. By selectively infecting T4 cells, the virus damages the cells which would normally organize a defense against its spread. The progressive infection and destruction of T4 cells is the basis for the immunologic abnormalities seen in AIDS (Grady, 1989). The diagnosis of AIDS is made when an HIV positive person exhibits one or more of the opportunistic infections associated with AIDS. There is no cure for AIDS, and the treatment to date is aimed at delaying the conversion from HIV positive to AIDS. According to Wicher (1993), there are an estimated 1.5 million people infected with the HIV virus in the United States. The five year survival rate for a person diagnosed with AIDS is 15%.

The only known method of transmission of the HIV virus is direct contact with blood or body fluids. There are five groups of people at risk for HIV/AIDS. They



are: (a) sexually active homosexual men with multiple sex partners, (b) present or past abusers of intravenous drugs, (c) patients who have been transfused with blood or blood products before 1985, (d) heterosexual partners of persons with HIV/AIDS, and (e) hemophiliacs (Grady, 1989).

AIDS typically affects individuals in the prime of life. Diagnosis of HIV/AIDS often forces public confrontation of behavior which was previously private. Persons with HIV/AIDS are at risk for developing psychological symptoms. When psychological issues are not resolved by individuals with HIV/AIDS, symptoms such as sadness, hopelessness, anxiety, withdrawal and isolation are likely to occur (DiPasquale, 1990). Support groups help individuals with HIV/AIDS cope with complex psychological issues.

Although improving, research to date is minimal on the actual effects support groups have on individuals with HIV/AIDS. The purpose of this study is to determine whether individuals with HIV/AIDS have decreased or constant levels of anxiety and hopelessness after participating in a support group. This study is a partial replication of a study conducted by DiPasquale (1990).

## CHAPTER 2

### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

#### Literature Review

The purpose of this section is to present a review of the current literature related to the psychological aspects of HIV/AIDS.

Responses to AIDS. Bennett (1990) studied the experience of stigmatization with AIDS patients. Using a qualitative design, she interviewed 10 homosexual men. Participants were asked open-ended questions regarding their relationships, changes in self-esteem, and examples of prejudice and discrimination. Two prevalent themes emerged from the study: rejection and self-protection. Rejection occurred both from family and friends. Self-protection was a strategy used to buffer the rejection.

Nokes and Carver (1991) used Parse's (1981) theory of man as a conceptual framework in a study of 14 men hospitalized with AIDS. A qualitative descriptive design was used to explore the meaning of life. Three themes arose from the study: (a) an abrupt shift in patterns of being gave rise to changing priorities, (b) fluctuating possibilities arose in the unpredictability of being with

and away from close others, and (c) changing hopes and dreams surfaced from the insights of suffering.

Korniewicz, O'Brien, and Larson (1990), designed a study to compare the aspects of psychological adaptation (self-concept, self-esteem, alienation and social functioning) among 63 adults who were HIV high-risk, HIV positive-asymptomatic, early stage AIDS, and late stage AIDS. There were no significant differences among the four groups for self-concept, self-esteem, or social functioning. The asymptomatic and the HIV high-risk groups had significantly higher alienation scores than the other two groups. The authors suggest that the high-risk and HIV positive groups were reacting to a new or potentially new diagnosis. They were in a crisis state, accounting for the higher alienation scores.

Effects of Support. Several authors have described the effectiveness of support groups on persons with chronic illnesses. Yalom (1975) described several curative factors that have healing effects in support groups; (a) installation of hope; (b) universality, a sense of lessened isolation; (c) altruism, helping others to help oneself; (d) catharsis, expressing one's feelings to move beyond the pain; and (e) existential factors, where the purpose of life is questioned and often takes on new meaning. Liebermann and Borman (1979) list four reasons for attending

support groups: (a) the group fulfills services not currently met by other systems, (b) the support group offers greater access unavailable through other resources, (c) the group is accessible and offers a necessary resource, and (d) the group offers a specific service that meets that individual's needs.

Bauman, Garvey, and Siegal (1992) examined the effects of participation by 154 cancer patients in two support groups. Self-report and follow up interviews were the data collection methods used. Social support was measured by reported size of the friendship network, reported emotional support, perceived adequacy of support, and intimate ties. The Family Environment Scale was used to measure emotional support within the home. Social support had a complex relationship to participation. Patients with inadequate social support were especially likely to participate, but patients with high scores on family support were most likely to attend the group. Those who needed the group the most were less likely to attend. Major motivations for attending support groups were to enable social comparison, and to obtain informational support and self-help.

Feather and Wainstock (1989) examined demographic and social network variables which related to social support. Breast cancer patients who had a mastectomy within the past 24 months responded in a self-report questionnaire

(N=613). The authors noted that breast cancer patients who participated in organized support groups indicated that they maintained or increased a positive self-concept and felt that they had more control over their own health. The authors also noted that most sought out the group to feel that they were not alone.

There are a few studies that focused on support groups for AIDS patients. Donlou, Wolcott, Gottlieb and Landsverk (1985) used a descriptive method to study the influence of social support on psychological well-being of patients with AIDS. The sample consisted of 21 homosexual or bisexual males diagnosed with AIDS. Social support, self-esteem, mood state and psychosocial needs were measured using The Profile of Mood States (POMS) (Weisman, Worden & Sobel, 1980), The Simmons Scale (Simmons, Klein, & Simmons, 1977), The Resources and Social Support Questionnaire (Meyers, 1982), and The AIDS Psychosocial Questionnaire (Donlou, 1985). The patients manifested marked mood disturbances, and one-third reported low self-esteem. In addition, they reported diminished social interactions and profound psychosocial stress.

In a case study involving 5 women with HIV/AIDS, Ribble (1989) found that support groups empowered clients, providing them with a place to go for unconditional acceptance. The women were interviewed at length using open-

ended questions. The author facilitated the support group She described, in detail, cases where support groups had an impact on patients' lives. The author described the process of facilitated empowerment to improve quality of life in her clients.

Ramsey (1990) studied the effect of peer group participation on an individual's ability to adjust to the influence of stress related to uncertainty and illness. A non-random sample of 95 subjects with asymptomatic and symptomatic HIV infections participated in the study. A quasi-experimental design was used. There were no significant differences in the adjustment scores between participant and control groups. However, there were significant differences in the scores between the asymptomatic and symptomatic groups. The findings suggested that community support groups were most effective for those who were symptomatic for HIV infection.

In a study of 60 male homosexuals attending an AIDS support group, Bolles (1988) examined the variables of social support, anxiety, and coping styles among three groups. Norbeck's Social Support Questionnaire (Norbeck, 1981), The Taylor Manifest Anxiety Scale (Taylor, 1953), and the Revised Ways of Coping (Vitaliano, 1985) were used in data collection. The groups were: (a) the worried

well- individuals who were asymptomatic with HIV status positive, negative, or not known, (b) individuals with AIDS-related-complex (ARC), and (c) individuals with AIDS. The findings indicated that the mean anxiety level for the three groups was the same. Lower levels of social support were seen in the ARC group than in the other two groups. No difference was seen in coping styles among the groups. The term ARC, an outdated and often ambiguous term used to indicate "pre-AIDS", is no longer used.

Turner, Hayes, and Coates (1993) examined the determinants of social support among gay men in the context of AIDS. A probability sample of gay men living in San Francisco was used for the study (N=1034). The authors used two waves of data: cross sectional and longitudinal analysis. The effects of five sets of factors (demographic, community integration, AIDS- related loss, individual satisfaction, and health) were correlated to satisfaction with three types of support (emotional, informational, and practical). The findings indicated that those most in need of support tended to be least satisfied with the support they received. Families appeared to have the potential to be particularly helpful or especially harmful to gay men trying to cope with AIDS.

Kendall (1992) explored the views, meanings, and perspectives of male homosexuals who sought help from each other in community support groups. Twenty nine participants were obtained by self-referral. The researcher used a qualitative design to generate an understanding of support groups for male homosexuals with HIV infection. The author made recommendations to foster a higher sense of well-being for individuals with HIV infection through use of HIV support groups.

DiPasquale (1990) studied the effect that participation in support groups had on levels of anxiety and hopelessness in individuals with AIDS. Subjects in the study were volunteers from three support groups. The groups included: (a) 11 men with classic AIDS, (b) 6 men with AIDS or ARC, and (c) 5 minority women with AIDS or ARC. Two questionnaires dealing with anxiety and hopelessness were administered as a pretest and again as a posttest 5 weeks later. Additional demographic data obtained by use of a questionnaire included age range, gender, marital status, previous attendance in a support group, length of attendance in the current support group, and length of time since AIDS diagnosis. The support groups were led by different facilitators. The hypothesis of the study was not



supported: pretest and posttest data were not significantly different for the three groups.

Because of the nature of the spread of AIDS, early studies targeted very specific population groups, primarily men. There were no studies found that focused on support groups for a heterosexual population. The changes in the terminology used in defining ARC versus HIV positive make future replication and comparisons difficult. The research to date has involved small, convenience samples with little control over variables.

Psychological issues which occur with HIV/AIDS are discussed in all of the studies. All of the studies infer a process of psychological adjustment. In the latter studies described, the benefits of support groups are explored. The relationship between social support and anxiety, coping, and hopelessness are predominant recurring themes. To date, the research is inconclusive. More research is needed in this area.

#### Conceptual Framework

House (1981) developed a paradigm of stress reaction that is helpful in understanding the relationship between social support and adjustment to illness. According to House, the relationship between stress and health outcomes is

affected by factors such as social support and individual perceptions. Stress occurs when the demands of a situation exceed the ability to handle certain events. House postulates that social support can counterbalance the negative effects of stress by enabling the individual to perceive an event as less stressful, facilitating the coping efforts, or by lessening the degree of reactivity of the individual to the stressor.

The diagnosis of HIV/AIDS is a stressful event. Anxiety is one of the most common behavioral manifestations observed in AIDS patients (DiPasquale, 1990). Hopelessness, an overall negative expectancy regarding the future, is also common. The diagnosis and disease progression associated with HIV/AIDS forces the individual to seek support from family and friends. Adequate support promotes coping and reduces the reactivity of the perceived stress of the situation, thereby reducing anxiety and hopelessness (House, 1981). Therefore, even if a situation is perceived as stressful, social support can lessen the response to the stressor. Individuals attend support groups when their support systems fail to meet their psychological needs. Support groups can provide the social support which is often lacking with HIV/AIDS patients.

The individual with HIV/AIDS is experiencing a stressful event. If he does not receive the social support he needs from his friends or family, he will seek it from other sources. Social support and/or support groups can decrease the perception of stress, enhance coping efforts and/or decrease the reactivity of the individual to the stressful event. This results in improved adjustment. Because of the terminal nature of AIDS, members of a support group may not have decreased anxiety and hopelessness, but they should be able to maintain their current level. Ideally, anxiety and hopelessness scores would decrease. However, because the disease progression is relentless, constant scores are considered acceptable.

The hypothesis to be tested in this study is: Individuals with HIV/AIDS will not experience increased levels of anxiety and hopelessness after participating in a support group.

#### Definition of Concepts

HIV/AIDS patient: Any individual who is infected with the HIV virus. For this study, it is assumed that anxiety and hopelessness occurs for HIV positive individuals and individuals with AIDS. Therefore HIV/AIDS is used synonymously.

**Social support:** The perception and interpretation of contributions of significant people in a person's life who provide needed information and help, convey caring and a willingness to listen, and affirm the individual's efforts to cope with the stressful situation.

**Anxiety:** An unstable and variable combination of interacting fundamental emotions (Spielberger, 1972). Spielberger describes state anxiety as a temporary condition that fluctuates over time in response to situational change.

**Hopelessness:** A state of despair characterized by a negative view of the self, a negative view of present functioning, and a negative view of the future (Beck, 1974).

## CHAPTER 3

### METHODOLOGY

#### Design

In this study, a one group pretest-posttest design was used to compare levels of hopelessness and anxiety before and after participation in a support group for persons with HIV/AIDS. This study was based on the assumption that what subjects gained from participating in the group would be positive and directed toward meeting their needs for social support. Perceived value of the support group was measured to validate this assumption.

The sample consisted of persons attending a support group at a local clinic. Subjects met the following criteria: (a) HIV positive, (b) able to read and write English, and (c) no history of psychiatric illness or HIV dementia, by self-report. A convenience sample of 40 men who met at least four times in a six week period was used. It was assumed that consistent attendance was important to justify the hypothesized relationship between the support group and the outcome variables. The sample size was limited by the size of the support group. The major weakness in the design of the study was lack of a control group. Other threats to internal validity included selection, testing and mortality.

## Instruments

The State Anxiety Inventory of the State-Trait Anxiety Inventory (STAI) (Consulting Psychologist Press, Inc., 1983), developed by Spielberger, was used to measure anxiety. It consists of 20 items to assess "how you feel right now at this moment". Items are presented in a counterbalanced order relative to anxiety. Examinees blacken the number to the right of each statement that best indicates the intensity of their feelings right now at this moment: (1) not at all; (2) somewhat; (3) moderately so; or (4) very much so. The scoring keys reverse the direction of nonanxiety items so that a high score suggests high state anxiety. Scores for the State-Anxiety can range from a minimum of 20 to a maximum of 80.

Test-retest reliability coefficients are reported for state scores separately for males and females at 20 days; .54 (males) and .27 (females). State reliability scores are not expected to be stable because state anxiety is a fluctuating condition.

Concurrent validity was established by correlating the scores with The Institute of Personality and Ability Depression Test (IPAT) (Cattell & Scheier, 1963), the Taylor Manifest Anxiety Scale (Taylor, 1953), and the Affect Adjective Check

List (Zuckerman, 1960). For 126 college women, coefficients were .75, .80, and .52 respectively (Spielberger, 1983).

The Hopelessness Scale (HS) (The Psychological Corporation, 1988), was designed by Beck (1974) to measure the construct of hopelessness. The questionnaire consists of a list of twenty statements. The examinee circles true or false next to each statement. The examinees are instructed to answer the statements in terms of how they have been feeling the past week, including the day of the exam. The tool is counterbalanced in terms of negative statements. For every statement, a score of 1 is assigned if the client's response agrees with the key (pessimistic answer). The maximum pessimistic score is 20. Non-matching responses are scored 0 (optimistic answer).

Analysis of internal consistency was done by means of Kuder-Richardson formula 20, which yielded a reliability coefficient of .93. Highly significant correlations between each item and the total HS were found. The item-total correlation coefficients ranged from .39 to .76.

Validity for the HS was determined in several ways. Clinician ratings were established by scoring patients based on assessment of severity of illness. Concurrent validity was determined by comparing HS scores with the Stuart

Future Test, with a correlation of .74. Beck (1974) also examined the relationship between clinical ratings of depression and HS scores. The correlations with the clinical ratings of hopelessness were .74. Construct validity was determined by using it concurrently with The Generalized Expectancy Scale (Minkoff, 1973). The results of the data indicated that the HS is positively correlated with depression. Repeated studies using the HS demonstrated that the HS was a better predictor of suicidal intent than was depression (Minkoff, 1973).

The Perceived Social Support Group Subscale (PSSGS) was developed by Underwood (1986) to incorporate the forms of social support suggested as important by House (1981) and Wortman (1984). The scale measures five dimensions of social support measured on a 7 point subscale (perceived satisfaction with love/caring, affirmation, information, listening, and aid given by salient providers). Thus, possible scores ranged from 4 to 28. Content validity was supported by the literature and by a panel of experts in the measurement of social support. In the development of the instrument, test-retest reliability coefficients for the subscale at a one week interval were computed in relation to groups in the individual's support network. Correlations ranged from .64 to .94 for salient groups. The Perceived Social Support Group Subscale was used in this



study to measure the subjects' perception of satisfaction of support needs by the group. It was assumed that if the subjects valued the support group, it provided further support for the hypothesized relationships.

### Procedure

A large support group for HIV/AIDS patients in a large metropolitan area met for weekly sessions. Volunteers were solicited from the group. In order to promote confidentiality of the members of the group, the facilitator served as the contact person for all data collection. The facilitator was educated in psychosocial counseling and had over six years of experience working with patients with HIV/AIDS. The format of the support groups was open, with no set curriculum for the sessions. Before the support group session began, the facilitator at the clinic where the support group met asked the members if they were willing to participate in a research study. The facilitator described the purpose of the study and briefly explained what would be involved. If the participants agreed, they were asked to sign a consent form (which the facilitator kept in his file for the purposes of confidentiality). After the support group was over, in a separate room at the clinic, the subjects completed the HS and the State

Anxiety Inventory (Appendix D and E). It took approximately ten minutes to complete the surveys.

All subjects completed a posttest of the HS and the State Anxiety Inventory six weeks after the initial date. The subjects also completed the PSSGS which reflected their satisfaction with the support group at the posttest. At that time, the subjects were also asked to complete a demographic questionnaire for the purpose of statistical comparison. Demographic items included age, gender, HIV status (HIV positive vs. AIDS), and the number of sessions the subject had attended in the 6 week interval (see Appendix A). Subjects must have attended at least four sessions in order to remain in the study. All the data collection was done at the clinic with the assistance of the group facilitator. The facilitator aided in confidentiality by keeping the test codes in his/her possession. Human subject approval was obtained before any data collection occurred.

This study was similar to DiPasquale (1990) in several ways. The hypothesis and the instruments measuring hopelessness and anxiety were the same. However, subjects were not involved in different support groups as they were in the DiPasquale study. All of the subjects in this study attended one support group led by the same facilitator. The posttest was given at a 6 week interval, as

opposed to the 5 week interval used by DiPasquale (1990). As suggested by DiPasquale, a greater interval between time-one and time-two testing was implemented in an attempt to improve the significance of the results. A longer interval between the posttest could dramatically increase attrition rates.

## CHAPTER 4

### RESULTS AND DATA ANALYSIS

#### Techniques

Data obtained via the demographics questionnaire was analyzed using descriptive statistics of frequency and percentage distributions. The hypothesis was tested using paired t-tests. The level of significance was established at  $p < 0.05$  level.

#### Characteristics of Subjects

Forty seven subjects were recruited to participate in the research. Seven subjects did not attend the support group a minimum of four times to be eligible for the posttest data collection. Health reasons were described in all seven cases as the reason for leaving the study. There were no significant differences on demographic variables between subjects who dropped out and those who completed the study. The remaining forty subjects met all criteria and completed participation in the study.

All subjects in the sample were male. Age of the participants ranged from 21-51 years, with a mean of 33.5 and a standard deviation of 6.7. Twenty six (65%) of the subjects described their health status as HIV positive. Fourteen (35%)

described their health status as AIDS. Subjects had been in the support group for different time periods, ranging from zero to eighteen months. Although criteria for inclusion in the study required a minimum of four sessions, all subjects attended at least five sessions. Sixteen (40%) of the subjects had attended at least five support group sessions in the six week data collection period. Twenty four (60%) had attended six sessions. The length of time subjects attended the support group is illustrated in Table 1. The length of time subjects had been aware of their HIV status is shown in Table 2. It ranged from three months or less to greater than twenty four months, with the largest percentage falling in the greater than twenty four month range (32.5%).

#### Perceived Social Support Scores

The Perceived Social Support Group Subscale results are shown in Table 3. Total scores were consistent with a perception of being at least somewhat satisfied with the group support. Fifty percent of the subjects were satisfied to totally satisfied with the support obtained from the group. These scores provided evidence that the support group was fulfilling its purpose. Therefore it was not unreasonable to attribute the stability or decrease in anxiety and hopelessness scores to social support provided by the group. There was also a high correlation

between posttest SAI and HS scores and PSSGS scores (0.73 and 0.84 respectively). This correlation further supports the relationship between group satisfaction and hopelessness and anxiety levels.

Table 1

Distribution by Time Attending Support Group

Time	f	Percent
0 - 3 months	3	7.5
3 - 6 months	16	40.0
6 - 12 months	19	47.5
12 - 18 months	2	5.0

Table 2

Distribution by Time Knowing HIV Status

---

Time	f	Percent
0 - 3 months	1	2.5
3 - 6 months	4	10.0
6 -12 months	10	25.0
12-18 months	5	12.5
18-24 months	7	17.5
> 24 months	13	32.5

---

Hypothesis and Research Questions

A mean anxiety level of 50 is considered a moderate level of anxiety (Spielberger, 1983). A mean score of 8 is a moderate level for hopelessness (Beck, 1974). DiPasquale's (1990) mean posttest anxiety and hopelessness scores were 46.77 and 10.88 respectively. The mean scores and standard deviations for anxiety and hopelessness in this study (pretest and posttest) are shown in Tables 4 and 5. There was very little contrast between the pretest and posttest scores in relation to anxiety. There was more contrast with

the hopelessness scores. Two paired t-tests were used to analyze the hypothesis: Individuals with HIV/AIDS will not have increased levels of anxiety and hopelessness after participating in a support group. Anxiety levels were not significantly different at the pretest and posttest times. Therefore the first part of the hypothesis was supported (Table 4). For hopelessness, there was a significant difference (paired  $t = 2.13$ ,  $p = .04$ ). However, hopelessness scores had decreased as shown in Table 5. Therefore, the second part of the hypothesis was also supported.



Table 3

Distribution of Perceived Social Support

---

Value	f	Percentage
17.0	1	2.5
18.0	7	17.5
19.0	1	2.5
20.0	4	10.0
22.0	2	5.0
23.0	5	12.5
24.0	11	27.5
25.0	3	7.5
26.0	1	2.5
27.0	2	5.0
28.0	3	7.5

---

Note. Maximum score = 28.0

Cronbach's alpha: .885

Table 4

Paired *t*-Test Results of State Anxiety Scores

---

Pretest <i>M</i>	Posttest <i>M</i>	Difference	Paired <i>t</i>
51.40	50.48	-0.92	1.49*
SD 6.08	SD 6.10		

---

Note. Anxiety Cronbach's alpha: .91

\**p* = .14

Table 5

Paired *t*-Test Results of Hopelessness Scores

---

Pretest <i>M</i>	Posttest <i>M</i>	Difference	Paired <i>t</i>
12.40	10.925	-1.475	2.13*
SD 4.43	SD 4.03		

---

Note. Hopelessness Cronbach's alpha: .85

\**p* = .039

## CHAPTER 5

### DISCUSSION AND IMPLICATIONS

#### Discussion of Findings

The hypothesis that individuals with HIV/AIDS will not experience increased levels of anxiety and hopelessness after participating in a support group was upheld. Anxiety scores did not change significantly. Hopelessness scores decreased significantly.

House's (1981) stress paradigm provided the conceptual framework for the study. House suggests that health outcomes are affected by individual perceptions and social support. Social support enhances coping efforts and decreases reactivity to stressful situations. Stress occurs when the perceived ability to handle a given event is insufficient under the circumstances. Living with HIV/AIDS is a very stressful circumstance. Fear, depression, anxiety, and suicide are common thought processes in persons with HIV/AIDS (Durham, 1991).

Individuals with HIV/AIDS often do not receive sufficient support from their families, friends and coworkers. Because stigmatization is still a very real issue, persons with HIV/AIDS may chose not to inform their families, friends and

coworkers of their diagnosis. Fears about loss of employment, rejection, and loss of available housing are not totally unfounded (Bennett, 1990). The diagnosis of HIV/AIDS can have negative social implications for many people. Revealing a diagnosis of HIV/AIDS may force a disclosure about lifestyles which were previously unknown. Therefore, isolation can lead to lack of adequate support. Even with extremely supportive friends and families, persons with HIV/AIDS often feel that their significant others cannot truly understand what they are going through (Korniewicz & O'Brien, 1990).

The participants were satisfied with the support they received from the group. Their needs for love and caring, affirmation, someone to listen, and advice were being met by the group. The support group gave them a haven where persons with the same diagnosis could come together in a safe place. The support group offered a place for the subjects to say things they couldn't say to their friends, things their family didn't want to hear about anymore. The support group offered a location where fears and emotions could be expressed. There were no rules for the group, and no subjects were taboo. The participants' need for additional support services was affirmed by their attendance at the support group. The high level of satisfaction with the support gained from the group helps to validate the

results of the study. Both the lack of change in anxiety scores and the decrease in hopelessness scores were important indicators of the effectiveness of the support group. Of special interest is the fact that, even when facing a terminal illness, participants experienced a decrease in their level of hopelessness.

### Application to Practice

The number of persons with HIV/AIDS is increasing. There is no cure to date. Living with HIV/AIDS is challenging, not only because of the constant physical illnesses that may occur, but also because of the emotional drain it places on the person with HIV/AIDS. Anxiety and hopelessness are common in persons with HIV/AIDS. Stigmatization is still a real issue. Discrimination because of perceived lifestyle differences is still common. Ignorance about the means of transmission is also still prevalent. The person with HIV/AIDS can feel physically and emotionally isolated from people around him or her (Turner & Hayes, 1993). It is sometimes easier for healthcare professionals to focus on physical rather than psychosocial needs, contributing to the feelings of isolation which a person with HIV/AIDS often has. Because the diagnosis of HIV/AIDS has so many emotional implications, psychosocial issues are just as important to the person with HIV/AIDS as physical ones (Bennett, 1990).

Due to the negative connotations of being diagnosed with HIV/AIDS, persons with HIV/AIDS often have little family support. Support groups assist individuals in coping with the stress of their disease. They offer a non-judgmental network of acceptance and companionship. They offer a place where questions about health, fears and concerns are answered in a supportive environment. The support group can provide one of the few safe places a person with HIV/AIDS feels he or she has.

Because support is often minimal for persons with HIV/AIDS, nurses should assess the amount of social support the person with HIV/AIDS has. The results of this study affirmed the use of support groups to assist patients with HIV/AIDS. Support groups can offer an effective strategy in increasing coping mechanisms for the person with HIV/AIDS. Nurses should be aware of support groups in the area and know how to access them. The nurse should also evaluate whether the person with HIV/AIDS is aware of local support groups, and if she/he has ever attended them. Many people avoid support groups for fear of appearing weak or unstable. Others feel that asking for help is admitting defeat. Lack of time, motivation, transportation, inability to miss work, inconvenient offerings, and child care issues can also be possible reasons for not attending a support group.

These reasons should be explored in a non-judgmental fashion. Possible strategies to overcome the barriers should be explored.

Convenient community-based organizations should continue to offer support groups to persons with HIV/AIDS. The support groups need to be promoted and advertised to the persons they serve. These organizations need to continually educate individuals with HIV/AIDS and professional persons who work with this population to be aware of the psychological benefits that support groups do provide. The nurse can facilitate sessions for both the persons with HIV/AIDS and their families. With their knowledge of the human response to health problems, nursing professionals are well qualified to develop and implement support groups for persons with HIV/AIDS.

This study was a partial replication of DiPasquale (1990). An additional instrument (PSSGS) was used to measure perceived satisfaction with the support group, and there was a 6 week interval between the pretest and the posttest. Also, DiPasquale's study involved 3 subgroups, some which were very small. DiPasquale's hypothesis was not supported. Differences in outcomes between the studies could be accounted for by the fact that this was a larger sample size and

had one large group. A larger group may have been more conducive to stabilizing anxiety and hopelessness levels among the members.

### Limitations

The generalizability of the results is limited by a number of weaknesses inherent in the study design. The fact that the research used a convenience sample with no control group is a major limitation to the study. The challenge of providing a control group is that most persons with HIV/AIDS who are not in a support group are hospitalized, and too ill to participate in a study. The group consisted of males only, all from one metropolitan area. Therefore, the results cannot be generalized beyond this sample. However, since the intervention is essentially without risk, the positive outcome demonstrated in this study should be considered sufficient to consider continued use of support groups for patients with HIV/AIDS.

Individuals chose to participate in the support group, representing self-selection. Likewise, individuals who do not attend support groups may have differing levels of hopelessness and anxiety. Those subjects who withdrew from the study by not attending all of the sessions may have had differing levels of anxiety and hopelessness.



The small sample size was also a limitation. A larger, more heterogeneous sample may produce very different results. The changes in the scores could have resulted from something other than the support group, such as increased support from family or friends, or support from additional groups, such as churches or hospital-based clinics. Scores could also have changed as a result of conditions unrelated to support, such as decreased financial hardship or increased level of health. However, the degree of satisfaction with the support provided by the group helps to validate the results. All of the subjects showed consistent attendance at the support group, attending at least five of the six sessions in the test interval. The Perceived Social Support Subscale scores also affirm the worth of the support group to the subjects.

Another limitation could be the level of support the participants had achieved prior to the study. A way to strengthen the study would be to measure hopelessness and anxiety before any participation in a support group and then at a six week interval. Ongoing measurement of hopelessness and anxiety levels would help to determine the long term effect of support groups. Fluctuations unrelated to the support group could be assessed by adding additional instruments to assess other sources of support.

### Suggestions for Further Research

Replications of this study should be done with a larger sample size. The number of women and adolescents with HIV/AIDS is increasing at an alarming rate. This study should be expanded to include such groups as women, adolescents, and significant others of persons with HIV/AIDS. Additionally, it would be interesting to see if hopelessness and anxiety scores changed after a longer interval, such as 3 or 6 months. Are the anxiety and hopelessness scores transient, or is there long-term effects of the support group? The study should also be repeated with a control group of persons with HIV/AIDS who were not attending any support group.

### Conclusion

HIV/AIDS continues to be a major health problem. The emotional aspects of the disease can be devastating for both persons with HIV/AIDS and their family. Social support will continue to be an important issue as the number of persons with HIV/AIDS increases. Research supporting the use of support groups in persons with HIV/AIDS has shown inconsistent results. This research affirms the use of support groups to assist persons with HIV/AIDS cope with their anxiety and hopelessness.

## APPENDICES

APPENDIX A  
DEMOGRAPHIC DATA

1. Age \_\_\_\_\_ (fill in)

2. Gender: (circle)

male      female

3. Health Status:(circle)

HIV Positive

HIV Positive/AIDS

4. How long have you been in this support group? (place a check ( ) next to the question).

- \_\_\_\_\_ 0 - 3 months
- \_\_\_\_\_ 3 - 6 months
- \_\_\_\_\_ 6 - 12 months
- \_\_\_\_\_ 12 - 18 months
- \_\_\_\_\_ 18 months or more

5. How long have you known you were HIV positive?

- \_\_\_\_\_ 0 - 3 months
- \_\_\_\_\_ 3 - 6 months
- \_\_\_\_\_ 6 - 12 months
- \_\_\_\_\_ 12 - 18 months
- \_\_\_\_\_ 18 - 24 months
- \_\_\_\_\_ 24 months or more

6. How many support group sessions have you attended since you completed the first group of surveys 6 weeks ago? (circle)

1 2 3 4 5 6

## APPENDIX B

### CONSENT FORM FOR RESEARCH PARTICIPANTS

The study in which you are being asked to participate is titled "Assessment of the effects of AIDS support groups". As a participant, you are being asked to complete 2 sets of questionnaires. The questionnaires will be given to you to complete once as baseline data, and again in 6 weeks. It should take no longer than 30 minutes to complete the questionnaires.

Confidentiality will be provided at all times. All data collected will be coded with a number--- your name will never be attached. All reports, papers, and articles will report findings in group format--- no individual data will ever be reported. It is not anticipated that you will be harmed in any way by participating in the study. You may withdraw your permission from participating in this study at any time without causing any change in the treatment you are receiving.

The personal (and direct) benefits to you are limited. The results of this study will help in evaluating the effectiveness of AIDS support groups and may be helpful in changing future support groups for AIDS patients.

This study is being completed by Karen Bouwman. She is a registered nurse who is completing graduate studies at Grand Valley State University. If you have any questions she can be contacted at the following number: (616) 784-1394. Results of the study will be communicated to you if you so desire.

I have read and understand the information presented above. I consent, of my free will, to participate in the study.

\_\_\_\_\_  
Participant                  Witness

\_\_\_\_\_  
Date                          ( ) check here if results  
   of study are desired

## APPENDIX C

### COVER LETTER TO SUBJECTS

Dear Participant:

Thank you for agreeing to participate in the study "Assessment of the effects of AIDS support groups".

Your willingness to participate will help promote research in a very important area.

You will complete a few questionnaires today, and again at the end of your support group session in six weeks.

The questionnaires are short, and will not take more than 30 minutes to complete.

Confidentiality will be maintained at all times, and you can withdraw from this study at any time for any reason.

Thank you again for your willingness to promote nursing research.

Sincerely

Karen Bouwman

APPENDIX D

SPIELBERGER'S STATE ANXIETY SCALE

This instrument is copyrighted

APPENDIX E

BECK'S HOPELESSNESS SCALE

This instrument is copyrighted



## APPENDIX F

### Perceived Social Support Group Subscale

1. How satisfied are you with the love and caring the group has shown you?

1	2	3	4	5	6	7
Totally Dissatisfied	Dissatisfied	Somewhat Dissatisfied	Mixed 1/2 & 1/2	Somewhat Satisfied	Satisfied	Totally Satisfied

2. How satisfied are you with the group's ability to agree with your point of view or make you feel like you are doing the best you can?

1	2	3	4	5	6	7
Totally Dissatisfied	Dissatisfied	Somewhat Dissatisfied	Mixed 1/2 & 1/2	Somewhat Satisfied	Satisfied	Totally Satisfied

3. How satisfied are you with the group's willingness to take time and listen when you want to talk about feelings or concerns?

1	2	3	4	5	6	7
Totally Dissatisfied	Dissatisfied	Somewhat Dissatisfied	Mixed 1/2 & 1/2	Somewhat Satisfied	Satisfied	Totally Satisfied

4. How satisfied are you with the information or advice the group has given you?

1	2	3	4	5	6	7
Totally Dissatisfied	Dissatisfied	Somewhat Dissatisfied	Mixed 1/2 & 1/2	Somewhat Satisfied	Satisfied	Totally Satisfied

## LIST OF REFERENCES

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