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ABSTRACT

This practicum evaluated a psychoeducational group format developed to support children living in families affected by HIV and AIDS. The major goals were to help children cope with stressful events, with chronic strain, and with role transitions. There were five objectives for the children: (1) decrease feelings of isolation, confusion, anger and fear; (2) increase feelings of belonging, competency, and self-esteem; (3) decrease maladaptive behaviors in school; (4) improve academic performance; and (5) increase awareness of resources for support. The children's support group met for ten weeks in one hour weekly sessions. In post-group questionnaires, children exhibited decreased feelings of isolation and confusion, increased awareness of resources for support and guidance, and increased feelings of belonging and competency. Students also reported continuance in their maladaptive behaviors in school and in their poor academic performance. The group format seemed most effective using an open and unstructured agenda which encouraged open-ended questions and discussion. The sharing of worries, fear, and confusions within a safe, nurturing environment appeared to foster feelings of trust and group cohesion. Four appendices list examples of questionnaires along with a summary of data. (Contains 33 references.) (RJM)

Providing Psychoeducational Support for Children Affected by AIDS

by

Sandra Black

Cluster 53

A Practicum I Report Presented to the
Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements
for the Degree of Education

NOVA UNIVERSITY

1994

PRACTICUM APPROVAL SHEET

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Approved:

April 15, 1994

Date of Final Approval of Report

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TABLE OF CONTENTS

ABSTRACT

Providing Psychoeducational Support for Children Affected by AIDS. Black, Sandra, M., 1994: Practicum Report, Nova University, Ed.D. Program in Child and Youth Studies. HIV/AIDS/Adolescents/Peer Support Groups/Community Mental Health Intervention/Peer Support Groups.

This practicum was designed to evaluate a psychoeducational group format developed to support children living in families affected by HIV and AIDS. The major goals were to help children cope with stressful events, chronic strain in their lives, and role transitions. Specific objectives were to: decrease feelings of isolation, confusion, anger and fear; increase feelings of belonging, competency, and self-esteem; decrease maladaptive behaviors in school; improve academic performance.

The writer developed and administrated information letters and permission forms, pre and post questionnaires for group members and their parents; participated as a panel member at a local AIDS workshop and presented a group in process report; submitted needs and goals of this group approach in a grant application to seek funding for the supporting agency.

Analysis of the data revealed that the participants of this psychoeducational support group shared worries, personal vulnerabilities, and expressed feeling less isolated and confused. They continued to express feelings of anger and fear. They developed a gradual increased awareness of resources for support and guidance. Issues of trust seem to be barriers to reaching out for needed supports. They developed increased feelings of belonging and self-esteem as evidenced by telephone calls from absent group members during group time. They felt connected and involved even when they were unable to be in attendance. School behaviors and academic performance remained problematic. The students reported interpersonal difficulties with peers and teachers, excessive and inappropriate demands of school environments, and inconsistent completion of homework assignments.

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CHAPTER I

INTRODUCTION

Description of Community

The writer works in a northeast urban community. Approximately 100,000 residents, with a median annual income of $39,990, live within 7.13 square miles. Its southeastern boundary is a narrow (one quarter mile wide), winding river which separates it from a larger urban community. This neighboring community is the state capitol. Its northwestern boundary is a railroad track which separates it from several suburban communities. Residents within these neighboring suburban communities commute to work in this community. Commuting is facilitated by accessible subway and bus transportation. Driving is discouraged by narrow streets, restricted parking areas, limited parking garages, and very conscientious Meter Maids who seem to anticipate the exact moment a parking meter will expire. In addition to offering employment opportunities, this community offers fine restaurants, theater, and museums. It is a frequent attraction for tourists with charming bed and breakfast facilities.

Two world renowned universities, several smaller colleges, and innovative technology companies are the principle industries of this community. Non-university (town) and university (gown) residents have lived together in a compatible manner. Within the past 10-15 years, town-gown relations have been challenged by changing demographics. Shifts in socioeconomic, cultural, and linguistic diversity have created increased tensions and concerns about safety. Socioeconomic diversities include people who are financially stable and people living on welfare. The two universities and several smaller colleges attract students from many foreign countries. Residents associated with the universities and the field of technology include Nobel prize laureates and professionals who tend to be preoccupied with

academic issues. These people usually are financially stable. Their children frequently attend private schools within the community or in adjacent communities. Cultural and lingual diversities include immigrants from Haiti, Africa, Brazil, Portugal, and Cambodia. Many are illegal, political refuges who are economically disabled and fearful of repatriation. Their children attend the local community public school.

Of the 100,000 residents, approximately 22.3% are immigrants; 15.2% of all children in this community live in poverty; 15% of families are headed by a single parent (Center for Labor Market Studies, personal communication, May 17, 1993). The community has 12 elementary schools, 1 middle school, and 1 high school. There is a total school enrollment of 7,710 students. Among this student population, 30.9% have a first language other than English. (S. Wortiz, State Department of Education, personal communication, May 17, 1993).

Increased tensions and concerns about safety have strained the town-gown relationships. Interaction between residents who are affiliated with the universities and those who are not periodically reflect town-gown tensions. Specifically, confrontations and violence between local high school students and university students create issues of safety. This past year, a foreign graduate student was murdered by a group of local high school students. The community mental health agency, in which the writer works, was one of several community agencies involved in addressing the mental health needs of the accused youth, their families, and peers.

Writer's Work Setting and Role

The writer's work setting is a private, nonprofit, outpatient, mental health agency within this community. Recent fiscal changes are threatening the existence and have affected the service delivery programs within the agency. For 35 years, a partnership between the state government and a local private association supported mental health services to residents within the community. This partnership ended three years ago. In an attempt to address the state's budget deficit, the newly elected governor terminated all state support to outpatient, mental health clinics. Clinics wishing to continue

providing outpatient, mental health services needed to become "privatized" (seek private funding sources). The local private association decided to continue its commitment to provide outpatient, community, mental health services through a privatized format. Presently, funding sources include continued support from the local private association (through community fund raisers and private donations), competitive contracts (from the State Department of Mental Health and United Way), grants, health insurance companies, and private payers. A sliding fee scale supports the agency's philosophy of providing services regardless of ability to pay.

Termination of state support to outpatient, mental health clinics resulted in the lay off of all state employees within the writer's agency. The abrupt firing of therapists created anxiety among the client population and the community shared the tensions and dismay of the terminated staff. Several staff members were rehired and a new staff was recruited. This clinic is still in the process of reestablishing itself internally (staff and programming) as well as externally (services within the community). Staffing patterns, treatment programs, and intervention modalities are still being developed. The clinical staff is multidisciplinary (psychiatrists, clinical psychologists, social workers, early childhood specialists, paraprofessional family workers), and multicultural (Haitian, Latino, African, Afro-American). The clerical staff includes an executive director, a billing supervisor, record keepers, intake workers, receptionists, team recorders, and a grant writer. The types of therapeutic interventions, the number of therapy sessions allowed, and clinical modalities are determined by health insurance company reimbursement policies and billing strategies.

Approximately 1,000 children, youth and families receive mental health services annually (Executive Director, Community Mental Health Agency, personal communication, July 20, 1993). Mental health services are provided to children and youth ranging in age from 3 months through late teens, and their families. Children are referred by early childhood programs, schools, health clinics, department of social service, courts, pediatricians, and parents. The reasons for referral include social and emotional problems which affect children. A family's economic and social difficulties, and related losses (separation, divorce, and death) impact children. Children reflect stresses

within families. Their worries, fears, and concerns are often expressed through disruptive behaviors. Disruptive behaviors may include acting out (physically aggressive with peers, verbally abusive with teachers and/or peers, frequent absences from school, use of drugs and alcohol) and regression (withdrawal, lack of involvement in academic and social activities). Mental health services are provided through the writer's agency. These services are accessible within the agency's community based center, early childhood and daycare centers, public and private schools, health clinics, and community sites. Modalities for therapeutic intervention include individual and family therapy, group therapy, parent education programs, consultation programs to schools, early childhood centers, and community agencies.

During the three year period of privatization (1989-1992), the need for mental health services within the community increased. Two causative factors were violence and acquired immune deficiency syndrome (AIDS). Violence has escalated and become more prevalent within the schools and community. Children feel unsafe and fearful as they witness friends and family members being hurt. The number of people with the human immunodeficiency virus (HIV) and AIDS has also increased. People with AIDS and their family members experience isolation, stigmatization, and discrimination. Children living in families affected by AIDS feel confused and frightened. Their worries, fears, and concerns are often expressed through disruptive behaviors.

The writer's role within this agency is coordinator of AIDS services. This role involves administrative and clinical responsibilities. Administrative responsibilities include community outreach, program development, and reporting to the administrative team and the Board of Directors of the agency. The Board of Directors serve as the power base of this agency. They are a voluntary group of community residents who are invited to serve as members of the board. The board meets monthly to review and revise agency policy, set goals and objectives, and oversee the financial status of the agency. As coordinator of the AIDS program, the writer is responsible for periodic meetings with individual board members and an annual presentation to one of the monthly Board of Directors meetings.

Clinical responsibilities include direct service to children who are

affected by AIDS and their families, consultation to schools and community agencies about HIV and AIDS related issues, and providing inservice education to the agency's staff.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

Children living in families affected by HIV and AIDS felt isolated, confused, angry, and lack coping skills. They presented maladaptive behaviors in school. They refused to go to school, had poor academic performance, became disruptive in class, and became argumentative with peers. They tended to deny that anything was wrong and rebuffed support offered by school personnel. Teachers and school guidance counselors observed changes in behaviors and referred children for psychological evaluations.

There was a need for psychoeducational support for children affected by HIV and AIDS. The number of referrals for AIDS related services increased within the writer's work setting. In 1989, two families were referred for AIDS related services. In 1992, twenty-five families were referred for AIDS related services (Executive Director, Community Mental Health Agency, personal communication, July 20, 1993).

Difficulties encountered in addressing the needs of children affected by AIDS included the need to respect confidentiality. A literature review reported that if a family member has HIV or AIDS, it is often considered a "family secret" and disclosure is not permitted by family norms. The reality of living in a family affected by HIV or AIDS may be acknowledged and discussed for the first time in the safety of a therapeutic environment. Children need permission to discuss this family secret and seek help coping with issues such as changing physical and mental status of family members, changing family roles, and pending losses (Cleveland, 1987; Urwin, 1988).

People affected by AIDS include those infected by the virus and those associated with people who have HIV or AIDS (family members, caregivers,

fellow workers, and friends). Family members include spouses and/or significant others, parents, children, siblings, and relatives. For many families, a members' diagnosis of AIDS may also be the first time the family becomes aware of an alternative lifestyle. Families may be challenged to accept the reality of a life threatening illness at the same time its moral and religious values may have been shaken (Brown & Powell-Cope, 1991).

Caregivers of people with HIV and AIDS may be professionals, paraprofessionals, volunteers, and family members. Professionals include physicians (Staley, 1991), nurses (Saymour, 1989), social workers (Reamer, 1991), and psychologists (Knox, 1989). Paraprofessionals include paid health care workers who care for people with HIV and AIDS (Wertz , Sorenson, Liebling, Kessler, & Heeren, 1988). Volunteers include unpaid health care workers who care for people with HIV and AIDS (Viney, Allwood, Stillson, & Walmsely, 1992). In the future, few people will not be affected by this disease (Corless, et al., 1992).

Children in families affected by AIDS may experience anxiety and sadness. Children living in families affected by chronic illness often become angry and confused about the disruption in their lives, fearful, and parentified (Masterman & Reams, 1988).

This problem has not yet been solved because society continues to wrestle with ethical and moral dilemmas associated with HIV and AIDS (Sontag, 1990). These dilemmas are challenging work environments, religious institutions, schools and family units to change and adapt to AIDS related issues. AIDS is a chronic medical illness with social, emotional, legal, and spiritual implications (Gilmore & Aggleton, 1993). Social and emotional implications include loss of family and friends, and feelings of guilt, fear, anger, anxiety, and depression (Knox, 1989). Legal implications include civil liberty issues and civil rights issues. Civil liberties refer to a person's right to confidentiality. Civil rights refers to a third parties' right to be protected from potentially harmful people or events. The rights of a person infected with HIV or AIDS may conflict with the rights of persons who are not infected. This conflict has been the topic of ongoing debate about how to protect an individual's rights while still protecting the health and safety of the community at large (Melton, 1988; O'Connell & Lebow, 1992; Reamer, 1991).

Spiritual implications include conflicts within the religious institutions between traditional religious teachings and needs of people affected by HIV and AIDS (McCoy, 1992; Weiss, 1989).

Children living in families affected by HIV and AIDS feel isolated, confused, angry, and lack coping skills. The problem was the need to provide psychoeducational support for children affected by HIV and AIDS.

Problem Documentation

There was a need to provide psychoeducational support for children affected by HIV and AIDS. Children affected by HIV and AIDS exhibited maladaptive behaviors and lacked coping strategies. Teachers reported they were often disruptive, distracted, inattentive, and had poor academic achievement. These children reportedly denied that anything was wrong and rejected school personnel efforts to be supportive. Concern about maladaptive behaviors prompted teachers and school guidance counselors to refer these children for psychological evaluations.

An informal needs assessment was done in response to the initial request for mental health services for children affected by HIV and AIDS. Contact with the state and local AIDS agencies, local hospitals, and area mental health agencies provided evidence that children affected by HIV and AIDS needed psychoeducational support. The State AIDS agency reported that within this State, there were support groups for people with AIDS and support groups for adults living with family members or friends affected by AIDS. They reported no support groups for children living in families affected by AIDS (State AIDS Action Committee, personal communication, October 20, 1989). The local hospitals reported support groups for adult family members of people with AIDS but no services for children living in families affected by AIDS. Area mental health agencies reported no services for children affected by HIV and AIDS.

The discrepancy between what was needed and what was available was further documented by the increase in the incidence of HIV and AIDS within the local community. The local community AIDS agency Spring 1992

Newsletter reported 1,000 cases within the local community. The Winter 1993 Newsletter reported approximately 1,500 cases. This report indicated a 33% increase in the number of HIV and AIDS cases within 4-6 months.

Within the past three years, the intake worker at the writer's mental health agency reported there had been a 75% increase in the number of referrals for AIDS related services. There was a need to provide psychoeducational support for children living in families affected by HIV and AIDS.

Causative Analysis

Children affected by HIV and AIDS needed psychoeducational support. Possible causes for this problem were the increased numbers of people with AIDS, the increased numbers of children living in families affected by AIDS, and increased school and community problems related to the impact of AIDS on families.

Despite knowledge and education about its cause, transmission, and prevention, AIDS continues to increase. In December 1992, the Centers for Disease Control reported that, in the United States, more than 200,000 AIDS cases had been reported and more than 100,000 people with AIDS had died. It was estimated that each year from 1500 to 2000 newborns and 40-80,000 adults acquire HIV infection (Fuller, 1992). There are approximately 1,500 cases of people with AIDS within the writer's local community. There is a need for integration of information into attitudinal and behavioral changes (Fennell, 1990; Reader, 1988; Strunin & Hingson, 1987).

The impact of these growing numbers of people with AIDS directly impacts family members. As more people are diagnosed with AIDS, there will be increased numbers of children living in families with AIDS. Children living in families affected by AIDS are relatively silent members of the family structure. They are expected to behave properly, help with household chores, attend to younger siblings, and not ask questions.

Children bring their worries and concerns to school. Their behaviors become nonverbal expressions of their feelings. Children who feel

frightened, confused, and guilty often either act- out (become disruptive, argumentative) or act-in (withdraw, regress, become inattentive). They may also become involved with illegal activities within the community (gangs, drugs, and related violence).

In the writer's work setting, there had been a steady increase in the number of referrals for mental health services for children affected by AIDS. The specific cause of this increase in referrals was that acute and chronic illness within a family impact on children of all ages.

Relationship of the Problem to the Literature

There was a need to provide psychoeducational support for children affected by HIV and AIDS. A review of the literature revealed that many professionals had written about other life stressors which created similar problems for children. Professionals reporting on these problems included teachers, psychologists, doctors, and public health officials. Life stressors which created similar problems for children included chronic illness, death and dying (Binger, et al., 1969; Cairns, Clark, Smith, & Lansky, 1979; Lavigne, 1980; Silverman & Worden, 1992).

Children living in families affected by chronic illness, such as cancer, experienced problems similar to those experienced by children living in families affected by AIDS. Chronic illness created similar behavioral, somatic, and psychological problems for children. Behavioral problems included enuresis, poor school performance, school refusal and severe separation difficulties. Somatic problems included headaches, abdominal pains, and symptoms similar to that of the sick sibling or parent. Psychological problems included heightened anxiety, low self-esteem, and feeling of rejection, isolation, and neglect (Binger et al., 1969; Cairns et al., 1979; Lavigne, 1980).

Children living in families affected by HIV and AIDS eventually will experience death and associated bereavement. Children who suffer early losses may be prone to depression, school difficulties, and may become sensitive to later threats of loss. They are also at risk for developing depression in adulthood (Bowlby, 1980). A child may cope and adapt to death

without developing behavioral difficulties. A child's reaction to the death of a parent is related to several factors. The availability of social support, the way the surviving parent responds to the child, and subsequent life circumstances make a difference in a child's recovery for the loss of a parent (Silverman & Worden, 1992). Teachers are often involved with a child at the time of death in a family. Reaction to death is also related to the age of the child. Younger children (4-12 years) have different cognitive understanding than older children (13-18 years). Adults need to be aware of a child's capacity to understand death. At the time of death, adult responses must respect a child's developmental age and provide cognitively appropriate support (Smilansky, 1987).

The literature provided documentation about the impact of AIDS on families and children. It suggested that children of all ages are affected and their different needs reflect their developmental ages (Kister & Patterson, 1980; Schvaneveldt, Lindauer, & Young, 1990; Sigelman, Maddock, Epstein, & Carpenter, 1993; Walsh & Bibace, 1990).

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The problem was the need for psychoeducational support for children affected by HIV and AIDS. The following goals and outcomes were projected for this practicum: to evaluate the effectiveness of a psychoeducational support group format for children living in families affected by HIV and AIDS. The goals of this group were to provide a supportive, nurturing environment for children living in families affected by HIV and AIDS, and to reduce their feelings of isolation, confusion, anger, and fear. The objectives of this group were to provide an educational format to foster emotional growth and development, to correct misconceptions through education, and to guide children through the chronic illness and acute stages of family members affected by HIV and AIDS.

Expected Outcomes

The expected changes included improved personal feelings, coping skills, behaviors, and academic performance of the children in the group. Specific expected outcomes were:

1. decreased feelings of isolation, confusion, anger and fear;
2. increased awareness of resources for support, guidance;
3. increased feelings of belonging, competency, and self-esteem;
4. decreased maladaptive behaviors in school (fewer disruptions in class, fewer arguments with peers);
5. improved academic performance (increased attentiveness in class, completion of homework).

The end result of the proposal was to indicate if a psychoeducational support group format addressed the needs of children living in families affected by HIV and AIDS.

Measurement of Outcomes

The evaluation tool that was used to measure the effectiveness of this group was a questionnaire. Two questionnaires were used. One questionnaire was for students (see Appendix A). One questionnaire was for teachers (see Appendix B). Because many children in this community lived in transient home environments and lacked consistent parenting, a home questionnaire was not originally planned for this evaluation. The writer's supporting agency reviewed the proposal and recommended three changes. The writer was advised that because of confidentiality issues: (a) it would be not be appropriate to involve teachers in this evaluation; (b) it would be appropriate to include parents or parent surrogates; and (c) a cover letter and permission to participate were required according to human rights code. A parent questionnaire and cover letter were developed (see Appendix C).

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Possible Solutions

Children living in families affected by HIV and AIDS feel isolated, confused, angry, and lack coping skills. The problem was the need to provide pyschoeducational support for children affected by HIV/AIDS. A review of the literature indicated that children living in families affected by chronic illness experience similar feelings and demonstrate similar behavioral dysfunctions. Children feel isolated, guilty, worried, parientified, confused, and sad about themselves and their loved ones. Isolation comes from spoken and/or unspoken messages within the family that the illness is a secret and not to be discussed with anyone. Guilt is related to their developmental age and reflects a child's perception that their "bad" behavior has caused the illness of a loved one. Worry is related to a child's concern for the unknown and uncertainty about who will take care of them. Parentification is related to the role reversals that occur in families when illness is present. Children are frequently expected to assume responsibilities for the care of the sick parent, younger siblings, and for household chores. Confusion is related to the discrepancies between normal developmental needs and family demands. Sadness is related to lack of support from family members due to preoccupation with the needs of the sick family member and the anticipated loss of the sick family member (Gottlieb, 1987; Kister & Patterson, 1980; Masterman & Reams, 1988; Silverman & Worden, 1992).

Possible solutions to this problem included the development of developmentally-based education programs within the school department, involvement of community members who reflect cultural and linguistic norms, involvement of religious institutions to ascertain spiritual teachings

and values, and involvement of local hospitals and hospices to collaborate and share resources (Corless, et al., 1992; McCoy, 1992; Schvaneveldt, Lindauer, & Young, 1990; Walsh & Bibace, 1990).

Each of these solutions had advantages and disadvantages. Development of educational programs which focus on the developmental ages of students addresses the cognitive stage and ensures presentation of age appropriate concepts. The problem with including information about HIV and AIDS within a school curriculum was related to parental concerns. Some parents strongly object to schools teaching children about sex, drugs, and alternative life styles. The involvement of community members who reflect cultural and linguistic norms enables the sharing of different beliefs and rituals. Communication within native languages ensures mutual understanding of needs and expectations. The problem with involving multicultural and multilingual members was that prejudicial issues may threaten the safety of participation and inhibit active participation. Issues of safety must have support from the community police force. Involvement of spiritual leaders enables the sharing of values and belief systems. The problem associated with spiritual institutions was related to traditional teachings which firmly reject alternative lifestyles and ostracize members from religious institutions. The involvement of local hospitals and hospices enables networking of services for family members who are sick and dying. The problem with involving these institutions was family reactions of denial and withdrawal. Some families perceive hospitals and hospices to be scary places and prefer not to bring their children to these institutions.

Description and Justification for Solution Selected

A psychoeducational support group for children affected by AIDS was evaluated to determine if a group format addressed the needs of these children. The goals of this group were to provide a supportive, nurturing environment for children living in families affected by HIV and AIDS, and to reduce their feelings of isolation and fear. The objectives of this group were to provide an educational format to foster emotional growth and development, to correct

misconceptions through education, and to guide children through the chronic illness and acute stages of families members affected by HIV and AIDS. Group members and staff leaders were representative of the sponsoring agency's multicultural and multiracial community.

The format for this group was one hour weekly sessions with a maximum of 8 students ranging in age from 13-16 years. The group was coeducational with an effort to include 4 male and 4 female students. The group was lead by two co-leaders (one male and one female) and reflected the multicultural and multiracial community. The group started and ended promptly.

The rationale for using a support group program was based on studies that identified the feelings and behaviors of children living in families affected by chronic illness, and recommended intervention strategies which are helpful to address these responses. Gottlieb (1987) recommends support services to help children cope with stressful events, chronic strain in their lives, and role transitions. The purpose of this proposal was to ascertain the value of using a support group program to address the needs of children living in families affected by HIV and AIDS.

Calendar Plan

The time frame of this group was 10 weeks. If a scheduled session conflicted with a school vacation day, the 10 week period was adjusted accordingly. The scheduled agenda for each session was as follows:

Week 1: Introductions: self (age, grade, favorite foods, music, teacher)
Expectations of group experience: past group involvements, experiences; why here
Confidentiality issues: information shared stays within confines of group; respect privacy of others
Snack request: favorite foods for group sessions

Week 2: Weekly check in: "rate-your-week" - 1 = terrible; 10 = terrific
Topic: HIV and AIDS: discussion of the basics: what is it; how can you get it; not get it; who told you what; what makes sense; what doesn't
Snack request: next week

Week 3: Weekly check in: "rate-your-week"
Topic: Feelings and behaviors: knowing a special person has HIV or AIDS, what kinds of feeling do you have; what do you do with these feelings
Snack request: next week

Week 4: Weekly check in: "rate-your-week"
Topic: Differences: since special person has HIV or AIDS, what's different about that person, other family members, yourself; feelings about changes
Snack request: next week

Week 5: Weekly check in: "rate-your-week"
Topic: Midpoint check in: review group experience; what's been helpful; disappointing; wishes for future discussion

Week 6: Weekly check in: "rate-your-week"
Topic: Secrets: who told you what; who else knows what; who doesn't; wishes about secrets
Snack request: next week

Week 7: Weekly check in: "rate -your-week"
Topic: Helpers: personal resources - who can be helpful with worries, fears; for fun times; options for finding helpers
Snack request: next week

Week 8: Weekly check in: "rate-your-week"
Topic: Fears, worries: worse fantacies - worse thing that could happen to self; siblings, parent(s)
Snack request: next week

Week 9: Weekly check in: "rate-your-week"
Topic: Termination: review personal goals, wishes needs; requests for "unfinished business" plans for final session

Week 10: Weekly check in: "rate-your-week"
Topic: Saying Goodbye: how have you changed since group experience; new awareness re: feelings, behaviors, helpers-people who can be helpful

Report of Action Taken

The start up of this group was announced in September. Flyers and cover letters were sent to approximately 100 community agencies within the greater urban community. Verbal announcements, accompanied by flyer handouts, were also made at community agency staff meetings and conferences. Approximately 30 families were referred to this group. Approximately 10 parents or parent surrogates completed an initial interview. Six children became members of this group.

Difficulties which prevented other interested families from becoming involved included distance from home, transportation, scheduling problems, and preoccupying health and family problems. Since the original 6 children began the group, 3 children terminated. One child was placed in foster care out of state; one child moved to live with a relative out of state; one child ran away from a residential home and has been in hiding.

The loss of these group members created anxiety and fear for the remaining group members. To deal with the unexpected loss of group members, the original scheduled agenda was changed. Group time focused on the immediate needs of the remaining members. They expressed concern

about their own vulnerability and safety, worries about their future as family members became sicker and died, and fears associated with sharing family secrets. These worries were shared and discussed. Group time was also used to identify resources within each child's community: who was available to keep group members safe; who could be trusted; who could provide needed support and guidance.

CHAPTER V

RESULTS, DISCUSSIONS, AND RECOMMENDATIONS

Summary of Problem and Solution Strategy Utilized

Children living in families affected by HIV and AIDS feel isolated, confused, angry, and lack coping skills. The problem was the need to provide psychoeducational support for children affected by HIV/AIDS. The solution strategy utilized was the evaluation of a psychoeducational support group for children affected by AIDS. The rationale for using a support group program was based on studies that identified the feelings and behaviors of children living in families affected by chronic illness, and recommended group support services to help children cope with stressful events, chronic strain in their lives, and role transitions (Gottlieb, 1987; Knox, 1989; Masterman & Reams, 1988).

The evaluation was completed within a 10 consecutive week period. There were a total of 10 weekly one hour sessions which started and ended promptly. The group was comprised of 6 children ranging in age from 13-16 years. It was coeducational and multiracial. The goals of this group were to provide a supportive, nurturing environment for children living in families affected by HIV and AIDS, and to reduce their feelings of isolation and fear. The objectives of this group were to provide an educational format to foster emotional growth and development, to correct misconceptions through education, and to guide children through the chronic illness and acute stages of family members affected by HIV and AIDS. Group members and staff leaders were representative of the sponsoring agency's multicultural and multiracial community.

Results

Expected Outcomes

The expected changes included improved personal feelings, coping skills, behaviors, and academic performance of the children in the group. The end result of the evaluation was to indicate if a psychoeducational support group format addressed the needs of children living in families affected by HIV and AIDS. Specific expected outcomes and results are presented in TABLE 1.

TABLE 1

EXPECTED OUTCOME	RESULT
1. Decreased feelings of isolation, confusion, anger and fear;	1. Expression of personal worries and vulnerabilities suggested that group members experienced decreased feelings of isolation and confusion. They continued to express feelings of anger and fear.
2. Increased awareness of resources for support, guidance;	2. There was gradual increased awareness of resources for support and guidance. Issues of trust were barriers to reaching out for needed supports.
3. Increased feelings of belonging, competency, and self-esteem;	3. Increased feelings of belonging and self esteem were evidenced by telephone calls from absent group members during group time. They felt connected and involved even when they were not in attendance.
4. Decreased maladaptive behaviors in school (fewer disruptions in class; fewer arguments with peers);	4. School behaviors and academic performance remained problematic.

5. Improved academic performance (increased attentiveness in class; completion of homework).	5. Students reported interpersonal difficulties with peers and teachers, and inconsistent completion of homework.

Two questionnaires (a pre-group and a post-group) were distributed to several mothers and each group participant. One mother completed a pre-group questionnaire; six group members completed pre-group questionnaires; three group members completed post-group questionnaires. The responses to the completed student questionnaires are summarized in Appendix D.

Discussion

The results indicate that a 10 week psychoeducational support group addressed the needs of children affected by HIV/AIDS. This intervention format provided a safe, nuturing environment which fostered the discussion of feelings, worries, and confusions. It provided education about misunderstandings and misconceptions, and guidance about resources for family and community supports.

The impact of HIV and AIDS has been discussed in many different professional arenas. The scientific and medical professions have addressed the cause, treatment and prevention of HIV and AIDS (Fuller, 1992; McCoy, 1992) . The religious profession has been challenged to explore doctrines and spiritual teachings to provide needed support for practitioners (McCoy, 1992). The mental health profession has addressed issues of anxiety, fear, depression, loss, and bereavement associated with chronic illness (Knox, 1989; Smilansky, 1987; Silverman, 1992). The education profession has addressed curriculum issues and attempted to develop culturally sensitive, developmentally appropriate information for schools. The needs and capacity of a child to understand and cope with HIV/AIDS is influenced by each child's developmental age (Potter, & Roberts, 1984; Schvaneveldt, et al., 1990; Sigelman, et al., 1993; Walsh & Bibace, 1990).

This paper confirmed the findings in the literature which identified

psychological, educational, and social needs of children living in families affected by HIV and AIDS. It evaluated the effectiveness of a psychoeducational support group to address the needs of children living in families affected by HIV and AIDS. Three out of five specific outcomes were met. Students reported decreased feelings of isolation and confusion, increased awareness of resources for support and guidance, and increased feelings of belonging and competency. Three implications of meeting these outcomes are: (a) a brief psychoeducational peer group facilitated by trained staff can have a positive impact on children affected by HIV and AIDS; (b) the format of the group is most effective within an open, unstructured agenda which encourages open ended questions and discussions; and (c) sharing of worries, fears, and confusions within a safe, nurturing enviornment fostered feelings of trust and connectedness.

Two out of five specific outcomes were not met. All students reported continued maladaptive behaviors in school, and continued difficulty with academic performance. They explained these school and academic difficulties were related to continued fears, worries, and preoccupying concerns about their family member's fluctuating health and well being, and their own issues of personal safety. The increased presence of violence, gangs, and weapons within the school and community has resulted in increased tension, vigilance, and alarm among many students. For all the students within this group, the combination of concerns (family members and self) inhibited their concentration on academic demands.

It is significant to report the experience of one group member who dropped out of the group. He was a 16 year old whose mother and 3 year old sister had AIDS. His mother was a prostitute. He and his three younger siblings lived with a maternal aunt and her three children. A maternal grandmother was also very involved in the care of this family and was very instrumental in instilling strong religious values. He was a good student with hopes to go to college. His attempts to attend to academic issues were ridiculed by peer groups within his neighborhood and school. When this young male entered the local high school, he experienced increasing demands from gangs. He was repeatedly threatened and beaten up. It became unsafe for him to leave his home or attend school. Clinicians within the writer's community

mental health agency advocated for him to be moved to a residential placement outside of this community. He has maintained contact with this psychoeducational group and reports feeling safe, relaxed, and doing good academic work. These reports have been confirmed by collaborating agencies.

Unexpected outcomes included additional requirements from the supporting agency, the decreased number of participants within the group, and a change in the scheduled agenda plans. The supporting agency adheres to human rights guidelines for all clients who are involved in any form of an evaluative process. Signed permission by group participants and their parents/parent surrogates was required. This change was dealt with by developing a cover letter for potential group members and their parents/parent surrogates. The letter explained the purpose of the evaluative process, invited questions or concerns, and requested signed permission for participation. Because of the confidential nature of HIV and AIDS, the supporting agency recommended not seeking teacher involvement and including parents/parent surrogate involvement. This change was dealt with by excluding the teacher questionnaire and developing of a parent/parent surrogate questionnaire. Copies of cover letters and parent questionnaires are in Appendix C.

In summary, a 10 week psychoeducational support group addressed the needs of 3 children affected by HIV/AIDS. It provided a safe, nurturing environment in which children discussed their fears, worries, and confusions. Group leaders provided information to clarify misunderstandings and misconceptions, and guidance about resources for family and community supports.

Recommendations

Children living in families affected by HIV and AIDS feel isolated, confused, angry, and lack coping skills. It is recommended that:

1. HIV and AIDS psychoeducational support groups become an intervention format to provide a safe, nurturing environment in which children express worries, fears, and confusions about the impact of HIV and

AIDS on their lives, clarify misunderstandings and misconceptions, and learn coping strategies for themselves;

2. Within the writer's work setting:

a. this 10 week group be continued as an open ended, year long group to provide a consistent place for the inconsistent, conflicting needs of group members, to provide an open door welcome policy for referrals throughout the year, and to facilitate networking and collaborating with other community agencies;

b. a second group be started to address the needs of younger children (8-12 years).

Plans for Dissemnation

Other professionals have expressed interest in this practicum project. The writer was invited to participate as a panel member of a workshop organized by the local AIDS organization. This workshop addressed: "HIV/AIDS and The Affected Child". It focused on legal, medical, mental health, and adoption/guardianship issues. Each panel member presented one issue and responded to questions. The writer described the psychological and educational needs of children affected by AIDS and discussed the psychoeducational support group being evaluated as a practicum project. Questions were asked about confidentiality, developmentally appropriate educational information and materials, group structure, format and dynamics, and financial reimbursements. Follow up telephone calls were received from attendees who requested additional information and assistance in starting a group within their community.

This writer has collaborated in the writing of a paper entitled: "Identifying the Mental Health Needs of Children Living in Families with AIDS or HIV Infection". This paper focuses on a three prong intervention strategy: individual therapy, psychoeducational groups, and consultation to families, schools, and community agencies. This paper has been accepted for publication in Community Mental Health Journal. Publication is scheduled for early 1995.

A grant was written seeking fiscal support for psychoeducational groups within the writer's work setting. A review of this practicum project was used to present the problem, solution, intervention approach, and results-to- date. The Polaroid Corporation reviewed the application, conducted a site visit, and awarded the sponsoring agency a $5,000 grant. This is the first private funding source to contribute funds to this agency for work specifically focused on HIV and AIDS related work.

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APPENDIX A
COVER LETTER AND
STUDENT QUESTIONNAIRES

October 7, 1993

Dear Group Member,

You will be participating in a group for children affected by HIV and AIDS. We want to be sure this group is helpful to you. Please help us evaluate how effective this group is by completing two questionnaires. The first questionnaire will be completed now, the second questionnaire will be completed in 10 weeks.

The information you put on these questionnaires will be confidential. If it feels uncomfortable to share any of the requested information, please talk with Sandra or Hugo. By sharing the requested information, you will help us be sure the group helps you.

If you are willing to participate in this evaluation, please sign below. Thank you for your help.

Sincerely,

_____
Sandra Black, M.Ed.

_____
Hugo Kamya, Ph. D.

I agree to participate in the evaluation of the group for children affected by HIV and AIDS.

Signed: _____

Date: _____

STUDENT QUESTIONNAIRE
PRE-GROUP

NAME: DATE:

A. Please check YES or NO:	YES	NO
1. Do you know someone who is HIV positive?		
2. Do you know someone who has AIDS?		
3. Is this person a family member?		
4. Is this person a family friend?		
5. Is this person a friend of yours?		

B. Because of your involvement with HIVand/or AIDS, please check which applies to you:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
1. I feel isolated					
2. I feel confused					
3. I feel stigmatized					
4. I feel angry					
5. I feel frightened					
6. My feelings affect my behavior					
7. My feelings affect my school work					
8. To help handle my feelings					
a) I talk with my mother					
b) I talk with my father					
c) I talk with my best friend					
d) I talk with a teacher					
e) I talk with a school nurse					
f) I talk with a school counselor					
g) I talk with a religious leader					

C. Please check YES or NO:

	YES	NO
1. This group will help me:		
a) with my feelings		
b) with my behavior		
c) with my school work		

D. Additional comments (Optional):

STUDENT QUESTIONNAIRE
POST-GROUP

NAME: DATE:

A. Please check YES or NO:	YES	NO
1. Do you know someone who is HIV positive?		
2. Do you know someone who has AIDS?		
3. Is this person a family member?		
4. Is this person a family friend?		
5. Is this person a friend of yours?		

B. Because of your involvement with HIVand/or AIDS, please check which applies to you:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
1. I feel isolated					
2. I feel confused					
3. I feel stigmatized					
4. I feel angry					
5. I feel frightened					
6. My feelings affect my behavior					
7. My feelings affect my school work					
8. To help handle my feelings					
a) I talk with my mother					
b) I talk with my father					
c) I talk with my best friend					
d) I talk with a teacher					
e) I talk with a school nurse					
f) I talk with a school counselor					
g) I talk with a religious leader					

C. Please check YES or NO:

	YES	NO
1. This group helped me:		
a) with my feelings		
b) with my behavior		
c) with my school work		

D. Additional comments (Optional):

APPENDIX B
COVER LETTER AND
TEACHER QUESTIONNAIRES

September 15, 1993

TEACHER
School
Avenue
CITY, MA. 0000

Dear TEACHER,

Thank you for referring (student) to the Peer Support Group. She will be participating in a 10 week program aimed at helping students address personal issues which adversely affect their school performance.

I ask your help in evaluating the effectiveness of this group experience. Please complete the attached pre-group questionnaire and return it to me in the enclosed envelope. Upon completion of the group, you will be asked to complete a post-group questionnaire.

If you have any questions or concerns during this group program, please feel free to contact me. I can be reached at: 354-2275.

Sincerely,

Sandra Black,
Peer Group Coleader

TEACHER QUESTIONNAIRE
PRE-GROUP

NAME: DATE:

STUDENT:

Please check which applies to this student's behavior in your classroom:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
A. Academic behaviors:					
1. Completes homework on time					
2. Participates in class discussions					
3. Achieves at expected levels					
4. Intellectually curious					
B. Social behaviors:					
1. Is disruptive in class					
2. Is cooperative with peers					
3. Is respectful of authority					
4. Is preoccupied, easily distracted					
5. Is able to cope with disappointment					

C. Additional comments (Optional):

October 30, 1993

TEACHER
School
Avenue
CITY, MA. 0000

Dear TEACHER,

(STUDENT) has participated in a 10 week program aimed at helping students address personal issues which adversely affect their school performance. She has been a steady member of this group and an active participant.

Thank you for completing the pre-group questionnaire. I am enclosing a post-group questionnaire. Please complete and return it to me in the enclosed envelope.

I appreciate your help in evaluating the effectiveness of this group experience. If you have any questions or concerns about this group program, please feel free to contact me. I can be reached at: 354-2275.

Sincerely,

Sandra Black,
Peer Group Coleader

TEACHER QUESTIONNAIRE
POST-GROUP

NAME: DATE:

STUDENT:

Please check which applies to this student's behavior in your classroom:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
A. Academic behaviors:					
1. Completes homework on time					
2. Participates in class discussions					
3. Achieves at expected levels					
4. Intellectually curious					
B. Social behaviors:					
1. Is disruptive in class					
2. Is cooperative with peers					
3. Is respectful of authority					
4. Is preoccupied, easily distracted					
5. Is able to cope with disappointment					

C. Additional comments (Optional):

APPENDIX C
COVER LETTER AND
PARENT QUESTIONNAIRES

October 7, 1993

Dear Parent,

Your child will be participating in a group for children affected by HIV and AIDS. We want to be sure this group is helpful to your child. Please help us evaluate how effective this group is by completing two questionnaires. The first questionnaire will be completed now, the second questionnaire will be completed in 10 weeks.

The information you put on these questionnaires will be confidential. If it feels uncomfortable to share any of the requested information, please talk with Sandra or Hugo. By sharing the requested information, you will help us be sure the group helps your child.

If you are willing to participate in this evaluation, please complete the form below and the attached questionnaire. Please return both the permission form and questionnaire in the enclosed envelope. Thank you for your help.

Sincerely,

Sandra Black, M. Ed.

Hugo Kamya, Ph.D.

I give permission for my child _____ to participate in the evaluation of the group for children affected by HIV and AIDS. I will complete the two questionnaires.

Signed: _____

Date: _____

PARENT QUESTIONNAIRE
PRE-GROUP

A. Please check YES or NO:

	YES	NO
1. Do you know someone who is HIV positive?		
2. Do you know someone who has AIDS?		
3. Is this person a family member?		
4. Is this person a family friend?		
5. Is this person a friend of yours?		

B. Because of your family involvement with HIVand/or AIDS, please check which applies to your child:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
1. He/she seems isolated					
2. He/she seems confused					
3. He/she seems stigmatized					
4. He/she seems angry					
5. He/she seems frightened					
6. His/her feelings affect behaviors at home					

C. Please check YES or NO:

	YES	NO
1. This group will help:		
a) him/her discuss problems		
b) his/her behavior at home		

D. Additional comments (Optional):

December 16, 1993

Dear Parent,

Your child has participated in a group for children affected by HIV and AIDS. We want to be sure this group was helpful to your child. To help us evaluate how effective this group was, we asked you to complete two questionnaires. The first questionnaire was completed at the beginning of group. The second questionnaire was to be completed in 10 weeks.

The information you put on these questionnaires will be confidential. If it feels uncomfortable to share any of the requested information, please talk with Sandra or Hugo. By sharing the requested information, you will help us be sure that this type of group was helpful to your child.

Please return the questionnaire in the enclosed envelope. Thank you for your help.

Sincerely,

Sandra Black, M. Ed.

Hugo Kamya, Ph.D.

PARENT QUESTIONNAIRE
POST-GROUP

A. Please check YES or NO:

	YES	NO
1. Do you know someone who is HIV positive?		
2. Do you know someone who has AIDS?		
3. Is this person a family member?		
4. Is this person a family friend?		
5. Is this person a friend of yours?		

B. Because of your family involvement with HIVand/or AIDS, please check which applies to your child:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER
1. He/she seems isolated					
2. He/she seems confused					
3. He/she seems stigmatized					
4. He/she seems angry					
5. He/she seems frightened					
6. His/her feelings affect behaviors at home					

C. Please check YES or NO:

	YES	NO
1. This group helped:		
a)him/her discuss problems more openly		
b) his/her behavior at home		

D. Additional comments (Optional):

APPENDIX D
SUMMARY OF
STUDENT QUESTIONNAIRES

SUMMARY OF STUDENT QUESTIONNAIRE

PRE/POST-GROUP

A. Please check YES or NO:

	PRE		POST	
	YES	NO	YES	NO
1. Do you know someone who is HIV positive?	6		3	
2. Do you know someone who has AIDS?	3	3	3	
3. Is this person a family member?	6		3	
4. Is this person a family friend?	2	4	3	
5. Is this person a friend of yours?	3	3	3	

B. Because of your involvement with HIVand/or AIDS, please check which applies to you:

KEY: PR = Pre-group
PO = Post-group

	ALWAYS		OFTEN		SOMETIMES		RARELY		NEVER	
	PR	PO	PR	PO	PR	PO	PR	PO	PR	PO
1. I feel isolated					2	1	1	1	3	1
2. I feel confused	1				3	2	1		1	1
3. I feel stigmatized				1	3	1			3	1
4. I feel angry	1		1		2	2		1	2	
5. I feel frightened					4	1	1	2	1	
6. My feelings affect my behavior	1				4	1	1			2
7. My feelings affect my school work					3	1		1	3	1
8. To help handle my feelings										
a) I talk with my mother			1				3	2	2	1
b) I talk with my father					1		1	2	4	1
c) I talk with my best friend	1						1	1	4	2
d) I talk with a teacher									6	3

e) I talk with a school nurse										6	3
f) I talk with a school counselor					1			1		5	2
g) I talk with a religious leader										6	3

C. Please check YES or NO:

	PRE		POST	
	YES	NO	YES	NO
1. This group will help/helped me:				
a) with my feelings	6		3	
b) with my behavior	4	2		3
c) with my school work	3	3		3

D. Additional comments (Optional):

"I enjoy this group because it helps me deal the anger and frustration that comes from knowing people that are close to me are dying of this virus."

"This has been helpful but it's hard to talk about it."