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UNIVERSITY OF ALBERTA

THE EXPERIENCE OF BEING A PARENT OF AN ADULT WITH SYMPTOMS RELATED TO HIV INFECTION

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE

DEPARTMENT OF FAMILY STUDIES

Edmonton, Alberta
Spring 1992

ISBN 0-315-73133-8

UNIVERSITY OF ALBERTA

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NAME OF AUTHOR: Dyan Siegl

TITLE OF THESIS: The Experience of Being a Parent of an Adult with Symptoms Related to HIV Infection

DEGREE: Master of Science

YEAR THIS DEGREE GRANTED: 1992

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF BEING A PARENT OF AN ADULT WITH SYMPTOMS RELATED TO HIV INFECTION submitted by DYAN SIEGL in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE.

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Date: Mar 24/92

This thesis is dedicated to my parents who encouraged and supported me throughout my graduate studies.

Abstract

Despite an abundance of research addressing the epidemiology and pathophysiology of AIDS, minimal research exists addressing the experience of individuals who are parents of adults with symptoms related to HIV infection. The purpose of this study was to identify the experience of parents of adults with symptoms related to HIV infection from an emic perspective. Data were collected from thirteen parents using open-ended interviewing techniques. Data analysis was conducted using the grounded theory approach. It was discovered that parents undergo a process comprised of six stages. These stages are closely related to the nature and progression of the disease and include: Suspecting, Taking it in, Going along with a changed reality, Sweeping along with the symptoms, Beating down the denial, and Learning to live with it. Parents engaged in the basic social process *Keeping reality at a tolerable level* in order to deal with the fear, horror, uncertainty, and helplessness they experienced in the face of the cruelty of their son's symptoms and the terminal nature of AIDS. *Keeping reality at a tolerable level* involved the following parental responses to threatening triggers: parents determined how they would view the situation, what they could do in response to the trigger, how they could manage, and how they could best support their son. In order to keep their reality at a tolerable level, parents employed a number of strategies which were either cognitive, behavioral, or a combination of the two. As their son's illness progressed, the manner in which parents viewed events and the strategies they employed changed accordingly.

Acknowledgements

I would like to acknowledge the assistance of many individuals who contributed to the process of completing this research.

I am particularly grateful to my supervisor, Dr. Janice Morse for her support, encouragement, guidance, expertise, patience and sense of humor.

I would also like to acknowledge and thank my committee members, Dr. Maryanne Poirier and Dr. Larry Jewell for their support, assistance, and encouragement throughout the research process. I also wish to thank Dr. Norah Keating for participating in the oral examination and for the mini "support sessions" in the locker room.

I am very grateful to the parents who so willingly shared their story with me.

I am thankful to all those involved with Karos House and the AIDS Network organizations in Edmonton and Calgary, particularly David Fitzgerald who assisted with recruiting parents and whose interest and valuable suggestions contributed to the research.

I thank Don Wells for his assistance in editing.

Finally, I thank Dr. Berna Skrypnek for giving me the good advice and support when I really needed it.

This research was financially supported by the Alberta Foundation of Nursing Research and the AIDS Network Research Trust Fund.

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I. INTRODUCTION

Statement of the Problem

In the past ten years, the most frightening disease to challenge health care professionals is Acquired Immunodeficiency Syndrome (AIDS). First identified in 1981, AIDS results from infection by a retrovirus called human immunodeficiency virus (HIV) (Glasner & Kaslow, 1990). Acquired immunodeficiency syndrome is progressive, ultimately fatal, and characterized by a crippling of the immune system. Epidemiologists predict that the number of AIDS cases will continue to increase globally, and with no cure or vaccine in sight for the disease, the rising numbers are cause for great concern (Ewing, 1990; Quinn, 1990; Royal Society of Canada, 1988).

Presently, homosexual and bisexual males between 30 to 39 years make up the majority of AIDS cases (Canada Federal Centre for AIDS, 1991). It is likely that these individuals have parents who are in the late adulthood stage. It is unusual for individuals in the young adult stage to face death, and it is unusual for parents to face either the possibility or the actual event of their child dying (Levav, 1982; Moss, Lesher, & Moss, 1986; Rando, 1985, 1986; Sanders, 1980, 1989). The predicted continuing increase of AIDS cases indicate that parents may increasingly be faced with the previously rare or even unheard of possibility of being predeceased by their child. The unusual nature of such an occurrence is reflected in the lack of research which presently exists addressing the experience of parents of adult children who are terminally ill or who have died.

Despite similarities between AIDS and other terminal illnesses (for example an unpredictable course, physiological and psychological deterioration, and eventual death), the overwhelming differences between the two are significant and cannot be ignored. Acquired Immunodeficiency Syndrome largely affects the younger, homosexual male population and is associated with stigmatized groups and criminal activities. Therefore, these additional stressors may be superimposed on those stressors that already exist for individuals witnessing a significant other experience psychological or physiological deterioration.

The majority of the available research in the area has focused primarily on gaining an understanding of the epidemiology and pathophysiology of the disease, finding a cure, and, to some extent, attempting to understand the psychosocial impact of the disease on both the person with AIDS and the family of attachment. Researchers studying AIDS and its impact on parents have relied primarily on survey methods (Cleveland, Walters, Skeen, & Robinson, 1988; Robinson, Skeen, & Walters, 1987). Many of the informants in these studies were parents of gay men who were aware of their child's sexual orientation, were actively involved in gay support groups, and lived in large centers (Cleveland, et al., 1988; Robinson et al., 1987). Because this may not be true in every parent's case, gaps in knowledge exist concerning the experience of those parents who are unaware of their child's sexual orientation, are not affiliated with gay support groups, or live in smaller cities and rural areas.

Other studies combined both family of attachment and family of origin when they investigated the impact of AIDS on the family (Brown & Powell-Cope, 1991; Chekyrn, 1989; Cowles & Rodgers, 1991; Frierson, Lippman, & Johnson, 1987; Giacquinta, 1989; Grief & Porembski, 1988); consequently, parents often made up a very small portion of the study participants. Moreover, fathers were grossly underrepresented in most studies, thus conclusions for parents do not necessarily reflect fathers' experiences.

Preliminary findings from qualitative and quantitative research investigating the effect of AIDS on parents, despite being greatly underrepresented by fathers, indicates that this disease results in great psychological pain (Chekryn, 1989; Cleveland et al., 1988; Cowles & Rodgers, 1991; Giacquinta, 1989; Robinson et al., 1987) and can induce trauma unlike that caused by any other crisis they have had to face (Giacquinta, 1989). These findings are supported by personal accounts provided by parents of adult children with AIDS (Haller, 1985; Peabody, 1986; Walker, 1989). The trauma experienced during this time may also have an adverse effect on the bereavement period (Trice, 1988). These findings, along with the many unknowns, support the need for additional research which investigates the experience of individuals who are parents of an adult with AIDS.

Purpose and Rationale

The increasing incidence of AIDS has important implications for the family. Despite similarities between AIDS and other chronic illnesses (for example chronicity) and the presence of profound psychological and physiological deterioration, AIDS is unique in that it primarily affects young adult males and is associated with stigmatized or criminal activities. Few studies have explored the impact on parents of having a child with AIDS, let alone the impact of having an adult child with a terminal illness. Yet the predicted continuing increase in AIDS cases indicates that parents will increasingly be faced with the unnatural possibility of being predeceased by their child. This, along with preliminary findings from research investigating the area, calls for further research that focuses on parents and investigates the experience of being a parent of an adult with AIDS-related symptoms from an emic perspective. A study that focuses specifically on parents of adults with symptoms related to HIV infection will shed light on their unique experiences as well as identifying parents who are at high risk for psychological and physiological difficulties and may require special support. Therefore, the purpose of this present study is to identify the process individuals undergo when they are parents of an adult with symptoms related to HIV infection. Within the context of this study, adult is defined as 18 years of age and older and symptoms related to HIV infection includes physiological and psychological manifestations associated with an HIV positive status.

II LITERATURE REVIEW

Acquired Immunodeficiency Syndrome is a medical and psychosocial crisis which affects not only the infected person, but also the family and significant others (Bowes & Dickson, 1991; Brown & Powell-Cope, 1991; Carr, 1989; Cates, Graham, Boeglin, & Tielker, 1990; Cowles & Rodgers, 1991; Dane, 1991; Macklin, 1988; McDonell, Abell, & Miller, 1991; O'Donnell & Bernier, 1990; Zlotnik, 1987). However, despite acknowledging this impact on significant others, minimal research exists which sheds light on the experience of parents of adults with symptoms related to HIV infection. The following review is based on the available literature, and it identifies what is currently known concerning the experience of parents with children who have AIDS. Because of the gaps in this area, relevant related literature also has been included.

Researchers have used two approaches when studying how a parent responds when their adult child has AIDS. One approach deals with surveying parents of gay men. Because these parents had children in a group which is currently primarily affected, researchers tried to determine how they would feel if they discovered that their child had AIDS (Cleveland et al., 1988). Other researchers have studied parental attitudes toward the AIDS epidemic, what it was like for parents to deal with their child's homosexuality, whether the threat of AIDS made coping more difficult, and what they would do if their child contracted AIDS. Both surveys include a small number of parents who had adult children with AIDS (Robinson et al., 1987; Robinson, Walters, Skeen, 1989). In contrast, Frierson et al. (1987) base their findings concerning the psychological stresses AIDS imposed on the family on observations made while conducting psychiatric consultations with relatives of AIDS patients. The remaining studies relied on open-ended interview techniques, combined family of attachment and family of origin, focused on the psychosocial issues facing family members (Grief & Porembski, 1988), the experience of AIDS as a terminal illness from the perspective of the family group (Chekryn, 1989;

Giacquinta, 1989), how significant others of persons with AIDS described their experiences, concerns, and needs (Cowles & Rodgers, 1991), and the experience of AIDS family caregiving (Brown & Powell-Cope, 1991). In addition, parents' personal accounts of the experience are available.

However, with the exception of Giacquinta (1989), Brown and Powell-Cope (1991), Cowles and Rodgers (1991), and Frierson et al. (1987) and the personal accounts (Haller, 1987; Peabody, 1986; Walker, 1989), the existing research was either strictly retrospective or required that subjects imagine what it would be like to have a child with AIDS. The very small number of parent informants in many of these studies may reflect parents reluctance to participate or may be based on the assumption that because the infected individuals are adults parents no longer experience the same bond with their adult child as they did when the child was younger. Combining family of attachment with family of origin also implies that it is possible to generalize the response to the loss of family of attachment members to the experience of the loss of a child to a parent. The lack of research investigating the area of the parental response to the death of an adult child along with the contradictory findings related to this area make this assumption premature and unfounded.

A number of models addressing the experiences of family when a family member is ill exist (Mailick, 1979; Moos & Tsu, 1977; Rolland, 1987). Some writers have attempted to gain an understanding of what occurs in the situation of AIDS by using conceptual frameworks designed for other chronic illnesses (Tiblier, Walker, & Rolland, 1989), while Lovejoy (1989) proposes an "AIDS adjustment process" based on a compilation of current knowledge concerning AIDS and AIDS issues. Recognizing the impact of AIDS on other family members, and particularly on parents, recent human services literature has proposed a conceptual framework of anticipatory mourning experienced by parents of adults with AIDS (Dane, 1991) and a psychosocial assessment model for determining families' willingness to care for a person with AIDS (McDonell, Abell, & Miller, 1991). However, not enough research exists to support the application of these frameworks to parents in this situation.

Following a content analysis of the available research, it was found that the experience and related responses of parents to an adult child with AIDS related symptoms, while ranging in type and severity, appears to be related to a number of issues: the nature of the disease, the stigma associated with AIDS, the possible lack of awareness by parents of their child's lifestyle, the "attitude" of the person with AIDS, and the unnatural event of a child dying before the parents. The following literature review will address these categories and identify the experience and specific responses of parents within the context of these categories.

The Nature of the Disease

Acquired Immunodeficiency Syndrome is a fatal disease which results from infection by HIV, a sexual and blood-borne pathogen (Glasner & Kaslow, 1990). Infection by the virus usually results in a progressive loss of the body's immune system. Acquired Immunodeficiency Syndrome is often characterized by periods of remissions and exacerbations and is marked by profound physical and mental deterioration. Literature addressing AIDS and its impact on the family suggests that the deterioration accompanying the disease may result in enormous stress for parents (Lovejoy, 1989; Stulberg & Buckingham, 1988; Tibler et al., 1989).

The research supports this and indicates that witnessing this deterioration, which is often rapid and unpredictable, results in parents experiencing a great deal of psychological pain (Chekryn, 1989; Peabody, 1986; Walker, 1989). For example, one mother expressed how the revulsion she occasionally felt toward her son and his condition resulted in her experiencing feelings of guilt and self-loathing (Giacquinta, 1989). Peabody (1986) describes the experience of watching her son deteriorate as an "emotional erosion" (p. 46). Parents in a similar situation describe the experience as an "emotional rollercoaster ride"

(Walker, 1989, p. C1). Similarly, Frierson et al. (1987) and Brown and Powell-Cope (1991) found that many families spoke of the "rollercoaster effect" associated with the unpredictable nature of the disease. Inherent in this rollercoaster effect were feeling of uncertainty and hope alternating with hopelessness (Brown & Powell-Cope, 1991; Cowles & Rodgers, 1991). This may account for findings indicating that family members sometimes felt it was easier to cope with a quick death which was accompanied by minimal loss of mental and physical function (Grief & Porembski, 1988).

A report of a qualitative study examining the experiences of AIDS as a terminal disease from the perspective of a family group identifies that in addition to stressors most families face when a family member is dying the family struggles with complex management and caregiving issues specific to AIDS (Chekryn, 1989). These complex management and caregiving issues were made more difficult because of the many unanswered questions concerning the nature and treatment of the disease. In response to this uncertainty, parents expressed feelings of helplessness and anger (Chekryn, 1989; Giacquinta, 1989; Peabody, 1986).

In some cases, the person with AIDS requested to be cared for by the family of origin. Retaining caregiving within the family occasionally created an additional burden for parents, particularly if family members had to relocate or commute from a great distance (Chekryn, 1989). Other parents experienced additional stress if conflict concerning caregiving and decision-making existed between themselves and their child's lover (Grief & Porembski, 1988). Family members involved in caregiving frequently reported that the unknowns surrounding the disease contributed to enormous emotional strain and made coping difficult (Brown & Powell-Cope, 1991; Grief & Porembski, 1988). Parents directly involved with caregiving reported experiencing extreme exhaustion and a tendency to neglect their personal needs in an attempt to meet the needs of their child (Chekryn, 1989; Peabody, 1986). Additional burdens associated with caregiving included taking over the daily responsibilities of the person with AIDS, disruption of the caregiver's life, and needing to establish a balance between the needs of the AIDS patient and other family members (McDonell et al., 1991). However, some parents felt that retaining the task of caregiving within the family contributed to a feeling of keeping things as "normal" as possible (Chekryn, 1989).

Tiblier's et al. (1989) suggestion that some parents are able to transcend the event by attaching meaning to the experience is supported by some of the available research. Parents capable of this assumed an attitude of support and indicated that the fact that they were supportive and took an active part in caregiving was "natural" and the "thing to do" (Cleveland et al., 1987; Peabody, 1986; Walker, 1989). In response to the increased need for family support experienced by some persons with AIDS, McDonell et al. (1991) propose a psychosocial assessment model in order to determine family members' willingness to care for a person with AIDS. Willingness to provide emotional, physical, and/or instrumental care are identified as being influenced by caregiver resources, caregiver coping characteristics, and caregiver perceptions and judgements (McDonell et al., 1991).

Fear of contagion appeared to be a concern for both caregiving and non-caregiving parents (Chekryn, 1989; Frierson et al., 1987; Giacquinta, 1989). Parents were torn between their desire to create a supportive environment for the person with AIDS and their responsibility for the well-being or health of other family members (Frierson et al., 1987). Frierson et al. (1987) cite this dilemma as the most common source of intrafamily stress. However, other parents actively sought information, educated themselves regarding transmission issues, and, consequently, appeared to overcome this dilemma (Haller, 1985; Walker, 1989).

Most parents in the available studies hospitalized their adult child when symptoms became too severe. The lack of control or input that parents perceived they had regarding treatment or care in the hospital setting resulted in parents experiencing additional stress (Chekryn, 1989; Peabody, 1987; Walker, 1989). Despite feeling that they should continue to be the primary caregivers and decision-makers, family caregivers were often unable to take an active role in these areas in hospital. This often resulted in feelings of frustration and bitterness (Chekyrn, 1989; Peabody, 1986; Walker, 1989).

The stresses related to the nature of the disease and issues associated with caregiving experienced by parents during the course of the illness also appeared to affect the bereavement period. A study by Trice (1988), conducted two to three years following the death of a son from AIDS, found that mothers who had spent extended time as caregivers for their dying sons, were more likely than non-caregiver mothers to experience symptoms such as night terrors, panic attacks, and psychosomatic complaints. These women also experienced a higher incidence of job turnovers and divorce (Trice, 1988). Although there was no significant difference for women in the two groups in relation to religious affiliation, employment status, marital status at the time of the son's illness, education, or race, caregiving mothers were older than the non-caregiving mothers and involvement in support groups varied widely between the two groups. While Trice (1988) identifies a number of limitations within the study, for example, the limited set of questions used to assess mothers, neglecting to include the sons' preference in caregiving or the role of the father/husband, not accounting for differences in outcomes between those who provided care in the son's environment as opposed to caring for their sons in their own home, and not considering the mitigating effect of support groups, the stresses associated with caregiving in relation to AIDS uncovered in this study have been documented in other studies (Brown & Powell-Cope, 1991; Pearlin, Semple, & Turner, 1988; Turner & Pearlin, 1989). Similarly, Matson's (1988) qualitative study found that families caring for a terminally ill family of origin member at home reported role changes, altered communication patterns, feelings of fatigue, exhaustion, sadness, grief, physical signs of anxiety and shock, and social isolation.

Even though a cure or vaccine for AIDS is not expected for some time, advances in medications and treatments may delay the onset of symptoms and extend the life expectancy of the person with HIV infection. Similar to other terminal diseases (for example cancer), AIDS is fatal, incurable, and persons with AIDS experience severe physiological and psychological deterioration. Howell (1986) found that spouses of a terminally ill patient reported experiencing anxiety, extreme fatigue, nervousness, depression, weight loss, sleep disturbances, disturbed thought processes, and lifestyle changes. Of particular significance was the frequency with which they reported the stress experienced from watching their spouse undergo physical symptoms (Howell, 1986). Participants also expressed concern about how to discuss the patient's illness, feelings, and fears in relation to death and dying. This concern was expressed more often by men than women (Howell, 1986). Finding someone to share feelings with and not receiving the required support was a problem expressed by approximately one-third of the subjects; again, men expressed this concern more often than women, and most of them reported it was helpful to share feelings with others (Howell, 1986). Participants reporting a problem finding someone to share problems with and those perceiving that they were not receiving necessary support reported an increase in physical symptoms and emotional responses (Howell, 1986).

In order to gain an understanding of living with cancer from the widows' perspective, Vachon, Freedman, Formo, Rogers, Lyall, and Freeman (1977) studied 73 widows of cancer patients. These widows stated that living in the shadow of the terminal illness was much worse than the stress of widowhood (Vachon et al., 1977). This may be related to the fact that long-term chronic illness may contribute to greater social isolation and higher intensities of bereavement following death (Sanders, 1982). During the final stages of the illness, Vachon et al. (1977) found that the widows experienced anger, denial, anxiety, guilt, and feelings of helplessness. These feelings continued into the bereavement period where widows experienced nightmares reliving memories of the pain, disfigurement, and breathlessness experienced by the terminally ill patient (Vachon et al., 1977).

Although these findings relate to other chronic illnesses, they have implications for parents of adults with AIDS. Acquired Immunodeficiency Syndrome has a variable time course and is characterized by high fevers, respiratory distress, extreme emaciation, dementia, seizures, pain, diarrhea, and skin and mucous membrane disfigurement. The available research and personal accounts of the experiences of parents of children with symptoms related to HIV infection indicate that the manifestations of the disease are disturbing and upsetting for parents. However, these findings are based on minimal research. Furthermore, parents, and particularly fathers, make up a very small proportion of the informants in the existing studies. Therefore, the present findings do not adequately reflect the experiences of parents when they have an adult child with AIDS.

Stigma Related to the Disease

Despite the significant parallels existing between AIDS and other terminal illnesses, the stigma associated with AIDS sets it apart from other diseases. Acquired Immunodeficiency Syndrome is perceived in a stigmatized fashion because it is related to stigmatized groups such as homosexuals and criminal activities such as drug abuse (Frierson et al., 1987; O'Donnell & Bernier, 1990). Herek and Glunt (1988) define stigma as a "mark of shame or discredit" (p. 886). Feelings of stigma are frequently accompanied by an underlying feeling of shame and may result in concealment of the condition (Limandri, 1989).

Literature addressing AIDS and the family identifies stigma as being an important factor influencing their experience (Bowes & Dickson, 1991; Cates et al., 1990; Macklin, 1988; McDonell et al., 1991). Parents of adult children with AIDS consistently reported the perception of being stigmatized (Chekryn, 1989; Cleveland et al., 1988; Frierson et al., 1987; Giacquinta, 1989; Grief & Porembski, 1988; Haller, 1985; Robinson et al.,1987). The stigma associated with AIDS resulted in some families going to extreme lengths to conceal the disease (Frierson et al., 1987). The enormous amount of energy expended in maintaining this facade along with trying to remember who was told what contributed to further psychological stress for both the person with AIDS and their families (Frierson et al., 1987; Rounds, 1988). Families experiencing the perception of stigma resorted to less communication between family members and were unlikely to disclose to people outside the family (Cleveland et al., 1988; Giacquinta, 1989; Grief & Porembski, 1988; Haller, 1987; Robinson et al., 1987; Rounds, 1988). Limited disclosure and negative responses when disclosure occ[illegible]sulted in additional stress being placed on the family (Cowles & Rodgers, 1991). Giacquinta (1989) describes this as an "emotional exile" that is sometimes accompanied by physical isolation. Some parents expressed feelings of hurt or anger in response to prevailing societal attitudes toward AIDS and homosexuality (Chekryn, 1989; Giacquinta, 1989; Peabody, 1988; Walker, 1989).

The impact of society's attitudes concerning AIDS and homosexual activities is demonstrated in two survey studies. Cleveland et al.'s (1988) survey was designed to determine how parents of gay men would feel if they discovered that their child had AIDS. Whereas Robinson et al. (1987, 1989) attempted to identify what it was like for parents to deal with their child's homosexuality, whether the threat of AIDS made coping more difficult, and what they would do if their child contracted AIDS. Parents in these studies were well educated, Caucasian, in a middle to high income bracket, minimally involved with a religion, politically liberal, and, perhaps of greater significance, recruited from gay support groups (Cleveland et al., 1988; Robinson et al., 1987, 1989). A minority of these parents thought gays were either sick, sinful, or wrong, and 94 % of the sample thought being gay was "normal" for some people (Cleveland, et al., 1988, p. 152). The Robinson et al. (1987) study reveals that two-thirds of the sample had undergone the grieving process when they discovered that their child was gay. Perhaps these attitudes contribute to the findings which indicate that between 47% (Cleveland et al., 1988) to 51% (Robinson et al., 1987, 1989) of the parents would not share a diagnosis of AIDS with people outside the family and approximately 15% (Robinson et al., 1987, 1989) to 16% (Cleveland et al., 1988) would not share the information with members within the family.

The impact of the perception by family members of being stigmatized in the context of other illnesses has been minimally addressed. In an attempt to gain more knowledge about how stigma affects family members and their ill relatives, Wahl and Harman (1989) conducted a questionnaire survey of families who had a family member with a mental illness. Wahl and Harman (1989) identify numerous methodological problems in their study; nevertheless, their findings provide insight into an area where little is known. Eighty-seven percent of the sample perceived that stigma was associated with mental illness, and disrupted family relationships and damaged self-esteem were most frequently reported to result from this perception (Wahl & Harman, 1989). Despite the fact that only 22% of the subjects could identify a specific impact of stigma, the researchers point out that simply having the perception of stigma may be problematic for families. In another article, a mother of a 28-year-old mentally ill male spoke of the feelings of guilt she and her husband experienced over their possible contribution to their child's illness and how this same "fault-finding" in other marriages has led to marriage breakdown (Mittleman, 1985). These parents also avoided social contact because they felt others blamed them for their son's illness (Mittleman, 1985).

Similar tendencies were identified in the research related to families touched by AIDS. In most cases, research and personal accounts from parents of an adult child with AIDS identify the perception of being stigmatized (Chekryn, 1989; Giacquinta, 1989; Haller, 1989). A small number of parents state they received enormous support from friends and colleagues (Walker, 1989). However, despite these exceptions, the findings suggest that generally parents experience a feeling of stigma, and this stigma may result in negative consequences for parents. Most frequently, parents, who under different circumstances would reach out for support, resorted to decreased communication both within the family and with outsiders. Again, findings related to parents who have an adult child with AIDS were based on minimal research, inadequately address the fathers' experience, and tended to reflect either strictly retrospective reflections or responses to hypothetical situations. Furthermore, the bulk of the research was conducted in large cities and during a time when AIDS received little public sympathy. Presently, greater public awareness and sympathy appears to exist, and this may have an affect on the parents' experience.

Awareness of Adult Child's Lifestyle

The Federal Centre for AIDS (1991) reports that homosexual and bisexual males make up 78% of all AIDS cases. Therefore, in addition to experiencing similar stressors to those experienced by most families when a loved one is dying, some parents have to deal with the discovery of their child's homosexuality at the same time they learn about the terminal nature of their child's illness (Chekryn, 1989; Cleveland et al, 1988; Giacquinta, 1989; Haller, 1987). This is sometimes referred to as the "double whammy" (Haller, 1987) or a "dual crisis" (Stulberg & Buckingham, 1988). Similar to this, Cleveland et al. (1988) found that parents experienced a "double death syndrome." "Double death syndrome" is defined as a phenomena experienced by parents who learn that their child is homosexual at the same time they learn of the AIDS diagnosis. This experience results in additional stress for parents (Chekryn, 1989; Haller, 1987).

Disclosure of homosexuality may result in parents' perceiving that their child is a "stranger" who does not fit into what they have defined as his family role (Strommen, 1989). Robinson et al. (1989) suggest that parents may have difficulty accepting their child's homosexuality because with this knowledge they must give up dreams of their child being part of a traditional marriage and becoming a parent. Other reasons include the fact that homosexuality or bisexuality may be associated with promiscuity and drug use (Frierson et al., 1987). Additionally, parents must acknowledge that their child is part of a minority which has a history of persecution (Robinson et al., 1989). Parents may feel that they are to blame for the lifestyle choice their child has made (Strommen, 1989). This tendency is supported by some of the research (Cleveland et al., 1988) and may be related to explanations by Freudian theory explaining why individuals are homosexual (Hyde, 1986; Robinson et al., 1989). Particularly relevant is the research which suggests that homosexuality results from fears of heterosexuality primarily due to the presence of a dominating, overly protective and intimate mother and a weak or passive father (Hyde, 1986). Consequently, parents may feel indirectly responsible for their child's illness

(Lovejoy, 1989). However, other parents, despite experiencing initial difficulty with accepting their child's sexuality, did so and maintained that despite the stigma associated with AIDS and homosexuality their son was their child and that was all that mattered (Cleveland, et al., 1988; Peabody, 1988; Robinson et al., 1987; Walker, 1989).

In his literature review on how the family of origin reacts to the disclosure of homosexuality, Strommer (1989) identifies a number of themes that influence parents' movement through the process of awareness and acceptance of their child's homosexuality. These themes, which may conflict, include: a strong belief in loving and accepting their child, adhering to popular social values and placing these values at the forefront, believing that the family must solve its own problems, and living their life according to the family's religious beliefs (Strommen, 1989).

Robinson et al.'s (1987) study reveals that two-thirds of the participants had undergone the grieving process when they discovered that their child was gay. Difficulty with the revelation of a homosexual lifestyle manifested itself in communication problems, primarily between AIDS patients and their fathers (Frierson et al., 1987; Haller, 1987). Numerous articles appear to assume that this is the norm and will continue to persist over time. This assumption is not consistently based on research nor is it supported by the homosexuality research. Cramer and Roach's (1988) study investigating the impact of "coming out" on the relationship between gay males and their parents found that despite an initial poor response by both parents over time the relationship either resumed as before disclosure or became more positive. Furthermore, research and personal narratives reveal several fathers who were accepting, supportive, and actively participated in the caregiving of their sons (Chekryn, 1989; Peabody, 1986; Walker, 1990).

Even though some parents were aware of their child's lifestyle prior to discovering that he or she had AIDS, having this knowledge did not guarantee that homosexuality would not result in difficulty for parents. Some parents, including those who had felt they were open-minded about their son's sexuality, found that the diagnosis of AIDS resulted in their re-experiencing the old wounds related to the initial discovery of their child's sexual orientation (Skeen, Walters, & Robinson, 1988; Walker, 1989) or, at the very least, a re-evaluation of their feelings concerning their son's sexuality (Cowles & Rodgers, 1991). This was also a time when unresolved homophobia or estrangement among family members as a result of the homosexuality reappeared and acted to increase the burden on the family (Chekryn, 1989).

Theoretical articles suggest that friction may occur between family of attachment and family of origin (Cates et al., 1990; Lovejoy, 1989; O'Donnell & Bernier, 1990; Stulberg & Buckingham, 1988; Tiblier et al., 1989). This is assumed to result from parents blaming their child's lover for possibly transmitting the disease. However, it was found that not all parents necessarily experienced conflict with family of attachment. Survey results from both Cleveland et al. (1988) and Robinson et al. (1987) indicate that some parents expressed concern for their son's family of attachment.

The available findings indicate that the impact of an adult child's homosexuality varies among parents and may result in a variety of responses. This is incongruent with some nonempirical literature which suggests that the homosexuality issue typically results in a rift in the relationship between the adult child and his parents, a rift, particularly in the case of the father and son, that may persist over time (Frierson et al., 1987).

Attitude of the Person with AIDS

Presently, AIDS primarily effects gay males between the ages of 30 and 39 years (Federal Centre for AIDS, 1991), and while it is unusual for individuals in this age group to face the possibility of death, theoretical articles addressing this area suggest that young men with AIDS progress through a number of stages in a predictable manner (Lomax & Sandler, 1988; Nichols, 1985). Nichols (1985) bases his four-stage model on the assumption that the emotional responses inherent in each stage are in response to the nature of the disease, societal views, and a multitude of additional adjustment issues faced by the person with AIDS. These issues include among others, fear of death and dying, loss of independence, loss of friends, and a need to prepare for ones' own death (Nichols, 1985). These issues take on catastrophic proportions and result in situational distress. Emotional reactions in response to these issues include shock, denial, anger, guilt, anxiety, depression, and finally acceptance. Several of these reactions were commonly demonstrated by withdrawal. Similar to this, Lomax and Sandler (1988) propose a four-stage model that incorporates each phase of the illness. Each stage is characterized by psychosocial issues that are accompanied by a number of tasks. Emotional reactions in this model are similar to those identified by Nichols (1985).

Other theoretical articles addressing the psychosocial reactions and needs of the person with AIDS support these models to some extent. They identify emotional reactions similiar to the reactions identified by Nichols (1985) and Lomax and Sandler (1988). In addition, they suggest that the reactions of the person with AIDS appear to be related to the terminal nature of the disease, the associated stigma, the age of those affected (Flaskerud, 1987; Moynihan, Christ, & Silver, 1988), along with a multitude of stressors, including the severity of the disease, attributions regarding the illness, reactions to the diagnosis, the availability of support systems (Kelley & St. Lawrence, 1988), and the presence of neuropsychiatric complications (Govoni, 1988; Salisbury, 1986).

Personal accounts of persons with AIDS support to some extent the issues faced and the emotional reactions identified by these models. However, limited data exist to support the idea that persons with AIDS actually experience the stages identified by Nichols (1985) and Lomax and Sandler (1988). In addition, a consistent theme in the personal accounts, yet not identified in the theoretical literature, is the importance of the "positive mindset" (Haney, 1988; Snowden & Cassidy, 1989; Weiss, 1986).

Assuming a "positive mindset" and an attitude of being prepared to fight the disease appears to have an influence on parents of adult children with AIDS. A mother in Grief and Porembski's (1988) study stated that a "good attitude," demonstrated by walking across the room despite being very ill, made it easier for her to cope. A "good attitude," having a sense of humor, or "living for today" also helped significant others cope with their son's illness (Grief & Porembski, 1988). Whereas, "giving up hope," "waiting for death," withdrawing from social contact, becoming physically weak quickly, and never regaining strength contributed to feelings of increasing burden for significant others (Grief & Porembski, 1988; Haller, 1985). Requests by the person with AIDS of family mei. to maintain secrecy concerning the diagnosis along with an obsession or hypervigilance over symptoms also increased the burden experienced by the parent (Chekryn, 1989; Walker, 1989).

Unnatural Event of a Child Dying Before Parents

Acquired Immunodeficiency Syndrome is a potentially fatal disease that, at the present time, primarily affects young gay adult males. The unnatural event of a child dying before parents has been found to be extremely difficult for parents to accept (Levav, 1982; Moss et al., 1986; Rando, 1985, 1986; Sanders, 1980; Stulberg & Buckingham, 1988). Parents of adults with AIDS confirmed that having to do so was a source of great difficulty (Chekryn, 1989; Cleveland et al., 1988; Giacquinta, 1989; Peabody, 1988; Robinson et al., 1987; Walker, 1989). Parents in Chekryn's (1989) study stated they experienced a "double insult" (p. 30). A "double insult" is defined as the loss of a child that seems out of order and unnatural and the loss of that child to a socially unacceptable disease. Mothers provided the majority of the data related to this, and their responses indicate that having an adult child die is a psychologically devastating experience. Their feelings of pain and grief extend into the bereavement period; however, often they are unable to disclose their pain to their usual support systems (Robinson et al., 1987; Rounds, 1988; Trice, 1989).

Frequently, because of the different grieving or coping styles assumed by each spouse, limited disclosure exists between parents, and this results in silent grieving by one or both partners (Haller, 1985; Robinson et al., 1987). This decrease in communication continues into the bereavement period and is perceived as an additional burden by women in these studies (Giacquinta, 1989; Robinson et al, 1987). Stifled communication also exists between parents and the person with AIDS. Consequently, minimal discussion concerning the illness and feelings regarding the illness, concerns about the upcoming death, or funeral arrangements took place between parents and the adult child (Chekryn, 1989; Giacquinta, 1989; Haller, 1987). Those family members who had even brief conversations concerning these subjects with the person with AIDS felt that doing so was very helpful and that talking at greater length and even more openly would have helped them resolve their grief more effectively (Chekryn, 1989).

It is generally acknowledged that while the diagnosis of a potentially fatal disease in a child affects the entire family the experience is particularly traumatic for parents (Geyman, 1983; Kupst, 1986; O'Donnell & Bernier, 1990; Rando, 1986; Ross-Alaolmolki, 1985; Sanders, 1989; Waechter, 1987). Minimal research studying either parents of an adult child with a terminal illness or bereaved parents of adult children exists. What little is available supports the idea that the death of an adult child results in higher intensities of parental grief (Owen, Fulton, & Markusen, 1982), greater difficulty in resolving the loss, and has the potential to contribute to higher levels of mortality (Levav, 1982) and psychological disorders (Levav, 1982; Sanders, 1980). Parents may feel a loss of identity as a parent when they lose a child, or they may feel guilty because they could not protect their child from the disease or death (Rando, 1985). Since parents are trying to cope with the loss or the potential loss at the same time, the person they would usually turn to is also grieving and frequently is unable to provide support (Rando, 1985). Based on observations made in the clinical area, Ross-Alaolmolki (1985) found that in an attempt to maintain normal family functioning parents often withheld their true feelings from others and even themselves. However, these actions often resulted in misunderstanding and pain between spouses, between parents and the ill child, and among siblings.

Also based on observations made in the clinical area, Lascari (1978) and Friedman (1967) identify common reactions by parents whose children had been diagnosed as having a fatal disease. Friedman (1967) found that some parents felt that it is almost impossible to comprehend the totality of the diagnosis when it is initially received from the physician. These same parents felt in retrospect that it took several days or weeks for the diagnosis to become a reality (Friedman, 1967). Common reactions to the diagnosis include guilt, searching for meaning, seeking information concerning the disease (Friedman, 1967; Lascari, 1978), and clinging to the hope for a cure (Ross-Alaolmolki, 1985). Denial of the diagnosis or the reality of the diagnosis (Lascari, 1978) and possible anger projected onto the attending physician by parents were also evident (Friedman, 1976; Geyman, 1983). When a disease was characterized by remissions and exacerbations, the first remission often resulted in shock, distress, and concern on the part of parents and forces them to realize that they must face the reality of the situation (Friedman, 1967; Kupst, 1987).

Research in the clinical area tends to support observations made in the nonempirical literature. The available studies primarily collected data through the use of interviews and observations and were designed to identify the psychosocial impact on the family who has a child with a terminal illness (Buchanen, LaBarbera, Roelofs, & Olson,1979; Chodoff, Friedman, & Hamburg, 1964; Friedman, Chodoff, Mason, & Hamburg, 1963; Mattsson & Gross, 1966; Witte, 1985), how parents cope and adapt when their child has a terminal illness (Buchanen et al., 1979; Chodoff et al., 1964; Friedman et al., 1963; Futterman, Hoffman, & Sabshin, 1972), and parents' perception of the emotional management provided in the hospital when their child has leukemia (Lascarie & Stephens, 1973). Several of these studies address what it is like for parents at each stage of the illness, including the diagnosis stage through to the terminal stage of the disease (Buchanan et al., 1979; Chodoff et al., 1964; Friedman et al., 1963; Futterman et al., 1972; Lascari & Stephens, 1973).

These studies found that early reactions by parents to the diagnosis, while being individual, tend to follow a "natural history" where parents attempt to adapt to the situation (Chodoff et al., 1964, p. 747; Friedman et al., 1963). It was found that the initial diagnosis was a shock and was generally accompanied by a feeling of unreality (Chodoff et al., 1964; Friedman et al., 1963). Parents appeared to accept the diagnosis and the probable prognosis at an intellectual level; however, many stated that in retrospect it took some time before the meaning of the diagnosis "sunk in" (Friedman et al., 1963, p 613). This delayed acknowledgement was thought to protect the parent at the time from the true meaning of the diagnosis (Chodoff et al., 1964).

In the case of Duchenne's disease, a crippling muscle wasting disease, parents who suspected that their child may have the disease felt that they had an opportunity to anticipate the diagnosis and that this helped decrease the psychological impact when actually presented with the diagnosis (Buchanan et al., 1979). While parents with no previous knowledge of the disease or suspicions that a disease existed stated that they were "shocked" or "numb" (Buchanan et al.,1979, p. 263). Several of these parents also experienced a number of somatic symptoms (Buchanan et al.,1979).

Early in the disease, evidence of guilt or self-blame appeared to exist among parents (Chodoff et al., 1964; Friedman et al., 1963; Lascari & Stephens, 1973; Mattsson & Gross, 1966; Witte, 1985). Anger and frustation also appeared (Buchanan et al., 1979), as did the parents' active search for information concerning the disease (Friedman et al., 1963; Lascari & Stephens, 1973).

Once the child was hospitalized, a split was observed to occur between parents' intellectual acceptance and their emotional non-acceptance (Chodoff et al., 1964). At this time, parents had to adjust to the new environment along with its routines, and it was felt that because of roles stereotypically attached to men and women mothers tended to cope with this better than fathers (Chodoff et al., 1964). Some parents were impressed with the medical institution and felt renewed hope that it would save their child. However, when physicians attempted to realistically present the diagnosis and probable prognosis, some of these parents reacted with hostility toward these physicians and the information (Friedman et al., 1963). Witte (1985) found that mothers of adolescents with a terminal form of muscular dystrophy tried to portray a normal psychological front despite experiencing guilt and depression. This suppression often resulted in the mothers acting out their feelings in the form of anger.

Certain aspects of the disease itself resulted in additional psychological strain for parents. These included the presence of remissions and exacerbations (Chodoff et al., 1964), the actual progression of the disease, for example, if the disease was characterized by an unpredictable course (Witte, 1985), the presence of a perception of social stigma, guilt on the part of mothers, and role changes between parents (Buchanen et al., 1979). It was at these times that individual coping styles predominated; however, again, some consistency did appear in the studies. Isolation of affect, characterized by an absence of feeling and often labelled as denial by the researchers, was common during the initial stages of the illness (Buchanan et al., 1979; Chodoff et al., 1964). Other coping strategies included magical thinking, which was characterized by the thought that their child would be the one exception among other cases and would survive the disease (Buchanan et al., 1979), overprotection of the child (Buchanan et al., 1979; Mattsson & Gross, 1966), increased motor activity (Chodoff et al., 1964), and self-imposed social isolation (Witte, 1985). Researchers indicate that well-adjusted families tend to communicate openly between all family members and particularly between parents, have some form of social support outside of the immediate family, and take a break once a week from caregiving (Buchanan et al., 1979). Whereas those families who tend to avoid acknowledgement and discussion of the disease along with their associated feelings (Witte, 1985) or persisted in denying the fatal prognosis of the disease (Chodoff et al., 1964) may experience difficulty throughout the course of the disease, as well as during the bereavement period. This finding is supported by Shanfield, Benjamin, and Swain (1984), who found that parents of adult children who had died of cancer experienced more psychiatric symptoms in the bereavement period if the relationship with their children had been frustrating.

As time passes and the child becomes increasingly ill, parents become more vulnerable to the inevitability of their child's prognosis. This process is abrupt with some parents, gradual or fluctuating with others, while some parents resist acknowledging this until close to the end of the child's illness (Chodoff et al., 1964). Parents who face the reality of their child's prognosis begin to engage in anticipatory mourning, and when their child dies, these parents generally are calm and appear relieved that the suffering is over (Chodoff et al., 1964; Friedman et al., 1963). Similarly, Friedman (1967) and Futterman, Hoffman, and Sabshin (1972) observe that parents who engage in anticipatory grieving appear to be better prepared for the inevitability of their child's death and tend to have a decreased tendency to experience prolonged grieving or difficulty accepting the loss. Consistent with this, parents of children with childhood leukemia stated that they looked forward to the end of the ordeal; however, they needed to know that it was normal to feel this way (Lascari & Stephens, 1973). Meanwhile, other parents could not believe that it was really over (Friedman et al., 1963).

The concept of anticipatory mourning was explored in greater detail by Futterman et al. (1972). Based on qualitative research conducted with parents of children diagnosed with leukemia, Futterman et al. (1972) propose that parents adapt to the possible loss by engaging in a series of processes inherent in anticipatory mourning. These processes include the following: acknowledgement, during which parents struggle between hope and despair with an awareness that intensified as parents realize that the death of their child is inevitable; grieving, where parents experience and express their emotions in response to the anticipated loss and during which the intensity of their grief fluctuates with the child's illness; reconciliation, which is designed to allow parents to reaffirm the value of their child's life and is characterized by parents reconstructing the child's past and present life; detachment, where, contingent on parents' concept of their child's life expectancy, parents gradually withdraw from their child and become increasingly involved in other relationships; and finally, memorialization, where memories of the child become fixed and idealized (Futterman et al., 1972).

Dane (1991) proposes that a similar conceptual framework of anticipatory mourning can be applied to middle-aged parents of adults with AIDS. However, in this case, the five processes, although identical to those described by Futterman et al. (1972), are identified as tasks, parental responses were explored and intervention strategies were suggested to facilitate meeting of these tasks (Dane, 1991). Underlying the use of this framework is the assumption that undergoing anticipatory mourning will help parents deal more effectively with the death when it occurred (Dane, 1991).

These findings from the empirical literature have important implications for parents of adult children with HIV infection. Occasionally, homosexuality may cause a rift in the parent-child relationship. In addition, the available research indicates that parents of adults with AIDS experience extreme psychological pain when faced with their child's death and may also perceive that they are experiencing multiple losses. However, the majority of these parents resort to decreased disclosure and tend to grieve in silence. This has important implications for the bereavement period. Bereavement literature suggests that disclosure of feelings facilitates adaptive grief resolution (Kast, 1988; Sanders, 1989). The concept of anticipatory mourning may also be relevant to parents of adults with AIDS. However, as the majority of these studies and models are based on research conducted with parents of young children, applying these findings to parents of terminally ill adults must be done with caution.

Interpretative Summary

Few studies have explored the impact of being a parent of an adult with HIV infection. The minimal existing research found that parents perceived having a child with this illness as a crisis unlike any other they had previously faced. The stress and pain associated with this crisis was something that frequently persisted into the bereavement period. Related literature suggests that chronicity, severity of symptoms, and the untimeliness of a child dying before the parent may influence immediate responses and coping as well as the subsequent bereavement period. Research exploring the impact of the death of an adult child on parents is limited; therefore, it is inadvisable to draw from this literature or even hypothesize as to what may occur in the situation of HIV infection.

Tiblier et al. (1989) and Lovejoy (1989) propose two models which identify the psychosocial phases and the accompanying emotions, concerns, and responses of family when a family member is HIV+. These models assume that family members proceed in a predictable fashion through the phases of disease and respond in a predictable, identical manner within each phase. Similarly, Dane (1991) proposes that a conceptual framework of anticipatory mourning initially identified by Futterman et al. (1972) can be applied to middle-aged parents of adults with AIDS. Applying chronic illness models along with the associated tasks to AIDS is inappropriate considering that the available literature and research suggests that different variables, which may differentiate this disease from other chronic terminal illnesses, exist in the case of AIDS. Of greater significance is that with the exception of Futterman et al. (1972) these models do not appear to be based on findings which reflect the experience of the parents from their perspective.

Despite findings that suggest parents' responses are influenced by the nature of the disease, the related stigma, level of awareness of their child's sexual orientation, the unnatural event of having a child die before parents, and the "attitude" of the person with AIDS, these findings are inconsistent and based on small numbers of parents and select informants. For example, little is known concerning the father's response, the response of parents living either in rural areas or smaller centers, or the experience of parents not actively involved in gay support groups. In addition, most of the studies are either strictly retrospective or prospective, and aside from Giacquinta's (1989) research in progress, they do not focus on specific stages of the disease. It remains unclear how parents respond during each stage of the disease, what it is that they respond to, what determines their response, what concerns them, and how they cope.

Findings from the related literature suggest that having to witness extreme deterioration in a loved one along with the perception of stigma may affect coping and can complicate the grieving process. This is particularly true if support is perceived to be unavailable or inaccessible. This has important implications for parents of adult children with AIDS-related symptoms, for in the context of a stigmatized disease, characterized by psychological and physiological deterioration, they must also face the possibility of being predeceased by their child.

The following question was used to guide this present study:

> What is the experience of being a parent of an adult with symptoms related to HIV infection?

The following subquestions were included within the main question:

> a). What are the responses of parents when they have an adult child with symptoms related to HIV infection?
>
> b). What are the issues parents perceive they face when they have an adult child with symptoms related to HIV infection?
>
> c). What strategies are utilized by parents in order to cope with their responses, and to deal with the issues they perceive they face, when their adult child has symptoms related to HIV infection?

III METHODS

The purpose of this study was to examine the experience of parents of adults with symptoms related to HIV infection and to identify the process they undergo when confronted with this crisis. Grounded theory, a qualitative research approach, was selected to gain an understanding of this phenomenon. Grounded theory, which focuses on the emic perspective, was appropriate for study in this area because of the nature of the research question and the gaps in knowledge concerning the experience of parents in this situation. In the past, researchers studying AIDS and its impact on the family have relied primarily on survey methods. Some qualitative research exists; however, in order to shed light on this unique experience, researchers agree that more qualitative research is necessary (Giacquinta, 1989; Lovejoy, 1989).

The following discussion will provide an overview of grounded theory and will address sample selection and informant characteristics, data collection and analysis, reliability and validity issues, and ethical considerations specific to conducting research in the area under study.

Grounded Theory

A grounded theory approach is appropriate when little is known about an area of study (Chenitz & Swanson, 1986; Field & Morse, 1985) or in situations where theory capable of predicting and explaining a group's behavior is inappropriate, biased, or does not exist (Hutchinson, 1986; Stern, 1980). The experience of parents of adults with symptoms related to HIV infection met these criteria.

Grounded theory is based on the assumption that individuals are capable of creating order and making sense of their environment (Hutchinson, 1986). This assumption along with the belief that individuals' perceptions of reality shift according to the definition and meanings they attribute to situations and their interactions with others reflect the influence of symbolic interactionism on the grounded theory approach (Morse & Johnson, 1991). Inherent in grounded theory is the assumption that individuals sharing common circumstances also share a specific social psychological problem which is resolved by social psychological processes (Hutchinson, 1986; Skodol Wilson & Hutchinson, 1991).

By systematically employing both inductive and deductive approaches, grounded theory is generated from the data (Chenitz & Swanson, 1986; Field & Morse, 1985; Glaser, 1978; Hutchinson, 1986; Stern, 1980, 1985; Strauss & Corbin, 1990). The inductive component identifies concepts which are derived from the data, while the deductive component takes place when hypotheses arising from the data are tested. Generating theory from data allows concepts and hypotheses to emerge from the date and ensures throughout the research process that these are "grounded" in the data, are systematically analyzed in relation to other data, and act to guide the emerging theory (Glaser, 1978).

Using a grounded theory approach allowed for the identification of the problems faced by parents of adults with symptoms related to HIV infection, and the process they employed to deal with these problems. The assumptions underlying the grounded theory approach were well suited for studying this area because what parents experienced and how they coped were closely linked to events in their environment and their interactions with others.

Sample

In order to obtain rich, experiential data, the researcher relied on volunteer and snowball sampling methods. Use of nonprobability methods are based on the assumption that not only does an uneven distribution of knowledge exist within individuals experiencing a phenomenon, but individuals also vary in terms of their capabilities and willingness to disclose information (Morse, 1986). Additionally, the stigma attached to AIDS and the previously cited difficulties associated with obtaining informants contributed to these methods being necessary and appropriate.

Parents who presently were or had in the past experienced the phenomenon under study were sought as informants. Efforts were made to include both mothers and fathers in this study as previous studies in the area included limited numbers of fathers as informants. Additional criteria for inclusion required that informants spoke and understood English.

A wide variety of agencies and institutions were approached in order to obtain assistance in informant recruitment. Individuals employed by these institutions and agencies had already established a relationship with the population under study, and it was hoped that relying on contact people would increase parents' willingness to participate in the study.

Contact individuals were provided with a letter describing the study, its purpose, how data would be collected, measures taken to ensure confidentiality, and the voluntary nature of the study (see Appendix A). These individuals were then asked to provide parents meeting the criteria for inclusion in the study with a similar letter and a return form (see Appendix B and C). Parents were invited to contact the researcher by telephone or with the return form in order to learn more about the study.

In addition, informants were recruited by word of mouth and by advertisements in a community-based newspaper, fliers, and posters posted in areas frequented by the targetted population. The newspaper advertisement, fliers, and posters provided a brief description of the study and invited volunteers to contact the researcher by telephone in order to learn more about the study (see Appendix D). Of the agencies and institutions approached, only two AIDS organizations and a group home for persons with AIDS agreed to assist in informant recruitment. Solicitation by posters, fliers, and newspaper advertisements were ineffective in obtaining informants.

When informants contacted the researcher, questions concerning the study were answered, permission was obtained to conduct and tape interviews, and arrangements were made to meet for an interview. At the same time, informants were made aware that additional interviews might be necessary, and permission to conduct follow-up interviews was also obtained. All informants who contacted the researcher for more information completed the interviews. With the exception of two cases, mothers initiated contact with the researcher. It was also these mothers who then spoke with their spouses and encouraged them to participate in the study.

A total of 13 parents, eight mothers and five fathers, participated in the study. Of this total, four had been obtained through solicitation by the AIDS organization, three due to their son's encouragement to participate, and the remaining six by snowball sampling. These individuals were parents of sons, ranging in age from 29 to 34, who were in various stages in the disease process or were deceased. One son was HIV+ but physically asymptomatic, another had AIDS related complex, two were in fullblown AIDS, while four were deceased. Of these sons, five were gay, one was bisexual, and two were IVDU. The variation in experiences facilitated theoretical sampling by providing the researcher with opportunities to collect data from parents who were at the critical points throughout the process.

In addition to these 13 primary informants, data were obtained from relevant literary works, documentaries, and two secondary informants. For example, a portion of a diary, the book *The Screaming Room*, transcripts obtained from a television program entitled "Too Little Too Late," and two information videos were included in data analysis. Secondary informants included a sibling who had been closely involved with her parents during her brother's illness and a social worker who worked with significant others of persons with HIV infection.

Data Collection

An unstructured interview was used to collect data. Unstructured interviews are commonly used in qualitative research to collect data and are designed to allow informants to tell their story freely and without the researcher imposing any preconceived ideas. Initial questions were general and derived from the research question. For example, parents were asked, "Tell me what it has been like for you, from when you found out about your son's illness up to now." Subsequent interviews were generally more directive, with questions being based on the ongoing data analysis, and were designed to clarify and expand on what had been disclosed in previous interviews.

While informants were given a choice between face-to-face and telephone interviews, the majority expressed a preference for face-to-face interviews. Interviews were conducted in the parents' homes or in a private interview room. Due to the sensitive nature of the interview topic and the tendency for informants to become tearful, care was taken to ensure that interview settings were private, free from interruption, and provided informants with an opportunity to linger f [illegible] a time following each interview. With the exception of one couple, informants were interviewed individually.

A total of 29 interviews were conducted. Interview length ranged from thirty minutes to two and one half hours. Despite the lengthy nature of some interviews, unlimited time was permitted in order to avoid interrupting informants as they were telling their story. Parents had a tendency to respond to the opening question by providing a brief synopsis of their experience. However, when asked to elaborate, parents generally responded by telling their story at length and in great detail.

Field notes and subjective accounts of thoughts and perceptions experienced by the researcher while interviewing and when reflecting on the interview were documented immediately following each interview or were taped on the way home from the interview. These notes supplemented data collection.

Data Analysis

Interview tapes were reviewed immediately following each interview and were transcribed verbatim by the researcher. All identifiers were removed from the transcripts, and data were stored and analyzed on a Macintosh Plus computer consistent with the method outlined by Morse (1991a).

From the point of initial data collection, data were simultaneously coded and analyzed. All coding was conducted using a constant comparative method of analysis. This method requires that at each step of the theory building process the researcher, while coding and analyzing, compares pieces of data, taking note of patterns, similarities, and differences (Chenitz & Swanson, 1986; Hutchinson, 1986; Stern, 1980). In addition, while coding, the data were constantly questioned in order to identify the basic social problem faced by informants and the process used to cope with their problems.

Initially, data were coded to capture and label the substance of the data. For example, the substantive code, "being fortunate in the way it turned out," emerged from the data. Codes which clustered were developed into categories. For example, codes similar to the earlier cited code were included within the category "Focusing on positives." Categories characteristics were developed, and linkages between categories were determined. Hypotheses concerning these categories, their linkages, and existing literature were formulated and tested in subsequent interviews. Meanwhile, the search for additional categories and a negative or atypical case continued.

Data analysis was facilitated by documenting memos. Memos are written records of the analytical process associated with the codes and their relationships (Glaser, 1978). Memos were also made following peer group discussions concerning the data and whenever ideas about the data, relationships between codes, and the emerging theory occurred. These memos served to document the thought process associated with coding, guided subsequent data collection, and were critical for theory development and for demonstrating integration of the theory. In addition to memoing, the researcher developed a large chart identifying the experiences of parents involved in the study. This chart was helpful in identifying patterns and remaining "grounded" in the data.

Data collection ceased when no new information was forthcoming. From this, the core category *keeping reality at a tolerable level* was identified. *Keeping reality at a tolerable level* occurred frequently in the data, linked data together, and explained the variations in the behavior of parents in the context of being a parent of an adult with symptoms related to HIV infection.

Reliability and Validity

Measures taken to ensure reliability and validity in qualitative studies, along with sources of error, differ from those found in quantitative research. The primary reason for these differences rests in the purpose of qualitative research, which is to describe and explain phenomenon from the emic perspective (Field & Morse, 1985). Field and Morse (1985) define validity as the soundness and degree to which a study represents reality. Reliability refers to the extent that random variation may have influenced the study results (Field & Morse, 1985). These definitions will guide the following discussion.

Validity was strengthened by purposely selecting informants who were most knowledgeable of the phenomenon under study and by including only those who were willing and able to provide detailed "experiential" information (Morse, 1991b, p. 132). Informants in this study volunteered, thus demonstrating their motivation to participate in the study. Focusing specifically on these particular parents and then employing theoretical sampling in order to collect data from parents at critical points as identified by individuals who had undergone the experience increased understanding and enhanced validity.

Conducting individual interviews and asking open-ended questions functioned to prevent possible threats to validity such as acquiescent responses, altering the truth, and social desirability (Brink, 1991; Field & Morse, 1985; Hutchinson, 1986; Morse, 1991b). The use of multiple data sources helps strengthen the validity of a study (Brink, 1991; May, 1986). Therefore, in addition to interviewing parents, a sibling and a support group worker were interviewed. Additional data were obtained by consulting relevant literary works and documentaries. This form of data collection primarily served to confirm data obtained from primary informants. In addition, the extended nature of the research process, and requiring follow-up interviews were useful reliability checks to ensure consistency of data. Data were collected until saturation of categories occurred and no new additional data were obtained. Throughout data collection, the researcher searched for a case which would refute the emerging categories. Periodically throughout the process, the researcher presented the data and the emerging categories to peers for discussion and to assist with theory development.

Each interview was tape recorded. Audiotapes were transcribed verbatim, and transcripts were checked for accuracy with the taped version. Actual informant terms were used in developing codes, and verbatim accounts were included in the final analysis. Findings were clarified and verified with informants, thereby further strengthening reliability and validity. Also, the use of the constant comparative method of analysis, structuring follow-up interviews based on data obtained during previous interviews, and testing hypotheses based on the data also ensured reliability and validity.

At the onset of the study, the investigator identified personal biases in relation to the subject area. To prevent the investigator from "going native" and losing objectivity, she also kept a personal journal and used introspection and discussions with peers to facilitate an awareness of these changes and to maintain objectivity.

Ethical Considerations

Prior to conducting interviews, the researcher sought and received ethical approval from the Faculty of Home Economics and from the other host agencies. Verbal and written consent were obtained from each informant prior to conducting an interview (see Appendix E). Prior to conducting interviews, informants were explicitly informed of the purpose of the study, nature of the questions, how confidentiality would be maintained, and the voluntary nature of the study. This provided informants with an awareness of what would be requested from them and helped them decide whether they wished to be involved in the study. Interviews conducted by telephone were prefaced by reading the consent over the telephone and obtaining verbal consent on the tape. Prior to conducting follow-up interviews, informants were reminded of the continuing nature of the consent. To facilitate privacy, interviews were conducted in a setting which was private and free from interruption.

Parents were informed at the onset of the study of the possibility that discussion of their son's illness and their experiences might be psychologically painful. While conducting interviews, the investigator had numbers and names available of individuals who could provide counselling in the event of psychological distress. Informants were reminded that they were free to refuse to answer questions and were free to withdraw from the study at any time without penalty. A debriefing session was conducted with each informant at the completion of the set of interviews in order to determine whether issues requiring intervention had surfaced as a result of the interviews. In addition, informants were provided with the name of an AIDS organization which could offer support in the event they experienced difficulties later.

Even though interviews were taped, names and other identification were not attached to the tapes or transcripts. Informants were identified in all data sources by code numbers. Tapes, names, and addresses of informants were stored in a locked drawer, and all information obtained from the participants was regarded as confidential. Discussion of data with peers or committee members and reference in the final written document did not include names or any other identifying information. Upon completion of the study, names and addresses were destroyed.

IV RESULTS

Parents of adults with symptoms related to HIV infection experience a process consisting of six stages, *Suspecting, Taking it in, Going along with a changed reality, Sweeping along with the symptoms, Beating down the denial, and Learning to live with it,* each with individual characteristics and coping strategies (see Figure 1). In this chapter, a brief overview of this process and discussion of the core variable will be provided, followed by an in-depth discussion of each stage. As children of the parents in the study were all adult males, the term child and son will be used interchangeably.

Overview

Suspecting is the first stage experienced by parents of adults with symptoms related to HIV. During this *Suspecting* stage, parents begin to suspect that their child may be HIV+ or have AIDS. In addition to the HIV+ status, some parents may also suspect that their child is gay. The *Suspecting* stage is followed by the *Taking It In* stage, a stage in which parents are made aware of and must absorb the fact that their child is HIV+ and perhaps is gay. Next, the *Going Along with a Changed Reality* stage occurs. In this stage parents and their infected adult child carry on with their respective lives, yet parents are constantly aware that something is wrong. Parents now live with the knowledge of their child's positive HIV status and, possibly, the awareness of their child's homosexuality or bisexuality. As symptoms increase in severity and intensity, parents enter the stage entitled *Sweeping Along with the Symptoms*, a stage in which the parents' experiences are dictated by the nature of the disease. As the disease progresses, parents gradually, and at an individualized pace, become aware that the disease is "winning" and their child is "losing." With this acknowledgement, the parents enter the stage *Beating Down the Denial.* Following their child's death, parents experience the stage *Learning to Live with It,* a stage

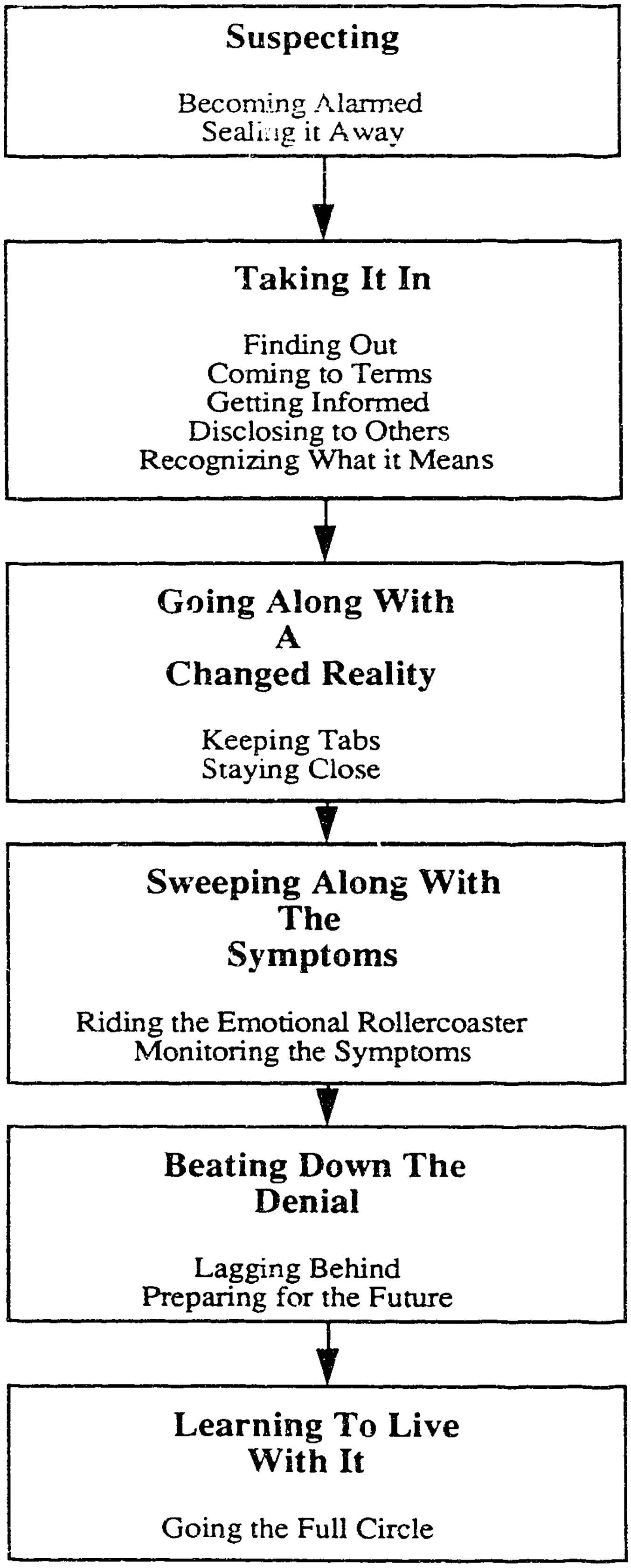

Figure 1. The Process of Being a Parent of an Adult with Symptoms Related to HIV Infection

in which, despite their child's death and their recent experience, parents attempt to carry on with their usual activities and with living.

Keeping Reality at a Tolerable Level

According to Hutchinson (1986), a group experiencing common circumstances share meaning. They may also share a specific social psychological problem which is not necessarily articulated. This social psychological problem is then resolved by means of a social psychological process. The basic social psychological problem shared by parents in this situation was the terminal nature of the disease, the horror and distress experienced when witnessing their child's suffering, and the fear they experienced when they observed their child's gradual deterioration. Not only did they have to cope with their own feelings in the face of this reality, but in many instances, they had to project a strong front in order to assist and support their child and/or other family members. Throughout the entire experience, it became apparent that parents were attempting to keep their evolving reality at a level they could tolerate. Parents in this study resolved their social psychological problem by a the basic social process called *keeping reality at a tolerable level* (see Figure 2).

Keeping reality at a tolerable level refers to the process whereby parents deliberately employ strategies, as one mother described, to stay in the "comfort zone." The process begins when parents are threatened by a certain trigger that comes in the form of an observation or an event. For example, an observation may be a physical manifestation, while an event may include either a meeting with the physician concerning the course of the disease or their son preparing for his own memorial. Parents then determine how they will view the situation, what they could do in response to the trigger, how they will manage, and how they will help their child. Following this assessment, strategies, which could be either cognitive or behavioral or a combination of the two, were employed. Underlying the use of these strategies was a measure of self-control that parents imposed on themselves as they worked to implement strategies which would facilitate reaching the "comfort zone." If

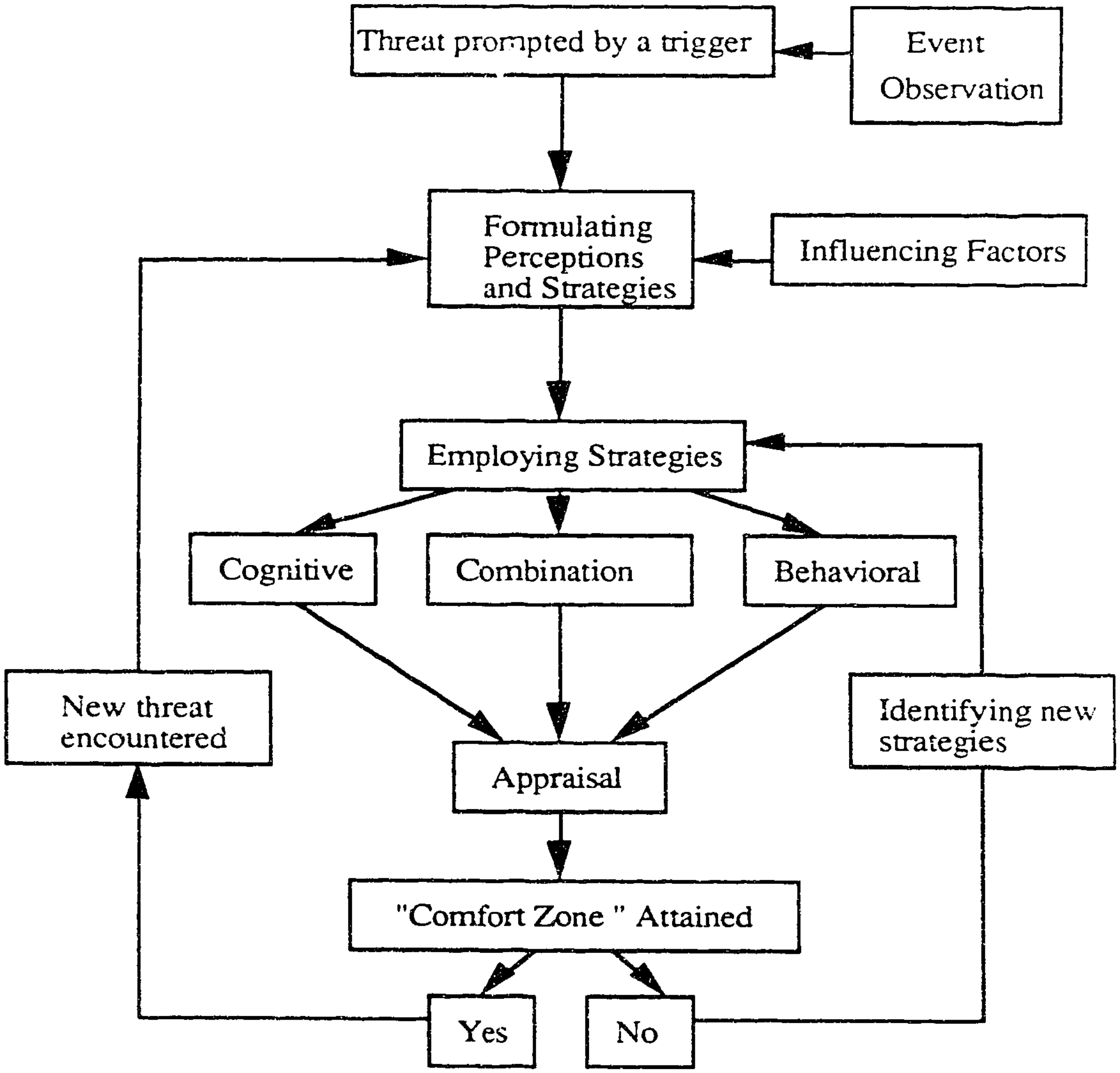

Figure 2. Keeping Reality at a Tolerable Level

the "comfort zone" was achieved, parents went along until the next trigger appeared. If the "comfort zone" was not achieved, parents re-evaluated their strategies and identified and employed new strategies. Parents' perceptions and the strategies they employed tended to evolve and change in nature as the disease progressed, symptoms became more severe, and their child's condition deteriorated.

Maintaining hope is key in *keeping reality at a tolerable level.* Hope initially appeared during the *Suspecting* stage and persisted throughout the remaining stages. Each parent in the study spoke of hope. Hope played a key role in the day-to-day lives of these parents and was identified by many parents as being the one thing that made it possible for them to "make it through" their experience. Similar to the other cognitive strategies, their hope was of a progressive, evolving nature.

Despite the commonalties of the experiences by parents, their perceptions and the strategies they employed were influenced by a number of intervening factors. These factors included personal attitude and the problem-solving approach of the parent, the personal attitude and the problem-solving approach of the child, whether congruence exists between parent and child in relation to personal attitude and the problem-solving approach, level of knowledge about AIDS and homosexuality or bisexuality, presence of other stresses, the severity of symptoms and stage of the disease, and the presence and type of support.

The stages parents experience when they are a parent of an adult child with symptoms related to HIV infection will be explored in detail in the following discussion. In addition, the responses of parents, issues parents perceive they face when their adult child has symptoms related to HIV infection, the strategies they employ in order to cope, and the changing nature of their hope will be addressed.

Suspecting

The *Suspecting* stage is comprised of two components: "Becoming alarmed" and "Sealing it away" (see Figure 3).

SUSPECTING

Becoming Alarmed
Sealing it Away

Figure 3. The Suspecting Stage

The entire process begins when parents suspect that something is wrong with their child. Most parents in this study reported being suspicious that their child was either HIV+ or had AIDS and was possibly gay, or they simply felt their child was "different." These suspicions came about as parents were alerted either by certain behaviors on the part of their sons, an awareness that they were experiencing symptoms indicative of an HIV+ status, or based on observations they had made of their sons. However, despite becoming alarmed, parents tended to seal their concerns away while continuing to worry and fear in silence. Denying that a member of their family could contract the disease was a common strategy employed by parents during this time.

"Becoming alarmed"

The majority of the parents reported becoming alarmed because they believed that their sons were engaging in behavior they considered to be "high risk." For example, one parent became alarmed when her son was caring for an individual with full-blown AIDS. This participant stated she had been relatively uninformed about AIDS and consequently believed he could contract the virus through casual contact. Whereas, parents who knew that their sons were intravenous drug users (IVDU) were alerted because of their knowledge that intravenous drug use was a high risk behavior. Two other parents became alarmed because they knew that their son was frequently consulting the doctor and going to a clinic for "tests." This, combined with the knowledge that he was an IVDU led them to suspect that he was HIV+.

Similarly, parents of gay men became alarmed because of their suspicions that their sons may be engaging in high risk behavior or because they were aware that at the time gay men were primarily affected by the disease:

> As time went on and the stories of the AIDS started to come, we encouraged [son] to get a test. I knew that he was living in some pretty wild times, rough times. He did all kinds of things. I worried, I worried a lot about the things that he got into, about the people he was with. By then I started to read about things, and the more you read, the worst you feared.

Some parents were alarmed because they knew that their sons were experiencing symptoms which were characteristic of an HIV+ status. For example, one parent became concerned because she knew her son was experiencing night sweats. Other parents were alerted by symptoms they observed, such as swollen glands. One parent described how despite being told by her son, who was an IVDU, that he was being hospitalized for lung cancer she immediately "knew" when she learned that he had pneumonia, that he had AIDS and not lung cancer. Another parent stated that he instinctively knew his son was going to tell him he had AIDS when his son indicated he had something to tell him. This parent attributed his "knowing" to the fact that his son had previously been hospitalized for severe headaches on a medical unit where AIDS patients were being treated.

Even parents who indicated that it had come as a complete surprise when they learned their child was either HIV+ or had AIDS stated that in retrospect there were certain clues that made them think that something was wrong. Their son's physical appearance was one of the most important clues. One parent haltingly described the time when it dawned on her that something was "not right" with her son:

> It came like a bolt out of the blue. It really did. . . . I never noticed, you know [son] was so meticulous about himself all the time and to me he looked just a bit drawn, and his hair wasn't as shiny as always. . . .I

> noticed that gosh, he really doesn't look that well. And I asked him. I said "Are you eating properly?" [I] said "You know, you're getting thinner you should eat properly, if you can't afford the food. we'll help you." But it was after he left, well it dawned on me then that if I didn't know better, you'd almost think that he had AIDS.

Along with their suspicions concerning an HIV+ status, some parents were suspicious that their child might be gay. This was prompted by certain behaviors such as not being married, living with another man, or participating in activities which are stereotypically associated with female behavior. Parents frequently said that participation in these activities could be traced back to their son's early childhood:

> He looked after that doll just the way any little girl would look after a doll. . . . He washed it, he dressed it, he made believe he was feeding it; he played with that doll. Of course in those days a boy playing with a doll - they do now - but those days they didn't do things like that.

> By the time he was two and a half or so, he was showing that he wanted to do things like a girl. Oh, in particular I remember doing carrots, and I'd pull the carrots, and there's the tops of the carrots. Well, he would put them on the back of his head and put a bonnet on his head and run around and have long hair.

Other parents reported being aware that their child was "different." Being "different" referred to the contrast between this particular son and the other children in the family or from other males:

> There's always that thing at the back [of your mind] that says why is he doing this kind of thing? It seemed that he was leaning in a certain direction, that seemed to be more effeminate, than other ways. I guess your mother's heart fears that it could be because he's going to be homosexual.

Parents who were aware of their child's lifestyle or that their child may possibly be engaging in high risk behavior were often pessimistic regarding the outcome of their child's lifestyle. One parent of a gay son was quite sure that her fears would become a reality:

> I knew right from the day that they announced AIDS. My son went from [large city] to [large city] to [large city] and had a great time. He really had fun in his life, and I knew almost from then. It sounds silly, but [I] knew he would probably have HIV.

"Sealing it away"

Despite their fears and concerns, for many parents, the idea that their son could actually be HIV+ or have AIDS was inconceivable. Even those parents who had reported either being aware of high risk behavior or of observing suspicious symptoms, clung to the belief that this disease could not possible affect their family:

> In [son's] case, it was his physical appearance that was unlike him. I thought that he looked unkempt and that was not characteristic of him . . . .So that was the first thing, that and then I'd seen people with AIDS on television. Then I thought, if I didn't know better, I'd swear he looked like somebody with AIDS. Yet I couldn't even envision it.

The majority of these parents kept their concerns to themselves. Rarely did they discuss their fears with other family members or outsiders. Also, despite assuming that each spouse probably suspected the same thing, couples rarely discussed their concerns with each other. In addition, parents rarely discussed their concerns with their sons. Only one parent in the entire sample approached her son suggesting that he should consider being tested for the virus. Another parent expressed her concerns regarding her son's physical appearance with another family member and asked this individual to suggest to the son that he be tested or, at the very least, to find out what was contributing to his sickly appearance.

The parents' rationale for keeping their concerns to themselves included fear, hoping, and trusting that their son would approach them and a lack of knowledge:

> It was all there, but it wasn't out in the open. We didn't ask cause I didn't think - well neither of us really knew whether to ask or not. I think we were quite afraid.

> I never talked to anyone about it, never raised the subject because if he wanted to, [and] had I known a lot more about it, then I would have raised the subject with him. Not knowing literally anything about it, I just

> thought, well I can't do anything about it. If he needs help, then he'll ask me, I hope, and I left it at that.

Additional reasons for limited disclosure included the perception that it would be inappropriate or accusatory to confront their son on their own initiative and the belief that AIDS would not affect their family.

Parents suspicions persisted over a varying period of time and tended to gnaw at the back of their minds. Prompted by her fears and concerns, and almost in trepidation, one parent began to try and learn more about the disease:

> I was trying to take in information about it any time I saw anything on television. I watched it, because there's that nagging fear all the time that you're going to be involved with it. So you watch it and you think, oh I hope not, but I better know this because it's going to be useful some day.

However, the majority of parents dealt with their concerns by denying that their child would contract the disease and by clinging to the belief that AIDS would not affect their family.

The *Suspicion* stage ended when parents suspicions were confirmed and they learned that their son was HIV+ or had AIDS. Some parents also learned that their son was gay. This signalled the beginning of the next stage, known as the *Taking it in* stage.

Taking it in

The *Taking it in* stage is comprised of five components: "Finding out," "Coming to terms," "Getting informed", "Disclosing to others", and "Recognizing what it means" (see Figure 4).

TAKING IT IN

Finding Out
Coming to Terms
Getting Informed
Disclosing to Others
Recognizing What it Means

Figure 4. The Taking it in Stage

Even though parents learned of their son's condition at different times, there were commonalties in the responses and strategies employed by parents in order to "come to terms" with their son's situation. Early in this stage, parents were grappling with the notion that this was really happening. Strategies employed during the *Taking it in* stage were primarily cognitive and functioned to help parents slowly take in what they had learned and deal with its meaning. These strategies included *denial*, engaging in *positive self-talk*, and *hoping*. In addition to these cognitive strategies, and primarily to alleviate their feelings of helplessness, parents began to engage in behavioral strategies, such as, *seeking information*, *getting support*, and *providing support*.

The personal attitude and the problem-solving approach of the parent were important intervening factors which influenced the manner in which parents viewed events, how they responded, and determined which strategies would be employed in the *Taking it in* stage and in subsequent stages.

"Finding out"

The *Taking it in* stage began when the news was broken to parents that their child was HIV+ or had AIDS. This confirmation came at varying points in the disease process. Some parents were informed when their child was HIV+ and physically asymptomatic, while others were informed when their child was diagnosed as having AIDS and was experiencing the initial critical bout of symptoms. In addition to the diagnosis, some parents learned their son had a lifestyle of which they were unaware. In this study, parents of IVDU had been aware of their child's drug lifestyle, however, three of the ten parents of gay men discovered that their sons were gay or bisexual at the same time they became aware of their positive HIV status. Parents who experienced the "double whammy" stated that even thought they felt that the homosexuality or bisexuality of their sons may have affected their initial response to *Finding out* the major factor that devastated them at the time was either the severity of the symptoms or the fear that they would lose their child. The increasing intensity of this was demonstrated by one father who stated that while finding out his son was homosexual was "kind of hard to take" learning that he had AIDS was "really hard to take." Therefore, the disease and the implications of being HIV+ positive took precedence over the fact that their son was gay:

> So we went over to the hospital, and we found all that out in five minutes, so needless to say, it was a great shock. The homosexuality part didn't bother me one bit; the fact that he was HIV+ was what was so devastating to me.

Most of the parents in the study were told of the diagnosis by their son. Occasionally, parents were told together, but more frequently, the son would tell one parent, usually, but not always, his mother, who would then tell the other parent. In cases where one parent was told, this parent occasionally chose not to tell the other parent immediately; instead, they tended to wait for an "appropriate" moment. In two situations, sons initially disclosed to a sibling, who in turn told one of the parents. In these cases it was usually the mother. Discussion between parent and child at the time of disclosure concerning the diagnosis and what it could mean was usually minimal. Less frequently, sons knew that they were HIV+ but chose to withhold this information from their parents. In another situation, the son told one parent that he had tested negative when he had in fact tested positive. However, these children shared their diagnosis with their parents at a later time. Reasons provided by parents explaining why their sons may have decided to withhold their HIV+ status from them included thinking that the parent would nag, would be unable to "handle it," or a fear of being disowned or of disappointing their parents.

Frequently, sharing the diagnosis with parents occurred when symptoms began to appear. With the appearance of symptoms, the reality of the diagnosis frightened the son into thinking that he was seriously ill and resulted in him reaching out for support. This is supported by the tendency of several children in this study to withhold the information from their parents until their symptoms became more severe.

Finding Out was a devastating and emotional time for parents. Initial responses included shock, disbelief, a sense of unreality, helplessness, and anger. Parents stated that during the *Finding out* stage they were responding to a number of issues, including the fact that their fears had become a reality, the severity of symptoms if their son was ill at the time of disclosure, and fear that they may lose their child.

Shock was the initial response identified by most parents in this study. One parent described that his main objective was to "keep from fainting" at the time of disclosure. Others described it as "a blow" or being "hard to take." Even those who stated that they had suspected that their child was HIV+ were shocked and devastated by the confirmation of their suspicions. These parents were shocked because despite their suspicions they had hoped that what they suspected was not true. However, others who had suspected stated that while *Finding Out* was a shock it was not really a surprise:

> I think it was two years ago. . . . It really wasn't a shock to us in the sense that it was a surprise. Of course it's a shock to hear about, but we weren't awfully surprised about it.

> In a sense it surprised [me]. In a sense it was kind of a gnawing in the back of the head. "Is it possible?" "Will it happen?" [There] was some shock in there, but I think it was sort of a softer shock rather than a hard shock.

Several parents described *Finding out* as being physically painful. This pain was "unlike anything they had ever experienced" and was likened to a "knife being forced into the heart and then twisted." Their grief and pain were evident as they cried again and explained:

> I imagine the worst time probably is when you first finally know. . . . I think I cried for four months, everytime I'd turn around you'd think about it.
>
> I was working at the time and he told me and I told him how sorry I felt for him. [tears] I went back to work and my glasses filled up with tears. [tears] And then you know weeks and months after that, everytime you'd think about it it upset you.

Some parents grieved openly, while others grieved privately or silently:

> I used to cry quite a bit, too. I would go to church every Sunday, sit in the back pew [and cry] almost through the entire service. And I was through [crying] for a week, I could go out and function normally or fairly close to normal for the remainder of the week. Then back to church again on Sunday for another good cry. That went on until Easter I think, Easter was the last really good cry I had in church. So that was like October till April.

Closely linked to the sense of shock was a sense of disbelief. Parents frequently could not believe what they were hearing or seeing:

> We were all in too much shock at that time. Crying. Our eyes were big, they looked around, nobody really believed it, that it had happened.

The sense of disbelief was closely linked to a sense of unreality. The sense of unreality was experienced more often by mothers in the study and tended to persist throughout the other stages for some parents. Parents described how they had to stop themselves periodically and acknowledge what was happening:

> That's very prominent [referring to the sense of unreality], especially at first. Even sometimes now you go along for several weeks and then all of a sudden you'll think "Oh my Lord, my son is homosexual and he's HIV+." Or just it comes on you . . . it's never gone away for me.

> I don't know if everyone who has someone going through something like this once and a while says it isn't happening. I think of it every once and awhile.

However, other parents, and primarily fathers, indicated that they did not experience this and stated that they were very aware at all times that what was happening was a reality.

A sense of helplessness pervaded most of the parents' experiences. In this early stage, the parents experienced a sense of helplessness because they felt that there was little they could do to help their child. This was made more difficult if parents learned of their son's diagnosis when he was experiencing severe symptoms. In this situation, the parent had to deal simultaneously with the diagnosis, the severity of the symptoms, and, in some cases, the acuity of the situation:

> The devastating part was that our suspicions were true and our son was lying there with tubes and all this sort of thing and you don't know. I didn't know what PCP was, for instance, and I didn't know how long he was going to be in the hospital. . . . So that was the devastating part, and seeing him and not wanting him to suffer is another part of the devastation. You're helpless. I mean, you can't do anything for him but give him moral support.

This sense of helplessness persisted throughout the remaining stages, increasing in intensity as symptoms became more severe.

Several parents described experiencing anger. This emotion appeared following the initial shock, and for some parents, it continued into the remaining stages. Much of their anger stemmed from their lack of knowledge, feelings of uncertainty, and sense of helplessness. Very rarely did parents indicate that their anger was directed at the son. However, one parent described how angry she had been with her son when she had been under the mistaken notion that he had contacted the virus from a dirty needle. She could not believe that he would be "so stupid" as to use intravenous drugs. More frequently, parents' anger was directed toward other individuals and institutions. Anger was directed at : the unfairness of the situation, the homophobic attitudes held by others, the government for failing to adequately fund AIDS research, the fragmented manner in which research was being conducted, that the infected had to fight for their rights while being so ill, the stigma associated with AIDS, the person who infected their son, the doctors for being unable to cure the disease, themselves for not being able to do anything, and the choice of treatments if it appeared that physicians were experimenting.

Several parents in this study were experiencing other stresses at the same time that they were dealing with their son's illness. Common additional stresses included their own illness or of another family member and having to maintain a "strong front" so the other partner would "hold up."

When parents found out that their son was HIV+ or had AIDS, they appeared to understand what they were being told during the immediate period following Finding Out, although they were unwilling or unable to acknowledge the true meaning of having AIDS and its implications. Parents described this as a time where the true meaning of the positive HIV status had registered in the "head" but not the "heart": a state of awareness where the true emotional meaning and the true implications of being positive were not realized:

> I know what terminally ill means, you know the brain knows. . . . I went home, and I knew that he was terminally ill, eighteen months to live at the tops. Never reached here [points at her heart], reached here [points at her head], never reached here [points at her heart].

> I knew it could happen, but I prayed that it wouldn't, and I think it took awhile to register just what it could mean.

This delay appeared to serve as a protective function for parents, allowing them to absorb what they had learned in a gradual manner:

> It was unbelievable. We didn't want to believe it, and this was the truth, running around poking you in the back with spears. This is the truth, and you avoid it as long as possible.

It is during this time that parents described *denying* what the diagnosis meant. One parent described how her denial was demonstrated by initially entertaining the notion that a mistake in diagnosis had been made or that perhaps her son's blood sample had been mixed up with someone else's blood sample. Another method of denial was demonstrated by "putting it out of your mind," which was easier to accomplish when no visible symptoms existed. Denial was sometimes demonstrated by searching for a possible solution in a situation where a solution was unavailable. This mechanism was usually employed in response to the acuity of the situation and the terminal nature of the disease:

> You take it in, but you're widely looking around in your mind for ways out . . . . I found this with myself: inside of my mind, I was running all over the place looking, looking, for ways out. I was trapped inside of this terminal thing, and so my mind is running here, maybe this will work, maybe this will work.

Some parents employed denial as a strategy more readily than others, with mothers employing this strategy more often than fathers.

Despite their devastation, most parents in the sample kept their true emotions from their child and, in some situations, from their partner. Parents did so by *maintaining a brave front* and by adopting a *fighting it* stance. These two strategies began in this stage and tended to remain present throughout the remaining stages. Assuming this "it's us united against the disease" stance was often initially based on the parents' hope that this disease would not progress and that their child would beat his illness:

> He said, "I've got AIDS mother." Well, that is an awful [thing] to hear that. It's a terrible feeling, and my first question was "Are you sure?" "Yah I'm sure", and I said, "Well that's awful." I said, "You know there's no cure for that," but I said "Don't worry about it, we'll stick together and we'll beat this." I was so confident that somehow or another it wasn't going to take him.

Maintaining a brave front also occurred when the parent perceived that their son was giving up, and to hide their true feelings from their son:

> I said, "What's wrong?" And he [said], "Well, I'm on my way out mom and dad, I've got AIDS." I said, "Come on [son]." "No, I am mom, I'm on my way out." Well I wasn't going to let him see that it got to me or anything. "Come on," I [said], "pull your socks up, you'll get over this." "Oh, I'll get over somewhat," he [said], "but I'll never be well again. I've got AIDS, and I will eventually die." I said, "We've gotta fight this [son]"....The doctor came on . . . . I said, "We understand [Doctor] but I wasn't going to give [son] the impression that I was giving up because he had done." I just hung on by the thin shreds.

Parents also assumed this stance when their son was maintaining a positive attitude and was assertive in ensuring his own care. Parents mirrored their son's positive attitude and felt that *maintaining a brave front* and assuming a *fighting it* stance were part of being supportive of their son. Many parents spoke frequently and with great admiration of the load that their sons carried, how difficult it must be for them to be positive, yet how positive and in control of their lives they remained.

It is during this time that *hope*, which initially appeared in the *Suspecting* stage, began in earnest and developed strength. Primarily parents hoped for a cure, and many were convinced that a cure would be found. Even parents who were aware that the diagnosis was serious and that presently no cure for the disease existed hoped that a cure would be found:

> When he told me, it hit, it hurt. I knew there wasn't a chance, but I lived in hopes that maybe they'll come through with something, and that's I guess the way I went through it.

One parent simply hoped that the disease would go away. Prayer was another means of hoping and was mentioned more often by the mothers in this study. One parent believed so strongly in her faith that she was convinced that her prayers for healing of her son would be answered.

Clinging to the hope that the disease would not progress and basing this hope on stories of other infected individuals who were "beating the odds" was also quite common in the early stages of the process:

> So then we knew that he had it, but then we didn't know. You know some people can carry it for ages and nothing happens.

For many parents, this hope was so strong that the possibility of the disease progressing was not even an option or a possibility. By hoping for a miracle cure or that somehow and in some way their son was going to make it or beat the odds, some parents were able to convince themselves that the disease would not progress:

> I didn't really expect that it would come to more, well, I guess I just hoped it wouldn't.

In situations where sons were in an early stage of the illness and on medication in order to control progression of the disease, parents placed great hope in these medications. The news, with its promises of breakthroughs and identification of new treatments and drugs, nd the continued efforts by researchers to find a cure for the disease also sustained the hope of parents.

"Coming to terms"

Closely following the responses commonly found during the *Finding out* stage came a time where parents worked to come to terms with what they had learned. One parent described this as the "what did I do wrong syndrome." Parents questioned how they may have been at fault for their son's illness. Consequently, they engaged in second guessing and in attempts to make sense of the situation.

Second guessing refers to the tendency by some parents to question how they themselves may have contributed to their child's lifestyle choice, which in turn may have resulted in his positive HIV status. Engaging in second guessing often resulted in feelings of guilt and a sense of responsibility. Many of the parents expressed thoughts and feelings concerning how they may have contributed to their son's condition. They reviewed their parenting and questioned what they had done as parents for their child to assume a gay lifestyle or to begin using intravenous drugs:

> You know you always think, where did we go wrong? Or, what went wrong and all that to make him go to turn to drugs?

One parent questioned whether his absence in the home may have contributed to his son assuming a gay lifestyle:

> [I] worked long hours, trying to raise six kids. So sometimes my kids were deprived of a father being at home. But when I was at home, I tried to do the best I could. [I] often wondered, did that make a difference? Because it didn't make a difference to the other kids. It was something that I had no control over, and I accepted it in a that way. But [I] always wondered, did I do something wrong?

Another parent questioned how her decision to support her child's interest in an area other than his initial interest in music may have contributed to her son's destiny:

> I wonder if had I bought him a saxophone when he wanted, would his life have taken a different turn? You know those things are there, they're always chewing away at you and kind of leaves you unsettled.

Second guessing haunted these parents and tended to reoccur in the other stages.

Other parents regretted their past behavior or things they might have said to their sons. This was particularly true for parents who had previously been unaware of their child's diagnosis or sexual orientation. Parents in this situation felt that if they had known they would have been more understanding and supportive of their child in the past. This was most evident in one case where a family had decided to withhold the son's positive status from one parent. This parent spoke at great length of how knowledge of the situation would have prevented some of her actions:

> I would be so annoyed with him and now I know, but it's too late. I was hard on him for a couple of things, like I told him, I said, "My gosh, I've never seen anybody with less ambition." I figured he should be so gung ho on this and that. Well he knew the score, but I didn't and I couldn't understand it, but if I would have understood it, I would have been a lot kinder. So for that I feel very guilty.

Trying to make sense of the situation was closely related to second guessing, and it occurred early in the disease and persisted throughout the remaining stages. Parents who had difficulty coming to terms with homosexuality tried to make sense of why their son was gay. They tried to determine how this came about by re-examining their family background. Parents of IVDU's also tried to make sense of why their son had turned to drugs. These parents frequently tried to reach some understanding of why one particular child out of a family of several children would chose this particular lifestyle.

Parents of IVDU resolved their guilt and sense of responsibility by seeking advice from professionals and by deciding that drug use was a personal choice made by their son. These parents also engaged in *positive self-talk* by telling themselves that they had done all they could and by reminding themselves their other children were "normal." Some parents of IVDUs described themselves as being "hardened." This "hardening" was usually a direct result of a long history of negative experiences associated with their child's use of drugs. These included broken promises, relapses, and problems with drug dealers and the law.

Parents who learned of their son's gay lifestyle described coming to terms with this in a manner similar to those who had previously been aware that their son was gay. Parents in this situation typically described themselves as being perplexed when they first learned that their son was gay or bisexual. They described themselves as being in "a haze." The concept of homosexuality or bisexuality was totally foreign to many parents, and a lack of knowledge concerning homosexuality and bisexuality appeared to compound reactions to the news:

> So he told me, he [said], "Mom, I'm gay." I looked at him, and I [said], "Gay, what's gay?" To me gay is to be happy.

These parents expressed the need to understand their child's sexuality and worked hard at trying to reach an understanding by seeking information. Parents gathered information concerning homosexuality by obtaining literature on the subject, consulting with family physicians and members of the clergy, or by approaching gay or AIDS organizations. However, obtaining accurate, unbiased information concerning homosexuality was not an easy task, particularly for those parents who were made aware of their child's homosexuality ten or more years ago:

> With my son I had no hesitation. It took me awhile. . . .Of course there wasn't much information then. . . . He was only sixteen or seventeen, so there wasn't much information on what gay was all about in those days. So what you got was the typical information. Well it was due to being raised in a family of women, and it was the influence of the mother, et cetera.

One parent described in detail the difficult and frustrating time she and her husband experienced while trying to find out all they could about homosexuality. They had been aware from their son's childhood that he was "different"; consequently, they consulted with various individuals including a school counsellor, the clergy, and their family physician in order to learn more, but they were unsuccessful in their attempts. Only following involvement with an AIDS organization support group where they were exposed to other gay individuals did they obtain the information they required.

Other parents were quite assertive about finding out what they needed to know, and one parent described how he felt his urgent need to understand and learn had resulted in his being almost hurtful to others:

> I hurt a number of people because I was pursuing it and asking questions. I wasn't going to let go. I had to learn about it. And people, speaking now of homosexual people who had not completely dealt with their own homophobia. Things like this are very sensitive, of course, and things I might say would offend them or arouse them in such a way as to hurt them or make them feel bad about themselves. I could see that happening, yet I had to get the answers. That was a very difficult time for me. Yet I had to understand all of that so I could understand [son] and be more supportive of him.

Learning appeared to facilitate understanding and support of their child; whereas, lack of knowledge meant you were "stumbling in the dark" or had a difficult time trying to grasp what was happening. Obtaining accurate information concerning homosexuality and receiving confirmation that they as parents were not responsible for their son's sexual orientation or had contributed in some way to their child assuming a particular form of sexual expression appeared to comfort some parents.

However, other parents found it difficult to understand their child's sexual orientation even with knowledge. These parents had to resolve the issue within themselves by focusing on other things. For example, one parent described how he had come to terms with his son's homosexuality by accepting that his son was different and by focusing on his son's positive aspects, for example, his son's creativity and athletic abilities, the fact that they shared similar values, and the quality of their relationship. He also felt that if his son accepted other family members, then in turn they should also accept him. Others came to terms with the issue by engaging in *positive self-talk* and telling themselves that individuals were born with a sexual orientation and that this was not something which resulted from faulty parenting.

Most of the parents in the study stated that they came to terms with their son's sexual orientation, and while they might not have condoned or understood his sexuality, they maintained that all that was important was that he was their child. Several parents in this study stated that they could not fathom how a parent could reject or abandon their own child simply because of his sexual orientation. Ultimately, parents were supportive of their child, and in some cases, this support was extended to the child's partner. Several of the parents showed concern for what their child's partner must be going though, thereby acknowledging the importance of this individual and his place in their son's life. This was demonstrated by spending time with the partner, offering him support, including him in meetings with the doctor, and sharing caregiving responsibilities. Others reported acknowledging their son's other "family" by holidaying with their son and his significant others, and by sending Christmas gifts which were described as being "from our house to yours."

"Getting Informed"

Each parent interviewed in this study had made some attempt to learn about the disease and bisexuality or homosexuality if it was applicable. The need for information generally began in this early stage, but for some parents, it continued throughout the remaining stages. An exception to this was the parents whose sons were IVDU. Despite having consulted various individuals throughout the course of their child's drug history, these parents did not express a need for additional information concerning intravenous drug use.

Information was necessary as many of the parents in the study knew very little concerning the disease or homosexuality or bisexuality, and this lack of knowledge made things difficult:

> I kind of stumbled along and learned as it was happening. [I] tried to read up on it, and you know, reading medical terms sometimes, if you can understand, it you're O.K. But if you don't understand it, you have an idea, but you're still in the dark, partially in the dark.

Uncertainty related to the nature of the disease itself and the inability to predict what would occur also presented a problem for some parents. Similarly, parents who remained uncertain and confused by media reports of how the disease could be transmitted found that they were concerned about day-to-day activities. For example, one parent stated concern about whether her son could transmit the virus through casual contact with her young granddaughter. These fears and concerns usually resulted in additional strain on the family.

Parents' information seeking strategies fell on a continuum ranging from reading pamphlets, "keeping your ears open," and watching what was offered on various television programs to actively trying to read everything that had been written about the subject:

> After you know for sure, then you read everything you can get your hands on. At least I did. . . . You listen to everything on radio [and] television. Whatever's coming, if you hear something, you try to get ahold of it. You're just constantly looking for information.

Some parents were prompted by their son to become informed or were assisted by their son when seeking information:

> I read lots of books at first you know, just about everything I could get my hands on, about AIDS and about people that you said they could cure it. . . You know how they beat it and and so on and so forth. Between [son] supplying me with books and pamphlets and documents and so on, I think we read just about everything that was ever written about it.

The most popular sources for accessing information were pamphlets provided by AIDS organizations, the library, family physicians, and by paying closer attention to information videos offered on television. Some parents had sons who were actively involved with presenting information. These parents frequently accompanied their sons to these sessions in order to learn more about the disease. Parents also attended information sessions organized by AIDS organizations or approached AIDS organizations directly in order to speak with counsellors or to attend support groups offered by the organization. Parents found the support groups and information provided by AIDS organizations particularly helpful. A great deal of support was obtained by speaking to other parents who were experiencing a similar situation. Several parents spoke of the warmth, support, and comradery they obtained by being involved in one AIDS support group. Members of this group appeared to "click," and even though the group had disbanded, members still maintained contact. However, some of the parents indicated that they were uncomfortable in groups, and either preferred a one-to-one interaction or felt that if they could keep the lines of communication open within their own family their needs would be met.

Despite wanting information early in the disease, many parents tended to focus on the success stories and were reluctant to hear the "gory details." One parent described how she deliberately did not attend support groups at the AIDS organization because there was too much discussion of the "gory details." "Gory details" meant the discussion of the numerous diseases associated with AIDS. She felt her husband, who was involved with the organization, would provide her with the appropriate information and in a form and amount she required. Another parent described an incident that occurred during a support group meeting where new members had asked a number of questions regarding the disease and its' course from established group members. The candid answers they received apparently angered the newcomers. This parent, whose son at the time was quite ill, reported that they had only tried to be honest and was puzzled by their reaction. She felt that giving these individuals a "soft sell" would have been misleading.

As parents became more informed, they began to search for alternative treatments which might be effective in combating AIDS. Herbs, vitamins, and the power of a positive attitude were explored as viable alternatives, and parents would prompt their son to suggest these treatments to their physician:

> We hoped, and we looked for, and we were quite diligent in our reading everything, absolutely everything, and trying to get the doctors to do this or that or the other thing.

"Disclosing to others"

At some point during the *Taking it in* stage, parents usually informed other family members and/or friends of their son's diagnosis. This typically occurred shortly after finding out, and in some cases, it took place almost immediately. One parent spoke of being "panic stricken" and, as a result phoned some family friends immediately upon learning of her son's diagnosis. In this case, the parent described this as a reflexive action, prompted by her feelings of panic and lack of knowledge. Some parents were more selective and simply told one close friend, while others were equally selective when they disclosed to immediate or extended family members. Deciding who to tell was determined by the parent's personal beliefs, perception of the presence of stigma, a request of the son, or belief that others did not need the "hassle." Fathers more frequently than mothers identified this as being "private" or "personal" and felt that other people would not be interested.

Some parents spoke of the stigma associated with the disease and identified this as the main reason for restricting what they told to a few close friends or certain family members. This perception of stigma and/or actual experiences with stigma were difficult for parents and limited their amount of disclosure. For example, one parent did not disclose to the grandparents because she felt that they would have difficulty understanding the disease, primarily because it was associated with homosexuality. Another spoke of the "chilly" reception she experienced at her beauty salon when she had been open about her experience.

Several parents decided to withhold the information from other family members. Reasons for doing so included the perception that a particular family member might be unable to handle the news or was already experiencing enough stress and did not need the extra burden. Others withheld the information because of their hope that the disease would not progress:

> I didn't tell all the members of his family right away because some people can have this infection and go on for years and not develop [into anything]. Of course we hoped that would happen.

When a parent was excluded from knowing, this sometimes resulted in resentment and feelings of guilt, particularly if this individual felt in retrospect that he/she had been insensitive with his/her son because of his/her lack of knowledge.

In families where limited disclosure was felt to be necessary between spouses or other family members, the individual carrying the load of maintaining "the secret" was often taxed to the limit. These individuals also perceived that they had no support. Whereas, the ability to talk and "keep it moving" with close friends, the immediate family, and between spouses was particularly helpful. In addition to family and close friends, parents also disclosed to family physicians, church members, and support groups. Disclosure in support groups afforded the greatest comfort, specifically because parents were provided with an opportunity to talk without censure.

With the exception of two situations, disclosure to family and outsiders was generally met with support and concern. Several parents expressed their gratitude for the acceptance and support they had received from others. Those who did not receive support either severed ties with those who had reacted negatively or were more selective with future disclosure. Several of the sons in this study were quite "public" in their disclosures. Generally in this situation, parents were quite proud of their son and stated that they were not uncomfortable with his public disclosure.

"Recognizing what it means"

As identified earlier, parents often felt that the true meaning of the diagnosis had not registered immediately. For some, knowing in the "head" as well as in the "heart" occurred in a relatively short period (for example, two weeks), while for others, this acknowledgement came later, such as in a month's time or more. Knowing in your "head" and in your "heart" referred to the point in time when parents acknowledged that their son was ill. This "registering" or "sinking in" appeared to be triggered by various events and was frequently accompanied by another grief response. For some, this acknowledgement occurred following the acquisition of information:

> R: I wondered what happened in between the times from when you knew till you went and talked with him [social worker at AIDS organization] ?
>
> I: Well, strange, it hadn't really sunk in. What it was, or what the outcome of it was. I wasn't quite sure, and maybe it was that I didn't want to. But it got to me, and then I phoned and wanted to talk to [social worker] cause [son] said I was to go and see [social worker]. It was something that shook me up pretty good, I guess. . . . It wasn't to maybe a month later, when I went down to the [AIDS organization] and saw [social worker] and got some explanation [that] it really struck me with what he had.

For others parents this recognition of their son's illness occurred when their son engaged in certain behavior, such as going on disability:

> When he went on disability leave, that meant he wasn't going to be working anymore, and of course, he had to be ill. So we knew then that there was some progression and that maybe he was going to get more ill . . . . So until he did well actually, go off on disability, that's when it really hit home I suppose.

Also, for other parents, acknowledgement was triggered by the progressive nature of the symptoms or an awareness of how the disease manifested itself:

> The next time I went in and saw him again, I saw the little skinny wrists. . . He dropped a lot of weight again, and his wrists were just like the size of my two fingers. That's when it hit me, what terminal meant, that I would lose him. I went out of the room and cried and cried and cried in the hallway. I just hung on the walls . . . .Just sobbed my heart out.
>
> When he started with a lot of diarrhea, and things like that, and then you think, well, maybe it's just the flu. I don't know if he was thinking that way or if he had an inkling that it was more development. He never really said, but I think that's when it really sunk in, that,"Yah, this could happen."

While for some parents the severity of the symptoms forced acknowledgement:

> I just wasn't aware of how sick he was until until it happened. All the kids gathered, and it was a helpless feeling because we were all there and there he is in a tent, with tubes from all sides. . . . Then you sit there and you wonder just what in the world! I mean it was like, [makes smacking movement with his hands] yah, this is serious. . . .That's when it started, so I think that was a shock and a realization that this could be it . . . . That's when it started to register. Up until then, your hopes are hopes, but when that happened, that's when I knew that he was sick.

It was during this time that the parents' personal attitude and problem-solving approach became evident in their responses and by the strategies they employed. Many of these responses and strategies were different for fathers and mothers. Fathers often spoke of "being in control," the importance of maintaining control, and that one's actions were a direct consequence of personal choice. Fathers generally spoke of their problem-solving approaches using phrases such as "being strong," "doing it on your own," "not dwelling on it," "accepting it," "taking it in stride," "moving ahead," "sticking together," and determining what had to be done and then "doing it." While some mothers shared these attitudes and problem-solving approaches, particularly of being active in meeting your own needs and "sticking together," they spoke more of the important role of religion and outside support when they were faced with problems.

Overall, a *taking it in stride* stance was most frequently assumed by parents during this time. There was an attitude of "O.K., this happened, now what's next." However, this strategy was employed more often by fathers in the study and appeared to reflect their attitudes of "maintaining control" and "moving on":

> But parts of it . . . . we could do without of course, but then you look at some other people and they've got bigger problems. We don't dwell on it. No, one has to get on with life and take it a step at a time type of thing. There's nothing you can do about it, and you can't reverse it.

Parents continued to engage in *maintaining a brave front* and assuming a *fighting it* attitude. Despite their awareness that their son was ill, parents remained hopeful. *Hope* revolved around the possibility of a miracle cure or that their son would defy the odds:

> But when the reality sunk in that this is real, I have to face this, and I denied to myself that he was going to die. I denied that. I figured somehow, some way there's going to be some kind of miracle. I clung to that somehow or another you know [that] he was going to make it.

The *Taking it in* stage ends when parents acknowledged the seriousness of the diagnosis. This signalled the beginning of the next stage, entitled *Going along with a changed reality*.

Going Along With a Changed Reality

During the *Going along with a changed reality* stage, parents and their infected sons carried on with their respective lives; however, life was not the way it was before. Instead, they were now living with the knowledge that their child was HIV+ and possibly gay. *Going along with a changed reality* could continue for an indefinite period of time and was largely dependent on the symptoms experienced by the son and the progression of the disease. *Going along with a changed reality* includes the components of "Keeping tabs" and "Staying close" (see Figure 5).

GOING ALONG WITH
A CHANGED
REALITY

Keeping Tabs
Staying Close

Figure 5. The Going Along with a Changed Reality Stage

Strategies employed by parents during this stage were the result of their response to their awareness that their son was seriously ill and to the symptoms of the disease. Following an assessment of the situation, parents would determine whether their usual coping strategies would be effective. At times, they were, especially if the son was physically asymptomatic. However, frequently their usual method was ineffective, which forced parents to seek an alternative strategy:

> My idea of dealing with something is to let it happen naturally, but then of course, you can't do that [with AIDS]. You have to do something, and my way was to become involved with [AIDS Organization].

Hoping, *denying* , engaging in *positive self-talk*, assuming a *fighting it* attitude, and *maintaining a strong front* continued to be used in this stage. However, as the disease progressed, parents began to employ *undoing* and *reframing*. Behavioral strategies such as *seeking information*, *getting support*, and *providing support* also increased in frequency. For many parents, providing support began to go beyond simply providing emotional and moral support and now began to include caregiving activities. These more active strategies complemented their cognitive strategies and were perceived by parents to be the best way that they could help their child.

"Keeping tabs"

During the *Going along with a changed reality* stage, parents were usually able to carry on with their other responsibilities; however, their son's illness was usually in the back of their minds. Parents of sons who were relatively asymptomatic physically were more likely to report less preoccupation with the diagnosis:

> Well, he had HIV two years before he developed AIDS. Until he started symptoms that I knew about, I guess I probably just kind of drifted along. I was working and busy, sure I thought about it, but he seemed to be doing alright.

Whereas in cases where sons were experiencing symptoms, parents reported greater awareness of the change in circumstances:

> There wasn't that feeling that life is going to go on as before, because it never did. . . .There was never that sense of his wellness again. Never. Not after that, it just went on.

Many parents spoke of keeping a closer eye on their son or, as one parent stated, taking a "second look." Parents were particularly watchful for visible symptoms. For example, one parent remarked that his son, who had tested positive two years earlier, still "looked pretty good." This reflected both this parent's awareness of how the virus affects the body and his watching behavior.

With their knowledge of their son's positive status, parents were no longer able to normalize seemly innocuous symptoms, something they may have tended to do under other circumstances. Symptoms were viewed as signs of a possible progression of the disease:

> I knew that he was HIV+. But as long as I didn't know any symptoms were there, it was like yes, I knew that he had this infection but nothing was developing so he was O.K. He just went along with life until he did develop different things which if [he] didn't have HIV could of just been say diarrhea. Could of been just intestinal flu or something like that. But of course, when you know, every little thing is maybe going to develop into something more.

During this stage parents also began to monitor their son's ability to manage independently. Based on their assessment, parents began to engage in caregiving activities such as ensuring that their child was eating properly or making sure that he had enough groceries. Despite assisting their child in this manner, parents consistently identified the importance of allowing their son to be as independent as possible. The parents stated that their belief in the importance of maintaining personal control and the fear of smothering or curtailing their son's independence affected their caregiving efforts.

For parents, *undoing* as a strategy began when their sons developed symptoms. *Undoing* refers to the belief shared by many parents in this study that they would be reunited with their son following death and that their son would again appear healthy. *Undoing* helped parents transcend the terminal nature of AIDS and the manifestations associated with the disease:

> [Undoing] helped me realize that only the body changes and [son] will become whole again and he will be our son as he was before . . . . What it changed was the outlook of the progression of the disease, and it also gave me the insight into death and dying. . . . It made me [feel] less devastated when contemplating the debilitating "down the road" possibilities of this disease and observing our son's pain and anguish.

This particular mother felt such relief from using this strategy and believed so strongly in its power that she provided the researcher with a copy which described the strategy and the underlying rational. She had also sent a similar copy to another mother who was experiencing difficulty coping with her son's death. *Undoing* as a strategy began during the *Going along with a changed reality* stage and continued for some parents throughout the remaining stages.

In addition to *undoing*, parents engaged in *reframing* by deliberately attempting to identify the positives in their present circumstances. This was particularly true of one couple. These parents felt that this crisis had resulted in the family becoming closer and more demonstrative with their feelings. They felt that their marriage and their relationship with other family members had been enriched due to the learning, sharing, and growing they had experienced due to this situation. Another father, who was very involved with an AIDS organization, described how he had experienced a potentially life threatening illness and, upon reevaluating his life, was satisfied, although he expressed a desire to "give back" to society. He placed his son's illness in a positive light by viewing it as an opportunity for him to contribute to society in a meaningful way. This parent became an advocate of persons with AIDS along with other groups of individuals who were stigmatized or experienced discrimination and derived a great deal of satisfaction by participating in this manner. Occasionally, *reframing* extended to reevaluating previous beliefs concerning life after death. For example, one parent described how he had changed his past beliefs and now believed that everyone went to heaven.

Parents continued to hope for a miracle drug or that the disease would not progress. Usually, if the child has not developed severe symptoms, hope for a cure was easier to maintain. However, even in the case where the child had developed some symptoms, the nature of the disease usually had a relief period following the initial bout and the next onslaught, and it was during this relief period that the parents' hope began to flourish once again. Prayer was a very significant part of parents' hope, and many parents referred to the important role that prayer had in their life, especially for sustaining their hope. Hope helped parents maintain a *brave front* and a *fighting it* attitude. Parents were no longer able to deny the presence of the illness and its implication. However, many parents reported "denying" in this stage. Upon clarification, what parents described as "denial" was the tendency to not allow themselves to think that their son might die.

In addition to these strategies, parents frequently became involved in various activities. Several parents in the study become involved in AIDS organizations or activities. Some parents participated openly, while others participated "from the sidelines." Other activities included helping their sons by driving them to and from appointments and speaking engagements. One parent assumed the role of being her son's "buddy." A "buddy's" role included being supportive and acting as a sounding board for the person with AIDS. Participating in these activities helped parents to ease their overwhelming sense of helplessness:

> [Referring to the sense of helplessness] Oh, it's terrible. I finally had to ask [son] if there wasn't something that I could do because I felt so helpless. He said, "No you're doing everything that is right," but it still doesn't change the feeling.

However, many of these activities left parents emotionally drained: this being particularly true if they had assumed a supportive role:

> [Referring to being a "buddy"] It's something that I can sometimes do quite casually. The next time it it just devastates me. But I never let [son] know there's any difference. I mean I suffer, [husband] and I suffer together, in behind the curtains sort of thing.

This usually made it necessary for parents to find a means for unloading themselves. Parents approached outside agencies for support or continued to participate with their support group if they had become involved at a earlier point.

The availability of outside support and perception of outside support as a viable option along with the level of open disclosure between spouses and within the family influenced the parents' experience, their coping strategies, and their perception of how they were coping (see Figure 6).

Outside Support Perceived as Available and Viable

		+	-
Disclosure Between Spouses and Within Family	+	Best of both worlds a	Satisfied b
	-	c Rely on outside support to "keep it moving"	d Isolated and overburdened

Figure 6. Typology Illustrating the Relationship Between Perception of Outside Support as Available and Viable and Disclosure Between Spouses and Within Family

In situations where parents discussed their feelings with each other and other family members and felt that outside support was an accessible and viable option (cell a), the parents perceived that their needs were being met and that they were coping successfully. Because these parents believed they had a wider variety of resources to draw from, they could select what avenue worked for them according to their needs. They also tended to be more optimistic concerning their future coping. This was especially true for two parents in this study. The mother had participated in support group activities and was receiving individualized counselling at the time of the study. Meanwhile, her husband was involved in leading support groups in an AIDS organization. These parents also shared their feelings with each other more readily than the other couples in the study.

Parents who discussed their feelings with each other and with the family, yet felt that obtaining outside support was not feasible, generally were satisfied that their immediate needs were being met (cell b). While one parent in this situation expressed a desire to be involved in outside support, overall she reported feeling satisfied with the support obtained from within the family. Those who could not disclose within the family or between spouses but felt that outside support was accessible and a viable option relied extensively on outside support to "keep things moving" (cell c). Sources of outside support included coworkers, fellow church members, and support groups offered by various AIDS organizations. In contrast, parents for whom open disclosure did not exist between spouses or other family members and who did not perceive outside support as a viable option expressed feelings of isolation and found keeping their feelings within very difficult and stressful (cell d).

Many of the spouses in this study had different ways of coping. However, despite not always agreeing with their partner's style of coping, they tended to be understanding of these differences and allowed their partners to proceed at their own pace. The key to achieve this for one couple was by being patient and understanding with each other and by sharing and making the other partner aware of strategies that they themselves had found helpful. This particular couple had worked out a system in which the son unloaded on the mother, who in turn unloaded on the father, who then unloaded at the support group.

"Staying Close"

"Staying Close" was an extension of "Keeping Tabs", but it was different from "Keeping tabs" because it included the parents' efforts to get closer or to be close to the child. This was a time when parents who perceived that there was something lacking in the relationship between themselves and their child would try to make the relationship "closer" or to set it right:

> When I found out he was HIV+, I think I kept a closer relationship then. Visit more often, get together more often. Just to be closer to him and see if [I'd] see any difference. Then you try to make up for time losses [when] you weren't there.

Proximity between parent and child was a major influencing factor. Most of the sons in this study lived independently in their own apartments and homes. Parents who lived in close proximity to their son and generally visited their son now tended to do so with greater frequency. Parents would often go out of their way in order to spend more time with their son. Also, those parents who communicated with their son by telephone also began to do so more often. This increased contact was viewed in a positive fashion, and it provided parents with another opportunity to support their son.

Staying close was also facilitated if a past history of shared personal attitudes and problem-solving approaches existed between parent and child. A history of shared attitudes and approaches combined with the son's attitude toward his present situation influenced parent's perceptions and how they responded (see Figure 7).

Past History of Shared Personal Attitudes and Problem Solving Approaches

		+	-
Son's Attitude to Present Situation	+	Parent and son assume a united front a	Parents work to be supportive to son b
	-	c Parents bolster and support son	d Parents keep a brave front/hardened/angry

Figure 7 Typology Illustrating the Relationship Between Past History of Shared Personal Attitude and Problem Solving Approaches and Son's Attitude to Present Situation

If a shared history existed between parent and son and the son held a positive attitude toward his situation, assuming a proactive approach toward his present situation, then there was a tendency for parents to feel they were engaged in a united front (cell a). A proactive approach was demonstrated by "being in control," "being positive," "taking it in stride," "fighting it," "not giving up," assertively seeking medical attention, and refusing to allow requests for medical intervention to be trivialized:

> He is in control of his life. When he was in the hospital and they weren't doing things the way he thought they should be done, he just ruddy well told them. I think that determination has pulled him along this far.

Many parents remarked on how their child remained positive, "took it in stride," and made light of his discomfort. Parents in this situation perceived that they had an easier time coping and often spoke with admiration of their child and tried to do all they could to support him.

When the son was positive and proactive but the parent and child had not previously shared personal attitudes and problem-solving approaches, parents lagged behind (cell b). However, these parents worked to become supportive of their child.

When a shared history existed but the son was negative or pessimistic about his situation, parents would assume a strong supportive role and would try to bolster their child (cell c).

Finally, in situations where the child was "giving in" or resigning to the worst, parents would respond by maintaining a brave front (cell d). Other parents in this situation became hardened or even angry at their son's behavior. In this study, the divergent attitudes of parents of IVDU's and their child was particularly problematic. For example, one father believed in taking control and "just doing" what had to be done, and he could not understand why his son would not discontinue his drug use.

As the disease progressed, symptoms became more severe, and occurred with greater frequency. Increasingly, parents' experiences revolved around what was happening to their son. This marked the beginning of the next stage, *Sweeping along with the symptoms*.

Sweeping Along with the Symptoms

Parents in this study described the course of their sons' disease as taking one of two forms. One course assumed a rollercoaster pattern, where periods of severe illness alternated with periods of recovery. The other course was one of a general progressive decline. If the course of the disease was a progressive decline, sons experienced no real recovery; however, periodically, the illness would be interrupted by periods of "relief" where the son would be weak but less ill than before.

The nature of the disease was very significant to parents during this stage and dominated and influenced what they experienced. Parents' emotions revolved around their child's symptoms or what was occurring with the child. One parent described this time as being similar to "being on a raft in the white waters" where there were "too many rocks ahead in one's path" and one was forced to "meet them head on." The unrelenting nature of the symptoms and the degree of incapacitation experienced by their children left parents shaken. As one mother described, she was watching her son die day by day. It was a time characterized by feelings of profound helplessness, loss of control, and uncertainty. One father identified this helplessness, caused primarily by not knowing what to do, as the hardest part of the experience:

> You don't know what to do, and you're helpless. You're relying on the doctors. In this case, it was my son, and you're helpless, totally helpless. You sit there like a zombie. This happened. What can I do? Nothing. They [medical team] don't even let you in because you're useless to them. I got pretty upset with myself just sitting around . . . .I wish I could of been able to do something. If you have a flat tire, you fix it; if the engine blows up, you put a new one in or rebuild it or whatever. But in this case, you can't fix it; you could if you knew how, but you don't know how.

This was echoed by other parents who described the difficulty they had in watching their son's deterioration and their inability to do anything but stand by helplessly. Watching the loss of control by the son over his own life and his own frustration with these gradual losses and deterioration was also difficult to witness.

The multiple issues confronting parents during this stage combined with the feeling evoked when faced with these issues resulted in parents employing various strategies in order to deal with what they were experiencing. Despite the close parallel between the parents' experience and the condition of their child, these strategies helped most parents maintain their evolving reality at a tolerable level:

> They were on a rollercoaster and so were you. When they were up, you were up; when they were down, you were down. But you didn't let yourself [get] to the point where you're not going to be able to navigate.

Parents continued to rely on *maintaining a brave front,* assuming a *fighting it* stance, engaging in *positive self-talk, undoing,* and *reframing.* Hope for a cure or of "beating the odds" still existed; however, the nature of parents' hope began to fluctuate with the disease process. Parents continued to report that they "denied," and this was again demonstrated by a refusal to think about or believe that their son would die:

> I didn't want to believe that [referring to her son's imminent death]. I knew it was going to happen, but I refused to let myself believe [that] it was. I don't know if this makes any sense to you or not, somehow or other you don't want to acknowledge in your mind that you're going to lose, the thought is too horrendous to contemplate, it just is.

However, these strategies by themselves proved to be ineffective in helping parents cope when they were being bombarded by their son's many symptoms and profound deterioration. Therefore, parents began to employ *selective focusing* strategies. Behavioral strategies such as participating in caregiving increased dramatically during this time and complemented cognitive strategies. By helping their sons, parents were able to overcome their feelings of helplessness. Caregiving was perceived by parents as being the one thing they could do to assist their child.

The *Sweeping Along with the Symptoms* stage is composed of two interrelated components: "Riding the emotional rollercoaster" and "Monitoring the symptoms" (see Figure 8).

SWEEPING ALONG
WITH
THE SYMPTOMS

Riding the Emotional Rollercoaster
Monitoring the Symptoms

Figure 8. The Sweeping Along with the Symptoms Stage

"Riding the emotional rollercoaster"

Parents frequently commented on the "rollercoaster-like" nature of their experience during this time, describing how their emotions paralleled their child's experience. Consequently, when their child was "up," parents were "up," and when their child was "down," the parents likewise were "down":

> I suppose the worst thing about it all is there's the ups and the downs. . . They seem to go down hill so fast, and then they have a good period for awhile, and then they go down again, and then they come back up. In fact, this last time he got sick, we thought it was another wave, and we weren't really all that concerned. [Of] course we didn't even know how sick he was. It's those kind of things that are really hard on the families, the waves.

One mother described how when her son's symptoms were alleviated she felt positively "euphoric" and was able to "gloss over" his decreasing energy levels; however, when he suddenly became ill again, she was "shaken." The uncertainty concerning the disease's course and the unexpected nature and severity of symptoms when they did occur filled parents with feelings of fear and helplessness:

> It's always scary when he does get sick, and when he's hospitalized for something, you don't know what the outcome is going to be.

> AIDS is very unpredictable because you don't know what's coming with it . . . Even doctors don't know which way it's going to jump or when. You don't have any idea of what to expect

This uncertainty made it very difficult to plan or anticipate for the future, for parents either expected the worst or were falsely lulled into assuming present exacerbations were similar to others their son had previously overcome:

> My daughter got married two years ago in July, and he came out for the wedding. He was on the first part of the chemo at that point, and he was all swollen up and really not good. Slept most of the time, didn't have much energy, couldn't [illegible] Then I went down in September, and I was intending

> to stay longer, but he got so well. He had his last big shot about the end of August, and when I first got there he was sick. And I don't know, he just came out of it then, and he was just super, strong and put on weight and really looked well. So I stayed until the end of November, and he was doing so well that it seemed stupid to be hanging around the apartment without enough to do when he was quite capable of doing it himself.

Despite this son's serious exacerbation, his remarkable recovery tricked this mother, and she was totally unprepared for his death a few months later.

The unrelenting nature of the symptoms was another characteristic of the disease that was difficult for parents. Symptoms reoccurred, and frequently, sons were fighting several opportunistic diseases at one time:

> These symptoms start coming. You've got this lung thing all the time, all the time. I mean it went away, but it never really went away. It was always constantly there. Then there was the Kaposi's, and then there was the thrush, and this stuff that's ongoing all the time. It never gave up, it never went away, it was always there. The last year of his life was spent in a lot of discomfort, a lot, and it's more than discomfort. I mean he was in pain a lot of the time, all the time, I mean it was relentless.

The *Sweeping along with the symptoms* stage was often marked by many hospitalizations. Hospitalization frequently required various diagnostic procedures and the use of numerous medications to alleviate symptoms and treat the manifestations of the disease. Diagnostic procedures were often painful and waiting for results produced anxiety. Occasionally, parents perceived that medications were being given in large or experimental doses, and these, in turn, were usually accompanied by side-effects and further discomfort. This concerned, angered, and distressed parents.

The severity of the symptoms experienced by their son often resulted in parents expecting the worst, namely that their son would not pull through. However, when their son recovered, the parents were hopeful for the future, only to have this hope dashed by another bout of symptoms. Parents described how their hope was "up and down," which referred to the tendency for their hope to be raised when their son was better and for it to plummet when their son experienced a setback:

> With the waves you're hopeful, [then] you know he's not going to make it. You're hopeful, [but then] you know he's not going to make it. So you're on this great emotional rollercoaster. One time you're full of hope and he's better and things are going well, and then the next time you're not.
>
> When the pneumonia set in, he was so ill you couldn't deny. But when he started feeling better, you think, well he's got this but it's no[illegible] be fatal, he's going to get over it.

Sometimes the fact that their son had overcome previous lows maintained the hope that he would overcome this low. However, with the reoccurrence of symptoms, hope plummeted once again and forced parents to acknowledge that the disease was probably getting worse.

For some parents, hope was maintained and denial of the possibility of death in the case of their son persisted because of a deep rooted belief that something like this would not happen to their family. Others felt that the possibility of their son dying before themselves was out of order and unnatural. Despite their increasing awareness that their son was critically ill, the hope in a miracle drug or cure or that their particular child would "beat the odds" continued for many parents. This hope occasionally resulted in some parents not accepting the medical opinion that their son's case was totally hopeless, a reaction that caused parents to search for alternative forms of treatment for the disease.

Parents be[illegible] engage in *selective focusing* in order to deal with what was occurring to their child and their feelings of helplessness, lack of control, and uncertainty concerning their child's future. *Selective focusing* referred to the tendency by parents during this stage to focus and deal with one aspect of their experience at a time. Doing so allowed parents to deal with what was happening on a moment to moment, day by day basis, thereby guarding themselves from being overwhelmed by the totality of what was occurring. Parents identified how they bracketed certain aspects of their experience.

Parents spoke of "narrowing their vision," "shutting doors," "shutting down parts of your brain," and "letting it in little by little":

> I don't think anybody wants to admit they're going to die. There's always that hope that there's going to be the miracle drug come out. There's always that hope that they're going to find something that's going to help them . . . . It's sort of denying it that they're going to die; not denying they're sick, you know they're sick, but denying it that they're going to die. So you sort of shut those doors, and you don't open them if you don't have to. I don't think that at any time you admit to them or to yourself that they're gonna die. You want to ignore that part of it maybe. No you don't ignore it, you think about it, and you probably in your own deal with it. I just say you shut it out of your mind or out of the door for awhile because you don't want to deal with that part of the whole thing.
>
> Dealing with the day-to-day emotions. That horrible fear inside of you that this is going to end in death. You go back and you think what is my belief about death, what can I do to prevent the death, what are my options, what are his options, can I shut this part of my brain off for today? Can I accept this today but not that, and we'll come back and look at that tomorrow or the next day in due course. I will look at it but not today. Today you're going to deal with the fact that he has considerable pain; you're not going to deal with that pain ending in death at that point. You're trying to solve the pain problem. You know, one thing at a time. So that's what you're doing: You're dealing with it one thing at a time.

Employing these strategies required a great deal of self-control on the part of parents. Parents spoke of "guarding" themselves, "not giving in to their fears," or not "allowing" themselves to experience what they were truly feeling. This self-control was in relation to themselves, but it also extended to guard others and particularly their child from what they as parents were experiencing:

> You are disciplined emotionally. You don't ever allow yourself to cry. You don't do it especially in their presence. I did that in the car. That's where I did all my crying, in the car, coming and going and running around.

Parents described how they "steeled" themselves in the face of their child's illness and the possible prognosis by "shoring" themselves, "straightening" their backs, not "giving in" to their fears, worries, and concerns, and by "keeping an even keel." "Keeping an even keel" was described as staying "level" and was achieved by not going to extremes emotionally or by not "letting yourself go" and becoming either depressed or hysterical. The parent who used this term achieved this state by not succumbing to any emotions, and he felt that his past experience with other traumatic events as well as the fact that he was male facilitated success at maintaining "an even keel."

These strategies were usually identified by parents as coping mechanisms. Using these strategies helped parents face the "stark reality" and put it in a place where they could "consciously handle it." These strategies also helped them to be supportive of their son and/or other family members.

"Monitoring the Symptoms"

During the *Sweeping along with the symptoms* stage, parents became acutely aware of their son's symptoms, began monitoring present symptoms, and remained vigilant for the [illegible]nce of additional symptoms or further deterioration. Parents described in great detail the symptoms experienced by their son, focusing on the extreme loss of weight, the ugliness of the Kaposi's sarcoma, and the severity of the pneumocystis pneumonia. Other parents spoke of the cruelty of the blindness and dementia experienced by their sons. Based on their observation, parents began to engage in certain behavioral strategies, of which *caregiving* and *being there* were primary. These more instrumental strategies helped parents overcome their helplessness and provided them with an opportunity to shift their focus and redirect their energies to an area other than their son's illness and his prognosis:

> If you just dwelled on [that] he's sick, he's going to die and that's all that's to it, you would go crazy. [Instead] you put your energy into making him that milkshake. You're doing something for him, to make life, what little there is left of it, the best that you can possible make it.

There are three actions inherent to "Monitoring the symptoms": accommodating behavior, compensating for deficiencies, and adjusting personal schedules and caregiving behavior.

Accommodating:

Parents tried to accommodate their son's behavior, but they were often frustrated in their attempts. This was made more difficult for parents when their son had dementia. Dementia was particularly difficult for parents as it was usually accompanied by changes in behavior, including confusion and abusive or noncompliant behavior. For example, one mother described in great detail how she tried to make the foods her son enjoyed so that he would eat; however, with each attempt, she was told by her son that the particular dish she had prepared tasted like "shit" and was not like the way she used to make it. Other times he would store the food in such a manner that it would be ruined, and this would also be blamed on the mother. Other parents, and particularly mothers, went to extreme lengths to ensure that their son would take some nourishment and spent a great deal of time preparing their son's favorite foods, exhausting every avenue to find something that he found palatable and could eat without discomfort. They spoke frequently of the foods they tried, and their successes and failures in trying to tempt their son to eat:

> He couldn't keep any food down and we tried this and that and the other thing. Just to try. Finally, he was eating this kind of fruit fudgical. That's the only thing he could eat at the last; I made sick soup, sick soup is pearl barley soup. . . . [But] he got tired of it; he could eat it, but it was just very boring, [and] he got tired of that very quickly. Oh I tried home cooking, cooked stuff and freeze it and [took] it over for him, and he'd eat a tiny little bit and that would be it.

Compensating:

Parents monitored their son's status very closely, remaining alert for changes in his level of functioning. As the son's condition began to deteriorate, parents often attempted to compensate for their child's deficiencies by identifying areas where assistance was required and trying to provide the appropriate intervention. Frequently, these measures were taken in the hopes of minimizing their son's frustration with his own deterioration and sparing him from the resultant feelings of despair:

> His was a gradual deterioration, every day I could see the changes. Sometim[illegible]ward the end it was daily. When he first moved home, it wasn't [illegible]able because he was still able get around and he still had some si[illegible] it wasn't too long after he came home that the sight really began t[illegible] mean we knew [to] put his coffee or his milk on the left hand side because he saw better with the left hand side, and this sort of thing. But o[illegible] health started really to go down, and he couldn't remember, he would [illegible] cross. He would start and would be searching for a word and then he'd come out with the word and it wasn't the right one and he would say, "No, not that!" He'd get so annoyed because he was so frustrated, and so [illegible] we'd be groping around for words and try and help him. Then finally somebody would click on to something and he'd say, "That's it!" He knew what he wanted to say, but he couldn't get it out.

Adjusting:

Based on their monitoring of their child's status, parents frequently adjusted their schedule in order to assist their child. Parents would often take turns doing this, and usually, other family members were also involved in spelling each other off. Arrangements were made so that someone would be with their son at various time during the day, which occurred more often during meal times.

> While he was in the apartment, we had to make sure that he ate. So somebody was there every day to make sure that he had something to eat for breakfast. It was usually [friend]. She'd stop on her way to the [place of employment] and see that he had his breakfast and made him his coffee. Then she'd go to work, and she'd go over there at noon lots of times and make sure that he was O.K. and that he had something for lunch. Then [husband] and I would go there for supper, you know one or the other. . . . He came home because it was so hard on us. We would send over the soup and food, but it got so that he really couldn't figure out how to make coffee, and if he found the stew, he didn't know what to do with it.

Based on their son's deteriorating status, parents involved in caregiving had to make adjustments in their caregiving behavior. Watching this gradual progressive deterioration was difficult for parents to witness, and making the appropriate adjustments was a constant painful reminder of their son's decline:

> He got [so that] he couldn't hardly walk. We were undressing him and putting him to bed. I had a touch lamp up there so that he wouldn't have to fiddle because he was blind. . . . but being as how he was blind, he probably didn't know whether the light was out or not. So I noticed first of all that there were a couple of nights that the light went out underneath the door and then the next time, I couldn't understand why it didn't go out. So I went in and he was sleeping and the light was on. After that we put the light out. But he [was] getting so that to climb the stair was getting so slow. He'd stop feeding himself. It got so that first of all when he first came here, as long as you told him where things were, he did the best he could to eat by himself. He'd eat by himself, but we'd actually put the food onto the fork. Then he had to use a spoon. Then it got so that we'd put the food on the spoon and he'd go to pick it up, and by the time he got up to here (points to midchest level), the spoon had (makes tipping gesture) and the food had gone down on the plate again. So then we started feeding him. I watched him die [tearful] every day, before my eyes, everyday something less that he was able to do.

Occasionally, adjustments had to be made in the physical environment. One set of parents had to construct a board barrier at the top of the stairs in order to prevent the son from falling down the stairs on the way to the bathroom.

Parent's involvement in caregiving increased dramatically during this time, and became an important strategy. Within this study, caregiving behavior fell on a continuum ranging from more frequent visits to the case of one couple who moved their son into their home and assumed total responsibility for caregiving. The extent to which parents were involved in caregiving and the nature of the care they provided was determined by proximity, resources, and the wishes of the child. Parents of sons who insisted on living in their own apartments and yet lived close to their sons would visit almost daily and assist with caregiving when necessary. It was at this point that one child moved back into the parent's home, or as in another case, the son moved into the same apartment complex as his parent. In the one situation where the son lived out of province, his parent would visit more frequently and for extended periods of time. Despite wishing to help their son as much as possible, some parents were unable to take their son into their home due to financial difficulties or a perceived lack of resources necessary to care for an ill individual. However, these parents compensated by visiting more often or by helping in other ways.

Several sons wished to remain independent and live in their own apartments. Parents of sons who insisted on remaining in their own apartment worried about their child and were sometimes hurt by the independence displayed by their son. Despite admiring their son's independence, it was difficult for these parents because they wanted to be more involved in caregiving. Parents wanted very much to help their children; however, they continued to be cognizant of not smothering their son and therefore respected their child's wishes for independence. Parents made a point of ensuring that they were allowing their child to live his own life and intervened only when he requested help. Maintaining this sense of normalcy in the face of their child's deteriorating status often caused a dilemma for some parents, for they were frequently concerned that their son's independence and activities were depleting what little strength he had left.

Parents who took their child into the home experienced difficulties. Often, the child was older, had lived on his own for a period of time, and had a past life and routines of which parents were unaware. Consequently, caregiving became a challenging trial by error activity. For example, something as simple as the placement of the bed or selection of music could be a problem. One parent described how in an effort to provide her son with some stimulation she had played a particular record for her son; however, unbeknownst to her, bad memories were associated with these particular tunes, and this upset her son. Even the placement of a framed picture on the wall could present a problem. A mother described how her blind son often had difficulty ambulating, and she was concerned that he would hit the wall and break the picture, which could result in him cutting himself.

Parents involved in caregiving were often pushed to their limits emotionally and physically. Not only was the stress and the horror of the disease exhausting, but in addition, their son's condition often required special care, and on occasion, around the clock monitoring. One son had become blind and had dementia while being cared for by his parents. This resulted in great stress for it was necessary for these parents to monitor their son's activities at all times and be readily available if he required assistance. In addition to monitoring this son during activities such as smoking and while ambulating, these parents were responsible for dispensing medications and for assisting their son with dressing and feeding.

Compounding the situation was the fact that many of the parents in this study were also employed outside the home or had other commitments. To alleviate their stress, parents continued to engage in *selective focusing*. Parents who were involved with support groups continued their participation in these groups. Others obtained support from friends and other family members. While another parent found keeping a journal cathartic.

In addition to participating in caregiving, *Being there* was another important strategy. *Being there* included spending time with their son, providing support with their presence, and participating in activities which were pleasurable for their son. Care was taken to ensure that these activities did not tire the son. This time together was perceived as more precious at time went on:

> You do things we hadn't done before, [like] go for walks when he had a good day and go to the theater. Or just stay home and watch T.V. if he wasn't well. You sort of fit in things around what he wanted to do or what he was up to doing.

Being there was a very important form of support and was especially important for fathers as frequently this was the only way in which they could participate in their son's care. In this study, the majority of mothers assumed the more traditional forms of caregiving such as preparing meals and providing physical care. Consequently, most fathers were left with few ways in which they could demonstrate their desire to help and be close to their son. Both fathers and mothers would also support their son by accompanying them to group meetings or doctor's appointments. Doing these types of things was helpful to parents and alleviated their sense of helplessness to some extent:

> He knows he can phone and I'll take him where-ever he needs to go. I like to come on his doctor's appointments with him, just to sit and wait. I guess it helps me more than him.

When the symptoms characterizing AIDS became so severe that death appeared to be inevitable, parent entered the stage entitled *Beating down the denial.*

Beating Down the Denial

As the disease progressed, symptoms increased in severity and were accompanied by a general decline in the son's condition. During the *Beating down the denial* stage, parents were bombarded by numerous triggers which forced them to acknowledge the terminal nature of their son's illness. Parents slowly began to acknowledge that the disease was "winning" and their son was "losing." The fact that their son would die became an unavoidable reality. However, acknowledging their son's impending death took time and proceeded from an initial resistance to an acknowledgement that death would occur to the hope that death would occur and free their son from his suffering.

In order to deal with these changing perceptions and maintain their reality at a tolerable level, parents engaged in a variety of strategies. *Selective focusing, undoing, reframing,* active involvement in *caregiving,* and *being there* continued to be important strategies during this stage. However, in response to their awareness that their son would die, parents included into their repertoire of strategies *creating meaning* and various behavioral strategies which were designed to prepare for the future. Despite maintaining a *brave front* before their son, parents slowly began to relinquished their *fighting it* stance and focused instead on ensuring that their son's remaining time on earth would be meaningful, peaceful, and filled with love and support. The nature of parents' hope also changed as they gradually abandoned their hope that a cure would be found in time to make a difference in their son's case. *Beating down the denial* includes the components of "Lagging behind" and "Preparing for the future" (see Figure 9).

BEATING DOWN THE DENIAL

Lagging Behind
Preparing for the Future

Figure 9. The Beating Down the Denial Stage

"Lagging behind"

Parents reported reaching a point where they were aware that their son's death was inevitable. Frequently, this was triggered by the severity of symptoms experienced by their son. Parents described how symptoms became severe, unrelenting, and at times appeared to overcome their son. The nature of this deterioration, the fact that medical intervention was ineffective, combined with the absence of any break in the disease's course reinforced the fact that recovery was not a possibility:

> Towards the last three or four months as he got weaker and weaker and the Kaposi's was starting to get very pronounced, I stopped and thought about how it works. It was just taking over more and more of his body. You've got this multiplication system going on all the time, and so I thought you know, he is not going to get out of it, he's not.

It was usually at this point that parents realized that everything that could be done medically to help their son had been done and further attempts would be futile.

Meeting with the physician in order to discuss what could be expected in the latter stages of the disease also forced parents to acknowledge that death would be the final outcome. In this study, these meetings were initiated either by the doctor or upon the request of the son.

Parents dreaded these meetings; however, they felt that knowing what to expect was useful. Occasionally, comments made by other health care professionals made parents aware that death was likely:

> I: It was only when he moved home and we were providing the care for him that it dawned on me you know he isn't going to make it. Then the nurse from the city referred to it as palliative care and I knew what that was, so in other words knew we were providing care for him prior to death.
>
> R: Is that what you meant by it sinking in, or was there a point before where it sunk in?
>
> I: It sunk in pretty good. It sunk in that he wasn't going to get better. That sunk in.

Their son's behavior also acted as a trigger for parents. In two instances, sons had decided to terminate their medical treatments. This proved to be difficult for parents as they were concerned that termination of treatment would accelerate their child's death. Consequently, parents would resist their son's decision. This resistance was demonstrated by one parent who had assumed responsibility for dispensing medication to her son. When her son refused to take his medication, she informed him that he had no choice but to take these medications. Only following a frantic consultation with a health care worker was she forced to acknowledge that this was a legitimate option and her son's right. Other parents described how their son and friends who were also HIV positive would make jokes concerning their future by suggesting that they draw "lots" to see who would die next. Parents found this type of humor "morbid" and upsetting.

Another trigger was preparation on the part of the son for his own memorial. Several of the sons in this study were actively preparing for their own memorials and would encourage other family members to participate in these preparations:

> It was about the time that he started preparing for his funeral [that] I felt that I had to get into tune with him and go along with him. He pushed us, he really pushed us. He wanted us to know what he was thinking, and he was constantly pushing us to think this way.

Despite acknowledging the importance of preparing in this manner, parents found doing so difficult and painful. One mother described how she was "hit hard" when her son identified a song he wished to have played at his funeral.

Several parents spoke of initially ignoring their son's preparation because they did not want to hear about him dying. However, the presence of the various triggers prevented this from occurring for any length of time. Parents of sons who were preparing for their own death spoke of working hard to remain supportive of their son by supporting his decisions and preparations. However, doing this did not come easily, and it required a deliberate effort on the part of parents to keep in pace with their son:

> I think first of all you're lagging behind, at least with me I felt that I was lagging behind. . . . [son] had come to the conclusion that he was going to die. O.K. so now he's preparing the family. So what is happening is that everybody is lagging behind in that belief. He's already talking about his funeral, and you don't want to discuss any such thing. So you kind of accept these things, you work away and you grind away and it's kind of a sanding process. You work at it, and finally you accept the fact that he's preparing for his funeral. And you say O.K., that's what he wants to do, that's what we will do. We will prepare for his funeral because he is facing his future. O.K., if he's gonna face his future, then we better get with him and face the future with him so that he is not alone facing it.

However, achieving this "acceptance" and participating in these activities did not mean that parents had reached a sense of completion:

> It's going to be pretty terrible when the time does come, and we'll probably still be accepting after. I guess it's kind of a different, like right now we're accepting that it's going to happen, and after we'll have to accept that it has.

Not all of the sons in the study reached the point where they were actively preparing for their funeral or memorial. Occasionally, the presence of dementia prevented them from doing so. In another situation, it was the parent's perception that her son was in denial and was incapable of planning for what she felt was the inevitable future. This parent felt that her son's denial was demonstrated by his returning to previous IVDU behavior. This was difficult for the parent because despite knowing that a cure would not be found in time she felt that something may turn up to "buy him time" and that if he was less abusive to his body this could extend his limited life expectancy. His noncompliance angered the parent who felt that not only was he short changing himself by his behavior, but he was also robbing his family of quality time. In situations where the child was incapable of preparing for his funeral, it was usually the parent or sibling who attempted to take steps to prepare the family and even the son.

When parents acknowledged that their sons would die, they ceased looking for miracle cures and directed their energy to ensuring that the time he had left was comfortable and filled with love and support. One parent described how the nature of her relationship with her son changed when she acknowledged that death would be the probable outcome of his illness. Making this change was designed to meet the son's needs during his final days:

> [It] was probably four or five months before he passed away, and I had come to the conclusion that this was so ongoing, so relentless, so terminal, that then the better thing to do instead of nagging him to try this and try that [was] to be with him, to be a companion, a mother, a friend, a whatever he needed.

Parents continued to employ *undoing* and *selective focusing* in order to deal with the deterioration and pain experienced by their son. However, as parents acknowledged that death would occur, *creating meaning* became an important strategy. *Creating meaning* as a strategy involved injecting special meaning into their child's experience, his suffering, and his purpose on earth. Doing this allowed parents to view their son's impending death with greater ease and reinforced that what was occurring was not in vain or was part of God's bigger plan:

> In a lot of ways in this last two years, he's had some of his most rewarding times. So I think our lives are planned out for us, and he was meant to do this.

> Sometimes I feel like this was maybe what my son's role in life was supposed to be. A way of helping others, and I guess if you look at it that way, it softens the blow.

During the *Beating down the denial* stage, hope still existed; however, some parents now referred to their hope as a "realistic" type of hope. A "realistic" type of hope was the hope that something would be discovered which would "buy some time" for their son. Many parents stated that hope was the last thing to go and that the hope was always there to some degree. As one parent indicated, "You're always hoping something is going to happen." This sentiment was reported more frequently by mothers in the study; however, the hope that their son would live for an extended period of time or be cured was no longer present. Also, there was often the hope that their son's suffering would not be too severe.

One parent stated she had hoped till the end that a miracle would happen. This parent's situation was slightly different from the other parents in the study. Her son lived in another province, and despite maintaining a very close and supportive relationship with her son, she had been unaware that he had experienced a severe exacerbation. Consequently, she was not present during the last stage of the illness or at his death. However, in a subsequent interview, she described experiencing the premonition when bidding her son goodbye at an earlier time that she would never see him alive again.

"Preparing for the future"

Parents began to prepare for the future when they realized that even if a cure was found it would be too late for their child. However, despite taking part in these preparations, the unnatural nature of a child dying before the parent was not lost to these parents. One parent commented how they should be preparing for her funeral and not for such a "young guy." Parents prepared for the future by assisting with memorial preparations, purchasing burial plots, settling estates, and rallying around their son. Preparing for the future facilitated preparation for the possible loss:

> I: There's things that we do I think to make ourselves realise that yes it really is happening.
>
> R: Like what?
>
> I: Well, like buying a burial plot, things like that, and making his quilt. It's kind of making yourself realise that there's going to be a loss.

It comforted this parent to select a plot that was beautiful, had trees, and was a place where they could go to remember. This particular family also made a loving quilt to show their son how much they cared. Religion and faith in God helped many parents through this time as many thought that God provided both strength and time to realize and prepare for the future.

Other parents prepared by settling unfinished business. If rifts existed in their son's relationships with other family members, parents worked to ensure that these were resolved. For example, one parent attempted to reunite the family and make them closer. Her reason for doing so was to provide her other children with the opportunity to come to know their brother as he now was, a gentler individual, before it was too late. Another motive was to spare them from having to experience guilt when their brother died. Another parent encouraged her spouse to spend more time with the son and would remain in the background so that father and son could have this time together:

> I didn't stay [overnight] because I just thought it would be better for me that I didn't. I had been with [son] quite a bit and he told me a lot of things. He may not of been as close to his father at times, so I thought this was a chance for them to be together.

In addition to reuniting individual family members, parents and families organized family gatherings or reunions. Care was taken to ensure that these reunions were as special and memorable as possible.

During this time, the severity of the son's symptoms often necessitated hospitalization. If he was hospitalized, parents visited frequently, and as his condition worsened, parents and other family members would maintain 24 hour vigils. If he lived in his own home, parents and family maintained vigils in this setting. These vigils were well organized and arranged in a fashion so that someone was with the son around the clock:

> We went around the clock for days and days and days. Somebody was always there. He was never ever left alone. See, we all took turns.

Even parents who lived out of town would often commute a great distance so that they could be near their son:

> [We'd] try to be there for him when he was in the hospital. We would go up and see him everyday if we could, even went into [large city] from here and stayed in pretty near a month at a time to be with him. We'd go in and sit some days for a day on end.

Another level of acknowledgement usually occurred when the symptoms became so severe that the son was totally debilitated. It was a this point that parents perceived that no quality of life remained. Triggers for this level of acknowledgement usually occurred when there was a general failure of every bodily system, and as one mother described, her son became a "large sightless infant." When the symptoms became so severe that the child was totally incapacitated, then and only then did all hope for a cure or a miracle cease. Now parents gave up the fight completely and hoped for an end to the suffering and prayed that the Lord would take their child "home":

> Well, as he got more incapacitated, you gradually assume that it's just a matter of time. I know there was with us, or with me. You hope that it

> won't be too long. There's no return, it's going to be final. It's not disrespect or anything, it's more that you hate to see them suffer, and it's not going to accomplish anything, if he was going to get better, yes, that [would be] a different story.
>
> After we started looking after him at home, I knew there was no happy ending, and that it's tearing everybody apart. He was suffering so you hope for an end to it, and it's a legitimate hope.

This determination of "quality of life" was important. It was the parent's evaluation or perception of quality of life based on their son's status which determined when their hope changed from "buying time" to hoping for an end to the suffering. The concept of "quality of life" was identified by several parents in various fashions. For example, some parents spoke directly of a loss of the quality of life; whereas, others spoke of the fact that their child had "nothing more to live for." For some parents, deciding that quality of life was no longer present occurred earlier than for others, with mothers lagging behind fathers in reaching this point.

Parents who were aware of how sick their child was usually made arrangements with hospital staff, other family members, or the partner to ensure that they would be made aware if their child's condition deteriorated so that they could be there to provide support and show their love. Parental and family support continued to the end, with five of the seven parents of sons who had died in this study being present at their child's bedside when he died. Following the death of their son, parents entered the *Learning to live with it* stage.

Learning to Live with It

The label *Learning to live with it* describes the parents' life following their son's death. Even though variation existed in the length of time sons had been deceased, parents agreed that what they had experienced would always be part of their life:

> You might accept it, there's nothing you can do and then you have to live with it. You're living with it without being able to accept it, but when you do accept it, you still have to live with it.

The time following their son's death was characterized by grief. For several parents, their feelings of sadness and grief persisted. During the interviews, several parents of sons who had been deceased for a number of years wept while relating their story.

Even though most parents had anticipated that their son would die, they now had to deal with the fact that what they had anticipated had actually occurred. In order to carry on with their lives, parents had to come to terms with their grief and resolve the past. This was achieved by *creating meaning*, engaging in *positive self-talk, selectively focusing*, *reframing*, and *giving back*. During this stage, the nature of parents' hope changed once again, with most parents expressing the hope that they could prevent someone else from going through the same experience.

Learning to live with it is comprised of the component, "Going the full circle."

"Going the full circle"

Parents of sons who were deceased identified a need to review the past and come to grips with what had transpired. Doing so meant going from "one extreme to another, [until] finally you figure it out." Resolving second guessing, trying to make sense of what had occurred, resolving multiple losses, and dealing with memories were part of this process. Time also influenced parents' progress. For example, one parent who had recently lost her son stated she felt that she would "never get over it," while parents whose son had died a number of years ago stated that they were able to put their experience on the "backburner." Being on the "backburner" meant that the experience with their son no longer dominated their mind as totally as it had during the time immediately following his death. The researcher also noted the progression of this with one parent whose son had died approximately 17 months from the time of the interview. When initially interviewed this mother felt that she was not yet ready to work on the quilt she and the rest of the family were making in memory of their son: however, approximately one month later during the second interview, she spoke enthusiastically about the quilt, had determined a target date for its completion, and described in detail what would be placed on the quilt and the theme around which the quilt was being developed.

Resolving second guessing:

Following their son's death, parents continued to second guess their own actions. They reviewed past events and questioned how they may have contributed to the final outcome. For example, one parent blamed herself for not realizing how ill her son was and for not being at his side when he died. While another mother chastised herself for forgetting to sit her son up when he was ill, feeling that she may have possibly preventing pneumonia if she had done so. This mother still questioned why God had not answered her prayers for healing of her son and indicated that perhaps she was to blame because she had experienced a spiritual block at the time of her son's illness.

Making Sense:

Parents also had to make sense of various issues which had occurred throughout their son's illness. One parent continued to be perplexed as to why her son, who had the advantage of good living conditions and was so strong and healthy, would be struck with the disease and deteriorate so rapidly when others, without benefit of these conditions, did not. This parent expressed anger at the injustice of the entire situation and could not understand why her son had died from AIDS when he was such a good and talented individual. She spoke at length of the many gifted young men who were being struck down by the disease. Other parents reported trying to make sense of why their son had deteriorated so rapidly while other individuals who were HIV+ were not yet exhibiting physical symptoms.

Resolving losses:

Parents also had to come to terms with the loss [illegible]ld. A child dying before a parent was perceived as being unnatural and out of order:

> It's very hard to lose a child. All parents figure they're going to go before their kids. It's natural that parents go first. It's very hard to cope with the death of a child.
>
> It is the most devastating thing in the world. . . .I'll never get over that. He was my only child, and when you lose your parents, you lose your past, but when you lose a child, you lose your future.

Parents often perceived that they were experiencing multiple losses. Not only did these parents lose a son, but frequently, they had lost a close and cherished companion. These more obvious losses were often accompanied by other less obvious losses such as the loss of a special talent, the loss of the great intelligence in the case of dementia, and the loss of personal control on the part of the child.

Parents described in great detail special mannerisms of their sons along with activities they had participated in with their son. Many parents spoke of how their life would never be the same and that there would always be a void where their son had been:

> It's just you miss them. I phoned every Sunday morning at eleven o'clock and it was like clock work for him. Eleven o'clock his time, so nine o'clock our time. . . . I'd phone him every Sunday, and all week I'd save up different things, and then I'd say, "What do you think of this and what's gonna happen?" . . . For awhile after he died I kept still doing that. I'd think, [I] have to remember to talk to [son] about this. I still find myself putting these things in little pockets to talk to him about. It's funny how you do that. . . . I'd get [to] Sunday morning, and then there was always a hole there.

Dealing with memories:

Parents who had witnessed the deterioration of their son found these memories to be very painful. Memories took the form of visions that remained before their eyes:

> I can still see him on his hands and knees behind the door. I had to push the door to get it open, and he was behind it. Here he was on his hands and

> knees groping around and saying, "I've got to go to the bathroom and I can't see!" [tearful] We got him up on his feet, and that is a vision I will never forget as long as I live . . . . Here's this great big man totally blind, and babbling and wanting to go to the bathroom, and I had to push the door open because he was behind it on the floor on his hands and knees. I still see that, regularly. . . .That is a vision I will never forget! Never! Very, very traumatic!

Parents employed a number of strategies in order to resolve second guessing, make sense of the situation, and deal with the memories and losses associated with their son's death. *Selective focusing* continued to be employed by several parents. For example, one parent found concentrating on "one day at a time" helpful. She also indicated that occasionally she simply tried to put the experience out of her mind because thinking about her son was too upsetting. Another parent described how she engaged in *selective focusing* by "letting it in little by little" after her son's death in an attempt to avoid being overwhelmed by what had occurred:

> Even when he passed away, I knew I had this feeling if I really let myself feel the way I really feel, if I let myself out of control, that my heart would break.

Others *reframed* the situation by focusing on the positives. One parent spoke of the many things that had been positive about the experience, being particularly grateful for the good times he had with his son before he died. He indicated that this was what prevented him from being bitter, and he felt he was a fortunate man for having had this quality time with his son. Parents frequently spoke of experiencing relief that it was all over. This relief stemmed from the parents' belief that their child's suffering was now over.

Parents needed to "set it right" in their own minds. Their nagging doubts were often eased when they were able to engage in *positive self-talk* by telling themselves that they had done all that was humanly possible and by focusing on the fact that there was nothing more that they could have done. The ability to do so was critical in order for parents to be able to come to terms with what had happened and to counter feelings of responsibility or guilt:

> I can't be bitter about any of that stuff. It does bother me, and it did bother me for a good period of time after he passed away. But you slowly have to come back to grips with yourself and say, "Well, it's too late." There's nothing virtually that I could have done. That's the hard thing to take because if there was something that we could have done and we didn't do [then] I'd [feel] bad, but we did [everything] possible. But there is no cure for anything like that, and you're up against a wall.

One parent described in detail the process he had undergone in an attempt to come to terms with what had happened. He described how he had initially been overwhelmed by his feelings of helplessness and anger and had moved from one extreme to the another. However, presently he was at a point where he was able to look back over what had transpired with a feeling of comfort and without passing blame. This was described as "coming to grips with it." Another father spoke of "gaining control of it." "Gaining control" was similar to "coming to grips with it" and was accompanied by the need to accept what had happened and move on. Fathers more frequently than mothers spoke of "gaining control of it" and the need to "straighten out," "not dwell on it," "move on," "take it in stride," and "carry on":

> It's done, and it's over with. The living have got to go on living. . . . . You can remember, but you can't mourn them forever. You have to realize that there's a life to be lived, your life. Got to go on, cause if you don't, you'll wind up a total wreck.

One father whose child had died echoed this belief and felt that activities such as sewing a memorial quilt may result in certain family members "hanging on" to the past:

> In some ways I wish there wasn't such a thing, it is a way of honoring. . . . It also has it's downside in that people dwell too much on making this thing. It's a downer for them, and some families get right at it, get it finished, and get it out of the way. Some families it hangs on, and then the people that were interested to start it's kind of forgotten, it's over with. And you don't get the help. In some ways I don't agree with the quilt, and this is the reason. The sooner you can put these things behind you, the better off you are; it's hard when it's hanging on.

"Hanging on too long" was defined as the tendency to keep certain mementos and memories for what was perceived by the other parent as a prolonged period of time.

Even though some fathers indicated that they felt their spouses were "hanging on too long," there generally was a tolerance of this, and they were allowed time to work it out at their own pace. Mothers tended to take longer than fathers to "let it go."

However, even in situations where the father maintained a brave front, mothers felt that the fathers were suffering just as much but were reluctant or unable to display their true feelings. This was supported by one father who described that maintaining a brave front and assuming a supportive role without benefit of support for himself may have fooled others but had resulted in him neglecting his own needs:

> They say I handled it better than they expected. But I was under the gun. [tears] . . . .But after he died, or even before he died, I had to calm her down. Having problems with her, trying to keep her on the even keel, staying on it myself. This is part of the problem you run into. Maybe the person you think is doing well isn't doing so good. . . . I have no real close friends. There's one that I worked with and a friend in the neighborhood. He has helped some. But that's where I messed up.

In addition to engaging in strategies such as *reframing*, using *positive self-talk*, and *selective focusing*, parents also relied on *undoing* and *creating meaning*. *Undoing* continued to be a powerful strategy for some parents, and parents looked forward to the time when they would be reunited with their child:

> I believe that with all my heart [the undoing will occur] . . . .If I didn't believe that completely, I would go batty. I feel that he can see, he is whole. . . . And we'll meet again, and he'll probably say, "What took you so long?" [laugh] Or if it's reasonably fast, he'll say, "My goodness, didn't expect to see you so soon!".

Other parents related stories which they felt had some meaning. For example, two parents told the story of a bird which had walked up onto their son one day when he was sitting outside the hospital. Apparently the bird hopped onto his shoulder and remained there even when he returned to his room. These parents were unable to identify what this incident meant, but they maintained that this event was significant and meaningful. Another parent described a meaningful occurrence which took place when the family had gone to scatter the ashes of their son. At the time, they had no intention of arriving at their destination on that particular day, but somehow, they were caught up in traffic and consequently ended up at the site earlier than they had anticipated, almost against their will. The weather at the time was rainy and stormy; however, as they approached the place where they had planned to scatter the ashes, the sun suddenly began to shine, and it continued to shine for the time period that they were scattering the ashes. Immediately following completion of the scattering, it became stormy again.

Other parents spoke of experiencing premonitions which they felt were meaningful. One parent spoke of telling other members in her church group that she wanted to minister to people with AIDS, this having occurred one month before she learned that her child had AIDS. While another mother spoke of experiencing an overwhelming sense of sadness while passing a certain point in the mountains. Later, her son told her that it was at this spot where he wished to have his ashes scattered when he died. Several parents spoke of feeling their son's presence. Two parents referred to the fact that their sons were probably watching the interviews, while another parent spoke of how her son was guiding the growth of a particularly beautiful hibiscus plant in her home.

During the interviews, sons were often idealized, and parents focused on the positive aspects of their son, commenting on his accomplishments, his virtues as an individual, his special talents, and how he had contributed to society. A sibling confirmed this finding by describing how her parents spoke frequently of their son for a lengthy period of time following his death. All parents in the study made a point of showing the researcher memorabilia associated with their son. They all appeared to try and acquaint the researcher with their son. There was a sense of pride about their sons. Pictures, trophies, high school assignments, cards he may have sent to parents in the past, drawings, and narratives written about their son were shared with the researcher.

The intensity of what they experienced in the time period before their son's death resulted in parents following a number of paths. One of the two paths which most of the parents chose included withdrawing and working on the self. The other more widely chosen path was to *give back*. Parents hoped to prevent another parent or child from experiencing the pain and trauma they and their child had experienced:

> You know when you see your son go from this guy that's 160 pounds and just six foot something, with full of muscles, down to 90 pounds and all purple. You know how Kaposi is, it's so ugly and so deforming. Oh, when you see all that, if you can stop even one child or one person from having to suffer that, maybe it's accomplished something.

For some parents, this began earlier; however for most parents, active involvement occurred at some time following their son's death. Many of the parents, along with other family members, became advocates of persons with AIDS and their families. Others became involved with AIDS organizations, engaging in activities such as sharing their experience in videos for the public, speaking at high-schools, and appearing in panel discussion for other parents in a similar situation. Additional ways of *giving back* included sending literature that had helped them to other parents or by functioning as a sounding board for a parent of a child with AIDS. One parent who was less publically involved stated that she had become a preacher to her nieces and nephews. While another couple whose son had died from AIDS showed their support by attending a funeral of another young man whom they were not acquainted with but who they learned had also died from AIDS.

Several parents of sons who had died from AIDS felt that they had come to terms with what had happened and were now able to resume their usual activities without their son's death being foremost in their mind. A number of factors appeared to facilitate achieving this state. Parents who were able to tell themselves that they had spent time with their son, had been supportive, and had done everything they possibly could to help him were able to achieve some inner peace. The presence of a supportive spouse, the ability to speak openly with family members, and family cohesiveness also eased the burden. Support from support groups, close friends, their church, and colleagues in the work place was also helpful. Parents of sons who had not developed dementia and maintained control of their bowels and bladder felt that this also decreased the burden.

Parents of adults with symptoms related to HIV infection described their experiences as being a "hell". Witnessing the ravages of the disease shook the parents to their core. The horror was inescapable. Their suffering was expressed as a sense of disbelief, helplessness, uncertainty, and fear in the face of the cruelty of the disease:

> It's a heartbreaking experience, I tell you, heartbreaking. There is nothing worse than to lose a child, but to lose a child to AIDS is really awful.

However, despite the intensity of their experience, the basic social psychological process *Keeping reality at a tolerable level* enabled parents to cope with their feelings and to continue functioning. By employing strategies which were either cognitive, behavioral, or a combination of the two, the parents worked hard to cope with the changing demands and stresses arising from each of the six stages. A common theme throughout the process was the presence of hope. While the nature of the parents' hope changed, the need for parents to have this hope and not to have it taken away was emphasized by one mother whose son had died. She described listening to a program where the announcers were discussing AIDS and the family, the message she received from this program was that in the case of AIDS there was no hope because the inevitable was death. She became very angry and phoned the announcers, something she had never done in the past and expressed her anger at these individuals for taking away hope something which she felt was all that parents had in this situation.

V DISCUSSION

The following discussion addresses the suitability of the grounded theory approach in studying this area and will provide a critique of the data collection method and research process. Also, findings will be examined in light of existing relevant empirical and nonempirical literature, and the implications of the findings will be identified.

Discussion of Research Approach

Grounded Theory

Little is known concerning the experience of parents of adults with symptoms related to HIV infection from the emic perspective. Therefore, the grounded theory method was found to be the most appropriate research approach for studying this phenomenon. The grounded theory approach ensured that relevant concepts emerged from the data. This was facilitated by the use of unstructured interviews and by basing subsequent interview questions on previous interviews. The use of this research approach, combined with the researcher focusing specifically on parents, contributed to a greater understanding of their experience.

The assumptions upon which grounded theory are based also contributed to the suitability of this approach. Of particular relevance was the assumption concerning individuals' ability to create order and make sense of their environment and the impact of this on meaning. The existence of the attitudes of others and society in general were important factors to consider in this study. Parents' changing perceptions were influenced by cues in their environment and their interactions with others and were key in determining how they kept their reality at a tolerable level.

The goal of this study was to elicit meaning in a given situation, to develop reality based theory which demonstrated the experience of parents in a particular situation at a particular point in time and to do so in a manner that is relevant and meaningful to these parents. The

BSP *Keeping reality at a tolerable level* may have theoretical generalizability to other similar phenomenon. Furthermore, by shedding light on what parents of adults with symptoms related to HIV infection experience and identifying relevant concepts future studies can be conducted to contribute and extend findings.

Reflections on the Research Process

Despite anticipating that there would be difficulty in obtaining participants for this study, the investigator was not prepared for the level of resistance encountered while attempting to recruit informants. Interestingly, several men infected with HIV and agencies who were directly involved with individuals who were HIV + were most supportive of this type of research. This may be due to their more reality based assessment of issues and concerns facing infected individuals and their families. Much of this resistance appeared to be rooted in several assumptions which were initially shared by the researcher.

One primary assumption was the belief that parents may become psychologically traumatized by discussing their experiences with their child. Contrary to this, parents stated that they found these discussions therapeutic. Several parents commented on how "good" it was to talk about their son, how these interviews were "cleansing," and that they appreciated that someone was interested in their experience. Conducting individualized interviews also provided spouses with an opportunity to disclose thoughts and feelings they may not have been previously disclosed to other family members.

Another assumption was based on the perception that the stigma experienced by parents due to the disease had a major impact on their experience and would be demonstrated by a reluctance to participate in the study. Certainly, stigma played an important role; however, with this particular group of parents, stigma assumed a secondary position to the impact of losing a child and their desire to help others in a similar situation. This may reflect the changing attitudes of society or the characteristics of the informants who volunteered to participate in the study.

An important component of the interview process was the apparent need on the part of parents to acquaint the investigator with their son. In addition to sharing stories which described their son, parents shared memorabilia associated with their son. Parents frequently interrupted their stories in order to show the investigator a trophy or a narrative written about their son. Frequently, this signalled the end of an interview, for parents became increasingly restless and would indicate by their movements that they wished to show the investigator certain items.

Conducting interviews on the topic of this nature was difficult. Interviews were highly emotional, and parents frequently became tearful while telling their story. Initially, the investigator had to overcome her fear that parents would "fall apart." This was resolved by spending time with informants following an interview discussing other things and remaining with parents until they were laughing and smiling once again. Furthermore, becoming "acquainted" with the sons through the parent's stories and sharing of memories frequently resulted in the investigator experiencing a sense of loss as well. These feelings were resolved by "taking time out" and documenting feelings in a journal.

Data Collection

Even though parents were provided with the choice of telephone or face-to-face interviews, most parents expressed a preference for face-to-face interviews. Several parents indicated that they found it difficult to communicate by telephone and that it was hard to "get things across" over the phone. Telephone interviews were employed for some interviews. However, in contrast to other studies, the data obtained during face-to-face interviews was richer than that obtained through telephone interviews. Parents may have preferred face-to-face interviews because it provided them with an opportunity to show the researcher items associated with their son, something which figured prominently during the interviews.

Comparing the Son's Disease Course with the Parents' Experience

The stages parents undergo occurred in relation to their perception and evaluation of events experienced by their sc [illegible] efore, transition from one stage to the next did not necessarily coincide with medical landmarks, instead they were signalled by parents' perceptions which typically resulted in a shift in cognitions (see Figure 10). For example, while the son may have been aware of his own positive status, and his parents may have suspected that he was gay and HIV+, their suspicions were not confirmed until the *Taking it in* stage. Their transition to the *Going Along with a Changed Reality* stage occurred following their personal acknowledgement of the seriousness of their son's condition and the implications of being HIV+. Reaching this awareness took time and did not necessarily coincide with their learning of their son's diagnosis. Movement from the *Going Along with a Changed Reality* stage to the *Sweeping Along with the Symptoms* stage occurred when their sons' symptoms became erratic, unpredictable and his condition gradually deteriorated. Passage to the *Beating Down the Denial* stage did not occur when the medical team indicated that the son's prognosis was certain death. Instead, this stage occurred when parents in an individualized manner reached the point, where based on their perceptions, they acknowledged that their son's condition was irreversible and death was a certainty. This acknowledgement and their son's death signalled the onset of the *Learning to Live with it* stage.

Critique of Findings

The following discussion will focus on the basic social process, *Keeping reality at a tolerable level*, experienced by parents in this investigation and the following critical points identified in their experience: The initial responses and first level of acknowledgement occurring during the *Taking it in* stage; the emotional turmoil experienced during the *Sweeping along with the symptoms* stage; and the final changes in acknowledgement taking place during the *Beating down the denial* stage. Since much of the literature has

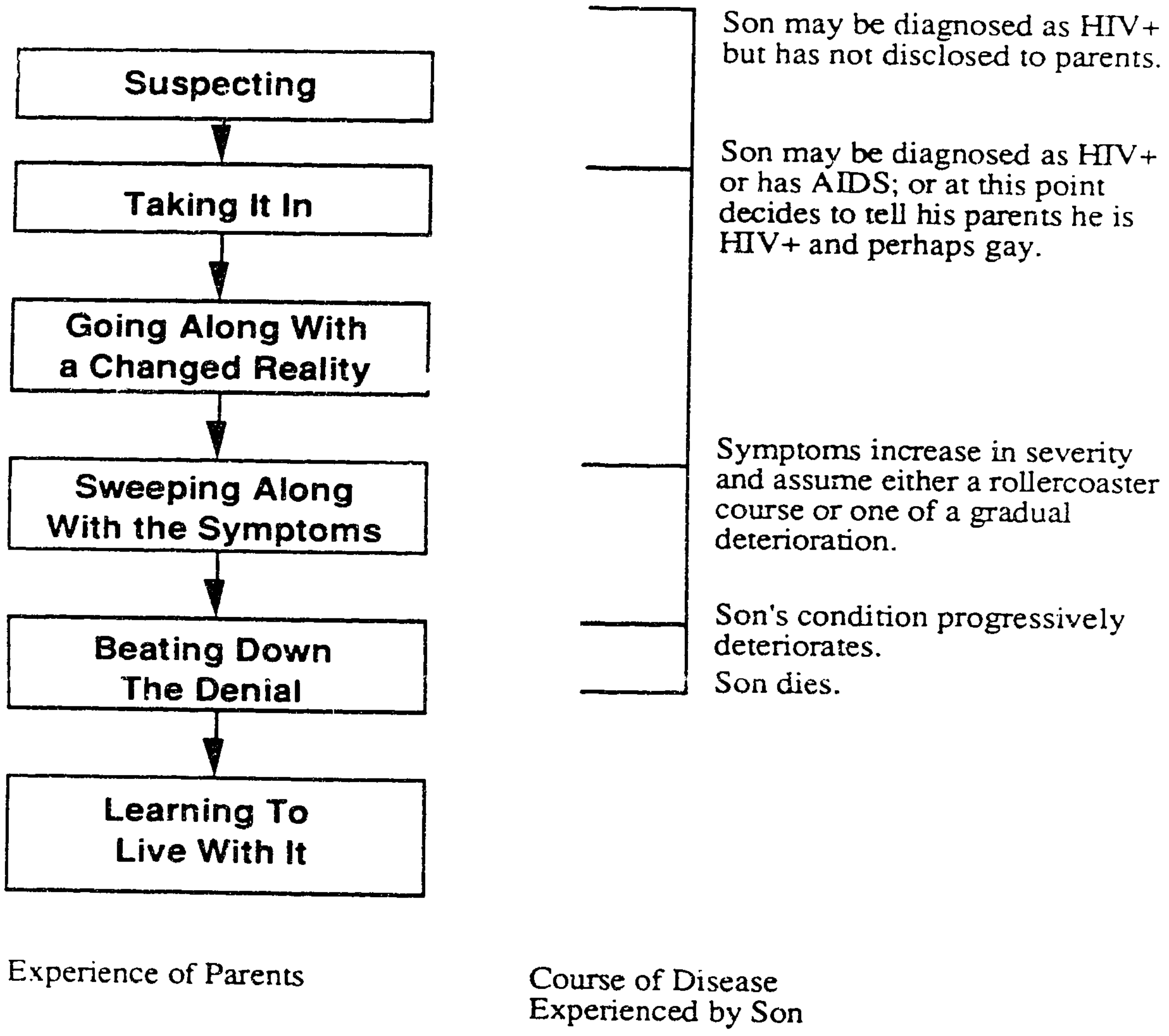

Figure 10. Comparison of Course of Disease as Experienced by the Son with the Parents' Experience

labelled the experiences of parents of terminally ill children as processes of anticipatory mourning, the findings from this study will also be examined in relation to this concept.

Keeping Reality at a Tolerable Level

Parents of adults with symptoms related to HIV infection reported that their experience was one filled with horror, fear, and uncertainty. In order to keep their experience at a tolerable level, parents employed various strategies which they identified as "coping" strategies. These strategies allowed parents to continue to function, frequently in a supportive role, and were part of the BSP, *Keeping Reality at a Tolerable level. Keeping reality at a tolerable level* is comprised of the following components: the initial threat prompted by a trigger; determining how the situation would be viewed and approached; employing strategies; appraising their situation in order to determine whether they had reached the "comfort zone"; and identifying alternative strategies if the "comfort zone" was not achieved.

The trigger and formulation of strategies

Keeping reality at a tolerable level began when parents were threatened by a trigger. Triggers could take the form of an event or an observation. In response, parents determined how they would view the situation, what they could do in response to the trigger, how they would manage, and how they could best help their child. These cognitive activities were influenced by a number of factors, including personal attitude and problem-solving approach on the part of the parent, personal attitude and problem-solving approach on the part of the child, whether congruence existed between parent and child in relation to personal attitude and problem-solving approach, level of knowledge about AIDS and homosexuality or bisexuality, if applicable, presence of other stresses, the severity of symptoms and stage of the disease, the presence of support, and the type of support available. As triggers and the influencing variables changed in nature throughout the course of their son's illness, the way parents viewed the situation and their method of approaching the situation also changed.

The important role of the parent's cognitive or affective evaluation, that is, interpretation of their child's condition, has been identified by other researchers (Hymovich, 1984; Wells, Heiney, Swygert, Troficanto, Stokes, and Ettinger, 1990) and was found to play an important role in determining how parents of terminally ill children cope (Chesler & Barabarin, 1987). According to Folkman and Lazarus (1980), a transactional relationship exists between the person and the environment, which is mediated by two processes, appraisal and coping. Lazarus (1966) identifies that when a threat occurs a primary appraisal is made, during which time it is determined what is at stake and what coping resources and options are available. This cognitive appraisal and an evaluation of the situation are based on the individual's knowledge and beliefs. Similarly, Moos and Tsu (1977) propose that when confronted by the crisis of a physical illness a cognitive appraisal, based on background and personal makeup, characteristics of the illness, and physical and social environmental factors, is made. Moreover, these factors influence the perceived meaning of the illness, the perception of tasks and initial choice of coping skills, along with subsequent changes in coping strategies (Moos & Tsu, 1977). Similarly, Rolland (1987) and Mailick (1979) identify the important influence of background, personal factors, and illness-related factors on families' responses and how they cope with a chronic or terminal illness.

Others have identified more specific factors. For example, Cates et al. (1990) suggest that the families' response to AIDS is dependent upon the role of the affected family member within the family, habitual responses to stresses, and values and beliefs of family members. Wells et al. (1990) conclude that parents' ability to cope with a terminally ill child is influenced by the age of the child, quality of marital and family relationships, economic and financial status, adequacy of support systems, and the presence of open communication with medical staff and within the family. While Friedman (1967) suggests that parental coping is influenced by how the parent has coped with past stresses, past experience with death and dying, the meaning of the child, and the course of the disease. These factors are consistent with those identified in this investigation. However, they neglect to include the important positive influence congruence between the parents' and child's personal attitude and problem-solving approach combined with a positive outlook on the part of the son had on the perceptions and responses of parents of adults with symptoms related to HIV infection throughout their experience. The important influence of the son's attitude has been previously identified by Grief and Porembski (1988).

Strategies

Parents of adults with symptoms related to HIV infection engaged in strategies which were either cognitive or behavioral or a combination of the two. Their repertoire of cognitive strategies included what parents labelled as "denial," engaging in positive self-talk, reframing, selective focusing, undoing, and creating meaning. These strategies functioned primarily to control the meaning of the event and regulate their distress. Behavioral strategies included seeking information, seeking support, giving support, being there, taking part in caregiving, and giving back. These behavioral strategies were frequently employed to alleviate the parents' sense of helplessness and were perceived as being the one way they could help their child when all else failed. The use of these strategies required a deliberate effort on the part of these parents, and they worked hard to employ strategies which kept their reality at a tolerable level, thereby facilitating day-to-day functioning. Strategies employed by parents evolved as the disease progressed and triggers occurred with increasing intensity and frequency. Also, similar to that suggested by Folkman and Lazarus (1980), these strategies changed as parents' view of the situation changed.

Parents in this investigation found that particular strategies were more relevant at specific points in their son's illness. For example, while seeking relevant information and denying and minimizing the seriousness of the crisis were employed more frequently during the early stages, seeking emotional support and learning illness-related procedures were relevant during the middle stages, while creating meaning played an important role in the final stages. Similarly, Chesler and Barabarin (1987) found that optimism and denial were common during the earlier stages; however, these changed or were unable to be sustained as the disease progressed and the parents' interpretation changed. For example, optimism changed from an initial hope for a cure to the belief near the end that "maybe this was for the best" (p. 111) and that the child may be "better off in another life" (Chesler & Barabarin, 1987, p. 111).

Research based on parents of terminally ill children have identified strategies similar to those experienced by parents in this investigation. This research also implies the presence of a deliberate, active manner in employing these strategies, as identified in this study. Chesler and Barabarin (1987) and Barabarin, Hughes, and Chesler (1985) have identified various strategies which they have divided into two categories. One category includes strategies which are internally directed and function primarily to manage and control emotional reactions, for example, denial, optimism, acceptance, maintenance of emotional balance, and reliance on religious faith (Barabarin et al., 1985; Chesler & Barabarin, 1987). While the other category includes externally directed strategies, which are designed to manage events and resources in the environment outside the person, for example, information seeking, problem solving, and seeking help (Barabarin et al., 1985; Chesler & Barabarin, 1987).

Birenbaum (1990) identifies the concept of encapsulation as an important strategy employed by parents of terminally ill children. Encapsulation includes both cognitive and behavioral function. For example, cognitive functions include realistic appraisal, maintaining an optimistic viewpoint, endowing the illness with meaning, affirming life, and assuming a philosophy of life which allows the family to continue living after the child dies; while encapsulating behaviors include living day-to-day, maintaining open communication, shielding or withholding information, maintaining role obligations, reorganizing life, treating the child as normal, and keeping their spirits up. Other researchers have identified similar strategies; however, in addition, parents in these studies reported that helping and supporting others in a similar situation (Hymovich, 1984), seeking support and assistance from within the family and from external sources (Wells et al., 1990), obtaining support from parents with a similar illness, a search for meaning (Bozeman et al., 1955; Chodoff et al., 1964; Friedman et al., 1963), and assuming a living day-to-day philosophy (Bozeman et al., 1955) were useful strategies.

Similarly, Moos and Tsu (1977) found that the family of the critically ill engage in coping skills which made the situation tolerable by either denying or minimizing the seriousness of the crisis, dissociating their emotions, seeking relevant information, requesting reassurance and emotional support, learning specific illness-related procedures, and finding meaning for what had occurred. These particular coping skills can be employed individually or in combination and, unlike strategies identified by others, include both mental and behavioral components (Moos & Tsu, 1977).

Folkman and Lazarus (1980) and Folkman (1984) propose that coping can take either the form of problem-focused coping, where the person-environment relationship is managed or altered, or emotion-focused coping, where stressful emotions are regulated. However, due to the anxiety, fear, and dread associated with illness, they claim that emotion-focused coping is more prevalent than problem-focused coping (Folkman & Lazarus, 1980). Additionally, the presence of uncertainty, generated due to illness-related events such as a disease course characterized by remissions and exacerbations, lack of knowledge or information concerning the disease outcome or medical technology used to treat the disease, or a general perception that nothing can be done, is also associated with an increased reliance on management of affect (Mishel, 1983; 1988). Consistent with this, Chesler and Barabarin (1987) and Barabarin et al. (1985) found that parents relied primarily on the internally directed strategies and that externally directed strategies such as searching for help and information were used with lesser frequency. Parents in this investigation did rely on information seeking extensively during the early stages of the process; however, as the disease progressed and their son's condition deteriorated, parents in this investigation, similar to that suggested by Chesler and Barabarin (1987), Folkman and Lazarus (1980), and Mishel (1983, 1988), relied heavily on strategies which were designed to manage affect and regulate meaning. While a variety of cognitive strategies contributed to this, hope was shown to have a powerful influence on parents' coping and was evident during each stage.

Hope:

Hope has been defined as the expectation of achieving a certain goal (Stotland, 1969) and the belief that a personal tomorrow exists (Hinds, 1984). Hope is said to be necessary for man to act, move, achieve (Stotland, 1969), and contributes to making life meaningful when confronted by stress or transition (McGee, 1984). While, Breznitz (1986) suggests that hope positively benefits health and morale. The importance of hope as a method of coping (Korner, 1970; Lazarus, 1966) and the positive relationship between hope and coping has been demonstrated (Herth, 1989). Friedman et al. (1963) maintain that hope experienced by parents of terminally ill children functioned to help parents accept "bad news." While optimism demonstrated by a sense of hope has been identified as helping parents deal with the stressful impact of the disease and treatments experienced by their child (Chesler & Barabarin, 1987). Hall (1990) argues that hope is an integral part of life and must be obtained in every stage of life and by all individuals, including the terminally ill, in order to enhance the quality of life. This argument can also apply to loved ones of individuals with a terminal illness, as in this case, the parents of sons with HIV infection.

Each parent in this study spoke of experiencing hope, and while their hope changed in nature as the process evolved, hope continued to exist in some form. At no time did parents describe themselves as hopeless. Parents stated that this hope was what helped them "keep going" and "energized," and at times, hope was perceived as being the only thing they had left. Even in the face of adverse conditions, parents maintained hope for a cure or some miracle. Maintaining this hope may be viewed as denial of reality; however, despite hoping, these parents appeared to function appropriately and, perhaps more importantly, perceived that they were coping effectively considering the trauma of their experience.

Initially, parents in this investigation hoped that the disease would not progress; however, when it became obvious that the disease was progressing, parents hoped for a cure or miracle. Finally, as their son became progressively incapacitated and they acknowledged that death was inevitable, parents hoped for something that would "buy some time." This was eventually replaced with the hope that their sons would be comfortable and not suffer at the time of his death. Even following death, hope continued to exist, but it was now a hope to prevent others from suffering in a similar manner.

Similar to parents in this investigation, findings from Laskiwski's (1989) study designed to develop an understanding of what it was like to be a spinal cord injury patient suggest that the patient, staff, and family always experienced hope in some form. However, their hope changed in nature with changing circumstances, for example, different stages in the rehabilitation process. Cowles and Rodgers (1991) identify a similar fluctuating and changing nature of hope experienced by families affected by AIDS in response to the course of the disease and medical treatment. Likewize, Friedman et al. (1963) and Natterson and Knudson (1960), found that when parents learned of their child's terminal illness they initially hoped for a cure or a miracle. However, their hope began to fluctuate during remissions and exacerbations, and as the disease progressed, parents' hope was restricted to a day-to-day context (Friedman et al., 1963). Gradually, as their child's condition deteriorated, parents hoped for one more day, and finally, parents hoped for an end to the suffering.

In this investigation, parent's hope shifted as symptoms increased in severity, relapses became more frequent, treatments proved ineffective, and their son's condition deteriorated. Miller's (1989) study with the critically ill identifies the following threats to hope: physical problems accumulating over a short period of time and becoming overwhelming, evidence of setbacks, knowing that other people have died from a similar health problem, feeling that no one cares, and negative hospital experiences. These threats to hope are consistent with the factors which changed the hope of parents of adults with symptoms related to HIV infection.

Dufault and Martocchio's (1985) multidimensional conceptualization of hope provides further insight into the nature of parent's hope in this investigation. Dufault and Martocchio (1985) conceptualize hope as consisting of two spheres: generalized hope and particularized hope. Generalized hope differs from particularized hope because it is more abstract and not attached to a particular hope object; whereas, particularized hope is attached to a hope object. Dufault and Martocchio (1985) maintain that hope and hopelessness are not at opposite ends of a continuum; instead, some sphere or dimension of hope is always present. Furthermore, throughout the process of hoping for a particularized hope, other hopes are identified, hopes which are perceived as being unrealistic are relinquished, and focusing upon alternative hopes is facilitated (Dufault & Martocchio, 1985). Moreover, the presence of two distinct spheres with different functions explains how generalized hope can protect individuals from despair when a particularized hope has not been realized. In this situation, the broad nature of the sphere of generalized hope allows for individuals to engage in a general hope which acts to sustain life. This conceptualization is useful in understanding the presence of and the changing nature of hope experienced by parents in this study. Initially, their hope was of a particularized nature; however, as they became increasingly aware that a positive outcome was not possible, parents' hope appeared to be in the generalized sphere as their hope became more broad and permitted them to carry on without giving in to despair.

Appraisal

An important component of the experience of parents in this study was appraising, which was used to determine whether they were keeping their reality at a tolerable level. This was measured by their evaluation of whether the "comfort zone" had been attained. If they appraised that they had not achieved this state or the strategies they were employing were inappropriate, parents actively sought and employed alternative strategies. This further reflected the conscious effort on the part of these parents to keep their reality at a tolerable level.

Chesler and Barabarin (1987) argue that other than the more obvious maladaptive strategies, such as denying the existence of an illness for a prolonged period of time, the effectiveness of the strategies can only be evaluated by the parents. Parents of terminally ill children felt that they were coping effectively; moreover, they maintained that "by simply being able to hold on, to keep on going, to ward off pessimism and a sense of doom" were major accomplishments (Chestler & Barabarin, 1987, p. 115). Similarly, Moos and Tsu (1977) do not label coping techniques as adaptive or maladaptive; instead, they assert that the type of strategy employed and its effectiveness are determined by the situation and the perception of the affected individual. Other than the one parent whose son had died six months before the interview, parents in this study felt they were coping effectively. Criteria used to determine effectiveness included continuing on with life and family activities, "keeping it out of your mind," and "maintaining your sanity."

Gender differences

Findings based on Chesler and Barabarin (1987) and Barabarin et al.'s (1985) studies with parents of terminally ill children indicate that fathers rely more extensively on denial when compared to mothers, while mothers rely on information seeking and religion more than fathers. In this investigation, mothers relied more on denial and religion when compared to fathers, and information seeking appeared equally among spouses. However, mothers appeared to prefer a more graduated manner of taking in information. In contrast, fathers tried to learn everything they could. This willingness to become informed may have facilitated the fathers in achieving the "getting control of it" attitude they tended to assume. This may also have influenced their reported earlier acknowledgement of their son's condition as compared to mothers.

Additional gender differences existed in the parents' use of seeking support, undoing, taking part in caregiving, and being there. In this investigation, mothers were more inclined to seek outside support, either from support groups, friends, colleagues, or their church; whereas, fathers tended to limit the people with whom they shared their experience. Fathers' perception that this was "private" and their attitude of "being in control" appeared to prevent them from seeking support from others. The increased tendency for mothers in this investigation to engage in undoing reflected the greater influence of religion on their beliefs. Mothers also primarily assumed responsibility for caregiving. This may be due to the traditional roles assumed by men and women in our society and particularly by the generation of parents participating in this study. The male equivalent to this was "being there," and fathers spoke frequently of simply spending time or providing support to their son by accompanying him to appointments and other similar activities. However, mothers also engaged in these activities, particularly in situations where the son demanded his independence or when she perceived she could not engage in caregiving.

Gender differences also existed in relation to parents' view of what was occurring. Fathers had a greater tendency than mothers to assume a "take it in stride" and "carry on" approach, this being facilitated by their increased use of "focusing on the positives." In general, mothers in this investigation assumed a view and engaged in strategies which involved affiliation with others. Whereas, fathers' strategies and outlook reflected an inner locus of control. While symmetrical patterns of coping did not always exist between parents in this study, as identified in previous studies (Barabarin et al., 1985), there generally was a tolerance on the part of spouses for differences between their coping styles and outlooks.

Critical Points in the Experience

Taking it in

The *Taking it in* stage began when parents learned of their son's positive HIV status and ended when they acknowledged the seriousness of their son's illness. Typically, parents reported experiencing shock and disbelief and occasionally, a sensation of physical pain. They also reported experiencing a lag in time between learning of the diagnosis and when they were able to acknowledge the implications of being HIV+. Therefore, while parents intellectually acknowledged the presence of the illness, they all reported being unable to grasp the true meaning of the illness at the time of learning of the diagnosis. The time taken for acknowledgement to occur and the triggers prompting acknowledgement varied among parents. Triggers prompting acknowledgement included obtaining information, the appearance of physical symptoms, or their son's behavior. Some parents stated that acknowledgement occurred within a couple of days, while for others, it took several weeks. This lag time appeared to serve as a protective device and prevented parents from being overwhelmed by the diagnosis and its implications.

This early period was characterized by intense emotions, during which time the parents struggled to come to terms with the diagnosis, their son's homosexuality, and their own feelings of shock, fear, guilt, anger, and disbelief. Frequently, this was achieved by denying and clinging to the hope that the disease would not progress or that a cure would be found. What was most commonly identified as "denial" by these parents was a refusal to dwell on the fatal prognosis of AIDS. Denial served as an important and effective strategy and helped parents keep their reality at a tolerable level. Defined in this manner, denial could be viewed as an emotion-focused coping strategy and would be a positive response, providing it did not interfere with problem-focused coping (Folkman & Lazarus, 1980). Additional strategies included positive self-talk and maintaining a "fighting it" attitude. Miller (1989) suggests that strategies such as engaging in self-talk, focusing on a positive outcome, and a mental attitude of determinism are hope inspiring strategies.

The majority of the research investigating the experience of parents of terminally ill children was conducted with parents of young children who were primarily diagnosed with leukemia during the 1950's and 1960's (Bozeman, Orbach, & Sutherland, 1955; Chodoff et al., 1964; Friedman et al., 1963; Natterson & Knudson, 1960). At the time, leukemia, similar to AIDS today, was considered a terminal illness. An identical pattern of a lag in time between learning of the diagnosis and acknowledging what it could mean and initial responses was identified in these studies (Bozeman et al. 1955; Chodoff et al. 1964; Friedman, 1967; Friedman et al., 1963; Natterson & Knudson, 1960). Friedman (1967) and Mann (1974) report that acknowledgement generally occurred following the first exacerbation and during subsequent relapses, while Bozeman et al. (1955) and Futterman, Hoffman, and Sabshin (1972) suggest that parents' acknowledgement shifted with the perception of threat to the child.

Similar to parents in this study, denial experienced by parents in Chesler and Barabarin's (1987) study referred to the use of beliefs and behaviors that did not demand attention upon the seriousness of the child's situation and included believing that the diagnosis was a mistake, denying the illness, denying the negative implications of the illness, and trying to keep their minds off of it. Denial was identified as an important coping strategy and served to "screen" parents from awareness of the threat of loss (Bozeman et al., 1955), and "buffered" them from the impact of having a child with a terminal illness (Chodoff et al., 1964; Friedman et al., 1963). The therapeutic nature of denial has been documented in other literature (Chesler & Barabarin, 1987; Ridley, 1989). Chesler and Barabarin (1987) argue that denial is an effective coping method in that it reduces the disease's impact on parents' lives, allows parents to deal with other issues, helps normalize the home environment, and minimizes the parents' fear.

Cowles and Rodgers's (1991) qualitative study investigating the experiences, concerns, and needs of significant others of persons diagnosed with AIDS identified similar findings. Cowles and Rodgers (1991) found that significant others reacted to the diagnosis with a "numbing sense of shock" (p. 8). This sense of shock was present even when significant others were aware of possible high risk behavior or recent illnesses (Cowles & Rodgers, 1991). In contrast, some parents in this study who suspected that their sons were HIV+ or knew they were engaging in high risk behaviors indicated that while they were shocked they were not surprised when they learned of the diagnosis.

Parents in this study engaged in information seeking during the initial stages to decrease their feelings of uncertainly and to gain some sense of control over their situation. Similarly, following the initial shock, parents in other studies tried to learn everything they could about the illness (Bozeman et al., 1955; Chodoff et al., 1964; Friedman et al., 1963; Lascari & Stephens, 1973). Cowles and Rodgers (1991) found that obtaining information concerning progression of the disease, availability of treatments, transmission issues, and how best to support their significant others frequently served as a coping mechanism for family members following the initial shock of learning that a family member was HIV+. With the exception of two parents in this study, transmission issues were not of great concern. Instead, parents in this present investigation were more concerned with the progression of the disease and grasping an understanding of AIDS and issues surrounding homosexuality and bisexuality. These divergent concerns may have appeared because Cowles and Rodgers (1991) study included partners where risk of transmission may well be a major concern. Additionally, the majority of mothers in this present study preferred receiving their information in a gradual manner consistent with their need at the time and without the degree of specificity identified by Cowles and Rodgers (1991).

Parents of terminally ill children frequently experience guilt because of their perception that they had done something wrong (Natterson & Knudson, 1960), should have identified symptoms earlier or because they feel they are being punished by God for some previous wrongdoing (Bozeman et al., 1955; Friedman et al., 1963; Lascari & Stehbens, 1973). The nonempirical literature frequently refers to the guilt and self-blame experienced by family when a family member contracts HIV through high risk behaviors such as IVDU and certain sexual practices (Cates et al., 1990; Lovejoy, 1989; Tiblier et al., 1989). Self-blame is usually experienced by parents as they question how their parenting may have resulted in their child assuming a particular lifestyle. The majority of the parents in this study reported grappling with guilt and self-blame. This was frequently accompanied by parents reviewing their parenting and chastising themselves for things they had done or said or not done or said in the past. Also, as indicated by Cates et al. (1990), when the virus is contracted through IVDU, the family of origin must grapple with the self-destructiveness of this type of behavior. The parents of the IVDU in this study struggled with this very issue, and at the time of the study, all three of these parents were unable to reach a satisfactory resolution. This struggle was particularly problematic in this situation because of the differences between parent and child in their personal attitudes and problem-solving approaches.

Several parents in this study learned that their son was gay at the same time as learning of his positive HIV status. For some, this came as a complete surprise, while others indicated they had suspected that their son was gay. Parents struggled to understand their son's sexual orientation, frequently in an attempt to be more supportive of him. Information facilitated understanding in most cases, but for other parents, acceptance of their son was achieved by focusing on the positive points in relation to their child. Also, parents who perceived that they and their son shared similar personal attitudes and problem-solving approaches found it easier to support their son in this situation. Consistent with the themes proposed by Strommen (1989) and other researchers (Chekryn, 1989; Cleveland et al., 1988; Cramer & Roach, 1988; Peabody, 1986; Robinson et al., 1987; Walker, 1989), parents of gay men in this investigation adhered most strongly to their strong belief in loving and accepting their child.

Sweeping along with the symptoms

The majority of the empirical literature exploring the experience of parents of a child with a terminal illness tend to focus on the diagnosis stage and the terminal stage. Little attention is paid to the middle stages or times of relapse. Krulik (1982) proposes that each stage of an illness, including the diagnosis, remission, reoccurrence, and terminal stage, poses unique problems for parents and requires that they modify coping skills and learn new behavious. The occurrence of a relapse reactivates feelings associated with the crisis of diagnosis, such as, uncertainty, loss of control, helplessness, powerlessness, fear, doubt, guilt, and anger (Krulik, 1982). The basis for these feelings is rooted in the parents' awareness at the time of each relapse that chances for a future recovery are reduced (Krulik, 1982).

The *Sweeping along with the symptoms* stage was characterized by periods of remissions and exacerbations and marked by increasing deterioration on the part of the son and feelings of uncertainty, fear, and loss of control on the part of parents. Parents described how their emotions and activities were dictated by the course of the disease. The manifestations of the disease were particularly difficult for parents to witness, as was their inability to predict what would occur or what to expect. Previous research has documented the distressing effect of deteriorating mental and physical function of one family member on the remaining family (Chekryn, 1989; Howell, 1986; Hull, 1990; Matson, 1988; Peabody, 1986; Trice, 1988; Walker, 1989; Vachon et al., 1977). Periods of exacerbation were marked by the loss of hope and the painful recognition that the disease was progressing and their son was deteriorating. This was replaced during the "up" times of the disease by the hope that a favorable outcome might be possible. However, with each exacerbation, these hopes were dashed. Parents lived in a state of "limbo," and as the symptoms increased in severity, their hope gradually diminished, and they were increasingly forced to acknowledge that the disease was progressing and their son was deteriorating.

Mann (1974) found that while the degree of acknowledgement on the part of parents varied with the condition of the child and the number of exacerbations experienced, acknowledgement did not mean parents relinquished their hope. However, similar to parents in this investigation, the nature of their hope did change. Natterson and Knudson (1960) define this time as an intermediate period and also found that mothers continued to hope for a miracle. At the same time, they reported that their denial had subsided, and they became increasingly focused on their child's comfort and emotional needs (Natterson & Knudson, 1960). However, Bozeman et al (1955) note that during remissions mothers abandoned their intellectual acceptance and, similar to some parents in this study, took up the "fight" again.

As the disease progressed, parents in this present study were bombarded by the manifestations of the disease; consequently, attempts to avoid thinking of the implications required more effort. By this time, parents knew there was little they could do other than to participate in caregiving and support their son by being there. These activities alleviated their sense of helplessness somewhat; however, did little to ease their fear and horror. As direct action strategies (Mishel, 1988) or problem-focused coping strategies (Folkman & Lazarus, 1980) were no longer functional or perceived by parents as not being feasable, there was an increased reliance on emotion-focused strategies (Folkman & Lazarus, 1980) and affect management (Mishel, 1988). This was demonstrated by the tendency of parents in this investigation to rely extensively on cognitive strategies which controlled the meaning of their experience and regulated their distress, for example, selective focusing, hoping, undoing, positive self-talk, and reframing. Conscious effort was required, and parents worked hard to guard themselves from the negative implications of the disease. Parents dealt with their fear during relapses by "shutting doors," "thinking about something else," and "keeping an even keel." These selective focusing strategies closely resemble those identified by Chesler and Barabarin (1987) as strategies used to maintain emotional balance. Maintaining emotional balance requires deliberate efforts to achieve inner peace and to avoid extreme mood swings (Chesler & Barabarin, 1987).

Beating down the denial

Beating down the denial marks a progression in the parent's level of acknowledgement from an awareness that their son was seriously ill to an awareness that he would die. The majority of parents in this study reported experiencing a point in time where they knew that their son would die. Accompanying this awareness was a gradual relinquishment of hope for a cure. Now, parents hoped that their son would be freed from his suffering. Parents in the documented research also reported reaching a stage where they were resigned to the fact that their child would die (Chodoff et al., 1964; Friedman et al., 1963; Lascari & Stephens, 1973; Natterson & Knudson, 1960). Some parents even expressed the wish for an end to their child's suffering. Despite still being involved in their child's care, parents began to redirect their energies from their child into other activities (Friedman et al., 1963; Natterson & Knudson, 1960). While several parents in this investigation reported praying that God would free their son from his suffering, they continued to be very involved with their son.

Davies, Chekryn Reimer, and Martens' (1990) study provides some insight into what prompts this final acknowledgement. Davies et al. (1990) found that a decline in the patient's physical condition resulted in family members perceiving that the patient was "fading away." This realization occurred suddenly, even though there had been clues along the way, and was usually based on the perception that the patient was not functioning "normally" and had worsened to such an extent that the inevitable could no longer be denied. Triggers prompting this realization included unrecoverable weakness, inability to move independently, loss of independence in physical care, and loss of mental clarity (Davies et al., 1990). Davies et al. (1990) suggest that this awareness requires that the old set of assumptions must be abandoned, and the family must learn to cope with this new meaning. These triggers are consistent with the threats to hope identified by Miller (1989) and correspond with the triggers which forced parents in this present investigation to acknowledge that their son's quality of life was minimal or nonexistance. This acknowledgement resulted in changes in the way parents viewed the present and the future and the strategies they employed.

Creating meaning was an important strategy employed by parents during the latter stages of the process, and its appearance coincided with parents' acknowledgement during the *Beating down the denial* stage and persisted throughout the *Learning to live with it* stage. While their son was still alive, creating meaning was in response to the meaningless of the event, their horror in the face of their son's symptoms, and the possibility of his death. Similarly, Hutchinson (1984) found that NICU nurses created meaning in response to their horror and in order to function and maintain their horror at manageable levels. Following their child's death, creating meaning comforted parents, helped them resolve what had occurred, and allowed them to believe that their son's death was not in vain. Frequently, religion was a manner of injecting some meaning into what had occurred. Creating meaning was demonstrated by statements concerning how their son had contributed to society, his accomplishments, and remarking on his "specialness." Other parents related stories which cast a "special" light on events surrounding their son's last days or his funeral.

Miles and Crandall (1986) suggest that the death of a child is one of life's most "profound human losses" (p. 236). In response, parents search for meaning (Chodoff et al, 1964; Miles & Crandall, 1986). Comerford's (1974) touching account of her experiences as a mother of child dying from leukemia stated, "Suffering ceases to be suffering when it has meaning" (p. 151). She created meaning by viewing her child and other terminally ill children as "exceptional human beings" (Comford, 1974, p. 152) who taught valuable lessons to the living. Searching for meaning has been identified as an important component in the grief process and is said to contribute to personal growth

(Craig, 1977; Miles & Crandall, 1986). Meaning may be found by adhering to religious and philosophical beliefs, identifying the uniqueness of the child's life and death, and memorialization of the child's memory (Miles & Crandall, 1986). Becoming involved with activities that helps others was also identified as facilitating the creation of meaning (Miles & Crandall, 1986).

Consistent with this the majority of parents in this study were involved in some type of activity related to AIDS. Parents expressed that they were motivated to become involved in order to alleviate their overwhelming sense of helplessness, a desire to help others in a similar situation, or to prevent someone else from experiencing what they had experienced. Participation included speaking to nieces and nephews about safe sex, taking part in videos for the public, and providing support to other parents of children with AIDS. Most parents indicated that their motivation to participate in this investigation was their desire to help other parents in a similar situation. Similarly, Cowles and Rodgers (1991) found that family of AIDS patients became involved in what they identified as "AIDS work." Their involvement is motivated by their personal experience and their increasing knowledge of the nature of the disease (Cowles & Rodgers, 1991). Others identified that this type of work helped them to understand family dynamics and AIDS and provided them with an opportunity to function as advocates for persons affected by AIDS (Cowles & Rodgers, 1991). Parents in this study derived satisfaction from becoming involved in a similar manner; however, while the majority of the parents in Cowles and Rodgers's (1991) study were involved in AIDS advocacy before the individual with AIDS had died, parents in this present study frequently maintained a high level of involvement following their son's death.

Anticipatory Mourning

Futterman et al. (1972) suggest that parents of terminally ill children undergo a process of anticipatory mourning that begins when they are made aware of their child's diagnosis.

Anticipatory mourning is defined as "a set of processes that are directly related to the awareness of the impending loss, to its emotional impact, and to the adaptive mechanisms whereby emotional attachment to the dying child is relinquished over time" (Futterman et al., 1972, p. 251). This process consists of the following interwoven processes: acknowledgement, grieving, reconciliation, detachment, and memorialization. Dane (1991) applies this process to middle-aged parents of adults with AIDS. Similarly, two models used to examine the experience of AIDS for the family suggest that issues related to death are addressed and resolution of mourning occur during the terminal phase (Rolland, 1987), and that families prepare for the patient's death by engaging in anticipatory mourning during the latter stages of the illness (Lovejoy, 1989). Likewise, Chodoff et al. (1964), Friedman et al. (1963), and Friedman (1967) suggest that parents of children whose terminal condition lasts longer than four months may begin to engage in anticipatory mourning. This is said to occur during the latter stages of the illness and is demonstrated by both an intellectual and emotional acceptance of the terminal nature of their child's illness (Chodoff et al., 1964), and an emotional detachment from their child (Friedman et al., 1963; Friedman, 1967).

Townes, Wold, and Holmes (1974) hypothesize that parents of children with leukemia experience a tri-phasic anticipatory mourning pattern. This pattern includes an initial shock and denial of the diagnosis, followed by an acceptance of the diagnosis but not the prognosis, and finally an acceptance of both the diagnosis and the prognosis, culminating in a hope for the end of their child's suffering and a cure for children with a similar illness. Contrary to their hypotheses, Townes et al. (1974) found that while fathers did experience a tri-phasic anticipatory mourning process while the child was alive mothers consistently reported higher levels of fear, negative feelings, and attitudes and had more sustained intense mourning beyond the death of the child when compared to fathers. They conclude that mothers may have a more difficult time completing the mourning process or that mothers may take longer to complete the process.

This tri-phasic anticipatory mourning process resembles the varying degrees of acknowledgement experienced by parents in this study. Consistent with this, fathers in this investigation more readily verbalized a need to "carry on" and "not dwell on the past." Also, fathers described mothers and mothers described themselves as taking longer to "get over it" and clinging more to memories and memoriabilia. However, it is questionable whether fathers in this investigation completed the various stages while their son was alive, as they described experiencing grief and sadness following their son's death and a need to work through issues during that time in order to come to grips with what had occurred. Furthermore, completion implies acceptance and while the findings from this investigation identified that parents may acknowledge the diagnosis and the prognosis, it may be inappropriate to assume that they have accepted what they have acknowledged.

Weiss (1988) questions whether it is possible to experience the grief that occurs after a loss prior to experiencing the actual loss. While agreeing that "rehearsal" is not the "real thing" and that the term anticipatory grief erroneously implies grieving strictly for future losses, Rando (1988) maintains that predeath grief exists. However, Rando (1988) suggests that anticipatory mourning must be conceptualized in a multidimensional fashion, taking into account two perspectives (both patient and the family), three time foci (past, present and future), and three classes of influencing variables (psychological, social, and physiological).

Findings from this study do not support the conceptualization of anticipatory mourning as proposed by Futterman et al. (1972) and Dane (1991), but they are congruous with that proposed by Rando (1986, 1988) and Townes et al. (1974). While Futterman et al. (1972) state that parents' acknowledgement shifts as the child becomes progressiviely more ill, they maintain that when parents learned of their child's diagnosis and prognosis they recognized the terminal nature of their child's condition and began to engage in anticipatory mourning. Parents in this present investigation were interviewed at various stages of their son's illness, and even though parents were intellectually aware that a cure for AIDS did not currently exist, the various levels of acknowledgement they experienced indicated that anticipatory mourning did not occur when they initially learned of the diagnosis because at that time they had not yet acknowledged the terminal nature of their son's illness. Parents must first acknowledge the terminal nature of the child's illness before they can prepare for his/her death (Mann, 1974). Instead, all parents in this present study reported experiencing a gradual acknowledgement of what the diagnosis could mean, and several parents "denied" or refused to think about the inevitable prognosis until near to the end of the disease's course. Engaging in denial for this length of time is not unusual and has been identified in previous research (Rando, 1986; Siegel & Weinstein, 1983).

The parents in this present study engaged in varying degrees of preparing for future losses; however, despite engaging in these activities, parents remained very involved with their sons, appeared to try to make the most of what time was left, and continued to hope for a miracle. And despite grieving for past losses and for the future loss of hopes and dreams, which is consistent with Rando's (1988) propositions, their grief prior to death was acknowledged by parents as being very different from the grief following death. This was demonstrated by one mother who said "Right now we've accepted that it's [death] going to happen, and after we'll have to accept that it has." Also, consistent with Siegel and Weinstein (1983), many of the factors which frequently accompany many terminal illnesses, such as, social isolation, wishing that the end would come, and the physical exhaustion involved with caregiving, may actually contribute to a cancelling out of the gains attributed to anticipatory grief. This appeared to hold true for the parents who were very involved in caring for their son and appeared to contribute to difficulty resolving the loss after death because of the negative memories associated with their son's physical and psychological deterioration.

It would appear that the greatest danger associated with adhering to anticipatory mourning would be in imposing time limits for when mourning should be resolved or expecting that engaging in anticipatory mourning mitigates grieving after death and diminishes the impact of the actual loss (Rando, 1986; Siegel & Weinstein, 1983). In this study, the sons' deaths from the time of the interview ranged from six months to three years. Several of the parents of sons who had died several years before the interview continued to tear and become upset when discussing their son. Parents of sons who had died described how it was an experience you never "got over" and that it was something they "learned to live with it." Similarly, Gyulay (1989) and Sanders (1989) suggest that with time the pain associated with the loss of a child subsides; however, the experience remains, and parents simply "go on with life."

Implications for the Family and Individuals Supporting the Family

The predicted increase in the number of AIDS cases and the unlikelihood of a cure being found in this decade indicate that family counsellors, health care professionals, and other support services will increasingly be faced with parents whose adult child is dying due to HIV infection. The following discussion will address the needs for support experienced by parents in the six stages identified in this study, and implication these needs have for family support workers such as those found at AIDS organizations, health care professionals, and program planners.

Suspecting

Parents usually kept their concerns to themselves during the *suspecting* stage. Consequently, this would not be a time when family support workers or health care professionals could intervene in a therapeutic manner. However, despite not knowing, in retrospect parents frequently expressed the wish that their son had confided in them earlier so that they could have provided him with support at the onset. During this time, parents in this study did appear to benefit from accurate information concerning AIDS and its transmission. This supports the advantages of the information excerpts available on television and the pamphlets and information hotlines provided by AIDS organizations.

Implications:

1. AIDS organizations and program planners should continue distributing information concerning HIV infection, transmission, and related issues through pamphlets, videos, and hotlines.
2. Those counselling HIV+ individuals could explore ways in which they could approach and disclose their positive status and if applicable their homosexuality to their parents.

Taking it in

Taking it in begins when parents first became aware of their son's illness, a time where they were in shock and often overwhelmed by their emotions. Consequently, parents were in need of a great deal of support. Unfortunately, support is often inaccessible to these parents because they are usually told by their son who may not be aware of existing support services.

There is a great need for information during the *Taking it in* stage. Information needs centered around obtaining an understanding of both the disease and homosexuality and bisexuality, if applicable. In this study, it was found that accurate information concerning homosexuality and drug abuse played an important role in reducing guilt and responsibility.

It is necessary for support group workers and health care professionals to be aware that despite being told that their son is HIV+ this does not necessarily mean that parents truly grasp the meaning and implications of such a diagnosis. It was found that parents experienced a time during which the true meaning had not "registered" or "sunk in." Therefore, support services must bear this in mind and not overwhelm parents with information. In addition, this study revealed that there is usually a point where parents finally acknowledge the true meaning of the diagnosis. This acknowledgement was accompanied by an emotional response and a need for additional information and support.

Implications:

1. Following permission from the infected individual to do so, health care professionals involved in disclosing the diagnosis and providing treatment to the infected individual should also extend their support to include parents by suggesting agencies where they could access support.
2. In situation where family support exists, health care professionals informing the infected individual of his/her positive status or progression of the disease, should do so after determining whether he/she would like family to be present or close at hand while discussing the disease.
3. Information distributed at this time should be provided in a supportive, gradual manner based on the expressed needs of the parents. Parents should not be overwhelmed with specifics or details concerning outcomes.
4. Family support workers and health care professionals should allow parents to ventilate feelings of guilt or self-blame.
5. Family support workers could explore the use of strategies such as focusing on the positives which may be helpful to those parents who are unable to resolve their feelings concerning homosexuality with information.
6. Program planners, family support workers, and health care professionals should be prepared to allot time and provide opportunities for parents to return for repeated or additional information and emotional support when the true meaning has "registered".

Going along with a changed reality

As the disease progresses, parents require continued support and assistance dealing with their feelings of fear and helplessness associated with their acknowledgement of the seriousness of their son's condition. In this study, helplessness was reduced by providing assistance to their child. Therefore, parents may require help in identifying how they can best help their child. Needs for support along with the type of support varied for parents in this study. Frequently, this was dependent on the nature of support available within the family and the personal attitude and problem-solving style of the parent. In turn, gender appeared to influence personal attitude and problem-solving styles.

Several parents identified how interacting with parents in a similar situation or with gay individuals was helpful. However, what occurs in the support group must be tailored to meet the needs of parents, with consideration of their level of acknowledgement concerning their son's illness and their son's status. And while there are benefits associated with interacting with other individuals in a similar situation, support group workers and program planners must be cognizant that if too great a divergence exists between the parents' needs and their acknowledgement the parents can experience anger, frustration, fear, and the perception that all hope is being removed.

<u>Implications</u>:

1. Support group workers and health care professionals should explore with parents practical ways in which they could help their child, for example by accompanying them to appointments or other engagements.
2. Program planners and support group workers must tailor what occurs in a support group based on consideration of the parents' level of acknowledgement concerning their son's illness and status.
3. During this time support group workers and health care professionals should impart practical issues related to transmission and treatments.
4. Support workers should carefully assess personal attitudes and problem-solving styles usually employed by parents prior to suggesting coping mechanisms or interventions.
5. Support group workers and health care professionals should explore the therapeutic use of reframing and positive self-talk as coping strategies.

Sweeping along with the symptoms

As the disease increases in severity and intensity, parents must be supported and allowed to ventilate their feelings in response to the manifestations of the disease. This study found that the "waves" experienced in response to the course of the disease were problematic. Uncertainty regarding the disease and the manner in which it progressed were of primary concern for parents. Physical and emotional exhaustion is likely for the parents during this time, particularly if they are involved in caregiving. Despite wanting to help, fathers are frequently not involved with traditional roles associated with caregiving.

Implications:

1. Health care professionals and family support workers must provide parents with clear information as to what to expect during this stage.
2. Support group workers and health care professionals must be aware of the emotional and physical exhaustion experienced by parents and intervene as necessary with support in the form of suggesting or providing respite care, identifying sources for financial support, and recommending support in the way of homecare services and aides for daily living.
3. Support group workers and health care professionals might assist fathers in identifying alternative ways in which they can meet their need to help their son such as *being there*, accompanying him to appointments, or participating in caregiving activities such as shaving.

Beating down the denial

This study found that parents in an individualized manner reached a point where they acknowledged that their son was going to die. With this acknowledgement comes further need for support as parents might feel it necessary to prepare for the impending death. However, support workers must not assume that parents engaging in preparation for the death have necessarily come to terms with what is occurring. Parents in this study reported needing to resolve their ambivalent feelings in relation to this preparation, and this was frequently accomplished by engaging in undoing and creating meaning.

Implications:

1. Support group workers and health care professionals must support and assist parents as they struggle to catch up with their sons who may be actively preparing for their memorials.
2. Discussion in support groups should explore parents' thoughts and feelings concerning death and dying, the grieving process, and what it means to lose a child.
3. Support group workers and health care professionals must support parents engaging in undoing and creating meaning, and these strategies should be explored as viable options for parents struggling with their son's prognosis and possibly his death.

Learning to live with it

Following death, parents benefitted by opportunities to discuss and reflect on their feelings concerning their son, his history, his death, and the memories and perceptions of multiple losses. Parents in this study also identified a wish to "give back" in order to prevent someone else from going through the same experience.

Implications:

1. During this time, support group workers should support parents while they work through their feelings of second-guessing and the need to make sense of what occurred.
2. Support groups, health care professionals, and program planners could provide parents with an opportunity to "give back." by informing them of avenues in which they could assist others, for example by acting as a "sounding board" for parents in a similar situation, or speaking to groups.

Individuals who could be identified as being at risk include: parents who do not have an avenue for support; families where limited disclosure exists between members; situations where a long history of negative experiences surrounding the child and his/her activities exists and/or if a past history of shared life attitude and problem-solving approach does not exist between parent and child; cases where parents perceive that they may have in some way contributed to the outcome; where divergent personal attitudes and problem-solving approaches exist between mother and father and this is not accompanied by a tolerance of these differences; and in situations where parents find it necessary to maintain a brave front or protect another family member.

Implications for Future Research

The findings from this study raise additional questions which can be investigated in future research. Individuals who agreed to participate in this study were parents of adults who were either gay or intravenous drug users. A similar study conducted with parents of adults affected by AIDS but who contracted the virus by means other than IVDU or who are not gay could shed further light on this experience. In addition, it would be interesting to compare and contrast the experiences and perceptions concerning coping between parents who participate in support groups and those who do not.

Further research should investigate the important role of hope, its changing nature, and the use of the other strategies identified in this investigation as therapeutic strategies when experiencing stressful events. Also, studies investigating the link between these strategies and the individual's perception of coping would be useful. While findings from this study identified that fathers may employ similar strategies as mothers, their perceived need to "get on with it" combined with their tendency to not share their concerns with others may be problematic. Gaps in knowledge exist regarding the needs, concerns, and strategies employed by men of terminally ill children; therefore, further research which focuses specifically on fathers is necessary. Also, as the findings in this study indicate that this experience is very traumatic for both parents, longitudinal studies investigating the long-term effects on the family, marriage, and coping would be insightful.

VI. SUMMARY

This study examined the experience of parents of adults with symptoms related to HIV infection. The lack of research which focuses specifically on the experience of parents in this context combined with a predicted increase in the numbers of AIDS cases made this study necessary and very timely. The grounded theory approach was employed in order to gain an understanding of the parents' experience from an emic perspective. Data were collected from a total of 13 parents of sons who represented each stage of the disease process characterizing AIDS. In addition, data were collected from two secondary informants and relevant literary works. Data collection was conducted with the use of open-ended interviews, and interviews were taped, transcribed, and analyzed consistent with the grounded theory approach.

Parents of adults with symptoms related to HIV infection undergo a process comprised of six stages. These stages are closely related to the nature and progression of the disease and include: *Suspecting*, *Taking it in*, *Going along with a changed reality*, *Sweeping along with the symptoms*, *Beating down the denial*, and *Learning to live with it*. The basic social psychological problem confronting parents during this process was the fear, horror, uncertainty, and helplessness they experienced in the face of the cruelty of their son's symptoms and the terminal nature of AIDS. Throughout this process, parents worked hard to achieve the "comfort zone," a state which enabled them to continue functioning, frequently in a supporting role. This was accomplished by the basic social psychological process, *Keeping reality at a tolerable level*. *Keeping reality at a tolerable level* is comprised of the following components: becoming threatened by a trigger which could be in the form of an event or an observation; determining of how the situation would be viewed and approached; employing strategies which could be either cognitive, behavioral, or a combination of the two; an appraisal to determine whether the comfort zone had been attained; and the identification of new strategies if the comfort zone had not been attained.

Cognitive strategies included: *denial, reframing, undoing, selective focusing*, engaging in *positive self-talk, creating meaning*, and *hoping*. These strategies controlled the meaning of what parents were experiencing and regulated their distress. Behavioral strategies such as *seeking information and support, being there, spending time* , and *caregiving* complemented cognitive strategies and were often a means to alleviate the parents' overwhelming sense of helplessness and uncertainty. Unlike many of the other strategies, hope was present during each stage; however, it changed in nature as parents proceeded through the process.

As parents proceeded through the six stages, they were confronted by a variety of triggers that increased in intensity and frequency as their son's illness progressed. Initially, during the first stage, parents were alarmed by their suspicions that their son may be at risk for contracting the HIV. High risk behavior, "different behavior," or the knowledge that their son was a member of groups of individuals who were presently primarily affected with HIV acted as triggers. In response, parents sealed their concerns away and hoped and prayed that what they feared would not become a reality. During the *Taking it in* stage, parents learned that their son was HIV+ and also perhaps that he was gay. This stage was an intensely emotional time for parents. Following an initial period where they appeared unable to acknowledge the true meaning of the diagnosis, parents attempted to cope with this new reality. This was accomplished by engaging in *denial*, defined by parents as refusing to dwell on the prognosis, *hoping*, and *positive self-talk*. Behavioral strategies included: *seeking information, getting support*, and providing their son with support. During this time, parents took up the fight, maintained a brave front, and hoped that the disease would not progress. However, as additional triggers such as the appearance of symptoms presented themselves, the parents' first hopes that their son would beat the odds were replaced by an acknowledgement that he was seriously ill and that his symptoms would develop into something more serious. During the *Going along with a changed reality* stage, parents continued with the strategies employed in the previous stages, but now, in response to their acknowledgement and the presence of symptoms, parents' strategies included *reframing* and *undoing*.

As their son's symptoms became more frequent, intense, and debilitating, parents entered the *Sweeping along with the symptoms* stage. This stage was characterized by helplessness, uncertainty, and hope for their son's recovery, alternating with the fear that he would not survive. *Undoing*, *reframing*, and *selective focusing* were relied on extensively to regulate the parents' distress. Also, behavioral strategies such as *being there* and participating in *caregiving* increased dramatically.

Finally, there came a point during the progression of the disease where parents could no longer avoid acknowledging that their son was "losing" and the disease was "winning". Additional triggers included their son's behavior or advice offered by health care professionals. In addition to the strategies employed in the previous stages, *creating meaning* was added to their repertoire of strategies. As their son's debilitation increased and parents perceived that he was experiencing an inadequate quality of life, parents completely abandoned "the fight" and hoped for an end to their son's suffering.

Following their son's death, parents worked to come to terms with the past, their sense of guilt, second-guessing, and their multiple losses. These issues were resolved by *undoing*, *selective focusing*, engaging in *positive self-talk*, *creating meaning*, and engaging in activities such as *giving back*, all of which helped them cope with their loss and helped them realize that their son's suffering had not been in vain. Despite resolving these issues, their son's death was not something which parents viewed as being "over"; instead, they simply learned to live with it.

Despite the commonalties of parents' experiences, several factors appeared to influence their experience and how they perceived they were coping. A shared history between the parent and child in relation to personal attitude and problem-solving approach had a positive impact on how parents coped and the strategies they employed. In addition, the presence of a supportive family or an external support system where parents could freely discuss their concerns was helpful. Finally, being able to tell themselves that they had done everything they could, being able to resolve any second-guessing, and making sense out of what had occurred, helped parents carry on with their lives and learn to live with it.

This study is one of the few studies which focuses specifically on parents of adult sons with symptoms related to HIV infection. By doing so, not only do the findings contribute to what is known concerning the experiences of parents whose children are diagnosed with a stigmatized disease for which there is not cure, but greater insight is gained about another area where little is known, that is, the experience of parents of terminally ill adult children. Furthermore, the findings identifying the varying levels of acknowledgement provide additional evidence against the proposition suggesting that anticipatory mourning begins when parents learn that their child has a terminal illness. Further research can expand on what has been discovered in this study by exploring the therapeutic value of the cognitive strategies identified in this study in other stressful situation, the impact of AIDS on individuals other than parents of gay men or IVDU, the long-term effect on these parents, and the needs and coping strategies of fathers of terminally ill children.

The six stages identified in this study and the manner in which parents employed strategies have important implications for family support workers and health care professionals. While each stage presented its own difficulties for parents, three points in the experience were identified as requiring special support and possibly intervention. These three points include the first level of acknowledgement occurring during the *Taking it in* stage, the emotional rollercoaster characterizing the *Sweeping along with the symptoms* stage, and the *Beating down the denial* stage, when parents acknowledged that their son will die. The type of strategies parents in this study used and found effective have a great deal to teach health care professionals and family support workers. The therapeutic use of hope, undoing, reframing, selective focusing, creating meaning, and "denying" by refusing to dwell on the prognosis was demonstrated in this study. While many of the strategies employed by these parents may be seen as denial or a refusal to "face facts." in the parents' view, they were essential in keeping their reality at a tolerable level.

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APPENDIX A

Letter to Intermediary Individuals

May _ 1991

5-112
Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2E1

Dear --------:

My name is Dyan Siegl, and I am a graduate student in the Department of Family Studies. I have developed a proposal which is designed to explore and describe the experiences of individuals who are parents of an adult with HIV infection related symptoms. Although research has been conducted investigating the experience of the person who is HIV positive or has AIDS, little is known of the experience of parents, or the support they may require when their adult child is HIV positive or has AIDS. Because this disease affects all significant others of the person with AIDS, I feel there is a desperate need to understand what parents in this situation are experiencing. Findings from this research will help other parents in the future. I am aware that you work with individuals who are HIV positive or have AIDS. Therefore, I am writing to request your assistance in contacting individuals who are HIV positive or have AIDS who think that their parents may wish to talk to me about their experiences, or to inform possible participants directly.

Parents wishing to participate in the study will be asked to meet individually with me at a time and place convenient for them to discuss their experience. The research design may require meeting with me from one to three times. If parents wish, interviews could be conducted by telephone. During the interview I will ask them to tell me about their experiences of being a parent of an adult with HIV infection related symptoms. All interviews will be taped, and each interview will take approximately 1 to 11/2 hours.

If you know of any parents who would be interested in the study, please contact me, and I will provide you with a formal letter for the parents. I have enclosed a copy of this letter for your perusal. If you have any questions or concerns about the study, I can be reached during the day at 492-8233. I am aware of your dedication to helping persons with AIDS, and once the study is completed I would be more than pleased to provide you with a summary of the findings.

I appreciate your consideration of this matter, and I look forward to hearing from you.

Sincerely,

Dyan Siegl, R.N.

APPENDIX B

Letter to Parents

May _, 1991

5-122
Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2E1

Dear "Parent":

My name is Dyan Siegl and I am a graduate student in the Department of Family Studies. I have developed a proposal which is designed to explore and describe the experience of parents of adults who have HIV infection related symptoms. Very little research has been conducted in this area, and I believe there is a desperate need to understand what you as a parent experience when you have a child with this disease. Findings from this study will help other parents in a similar situation, and will provide health care professionals and support group leaders with knowledge concerning special needs, or situations requiring intervention.

Participation in the study is voluntary, and requires that you meet individually with me at a time, and in a place, convenient for you. If telephone interviews are preferable to you, this will be arranged. During the interview I will ask very broad questions concerning your experience of having a child with this illness. During this interview you may, at any time without penalty, decide not to answer a question. Because of the research process I am using, you may be asked to be interviewed up to three times. During these additional interviews you would be asked to expand on what was said in previous interviews. Each interview will be approximately 1 to 1 1/2 hours in length. Interviews will be taped and transcribed, however all information you provide will be kept strictly anonymous. Portions of these transcripts describing your experiences may be published, however these will not include your name or any other identifiers.

If you would be interested in participating in the study, or have any concerns or questions about the study, please contact me by telephone, or return the enclosed form by June _, 1991. I can be reached during the day at 492-8233. Returning the form, or telephoning for more information will not be viewed as a commitment to take part in the study. And if you do decide to participate, you are free to withdraw from the study at any time.

I hope you will consider participating in this important and timely study, and I look forward to hearing from you. Even if you decide not to participate, a summary of the findings will be made available to you through the individual who contacted you.

Sincerely,

Dyan Siegl, R.N.

APPENDIX C

Return Form

To: Dyan Siegl
3rd Floor
Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2E1

Office phone #: 492-8233, between 9:00 and 4:00 o'clock, ask for Dyan.

Re: The experience of being a parent of an adult with
HIV infection related symptoms.

- -

Return Form

Re: The experience of being a parent of an adult with
HIV infection related symptoms.

I would like to learn more about this study. You can reach me at:
__________. Best time to reach me at home is: ______________.

Please call, or return this form in the enclosed, stamped envelope before September 1, 1991.

Office phone #: 492-8233 between 9:00 and 4:00 o'clock, ask for Dyan.

Sincerely,

Name: ______________________________(please print)

Thank you!!!

APPENDIX D

Newspaper Advertisement

Are you a parent of an adult who has, or had HIV-related symptoms? I am graduate student/ nurse at the University of Alberta who is interested in your experience. If interested, please call Dyan at 492-8233. All inquiries confidential.

Flyer

Are you a parent of an adult who has, or had HIV-related symptoms? I am a graduate student/nurse at the University of Alberta who is interested in your experience. If you are interested in taking part in a research study designed to investigate the experience of parents who have, or had an adult child with HIV-related symptoms, please call 492-8233 between 9:00 and 4:00 o'clock, and ask for Dyan. All inquires confidential.

APPENDIX E

Informed Consent Form

PROJECT TITLE: The parental experience of having an adult child with HIV-related symptoms.

INVESTIGATOR: Dyan Siegl, R.N. Telephone: 492-8233 (O)
Master of Science Candidate in
Family Studies
University of Alberta

THESIS SUPERVISOR: Dr. Janice Morse Telephone: 492-6250 (O)

The purpose of this research project is to investigate the experience of parents of adults who have HIV-related symptoms. A maximum of three interviews will be conducted, and may be either face-to-face or telephone interviews. These interviews will be done individually, and each interview will last approximately 60 to 90 minutes. Interviews will be taped, and transcribed by a typist. During the interview, questions will be asked regarding what it has been like to be a parent of an adult with HIV-related symptoms. Your identity will in no way be included on the transcripts, or in the final written report of the study. The only product available to the public will be the final report and a journal article.

THIS IS TO CERTIFY THAT I, ______________________________
(print name)
hereby agree to participate as a volunteer in the above named project.

I understand that there may be no direct benefits to me for participating in this study, but knowledge gained from this study may help parents in a similar situation, and may help health care professionals provide support to parents in a similar situation.

I hereby give permission to be interviewed, and for interviews to be tape recorded and transcribed by a typist. I understand that my name or other identifying information will not be included on the tape, transcripts, or final report. I understand that my name, address, and telephone number will be kept in a locked drawer, separate from the transcripts. This information will be destroyed when this study is completed. I understand that interview transcripts may be kept and utilized for future projects. I understand that the information I provide will only be discussed with peers, theses committee members, and will be published in the form of a thesis, and in a journal article. However at these times, my name or any other identifying information will not be included.

I understand that participation in this study is strictly voluntary and I am free to refuse to answer any question. I understand that I may withdraw from this study at any time without penalty.

I have been given an opportunity to ask questions, and these questions have been answered to my satisfaction. In addition, I know that I may contact the investigator designated on this form, if I have further questions either now, or in the future.

____________ Participant	____________ Witness (if available)	____________ Researcher

__________ (date)