SUPPORT FOR CHILDREN AND FAMILIES AFFECTED BY HIV/AIDS: A SYSTEMIC INTERVENTION

\mathbf{BY}

THERESA GRAHAM

A Practicum Report
Submitted to the Faculty of Graduate Studies
in Partial Fulfilment of the Requirements
for the Degree of

MASTER OF SOCIAL WORK

Faculty of Social Work University of Manitoba Winnipeg, Manitoba

(C) Copyright by Theresa Graham, July 2003

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

COPYRIGHT PERMISSION PAGE

Support for Children and Families Affected by HIV/AIDS:

A Systemic Intervention

BY

Theresa Graham

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

of

MASTER OF SOCIAL WORK

THERESA GRAHAM ©2003

Permission has been granted to the Library of The University of Manitoba to lend or sell copies of this thesis/practicum, to the National Library of Canada to microfilm this thesis and to lend or sell copies of the film, and to University Microfilm Inc. to publish an abstract of this thesis/practicum.

The author reserves other publication rights, and neither this thesis/practicum nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

"The Wonderful Group"

"I still want to know, why do we have to get HIV?"

By: "Fallon-a"

Twelve years old,

1996

TABLE OF CONTENTS

Page
ACKNOWLEDGMENTS
"The Wonderful Group"ii
LIST OF TABLESvii
LIST OF FIGURESviii
ABSTRACTix
INTRODUCTION1
1. REVIEW OF THE LITERATURE7
HIV/AIDS History, and Transmission7
Psycho-social Issues11
Attachment Theory in Brief13
Impact of Terminal Illness and Death on Attachment14
Anticipatory Grief16
Disenfranchised Grief21
Developmental Stages and Grief Responses: Infancy to Preschool22
Latency Age Children25
Adolescence27
Issues Impacting Child Adjustment to Parental Terminal Illness and
Death31
Social Work Practice and HIV/AIDS36
Interventions with Children and Families40

Group Work41				
Family and Individual Intervention47				
Systems Perspective49				
Summary53				
2. THE PRACTICUM54				
The Team Approach54				
Intervention Overview55				
Group Intervention56				
Family and Larger Systems Interventions57				
Individual Interventions58				
Environment58				
The Referral Process60				
Evaluation Measures61				
Family Assessment Measure -III (FAM III)61				
The Child Depression Inventory (CDI-S)62				
Child Behaviour Checklist (CBCL)62				
Eco-Map63				
Subjective Group Evaluation and Feedback Form64				
Confidentiality64				
The Participants64				
3. GROUP INTERVENTIONS66				
Intake and Pregroup Procedures				

Group Process67
Child Feedback77
Parent Meeting, Feedback and Evaluation78
4. FAMILY SYSTEMS INTERVENTIONS AND EVALUATION79
Family System A79
Intake Information79
System Treatment Summary81
Individual Child Treatment Summary83
Evaluation88
Clinical Observation and Attainment of Goals93
Family System B95
Intake Information95
System Treatment Summary96
Evaluation98
Clinical Observation and Attainment of Goals101
Family System C102
Intake Information102
System Treatment Summary103
Evaluation106
Clinical Observation and Attainment of Goals109
5. LEARNING THEMES110
The Referral Process110

(Group Analysi	is	114
A	analysis of Fai	mily Interventions	120
F	fficacy of Cli	nical Measures	126
7	eam Approac	ch	126
6. CON	CLUSIONS A	ND RECOMMENDATIONS	129
(Conclusions		129
Recommendations			133
REFER	ENCES		135
APPEN	DICES		146
	A Advertis	sement	146
	B Consent	For Treatment	149
	C Permissi	ion for Observation	152
	D Group I	nterventions	154
	E Circle of	f Life Photographs	166
	F Child Fe	eedback Forms	169
	G Families	s Served and Number of Interventions	172

LIST OF TABLES

		PAGE
1.	System A Measure Results	90
2.	System B Measure Results	99
3.	System C Measure Results	107
4.	Families Served and Number of Interventions	173

LIST OF FIGURES

		PAGE
1.	Eco-Map Family A at Intake	91
2.	Eco-Map Family A at Discharge	92
3.	Eco-Map Family B at Intake	100
4.	Eco-Map Family C at Intake	108

ABSTRACT

This practicum report describes systemic interventions with AIDS affected children. Over a period of ten months, two children's support groups, as well as individual and family support sessions were conducted for three family systems experiencing multifaceted issues while living with HIV/AIDS in the family. This report focusses on the children's support group and family systems interventions with three families. Therapy with individuals and subsystems were incorporated to facilitate supportive family relationships and integrate treatment issues. Systems concepts were combined with play and family therapy models addressing such issues as: HIV/AIDS education; secrecy; stigmatization; peer, family, and community support; empowerment; boundary establishment and roles; anticipatory grief; communication; and the development of coping skills. This practicum also recognized the importance of a team oriented approach to therapy as well as coordination of services with the larger community.

The general conclusions are that group support for AIDS affected children, coupled with individual, family, and systemic intervention were beneficial to the families involved in this practicum. The benefits included an improvement in family and individual functioning as well as a reduction in isolation. The group dynamics became a sibling composition, however group and individual goals were met and all children reported having a positive experience.

INTRODUCTION

There were a number of reasons for me to return to university to complete graduate studies. The first is the fact that working with an undergraduate degree in Social Work for five years gave me solid clinical skills and knowledge base which provided me with a framework to challenge my further education. Secondly, the experience and knowledge I gained from clients, fellow social workers, and interdisciplinary teams had been invaluable and I believed a graduate degree would enable me to have an expanded sense of self and the Social Work profession. Lastly, I felt that I would be able to provide future clients with better service should I challenge my current belief system.

My intent with this practicum was to fill a gap in service to clients in Manitoba. As much of my background has been working with families, children and small groups, I sought to design a practicum which would expand my experiences in all of these areas. I did not realize where my journey would take me nor the amount of inner soul searching, sorrow and joy I would find.

It was evident that a large gap in services existed regarding families living with Human Immunodeficiency Virus (HIV) and Acquired Immuno Deficiency Syndrome (AIDS). This was confirmed through community contacts with several AIDS organizations and caregivers to individuals with HIV/AIDS. When this practicum was established, there were very few services to families; and services related to negative children of HIV positive parents did not exist in Manitoba. The gap in treatment literature in Canada and the scarcity of it universally, prompted me to explore this issue in-depth. Preliminary research findings indicated that support groups aided in reducing the stigma

and isolation felt by these families. It was also apparent that group support must be matched with family systems interventions. This type of practice approach with this population could be beneficial on a larger systems scale (Antle 1998; Aronson, 1994; Canadian Children With Positive Parents, 1994). Therefore the purpose of this practicum was twofold: 1) to provide support groups to children of parents with HIV/AIDS; and 2) to provide support to parents of group members.

The learning goals of this practicum were as follows:

- 1. To effectively utilize play therapy techniques in a group format;
- 2. To gain competence working with children and families living with HIV/AIDS;
- 3. To increase my knowledge of and become sensitized to the impact of HIV/AIDS;
- 4. To work cooperatively with community agencies in facilitating services to children and families living with HIV/AIDS;
- 5. To increase clinical skills in family, individual and group therapy;
- 6. To implement and assess the efficacy of evaluation measures.

This practicum report provides an account of over two years of preparation, intake, implementation and research, including ten months of direct service. The learning goals as listed above were met, however it is important to note that much of the learning was beyond the scope of the goals and will be discussed throughout this report. The overview of the literature available in the area of HIV/AIDS and the lack of research pertaining to negative children of HIV positive parents or persons with AIDS (PWA's), is evident in chapter one. The practicum report is aimed at assisting the practitioner to understand the complex phenomena of HIV/AIDS in order to help those who live with the

affects of HIV/AIDS. The first section of chapter one provides a knowledge base and a brief history regarding HIV/AIDS research and services currently available to individuals and families in general. The practitioner's ability to differentiate between facts and fallacies as well as the varying treatment modalities lends to one's credibility within the HIV/AIDS field. The report provides a discussion of the modes of transmission and education as well as the effects of the disease and treatments available.

The second section provides an overview of the salient psycho-social issues that the literature highlights as relevant regarding parental disclosure of HIV status to children. Issues of developmental age and stage, coping abilities of children and parents, available supports and family structure will be addressed in relation to disclosure. External issues such as social rejection and discrimination will be discussed in relation to stigma, ostracization and isolation in the community. The impact of family secrets on the child and family relationships will be addressed. Relevant research in areas of family shame and secrecy are included. Theoretical constructs of attachment theory are briefly discussed in the report as it is important for the practitioner to have an understanding of what healthy attachment involves, if one is to recognize and deal with specific reactions as a result of multiple separations and losses.

The third area in this section is anticipatory grief in relation to children and the impact this grief has on the family. HIV/AIDS is a deadly disease, however treatment interventions are moving HIV toward a chronic illness. Hence the practitioner needs to be aware of the impact anticipatory grief and multiple losses have upon the family throughout the life cycle. A review of children's grief reactions relating to developmental age and

stage is undertaken. Denial will be addressed as a coping mechanism and a discussion of attachment theory and the impact of anticipatory grief upon attachment including the issue of complicated grief or disenfranchised grief in children is addressed. The term "AIDS Orphans" will be discussed as well as the issue of grief counselling with children. A fourth section deals with vicarious trauma and the impact HIV/AIDS has on the individual worker and how burnout can be avoided in this challenging yet rewarding field of practice. The importance of co-facilitation will also be addressed as a strategy for support and clinical enhancement.

The final area in this chapter focuses on interventions with children and families. This section provides the practitioner with an introduction to several models of interventions with children and families living with HIV/AIDS. The practice models include family systems theory, group work utilizing play therapy as well as social and international systems. A review of studies directly focussed on the support of children of HIV positive parents is examined. The effectiveness of the work with the children is discussed to provide the practitioner with case examples that describe and discuss salient issues regarding how children deal with HIV in the family and how helpers can work with the family. The issue of sibling subsystems within a family is considered. Family systems theory as it relates to HIV/AIDS in the family will be discussed. A final section in this chapter is the review of the systems perspective that provides an arena to discuss the impact of larger systems upon families and how the practitioner can intervene in a therapeutic manner. The conclusion of chapter one highlights the areas addressed and integrates the theoretical constructs presented. It will also provide the reader with my

own conclusions about group interventions based on the literature presented.

Chapter two will review the practicum including teamwork, goals and objectives, outline interventions, the environment as well as the amount of advertisement, time and energy that went into the referral process. Other areas in this section will include the method of evaluation and issue of client confidentiality. Chapter three discusses the specific intake and pre-group procedures and objectives for groups one and two pre-group sessions; group process and analysis. The child and parent feedback and an evaluation of the program is undertaken. Chapter four provides an in-depth synapsis of family systems interventions. A review of the intake information, system treatment summary and individual child treatment summary will be addressed. Additionally an evaluation of the measures implemented and an examination of the clinical attainment of goals are considered.

Chapter five provides an overview of my learning objectives. My belief that the HIV/AIDS community would embrace support services for these families and subsequent learning in this area is discussed. The difficulties in reaching the target population and the possible reasons for this phenomenon will be examined. Systems within Manitoba and Canada will be addressed in order to come to some understanding of the barriers and what may need to occur in order to overcome these obstacles. The positive aspects of the systems involved will be established. The team approach and the significance to this practicum as well as my learning experience is considered. Overall conclusions are reported in chapter six. Reflections are made on the entire practicum experience and the most valuable and salient information within the report is highlighted.

This practicum report serves as a detailed record of the search to fill a gap in services to families living with HIV/AIDS, in particular, services for negative children of HIV positive parents. This report goes beyond a description of family systems interventions to a consideration of the systemic interventions necessary in order to fill gaps in service.

CHAPTER 1. REVIEW OF THE LITERATURE

HIV/AIDS History, Transmission, and Impact on the Family

The current AIDS research literature pertaining to AIDS affected children is limited. AIDS has a recent history dating back to 1981 in North America (AIDS Care and Treatment, 1994). Research and services were initially focussed on transmission, testing, education and support for person's with AIDS (PWA's). In order to understand how HIV and AIDS impacts upon the family it is important to provide a brief overview of how this disease progresses. The following medical information was taken from AIDS Care and Treatment, 1994; AIDS-Info.com, 1998; Johnston, 1994; and Patterson and Robichaud, 1996. HIV stands for Human Immunodeficiency Virus. HIV is a retrovirus, which means it has the ability to attach itself to a host cell and replicate itself. Once HIV is transmitted into the body, it lives and multiplies in the CD4, also known as T4 helper cells. These cells assist the body in protecting itself against disease. HIV then changes its RNA into human double stranded DNA. This DNA may also begin to reproduce its own RNA again. This process occurs in large numbers of T-cells and eventually HIV takes over and destroys these cells. When HIV has destroyed enough immune cells the body is unable to fight off many infections. It is important to note that this process can take up to ten years to begin affecting the body. There are known cases of people with HIV infection to be asymptomatic for up to twenty years. Asymptomatic means that the person does not have any HIV related illnesses and she/he may not be aware that she/he is HIV positive. The only way to know if a person is carrying the HIV antibody is through testing. A person can be infected today, be tested immediately and they could receive a false negative as the

HIV antibody can take up to three months or longer to produce a seropositive status.

AIDS-Info.com (1998) reports approximately seventy percent of infected people show initial symptoms of HIV infection through a sore throat, headache, fever and swollen lymph nodes which persist for approximately two or three weeks. Many people believe they have the flu although this stage is referred to as the acute stage of infection. As a person becomes symptomatic by the depletion of healthy T cells, the body begins to demonstrate visual and more chronic symptoms. Some of these include weight loss, fever, night sweats, fatigue, diarrhea, thrush, swollen lymph nodes, Peripheral Neuropathy, (described by Patterson and Robichaud (1996), as a condition which results in pain at the nerve endings, the legs and muscles become weak resulting in difficulty in walking and balance), Pelvic Inflammatory Disease which is common in women, and oral ulcerations. This list of illnesses is not exhaustive; however the most common have been presented.

The final stage of HIV infection is AIDS. AIDS stands for Acquired

Immunodeficiency Syndrome. The diagnosis of AIDS occurs when a person develops an opportunistic infection or when her/his T4 cell (or CD4 cell) count is below two hundred. These people have very weak immune and nervous systems and often experience several life-threatening infections within a span of months. It is important to note that many people take medications to maintain an undetectable or very low viral load which improves survival and quality of life for those living with HIV and AIDS. As well, many people living with HIV and AIDS have turned to Naturopathy and Therapeutic Touch as a system of medicine as their primary mode of health care or in conjunction with conventional means of medical care (Wynott, 1997). People do not die of AIDS, rather it

is the complications created by the process of AIDS that causes people to die. As Health Canada's Annual Report on AIDS in Canada (December 1996) states, 14,185 cases of AIDS have been reported in Canada. However this number is estimated to be approximately 20,000 cases. The report also states approximately seventy-two percent of the reported cases have resulted in death. Health Canada (December 1996) also reports the total number of persons infected with HIV virus by the end of 1994 in Canada was approximately forty-five thousand people. Manitoba Health (1996) reports that the total number of individuals who tested HIV antibody positive in Manitoba between 1985 and 1996 was 563. In this same period 146 persons were diagnosed with AIDS and 112 people died as a result of AIDS related illnesses. (Health Canada, 1996; Manitoba Health, 1996).

A final issue which is vital to cover in this report is the myths and facts regarding transmission (AIDS-Info.com, 1998; AIDS Care and Treatment, December 1994;

Johnson, 1994; Patterson & Robichaud, 1996). It is a common fallacy that there are categories of people who are more prone to become infected with the HIV virus than others. It is important to note that there are behaviours which place people at risk for HIV transmission rather than a category of persons. HIV is considered to be a bloodborne, sexually transmitted, infectious disease. There are several behaviours an individual can engage in that increases one's susceptibility to the transmission of HIV. Two of the highest risk activities are unprotected sexual intercourse, including vaginal, anal and oral intercourse and, sharing infected needles or instruments as blood can remain in these objects and can transmit the virus into a partner. Another mode of transmission is maternal

to child; babies born to HIV infected mothers either carry the mother's HIV antibodies or the HIV virus itself. Mother to child transmissions can occur in three areas: in utero, as the fetus is developing inside the mother; during delivery, where there is an ingestion of maternal blood and infected fluids or during breastfeeding. It has been proven that after eighteen months, the babies will either rid themselves of the HIV antibodies or the baby will continue to test seropositive and become clinically sick. Infants with an AIDS diagnosis have a much lower survival rate than adults with AIDS. Prior to 1985 the HIV antibody test was not available to the general public to screen blood donations, therefore increasing the risk of transmission by blood transfusion. Since that time all blood and blood products donated to hospitals or blood banks have been tested and donation centres have become a source for individuals to discover his/her HIV status. Presently there is a low risk of transmitting the HIV virus through blood transfusions or blood products such as organ transplants and artificial insemination.

Individuals can not spread the HIV virus through hugging, insect bites, swimming pools, kissing, shared utensils, mutual masturbation, food handling, spitting and biting, or toilet seats. The HIV virus is actually quite fragile and dies with heat, chlorine, and open air. As previously discussed, HIV is transmitted through body fluids and the recipient needs to have an open wound or sore which comes in contact with the infected person's blood. It is important for all individuals to use universal precautions when handling any body fluid of another person. These precautions include the use of latex gloves when assisting anyone, regardless of whether they are known to be HIV positive or a person living with AIDS (AIDS-Info.com, 1998; AIDS, Care and Treatment, December 1994;

Johnston, 1994; Patterson & Robichaud, 1996). Latex condoms and dental dams will decrease a person's risk for HIV infection, however the only one hundred percent method is to abstain from sexual intercourse completely. People who are HIV positive, or living with AIDS, need society's continued support and understanding. Educating oneself about the realities of this disease is important, as is realizing that this disease affects everyone regardless of age, race, gender or sexuality.

Psychosocial Issues

Recently, the impact on children in families living with HIV/AIDS has also begun to be noticed. There are several significant articles which address the impact of HIV/AIDS in families and the needs of these children. The articles describe the salient psycho-social issues which include fear of disclosure (Lewert, 1988; Lipson, 1994; Stulberg & Buckingham, 1988). There is much controversy regarding the disclosure of a parent's HIV status to children. Families need to determine what is best for them. However, this determination needs to be decided with several considerations in mind including the children's developmental age, coping abilities, the amount of social support available and family structure. (Lipson, 1994; Mellins & Ehrhardt, 1994; Melvin & Sherr, 1993;). In many circumstances parents do not disclose for fear of the consequences for their children such as social rejection and discrimination. Dansky (1994) states:

HIV disease within a family system has important consequences for children who are protected from illness-related information and who may be isolated and excluded from major family decisions. A 'Web of Silence' surrounds the family, and children observe parental anxiety, preoccupation, physical absence, and illness,

and death with poor information, so they lose confidence in their parents and become anxious about their future. (p. 195)

Other issues include stigma, ostracization and isolation (Aronson, 1994; Demb, 1989; Roth, Siegel, & Black, 1994). Children who are informed of a parent's HIV status find there may be a need to keep the disclosure a secret. Society is not yet at a place where PWA's and their families can disclose without fear. The community is often uneducated about the transmission of HIV/AIDS and react to children and families in a state of fear and panic ((Lewert,1988; Lipson,1994; Stulberg & Buckingham,1988). This leads to isolation from peers and the community. Many of these children experience depression or act out as they can not readily share their feelings (Fietz & Andrews, 1991; Lynch, Lloyd & Fimbres, 1993; Roth, Siegel & Black, 1994).

Denial is a defence mechanism used by adults and children and is defined as the refusal to accept the reality of a situation. Denial is used for a variety of reasons. Halperin (1993) proposes that children of PWA's use denial to protect themselves from the stress of chronic problems and it aids in the organization of their "shame" of the illness, placement in foster care and ultimately parental death. Denial also provides the family with hope and a positive attitude. Kubler-Ross (1969) states "one cannot look at the sun all the time; sometimes it is necessary to put away consideration of death in order to pursue life." Lewert (1988) believes there is a tendency in families to deny and evade the inevitable ramifications of AIDS and workers need to work with the family system in a respectful manner. Stulberg and Buckingham (1988) support the belief that maladaptive denial in a family system can severely complicate grief.

Attachment Theory in Brief

The next section examines the impact of parental terminal illness and death on childhood attachment. It is important for the practitioner to understand the meaning of secure attachment in order to recognize and confront issues of specific reactions resulting from multiple separations and losses in the lives of children living within the realm of HIV. I needed to have a solid understanding of the developmental stages and grief responses across childhood to allow intervention to occur in an appropriate manner. Issues regarding the implications of anticipatory grief and grief reactions at three developmental stages are discussed and a summary of the issues which can influence a child's adjustment to parental death will be addressed in the next section.

The basic assumption of attachment is that a child's primary relationship with a caregiver, most often the mother, predicts the future strength of affectional bonds to significant others (Bowlby, 1977). Bowlby further states that separation and loss from the primary attachment figure can produce emotional reactions of anxiety, anger, depression and emotional detachment. These reactions are related to the breaking of the affectional bond. Pearce and Pezzot-Pearce (1994) states that the degree in which caring relationships and social supports are viewed positively by an individual, greatly depends upon the internal working model gained by earlier experiences. The internal working model is described by Bowlby (1977) as a representational model of attachment figures and self. Children are viewed by Bowlby to use this framework as a base to compare and fit all other attachment experiences. Belsky and Nezworki (1988) states:

If an attachment figure frequently rejects or ridicules the child's bids for

comfort in stressful situations, the internal working model of the child may come to develop an internal working model of the parent as rejecting but also one of himself or herself as not worthy of help or comfort.

Conversely, if the attachment figure gives help and comfort when needed, the child will tend to develop a working model of the parent as loving and of himself or herself as a person worthy of such support. (p. 193)

Brownlee (1994) states that it is a basic emotional need for all children to form secure attachments to a primary caregiver. Attachment is defined as a bond of caring and craving that ties the child and caregiver to one another. According to Brownlee, children form multiple attachments; however, due to selective bonding, they have the strongest attachment to their parents. She also states that attachments formed through high quality and continuity of care giving provides an environment in which children grow with a secure and loved feeling. This security enables children to separate from the primary caregiver later in development. There are many situations which can cause disruptions to a child's attachment relationship. These include separating due to alternate care situations, adoptions, parental divorce, children's repeated hospitalizations and parental/primary caregiver terminal illness and death (Belsky & Nezworski, 1988; Brownlee, 1994; James, 1989; Melina, 1988; Seigal & Gory, 1994). The balance of this section will focus on the impact of parental terminal illness and death.

Impact Of Terminal Illness and Death on Attachment

The terminal illness of a parent has a profound impact on children. Drotar (1994) identifies two main factors which determine a child's psychological response to their

parent's health problems. The first factor is developmental influences, which addresses the ability of the child to understand and respond to parental health problems. Children experience individual effects of their parent's illness due to age related differences in coping, roles in the family, and peer interaction opportunities. The second factor is compensatory factors which include the family's ability to cope with the effects of the illness and the stage of the parental illness. Children who have negative, conflictual and exclusive relationships with caregivers who are overburdened, encounter different coping styles and relationships than children who have alternate caregivers. The alternate caregivers provide children with the opportunity and ability to create positive relationships outside the family unit.

James (1989) states that children who experience attachment disturbances in early childhood due to parental death may develop maladaptive coping strategies. The author further states that children can become attention seeking, clingy, rebellious, distant and can develop an inability to trust. She notes that the severity and length of the attachment disturbance is influenced by the quality of attachment prior to the loss. Brownlee (1994) support James' view of attachment disorder and states that children can have a number of responses to primary caregiver separation including acute and chronic distress, conduct and emotional disorders, learning difficulties and a deterioration of social relationships.

Masur (1991) states the original alliance between a mother and child is the most significant of relationships. The authors view the alliance as a foundation for all subsequent attachments which enables the child to gain a sense of her/himself. The authors further state that interruption of the relationship during the early stages of life can

have devastating effects on the child's future interpersonal relationships and personality development. Masur believes that the warm, intimate and continuous relationship that an infant experiences with her/his mother, which is both mutually satisfactory and joyful, is essential for infant mental health. According to Masur (1991) a child who experiences parental death enters into a unique and dangerous situation. The impact of parental death on a child is individual and the way in which the child attempts to cope is critical in shaping his or her future personality.

Freeman (1984) states that there is an increasing number of children who are experiencing grief through bereavement and separation from parents. She points out that adults in society lack awareness the number of children who have experienced the death of a significant other. Freeman also states that the lack of knowledge is a result of a massive denial of death in our society and the taboos which forbid discussion of grief reactions leads to children's experiences of grief to be a hidden phenomena.

Anticipatory Grief

Van Dexter (1986) defines anticipatory grief as the process of normal mourning that occurs in anticipation of death and its consequences. She states that children and families who are informed of the diagnosis of terminal illness are immediately confronted with the crisis of the knowledge of death. According to Webb (1991) anticipated crisis is a gradual buildup of a stressful event. This event has a predictable outcome and allows the child to gradually comprehend and assimilate the impending transition or loss. The terminal illness of a family member is noted by Webb to be an unanticipated crisis.

Barton (1977) states that children, regardless of age and the child's relationship with the dying family member, are affected by parental death. There are a number of factors which Barton views as impacting on a child's adaptation to the dying and death of a family member. These factors include age, stage of development, pattern of closeness or relatedness, need for dependency and nurturing and changing identification with one or the other parent. Barton also believes children confront the dying and death of a family member and react according to their own level of understanding and ability to integrate the experience. He further states that the grief process of the family begins either the moment the life threatening illness is suspected or upon diagnosis by a doctor.

According to Rando (1984) there are inhibitors in a child's ability to deal with anticipatory grief. These inhibitors include the inability of the parent or adult to mourn; a lack of a caring environment for the child; confusion on the part of the child regarding the illness; the child's ambivalence toward the dying person; an inability of the child to express feelings verbally; instability within the family unit; adolescent issues which exacerbate normal conflicts; and emotional problems and intellectual limitations such as a developmental disability.

Children's coping abilities are significantly influenced by their home environment and upbringing (Van Dexter, 1986). Children who are permitted to openly share and be involved in dealing with the loss directly are viewed by Van Dexter as being better able to cope. Children who are denied the right to grieve are excluded from significant events such as activities with the ill parent and arrangements for impending death and will ultimately have increased difficulty with the final loss. This is due to the child being

unable to prepare for the loss. The type and length of illness are also factors which can complicate anticipatory grief. Walker, Pomeroy, McNeil, and Franklin (1996) discuss Rando's (1986) contention that there is an optimal period of time (between six and eighteen months) in which anticipatory grief is considered to be beneficial to grievers. Walker et al. (1996) states that the course of HIV/AIDS often goes beyond the eighteen months of time for beneficial anticipatory grief. Walker et al. (1996) identifies two significant factors that can also complicate anticipatory grief which are multiple losses and social stigma. The first factor is multiple losses. Walker et al. (1996) describes one loss as health, stating individuals diagnosed with HIV often progress rapidly to AIDS. The person with AIDS then cycles repeatedly between periods of health and the fighting of opportunistic diseases. Multiple losses complicate anticipatory grief. Family members of persons with AIDS experience significant, yet not always apparent, losses prior to the death of the loved one. Children need to learn to cope with parental dementia which often begins with memory loss and progresses to rambling and periods of lucidness. The parent has a decline in physical appearance and the child may lose the parent as a social convener as the parent becomes physically unable to participate in activities outside the home with the child. The stigma attached to the disease of AIDS will also impact on the parent's ability to partake in community activities. The child also copes with the loss of parental support due to the many separations that are caused by hospitalizations of the parent (Aronson, 1994; Seigal & Gory, 1994; Walker et al., 1996). Many times children are also dealing with the multiple loss of other significant relationships in their lives. This can include the death of other family members and loss of community relationships; Kalish

(1985) terms this bereavement overload. The literature labels these children AIDS Orphans (Ankrah, 1993; Foster et al., 1995; Levine, 1995). The majority of research in this area focuses on maternal loss due to single parent families. However, the literature does recognize the issue of paternal loss and multiple losses, such as death of sibling, extended family and friends. These additional losses can include loss of familiar environment, due to foster care or other care situation. Families also deal with potential losses such as couple relationship, partner, parent, health and future (Fanos & Weiner, 1994; Salter, King, DeMatteo & Bergman 1994; Seigal and Gorey, 1994).

The second factor is the social stigma frequently attached to the person diagnosed as being HIV positive or having AIDS. This stigma has also been labelled "courtesy stigma" by Goffman (1963) as cited in Siegal and Gory (1994), which he states extends to family members including children. Children with a terminally ill parent are frequently the target of ridicule by peers who taunt and discriminate against them. This type of stigma can have serious effects on a child's emotional well-being, social competence and achievement. According to Walker et al. (1996) this stigma can impede anticipatory grief in a number of ways. Firstly, the caregiver or family member may respond to the stigma and devalue the person with AIDS or attempt to move through the grief process quickly by detaching from the ill person. This detachment can lead to severed or strained attachments to the loved one and in turn complicate grief reactions and subsequent attachments.

Another consequence of stigma is the secrecy that surrounds the illness. Walker et al. (1996) states shame, guilt, embarrassment and anger keep the family member grieving

secretly. Families need the support of others in order to enter into anticipatory grief and the secrecy does not allow the facilitation of outside resources. Siegal and Gory (1994) state that children believe that something shameful has occurred due to the secrecy that surrounds parental diagnosis of HIV or subsequent death. The authors describe a study by Draimin, Hudis and Segura (1992) in which the results showed all of the adolescents participating in the research indicated they did not disclose their mother's HIV diagnosis to anyone, not even to their closest friends. Salter et al. (1994) states that families living with HIV have to deal with the invisible but real barriers between PWA's and their natural, informal social support networks. Salter et al. (1994) found that this barrier creates secrecy in order to protect the family which in turn leads to additional stressors on the family. "These additional stressors are thought to act like a domino effect on the families: 1) stigma leads to 2) secrecy, which leads to 3) isolation, which leads to 4) lack of support and services" (p. 43).

Stulberg and Buckingham (1988) states that secrecy drains family members' energy and causes tension between the dying person and the family. This tension is perceived to generate unfinished business at a point when time is relatively short. Walker et al. (1996) states that it is the goal of the social worker to discourage premature detachment of the family from the person with terminal illness. Interventions need to be designed to assist in the grieving process but not to do it so well that the family withdraws from their loved one prior to death. Salter et al. (1994) states that isolation results in lack of support and services to the family as a whole and workers need to be aware of how to work with the entire family system.

Disenfranchised Grief

Many children cannot openly share that their parent died from AIDS due to social stigma and fear of contagion. Worden (1991) discusses three social factors that complicate grief: 1) the loss is socially unspeakable; 2) the loss is socially negated; and 3) the absence of a social network. These three factors are prevalent in the lives of HIV affected children. Doka (1989) defines disenfranchised grief as grief that cannot be openly acknowledged, publicly mourned or socially supported. Doka believes that disenfranchised grief occurs for three reasons. The first is the relationship to the deceased is not recognized. Many children are excluded from the family grieving process by adults who may be well-meaning and loving in their decisions yet ultimately misguided. Other times children are excluded due to a lack of parental understanding or information and the parent's own death anxieties impact on the recognition of childhood bereavement. Parents are often caught up in their own grieving process and fail to recognize that the child also had a relationship to the deceased (Doka, 1989).

The second reason is the loss may not be recognized. An example of this loss may include a child who has been informed of parental pregnancy and the birth does not occur or the parent dies in childbirth. The surviving parent may be able to grieve their dual losses openly and receive community support. However the child may grieve not only the loss of the mother but also the loss of a sibling which may not be recognized as significant.

The third reason Doka also noted is that the griever may not be recognized.

Children are often not viewed as being capable of grieving. There is little or no social recognition of his or her sense of loss and need to mourn. Many times children are sent

out of the home during times of grieving. The parent again lost within her or his own grieving process, does not recognize the child as either being capable of experiencing grief or having their own grieving process.

Developmental Stages and Grief Responses

Infancy to Pre-school

Children under the age of five have an idea that death exists; however they are unable to understand its finality (Worden 1991). This lack of understanding is due to the child's inability to formulate cause and effect and object constancy. Bowlby, as cited in Worden (1991), believes infants are capable of grief, as the separation from the attachment figure triggers grief reactions. Infants who are very young cry and show signs of distress due to the withdrawal of life giving needs that were provided by the deceased or absent mother. An alternate caregiver can quickly soothe the separation reaction (Rando, 1984). Lieberman and Pawl (1988) states that a child's coping mechanisms can become overpowered when triggered by intense anxiety related to separation from the caregiver. The separation can have negative long term consequences for the child's personality development and the ability for the child to form lasting and trusting relationships. Lieberman and Pawl (1988) views the attachment work of John Bowlby (1980) and Mary Ainsworth (1982) as a useful framework for understanding the impact of separation and loss from the primary attachment figure on infants and future development.

Infants from the ages of four months express bereavement through nonspecific distress which is an ongoing reaction to the absence of the infant's mother (Worden, 1991). Rando (1984) views this reaction as the earliest indication of grief. She clarifies

the reaction by this statement "although this child probably lacks any true internal image of the mother, part of him responds to the absence of the mother as specific person" (p. 157). Masur (1991) believes children can begin to mourn after the stage of object constancy is established through an internalized image of the mother. Masur (1991) views children in early childhood and infancy as being able to clearly understand the reasons for parental death. She states that children's perceptions of loss, understanding and coping abilities are determined by the age and stage of development a child is at when he or she experiences a significant loss. Children may also encounter difficulties later regarding separation and independent functioning.

Rando (1984) describes the separation of the infant from the mother according to Bowlby (1980). The child ages six months to two years experiences shock which is followed by a protest about the separation. This protest is viewed as the child's attempt to return the mother and to prevent a reoccurrence of the event. As the child's need for the primary attachment figure is not met, his or her despair increases and recollection, longing and pain are the result. Children are unable to sustain the behaviour as his or her 'immature ego' can't sustain prolonged yearning and eventually the child gives up looking for the mother. The despair and sadness become apparent through a lack of interest in normal activities which have provided joy to the child in the past. If an alternate caregiver does not provide the child with an opportunity to reattach, detachment from all adults can become constant. This can result in children who have difficulty forming meaningful relationships throughout all developmental stages. This can also have ramifications into adulthood. Exaggerated separation responses are often displayed by the bereaved child

such as clinging, screaming, refusal to separate from other attachment figures, constant distress and eating and sleeping disturbances. Raphael (1983) as cited in Rando (1984) states:

It is at this age that the infant is first inconsolable for his 'own and only mother' whom he has lost. No other person can replace her, can take away the anguish of his screams, at least initially. So no matter how much comfort and consolation is offered, it is not what he wants. He wants simply her . . . The cry of the infant's anguish awakens every fibre of our response to hold and comfort him. It reawakens the pain of our own inner experiences of separation and fear. Yet our comforting does not ease the pain, at least initially, for he wants only her. Yet it is only with our comforting that the pain will eventually ease and he will be supported to accept his loss, to relinquish the bond. This same pattern applies to bereavement throughout the life cycle, but never so poignantly as at this early stage. (p. 158)

Infants from the ages of eighteen months have an understanding of death as a disappearance rather than a final loss. The child at this age is egocentric and the loss will be impacted by this stage of development and therefore the child may feel responsible for the parent's disappearance. The loss of a parent at this stage of development can interfere with the integrated internalized image of the parent (Masur, 1991). Children's grief at this age is also intermittent, alternating between periods of apparent non-reactions and an expression of regressive behaviour such as clinging and demanding behaviour. Children's

aggressive behaviour may increase due to the feeling of desertion and oftentimes results with chaos in the family. Much of this anger is directed at the surviving parent. A child's anxiety over the death can be heightened by additional losses such as parental grief, environment and loss of the view of life as secure and predictable.

Hurley (1991) reports on several studies that found relationships between early childhood parental loss and an older child's increased risk for suicide or depression. This suicide and depression risk can either be a direct result of the loss, or lead to an increased vulnerability to later life stressors. Hurley (1991) states that the impact of the loss depends upon family dynamics prior to the loss and how quickly the family can reorganize and meet the needs of the child after the death.

Latency Age Children

Rando (1984) states that children ages five to eight have a cognitive understanding of death and its implications. Siegal and Gory (1994) states that children in the latency age begin to grasp the finality of death and by age eleven, the causes of death can be understood.

There are diverse reactions in children to bereavement. The death of a parent is also viewed as final and inevitable. The authors argue that children grieve, however there are two main differences between adult and child mourning. The first difference is that children grieve to accept and avoid the reality of death. Children of this age know their parent is deceased and they work hard to maintain a relationship with the dead in order to work through emotional pain. Adults however, attempt to detach from the memories and hopes of the dead. Silverman, Nickman, and Worden (1992) support this premise and

defined this need for connection with the deceased as an internal representation of the dead. This connection permits the child to mourn the deceased by remembering both publicly and privately. At the same time the child can integrate her/his memories into her/his present life and in new relationships with others.

The second difference between adult and child mourning is the fact that children grieve intermittently whereby adults mourn on an ongoing basis. Children outwardly express emotion and then have periods of time when they do not seem to acknowledge parental loss. Children are viewed by some as being limited in their ability to deal with the emotional impact of the loss over an extended period of time. Rando (1984) notes that latency age children tend to hide their feelings of grief in order to appear mature. These children express grief privately, crying and releasing feelings without adult support. Many adults view these children as being uncaring, unloving and unaffected. This exacerbates the child's sense of loneliness when adult support and comfort is withheld. Latency age children need permission to grieve openly. In order to cope with their loss many children develop a strong fantasy life in order to maintain a relationship with the deceased. Schowalter (1975) states that children who experience loss in preadolescence find the loss extremely painful. These children have some cognitive limitations in their ability to accept the reality of the loss and tend to idealize, identify with and cling to the image of deceased parent. The child is viewed by the author as being unable to face the intra psychic separations that are part of the mourning process.

In younger children, regressive behaviour such as thumb-sucking and bed wetting are common reactions to loss. The child may experience anxiety and fear of separation

from other loved ones which results in clingy and dependent behaviours. Expression of anger may be demonstrated through aggressive behaviour, temper tantrums and disciplinary problems. Children who are grieving can also experience physical symptomology such as headaches and appetite loss. School difficulties are also identified due to difficulty in concentration and grief related behaviour which not only affects academic performance but also peer relationships. Children's grief reactions can cause a number of other life problems which can include excessive withdrawal, repeated anger outbursts and involvement in repetitive, ritualistic and symbolic acts (Barton, 1977; Cook & Dworkin, 1992).

Other authors report that children act out behaviourally when they are unable to effectively relate their feelings of sadness, anxiety and fear of separation (Chachkes, 1987; Elizur & Kaffman, 1983). An alternate reaction can be a total emotional withdrawal. Younger children are also more likely than older children to show a declined interest in normal daily activities and they have increased tantrums and bed wetting (Chachkes, 1987; Elizur & Kaffman, 1983).

Latency age children do grieve and have many reactions to parent illness and death. Parental recognition of children's grief, as discussed previously, has a great impact on how children cope with parental loss. It is apparent that children of this age grieve quite differently than adults. It is important to understand the child's developmental stage and age in relation to the grieving process (Chachkes, 1987; Elizur & Kaffman, 1983).

Adolescence

According to Kalish (1985) adolescents have an increased cognitive capacity and

emotional response to understand their experiences. Death seems remote to children in early adolescence, it is recognized intellectually yet seems remote. Moore and Herlihy (1993) states that the challenges of bereavement are different for teens than they are for children because adolescents are simultaneously struggling to work through their adolescent developmental tasks as well as attempting to deal with their bereavement. The authors viewed adolescents as being capable of complex and abstract thought which enables them to view death on a level similar to adults.

Van Dexter (1986) reports the adolescents' ongoing tasks of development can preclude mourning during parental terminal illness. The teen may be attempting to promote autonomy through rebellion during a parent's diagnosis of terminal illness and this can trigger the adolescent's feelings of guilt or resentment. Adolescents are also extremely concerned with peer acceptance and belonging. According to Van Dexter, adolescents become alienated due to lack of knowledge of social expectations. Teenagers are unsure of the 'rules' that determine appropriate behaviour during parental illness and can become isolated and depressed. Adolescents have an understanding of the future effects of death and can envision the absence of the loved one from important events yet to come such as graduations, weddings and other milestones. Adolescents who can not grieve directly may demonstrate it through 'exaggerated pseudo-adult behaviours' such as an identification with the dying person. The teen becomes over identified with the dying parent and can begin to sacrifice his or her own development in order to fulfill the need of the ill parent or other family members. Siegal and Gory (1994) states that older children with younger siblings often become the primary caregivers during parental illness. The

authors believe that the dependency on and attachment to older siblings can become very strong. According to Levine (1995) this phenomena is defined as 'skip-generation' parenting, when generations other than the parent assume responsibilities different from the norms of family life. The parentified adolescent can encounter positive effects from caregiving by learning skills such as family management, responsibility and nurturing. However the negative effects can result in the child becoming overburdened and resentful.

Adolescents can demonstrate grieving through withdrawing from peer and family relationships which often results in depression. Wolfenstein (1966), as cited in Podell (1989), reports his findings that adolescents tend to develop 'hyper cathexis' to a lost object and they hide their feelings of despair and sadness. This is caused by an inability of the adolescent to detach from the deceased. Van Dexter (1986) also identifies that adolescents can act out their grief and concern for the ill parent behaviourally. This can include acting out sexually, engagement in self punishing behaviour and behaving in a manner which elicits a response from caregivers which aids in the release of tension.

Many times the grief of adolescents goes unnoticed by family members as the grief is not presented clearly. The adolescent's grief is often viewed as an expression of developmental conflicts or acting out in response to the family's disorganization (Podell, 1989).

Rando (1984) states that adolescents often feel helpless and frightened after a significant loss. Teenagers often want to revert to childhood coping behaviours in order to receive protection from the surviving parent, however, due to their developmental stage and social expectations they are compelled to act in an adult manner. At times this

internal conflict is compounded by expectations to comfort family members and the adolescent's need for attachment to the deceased person. Rando (1984) views anger as being an easily expressed emotion for the adolescent that provides a sense of power which counteracts the feelings of hopelessness. Anger can be an expression of inner feelings of guilt about the loss. Adolescents can feel responsible for the death and this 'magical thinking' may represent a manifestation of prior early childhood loss and the grieving teenagers' regression to an earlier developmental state. Guilt can be increased by a high degree of ambivalence and aggressive ideation in relationships which is associated with an earlier loss. The adolescent can also express anger over the loss of a parent and guilt over a real or envisioned contribution to the death or a minor transgression of the deceased person (Kalish, 1985; Podell,1989; Siegal & Gory, 1994). Many adolescents who have suffered the loss of a parent show an increase in delinquent behaviour, dependent personality styles, introversion, suicidal ideation and a preoccupation with issues of loss (Masterman & Reams,1988).

Adolescents are not confined to a meaningless existence after the death of a parent.

The teenager's ego development does not have to be damaged, indeed it can be strengthened by a loss. Podell (1989) states:

We have to specify the antecedent conditions in the child's ego and the dynamics with the ego at the time of the occurrence of the event. In doing so, we take into account constitutional factors, predisposing factors, and factors relating to the specific manner in which the child responded to the event (p. 216).

The outcome depends greatly upon the availability of caring adults during parental

illness and death. Alternate caregivers need to recognize adolescent grieving and assist the teen to experience grief. Support and reattachment can be offered to the child without compromising teenage autonomy and integrity. This support and reconnection will have a positive impact on the manner in which parental loss in adolescence affects their immediate life and future.

Issues Impacting Child Adjustment to Parental Terminal Illness and Death

There are a number of factors which can impact a child's ability to adjust to parental death and illness. Bowlby (1980) as cited in Rando (1984) identifies three main variables which affect a child's emotional responses to the death of a parent.

The first factor is the cause and circumstances of the loss, especially with reference as to where and what the child is told and what opportunities are later provided in order for the child to inquire about the event. Anticipated death may be easier for children to cope with than a sudden death; however, all deaths are difficult and a cause for childhood anxiety. Children need to be informed of the cause of death as unexplained deaths increase anxiety and concerns can be diminished by open communication with children. Schowalter (1975) states:

A terminally ill parent should explain that he or she has no control over death, but is receiving the best possible care and will remain alive as long as possible. Being able to think and talk about the approaching separation often facilitates the child's ability to cope with his or her reactions to its occurrence. When the death occurs, the child should be told quickly and in a straightforward manner. (p. 175)

When children are prevented from asking questions about a parent's illness or death, the misconceptions can be a great source of distress. Children can have a healthy adaptation to parental death when the family communicates, openly shares information and makes decisions collectively (Cook & Dworkin, 1992; Kalish, 1985; Osterweis, Solomon, & Green, 1984; Siegal & Gory, 1994).

The second factor Bowlby identifies, is the family relationship after the loss, where special attention is given to whether a child remains with the surviving parent and if so, how the relationship pattern has changed as a result of the death. Children react to the death of a parent with less stress when they have a minimal amount of changes in their environment. The secondary losses a child experiences after the death of a parent greatly impact upon the child's ability to cope. Children who are grieving need to feel secure and gain comfort from familiar surroundings and predictable routines. Children's need for reattachment to other caregivers is extremely important and can assist with their ability to grieve and prevent later pathological reactions. The quality of care and support from an alternate caregiver is vital to a child's coping ability after the death of a parent. How roles are reorganized in the family as a result of loss greatly influences bereavement. When children's developmental needs are taken into consideration along with the child's input, changes in family rules regarding expressing feelings, receiving support and management of the household can assist children in adjustment (Brownlee, 1994; Cook & Skinner, 1992; Dickinson, 1992; Kalish, 1985; Osterweiss et al., 1984; Rando, 1984; Siegal & Gory, 1994).

The third variable identified by Bowlby, is the pattern of relationships within the

family prior to the loss. Special reference is given to the patterns between the parents themselves and between them and the bereaved child. The relationship the child has with the parent can be positive and children can become closer to the dying parent prior to death. Other times the illness causes the child to become separated from the parent due to the amount of hospitalizations, changes in family routines and the psychological state of both the dying parent and the healthy parent. As previously noted children can become caregivers of parents and siblings, many times putting their needs aside to meet the needs of others. Children can also over identify with the dying parent, becoming quite close to the exclusion of the healthy parent. Once parental loss due to death has occurred the child may have difficulty reattaching to the remaining parent or caregiver. This difficulty can be due to the child blaming either her/himself or the remaining parent for the loss (Altschul & Pollock, 1988, Cook & Skinner, 1992; Dickenson, 1992; Osterweis et al., 1984; Rando, 1984; Siegal & Gory, 1994).

Gender is another factor which can influence a child's adaptation to parental terminal illness and death. Gender is noted to affect adaptation to parental illness and death due to sex-role conditioning. Rando (1984) states that in western culture males have been conditioned to control and avoid their feelings. Expression of anger and hostility are viewed as acceptable; however, expressions of sadness, loss, depression and loneliness are not widely accepted. Males who are grieving experience conflict due to society's expectations and sex-role conditioning. Cook and Dworkin (1992) hypothesizes that gender differences are due to early identity development. Boys are viewed as establishing their masculinity by separating from the primary caregiver who is usually the

mother. Separation caused by a death of a parent can apparently put the male back to a familiar and at times a comfortable place which is an independent existence where challenges to identity are removed. Cook and Dworkin (1992) report male loss as an experience of less intense separation and loss although still viewed as a difficult process. This may be related to who the primary caregiver was. DeMatteo, Harrison, and Salter (1999) reports males often want to be immediately told all the information about HIV. They found males valued knowing about HIV as the information appeared to decrease the boys' worries while their parent's health was stable. Males tended to be able to separate knowledge of HIV from their feelings and seemed to take an optimistic view of the disease. Women are viewed by Rando (1984) as having less conflict regarding sex-role conditioning and grief. Feelings of grief and the outward behaviours are well tolerated in females. Rando also states that females tend to have difficulty expressing anger. Cook and Dworkin (1992) view females as having an identity that is related to the connectedness to others. Female grief is viewed differently as a consequence of the emphasis on connection to others. DeMatteo et al. (1999) found females often state they did not wish to know about the HIV status of their parents. They report that they were ambivalent about knowing information about the disease and had difficulty putting HIV and its impact on the family out of their minds. Females also report feeling angry about HIV and fearful of being ostracized due to the disease. Osterweis et al. (1984) report on several studies which address the impact of gender on childhood mourning and noted that a child's yearnings for a dead parent tend to be more conspicuous when the opposite sex parent dies and anxieties may increase when a same-sex parent dies due to fears that the child

must become the 'new daddy' or 'new mommy' in the family. Osterweis et al. also note several other studies that link early parental loss and adult depression. The studies suggested that girls are more vulnerable than boys to be eavement related to parental death in general and are more vulnerable to the loss of a father during adolescence. However it is important to note this may be a cultural impact. Elizur and Kaffman (1983), however, found few differences between males and females in their study of twenty-five preadolescent Kibbutz children who fathers died during a war. This shows that the response to loss may be a result of a cultural impact rather than a gender issue.

In conclusion, children with positive parents can lead a thriving life if they have access to a nurturing environment. (Roth et al., 1994). The importance of attachment relationships is vital to children of seropositive parents. As previously demonstrated in this chapter, Bowlby (1977) and Ainsworth (1982), have done extensive research on the importance of attachment in children. Children with secure attachments are able to accept the support of other caregivers such as extended family and teachers (Holmes,1993). Children need the support of others in order to reorganize and adapt to changing family patterns in a healthy manner.

This section has endeavoured to explore the impact of parental terminal illness and death on childhood attachment. It is apparent that children's early experiences of grief, related to parental separation and loss, has a profound impact upon later development. This section has demonstrated the importance of understanding grief at many layers and across developmental stages. It is evident that further studies and research are needed in the area of gender differences and children's grief reactions.

Social Work Practice in HIV/AIDS

The following section will provide a description of the unique issues relevant to social work practice with families facing HIV/AIDS. Clinical considerations practitioners need to know are discussed in order to provide support and counselling to this population in a sensitive manner. Salient issues regarding the social worker's own well-being and need for support are also addressed.

Social workers need to be aware of the vicarious effects of working with families living with HIV/AIDS. Fietz and Andrews (1991) identify the numerous issues facing social workers, some of these issues included the amount of time required to work with the diverse clients and the energy needed to arrange the services necessary to meet clients' needs. In smaller centres and in rural agencies, many counsellors become the "expert" in HIV/AIDS in their workplace and are overburdened quickly. Much of this burden, as reported by counsellors, includes dealing with homophobia and the myths and misconceptions about transmission of HIV/AIDS within the agency itself. Ross (1993) supports the notion of this burden, however, she relates it to the individual's own homophobia. She discusses the fact that caring for HIV/AIDS patients may be a counselor's first experience in working with gay people. She states that emotional reactions to a person's sexuality can be vital in determining how workers respond to AIDS in general. She also cites a study by Wisniewski and Toomey (1987) which found one third of the social workers they studied had scores falling in the homophobic range. Homophobic attitudes can have a significant impact upon the quality of care to homosexual persons with HIV/AIDS and may cause stress and discomfort to the helping

professional. The worker not only faces co-workers' concerns, but the fears and concerns of their own families and the community at large. Spouses and children may not be supportive of the worker's occupation or client group. The study of 210 social workers found that seventy-nine percent of workers felt that their family or close friends were or would be concerned about their work with AIDS patients. This increases social workers' stress as they perceive their support system being unavailable to them for fear of burdening others, alienating loved ones and sensing a reluctance to discuss the issue of HIV/AIDS. This often challenges workers to deal with their own mortality, risk behaviours and sexuality. Many clients who are living with HIV/AIDS are in the same age group as the worker. Working with this population confronts the worker's emotionally complex values and belief systems.

Worden (1991) emphasizes the importance of counsellors addressing their own pain when working with families and grief issues. He discusses that the grief experience makes it difficult for the counselor to be or feel helpful to the bereaved person. This can result in the helper possibly feeling frustrated, or angry or the counselor being so uncomfortable witnessing the pain in another person that the discomfort ends the relationship prematurely. Worden (1991) also states three ways that the grief experience personally touches the counselor.

The first is that working with the bereaved may make one painfully aware of her/his own losses. A worker's own loss can have several implications in counseling. A positive impact upon the helping relationship can be experienced if the worker's own past losses are resolved. If the loss is not integrated the worker will find it extremely difficult if

not impossible to work with those who have had a similar loss. Ross (1993) supports this premise in HIV/AIDS related work. She states that professionals can over identify with their clients and find the task to help them endure the pain, debilitation, face disfigurement, disability and death frequently overwhelming.

The second area Worden (1991) identifies as possibly interfering in the helping relationship is the counsellor's own feared losses. He discusses several areas which can result in blurred boundaries between client and helper. Ross (1993) discusses how practitioners may feel the need to like all persons with HIV or that they have to meet all of the client's needs. This often results in failure to set appropriate boundaries.

The final area deals with the counsellor's own existential anxiety and own awareness of death. Ross (1993) discusses this existential questioning of the counsellor's own mortality as being heightened by the exposure to several issues related to HIV/AIDS care. She includes the stress related to assisting those who are asymptomatic yet HIV positive. She states that living with uncertainty, the unpredictable nature of the disease and fear of the unknown exacerbates the strain of working in the HIV/AIDS field.

There are a number of signs and symptoms which the social worker and other professionals can be aware of in order to combat the harmful effects of burnout. Ross (1993) describes these signs as including difficulty in self motivation, inability to complete tasks, agitated depression, a sense of being overwhelmed and chronic fatigue. Other symptoms include psychosomatic complaints, insomnia, use of drugs, difficulty empathizing with clients and reluctance to socialize.

Burnout affects the whole person as well as having a negative impact upon clients,

the worker's own family and the organization which employs the social worker (Ross, 1993). In order to avoid becoming burned out counsellors need to have outlets for their own stress and grief, proper training, HIV/AIDS education and a strong support system. A holistic approach to the prevention of burnout appears to be the optimum approach. This model needs to encompass cognitive, emotional, social, spiritual-philosophical and physical dimensions (Dansky, 1994, Dukes, Turpin & Atwood, 1995, Ross 1993, Worden, 1991). It is apparent from the above research, that the social worker can become more effective with clients and families when workers have their own emotional needs met.

Social workers have an important role in supporting families with HIV/AIDS. The initial disclosure is neither a beginning or end in the work with families. Social workers will encounter AIDS and need the knowledge and skills to provide assistance to these families. Support needs to continue across the lifespan. AIDS affects everyone, including parents, grandparents, lovers, children and community. However, as noted previously, families are resilient and with support, can become stronger in the face of HIV/AIDS. It is vital to remember that although AIDS is perceived as death, it is the social worker's role to support the family in life.

In conclusion, it is apparent that HIV/AIDS will likely touch all social workers within the near future. In order to continue to provide high quality care for these people, the social work profession as a whole needs to confront the issues outlined in this section. It is important for social workers to continue developing creative measures to prevent burnout for all practitioners. Working with individuals, families and communities living with HIV/AIDS is a challenging proposition. Social workers need to be pro-active in

learning to cope with the strain of HIV/AIDS work. However AIDS affected people can help us in learning about courage, compassion, life, death and the human spirit (Macks, 1988 as cited in Ross, 1993).

Interventions with Children and Families

The research in the area of interventions with children and families, is becoming solution and future oriented. The strengths and coping abilities of the family unit in the face of the pandemic of HIV/AIDS are being honoured (Salter-Goldie, King, DeMatteo & Bergman, 1994; Lynch et al., 1993). It is important to recognize the coping abilities of these families and work on enhancing their strengths. Melvin and Sherr (1993) states that services to families must be set up in a manner which support the whole family structure and not parts as if they exist in isolation. The literature suggests it is important to strengthen family cohesion through a supportive and empowering process (Kubler-Ross, 1987; Lewert, 1988).

Throughout the literature there are several interventions that are deemed to be helpful to families living with HIV/AIDS which include individual, couple and family counselling; education; ensuring basic needs are being met; and social support through the group process. The focus in this section will be on the importance of the group process with children of positive parents and individual therapeutic support. The second intervention which is vital to focus on concurrently, is the support of the family system. As stated in the previous sections there are many issues that these children and families face once a diagnosis has been made regarding HIV status. There are also a number of ways children cope with the disclosure of HIV and subsequent illness in the family.

Group Work

Group work with children using play therapy techniques has its origins with Virginia Axline (1969). Since that time, therapists have continued to use play therapy techniques in children's groups. Many techniques used with children work well with adolescents, adults and families. (Guerney, 1983; Schaefer & O'Conner, 1983). There are numerous studies that focus on the use of art therapy, role playing, games and group intervention with children who have experienced illness or death, or other significant loss in the family (Aldrich, 1995; Grollman, 1995, Shepherdson, 1991; Silveira et al., 1988; Skinner Cook & Dworkin, 1992; Webb, 1991; Worden, 1991). Additionally, there is an abundance of information regarding activities which are helpful in every phase of the group process (Amelio, 1993; Barnes, 1993; Dennison & Glassman, 1987; Lehna, 1993; O'Conner, 1991; Sikkema, Kalichman, Kelly & Koob, 1995). These range from general group warm ups and specific activities to termination rituals in the beginning, middle and end phases.

Currently, the literature is severely limited in studies of group play therapy as a means of intervention with children who live in families with a HIV positive member. However, there are two studies which focus directly on the effectiveness of group intervention with children of parents with HIV/AIDS. These studies did not report an evaluation process, however they do appear to be clinically based as the facilitators utilized the available research regarding grief and loss groups for children. The first is by Aronson (1994) whose study discusses and describes the use of group intervention with children of parents with AIDS. His research is based upon groups implemented in

Boston. He endorses the appropriateness of group support and states:

As we move further into the 1990's, the number of children of parents with AIDS continues to rise. Support groups represent an important form of service for these children. In such groups, they are not labelled a patient but can receive information, begin to accept their difficult situations, and develop a sense of kinship with peers in similar situations. (p. 139)

Aronson (1994) views children's groups as qualitatively different from adult groups. Major differences are the use of traditional play therapy and activity. He stresses the significance of integrating play with group discussion. In planning support groups, he emphasizes how important it is for facilitators to understand the potential member's developmental levels, awareness of parental illness and understanding of HIV/AIDS. The study also discusses the importance of peer groups in reducing isolation and shame through universality, improving communication and expression of feeling. Emotional support is facilitated through a feeling of safety and containment. Children learn new coping abilities through the group process and are able to practice new skills through role plays and activities. Aronson (1994) discusses the phases of group development and salient issues of which facilitators need to be aware. These support groups have a focus and need to be time limited. He suggests that they be twelve to fifteen weeks in duration and be held in nontraditional settings. The facilitators must be conscious of confidentiality and counter-transference issues.

Roth et al. (1994) also discuss the importance of using play therapy groups for these children. They implemented a pilot group program designed for children ages

eleven and twelve. The group ran for six weeks. The pilot project was followed by weekly groups of three years in duration. Additionally, groups for younger children were also being implemented. The facilitators determined that a flexible multi-modal approach was necessary to meet the needs of the children. Intervention which supported family relationships and promoted peer relationships was considered beneficial. Ongoing meetings with parents and caregivers were of utmost importance. This enabled the facilitators to develop an understanding of cultural issues regarding death, illness, healing and care of children. The social ostracism parents felt which has been paramount in the literature, was not the most pressing stressor for these children. The study reports that children focussed on family instability and disorganization.

The groups were viewed as a forum for AIDS education and information. The groups provided the participants with a safe arena to express their anxiety, learn new coping skills and roles in families living with HIV/AIDS. Roth et al. (1994) states:

While the groups touched upon issues that many children from multi-problem families living in the inner city face, children in these groups are brought together by the shared experience of living with HIV or AIDS. These children are less likely to participate in general psycho-therapy groups because of the secrecy and ostracism associated with AIDS and HIV. (p. 589)

In Canada there are many AIDS Service Organizations (ASO's). Services to HIV negative children of HIV positive parents became a focus in three AIDS Organizations

which address the needs of negative children of positive parents. The first group in Canada, "Leading The Way" was sponsored by The Teresa Group, a non-profit, charitable organization which is dedicated to the support of children and families living with HIV/AIDS. This group began in the Spring of 1995 and was based in Toronto, Ontario. The first group served thirteen children and youth as well as eleven parents and relatives. Since its first inception, "Leading the Way" has reached more than sixty individuals and has begun two new programs in response to gaps in services identified through the work in the groups. The goals of the support group program for the children, youth, parents and caregivers were to reduce isolation, provide information about HIV and AIDS and to support the development of coping strategies (Antle, 1998).

Canadian Children of Positive Parents is an organization developed in Saskatoon, Saskatchewan to meet the needs of AIDS affected children (Hicks, 1994). A support group was created to provide children an opportunity to meet and play as well as share their hopes and fears with other children who are affected by AIDS. The group serviced children from the ages of one year to age seventeen. A counsellor was available for the children to discuss and deal with concerns and/or losses that the children were facing. When a parent becomes ill or dies a child needs to have someone to talk with to increase her/his well being. Hicks (1994) recognized that many children may not need or want counselling; however, having an opportunity to connect with others in similar situations may be helpful. The Canadian Children With Positive Parents (1994) newsletter states that children may have difficulty dealing with their own HIV status. The creator of the group Canadian Children With Positive Parents, Darryl Hicks, believes building

friendships, security for children's futures and having an opportunity for children to be together will support children through the grieving process. The children in the Canadian Children With Positive Parents Support Group deal with issues regarding discovering a parents' HIV/AIDS status, dealing with the loss of their parent(s), discovering their own HIV status, being ostracized from family, friends or communities as well as struggling to live on social assistance. Canadian Children with Positive Parents also began a newsletter for HIV positive families across Canada. This newsletter served to break isolation nationally and provided a forum for children and parents to express themselves through articles, poetry and stories. The publication also provided information regarding HIV/AIDS as it affects families (Canadian Children With Positive Parents, 1994).

Kali Shiva AIDS Services is a non-profit community based organization that was initially created in 1987 when a man living with AIDS decided to live and die at home in Winnipeg, Manitoba. His family and friends formed the Kali Shiva twenty-four hour home hospice. Since that time Kali Shiva AIDS Services has evolved from individual support services to include family support. Kali Shiva has a support group for women living with HIV/AIDS and recently secured funding for a children's support group for children affected by HIV/AIDS. The children's group became a reality directly from requests of those children and families involved in this practicum report. The families expressed a desire to continue receiving group and individual support and Kali Shiva worked to meet those needs. Volunteers were matched with children requiring individual support and positive feedback was received from the families involved. Co-facilitators were also recruited for the support group for AIDS affected children. Kali Shiva recognized that

these children included not only the children of those with HIV/AIDS but affected nieces, nephews and siblings. The objective of the group was to reduce the stigma and isolation felt by children and their families. Also several issues which have been noted previously were deemed as being important to be addressed. Kali Shiva noted that the disclosure of HIV status by parents to children is a difficult decision. The disease of HIV within a family system has important consequences for children who are protected from illness-related information and children may be isolated and excluded from major family decisions. Kali Shiva noted that many children may become anxious about their future due to the "Web of Silence" which surrounds the family regarding the issue of HIV, parental anxiety, preoccupation, physical absence and illness, as well as death that children must live with and observe. The children often receive poor information regarding the disease and lose confidence in their parents which adds to the stressors (Kali Shiva Project Description, March 1997).

It is interesting to note that in all of the literature regarding group intervention for children of parents with HIV/AIDS, there are not any published evaluation data on the efficacy of support groups for this population. Aronson (1994) discusses the need for future empirical research in the area of support groups for children of parents with AIDS. He referred to several authors who have completed studies demonstrating the importance of support groups in the promotion of an adaptive response to bereavement. (Elizur & Kaffman, 1983; Gray, 1987). Aronson further suggests that future research should examine the efficacy of support groups for children of parents living with AIDS in the areas of academic improvement, behavioural problems and school attendance.

I believe that there are several factors that need to be addressed in support groups for children affected by HIV/AIDS in the family. Participant safety, confidentiality, and facilitators who are knowledgeable in the area of HIV/AIDS information are key issues. Other factors that are important to address are anticipatory grief, coping skills and the use of a flexible multi-modal approach which is vital for the group to meet the varying needs of the participants. Facilitator awareness of transference and counter transference issues are important to the success of the group. A final factor to address is the systemic issues facing these families. The support group can become a catalyst for change through empirical research which is necessary to promote an awareness of the issues facing families living with HIV/AIDS in today's society and is lacking within this population.

Family and Individual Interventions

Marshall as cited in DeMatteo, et al. (1999), states that families living with HIV have detailed the resilience and strength of individual family members including a willingness to accommodate and care for infected family members. Walsh (1996), Hawley and DeHann (1996), and Salter et al. (1996) are several other researchers who have viewed the family as a source of resiliency. McCubbin et al. (1993) as cited in DeMatteo et al. (1999) believe families who are able to take a "we" perspective rather than "I" strengthens families and enables them to reframe problems in the family. There are many resources within the family and outside the family that are needed in order to assist the family with maintaining a sense of balance and stability in the face of HIV/AIDS (Walsh, 1996). He also states that families who can survive crises are most often able to develop deeper relationships with one another. Hartman's (1978) discussion of the diagrammatic

assessment of family relationships provides a powerful overview of the family's situation through the use of eco-maps. The ecological perspective encourages social workers to view the individual as a part of a complex ecological system rather than an isolated entity (Germain & Gitterman, 1980; Hartman, 1978). Hartman's view of the family is supported in the AIDS literature (e.g., DeMatteo et al., 1999, Roth et al., 1994; Walsh, 1996).

Family relationships such as sibling bonds are important to address. DeMatteo et al. (1999) further report that in their research there was evidence that parent-child bonds were more developed than sibling bonds. They identified several reasons why this phenomenon may occur. These included differences in children's ages, perceived differences associated with gender, competition between siblings, split families, as well as how a child copes with the knowledge of HIV/AIDS in the family. In their study few children report discussing HIV with siblings; however, the children identified wishing they could have been more supportive of one another. They noted that more research needs to be conducted in the area of sibling relationships prior to any conclusions being drawn from this information. They state that "not discussing" family HIV could be a "support strategy for maintaining hope." Parents in the study report sibling relationships were more likely to grow stronger after disclosure. Fanos and Weiner (1994) discuss sibling relationships in relation to a sibling with HIV as well as a parent with HIV. They found that some sibling relationships respond to the illness by becoming intensified. The siblings become one another's "best friend" due to their sense of isolation. Bank and Kahn, as reported in Fanos and Weiner (1994), point out that the sibling bond is emphasized in families where parental involvement is low. They discuss that in the case of sibling death, the surviving

sibling becomes vulnerable as the loss mirrors a loss of self. The sibling who is affected by HIV in the family may also experience survivor guilt or anger at the parent for perceived cause of infection. These studies and interventions support the premise that children who are affected by HIV/AIDS benefit from support. Fanos and Weiner (1994) recommend that medical settings need to set up preventative models to assist siblings. They believe siblings need to be viewed as a "real" part of the medical "entity" as the child requires direct assistance before maladaptive behaviour to the losses are set in motion.

Throughout all of the research discussed, family intervention, as well as individual counselling are suggested as necessary to meet the needs of the entire family system.

Systems Perspective

A final area to address in this section is the impact systems have upon interfacing relationships, including therapists, clients and the larger systems such as other agencies, the community and the HIV/AIDS global community. The systems perspective will provide a brief arena to discuss the impact of these areas as they interface. Breunlin, Schwartz, and Kune-Karrer (1992) describe systems theory as a generic term for several concepts that allow therapists to work with problems in the context in which they appear. Bruenlin et al. (1992) also state that systems are organized by a set of rules which govern how the parts are structured together including the function which each part performs to serve the whole structure. They describe these systems as a multilevel system.

Throughout this literature review several levels of systems have already been addressed.

These have included biological and mental process in individuals, relational systems within the family and the social context of the system including the helping system.

The two levels which need to be examined include the national social system in which the family exists as well as the international system. It is important to note that research regarding how these larger systems have affected families living with HIV/AIDS are scarce in Canada. There are several articles related to the amount of assistance the larger governmental system has provided the HIV/AIDS community (Canadian AIDS News, 1996, 1997; Health Canada, 1996; Manitoba Health, 1996). In Canada, communities affected by HIV/AIDS have been involved in policy development and decision making in many levels of the political arena. The Canadian AIDS Society and other organizations were able to successfully lobby the federal government to develop a national strategy to address the funding and program needs for the AIDS movement in Canada (Deburger, 1997; Wong, 1997). In 1989 the federal government provided \$37 million for the National AIDS Strategy (NAS) (Health Canada, 1996). This provided much of the core funding for many organizations to continue HIV/AIDS prevention at a community level. The government did increase its funding between 1990 and 1993. Several provinces developed their own AIDS strategies such as the Manitoba AIDS Strategy (Manitoba Health, 1996). However it is apparent that the lack of provincial support affected the community's ability to respond to the population need.

Deburger (1997) reports that the Canadian government moved from Health
Promotion to Population Health in 1994. It is important to note that this move shifted the
focus from the individual and community to the population at large. De Burger states that
this shift was driven by both ideology as well as an attempt to gain control over health
care spending. There have been several concerns that government preoccupation with the

population health perspective does not recognize the importance of individual, community based initiatives, and that diversity is not recognized within populations. Trussler and Marchand (1997) support this view by stating that there is a weakness with the population model as it appears to be a "top down" approach through large scale policy initiatives. They also state that personal, group and community development, which is central to health promotion, is not considered. Trussler and Marchand (1997) states that an advantage this model may have is the social focus of the past HIV health promotion efforts, as well as the population model will provide an arena for advocacy in the renewal of HIV strategy on local, national and international levels.

Wong (1997) states that there is a challenge in developing a framework which will effectively combine a dedicated approach to HIV/AIDS as well as a broader population health approach. Wong further states that an open dialogue regarding how to maintain the balance between long term evidence-based initiatives and immediate, action-oriented efforts must be undertaken. He believes that without this dialogue both health promotion and population health will be devalued. It is important to note that while the NAS was helpful in addressing many needs of those living with HIV/AIDS, it has also served to set up much competition between AIDS Service Organizations. As Canadian AIDS News reports (1996):

Fatigue and uncertainty about the future direction of NAS are taking their toll on communities. Many individuals are weary of the tension between the need to constantly advocate to maintain existing levels of support, and the increasing demand for services. (p. 5)

There is much evidence of the amount of stress placed upon AID Service

Organizations; several services have shut their doors as discussed in previous sections of this chapter. Redpath (1996) reports that many AIDS educators in Canada work hard to deliver educational programs as well as provide support to those affected by HIV/AIDS.

She states that they are meeting these needs under great financial constraints. She believes that innovation is the key word for resource development and programming.

In 1998, the NAS expired and it appears that population health has become the leader in addressing HIV/AIDS in Canada. According to Kali Shiva AIDS Services (December, 1999) several of the AIDS Service Organizations in Winnipeg, Manitoba have amalgamated and pooled funding in order to develop an umbrella organization to continue to provide HIV/AIDS services to the Manitoba community. The organization is known as "The Nine Circles Community Health Centre". As Redpath (1996) reports there is not one model, treatment, prevention technique or research protocol that can resolve the many layered challenges of HIV/AIDS. She believes that building on lessons learned by the individual will address the complex HIV/AIDS epidemic and this must be done as a collaborative effort.

Kirby (1996) states that individual and community level actions influence global trends. He believes that a danger that faces the political arena, including the global community, is the fact that statistics in HIV/AIDS do not have an identity. He states that it is vital to place a face on the problem in order for social change to be effective. He feels people living with HIV/AIDS must be involved in all prevention strategies as well as their caregivers, families and loved ones in order to bring the epidemic to the forefront.

Summary

This chapter has endeavoured to bring the reader the multifaceted and multi-layered epidemic of HIV/AIDS and how it impacts upon the family. It is apparent that there is not one specific intervention model that is effective with all family members, communities or global community. Systems theory provides a base for intervention (Breunlin et al., 1992; Dansky 1994; DeMatteo et al., 1999; Germain & Gitterman, 1980; Green 1993; Melvin & Sherr, 1993 Salter et al., 1994). Systems allows the therapist to provide service on several levels and provide a structure for intervening on several levels dependent upon individual or family needs. This multilevel perspective allows for the AIDS service organizations to provide a wide range of services which, as this literature review demonstrates, are intricately connected and complex.

This literature review has provided a framework from which this practicum has been created. It is impossible to work with an isolated part of the family or larger system. As the practicum report will demonstrate, the majority of issues discussed, as well as the number of levels on which intervention was initiated will become clear. The reader will gain an understanding of the interconnectedness as well as the stress experienced by the AIDS Service Organizations within not only Winnipeg, Manitoba, but the country at large.

CHAPTER 2. THE PRACTICUM

The Team Approach

This practicum was conducted as a team approach in all areas of service delivery from the referral and intake process to aftercare planning for families living with HIV/AIDS. This practicum was initiated by myself, a Master of Social Work student and co-facilitation was provided on a volunteer basis by two Master of Social Work students, Joanna Salit and Claire Milgrom. Without their support, encouragement and expertise, this endeavour would have been a monumental undertaking. It is important to note that the team also included the families we served, and individuals withinsister AIDS Service Organizations (ASO's).

This practicum initially began as a grassroots effort to fill a gap in services to children living in families with HIV/AIDS in Winnipeg, Manitoba. It will become apparent to the reader that this effort widened from the individual child to the family, community and nation, to become a systemic intervention. This report addresses the need for services to families living with HIV/AIDS and the importance of providing systemic intervention in a non-threatening manner. I served as case manager for all interventions during the practicum, including intake, crises intervention, transportation, pre- and post-evaluations and systems interventions. This report will discuss individual, group, family and systems interventions.

The practicum committee consisted of David Charabin (advisor), Dr. Diane
Hiebert-Murphy and Karen Ingebrigtson. Additional support was provided by Shirley
Grosser and Maureen Hautmacher. Supervision and consultation were as follows:

- 1. David Charabin, 20 Consultations for individual, group, family and systems.
- 2. Karen Ingebrigtson, 4 Consultations for individual and systems interventions.
- 3. Shirley Grosser, 4 Consultations for individual and systems interventions.
- 4. Maureen Hautmacher, 4 Consultations for individual and pediatric AIDS information.
- 5. Team supervision for Theresa Graham, Joanne Salit and Claire Milgrom provided by David Charibin, eight conferences.
- 6. Weekly preparation and de-brief with the co-facilitators.

INTERVENTION OVERVIEW

The purpose of this practicum was to develop and run a support group for children whose parents were living with HIV/AIDS. The group was to provide an opportunity for children to share with others who were experiencing similar stressors. Group play therapy, role playing and art therapy were to be the primary modalities for expression, learning and support. Systemic interventions with families were also undertaken. The goals and objectives of the intervention were:

- 1. To provide children with a safe, confidential contained environment.
- To provide children with a forum for expressing their feelings and discussing other issues related to the impact of HIV/AIDS in the family.
- 3. To create a supportive peer environment which would enable and empower children to deal with anticipatory grief and the stigma and isolation experienced due to HIV/AIDS in the family.
- 4. To provide children and families with opportunities to learn, practice and integrate alternative coping methods, expression of feelings and adaption to life changes.
- 5. To provide factual knowledge and open discussion of the realities of HIV/AIDS.

6. To provide support to families of participants.

Group Intervention

The group intervention consisted of two groups: one of six sessions and one of eight sessions. The groups followed a basic routine of: Snack and social time, sharing circle, group warm-ups, presentation of theme, use of directive and non-directive play therapy, music, psychodramatic and art therapy techniques, and closing circle. The second group was increased to eight weeks to incorporate my learning regarding the group needs for additional sessions focussing on feeling and coping skills. The progression of the group followed Aronson (1994) and Roth et al. (1994), as these groups were designed specifically for children living with HIV/AIDS in their family. The specific group activities were drawn from leaders in the field of group intervention. These individuals have demonstrated the positive aspects of using play therapy, art therapy, psychodrama or role playing, games and music with children's groups involving children who are experiencing illness or death in the family: Aldrich (1995), Axline (1969), Guerney (1983) Schaefer and O'Conner (1983), Shepherdson (1991), Silveira et al. (1988), Skinner Cook and Dworkin (1992), Webb (1991), and Worden (1991). Additionally, there was an abundance of information regarding activities which are helpful in every stage of the group process. Useful resources included Amelio (1993), Barnes (1993), Dennison and Glassman (1987), Lehna (1993), O'Conner (1991), and Sikkema et al.(1995) on topics ranging from general group warm ups and specific activities to termination ritual. The themes, weekly goals and activities for the children's group were as follows: Group One: Beginnings; HIV/AIDS Education, Feelings, Changes, Coping, Review and Termination,

and a parents meeting. Group Two: Beginnings; HIV/AIDS in the Family; Dealing with Feelings, Dealing with Feelings Continued; HIV/AIDS Facts; Coping with Changes; Termination and Celebration and a parents' meeting

Family and Larger System Interventions

Three family systems participated in the practicum, herein known as Family A, B and C. There were five family systems which initially agreed to participate in the group program, however after the initial interview two families determined their children, nor were they, prepared to address the issue of HIV/AIDS openly for fear of ostracism by family and the community. There were also several phone calls from interested individuals regarding services. These families either did not meet the criterion for acceptance or were not ready to partake in the treatment process. The family interventions and outcomes will be discussed further in the next chapter. Family interventions were followed as per recommendations suggested in studies by: Fanos and Weiner (1994); Germain and Gitterman (1980), Hartman (1978), Hawley and DeHann (1996), Melvin and Sherr (1993), Osterweis et al. (1984), Salter et al. (1996), Seigal and Gorey (1994), and Walsh, (1996). The research indicated that treating the families as individual parts is not helpful and as the following chapters will demonstrate this also proved true in this practicum. Additional primary resources which guided therapeutic interventions with the family included: Levine (1995), Holmes (1993), Kalish (1985) and Cook and Dworkin (1992).

The systemic interventions were designed to meet the most significant needs of the family. The interventions included assisting the family with interfacing with other helping professionals and the larger community. Much time was utilized in facilitating a

cooperative, reciprocal environment with other helping professionals. Several reports support the premise of working with multilevel systems which include all family members, communities and the global community (Breunlin et al., 1992; Dansky 1994; DeMatteo et al., 1999; Fanos & Weiner, 1994; Green, 1993; Mellins & Ehrhardt, 1994; Melvin & Sherr, 1993; Salter et al., 1994; Stulberg & Buckingham, 1988). This focus enabled the families' needs to be met through the group and family therapy process, as well as follow-up support once the group was complete. Priorities for the case manager were whole family and sibling support, education, dealing with anticipatory grief issues and strengthening the family bond as well as drawing on the strength of the larger community.

Individual Interventions

The individual therapy interventions occurred after consultations with the family and supervisor. Individual support was provided to three siblings in Family A. The individual sessions followed widely accepted practices of play, art and sand therapy as prescribed by Axline (1969), Brownlee (1994), Shaefer and O'Conner (1983), Guerney (1983), Aldrich (1995), Webb (1991), Silverira et al. (1988), and Skinner et al. (1992). Additional support and guidance was provided by the work of Worden (1991), Shepherdson (1991), and Roth et al. (1994). For this system, it was apparent that group and family support did not meet the unique needs of the individual. These sessions will be discussed in greater detail in the next chapter.

Environment

This practicum commenced at the Elizabeth Hill Counselling Centre (EHCC) under the supervision of David Charabin. The EHCC is located at 301-321 McDermot

Avenue, Winnipeg, Manitoba, Canada. The EHCC serves as a training facility for Faculty of Social Work Students, in both graduate and undergraduate programs at the University of Manitoba. The Department of Psychology also utilizes the EHCC. The facility contains four therapy rooms for family or group sessions, four rooms for individual or couple sessions, a fully equipped play therapy room which has an attached one way mirror and one large conference/group room. Each therapy room is equipped with videotape recording equipment. The conference/group room was furnished with portable videotaping equipment when the group was in session.

A family therapy room was utilized for parents to wait and have an informal peer support system while the group was running. Current articles and books regarding HIV/AIDS in the family as well as child guidance information was provided for the families in the room. A family therapy room was also used for family and individual sessions. At times the client's home was used for system sessions. On one occasion a local AIDS Service Organization (ASO) was used for a family session. Group and family sessions were videotaped in accordance with EHCC regulations when possible.

The conference room was used as the primary setting for the children's group sessions. The conference room is carpeted and contains couches, tables and bookshelves. The room had two doors and three walls were frosted glass. Equipment was transported to the conference room for each group. The equipment included a video camera, flip chart, art supplies, stuffed animals, cushions, stereo, television, blankets, snacks, puppets, and journals.

Individual sessions were conducted in either the play therapy room or a family

therapy room. The larger rooms were utilized in order for the sessions to be as interactive as possible when the play therapy room was either unavailable or inappropriate. The play therapy room was inappropriate for adolescent sessions as well as directed play therapy when stimuli needed to be limited.

The Referral Process

The criterion for participation in the support group for children whose parents are living with HIV/AIDS were as follows:

- 1. Male and female children with a parent/caregiver living with HIV/AIDS.
- 2. Children ages 8-11 years old and children 12-15 yrs old.

Initially referrals were made through parent/caregivers, community agencies and hospitals. Insufficient referrals were obtained over a three month period. As a result referrals were made open to over seventy-five community agencies, including all ASO's, child and family service centres, health care centres, schools, boys and girls clubs etc. These agencies were contacted by phone, fax and personal interviews. Local newsletters and the community newspaper were also utilized to reach a greater audience. A public service announcement was placed on a community access channel. Flyers were also placed throughout the city on bulletin boards, bathrooms, windows and telephone poles. (See Appendix A for Advertisements).

Group size was targeted at six to eight individuals for the children's group. There were five children referred for the first group and screening occurred through telephone contact and personal interviews. Parents/caregivers were informed of rules of confidentiality, group goals, importance of parental participation and expectations. Prior

to group commencement, family interviews were conducted. During the interview group purpose and methods were explained to the child and family to ensure informed consent.

The parents/caregivers signed consent forms (See Appendix B) and permission for observation (See Appendix C).

Evaluation Measures

A pre- and post-treatment design was used in the evaluation of the practicum. The measures were chosen to provide information on the functioning of the families and children prior to treatment and were to indicate whether the intervention was effective.

The number of instruments administered was limited as it is believed that many measures could alienate families who may already be overwhelmed. The following measures were administered during pre-group meetings with the primary caregiver and participants and upon completion of the group: Family Assessment Measure - III (FAM-III) (Multi-Health Systems, 1993), the Children's Depression Inventory (CDI-S) (Kovacs, 1982), and the Child Behaviour Checklist (CBCL) (Achenbach, 1991). The eco-map (Hartman, 1978) (see Figures 1-4), was also completed with the caregiver to provide an evaluation tool and examine the social system of the family. The participants and parents also completed a subjective group feedback form at the end of the group (See Appendix F).

Family Assessment Measure - III (FAM-III)

This self report measure was chosen to gain a global measurement of family functioning and provide an indicator of the families' ability to cope with HIV/AIDS in the family, level of support and assess the overall family environment. The FAM-III has 50 statements about the family as a whole. According to Skinner, Steinhauer, and Santa-

Barbara (1983), studies "have shown that the FAM scales are quite reliable, and they significantly differentiate between problem and nonproblem families" (p. 104). The FAM is based on a family process model which includes the assessment of family task accomplishment, role performance, communication, affective expression, involvement, control, values and norms. The FAM-III has an excellent internal consistency reliability (co-efficient alpha = .95). The authors believe that effective families experience as many problems as ineffective families but are better able to deal with problems (Skinner et al., 1983).

The Children's Depression Inventory (CDI-S)

The CDI-S is a ten item self-rated symptom oriented scale suitable for both latency age children and adolescents. Each item consists of three statements (e.g., "I am sad once in a while," "I am sad many times," "I am sad all the time"), of which the child chooses one item. The 10 items also assess several depressive symptoms including social isolation and suidicidal ideation. Sweetland (1984) state the CDI may be used to assess the severity of depression in group members. The short form of the CDI was chosen due to the short administration time and its high correlation with the original CDI twenty-seven item scale. The CDI has good internal consistency reliability (coefficient alpha = .86) and correlates well with clinicians' independent global ratings of depression (r = .55, p < .0001). The CDI also requires the lowest reading level for children in the measurement of depression (Kovacs, 1982).

The Child Behaviour Checklist (CBCL)

As reported in previous chapters, the literature indicates depression and acting out

behaviours are widely occurring psychological symptoms of stress in children who have parents with HIV/AIDS. The CBCL was selected to provide an evaluation of the level of acting out behaviour and competencies of children participating in this practicum as determined by the caregivers' observation of the child. The measure was completed by the caregiver of the participant both pre- and post-treatment. Achenbach (1991) reports that the test-retest reliability of the scale scores were reported by to be high. He also reports it is advisable to wait at least 2 months between assessments when the CBCL is used to reassess individual children. This allows time for behavioural changes to occur and become apparent to the raters and also minimizes the possible "practice effects" (Achenbach, 1991).

Eco-Map

The purpose of utilizing the eco-map in this practica was to have an assessment tool to map the ecological system changes of the family from intake to termination (Hartman, 1978). The eco-map also provides an overview of the major systems involved in the family and the nature of the family relationships with those systems. The eco-map highlights the resources the family currently has and areas that require building. The eco-map allowed me to join with the caregiver in examining the strengths of the family, tracking progress and celebrating success. The caregiver whose family completed the treatment process reports the eco-map was helpful in identifying family strengths and the changes. The eco-map is discussed further in the examination of the family systems (See Figures 1-4).

Subjective Group Evaluation and Feedback Form

As this practicum was a pilot project in Manitoba, a subjective group evaluation and feedback form was created for this report. The forms were intended to provide a written forum for participants and caregivers to express their opinions regarding the treatment program. The forms also provided feedback regarding learning experiences and information to be integrated into other groups and family interventions (See Appendix F).

Confidentiality

Client confidentiality was maintained throughout this practicum. The clients signed informed consents regarding videotaping, storage and use of information. The clients were ensured that the videos would be erased once viewed for consultation purposes. The group was conducted when the centre was officially closed for business to the general public. Many families need to maintain a code of silence regarding the family's HIV status. As previously discussed in chapter one, many families face social rejection and discrimination. It was the goal of this practicum to respect the families' need for privacy while attempting to increase the social support network with the family. The impact confidentiality and secrecy had upon this practicum will be further discussed in chapter five.

The Participants

This section will provide a brief introduction to the participants of this practicum. As previously noted in this chapter, three families participated in this practicum. Family system A includes a natural mother Ruth-a who has a positive HIV status. Ruth-a has four children, Amber-a, age two; Cassie-a, age ten; Skye-a, age eleven; and Fallon-a, age

twelve. The main concerns by the mother included psychosomatic complaints by Skye-a, pseudo-maturity by Fallon-a, and a preoccupation with death by Cassie-a. The two middle children, Cassie-a and Skye-a participated in both groups discussed within this practicum, Fallon-a attended the second group offered. This family is of Aboriginal descent and Ruth-a reports a history of alcoholism. The biological father died since before the birth of Amber-a.

Family system B is comprised of a separated couple, David-b and his wife Donnab, b, both of whom are HIV positive. The couple have two sons, Tommy-b, age eight, and Jon-b, age six. The Issue of concern by the parents was the eldest son's acting out behaviour. Tommy-b participated briefly in both groups and Jon-b participated in the second group for a partial session. Family B is of Aboriginal descent with a history of drug abuse.

Family system C's members includes a natural mother Diana-c, married to Tony-c, who was HIV positive. Diana-c has three children, one of whom participated in the practicum. Trey-c, age thirteen, participated in the second group, however he dropped out before the fourth session. The main concern for this family was Trey-c's fear he would contract the virus from his father and his anger outbursts. This family has a history of family violence.

The next chapter provides an overview of the group process and an analysis of the group component, while chapter four presents the family systems interventions and evaluation outcomes.

CHAPTER 3. GROUP INTERVENTIONS

Intake and Pre-group Procedures, Group 1 and 2

The objectives of the intake and pre-group sessions were as follows:

- Personal interview with the primary caregiver and child to outline group criteria,
 program, goals and expectations.
- 2. Gather intake information and explain confidentiality issues.
- 3. Ensure informed consent was provided for the videotaping and recording regulations.
- 4. Complete pre-measures and complete initial assessment.
- 5. Engage family in the therapeutic relationship.

The objectives were met first with the primary caregiver in an individual interview.

This enabled the caregiver to determine if the program was a good fit for the family without undo pressure from other members of the family. This also served to assist the me in establishing rapport with the primary caregiver.

A family intake session was initiated after the primary caregiver agreed to participate in the program. The worker attended two pre-group sessions with the family. The first was offered within the family home to assist in establishing rapport. This approach also provided me with an opportunity to assess family relationships within the context of their own environment. The second session took place at the Elizabeth Hill Counselling Centre (EHCC). The first part of the session was with all family members and the remainder of the session was focussed on individual assessment. The purpose of the sessions were to continue the establishment of rapport, and to prepare the family for participation in the group, including videotaping, and completion of the pre-measures.

Group Process

The support group model developed by Aronson (1994) is utilized in the discussion of the practicum to provide an analysis of the groups through a comparison to his format and findings. The process of group development, dynamics, and interventions that facilitated the group process in this practicum will be considered and discussed. Aronson's model was chosen to provide a base for the group analysis as his format addresses the therapeutic factors that are specific for group intervention with children of parents with AIDS. As well he clearly identifies the three phases of group development in his own analysis. Aronson's model had three phases of group development; a beginning, middle working and termination phase. Within these three phases, Aronson reviews several common themes which will be discussed in relation to the practicum. Aronson's phases and themes were consistent within the practicum groups. A description of the practicum group sessions outlines are available in the appendix (see Appendix D).

The first practicum group ran for six weeks, and the second had eight sessions. Both were held on Monday evenings with sessions of one and one-half hours. It was important to provide these children with a safe, confidential environment and the Centre was closed on Mondays after 4:30 p.m. The groups were closed once initiated. The groups followed a similar routine of snack and social time, sharing circle, group warm-ups, presentation of weekly theme, directive and non directive play therapy, journaling, and closing circle. The group was co-led by female facilitators, and clients were both male and female. Participants were between the ages of eight and twelve and had a parent/caregiver living with HIV/AIDS. Group activities were structured to meet the

developmental needs of the group members.

Within the groups, the beginning phase consisted of two sessions, and focus was placed on establishing trust and commonalities. The group's anxiety was contained through the rituals, and structure provided by the co-facilitators. The creation of safety was paramount in the group. Initially in Group One, there was shyness and hesitancy in the group, as well as issues of mistrust. Group Two had participants who attended group one of the practicum. These participants demonstrated an openness to disclosing information that assisted the other group members to emulate their lead. Group Two became cohesive more readily than Group One.

Aronson (1994) points out that a benefit of support groups in the beginning phase is altruism. He states when group members learn to develop empathy, and think of others, their own self-esteem is enhanced, and feelings of helplessness, and hopelessness are reduced. This was evident when one child in the group was unable to concretely visualize a safe environment through a group visualization, and another group member provided encouragement, shared his own experience, and permitted the child to imitate his safe place. The issue of trust was apparent through the group's hesitancy to share personal information, and an awareness that the sessions were being videotaped. The facilitators assisted the group in developing cohesion through group warm up games, and emphasizing confidentiality. The establishment of rules, and encouragement of group input further enhanced cohesion. The theme and focus became sharpened as the children in the group were able to establish commonalities. This in turn allowed other themes to emerge, such as issues of disclosure and secrecy. It was interesting to note that with each

successive activity, the practicum group became more comfortable with sharing information and expressing humour. The participants of Group Two knew one another outside of the group, and it appeared this aided in the increase of participant comfort level. Aronson (1994) notes in the initial stage of the group, children can discuss their parent's condition, however, they tend to have little affect. This was evident in the first and second groups where the children were able to disclose "My mom has HIV", however they did not show any outward emotion. The group structure of posting an agenda, and rituals such as opening and closing circles, assisted the group in establishing a safe environment.

The beginning phase of these groups corresponds to Aronson's (1994) discussion of the importance of universality in establishing common themes among group members. He discusses how children's support groups often reflect the stages of grief work as outlined in the research. He states children's first stage of reaction to loss is anger, then sadness. Within the groups, the children did express some anger and frustration regarding having HIV/AIDS in the family, however this was not clearly expressed until the middle phase of the group. Aronson's (1994) group model notes that children's questions about HIV/AIDS seem to dominate the beginning phase. He also states children will allow leaders to explore their emotional reactions once their questions about HIV/AIDS are answered.

The practicum group was developed with education as an integral part of the group process. The participants in Group One had several questions about HIV/AIDS, and the lack of affect supports Aronson's (1994) findings that emotional content emerges in later group phases. The children in Group One were able to demonstrate some

knowledge of HIV/AIDS. The group's initial hesitancy to share may have been impacted by the fact that a guest speaker presented the HIV/AIDS information through a video, written activities and art, rather than by the established facilitators. The practicum participants shared more readily after the guest speaker left the session. Group Two participants were able to share their prior knowledge of HIV transmission with another group member struggling with a fear of contagion from his HIV positive caregiver. It was apparent as the group shared their own feelings and fears, the participant's own anxiety was decreased.

Aronson (1994) notes fear of social ostracism is apparent for children affected by HIV/AIDS. Group One participants echoed this premise by stating they had to keep their loved one's HIV status a secret. Issues of secrecy, isolation and decisions over disclosure were prevalent for the children in both groups. The children also cited lack of community education, and fear of rejection as reasons for lack of disclosure. The participants felt their friends wouldn't play with them due to being afraid of "catching" HIV. The group became an arena to lessen the participant's sense of isolation and shame through the commonalities they shared.

Aronson (1994) notes children in the beginning phase of group also try to assert a cognitive mastery over their pending losses. This was evident in Group One and Two through the children's discussion of their knowledge of HIV facts and ongoing need for more information.

Aronson (1994) discusses many HIV infected parents are uncomfortable or ashamed of discussing their illness with their children. However, for the children in the

practicum group, it was evident their caregivers were forthright and direct with their offspring in sharing information about HIV/AIDS. This was demonstrated by the children in Group One requesting to share their artwork and HIV/AIDS fact sheets with their caregivers. Group Two participants stated the disclosure of a positive HIV status brought their family closer together.

The middle working phase Aronson (1994) discusses was evident in sessions three, four and five of Group One. The second group's working phase included sessions three through seven. Aronson's (1994) middle working phase themes include exploring emotional reactions, future health and care, as well as coping strategies. The practicum Group One was encouraged to continue the cohesion process through the development of a group name "The Wonderful Group", which allowed them to demonstrate their ability to take ownership of the group and have a sense of belonging. Feelings were explored through a variety of modalities in both groups including discussion, art and games that assisted the group in sharing experiences and feelings. Aronson (1994) notes sessions in the middle working phase can become difficult as children painfully acknowledge their situation and come to an understanding how loss could become a reality at any time. This was apparent in the practicum Group One and Two where food appeared to be symbolic of the participants' desire for emotional nurturing, care and protection. The need for food did not seem to be physical, and the facilitators reflected the connection between emotional needs, and the availability of food within the group.

The children in both practicum groups also related other stressors in their lives, including poverty and the impact of HIV on themselves. The second group of participants

worked together to identify ways to deal with the practical and emotional realities of having a parent living with HIV/AIDS. This group also watched a video to address the issue of sexuality in a non-threatening manner. This video became a springboard for a discussion of the stigma often experienced by families living with HIV/AIDS. The group's decision to concretely combat the myths associated with HIV/AIDS appeared to increase the participants' sense of self esteem and reduced their sense of helplessness and hopelessness. Another example of the children's difficulty in managing emotions became apparent when one child developed stomach problems whenever he was separated from his mother. This participant's anxiety decreased during the second group. (See Individual child treatment summary for details). Group Two was able to provide an arena for the participants to decrease their sense of shame and secrecy of living with HIV/AIDS in the family. The sense of connectedness appeared to be helpful in decreasing the isolation that group members stated they faced on a daily basis, as many of them could not share their reality within their home communities.

Within the practicum groups, it became clear as the children expressed their feelings, their need for the facilitators to continue to create a place of safety and security increased. This was accomplished through reinforcement of group structure and limit setting which served two purposes: it permitted the group to test limits in a safe manner and established a safe and secure environment. As previously discussed, Aronson's (1994) model notes that anger and sadness are strong emotional themes. The participants in practicum Group One related they felt shock, sadness and anger when describing their emotional reactions to their caregiver's disclosure of a positive HIV status. The

participants also state they could not share these feelings with their caregivers as they were concerned it may cause upset in the family. The facilitators normalized the feelings expressed in the group through sharing information obtained from other children who felt similar during parental disclosure. In Group Two, several activities were introduced by the facilitators. These included role-playing and family sculpting which encouraged the group to examine feelings, family beliefs and fears. A dominate theme in group two was the feeling of outrage over how the community feared those living with HIV/AIDS. The group supported one another to find positive strategies for coping with anger. The group also took ownership over how they could educate the public and developed posters to accomplish this task. Aronson (1994) notes this phenomena in his discussion of how outrage can become a force for the establishment of cohesion in a group that ultimately allows the group to work together. Group Two's need to be pro-active in educating the community appeared to alleviate the participants' outward anger and provided a positive channel for their intense feelings.

Aronson (1994) notes rituals in support groups in the middle working phase can be a key therapeutic tool. Rituals proved to be helpful to the group when the group themes of coping and change were introduced through listening to The Lion King Soundtrack - Circle of Life (John, 1994). The use of familiar music provided a common base to the session's theme. The ritual of creating a circle of life through the introduction of four cycles or seasons of life, which include birth/spring, growing/summer, growing older/fall, and elderly/winter provided an excellent discussion stepping stone in group one (See Appendix E). The review of the meanings of the circle of life assisted the children in

exploring alternative living arrangements in the event of their parent's death, as well as finding meaningful ways to remember their parents after death. Aronson (1994) identifies health as a concern for HIV/AIDS affected children. In Group Two, a major theme developed around ways to provide hope for a healthy future. A guest speaker who was a person with AIDS (PWA) was effective with the group in discussing information regarding the health and welfare of PWA's and their families. The guest conducted an open and frank discussion about death with the children at their developmental level. The participants who attended the first group's discussion of death, had as much difficulty witnessing and facing the reality of HIV/AIDS by someone living with the disease, as the other children in the group. The children in the groups did have some cognitive understanding of death and its implications due to their developmental stages of late childhood and early adolescence. The group did appear limited in their ability to accept the reality of their potential loss. Children in these stages find death to be remote, yet they do recognize it intellectually. Consistent rituals continued throughout all practicum group sessions including snack time, opening and closing circles with stuffed animals to hold and a journaling time.

According to Aronson (1994), the middle working phase provides coping strategies to deal with the stress group members face daily. He states many children become angry and act out at home or school. The working phase gives the participants in the group an opportunity to learn new and more appropriate ways to deal with the concrete and emotional difficulties of having a caregiver with HIV/AIDS. The working phase of the practicum Group One and Two did provide coping strategies for the

participants. The use of the reverse brainstorming technique (Toseland & Rivas, 1984) was helpful to both groups by addressing harmful and unhealthy coping skills, such as physical violence or running away. The group members were able to identify with one another, analyse reactions and practice coping skills while providing one another with positive coping strategies. Aronson's (1994) model did not discuss support systems, however the practicum groups participated in art, discussion and the psychodramatic method of role reversal to enhance the utilization of support systems to improve coping skills.

Aronson's (1994) final group phase of termination was evident in sessions five and six of Group One and sessions seven and eight of Group Two. Aronson's model focusses on four areas in the termination phase. The first area includes the child being able to incorporate the experience of losing the group into his or her identity. The second area bolsters the child's sense of efficacy prior to leaving the group. The third area provides a review of the new coping strategies and information learned in the group. The final area of termination is the importance of transitional objects and celebration, designed to lessen the pain of leaving the group and potential loss of their caregiver. The participants in Group One initially had difficulty incorporating the loss of the group into their identity due to the overwhelming fear of loss they were already experiencing. The children in Group One had little response to the facilitators' discussion of termination. In Group Two, one of the participants initially reverted to prior coping skills by shutting down emotionally. The group was able to support the participant by giving him permission to experience and express his feelings. It was apparent that the children were in the process of experiencing

multiple losses due to living with HIV in their families, and this greatly impacted on the group's ability to acknowledge the group was ending. The facilitators were able to bolster the participants' sense of efficacy by praising the group's efforts, reviewing group themes and stating how brave they were to attend the group and learn new coping skills. The facilitators utilized an empowering approach of non directive play techniques by encouraging the group to take control over their choice of play. The practicum participants in Group One were able to spontaneously demonstrate a mastery of skills through the play, and provided the facilitators with a forum to praise their efforts and express confidence in their ability to be resourceful outside of the group.

The rituals Aronson (1994) notes as important were utilized in the closing circle. The practicum participants in Group Two were able to express their sadness over the group ending. This expression was another demonstration of the benefits of the group process, as in the beginning phase the children had great difficulty expressing their feelings. The facilitators provided a graduation ceremony which consisted of a transitional gift of a stuffed animal, a certificate and a return of journals. The final termination activity in Group Two concluded with a family activity requested by group participants. Aronson (1994) did not address parental involvement in the group process, as he seemed to have a more narrow focus for his group, however he did note parental involvement to be important for future work. I believed it was important to promote family unity and I honoured the group's request for parental involvement in the celebration. The fact the children were able to state their needs, demonstrated ownership of the group by the group members and also showed their ability to practice skills learned within the group regarding

assertiveness. Aronson's (1994) model was based on a time limited group. It became apparent to me that ongoing group support was warranted through the children comments that they did not want the group to end, one child's regression to former coping skills during a discussion of termination as well as their written feedback. The children also appeared to need more time to integrate the learning obtained in the sessions. The group was informed at the final activity that a community agency with whom they were familiar, would be offering the group on a continual basis. The information given to the group about ongoing support appeared to decrease the group's anxiety about the group ending, and provided containment for the participants' feelings regarding termination.

Child Feedback: Group Evaluation

The feedback form was entitled "The Wonderful Group," as previously named by a member of the group. Three of the four original members completed the Child Feedback Form regarding their experiences in the group. All of the members statements were positive (e.g., I think this group was...fun, made me happy). The feedback form indicated that the group was helpful to the participants and assisted one member with coping with loneliness. They stated that the best thing about group was coming every week! The worst thing was that it was ending. The children stated they learned more about HIV/AIDS and handling feelings. All participants stated they wanted to attend another group and report they felt sad that the group was over. One child reported that the family was closer since group started. (See Appendix F for summary of Child Feedback responses).

Parent Meeting, Evaluation and Feedback

The facilitator met with the only parent, Ruth-a, whose children completed the program. This parent was the same parent from the first group. The parent stated the group was helpful to her children and brought them closer, it also provided them with a greater understanding of HIV/AIDS. She also felt her children learned the importance of educating others about HIV/AIDS. The parent stated she didn't ask her children what happened in the group. She stated that her children's unwillingness to share what happened in the group demonstrated their understanding of confidentiality. The parent reported that her children looked forward to each session. She found the parent waiting room to be quiet and comfortable and the information provided to be useful.

The parent stated she was attending two Positive Women's Support Groups with local ASO's. The parent informed me that she was interested in an ongoing group for her children which would allow her more time for her to receive her own support. The parent also stated that she appreciated the individual and family sessions in addition to the group.

CHAPTER 4. FAMILY SYSTEMS INTERVENTIONS AND EVALUATIONS

Family System A

Amber-a	Sibling	Age 2 years
Cassie-a	Group, Individual and Family participant	Age 10 years
Skye-a	Group, Individual and Family participant	Age 11 years
Fallon-a	Group, Individual and Family participant	Age 12 years

Ruth-a Natural mother

Kali-Shiva Kali Shiva AIDS Services

Kali-Shiva CSV1 Kali-Shiva AIDS Services Community Support Volunteer One
Kali-Shiva CSV2 Kali-Shiva AIDS Services Community Support Volunteer Two
Total number of contacts with this system: 45 over ten months.

Intake Information

Ruth-a contacted the EHCC to refer her children to the Support Group for Children with a Parent Living with HIV/AIDS. At intake Ruth-a reported she had disclosed her positive HIV status to her children the previous year and felt they needed additional support to deal with the information and family changes. Ruth-a stated her son had also developed separation anxiety when she had to attend meetings or appointments (e.g., clinging, crying, somatic complaints). Additionally Ruth-a reported that the children were not permitted to talk about the family's positive HIV status outside the immediate family due to fears of ostracism. Ruth-a stated the family was close-knit and generally got along well and discipline problems were not an issue.

Ruth-a stated her eldest daughter Fallon-a would like to spend time away from the

family doing activities with friends or babysitting her younger siblings. Ruth-a stated she was fearful of having Fallon-a involved in extracurricular activities.

Cassie-a is the second youngest child in the family. Ruth-a informed the me that Cassie failed the second grade due to refusing to speak in class. Ruth-a had to audiotape her child in order for the teacher to believe she knew how to speak. Cassie-a now speaks in class; however, Ruth-a was concerned about her isolation from others. According to Ruth-a, Cassie-a was concerned about what will happen to the family should mom die.

Family A is of aboriginal descent. Ruth-a reported a history of alcohol abuse and family violence. Ruth-a has been sober for five years and is currently on medication to control her HIV symptoms. Ruth-a disclosed her positive HIV status to her children the previous year; she also had her doctor share information about HIV/AIDS to the children. Ruth-a stated she wanted them to understand the implications of the disease.

Ruth-a has been receiving support through attendance at a women's support group and her physician. At the time of intake Ruth-a's mother and siblings were not supportive of her and became distant when she disclosed her positive HIV status. Ruth-a does not attend her support group regularly due to her concerns for her children's well being.

Based on the assessment, it appeared that significant issues for this family included: Ruth-a's need for emotional support, and an understanding of normal childhood development and the impact of parental illness upon children; Skye-a's somatic complaints and separation anxiety; Fallon-a's need for normal developmental separation from the family and adolescent identity; Cassie-a's need to feel secure within the family and development of social connections.

System Treatment Summary

Ruth-a attended one pre-group session individually and two sessions with her children. The first family session was held in the family home to assist mom and the children in feeling comfortable with me. The family was open to having me in the home and all engaged in conversation. All children stated they were interested in attending the group. The second family session was held at the EHCC. The session included reviewing the purpose of the group sessions, confidentiality and videotaping. During the session Ruth-a demonstrated positive parenting skills and was encouraging to her children.

Individual sessions were conducted in the play therapy room with the children.

Skye-a volunteered to go first. He was quiet in the playroom and engaged verbally when asked a direct question. His play included board games such as Sorry and cards. Skye-a did not reveal any concerns about his mother's HIV status, family life or school. Skye-a appeared prepared in terms of the purpose of the group, although he seemed uncomfortable with the content and context of the group. Skye-a completed his CDI-Short form (CDI-S) and Family Assessment Measure (FAM III). Cassie-a was next in the play therapy room. She was more verbal in the individual session than the family session. Cassie-a discussed her class and favourite activities. Cassie-a appeared comfortable with the context and content of the group as well as the purpose. She did state she was fearful her mother would die of HIV and wanted to learn more about HIV/AIDS. Her play included sand play, dollhouse and drawing. Cassie-a completed her CDI-S and FAM III during the session. Fallon-a attended the individual session last. Fallon-a shared very little regarding her school and home life. Fallon-a chose to play cards during her individual

session. She answered direct questions about her favourite music and movies. Fallon-a was prepared in terms of the purpose of the group and appeared comfortable with the content and context. Fallon-a stated "my Mom has HIV and we can't talk about it." Fallon-a completed the CDI-S and FAM III during this session. Fallon-a was to have attended an older children's support group; however, due to lack of referrals, it was postponed. Fallon-a was offered individual sessions while waiting for the next session and she accepted.

A family session was held following the close of the first group. Cassie-a and Skye-a shared their experiences in the group with their mom and sister. The family reviewed the positive changes in the family since the group began.

Ruth-a remained in the parent's room throughout both groups. On occasion she brought her youngest daughter Amber with her. Ruth-a was provided with material regarding families living with HIV/AIDS, parenting information and updated information on community awareness events. Ruth-a's goal of connecting with other parents was met in a limited fashion due to the dropout rate. Ruth-a stated she enjoyed having the other parent present.

System sessions were conducted monthly with all five family members attending. The following issues were addressed: Family and individual support through Kali-Shiva AIDS Services; transportation issues; clarification of Kali-Shiva AIDS Services' CWV 1 and CWV 2's role with family A; family communication; disclosure of family HIV status to school systems; family and individual support systems; parenting roles and boundaries and family planning for the future. The family was able to address the concerns they

presented to the therapist and significant progress was made in the area of Ruth-a's parenting role and boundaries regarding meeting her own needs and understanding Skye-a's somatic concerns, Fallon-a's need for separation from the family in a safe manner and Cassie-a's concern for family unity should Mom die. Ruth-a was able to open communication with her children regarding her plan for the future in the event of her death. Ruth-a was also able to disclose her HIV status to the children's teachers and principal, which resulted in the children receiving support at school and an understanding system that appeared to maintain the family's confidentiality.

A systems issue did develop regarding CSV 1 and 2. The volunteers became sporadic in maintaining a schedule with the family. Ruth-a was able, with support, to address the issue and established a strong supportive partnership with Kali-Shiva volunteers. Transportation issues to and from the EHCC were resolved by the use of taxi vouchers.

Individual Child Treatment Summary

The group summaries discuss group themes, individual progress, interactions and issues. This section will discuss individual sessions conducted with Fallon-a, Skye-a and Cassie-a.

Fallon-a

Fallon attended six individual sessions. Ruth-a was concerned about Fallon-a's isolation from the family and developmental issues of adolescence. The goals of the intervention were to increase Fallon-a's connectedness with the family while providing support for healthy separation and individual identity. Fallon-a's sessions were held in a

therapy room. Initially in the first session, Fallon-a was quiet; however, she listened attentively and responded to direct questions. Fallon-a visibly relaxed as the session progressed and began to volunteer personal information. The second session and third session focussed on information about HIV/AIDS and her mother's disclosure. Fallon-a demonstrated a good knowledge base and stated she had spoken to her mother's doctor regarding HIV/AIDS. Fallon-a did have questions and concerns about family secrecy and her desire to disclose to others. I encouraged Fallon-a to create a list of "safe" people to whom she could disclose her mother's HIV status and role-played this disclosure to assist her in becoming comfortable with the disclosure. Fallon-a shared her feelings about her mother's disclosure of HIV to the family. I utilized an art activity of body tracing to assist Fallon-a in demonstrating her strong sense of herself. Fallon-a labelled areas on her body with feelings about the disclosure and outside influences in her life. Through the art and discussion she was able to share her shock, fear and sadness over the disclosure. The utilization of expressive therapies enabled Fallon-a to deal with changes in the family in an open manner by the fourth session. Fallon-a's statement that the HIV diagnosis brought the family closer together proved to be interesting as Fallon-a had been isolating herself from the family since the disclosure. Therapy provided a forum for Fallon-a to explore her present difficulties in relating to friends and her lack of participation in outside activities. She also was able to review her relationship with her siblings and her desire to provide babysitting services for her mother. I recognized that Fallon-a needed someone outside of the family to mentor her, as demonstrated by her desire to individuate from her family. Fallon-a was able to demonstrate some healthy coping skills with her situation; however,

her isolation and need for appropriate individuation from the family was apparent. Ruth-a agreed to having a Kali-Shiva CWV support Fallon-a. A transition session was held with Fallon-a, Kali-Shiva AIDS Services' coordinator and volunteer. During the final session Fallon-a reported she was pleased with her volunteer and she verbalized her readiness to end individual sessions and attend the next group session. During the intervention Ruth-a was able to recognize Fallon-a's need for greater responsibility within the family unit and would allow Fallon-a to babysit or be left at home on occasion.

Cassie-a

Six individual sessions were held with Cassie-a at her mother's request. Ruth-a was concerned about Cassie-a's preoccupation with death. The goals of the sessions were to provide a forum for Cassie-a to work through her preoccupation with death and provide an arena for a release of any feelings regarding death and the second goal was to increase her connectedness to her family. Cassie-a was initially very quiet in the playroom. She chose non-directive play in the sandbox. Initially, her play focussed on burying all the toys. Cassie-a kept one female figure out of the sand; however, she did not utilize the figure until the third session. During the third session, Cassie-a identified the figure as the mom and after burying all of the figures, set about having the mom figure rescue all the buried people. Cassie-a was open to discussing death and dying. She related the mom figure to her mother. Cassie-a then abandoned the sand box in the fourth session and began drawing. Cassie-a drew her family. When discussing family love, Cassie-a stated she thought her mom and siblings loved her. She was able to make a list with my assistance of all the ways her family showed their love for each other. When asked to

draw a picture of she and her mother doing an activity, Cassie-a stated she and mom have started walking together after school. By session five it was apparent that Cassie-a would benefit from individual time with her mother. A session was held with Ruth-a to discuss a plan of action. Ruth-a stated Cassie-a appeared to be less focussed on death and she would increase individual time with Cassie-a. At the final session, Cassie-a engaged in non-directive play with the dollhouse. She sorted the rooms and talked openly about her family and school. Cassie-a stated she looked forward to the second group session.

Skye-a

Individual sessions were conducted with Skye-a due to Ruth-a's concern over his somatic complaints and clinging behaviour. Ruth-a stated this behaviour increased whenever she had to attend her HIV/AIDS support group or an appointment. Individual sessions were conducted in the play therapy room. The first two sessions focussed on Skye-a establishing trust and rapport with me. Initially, Skye-a chose structured games of cards and board games. He was quiet and did not readily discuss his somatic complaints. Skye-a did acknowledge he became sick to his stomach when mom left the house. During the third session the I assisted Skye-a in developing a self-care worry plan. The basic premise of the plan was to practice thought stopping techniques whenever his stomach pains occurred. In session four Skye-a stated that he hadn't been feeling ill. It was apparent that Skye-a enjoyed feeling well as he related several positive aspects of this fact. Skye-a did acknowledge that his mother had missed her support meeting that week. Skye-a did state that he may have been ill had his mother attended her meeting. Skye-a did practice his thought stopping techniques in the session. He continued to choose

structured games during the session. It was apparent to the therapist that Skye-a required a mentor outside the family to assist him with positive activities and thought stopping. Ruth-a agreed to have another volunteer from Kali-Shiva AIDS Services provide individual support to her son. The idea was presented to Skye-a during session five. Initially, Skye-a was uneasy with the idea. However, after he created a list of activities he could do with the volunteer, he became excited about the prospect. Session six and seven focussed on the development of a calender to assist Skye-a in tracking his progress of thought stopping his worries and becoming ill. Skye-a was very creative in making his calender and shared the concept with Ruth-a. Session eight and nine focussed on reviewing his progress with thought stopping and his formation of his relationship with his Kali-Shiva CWV. A session was held with Ruth-a, Kali-Shiva and the volunteer when follow-through became inconsistent. The issue was rectified and the relationship continued. During the final session, it was apparent that the individual sessions assisted Skye-a in reducing the incidents and severity of somatic complaints.

EVALUATION

System A Measure Results

The following section provides a discussion of the measurement results for Family System A for the CDI-S, CBCL and FAM III. The Eco-Map was also utilized to measure family support systems during intake and discharge (See Figures 1 and 2).

As shown in Table 1, the CDI-S scores for both the pre- and post-tests were below the cutoff indicating depression. The CDI-S raw scores indicated a reduction in depressive symptoms for all three children. The pre- and post-measures of the FAM III were relatively stable and did not indicate any significant changes for this family. Overall it showed better functioning than the mean for clinical families.

The CBCL was completed by Ruth-a. Cassie-a's scores were in the normal range for the pre- and post-measures in competency and problem scales. Skye-a's somatic complaints in the internalized problem scales decreased from the borderline clinical range to the normal range at the post-test. Fallon-a scored in the borderline clinical range in the competency scales in the activity subscale for both the pre- and post-test. This is consistent with the intake concerns of social isolation for this child.

Overall the test results for family-a indicated that the group, individual and family interventions were beneficial for this family. There were reductions in depressive symptoms and an increase in family functioning. As well there was a decrease in competency and problem scales. Although this was a small sample, it does indicate the need for ongoing research with this population.

As shown in Figure 1, the Eco-Map for this family demonstrates a fairly closed

system at intake. At the end of treatment, one can see the system opened and the family increased its support. (See Figure 2).

The child's feedback responses (Appendix F) showed progress in awareness of HIV/AIDS information, feelings and coping skills. This was consistent with my observations that this family began to communicate more openly and became more comfortable in discussing difficult topics such as family planning and individuation. Cassie-a, Skye-a and Fallon-a expressed their sense of usefulness of the group by statements on the child feedback form.

On the parent feedback form response Ruth-a indicated the group was helpful to her family and brought them closer together. Ruth-a did state it would have been more helpful to her individually had more parents been involved in the program.

Post-test

Ruth-a

EVALUATION Table 1 System A Measure Results

Measure	Cassie-a			Skye-a				Fallon-a				
	CDI-S T- score	FAM III T- Score	CBCL Competency Scales T-score	CBCL Problem Scales T-score	CDI-S	FAM III T- score	CBCL Competency Scales T-score	CBCL Problem Scales T-score	CDI-S T- score	FAM III T- score	CBCL Com- petency Scales T-score	CBCL Proble m Scales T-score
Pre-test	50	30	59 -Normal range	53- Normal range	46	37	57 -Normal range	Normal range Somatic complaint (70) borderline clinical	42	43	Activities (33) Border- line clinical	57 - Normal With- drawn (60) highest score
Post-test	44	34	53- Normal range	44 - Normal range	40	37	48 - Normal range	Normal range Somatic complaint (60) decreased to normal range	39	45	45 - Normal range	55 - Normal range
Pretest	Ruth-a	29										L

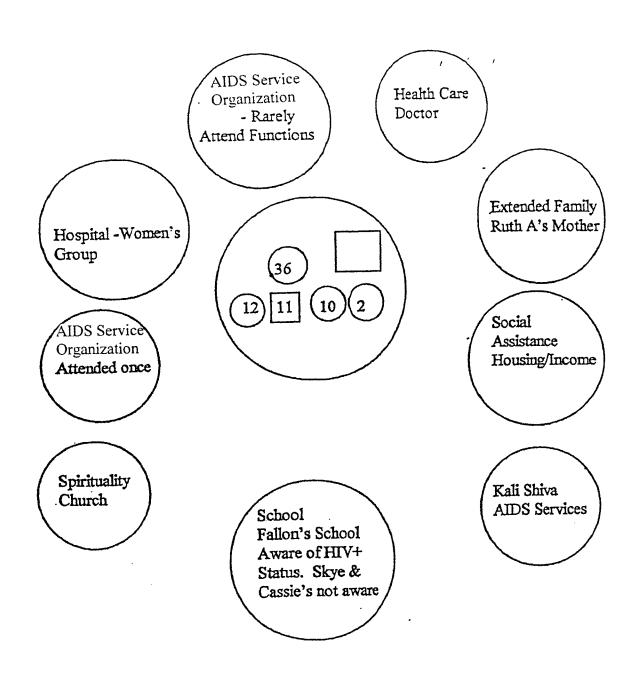


Figure 1. Eco-Map of family A at Intake

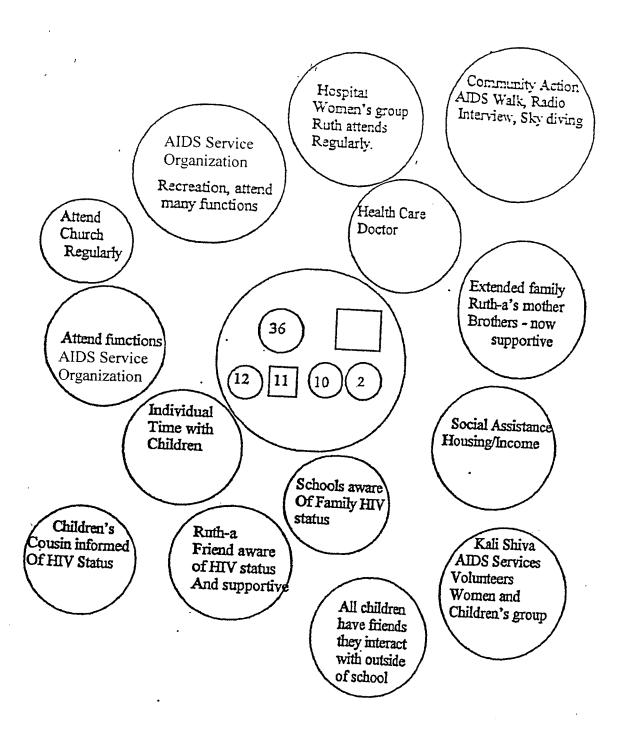


Figure 2. Eco-Map of family A at Discharge

CLINICAL OBSERVATIONS AND ATTAINMENT OF GOALS

Family a's progress and ability to benefit from individual group and family therapy was reflected in the following observations:

- 1. Although Cassie-a's initial, verbal participation was minimal, she progressed to become open and insightful with her comments and participation in activity.
- 2. Cassie-a's ability to interact through non-directive play during individual sessions indicated her need to play out her feelings through her own therapeutic direction enabling her to work through her preoccupation with death.
- 3. Cassie-a's increased participation in family sessions in putting forth her need to spend individual time with her mother and the development of a plan for future possible guardianship.
- 4. Skye-a's ability to gain control over his worries through thought stopping techniques.
- 5. Skye-a's ability to connect with his volunteer and individuate from his mother.
- 6. Skye-a's ability to become increasingly more verbal in the group, family sessions and participation in activities.
- 7. Fallon-a's ability to gain an understanding of herself and her need to separate from the family in a positive manner.
- 8. Fallon-a's ability to decrease her social isolation through connecting with her volunteer and increasing her social circle.
- The children's ability to discuss and develop coping skills regarding the family's HIV status.

- 10. Ruth-a's ability to recognize, identify and work toward meeting her own needs.
- 12. Ruth-a's strength in challenging her own parenting style to allow her children to individuate and separate in an appropriate manner.
- 13. Ruth-a's apparent love for her children in developing a family plan in the event of her death and allowing outside sources to support the family.
- 14. Ruth-a's increase in trust in systems and self disclosure of HIV status to the school system, her interview with a national news broadcast regarding living with HIV and community awareness of the disease by attendance and participation in AIDS walks and Skydiving for Hope.

The findings of the standardized measures that were implemented fit with the observations and attainment of goals for this family. The pre- and post-tests of the CDI-S revealed that over the course of treatment, depression and social isolation were decreased. The CBCL indicated that overall the program was effective in raising competency scores which is reflected in the family's ability to allow support to flow into the family system. The FAM III did provide an indicator that supported my belief that some families can be effective in coping with HIV/AIDS dependent upon the level of support available at the time of crises.

Family System B

Tommy-b Group, Individual and Family participant

Age 8 years

Jon-b

Sibling, Group participant

Age 6 years

Donna-b

Natural mother

David-b

Natural father

Child and Family Services Caseworker

Total number of contacts with this system: 7 over ten months.

Intake Information

Donna-b contacted the EHCC to refer her children to the support group for Children with Parents Living with HIV/AIDS as suggested by Child and Family Services. At intake, Donna-b stated she and her estranged husband were HIV positive and had known for approximately a year. Donna-b stated her health was stable at present; however, David-b's health was deteriorating and he has primary care of their two sons. Donna-b reported she and David-b have been open with both children about their HIV status. They have endeavoured to educate them about the virus. Donna-b stated her older son was having difficulty dealing with his feelings about the family's HIV status and the subsequent changes. He had been acting out while with her, i.e., destroying property, arguing and temper tantrums. Donna-b stated both children tend to listen better to their father. She also stated David-b would be the primary contact for the children as they lived with him full time. Donna-b was informed that Jon-b was too young to be in the group as he was only 6 years old. Donna-b stated she still wanted her eldest son in the group and that David-b would bring him for the individual and group sessions.

David-b attended a separate intake session and completed the paperwork for treatment including the CBCL pretest for Tommy-b. David-b stated although his children are well educated about HIV/AIDS, he felt that Tommy-b would benefit from attendance in the group. David-b also stated he would gain support through the informal parent meeting.

Family b was of Aboriginal descent and Donna-b reported a history of drug abuse in the family. Donna-b and David-b separated due to the stressors of living with HIV and financial difficulties. Donna-b's health was currently stable and she was receiving medication to manage HIV symptoms. David-b's health had been deteriorating and he had a recent diagnosis of AIDS. Tommy-b and Jon-b were informed of the family's HIV status shortly after diagnosis. David-b and Donna-b have been receiving support through Child and Family Services. At the time of intake, this family was estranged from all extended family due to the HIV/AIDS disclosure.

Significant issues for this family included the following: a) Donna-b and Davidb's familial support, b) Tommy-b's lack of social support and an outlet for dealing with the stressor's of HIV in the family, and c) financial difficulties for the family.

System Treatment Summary

Donna-b and David-b attended one pre-group session separately. David-b attended one pre-group session with Tommy-b. The individual adult sessions were held in the EHCC counselling room. During the pre-group sessions, the following issues were addressed: rules of confidentiality, group goals and importance of parental participation and expectations. Intake information was gathered and the parents signed consent forms

and completed the CBCL.

A family interview was conducted with David-b and Tommy-b. It was evident in this session that they were closely bonded. Tommy-b remained beside his father in the family therapy room. He was able to appropriately separate from his father when the playroom was suggested. Tommy-b was quite verbal in the playroom. He chose to play in the sandbox and had several characters engaged in a "war." Tommy-b openly discussed his family's HIV status. Tommy-b stated he was sad about his dad being sick. He stated he wanted to attend the group and meet the other children. Tommy-b appeared to understand the purpose, content and context of the group.

Tommy-b attended one group session in the first group. He participated well with the other members and disclosed that both of his parents had HIV. Tommy-b was active in all games and worked cooperatively with all group members. Tommy-b had difficulty finding a safe place during a relaxation exercise. He appeared to mimic the other male member of the group, changing his safe place from an unknown to his back yard. In the closing circle, Tommy-b stated he wanted to come back.

David-b remained in the parent room with family-a during this one session. He was provided with information about families and HIV, pamphlets and community awareness activities. He stated, prior to leaving, that he found the support helpful and would return the following week. The family did not return.

His case manager was contacted and I was informed that the family was experiencing housing and health issues. The worker stated the family wanted to attend the next group and she would meet with Tommy-b individually to provide support.

The family contacted the me prior to the second group beginning and stated they would like to attend. Jon-b was accepted into the group as he had turned seven. He did not meet the intake age criteria of age eight, however, it was determined he would benefit from the group. The family arrived during the second week of the group. David-b and Donna-b stated they had reunited. The parents stated they could not stay for the group, however they wanted to complete the necessary paperwork and return the following week. Tommy-b and Jon-b were introduced to the group and welcomed back for the next session. Donna-b and David-b did not attend any subsequent sessions with their children. The case manager was contacted and she informed me that they had moved from the city.

EVALUATION

System B Measure Results

The following section provides a discussion of the measurement results for Family System B for the CDI-S and CBCL. The FAM III was not administered to this family. The Eco-Map was also utilized to measure family support systems during intake and discharge. (See Figure 3). The CDI-S score demonstrates that Tommy-b may have benefited from intervention. His scores were in the clinically significant range. The CBCL pretest was completed by David-b. Tommy-b's scores demonstrated his competency scales were in the borderline clinical range for the subscale of school. Tommy-b's delinquent behaviour was in the borderline clinical range and his aggressive behaviour subscale proved to be clinically significant.

The family's Eco-Map indicated a closed system with very few resources and supports. The actual map depicts this families struggles. (See Figure 3).

EVALUATION

Table 2

System B Measure Results

Measure	Tommy-b					
	CDI-S T-score	FAM III	CBCL Competency Scales T-score	CBCL Problem Scales T-scores		
Pre-test	53 Clinically significant		School (30) borderline clinical	Delinquent behaviour (72) - borderline clinical Aggressive Behaviour (68) - clinically significant		
Post-test						

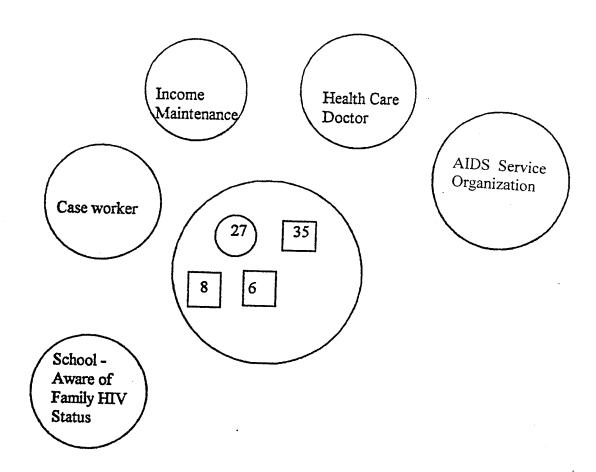


Figure 3. Eco-Map of family B at Intake

CLINICAL OBSERVATIONS AND ATTAINMENT OF GOALS

It is apparent that Tommy-b and Jon-b were able to break the isolation and connect with other children affected by HIV/AIDS in the family by meeting the other children involved in the program. However, it is evident that Family-b was unable to progress and benefit from treatment due to premature termination of treatment.

Family System C

Amy-c Sibling Age 2 years

Carley-c Sibling Age 3 years

Andy-c Sibling Age 5 years

Trey-c Group, Individual and Family participant Age 13 years

Diana-c Natural mother

Father

Case Manager AIDS Service Organization

Total number of contacts with this system: 3 over one month

Intake Information

Tony-c

Diana-c contacted the EHCC after a referral by their Case Manager at an AIDS Service Organization. Diana-c was interested in enrolling her son in the Support Group for Children with Parents Living With HIV/AIDS.

Diana-c reported at intake she was married to Tony-c who was diagnosed with HIV ten months previously. Tony-c's health was stable at the time of intake. Diana-c stated their relationship had been conflictual with family violence and alcoholism. Diana-c stated Trey-c was informed of the Family's HIV status shortly after diagnosis. Diana-c stated she endeavoured to provide her children with information about HIV/AIDS. Despite her efforts however, Trey-c had great difficulty with the disclosure and refused to eat with his father due to his concerns with contagion and misinformation about HIV. Trey-c has also been involved with the juvenile court system. At the time of intake he was on probation. According to Diana-c, Trey-c has experienced school problems manifesting

in anger outbursts and truancy. The school is unaware of the family HIV status and Diana-c believes this has caused difficulties in Trey-c receiving support at school. Diana-c stated she was fearful of the ramifications for her children, family and self should her children's peers discover her husband's HIV status. At the time of intake the family received support from an AIDS Service Organization. The family lives in a rural area and does not have access to a vehicle. Diana-c stated she was willing to take the bus into the city in order for her son to attend the group. Diana-c stated she thought she would find the parent support helpful. She further stated the group would assist her son in receiving factual information about HIV/AIDS, gain assistance in dealing with any issues and have the support of other children.

Significant issues for this family included the following: Trey-c's lack of factual information and a healthy outlet for his feelings, Trey-c's isolation and lack of a support system, Diana-c's lack of support in parenting and dealing with her husband's HIV diagnosis and other family issues such as alcoholism and family violence, and Tony-c and Diana-c's isolation.

System Treatment Summary

Diana-c and Trey-c attended one pre-group session each and one family session.

During Diana-c's individual session it was apparent that she understood the rules of confidentiality, videotaping, group goals, importance of parental participation and expectations. Diana-c completed the CBCL and FAM III measures and signed consent forms. Diana-c stated she was eager to have her son in the group and requested information that would be helpful in dealing with her younger children. She was willing to

share personal information and it was obvious she had her children's best interests in mind. Diana-c informed me that her husband would not participate in treatment. I encouraged her to ask him to attend and for her to share information with him. Diana-c was open to trying to engage Tony-c in the treatment process. Diana-c asked appropriate questions regarding the group process and stated concerns that Trey-c was in need of group support, however, she was unsure if he would follow through with the entire group as his behaviour was unpredictable. However, Diana-c expressed hope that Trey-c would benefit from the group process. She believed that being with peers would provide the support and assistance he needed regarding the family's HIV status.

The family interview was conducted with Diana-c and Trey-c. Diana-c was open with her son in the session and expressed to him her concerns and fears in an appropriate manner. Trey-c presented with appropriate boundaries. He was initially very quiet in the family session. Trey-c did express curiosity about the group and appeared able to understand the reasons he would be attending. As this session progressed Trey-c appeared more comfortable with me and shared honestly regarding his involvement with the law and family life.

During the individual session, Trey-c opened up about his fear of contagion, parental concerns, alcoholism and conflicts with his mother and father. Trey-c completed the CDI-S and FAM III. I provided Trey-c with factual information regarding HIV transmission and provided written materials to take home.

Trey-c attended one group session. He participated well in this session. Trey-c interacted in a positive manner with all members. Trey-c was able to share his family's

HIV status. Trey-c was very creative during the art activity.

Diana-c remained in the parent room during the group. She reviewed the material provided regarding families living with HIV/AIDS and took information with her to share with her husband. Diana-c appeared to interact well with the other parents in the informal support group.

The family did not return for the second group. Diana-c was contacted and she informed me that Trey-c had run away from home. Trey-c returned for session three:

Dealing with Feelings. The group reviewed the previous week's theme with Trey-c.

Trey-c was very involved in discussions, activities and role plays regarding dealing with anger. The co-facilitators reviewed modes of transmission with the group and ostracism.

Trey-c stated he was not allowed to talk about his family's HIV status outside the group.

The group provided Trey-c with strategies for dealing with the isolation.

Trey-c did not attend any subsequent sessions. I contacted Diana-c and she stated Trey-c would not be returning to group. I provided telephone support regarding Trey-c's behaviour and suggested that Trey-c would benefit from individual therapy. Diana-c stated she would ensure Trey-c received individual therapy. I informed Diana-c that the referral source at an AIDS Service Organization would be informed of the recommendation. The ASO was contacted and the case manager was informed of the recommendation. The case manager informed me that she was aware of the family dynamics and would assist the family in gaining additional support.

EVALUATION OF MEASURES

System C Measure Results

The following section provides a discussion of the measurement results for Family System C for the CDI-S, CBCL and FAM III. The Eco-Map was also utilized to measure family support systems during intake and discharge (See Figure 4).

Trey-c's CDI-S t-score of fifty indicated that he may have benefited from completing treatment. The FAM III t-score of seventy-two is considered clinically significant and Trey-c's score was seventy-five All of the specific areas of the Family Functioning Scales were clinically significant indicating intervention was necessary.

Diana-c completed the CBCL pre-test measure that indicated the competency scale subscale of school competencies was in the clinically significant range. In the problem scales, Trey-c scored in the clinically significant range for the internalizing subscales of withdrawn, anxious/depressed and attention problems. In the externalizing subscale, he scored in the clinically significant range for delinquent and aggressive behaviour. These scores are consistent with the clinical findings that intervention is indicated.

Diana-c's overall rating of sixty eight on the FAM III was clinically significant. All areas of family functioning except the communication and effective expression scales were in the clinically significant range. The scores indicate that this family would benefit from intervention.

The Eco-Map denotes a family system very isolated from resources and support (See Figure 4).

Post-test

Diana-c

EVALUATION

Table 3

System C Measure Results

Measure	Trey-c					
	CDI-S t-score	FAM III t-score	CBC Competency Scales t-score	CBC Problem Scales t-scores		
Pre-test	50	75	School (32) borderline clinical	Delinquent behaviour (93) - clinically significant Aggressive Behaviour (83) - clinically significant Anxiousness/Depressed (83) - clinically significant Withdrawn (82) - borderline clinical range		
Post-test	w					
Pre-test	Diana-c	68				

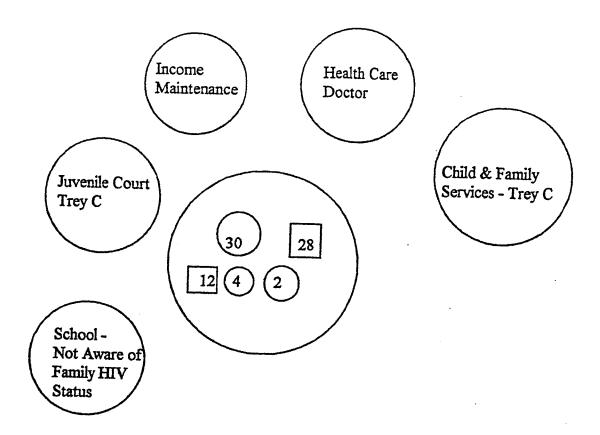


Figure 4. Eco-Map of family C at Intake

Clinical Dimensions and Attainment of Goals

Family c's progress and ability to benefit from the interventions was severely affected by early termination. However, it appears there was some benefit to this family as reflected in the following dimensions:

- 1. Trey-c's ability to connect with other children and his decrease in sense of isolation provided a forum for his support, learning and expression.
- 2. Trey-c's ability to dispel the myths of HIV/AIDS and assist him in feeling comfortable eating with his family again.
- 3. Trey-c and Diana-c were able to connect with one another while travelling to and from the group that assisted in the bonding process.
- 4. Diana-c was able to decrease her isolation by having the informal support session during her son's group.
- Diana-c was able to gain access to information about families living with HIV/AIDS and share the information with her spouse and younger children.
- 6. Diana-c recognized her son required clinical assistance and was open to receiving help from an AIDS Service Organization.

CHAPTER 5. LEARNING THEMES

The Referral Process

In the initial planning stages of this practicum, I believed that the HIV/AIDS community would embrace support services for children of HIV positive parents. I also assumed that the pandemic of HIV/AIDS in Manitoba would lend to ample and attainable referrals. It is apparent that this expectation was not realized. The difficulties in reaching the target population for referrals was alluded to in Chapter Three by the numerous community contacts and resulting referrals of only five families. The lack of referrals resulted in sibling group compositions.

Upon reflection of this phenomenon of difficulty reaching the target population, it appears there were several mitigating factors. HIV/AIDS remains shrouded in secrecy and shameful stigmatization. Several families who contacted the EHCC for services had not yet reached the decision to disclose the family's positive HIV status and struggled with acknowledging their situation. Other families expressed fear that known involvement in the group would compromise family safety due to the stigmatization of the disease.

One family contacted me and discussed their experience with their HIV positive child's school. The family understood their child did not meet the criterion for treatment. However, they wanted to bring to my attention, the ostracism that they were experiencing and the impact on their family when their child was expelled from school for biting. This family was provided support and referrals to appropriate agencies who could intervene on their behalf.

Secrecy was not only an issue for the family, it also appeared to be an issue for

community agencies. The importance of confidentiality is paramount for persons with AIDS (PWA) due to the very real threat of ostracism and community hysteria. I offered to personally meet with those individuals in PWA support groups through the existing AIDS service organizations. The community did not embrace this suggestion. It appears that these workers/agencies were protective of their families and endeavoured to maintain a high level of respect to the family's right to privacy. I respect the worker/agency's integrity and focus on the family. However, this did seem to impede on the family's right to treatment options. These findings are supported by Chachkes (1987) in her report that patients' access to services is impeded by the inflexibility of bureaucratic systems. She also discusses that workers in community agencies and social institutions react with stigma and fear when dealing with their families. She also states this reaction only serves to further alienate families when they need the connections most.

Financial difficulties for families also appeared to have an impact upon referrals. Several of the families referred experienced transportation, housing, income maintenance and medical care issues which revolved around financial difficulties and support issues. Ennis, Boland and Murphy (1995) support my belief that families cannot reach to heal emotionally when basic needs are not met. This area also demonstrates the incredible multiple losses, changes and transitions families must make in the face of HIV/AIDS.

Funding may have been another reason community agencies were reticent to refer. Canadian AIDS News (1996) reports that many agencies have to justify their existence in order to maintain funding for much needed services for PWA's. I was involved in a Multi disciplinary Panel Discussion regarding services to PWA's. During the panel and small

group discussions it was apparent that agencies were fearful of sharing client loads due to potential loss of funding should client numbers decrease. There was much discussion about amalgamating services for people living with HIV/AIDS, however, at that time a consensus could not be reached as to which agency would best oversee the umbrella services. Canadian AIDS News (1996) supports my experience of territorialism with some AIDS Service Organizations. The report stated that the mosaic of disciplines involved in the HIV/AIDS field need to work together. The report questioned how society and organizations can change to improve the lives of PWA's ensuring cooperation and coordination of services without territorialism. I found referrals to be more forthcoming when PWA's were directly involved with the agency. Directly involved includes providing services to other PWA's and actively involved in community awareness projects. Salter et al. (1994) supports the importance of PWA's involvement in and leadership in service planning. It is my opinion that this territorialism is not particular to the field of HIV/AIDS as it reflects a more general picture of how the helping system operates.

The final area to be examined is the impact systems had upon the referral process for this practicum. Individual family systems and community agencies have been discussed previously in this section. Larger systems such as provincial, national and international systems need to be reviewed in order to come to a global understanding of my difficulty.

As discussed in the funding issues on a local level, several agencies at the time of this practicum, were struggling to remain open to service PWA's. AIDS Manitoba was an information and referral source to those living with HIV/AIDS and the larger community.

The agency was helpful in arranging workshops such as "Care for the Caregiver" to which I was invited to attend. Unfortunately, AIDS Manitoba closed during the course of this practicum. The closure appeared to have a negative impact upon subsequent AIDS Service Organizations. The federal government created the National AIDS Strategy (NAS), in 1989 as discussed in chapter two and shifted from health promotion to population health. This health perspective did not recognize the importance of community based initiatives. The local AIDS Service Organizations appeared to be forced to attempt to provide mores services with less funds, causing further territorialism.

Initially, there appeared to be the territorialism previously discussed which seemed to last almost two years, which was the life of this practicum. The shift from territorialism to an arena of advocacy for renewing the HIV strategy on local, national and international levels was a positive advantage I experienced. This positive shift is well documented by Canadian AIDS News (1996), De Burger, (1997), Trussler and Marchand (1997) and Wong (1997). After this practicum was completed, I began to be invited to attend local and national meetings regarding services to PWA's and their families. It is interesting to note that once this practicum was completed, I participated as a co-investigator for a national study for Toronto Sick Children's Hospital *Disclosing HIV/AIDS to Children:* The Paths Families Take to Truthtelling (DeMatteo et al., 1998) and a provincial study in Manitoba regarding services for families living with HIV/AIDS in Winnipeg. AIDS Service Organizations were much more open to referring clients for the studies. It is unclear if this is due to my reciprocal relationships with AIDS Service Organizations or the political climate. Nevertheless, I believe the importance of working together in the

face of HIV/AIDS outweighed the pressure to self preserve. As previously discussed, the local ASO's began a dialogue which resulted in amalgamated services for HIV positive families. It is evident that Kirby's (1996) fear that the statistics of HIV/AIDS do not have an identity, did not hold true in Manitoba. PWA's, their families, Community ASO's as well as local and national action led to positive changes in Manitoba. Together they created a global arena and put a face on the epidemic.

Group Analysis

The group analysis will endeavour to follow the literature review as a means to compare and contrast my learning during the group process. Chapter three already discussed the process of group development, dynamics and interventions as compared to Aronson's (1994) group model of intervention with children of parents with AIDS. In this section an in-depth view of the issues discovered during the practicum group process will be explored in relation to the literature review. Family issues will be discussed in the next section.

It was apparent that the issue of HIV/AIDS education as discussed in the literature (Aronson, 1994; Patterson & Robichaud, 1996l; Roth et al., 1994) was an important factor in the practicum groups. HIV/AIDS information appeared to be well disseminated throughout the media during the early and mid 1990's. However, the group participants appeared to welcome any and all information about HIV/AIDS transmission, myths, facts and treatment opportunities. As previously discussed in chapter 3, one of the participants refused to eat with his family due to a fear of contagion. This demonstrated the need for on-going education and support for these children. It was interesting to note that as the

children became educated about HIV/AIDS, they in turn sought opportunities to teach others about the disease.

The salient psycho-social issues outlined by Lipson (1994), and Stulberg and Buckingham (1988), regarding the disclosure of HIV/AIDS status had a definite impact upon the practicum group members. The fear of social rejection was apparent within the group. Roth et al., (1994) did not find social ostracism to be a pressing factor with her study participants, however with this practicum group the children related several instances of rejection from extended family members as well as a constant struggle to maintain the veil of secrecy about the disease as described by Dansky (1994), Demb, (1989) and, Lewert, (1988). It was evident that Salter et al.'s (1994) findings mirrored the group's experience of the effects of secrecy. The fear of stigma did lead to the group participants being secretive about their parent's positive HIV status and resulted in a severe lack of support and services being accessible to the children. The group format did provide a forum for the participants to disclose the family HIV status and ultimately for three of the participants, the social support system was increased as a result of appropriate disclosure and an opening of closed family boundaries.

Denial of parental HIV status was not a defence mechanism observed in the practicum groups. Denial was apparent in the group when issues of dealing with possible death of a parent was discussed. The children demonstrated this denial through silence when a guest speaker addressed the issue of death as a result of AIDS. It appeared that although two of the group members had reviewed the issue of death previously, facing the reality of HIV/AIDS by someone living with the disease was difficult to witness. The

connection to their potential loss was painful to bear. This supports the findings of Halperin (1993) and, Lewert (1988), where denial is used by children of PWA's to protect themselves from stressors and enabled them to deny and evade the ramifications of AIDS. During the practicum, none of the participants experienced the death of a parent, however issues of anticipatory grief were evident within the practicum group. It is my belief that early childhood attachment theory as described by Bowlby (1977) and Brownlee (1994) had significant impacts on how the children in the group responded to anticipatory grief. Through the intake information it was apparent that all of the group members had some issues of separation and loss from their primary caregiver during early childhood through substance abuse, family disorganization, or involvement with children being removed from the home due to family dysfunction. The group participants attachment disruptions appeared to greatly impacted upon their ability to integrate and deal with their current family situation.

James (1989) states that children who have attachment disturbances in early childhood can develop maladaptive coping strategies in later childhood. The children in the group did exhibit several of the coping strategies outlined by James, including attention seeking behaviour, clinging to current caregivers, rebelliousness, emotional distance as well as an inability to trust others. The group mirrored Brownlee's (1994) findings that children can develop conduct and emotional disorders, learning difficulties and acute distress. The participants in this practicum exhibited behaviour ranging from acute stress reactions of stomach ailments, refusal to speak in public, juvenile delinquency, and pseudo maturity, as well as depressive symptoms of isolation and anger outbursts.

The severity of the problems was evident on the assessment measures. (See Tables 1-4).

Anticipatory grief, as defined by Webb (1991), is the anticipated crises of a gradual buildup of a stressful event. Walker et al. (1996) discusses that HIV/AIDS anticipatory grief can go beyond the optimal period of time in which anticipatory grief is considered beneficial, which is six to eighteen months.. HIV positive parents cycle through periods of health and the fighting of opportunistic diseases. This was apparent within the parents of the group members. One parent developed full blown AIDS, and his health fluctuated greatly. This served to cause confusion and fear in the children and it served to complicate the anticipatory grief process. The participants in the group were able to identify several multiple losses as Aronson (1994), Seigal and Gory (1994) and Walker et al. (1996) discuss, including, loss of a familiar environment during hospitalizations, loss of parental support during illness as well as the loss of a parent as a social convener when their parent became unable to join them in the community due to physical limitations or stigma impacting on the parent's ability to participate in community events. The issue of potential losses were observed to be a stress producer for the participants in the group. The children in the group expressed great concern about what would happen to them in the event of parental death. This was a very difficult issue to address due to denial as previously discussed, however, group activities such as the "Circle of Life" and guest speakers assisted the group in acknowledging the issue of parental death. The information gained in the group was helpful in approaching parents and disseminating information about future estate planning and choosing a guardian (The Teresa Group, 1996). It was painful for the parents to discuss this issue with their children, however one parent stated

that it was a sense of relief to have a plan for the future. This plan was shared with the children who became visibly relieved at knowing their future care had been addressed.

The group members' developmental stages had an impact upon their ability to cope with the family changes and impending parental death. The children in the group were in the developmental stage Seigal and Gory (1994) describe as latency age and early adolescence. The children in the group did demonstrate an understanding that death was final. The circle of life activity (Appendix E) demonstrated this developmental stage of understanding death quite clearly. These children, as discussed in chapter three, were able to recognize death intellectually, however it did seem remote to them. One child in the group was struggling with the task of autonomy which manifested itself through mild rebellion and mild depression. One of the group members also exhibited pseudo-adult behaviours as described by Van Dexter (1986). The child appeared to become over identified with the parent with a positive HIV status that resulted in a sacrificing of her own developmental needs in order to meet family needs.

The group was also comprised of sibling compositions. The initial concern about siblings in the group, came from the research conducted by Siegal and Gory (1994) regarding a dependency on older siblings. I expected that this might be a potential problem in the group. The siblings in the group supported one another and they did accept facilitator direction to allow one another to problem solve autonomously rather than completing tasks for each other. Sibling rivalry was not an issue for the group.

It is interesting to note the gender issues of the children who participated in this practicum. Two of the male participants exhibited the sex-role conditioning as reported

by Rando (1984), through the expression of feelings of anger and hostility. One male participant did not meld into this model as he expressed his feelings through sadness, loss, depression and loneliness. Society's expectations were not consistent for all males in this practicum. The females' grief reactions as reported by Cook and Dworkin (1992) and DeMatteo et al. (1999) appeared to be consistent for the participants in the practicum. Both female participants appeared to have difficulty expressing anger and putting HIV/AIDS and the impact on themselves and their family out of their minds.

The group intervention focussed on many issues as outlined in the literature. It was apparent that the group's goals and objectives were met. The environment provided a safe, confidential and contained structure that gave the participants a forum for expressing their feelings and enabled them to discuss other issues related to the impact of HIV/AIDS in their family. The supportive peer environment was difficult to maintain due to the several drop outs, however, the children were able to deal with issues of anticipatory grief, stigma and isolation. The children were able to learn, practice and integrate alternative coping methods and adapt to their life changes. This was evident in the opening of boundaries, strengthening of family bonds and increase in social supports systems. The factual information disseminated about HIV/AIDS did serve to relieve stress regarding transmission, however it is evident that ongoing education is important during each developmental stage and progression of the disease process. Recommendations for future support groups for children affected by HIV/AIDS is undertaken in the conclusion section.

Analysis of Family Interventions

In order to provide an in-depth synopsis of family interventions, it is prudent to follow the literature review and compare the review to the experience contained in the practicum. I will also discuss the particular interventions that I implemented beyond what was presented in the literature. The issue of disclosure discovered in this practicum mirrored the research as described by Aronson (1994), DeMatteo et al. (1999), Demb (1989), Lewert (1988), Lipson (1994), Roth et al. (1994), and Stulberg and Buckingham (1988). The three families who participated in the practicum disclosed the family's positive HIV status to their children within a year of diagnosis. These families determined which was the best manner to disclose. Several families who contacted me regarding services were unable to disclose their positive HIV status or participate in the program due to fears of ostracism, stigma and isolation. I referred these families to area AIDS Service Organizations in order to provide support services. Aronson (1994), Demb (1989), and Roth et al. (1994) report the need to keep disclosure a secret. Two of the families discussed herein related that they stressed to their children the need to keep the disclosure of HIV/AIDS a secret. One child reacted to the disclosure with fear and panic which resulted in strained family relations compounded by existing family issues.

I assisted one family in disclosing their HIV status to increase their support system. This was accomplished by the family identifying people and systems that they believe needed to know and could potentially provide support. The main system was the children's schools as well as significant friends and extended family members. Within several family sessions, the children and parents made agreements as to whom to tell. The

family then role played how to disclose and were supportive of each other during this process.

Depression in the children was not clinically significant for one of the families involved. Children from two of the families who terminated treatment were found to have clinically significant scores of depression. Children from the family who completed treatment was identified as having a reduction in CDI-S scores relating to depression. Fietz and Andrew (1991) and Lynch et al. (1993) also report acting out behaviour as a means of expressing feelings. All three families experienced some degree of acting out behaviour, ranging from minor rebelliousness and poor school performance to temper tantrums and criminal behaviour.

The use of denial as a defence mechanism as reported by Halperin (1993), Lewert (1988), and Stulberg and Buckingham (1988) was noted in one family in the initial stage of treatment. I believed that the inability or refusal to have a family plan in the event of death is a form of denial. Belsky and Nezworski (1988), Brownlee (1994), James (1989), Melina (1988), and Seigal and Gory (1994) discuss the impact of terminal illness and death upon attachment to caregivers. It was evident that the families who participated in the practicum not only had attachment issues relating to the family's positive HIV/AIDS status, but also to the impact of previous separations. These included separation due to foster care, alcoholism and parental divorce. The ages of the child participants ranged from latency age to early adolescence. Drotar's (1994) identification of two factors impacting on a child's response to parental health problems was apparent in this practicum. The developmental influence as well as the family's ability to cope with illness

effects and stage of parental illness was found to be related to the child's response. The children who had a conflictual relationship with their overburdened caregiver appeared to have a more negative coping style than the children who had a positive relationship.

As previously reported, none of the families who participated in the program experienced a death while the intervention was conducted. However anticipatory grief issues as defined by Van Dexter (1986), Web (1991), and Walker et al. (1996) were prevalent for the families discussed herein. The families encountered multiple losses such as housing, finances, parental, extended family and community support. The potential losses for these families was also evident in discussion regarding the loss of a parent, health and future planning as described in the group analysis.

I was able to be helpful to families in addressing anticipatory grief issues through the family sessions. The children were able to inform their parents that they had fears about their potential loss. The Circle of Life pictures (Appendix E), was helpful in addressing anticipatory grief as the children chose to bring the information to the family session, this in turn provided a starting point for the children to discuss their fear of loss as well as their need for support spiritually. The family began to attend church after this family session in response to the children's need to be connected spiritually. The parent also devised a future plan of care for the children in the event of her death.

The domino effect of stressors as reported by Salter et al. (1994) was apparent in the families participating in this program. The stigma of HIV/AIDS led to the families maintaining a shroud of secrecy regarding the family HIV/AIDS status. This secrecy led to isolation of the entire family system which in turn led to an obvious lack of support and

services as depicted in the eco-map (Hartman, 1978), Communication and collective decisions by the family as discussed by Cook and Dworkin (1992), Kalish (1985),

Osterweis et al. (1984), and Seigal and Gory (1994) appeared to be helpful to the families involved in this practicum. The families who increased their own internal collaboration seemed to respond to daily stressors in a more positive manner. This was demonstrated through the families ability to review disclosing the families HIV status and collectively decide on whom to disclose to, as well as methods of disclosure. Another example of a positive response to stressors were apparent when one of the helping systems involved with a family become sporadic in their support. The parent was able to identify the source stress and develop a plan to address her concerns, which included having a meeting with the parties involved with her ideas for rectifying the situation. The parent requested that I be present for additional support, however she was able to handle the situation in an appropriate manner with a positive outcome. The helping system was supportive and open to addressing her concerns.

Sibling bonds, as discussed by Fanos and Weiner (1994), and Salter et al. (1994) were found to be consistent with the research. The sibling relationships were intensified at times, however, the parent-child bonds appeared to be more developed than the sibling bonds. The children did not discuss the HIV disclosure openly with their siblings prior to intervention. It is important to note that the one family who completed the intervention had strong parental involvement and an open relationship with the medical caregiver who intervened with the siblings and provided HIV/AIDS education. The family who completed the intervention reported feeling closer and communication was improved.

The family interventions in this practicum focussed on several areas and endeavoured to strengthen the family cohesion through a supportive and empowering process as discussed in the literature by Salter et al. (1994), Kubler-Ross (1987), Lynch et al. (1993), Melvin and Sherr (1993), and Wilson (1993).

A significant part of my work involved working with Aboriginal families. Two of the three families were of Aboriginal descent. I explored cultural issues with the families initially through the intake process. I asked questions about community organizations the family had contact with, either in the past or presently that led to the family sharing how they were involved culturally as the agencies they identified were set up to assist the Aboriginal population. The Eco-maps (Figures 1-4) were helpful in examining the families support systems. All families identified cultural influences when constructing their Ecomaps. I was able to incorporate cultural issues into the family sessions by utilizing a talking circle, a technique that I learned while I was employed as a family counselor with an Aboriginal organization in Northern Ontario. The talking circle allows all members to speak without interruption from the other members, to demonstrate this respect, the person speaking holds a talking stick and then passes it on to the next person when they are finished. I also have a background and knowledge in Aboriginal traditional healing methods such a sweatlodges, smudges and teas. I believe my comfort level with Aboriginal healing methods allows the families to openly discuss how they incorporate their culture into their own lives. Spirituality is a very personal issue, I feel I was able to empower the families to explore their own sense of spirituality in a manner that made sense to them. I was a witness to their experience without imposing my own views

through active listening and a demonstration of my comfort level.

It was evident that the stigmatization regarding HIV/AIDS is not the only form of ostracization that these families experience. One family described a negative experience they had while waiting for a taxi that was arranged for the group from the Elizabeth Hill Counseling Centre. They informed me that the taxi slowed up for them, saw they were Aboriginal and then drove away. The entire family required debriefing from this incident when they arrived at the program. I was able to have them discuss the parallels between racial discrimination and HIV stigmatization and how to deal with these situations.

The underlying struggle with this aspect of the practicum was balancing individual and family support sessions. I endeavoured to provide support for the family without creating dependency. It is important for families to develop a healthy interdependence with their community. The interdependence also assists the family in being connected with others in the helping arena which counteracted possible burn-out effects of working in the HIV/AIDS field. This was created by enhancing the existing formal and informal support systems. Germain and Gitterman's (1980) ecological approach with the family assisted me to address the families' overall functioning. Walsh (1996), Hawley and DeHann (1996), and DeMatteo et al. (1999) noted in their research, and was also evidenced in this practicum, that secrecy, shame and isolation are decreased when families begin to connect with existing and new support systems. My findings support this fact as evidenced by the positive changes in the diagrammatic assessment of family-a's Eco-Map from intake to termination.

Efficacy of Clinical Measures

The clinical measures that were chosen appeared to be time consuming and cumbersome for the families involved. The FAM III (Skinner et al. 1983) provided excellent information regarding overall family functioning and highlighted the problem areas in the families. The CBCL (Achenbach, 1991) proved to be particularly overwhelming for the participants, however the information was quite useful and reflected the findings regarding affected children's mental health. The CDI-S (Kovacs, 1982), was the easiest of the selected measures to implement. It also provided a synapsis of the child's depression. I believe the long form would have provided a more in-depth view of the child's situation. The families with multiple children appeared to have the most difficulty in completing the forms. The Eco-map (Hartman, 1978) was the most helpful of all the tools selected as it assisted in joining with the caregiver and provided a picture of the family situation and a direction for intervention.

Team Approach

This practicum from development to completion was a two year process. A significant amount of time was required for consultation and preparation when utilizing a co-facilitator approach. I discovered that more time was required to debrief from group content with the co-therapist and the time frame was adjusted to ensure both parties had the benefit of debriefing. The co-therapists met for approximately one hour a week to confirm session themes and prepare activities. At least one hour was required for setting up the room, video and other equipment as well as snack preparation. Another hour was necessary for clean up and completion of contact notes.

It would have been helpful to the team if more attention had been focussed on vicarious trauma and the issue of co-facilitation. Antle (1998), Ross (1993), Fietz and Andrews (1991), Weiner and Seigal (1990), and Zamierowski and Gordon (1995) focus on the importance of addressing vicarious trauma in the field of HIV/AIDS. I did experience vicarious trauma. Through the utilization of the co-facilitator and field advisor as well as consultations with most of the practicum team, I was able to address clinical concerns in an appropriate manner.

During this practicum, I also experienced a number of life changes as well as community ostracism. I had to face the fears and concerns of immediate and extended family when sharing the scope of this practicum. Initially, this led to an unsupportive environment outside of the workplace as I felt I could not express my feelings about the work I was doing and the impact it had on me. I also experienced discomfort with University staff who were not educated on the realities and facts about HIV/AIDS as I heard derogatory comments about people rather than risk behaviour. Upon first experiencing these situations, I became frustrated and angry. After internal reflection and discussion with the team, I was able to turn these encounters into a learning experience for all involved. Information was disseminated and I became an advocate for not only families living with HIV/AIDS but for workers in the field.

A life change I experienced was the death of a close friend. I was able to address the loss with a professional counsellor and discussion with the team was undertaken to ensure I maintained healthy boundaries in the helping process while in the practicum.

Worden (1991) and Ross (1993) stress the importance of the workers' resolution of their

own losses. They also report that workers who deal with loss can have a positive impact upon the helping relationship. I believe that by dealing with the loss in a structured manner with the team, this assisted the participants by maintaining healthy boundaries which reduced transference and counter -transference issues.

I discovered that the team approach needed to include my supervisor and committee members, as well as consultations outside the committee with professionals in the field. The committee meetings and consultations were found to be very conducive to reviewing systemic issues and evaluation measures. Separate supervision time was needed with the field advisor to review videotapes. Review of the tapes was found to be essential to my learning process.

CHAPTER 6. CONCLUSIONS AND RECOMMENDATIONS

As noted in chapter one, this practicum report has served to provide a record of my search to fill a gap in services for families living with HIV/AIDS in Manitoba. I moved away from the original focus of my practicum, which was to run support groups for children living with parents who had HIV/AIDS to an emphasis on working with the family system and an emphasis on broader systemic interventions with families affected by this disease. As my practicum progressed I came to understand that the importance of working with the entire family system and the community resources available to these families, was becoming the focus of my work. As my awareness and understanding developed, I then changed the emphasis of how I was implementing my practicum to include working with families and community resources.

I also discovered that although the "group" dissolved to a sibling composition, the goals for both myself and the families were achieved. The general conclusion based on this practicum is, that group support for negative children of HIV positive parents, coupled with individual and family intervention, can be beneficial in reducing isolation and increasing healthy coping skills. This was evidenced in the children's group, and family and individual sessions when secrecy and isolation were main themes throughout treatment. The eco-maps demonstrate the increase of social support systems for one of the three families involved. The fact that Family-A was able to include the school system in the disclosure process assisted the family in breaking barriers to support. The findings in the practicum are supported by the literature (Antle, 1998; Aronson, 1994; Lynch et al., 1993; Melvin & Sherr, 1993; Roth et al., 1994; Salter et al., 1994). The clinical

evaluations, client feedback, as well as observations indicated that this practicum was a positive experience for the participants. It appears that the indicators of positive feedback, the willingness of the participants to complete activities, engage and respond in discussions, attendance, as well as the request for an on-going group demonstrate that the practicum was a positive experience. The number of "dropouts" during the treatment process was a major complication. However, the treatment goals as outlined in chapter three as well as individual goals were adequately met.

The group would have had a stronger impact with more participants. The children learned they were not the only ones dealing with HIV/AIDS, however if more children were involved they would have been able to develop lasting friendships. The increase to eight weeks in the second group provided additional time for exploration of feelings and mastery of healthy coping skills in the middle group phase. Additional sessions could have been added to provide a more supportive environment. It was difficult for the children to open up to the guest speakers. If the children been able to develop a stronger sense of cohesion and connectedness, they would have been able to tolerate and appreciate new additions to the group in a more positive and less stressful manner. The group members were also not ready for termination even after eight weeks. The group and caregiver requested an on-going group. It was evident that a time limited group did not meet all of the family's needs; this is also supported in the literature (Aronson, 1994; Roth et al., 1994).

I, as was discussed in chapter two, did assist Kali-Shiva AIDS Services in applying for a grant to provide a year round open support group for children impacted by

HIV/AIDS. This group was also open to children who had experienced a death of anyone in their family due to HIV/AIDS. I learned through this practicum that support is not a time limited process. I also learned from other national centres in Canada such as the Teresa Group in Toronto and Canadian Children With Positive Parents in Saskatchewan. I appreciate their ability to share their experiences which enhanced my learning and support network. All ASO's involved in this practicum are heralded as a beacon of light and hope to all persons affected by HIV/AIDS.

The option of referring participants for additional support was available and recommended for all family systems involved. I was able to assist the families in gaining support in a multidisciplinary manner through the other AIDS Service Organizations and community agencies. Only one family achieved the final goal of receiving support as a family and completion of the entire intervention. My belief of an embracing community was challenged. I expected that my willingness to fill a gap in service for families living with HIV/AIDS would be widely accepted and referrals would not be an issue. However as discussed in chapter one, I was able to gain an understanding of the systemic issues inherent in the HIV/AIDS field. I learned that although at times systems appeared closed, upon closer examination, most have the clients' best interest and wishes in the forefront. This appearance could be a reflection of the political nature of the HIV/AIDS issue, however, as previously discussed this seems to be constant factor within the helping system in general. Involving the client in the change process on a systemic level is paramount.

The experience of working intensely with the children and families provided me

with valuable insight into the multilayered issue of HIV/AIDS and the family. Significant learning themes went beyond the stated learning goals of this practicum. These themes included: establishment of clear roles and boundaries with community agencies and clients; allowing self to be present and slow the therapy process to meet client need; appropriate boundaries with families; vicarious trauma; utilizing measures in a clinical practice and the use of play therapy techniques in group therapy.

The professional growth I experienced was advantageous for the future. I was able to continually challenge myself to become knowledgeable regarding HIV/AIDS. I have become more open to traditional and nontraditional healing methods and global issues through the literature available. I learned from the families contained herein as well as those I interviewed for the two pieces of research I participated in as a co-investigator. Having the opportunity to work with a team consisting of a co-therapist, consultants, committee and supervisor contributed significantly to both theoretical and practical learning.

One of the most prominent personal achievements of this practicum was an increased awareness of my own biases and skills. I had to constantly challenge my own thinking and analyse my motivations. Being a facilitator to another's healing increases one's awareness of ensuring that one's own needs are met in the process. Achieving this through involvement in personal therapy, self healing and healthy outlets only increases ones' sense of well-being. This practicum enabled me to gain competence in working with children and families living with and affected by HIV/AIDS. I was also able to increase my clinical skills in family, group and individual therapy.

There were two meaningful experiences in this practicum which stand out to be recognized. The first is the progression of Family-a's journey to social connectedness and self-determination. The Eco-Map demonstrates this path from a closed family system to one with appropriate open boundaries. The second was the powerful impact the circle of life activity had upon both myself and the group. The picture taken of this activity and shown in Appendix E denotes the children's understanding of and willingness to address the issue of anticipatory grief.

Recommendations

Although this practicum impacted three families and the data acquired was limited, I feel it is prudent to make some recommendations for future work with families living with HIV/AIDS. A key issue that I believe needs immediate attention is an ongoing examination of the relationship between funding bodies and the community. ASO's are beginning to work together to meet the needs of families living with HIV/AIDS, however funding competition only serves to prevent services from collaborating to meet client need.

Another priority area which should be central to working with families living with HIV/AIDS is the issue of an interdisciplinary approach to support. Social workers understand systemic issues and can effect change by working together with an interdisciplinary team. Effective change can only take place if the family living with HIV/AIDS is an integral part of the team. The team approach will also provide support to the individual worker and reduce the impact of vicarious trauma and potential burn out as workers walk the path of HIV/AIDS with families.

A third issue is the need for ongoing HIV/AIDS education. HIV and AIDS are not static issues, there are new developments in treatment options and research monthly; if workers are not continually educated, it will be difficult to support clients and provide up to date resources to the community. Social workers who understand the disease process are also better able to advocate with their clients for much needed services as HIV/AIDS progresses.

A final issue is the support and treatment of families. Social workers can not work with isolated parts of the family system. The entire family needs support, it is important for AIDS Service Organizations to provide services which enhance family unity and support. This can include support groups, education, individual and family therapy as well as opportunities to increase social support systems. It is vital that this support be available throughout the family's lifespan.

I am hopeful that the ASO's on local, provincial, national and international levels will continue to collaborate with all families affected by HIV/AIDS to eradicate the stigma attached to this disease and provide much needed services to all who are affected by HIV/AIDS. I have been honoured to be a part of the healing journey of the families involved in this practicum. I appreciate the courage and sharing by the families and their willingness to risk of themselves in an effort to confront HIV/AIDS.

REFERENCES

- AIDS Care and Treatment (1994). *Learning together about HIV*. National AIDS Clearinghouse.
- Achenbach, T. M. (1991). Manual for the CBCL/4-18 and 1991 Profile. Burlington, VT: University of Vermont Department of Psychiatry.
- AIDS-Info.com (1998). Focussing on an epidemic for laypersons and professionals. http://www.aids-info.com.
- Aldrich, L. (1995). Children adjusting to new situations (CANS): A grief support group. Caring Magazine, April, 46-52.
- Altschul, S. & Pollock, G. (1988). *Childhood bereavement and its aftermath.* Madison: International Universities Press.
- Amelio, R. (1993). An AIDS bereavement support group: One model of intervention in a time of crises", Social Work with Groups, 16 (2), 43-45.
- Ankrah, M. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited", *AIDS Care*, 5 (1), 22-26.
- Antle, B. (1998). No longer invisible: Group work with children and youth affected by HIV and AIDS. Submitted to 20° Annual Symposium of the Association for the Advancement of Social Work in Groups.
- Aronson, S. (1994, Fall). Group intervention with children of parents with AIDS. *Group*, 18 (3), 133-140.
- Axline, V. (1969). Play therapy. New York: Ballantine Books.

- Barton, D. (1977). *Dying and death: A clinical guide for caregivers*. Baltimore: The Williams and Wilkens Company.
- Barnes, M. (1993). *Magic of play therapy*. Kingston, Ontario: Mandala Therapeutic Services.
- Belsky, J. & Nezworski, T. (1988). *Clinical implications of attachment*. New Jersey: Lawrence Erlbaum Associates.
- Bowlby, J. (1977). The Making and breaking of affectional bonds. *British Journal of Psychiatry*, 130 421-431.
- Brownlee, E. (1994). *Issues of attachment, separation and loss*. Thunder Bay, Ontario: Meno Bimahdizewin Child and Family Services.
- Bruenlin, D., Schwartz, R. & Kune Karrer, B. (1992). *Metaframeworks*. San Francisco: Jossy-Bass Inc.
- Canadian Children With Positive Parents. (1994, November). *Our children*. 404 Avenue I North, Saskatoon, Saskatchewan, S7L 2G8.
- Canadian AIDS News. (1996, Fall). Special insert, 1-4.
- Chachkes, E. (1987). Women and children with AIDS. *Responding to AIDS:*psychosocial initiatives. Silverspring, MD: National Association of Social Workers.
- Chorney, R. & Payne, M. (1995). Housing & money for people living with HIV/AIDS.

 AIDS Shelter Coalition of Manitoba Inc.
- Cook, A. & Dworkin, D. (1992). Helping the bereaved: Thereapeutic interventions for children, adolescents and adults. Basic Books.

- Dansky, S. (1994). Now dare everything: Tales of HIV related psychotherapy, Haworth Press, Inc.
- Deburger, D. (1997). Health promotion to population health. *Canadian AIDS News*. Fall, 1-9.
- DeMatteo, D., Harrison, C., Salter Goldie, R., King, S., Arneson, C., Louch, D.,

 Lefebvre, A., Read, S., Aykroyd, G., Bennett, C., Defend, M., Sheckter, L.,

 Boland, B. & Graham, T. (1999). Disclosing HIV/AIDS to children: The paths
 families take to truthtelling. Toronto: The Hospital for Sick Children.
- Demb, J. (1989). Adolescent survivors of parents with AIDS. Family Systems Medicine, 7 (3)., 339-343.
- Dennehy, E., Edwards, C. & Keller, R. (1995). AIDS education intervention: Utilizing a person with AIDS: Examination and clarification. *AIDS Education and Prevention*. Guilford Press, 124-133.
- Dennison, S. and Glassman, C. (1987). *Activities for children in therapy*, Springfield, Illinois: Charles C. Thomas Publisher.
- Dickenson, G. (1992). First childhood death experiences. Omega, 25 (3), 169-182.
- Doka, Kenneth J. (ed.). (1989). Disenfranchised grief recognizing hidden sorrow. Lexington Books.
- Drotar, D. (1994). Impact of parental health problems on children: Concepts, methods, and unanswered questions. *Journal of Pediatric Psychology*, 19 (5), 525-536.
- Elizur, E. & Kaffman, M. (1983, October). Factors influencing the severity of childhood bereavement reactions. *American Journal of Orthopsychiatry*, 53 (4), 668-676.

- Fanos, Felissa L. and Wiener, L. (1994, June). Tomorrow's survivors: Siblings of human immunodeficiency virus-infected children. *Journal of Developmental and Behavioural Pediatrics*, 15 (3), S43-S48.
- Fietz, M.& Andrews, L. (1991). HIV/AIDS: Improving our response: An in-service training for social workers: Participants manual. Canadian Cataloguing In Publication Data.
- Freeman, E. (1984). Loss and grief in children: Implications for school social workers. Social Work in Education, 6 (4), 241-258.
- Germain, C. & Gitterman, A. (1980). *The life model of social work practice*. New York: Columbia University Press.
- Gil, E. (1994). Play in family therapy. New York: The Guilford Press.
- Green, G. (1993). Editorial review: Social support and HIV. AIDS Care, 5 (1), 1-4.
- Grollman, Earl A., Ed. (1995). Bereaved children and teens. Beacon Press.
- Halperin, E. (1993). Denial in the children whose parents died of AIDS. *Child Psychiatry and Human Development*, 23 (4), 249-257.
- Hartman, A. (1978, October). Diagrammatic assessment of family relationships. *Social Casework*, 465-476.
- Hawley, D. & DeHaan, L. (1996). Toward a definition of family resilience: Integrating lifespan and family perspectives. *Family Process*, 35 (3), 283-298.
- Health Canada (1996). *Annual report on AIDS in Canada*. Minister of Public Works and Government Services Canada.
- Hicks, D. (1994, November). Our children. Canadian children with positive parents

- Newsletter.
- HIV Prevention Works Report (1996). Highlights of the HIV prevention works

 symposium, an official satellite symposium of the XI international conference on

 AIDS. Vancouver: Canadian Public Health Association, 1-9.
- Holmes, J. (1993). John Bowlby and attachment theory. New York: Routledge.
- Hurley, D. (1991). Chapter In. *Play therapy with children in crises: A casebook for practitioners*. The Guilford Press: New York.
- James, B. (1989). Treating traumatized children: New insights and creative interventions. Toronto: Lexington Books.
- John, E. (1994). Circle of life. On *The Lion king soundtrack* [Cassette]. Burbank, CA: BMI/The Walt Disney Company.
- Johnson, A. (1994). Living with dying dying at home: An AIDS care team resource manual. Canadian Cataloguing in Publication Data.
- Johnson Institute (1994). Helping kids prevent violence: Skill building for anger management and conflict resolution [Videotape]. Minneapolis: Johnson Institute QVS Inc.
- Kali Shiva (1997, March). Project description Manitoba: Kali Shiva AIDS Services.
- Kalish, R. A. (1985). Death, grief, and caring relationships. Monterey: Brooks/Cole.
- Kirby (1996, Fall). Facts and figures, IX International Conference on AIDS. *Canadian AIDS News*, 1-21.
- Kovacs, M. (1982). *The children's depression inventory manual*. Toronto: Multi-Health Systems Inc.

- Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.
- Kubler-Ross, E. (1987). AIDS: The ultimate challenge. New York: Collier Books.
- Lehna, C. (1993 September/October). Children's descriptions of their feelings and what they found helpful during bereavement. *The American Journal of Hospice & Palliative Care*, 24-30.
- Levine, C. (1995). Orphans of the HIV epidemic: Unmet needs in six US cities. *AIDS Care.* 7 (1), S57-S62.
- Lewert, G. (1988, June). Children and AIDS. Social Casework: The Journal of Contemporary Social Work, 348-354.
- Lieberman, A. & Pawl, J. (1988). Attachment and the ontogeny of conduct problems.

 Clinical Implications of Attachment. New Jersey: Lawrence Erlbaum & Associates.
- Lipson, M. (1994, June). Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. *Journal of Developmental and Behavioural Pediatrics*, S61-S65.
- Lynch, V., Lloyd, G. & Fimbres, M. (1993). The changing face of AIDS: Implications for social work practice. Auburn House.
- Manitoba Health (1996). Manitoba's Provincial AIDS Strategy. Manitoba.
- Masterman, S., & Reams, R. (1988). Support groups for bereaved preschool and school age children. *American Journal of Orthopsychiatry*, 58 (4), 562-570.
- Masur, C. (1991). Chapter In. *Play therapy with children in crises: A casebook for practitioners*. New York: The Guilford Press.

- Melina, L. (1988, May). A loss can cause a child to miss developmental tasks. *Adopted Child*, 7 (5), 1-4.
- Mellins, C. & Ehrhardt, A. (1994, June). Families affected by pediatric acquired immunodeficiency syndrome: Sources of stress and coping. *Journal of Developmental and Behavioural Pediatrics*, 15 (3), Supplement, S55-S60.
- Melvin, D. & Sherr, L. (1993). "The child in the family-responding to AIDS and HIV", AIDS Care. 5 (1), 35-42.
- Merrifield, M. (1990). Come sit by me. Toronto: Women's Press.
- Minister of National Health and Welfare (1995). We need to know about AIDS: A guide for parents on talking with their children about AIDS. Minister of Supply and Services.
- Moore, J. & Herlihy, B., (1993). Grief groups for students who have had a parent die. The School Counsellor, 41 54-59.
- Multi Health Systems (1993). Family assessment measure (FAM III). Multi Health Systems Inc.
- O'Connor, K. (1991). The play therapy primer: An integration of theories and techniques. New York: John Wiley & Sons, Inc.
- Osterweis, M., Solomon, F. & Green, M. (1984). Bereavement: reactions, consequences and care. Washington: National Academy Press.
- Paramount Pictures Corporation (1992). *Time out: The truth about HIV, AIDS and you* [Videotape]. Paramount Pictures.

- Patterson, B. & Robichaud, F. (1996). Managing your health: A guide for people living with HIV and AIDS. Toronto: Community AIDS Treatment Information Exchange and the Toronto People With AIDS Foundation.
- Pearce, J. & Pezzot-Pearce, T. (1994). Attachment theory and its implications for psychotherapy with maltreated children. *Child Abuse and Neglect*, 18 (5) 425-438.
- Podell, C. (1989). Adolescent mourning: The sudden death of a peer. *Clincial Social Work, 17*, 64-78.
- Prichard, E.R. (1974). The social worker's responsibility. *Anticipatory Grief.* New York: Columbia University Press, 237-245.
- Redpath, J. (1996, Fall). Doing more with less. Canadian AIDS News. 9(2), 1-2.
- Rando, T. (1984). Grief, dying and death. Illinois: Research Press Company.
- Rando, T. (1986). Loss and anticipatory grief. Lexington Books: Massachusetts.
- Ross, E. (1993). Preventing burnout among social workers employed in the field of AIDS/HIV. *Health and Social Work.* 18 (2), 91-108.
- Roth, J., Siegel, R. & Black, S. (1994, December). Identifying the mental health needs of children living in families with AIDS or HIV infection. *Community Mental Health Journal*, 30 (6), 581-593.
- Salter-Goldie, R., King, S., DeMatteo, D. & Bergman, A. (1994). *Children born to mothers with HIV/AIDS: Family psychosocial issues*. Toronto: The Hospital for Sick Children.
- Salter Goldie, R., DeMatteo, D., King, S.M., Wells, L. M., Aykroyd, G., Bennett, M. B., Doutrelepont, F., Harrison, C., Ingebrigtson, K., Miller, W., Modrovsky, B.,

- Montambault, I., Pottier, B., Scheckter, L., Snow, B., St. Pierre, R., Stevenson, D., Tataryn, K. & Vibien, M. (1997). Children born to mothers with HIV/AIDS. *The Social worker*, 64, 55-66.
- Schaefer, C. & O' Conner, K. (1983). Handbook of play therapy. Wiley & Sons Inc.
- Schowalter, J. (1975). Parent Death and Child Bereavement. *Bereavement: Its*psychosocial aspects. New York: Columbia University Press.
- Serovich, J. & Greene, K. (1993). Perceptions of family boundaries: The case of disclosure of HIV testing information. *Family Relations*, 42, 193-197.
- Shearon, E. (1980). Psychodrama with children. *Group Psychotherapy. Psychodrama* and Sociometry, 33., 142-155.
- Shepherdson, L. (1991 Winter). Play therapy applications for separation/loss/change. *Playground*, 30-39.
- Siegel, K. & Gorey, E. (1994, June). Childhood bereavement due to parental death from acquired immunodeficiency syndrome. *Journal of Developmental and Behavioural Pediatrics*. 15 (3), S66-S70.
- Sikkema, K. J., Kalichman S., Kelly J. & Koob, J. (1995). Group intervention to improve coping with AIDS-related bereavement: Model development and an illustrative clinical example. *AIDS Care*, 7 (4), 463-475.
- Silveira, W., Trafford, G. & Musgrove, R. (1988). Children need groups: A practical manual for group work with young children. Aberdeen University Press.
- Silverman, P., Nickman, S. & Worden W. (1992, October). Detachment revisited: The child's reconstruction of a dead parent. *American Journal of Orthopsychiatry*, 62

- (4), 494-503.
- Skinner, H., Steinhauer, P. & Santa Barbara, J. (1983). Family assessment measure.

 Canadian Journal of Mental Community Health, 2 (2): 91-105.
- Skinner, H., Steinhauer, P. & Santa Barbara, J. (1993). Family assessment measure:

 Version III. Toronto: Multi Health Systems Inc.
- Stulberg, I. & Buckingham, S. (1988, June). Parallel Issues for AIDS Patients, Families, and Others. *Social Casework*. 355-61.
- Sweetland, R. (1984). Tests: A comprehensive reference for assessments in psychological and education and business. Kansas City: Tests Corporation of America.
- The Teresa Group (1996). Our children, their future: A guide to future care planning for families living with HIV. Toronto: The Hospital for Sick Children.
- Toseland, R. & Rivas, R. (1995). *Introduction to group work practice*. Boston: Allyn & Bacon.
- Trussler, A. & Marchand, F. (1977, Fall). Population health model. *Canadian AIDS News*. Van Dexter, J. (1986). Anticipatory grief: Strategies for the classroom. *Loss and Anticipatory Grief*. Toronto: Lexington Books.
- Walker, R., Pomeroy, E., McNeil, J. & Franklin, C. (1996, February). Anticipatory grief and AIDS: Strategies for intervening with caregivers. *Health & Social Work, 21*(1), 49-57.
- Warmbrod, M. (1986). Counselling bereaved children: Stages in the process. *Social Casework*, 45. 351-358.
- Webb, N. (1991). Play therapy with children in crises: A casebook for practitioners.

- New York: The Guilford Press.
- Weinberg, N. (1985). The health care social worker's role in facilitating grief work: An empirical study. *Social Work in Health Care*, 10 (3), 107-117.
- Wong, C. (1997, Fall). Shift to population health. Canadian AIDS News, 10 (1), 1-4.
- Worden, J. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer Publishing Company.
- Wynott, G. (1997, November.). Naturopathy. Kali Shiva AIDS Services Newsletter, 6 (5),
- Zambelli, G. & DeRosa, A. (1992). Bereavement support groups for school-age children:

 Theory, intervention and case example. *American Journal of Orthopsychiatry*, 62

 (4), 484-493.
- Zambelli, G., Clark, E.& Heegaard, M. (1989). Art therapy for bereaved children, advances in art therapy. New York: John Wiley & Sons.
- Zamierowski, M. & Gordon, G. (1995, January/February). The use of creative art forms to enhance counselling skills of hospice professionals in dealing with the bereaved.

 The American Journal of Hospice & Palliative Care, 5-8.

APPENDIX A ADVERTISEMENT

CHILDREN'S SUPPORT GROUP

FOR THOSE WHO HAVE A LOVED ONE

LIVING WITH HIV OR AIDS

The Elizabeth Hill Counselling Centre is offering a support group for children who have a loved one living with HIV or AIDS. The group will provide an opportunity for children ages six to eleven years to share with others who are living in similar situation. The methods used for expression, learning and support will include art, play, discussion and music.

The Objectives of the Group include:

To provide children with a safe and confidential environment. To provide children with a forum for expressing their feelings and discuss other issues related to the impact of HIV/AIDS in their lives. To create a supportive peer environment which will enable and empower children to cope with issues and concerns regarding HIV and AIDS.

To provide support to families through the group process.

The group will begin on April 18, 1996 and will run for six weeks from 4:30 -6:00 p.m.

IF YOU ARE INTERESTED, PLEASE CONTACT THERESA AT 956-6560. REGISTRATION IS LIMITED AND THE GROUP IS FREE.

COMMUNITY AD

CHILDREN'S SUPPORT GROUP

For those who have
a loved one living with HIV or AIDS.
The group will be for children ages 11-15.
Methods used:
Discussion, role-playing, music, art and more.
Sessions begin October 1, 1996 and run for eight weeks.
From 4:30 -6:00 Snacks and beverages provided.

If interested please contact Theresa at 956-6560 Elizabeth Hill Counselling Centre 301-321 McDermot Avenue

APPENDIX B CONSENT FOR TREATMENT

CONSENT FORM

I hereby con	sent to allow the Elizabeth Hill Counselling Centre of the University of Manitoba
to assess an	d/or treat the following minor child:
Signature:	(Parent or Guardian)
Witness:	(i dione of oddinary
Date:	

PERMISSION TO OBTAIN/RELEASE INFORMATION

Date of Birth:		
Information Will Be Obtained/Released.		
Mailing Address:		
beth Hill Counselling Centre to release on tity, diagnosis, prognosis, or treatment to ed above.		
Date:		
ss: Date:		
to the agency or individual named aboveabout this client.		
Date:		

APPENDIX C PERMISSION FOR OBSERVATION

PERMISSION FOR OBSERVATION

In utilizing the services of the Elizabeth Hill Counselling Centre of the University of Manitoba, clients are participating in the activities of a teaching course. As a client, I understand:

That information obtained from psychological tests, interviews, psychotherapy sessions, or follow-up questionnaires may be shared with clinical supervisors and with other clinicians-in-training during case conferences;

That information, whether on paper or computer record, is shared solely for the purposes of aiding treatment, contributing to student training, and Centre administration and research;

That all information is kept under strict conditions of professional confidentiality; That observation and/or audio taping or videotaping of therapy session may be required.

Read and agreed to: Name of Client(s)	
Signature of Client(s) of Parent/Guardian(s):	
Signature of Clinician	Date
or Other Witness:	Date

APPENDIX D GROUP INTERVENTIONS

Group 1

Session 1: Beginnings

Goals

Trust and Confidentiality

Establish Mutuality - define groups purpose

Establish rapport between children and therapist

Establish Group Rules

Sharing of disclosure of Parent

Activities

Introduction of group leaders and children

Snack/social time

Sharing circle, choose stuffed animal to provide physical comfort

-group purpose - all children have a parent living with HIV/AIDS

Reviewed videotaping, confidentiality

"Well of Confidentiality" activity

Brainstorm group rules - children participated in creating rules

Group Warmups - Name Game - ball toss and action

Tangle game

Group Relaxation Exercise

Introduce journals with drawing activity

Closing circle

Session 2:HIV/AIDS Questions and Answers

Goals

Provide information about HIV/AIDS

Dispel myths about HIV/AIDS

Provide a forum to discuss parental HIV/AIDS disclosure and secrecy

Acknowledge impact of stigmas

Provide awareness of impact on self

Activities

Introduction of guest speaker and group members

Sharing circle with stuffed animal

Snack/social time.

Guest speaker Expert on HIV/AIDS and Children did a presentation regarding HIV/AIDS

Completed FACT sheets on HIV/AIDS

Question and answers

Video "Come Sit By Me"

Discussion of video and impact of disclosure on themselves

Picture in journal of what HIV looks like.

Sharing of Pictures with group.

Art activity thank you card for guest speaker

Closing Circle

Session 3: Feelings

Goals

Provide opportunity to recognize and share feelings

Validate children's feelings regarding HIV/AIDS disclosure

Begin to Learn effective ways of dealing with feelings

Ownership of the group for members

Activities

Snack and Sharing Circle with stuffed animal

Introduction of Group Theme of Feelings by leader discussion

Drawing activity of drawing feeling faces

Sharing of experiences and feelings

Group Game - Frozen feeling tag

Body tracing on paper with colour - Draw outline of body and label areas of the body using self created colour code when they were told of HIV/AIDS disclosure by parent Closing Circle

Session 4: Changes

GOALS

Provide a forum to discuss feelings regarding the Cycle of Life

Validate children's feelings regarding death

Provide hope for the future of the family

Session 4 Activities

Gathering activity

Sharing circle/snack

Introduced group theme of Life Cycle

Created the Circle of Life utilizing rocks, plants, twigs, grass, moss, stuffed animals and

flowers.

Lion King - Circle of Life Song - Elton John

Discussion of the groups creation and meaning for themselves

Photograph creation

Closing circle

Session 5: Coping

Goals

Assist group in learning coping skills

Encourage children to identify personal strengths

Encourage children to recognize support systems

Prepare for group closure

Plan and prepare for final party

Activities

Leader discussion regarding changing group time

Gathering Activity - family drawing

Snack and Sharing Circle with stuffed animal

Introduction of Group Theme of Coping with Feelings by leader discussion

Session 5 Activities Continued

Shared family picture with group

Created a "Hot Air Balloon" from colourful clothes

Write situations that children cope with in life - children wrote own situations

Placed situations in the balloon

Brain stormed ways of handling feelings

Practised methods of coping i.e. hitting pillow, talking, walking away

Created a list of those available for support

Roleplayed situation in the hot air balloon

Deflation of balloon

Discussion of final group and party plans and closing circle

Session 6: Review and Termination

Goals

Provide a positive closure to therapeutic process

Review the group's purpose and themes presented

Provide children with a celebration of accomplishments and recognize this with a

graduation certificate

Reassure children that support systems are available

Activities

Celebration Dinner

Sharing Circle/stuffed animal

Completion of group evaluation and feedback forms

Session 6 Activities Continued

Play games to promote fun activities - tangle game, ball tag

Magic Carpet Ride - Relaxation

Reviewed use of relaxation

Final closing circle

Graduation awards

Group 2

Session 1: Beginnings

Goals

Trust and Confidentiality

Establish Mutuality - define groups purpose and establish rapport between children and therapist

Establish Group Rules

Sharing of disclosure of Parent

ACTIVITIES

Introduction of group leaders and children

Snack/social time.

Sharing circle, choose stuffed animal to provide physical comfort

Group purpose - all children have a parent living with HIV/AIDS

Reviewed videotaping, confidentiality

"Well of Confidentiality" activity

Brainstorm group rules - children participated in creating rules

Group 2 Session 1 Activities Continued

Group Warmups - Name Game - ball toss and action, tangle game

Create a puppet of caregiver with HIV and introduce to the group

Introduce journal with drawing activity

Closing circle

Group 2 - Session 2: HIV/AIDS in the Family

Goals

Provide opportunity to recognize and share feelings

Learn effective methods of dealing with feelings.

Validate children's feelings regarding HIV/AIDS disclosure

Continue to build group cohesiveness

Activities

Introduction of group leaders and children

Snack/social time.

Group Warmups - Tangle Game

Pass the Feeling Face

Family Memories

Complete creation of puppet of caregiver with HIV and introduce to the group

Closing circle

Group 2 - Session 3 : Dealing with Feelings

Goals

Continue to provide opportunity to recognize and share feelings

Group 2 Goals Continued

Continue to learn effective methods of dealing with feelings

Continue to validate children's feelings

Learn strategies for handling anger

Activities

Introduction of group leaders and children

Snack/social time

Group discussion on theme of the week - Dealing with Feelings

Brain stormed issue of violence and identified forms

Group discussion regarding anger

Watched a video - Anger Commando

Discussion of video messages

Related anger to HIV/AIDS issues

Played Shark Island game with HIV/AIDS myths

Role play situations using ABCD method of anger control

Feeling card game

Closing Circle - discussed final group activity

Group 2 - Session 4: Dealing With Feelings Continued

Goals

Continue to provide opportunity to recognize and share feelings

Continue to learn effective methods of dealing with feelings

Continue to validate children's feelings and practice strategies for handling anger/stress

Activities

Introduction of group leaders and children

Snack/social time.

Group Warmups - Best and Worst of the Week

Review ABCD Strategies

Feeling Tag

Relaxation Exercise

Closing circle

Group 2 - Session 5: HIV/AIDS Facts

Goals

Learn the facts about HIV/AIDS

Dispel myths about HIV/AIDS

Continue to validate children's feelings

Learn strategies for handling societal issues regarding HIV/AIDS

Activities

Opening circle - the best and worst of the week

Snack/social time

Group discussion on theme of the week - Learning more about HIV/AIDS

Watch video "Time Out - The Truth About HIV/AIDS and You"

Group discussion regarding messages in the video, feelings it evoked

Played feeling game

Created HIV/AIDS posters/ Closing Circle - What I learned

Group 2 - Session 6: Coping with Changes

Goals

Validate children's feelings regarding death and change

Provide hope for the future of the family

Learn how to cope with changes in the family

Provide an opportunity to discuss family change since HIV/AIDS disclosure

Continue to validate children's feelings

Activities

Opening Circle - Introduce guest speaker - Person with AIDS (PWA)

Snack/social time

Group discussion on theme of the week - Dealing with Feelings/change and Hope for future.

PWA guest speaker

Group discussion regarding families living with HIV/AIDS - guest leaves following discussion

Feeling card game

Make Thank you cards for guest

Closing circle - discussed speaker and group closure

Group 2 - Session7: Support

GOALS

Identify support systems

Begin group closure

Complete measures

Continue to validate children's feelings

Group 2 - Session 7 Activities

Gathering activity - Complete CBCL

Opening circle - what we learned from group, feelings about group ending

Snack/social time - Celebrate member's birthday

Group discussion on theme of the week - Support

Play Shark Island game

Social Atom of Support - brainstorm support systems

Social Atom in Action - role reversal - positive messages

Games - Marco Polo, tangle game

Feedback forms

Closing circle - Feelings that group is ending, positive aspects of a new group

GROUP 2 SESSION 8:Termination

Goals

Identify support systems

Complete group closure

Continue to validate children's feelings

Promote Family Unity

To have fun

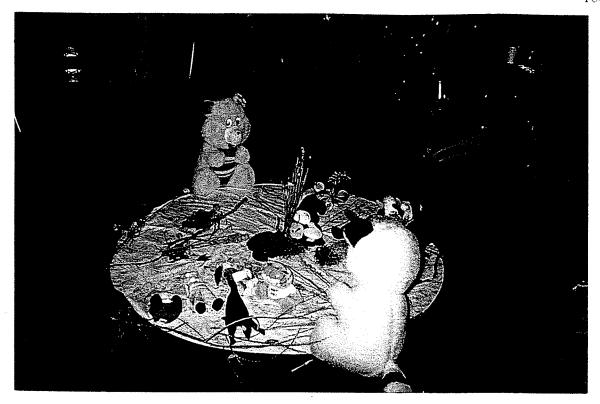
Activity

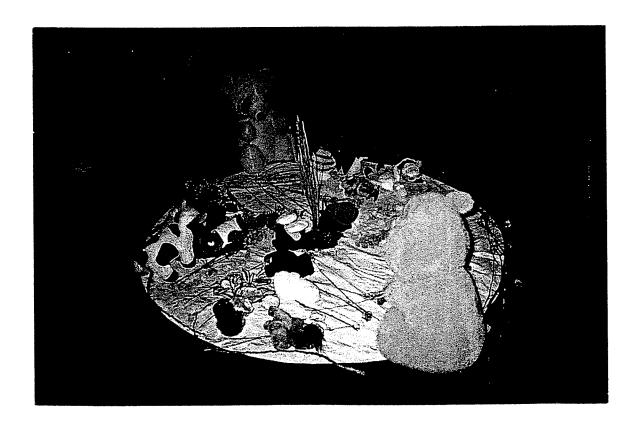
Bumper Bowling

APPENDIX E CIRCLE OF LIFE PHOTOGRAPHS

CIRCLE OF LIFE PHOTOGRAPHS

The following photographs are two pictures of Group One's depiction of the "Circle of Life". During the group the children were asked to create their version of the "Circle of Life" by utilizing materials made available by the facilitators. The two pictures are different angles taken of the same "Circle of Life". The children were given copies of the pictures to remember their creation. The "Circle of Life" creation provided a forum to discuss the life cycle and AIDS. It also provided an opportunity for the children to explore their idea of spirituality, culture and feelings related to the life cycle.





APPENDIX F CHILD FEEDBACK FORM

THE WONDERFUL GROUP: CHILD FEEDBACK GROUP ONE

I think this group was: Fun; exciting.

Being in this group helped me to: Learn about HIV; Have fun

The best things about group were: Coming every week; snacks; drawing

The worst things about group were: It was ending; it has to end.

Before I came to group I felt: Sad; lonely Now I feel: happy I came here; happy.

Some things I learned from group are: What HIV/AIDS is; How to handle my feelings.

Some things I still want to learn about are: More about HIV/AIDS; Nothing.

Since I have been in group my family: Is nicer to each other; do more things

together.

I feel: Sad; Sad and lonely Now group is over.

I also want to let you know: I want to come back; When is another group starting.

THE WONDERFUL GROUP: CHILD FEEDBACK GROUP TWO

I think this group was: Fun; Made me happy; Fun.

Being in this group helped me to: I am not lonely and sad when I come to group; Learn more about HIV/AIDS; To be happy.

The best things about group were: Coming every week; Games; Art

The worst things about group were: It was ending; it has to end; Does it have to end.

Before I came to group I felt: Sad; Lonely; Sad.

Some things I learned from group are: More about HIV/AIDS; How to handle my feelings; I am not the only one.

Some things I still want to learn about are: I still want to know why do we have to get HIV; More about HIV/AIDS; No answer.

Since I have been in group my family: Is closer to each other; Get along better; Happy.

I feel: Sad, when is another group starting; Sad, I want another group; Sad, when is another group running. Now group is over.

I also want to let you know: Please have another group; I want to come back; Can we have another group that never ends?

APPENDIX G FAMILIES SERVED AND NUMBER OF INTERVENTIONS

FAMILY CODE	NUMBER OF INDIVIDUAL SESSIONS	NUMBER OF GROUP 1 SESSIONS ATTENDED	NUMBER OF GROUP 2 SESSIONS ATTENDED	NUMBER OF FAMILY SESSIONS ATTENDED
Family A Ruth-a (mother)	5	1 - caregiver informal support session with another parent	1 - only parent to attend	15
FAMILY A Amber-a (sibling)	0 ·	0	0	15
FAMILY A Fallon-a (sibling)	6	0	8	15
FAMILY A Skye-a(sibling)	10	6	8	15
FAMILY A Cassie-a (sibling)	6	6	8	15
FAMILY B Donna-b (mother)	2	0	0	0
FAMILY B David-b (father)	2	1	0	1
FAMILY B Tommy-b (sibling)	1	1	1	1
FAMILY B Jon-b (sibling)	0	0	1	0
FAMILY C Diana-c (mother)	1	0	0	1
FAMILY C Trey-c (son)	1	0	2	1
FAMILY C Tony-c (Stepfather)	0	0	0	0