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THE UNIVERSITY OF ALBERTA

THE STRESS OF LIVING WITH AIDS IN THE FAMILY

BY

PAULA BRINDLEY ©

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE
STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE
IN FAMILY STUDIES

IN

DEPARTMENT OF HUMAN ECOLOGY

EDMONTON, ALBERTA

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DEDICATED

TO THE LOVE OF FAMILIES

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MINE IN PARTICULAR

AND IN ADDITION

THOSE LIVING WITH AIDS

ABSTRACT

As AIDS enters into the second decade, it remains a disease that evokes for family members the horrors of physical deterioration, death, stigma and suffering. Understanding the stressful nature of the family members' experience is the topic of this thesis.

The familys' experience has been the focus of many empirical studies and first person accounts. However, currently there is no internally coherent framework for interpreting and analysing disparate findings.

The objective of this thesis was to rectify the observed deficiency through a synthesis of existing literature. The framework for doing this was developed by drawing together strands from grounded theory, meta-ethnography, concepts of the double ABCX model of stress, and stages derived from the bio-medical model of the disease

The resulting synthesis represents experience from diagnosis to death by a trajectory having a downward slope that traverses through four qualitatively different stages named "cataclysmic", "chaotic", "constant caregiving", and "relinquishment"

The integration achieved provides an holistic yet succinct model to further our understanding of "living with AIDS in the family", and offers invaluable knowledge for utilization in interventions and future research..

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" And what is as important as knowledge?" asked the mind.
"Caring and seeing with the heart" answered the soul.

The overwhelming knowledge, care and support that I have been privileged to receive throughout this epic academic journey has come from several disciplines, many perspectives and in numerous forms.

To Judith Golec, Carol Morgaine, Brenda Munro, and MaryAnne Poirier, my stalwart team of academic advisers, who recognized my struggles, patiently and positively stepped in where necessary, and supported me all the way, I am indebted. Each played a vital role in the process, and my success could not have been achieved without them. As author I reserve the right to give special mention to Judith, for giving far more than the title of Co-Supervisor requires, or suggests. I will never forget her efforts on my behalf. As a nurse and professor, she combined her skills superbly, always recognizing my perspective, healing where necessary, and relentlessly and patiently moving alongside to bring out more.

Throughout my journey, the meaning of true friendship, a rare and precious commodity, became all too apparent. Here I consider myself fortunate in having three special friends, Margaret Allen, Leslie Cruickshank and Maria Mayan, who where always there for me, no matter what. In addition I wish to thank Frances, for sharing so openly her painful experience of living with AIDS. Her brother's premature death from AIDS will never be in vain whilst she carries on the struggle with the disease.

Last, but definitely not least, my family. Like most people I have two of them. Sadly, my family of origin is overseas, but physical distance never stood in their way when it came to giving love and support. To my family of procreation words almost fail me (a rare event). From my sons, Guy and Pete I received boundless love, and their unique sense of youthful wisdom and fun. This precious gift always enabled me to look at life from a different perspective. To my husband and best friend Dave, who has sustained and encouraged me for most of my adult life, it is hard to convey my true feelings in words alone. His support and dedication to my struggles has been a constant resource, without which I would not have survived let alone succeeded.

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CHAPTER 1

INTRODUCTION

FORMULATION OF THE TOPIC

My interest in the family member's experience of living with AIDS dates back to January 1991, to my work as a grief counsellor. The AIDS Network of Edmonton asked me to lead the Network's first support group established to help the family members of persons who had died with AIDS. In working with this group it became clear that an understanding of grief rests on a prior knowledge of the nature of the disease as well as the member's experience of living with AIDS in the family.

AIDS is a widely used acronym for an infectious disease called acquired immune deficiency syndrome. Although the first case reported in the United States was in late 1979 (Mass, 1985, p. 56), the disease was not actually named until 1982; the same year that the first case was reported in Canada (Greig, 1987, p. 24). As of December 1993, a total of 9083 cases were diagnosed and reported to the national surveillance centre in Canada (Health Canada, 1994).

The cause of AIDS is a retrovirus known as the human immunodeficiency virus (HIV). In 1991, Health and Welfare Canada estimated that by 1993, between 20,000 and 50,000 persons would be infected with HIV (Health & Welfare Canada, 1991). Most persons who carry the virus do not have AIDS and the number of carriers who will actually develop it at some future point currently remains unclear. Some researchers have estimated the incubation period for

AIDS to be as long as eleven (Drucker, 1990), or sixteen (Eidson, 1986) years.

AIDS involves a breakdown in the body's immune system. HIV has the ability to transcribe its genetic material (RNA) into DNA and to insert this into the DNA of the host cell. This property of integration eventually results in a breakdown of the immune system. Those who develop what clinicians call "full blown" AIDS become vulnerable to a number of serious and frequently fatal opportunistic infections and malignancies. Two of the most frequent are a protozoan infection of the lungs called Pneumocystis Carinii Pneumonia (PCP) and Kaposi's sarcoma (KS). PCP and KS are rare in people with healthy immune systems. Consequently, a diagnosis of PCP or KS is often used by physicians to confirm the presence of AIDS. In Canada, 77% of all reported cases of AIDS are associated with either PCP, or KS (Health Canada, 1994).

The symptoms of AIDS vary by individual case, although the course of the illness is often described as a process of wasting characterized by deterioration of both physical and mental functioning (Eidson, 1986; Grieg, 1987). Symptoms may, for example, include fatigue, weight loss, anxiety, disfigurement (due to lesions and malignant growths), incontinence of urine and feces, blindness and dementia. The disease is fatal. By December 1993, 68% of all reported cases (6187 of 9083) in Canada were already dead (Health Canada, 1994).

There are three major modes of HIV transmission, namely, through sexual transmission, direct injection of contaminated blood, or perinatal transfer from infected mothers to their infants. The majority of reported cases in North America are associated with sexual transmission among partners engaging in homosexual, or bisexual practices. The cumulative data in Canada supports this profile. By December 1993, 94% of all reported cases (8508 of 9083) occurred among adult males (age 15 or older) of whom 82% reportedly have a history of homosexual, or bisexual behavior. Of the remaining cases, 4% (482) are female adults and 1% (93) are children under fifteen years of age. The most common mode of transmission for adult females (64%) appears to be heterosexual activity; and for children under 15 years, most have contracted the disease from their mothers (Health Canada, 1994).

Despite breakthroughs in medical and pharmaceutical research, the knowledge of AIDS remains incomplete. At present there is no vaccine to prevent the transmission of HIV and medical science has not yet discovered why some people who carry the virus develop AIDS, and others do not. Treatment for the symptoms of AIDS often produces serious and debilitating side effects. There is no known cure.

What is the family member's experience of living with a person who has AIDS? There is a fairly large body of literature written about this topic, yet the answer to this question is not as clear, or straightforward as one would wish. Nonetheless, from reading this literature some themes emerge as dominant.

In writing about the social meaning of AIDS, Weston and Jeffrey (1994, p. 721) for example, underscore the "fear, uncertainty and mythology" that surrounds this disease and produces a stigma affecting all persons associated with AIDS. Others have observed that the experience of family members appears to parallel the experience of the persons living and dying with AIDS (Stullberg & Buckingham, 1988; Tiblier, Walker & Rolland, 1989). Many accounts point either directly, or indirectly to the "stress" of living with AIDS in the family. Atkins & O'Rawe Amenta (1991) conducted a comparative study of stress and chronic illness. They discovered that families living with AIDS have higher levels of stress than families living with other chronic illnesses.

These themes offer important insights into the family member's experience. However, an important characteristic of this literature concerns what is absent. What is missing is an internally coherent framework which would facilitate an interpretation and synthesization of individual findings from studies into an understanding of a family member's experience as a whole.

RESEARCH QUESTION AND APPROACH

The research question that directs this thesis is what is the family member's experience of living with a person who has AIDS? This question contains two separate, but related questions: what are the realities of AIDS, and how do families members manage them? This thesis therefore focuses on the experience of the family member, and not the person who has contracted AIDS. Consequently, the use of terms "living with a person with AIDS", and "living with AIDS in the family", applies strictly to the members of the family as defined by Koff (1980), Kristjanson (1989), and page 31 of this thesis.

The methodology for answering these questions is taken from Noblit and Hare (1988) who offer a rigorous method for synthesizing and interpreting the findings already produced by multiple studies. They point out somewhat critically that researchers typically do a literature review as a necessary but incidental prelude to initiating a new research project. In contrast, they suggest that the "literature review" should be treated more seriously as a "complete study in itself" in order to derive "substantive interpretations" (Noblit & Hare, 1988, p. 9) that would extract the maximum benefits from accumulated knowledge.

The concepts which emerge as dominant in the literature, as noted above, reflect the importance of stress as an interpretive concept. In addition, "stigma", "uncertainty", and "fear" are concepts that are readily incorporated into the stress framework. Accordingly, the stress framework, the double ABCX model, as refined by McCubbin and Patterson (1983), will be used as a starting point to synthesize what is already known about the family's experience of living with AIDS.

There are four reasons for selecting the double ABCX model. First, the double ABCX model is a recognized theoretical framework for studying how families manage stressful situations (Atkins & O'Rawe Amenta, 1991; Koch, 1983; Lavee, McCubbin & Olson, 1987; Lewis & Looney, 1984; Mcdonell, Abell & Miller, 1991). It was built on two previous family stress models, specifically the work of Koos (1946) and Hill (1958); five decades of research to establish how and why families successfully manage stressors associated with different situations, and a set of assumptions which it will be argued are applicable to AIDS families.

Second, the double ABCX model has been used to study the family management of chronic illness (Koch-Hatten, 1987; McCubbin, 1986; Sterling, 1985). Since AIDS is a chronic illness, in which the realities of the experience of those involved show many similarities to family members coping with other chronic illnesses (Davies, Chekryn, Reimer & Martens, 1990; Mailick, 1979; Matson, 1988; Rando, 1985; Stullberg & Buckingham, 1988), the model has a general applicability to AIDS.

Third, the language of the double ABCX model lends itself to the study of experience. Terms such as "stressors", "resources", "pile up" and "coping" offer an intelligible set of concepts to capture and explain the experience of everyday life. Therefore, the model serves as an excellent vehicle to link family studies research and lay understanding.

Fourth, although other stress models could have been used for the synthesis, the double ABCX focus is explicitly on the management of stressful events. Since the objective of this thesis is to link the reality of AIDS with the management of the stress of having a family member diagnosed with AIDS, the emphasis is appropriate.

CONCLUSION

Although a considerable amount has been discovered about AIDS as a disease and much has been written about the experience of family members living with AIDS, it is difficult to obtain a clear grasp of the family experience as a whole. Current knowledge is neither accessible, nor clearly organized in a way that permits researchers or practitioners to conceptualize the experience in totality. Planning future research and formulating effective interventions depends on the development of an overall conceptualization of the experience from diagnosis of AIDS to death. This thesis applies the concepts and relationships of the stress model to interpret the findings of existing studies, and by so doing, attempts to contribute to the efforts of future researchers and practitioners.

CHAPTER TWO

STRESS MODEL AND METHOD

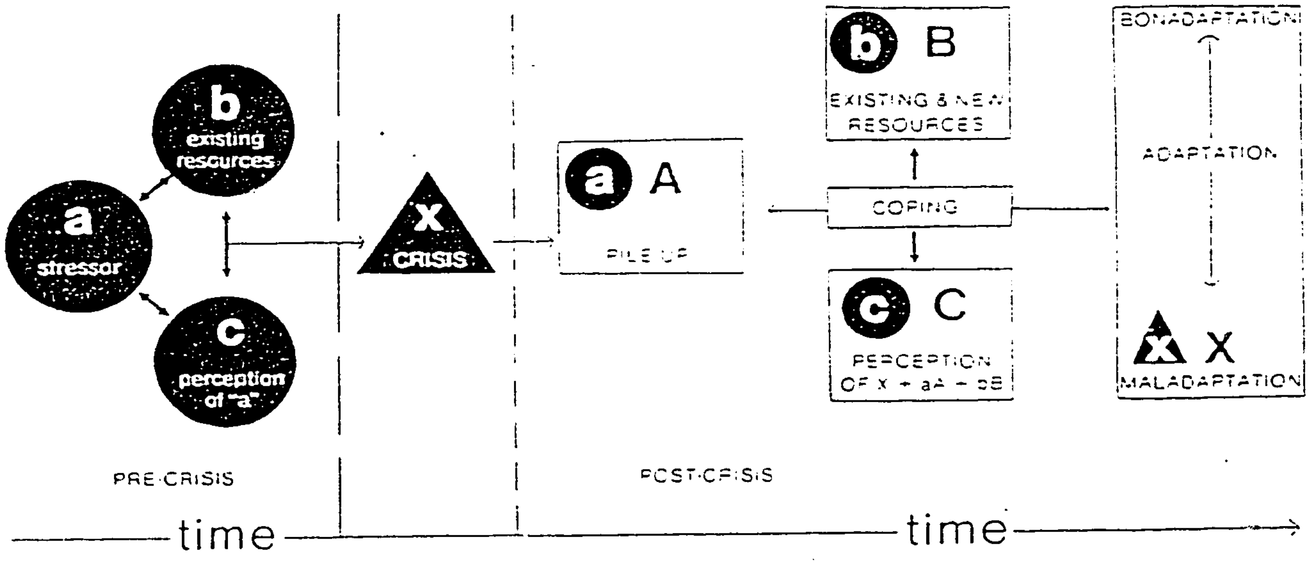
INTRODUCTION

The purpose of this chapter is to introduce the double ABCX model and to consider the methodological issues in using this framework to synthesize the knowledge which exists on the topic of living with a family member diagnosed with AIDS. The double ABCX model will be discussed first.

It is commonly accepted by writers, and acknowledged by McCubbin and Patterson (1983) that the foundation for the double ABCX can be traced through two earlier family stress models, the Koos Profile of Troubles (1946) and Hill's ABCX model (1958). All three models were developed and subsequently used to identify the families, the conditions, the resources and the coping strategies that are able to make positive adjustments and adaptations to stressful situations. A brief historical outline and comparison of these models is offered to the reader in Appendix 1.

This chapter focuses on the double ABCX model (see Fig. 2.1). Formulation of this particular family stress model is attributed to McCubbin and Patterson in 1983, and the integration of decades of family stress research embodied in their work in association with several colleagues (McCubbin, Dahl, Lester, Benson & Robertson, 1976; McCubbin, McCubbin, Nevin & Cauble, 1979; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; McCubbin, Comeau, & Harkins, 1980; McCubbin, Boss, Wilson & Lester, 1980; McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson, 1982; McCubbin, Larsen, & Olsen, 1982). One primary source in which the reformulation of the ABCX model is addressed is "Family Stress and Adaptation to Crises" (1983), and the discussion that follows draws substantively from that publication.

Figure 2.1 **The Double ABCX Model.**



Source: McCubbin and Patterson, 1983, p.91.

THE DOUBLE ABCX FORMULATION.

The double ABCX model (see Fig. 2.1) is conceptualized as a two stage interactive model of adjustment and adaptation over time which families engage in to "reduce or eliminate disruptiveness in the family system, and restore homeostasis" (McCubbin & Patterson, 1982, p. 37). The model is bi-phasic. It depicts a three variable pre-crisis phase (Hill, 1958) of stressor(a), existing resources (b), and perception (c). This is followed by a post-crisis phase in which the pre-crisis variables are repeated, and additions are made. This has been clearly symbolized in figure 2.1. The components of the post-crisis phase are conceptualized as pile up (aA), existing and new resources (bB); coping, a separate entity or state juxtaposed to crisis, perception of crisis, pile up and resources (cC); and adaptation at three levels; bonadaptation, adaptation and maladaptation, or crisis (xX).

The concepts, relationships and process which are contained in the logic of the framework will be addressed in more detail in order to acquaint the reader with the double ABCX model more fully.

CONCEPTS OF THE DOUBLE ABCX MODEL

Stressor (a)

Although the term stressor is used in the conceptualization of the double ABCX model, there is often confusion regarding the term stressor as it is used interchangeably in family stress theory with stress and stressor event. Stress is defined psychologically and physiologically. Psychological stress is an interaction between the person, the environment and coping or appraisal processes invoking a perceived threat to well-being (Lazarus & Folkman, 1984). Physiological stress is a"flight or fight" response to a stressor that can be characterized as an increase in cortisol, catecholamines, fatty acids and glucose concentrations in the blood (Brindley, McCann, Niaura, Stoney, & Suarez, 1993). These latter reactions provide a quantifiable definition of stress that arises from a perceived imbalance between the stressor and the individual's perception of his or her ability to deal with it (Antonovsky, 1979; Boss,1986; Hill, 1949; Selye, 1956). Stress is therefore a relational term which emerges when the family fails to overcome a stressor and its related hardships.

A "stressor" and a "stressor event" are effectively synonymous terms. Stressors are markers which family members react to. A stressor, as defined in the double ABCX model, is a life event or transition of significant magnitude, that impacts upon the family unit, and provokes change in the family social system (McCubbin & Patterson, 1983). Such systemic change is "of a magnitude greater than day to day routine family change" (Hill, 1958, p. 88). Changes may occur in various areas of family life, such as boundaries, goals, patterns of interaction, roles or values. McCubbin & Patterson (1983) claim, that stressors and their associated hardships simultaneously place demands on the family system which need to be changed. They define hardships as demands on the family unit specifically associated with the stressor event. Examples of related hardships for family members in the diagnosis of AIDS include social stigma, death of the diagnosed individual, chronic fatigue and loss of income that develop from the demands of constant caregiving.

Stressor events are varied and multiple, and are classified by type. These classifications are important because they ultimately affect the family member's response to them. Types of stressors most affecting AIDS family members are those classified as normative or non-normative, internal or external, chronic or acute, ambiguous or non-ambiguous, and according to their effect and impact on the family.

It is assumed in family stress theory that families will face normative hardships and changes as a natural and predictable aspect of their life cycle, and these will occur in various areas of family life (McCubbin & McCubbin, 1987). Normative stressors are predictable family events like births or death of elderly members. They are expected, ubiquitous, and of relatively short-term duration. The more the event is expected and prepared for, the less disruption is felt. Anticipated events allow time for preparation and gradual adjustment, and are invariably perceived as relatively manageable (Hill, 1958).

Whereas, an unpredictable events like the diagnosis of AIDS, is a non-normative aspect of the family life cycle. Non-normative stressors occur at unpredictable times in the family life cycle, or represent sudden or unique situations, like wars, earthquakes, or tornadoes. Family members are less prepared for their effects and management. Consequently, non-normative events are associated with a higher level of severity and change and are more problematic than normative stressors (Hill, 1958). Since 99% of adults infected with AIDS are between 15 and 49 (Health Canada, 1994), this represents a non-normative event in the family life cycle in which a death occurs out of sequence with older family members, and most especially that of the parents.

An internal, or external classification relates to the source of a stressor. Internal, or intra-family events, like AIDS, suicide, or lifestyles such as drug abuse or alcoholism are developed and controlled by individual family members. By contrast, external family events, such as a war, economic depression or acts of God, are considered beyond the family member's control, and are often thrust upon them. Both internal and external events have the potential to create family problems, but invariably evoke different societal responses. For example, the diagnosis of AIDS is affected negatively by psychosocial values associated with failure, stigma and shame. By contrast the death of a family member killed at war, may be positively affected by sympathy and support.

According to Boss (1988) chronic stressors have three special characteristics. They involve a level of ambiguity, rather than predictability; result from a larger context, and the situation is visible. AIDS diagnosis equates to all of these. The disease trajectory is short relative to other chronic diseases, for example Alzheimer's disease, but its symptomatology is chronic and fatal. Because AIDS is a relatively new disease with an evolving therapeutic regimen, and an idiosyncratic, erratic trajectory and prognosis, an AIDS diagnosis involves high levels of ambiguity and uncertainy. Family members are never quite sure what will come next, what form the disease will take, or how long it will last. The context in which the diagnosis of AIDS develops is often one of unacceptable life styles and practices, and the symptomatology, in the form of skin lesions, degeneration, dementia, and blindness is highly visible. Consequently these all represent chronic stressor situations.

A stressor classified by its effect on the family, is one of dismemberment, accession, demoralization, or a combination of the three (Hill, 1958). Dismemberment refers to the loss of family members through death or separation. Accession refers to gains through birth adoption and marriage, and, demoralization to events such as AIDS which bring disgrace on the family. Therefore when an individual dying with AIDS discloses a previously unknown homosexual partner to the family, this event encompasses all three.

A stressor classified by the type of impact which it causes, is a sudden change in family status, which is economic, social, or a difference in family role expectations (Burgess, 1947; Hill, 1958). The impact of AIDS constitutes a negative change in family status, and role conflict. Economic and role changes are experienced by AIDS families when a member is forced to take on an extra long-term role such as the sole breadwinner, when the diagnosed individual no longer fulfils this role. This sudden unexpected acquisition of roles is considered more stressful than the loss of roles. The impact can be particularly problematic for AIDS families who discover simultaneously the AIDS diagnosis and homosexual lifestyle of one of its members, since homosexuals do not fit an accepted family role (O'Donnell & Bernier, 1990).

Resources (b).

Resources are tangible assets which families possess, access, and use in conjunction with other variables to mitigate the impact of stressors inherent in a situation, and to reduce the probability of crisis (Tiblier, Walker & Rolland, 1989). They include the psychological, social, interpersonal, and material characteristics of individual family members; the family unit, and, the community (McCubbin & Patterson, 1983). Examples of individual resources are previous experience and knowledge of AIDS, or nursing skills. Family resources include flexibility, shared values, affection and concern for each other, whereas community resources include networks offering medical support. Together the resources enable families to care physically and psychologically for the diagnosed individual.

Resources are built out of previous experience with problems and are developed or strengthened in response to a potential crisis situation (Burr, 1973; McCubbin & Patterson, 1983). One basic assumption of the double ABCX model is that families benefit particularly from resources, and contribute to relationships and community resources, during periods of family stress and crisis (McCubbin & McCubbin, 1987). However, to be considered effective the recipient(s) must perceive the resources as valuable.

Some valuable resources most often used by AIDS families include personal well-being, information about AIDS, and social support. Social support is defined as the information that a family member is cared for and loved, esteemed and valued, and belongs to a network of mutual obligation and understanding, such as a support group or religious affiliation. Families who are able to develop social support are considered more resistant to major crises, and better able to restore stability to the family system (Cobb, 1976; McCubbin & Patterson; 1983).

However, over time, existing resources become inadequate to deal with new or additional demands, and crisis may occur. Therefore, in the post-crisis phase when family members experience a pile up of stressors, with new demands and needs, existing resources may prove inadequate to sustain the coping process. At such times old resources are expanded, and new, or adaptive resources are brought in to augment existing ones (McCubbin & Patterson, 1983). Post-crisis resources are therefore defined in terms of existing and new resources, at the individual, family and community level.

Perception (c)

Perception can be expressed in terms of "outlook on a situation". A family's perception as defined by McCubbin and Patterson (1983), is a subjective definition which is attributed to the seriousness of the experienced stressor, and how the family is affected by it. Family members react or respond to a stressor event by ascribing a meaning to it. Meaning affects their outlook, whereby a situation is viewed as a challenge, or a disaster (Hill, 1958). Following the impact of a stressor event, a family perceives the situation according to the current condition, the level of changes involved, and the subsequent effect on the family. Family perception is therefore influenced by the presence, or absence of explanations with which to make sense of what happened, and knowledge of how to overcome the situation. The more seriously the family perceives the situation, the more it is defined as crisis provoking.

Although McCubbin & Patterson (1983) restrict perception in the double ABCX model to the subjective definition, they acknowledge that additional objective cultural definitions of the seriousness of life events exist, that represent the collective judgement of the social community. Recognition of both aspects is particularly important in the case of AIDS, since family members are capable of holding idiosyncratic sets of perceptions from others in the family or society (Hill, 1958). Objective definitions are based on the family's social, and the community's cultural definition of the seriousness of the event, and are influenced by societal values, and the context in which it occurs. By contrast, the subjective definition, which is considered the most relevant in determining a family's susceptibility to crisis, relies on the meaning which the family members collectively attach to the event. It is strongly influenced by family values, and the family's previous ability and experience in handling stressful situations.

Perception is mediated by several dimensions external to the family context. These include historical, economic, developmental, constitutional, religious and cultural dimensions. For families managing the realities of AIDS, the external context involves dealing with a new, incurable, culturally unacceptable, and stigmatized disease probably at a time when health and family budgets may be restricted.

In the double ABCX model perception is differentiated by time. Consequently, in the post-crisis management phase it is referenced to the family's response following the occurrence of the crisis. Therefore, perception represents the family's current appraisal of the total crisis situation, and encapsulates both the appraisal of the situation and the attempts at rectifying it. In order to adapt, the family's perception is orientated towards redefining the situation. This requires a major analysis of the situation involving: reclarification of the issues, hardships, demands, and tasks inherent in the perceived situation; pile up of life events; levels of emotional burden; available resources; estimates of needs to enable coping; the perceived level of coping and integration with respect to all family members, plus redefinition and endowment of meaning both to the stressor and the family's handling of the situation. (Lavee, McCubbin & Olsen, 1987; .McCubbin, et al., 1982). In addition, some researchers suggest that post-crisis perception is idiosyncratic and transitory (McCubbin & Patterson, 1983; Oberst, Gass & Ward, 1989). It is therefore noted here that a family's post-crisis perception is an extremely complex and dynamic variable which is vulnerable to inherent factors in the situation, the family matrix, society and time.

Crisis (x)

Crisis is conceptualized as a continuous variable which denotes a temporary amount of disruptiveness, disorganization, or incapacitatedness in the family system, which effects its functioning (Burr, 1973). McCubbin & Patterson (1983, p10) acknowledge this definition and indicate that crisis is distinct from stress, because it is "characterized by the family's inability to restore stability, and by the continuous pressure to make changes in the family structure and patterns of interaction". It involves three elements: a) recognition, or an awareness of a stressor; b) disorganization, in the form of an unusual cognitive and effective disruption following rapidly after the stressor occurs; and c) the duration of the experience which lasts for an extended period of time, usually several days (Bloom, 1965).

Hill (1958) believed that crisis represents a relatively severe disruption of the family's previously established state of affairs which subsequently creates a temporary sense of insecurity, or imbalance in the critical dimensions of family functioning. When a family is in crisis, it becomes unable to support family members or maintain boundaries. Indicators of family crisis include an inability to perform roles and tasks, to make decisions, to solve problems, to care for one another, or even themselves (Boss, 1988). Although it is an assumption of family stress theory that a family may experience a crisis in response to external or internal family stressors (McCubbin & Patterson, 1983), crisis is not a common, or inevitable aspect of family life. As such it is dependent upon the number and type of stressors the family faces concurrently, and its strengths for managing them. The change in definition from a stressor to a crisis will only evolve when the amount of change in the family system is considered acute, and insurmountable through the usual methods of problem solving (Hill, 1949). Furthermore, since families are idiosyncratic, what may prove problematic to one may be beneficial to another.

Consequently in the pre-crisis phase of the double ABCX model, crisis is represented as the outcome of an interactional process which is dependent upon three intervening variables; the stressor, the family's resources for contending with the change, and the meaning which the family gives to the event. For a stressor to be defined as a family crisis requires the collective consideration of these variables. The definition is heavily influenced by the subjective meaning of the situation. The perceived imbalance has to be considered such that the family can no longer operate until new patterns of action are established.

Definitions of crisis are determined moralistically, and held by practitioners as negative, or positive. In the post-crisis phase of the double ABCX model, crisis is conceptualized as a negative outcome which results from the collective attempts to manage the situation. However, McCubbin & Patterson (1983, p.26), state that a family "in crisis" does not carry the stigmatizing value judgement that "somehow the family has failed, is dysfunctional, or in need of professional counselling". From this more positive perspective they define family crises, as "normative yet critical role transitions, involving changes in family structure, and established patterns of interaction, to cope with developmental changes in family members and in the family system". Therefore, using this definition, a family crisis such as AIDS can be viewed as a painful yet proactive instigator of decisions to make changes for improved family conditions and functioning.

Pile-Up (aA).

Pile Up represents the accumulation of stressors and life events which family members manage at any given time (McCubbin & Patterson, 1983). These may occur all at once, or slowly accumulate. Pile up is comprised of five broad types of stressors; the initial stressor event, normative transitions, prior strains, ambiguity, and the consequences of family efforts to cope. As discussed previously, families experiencing stressful events such as an AIDS diagnosis face many changes and hardships which evolve naturally from the initial situation. These involve cognitive, behavioral, and emotional concerns, such as changing family roles, decision making, anxieties, conflicts, health and emotional problems. The persistency of these hardships become additional stressors in themselves.

Normative transitions are family life changes and events which occur irrespective of the initial stressor, and independently of other non-normative stressor events. Examples include births, children leaving home and deaths of elderly members. Given the young mean age for diagnosis of AIDS. it is quite probable that many families will be dealing with all of these, and caring for the person with AIDS simultaneously.

Prior strains represent unresolved family issues and stressors. As family members face many stressors over the life cycle (McCubbin & Patterson, 1983), it is often the case that the development of a new one evokes unresolved problems from the past. One likely problem in an AIDS family is the associated "lifestyle" which is often held as the contributory factor in contraction of the disease among homosexuals. Where this issue remains unresolved family relationships are often strained or hostile, and the diagnosed individual may have been disowned prior to the diagnosis, (O'Donnell & Bernier, 1990). Additional problems therefore arise when families are confronted with the estranged individual returning home to die. In addition to lifestyle issues, the anticipation of death may also rekindle emotions associated with unresolved grief issues from previous family deaths which were managed inadequately.

As discussed previously, ambiguity is inherent in most stressful events. It is most often expressed in situations where uncertainty and a lack of legitimate paths and procedures for dealing with a stressor event exist. Two types of ambiguity particularly pertinent to this thesis are boundary and social ambiguity. Boundary ambiguity may develop from a lack of information regarding the prognosis of a terminal AIDS family member, and confusion regarding the necessary procedures and behavior to maintain family functioning. Family functioning requires that family members adjust to the death of a member by relinquishing old roles with the diagnosed person and adopting new ones. In this example, boundary ambiguity represents the uncertainty of whether a terminally ill family member is considered in, or out, of the family unit. Ambiguity is intensified when the need for adjustment is acknowledged, but can neither be addressed, nor achieved legitimately before the death occurs. Pile up in this case may be compounded further by lack of family communication, feedback, and subsequent adjustment over time. Social ambiguity represents the absence of appropriate norms for managing a stressful situation (McCubbin & Patterson, 1983). The experience of having a family member living with AIDS does not fit a recognized social norm. Consequently, there is no blueprint available for families of AIDS patients to deal positively with the stressors involved.

There are three consequences of family member's efforts to manage the hardships of the situation. First, the indirect damage to the family system, for example, the economic deprivations which cause risk to the future health of family members. Secondly, the direct damage to the family system. Here family members may suffer through through excessive use of negative coping strategies like alcohol, which cause interpersonal conflict. Thirdly, the interference with additional adaptive behaviors, such as excessive use of denial which delays problem solving and long-term management of family life.

The pile up associated with the realities and management of an AIDS diagnosis in the family will therefore involve a complex problem within a context of interrelated past, present and future strains. Past strains may relate to the breakdown of family relationships following disapproval of a lifestyle which is ultimately held responsible for the present strain, namely the contraction of AIDS. Future strains may relate to concerns of how the family will come to terms with a terminal disease, given the stigma associated with death from AIDS.

Coping.

McCubbin and Patterson (1983, p. 98) define coping as a multi-faceted management process, which is progressively modified and improved, wherein resources, perception and behavioral responses interact as families try to achieve a balance in family functioning The process is temporarily adopted at the individual, family or community level, either as a direct response to a stressor event, or to control the event and deter the occurrence of crisis (Lazarus, 1976; Lazarus & Folkman, 1984; McCubbin & Patterson, 1983; McCubbin &

McCubbin, 1987; Pearlin & Schooler, 1982). Coping is used to eliminate or avoid stress, manage the hardships of the situation, maintain family integrity and morale, acquire and develop resources to meet demands, and implement structural changes to adjust to the new demands (McCubbin & Patterson, 1983). In addition, it encompasses all the efforts which individuals make to overcome internal and external demands like fear and physical care (Krohne, 1986), while simultaneously managing the dimensions of family life, such as communication, organization, independence, coherence and family unity. Family level coping is therefore a "balancing act" between the demands and resources within the situation and family life.

In the double ABCX model family level coping is conceptualized as a process over time which is modified progressively and improved (McCubbin and Patterson, 1983). It represents an interactional process involving family resources, the appraisal or definition of the event, and behavioral responses to the stressors. The aim of coping is the satisfactory adaptation to a stressful situation, and facilitation of organization and unity in the family system, while promoting individual growth and development. This reflects the assumption inherent in family stress theory that a family faces hardships and changes as a natural and predictable aspect of family life; yet through its capacity for rehabilitation of family members, the family is able to protect and adapt itself, from a perpetual state of crisis (Hill, 1949).

Balance is achieved by numerous direct actions to reduce the number and/or intensity of demands. Actions may rely on decision making such as admitting a family member to hospital, acquiring community support, or maintaining resources through existing contact with social networks. Equally it may involve re-managing the tension associated with ongoing strains, by taking time out to enjoy family time together, or re-appraisal of the situation to make it more manageable. The latter is often achieved by lowering the standard of family expectations and recognizing that the family is managing well given the stressors involved (McCubbin & McCubbin, 1987).

Family members employ coping mechanisms, and strategies designed to facilitate the balancing act. These are behavioral, emotional and cognitive in nature. Cognitive coping is a technique whereby family members alter their primary and secondary appraisal of a stressful situation (Lazarus, 1966). Primary appraisal relates to how individuals feel about the stressful situation, whereas secondary appraisal reflects the subjective perceptions regarding resources and the individual's ability to cope. Having perceived both aspects of the situation, individuals use coping strategies to alter the appraisal. Two examples of this method include the reframing of a problem to give it a positive meaning, and denial of its existence in order to reduce the level of emotional arousal which it evokes.

However, not all coping strategies are considered efficient in the long-term. One strategy commonly used in AIDS families is denial. Although it can be utilized successfully as a temporary respite strategy, denial has the potential to produce an exaggerated long-term response, which ultimately intensifies and prolongs the effect of the initial stressor (Greif & Porembski, 1988; Kubler-Ross, 1987; Pohl et al., 1990; Stulberg & Buckingham, 1988).

Adaptation.

Adaptation is a descriptive term used to represent the outcome of the post-crisis phase. As such it simulates all the efforts to achieve a new level of balance in family functioning following a temporary upset from crisis (McCubbin & Patterson, 1987). As such, adaptation is a qualitative measurement comprised of the short- and long-term maintenance of emotional stability and family well-being, the utilization of family and community resources, the control of management situations, and the initiation of efforts to resolve family hardships created by normative and non-normative transitions and stressors. Therefore adaptation reflects the totality of the family's efforts to regulate the stimulus, control the environment and regain a balance in functioning (McCubbin & Patterson, 1983).

McCubbin and Patterson (1983) point out that family adaptation to a crisis can be achieved at three levels, individual, family system, and the community. Balance, or fit, is achieved through reciprocal relationships across these levels, whereby the demands of one level are met by the capabilities of another. For example, the demands of an AIDS patient may be temporarily balanced by family members. In this case adaptation is achieved. However, efforts to maintain this may precipitate additional strains and demands in a different part of the family system, or at the family to community level (McCubbin & Patterson, 1983). For example, the inability to continue working and caring for the sick family member. Ultimately, as the patient's condition deteriorates and he, or she develops total dependency on the family, an imbalance may re-occur as demands exceed the expectations, or capabilities of the family giving care. According to Melson (1982), family adaptation is achieved only when the discrepancy between the demands on the family unit and their resources is at an absolute minimum. Therefore to reconcile the imbalance, family members will need to seek help at the community level, in the form of home-care or economic assistance towards the cost of ongoing care. Where this meets the demands adequately, family balance will be maintained. However, as is often the case, when community resource levels are insufficient to maintain the situation, the family is once more thrown into imbalance and a crisis may result.

In the double ABCX model adaptation is the central concept used to depict the outcome of family efforts to deal with change. It is conceptualized as a continuum on which bonadaptation is placed at the positive end, and maladaptation, or crisis at the negative end. An outcome classified as maladaptation ranges from limited to continual imbalance and deterioration in family functioning at both levels of interaction. Therefore maladaptation resembles Hill's (1958) definition of crisis and is symbolized as (xX) (McCubbin & Patterson, 1983).

However, it is an assumption of family stress theory that over time families usually reorganize to a new level of functioning which may be higher or lower than before (Hill, 1958). Therefore bonadaptation reflects a balance of functioning at the individual to family, and family to community level, plus continued family development, maintenance of independence and sense of control. A family which adapts well is thought to develop a resistence which protects it against future stressors, or long-term effects of chronic stressors (McCubbin & Patterson, 1983). Consequently dealing with normative and non-normative hardships is considered to be both beneficial and developmental for the family as the results represent a higher level of family functioning.

This assumption provides an element of hope to family members and practitioners supporting the long-term care of individuals with AIDS. Despite the realities which they face, it seems possible to assume that AIDS families may transcend their problems and ultimately benefit from the experience. However, when considering a level of adaptation for an AIDS family several significant factors will influence the results. These include the duration of the management process, since AIDS can represent a long-term illness; the level of family functioning prior to the diagnosis, and the ability or desire to come to terms with a family member's socially unacceptable lifestyle and premature death, while still maintaining family balance.

RELATIONSHIPS.

The Double ABCX model depicts a two stage interactive process. According to its conceptualization, when a stressor (a) impacts upon the family in the pre-crisis phase, the process of countering its effects, involves a simultaneous interaction of existing resources (b), and perception of the stressor. Once the maintenance of this process is unmanageable the outcome is crisis (x). At this point families progress to the post-crisis management phase. Here they face a pile up (aA) of additional stressors arising from the original stressor, and their attempts to counter its effects. Pile up (aA) is subsequently reduced by a second interactive process which revolves around coping. This process involves the interaction of existing and new resources (bB), together with the perception of the crisis (x), pile up (aA), along with existing and new resources. The outcome of the post-crisis management phase is represented by an adaptational continuum on which a positive homeostatic adaptation to the stressors is represented by bonadaptation, and a negative one by maladaptation, or crisis (xX).

METHODOLOGY

The methodology for this thesis derives from the seminal work of Glaser and Strauss (1967), entitled *The Discovery of Grounded Theory*. Their approach, first outlined in this work is popularly known as "grounded theory", for which the most recent statement, co-authored by Strauss and Corbin (1944), may be found in a *Handbook of Qualitative Methods*. Although the grounded theory approach is used commonly with primary data to study reality as experienced by ordinary people, Glaser and Strauss (1967, p. 176-183) laid out the possibility of using the grounded theory approach with secondary, or library data. Subsequently, Noblit and Hare (1988) followed this possibility explicitly, and outlined a methodology for grounding theory without using primary data; for synthesizing the findings from empirical studies. They called this approach meta-ethnography (Noblit & Hare, 1988, p. 10), and defined it as "the synthesis of interpretive research"....involving "the translation of studies into one another".

In brief, this method requires that the researcher should first identify the studies belonging to the topic of interest. The second step is to examine the studies for similarities and differences in order to synthesize the findings into a common and more general framework. In this thesis the findings from existing studies "involves a translation" (Noblit and Hare, 1988. p.10) into the concepts comprising the double ABCX framework. In this sense, the concepts and relationships of the double ABCX model, i.e., the more general framework, are used to "read" the studies, to identify relevant concepts, and to compare concepts and findings across studies. Thus the interplay between concepts in the studies and interpretive framework involves a "constant comparative method" to use the terminology of Glaser and Strauss (1967, p.101-115). The aim is to develop a general theory of the phenomenon under study, by remaining close to, or "grounded in" the empirical findings (Glaser & Strauss, 1967).

A literature search was undertaken to identify publications relevant to the topic of this thesis. The initial search began directly with the key terms "Family" and "AIDS". It was immediately apparent that the term family was problematic in this context. The traditional meaning of family as defined by its biological, legal and structural sense, was too restrictive since many individuals living with AIDS and their "families" are bound together by a definition of intimacy and shared meaning, rather than by legal ties. Accordingly, the definition of family was expanded to represent the individual's community or circle of "significant others" affected by the illness, irrespective of attachment, or kinship (Koff, 1980; Kristjanson, 1989). This led to an expansion of key terms, which included in addition to partners and kin, lovers, significant others, informal care-persons and buddies. The expanded search yielded a large number of studies which were then restricted by eliminating topics which although related, were not considered germane to this study of the experience of living with AIDS in the family. For example, studies focussing on HIV disease rather than AIDS, post-death grief, suicide, and philosophical issues were excluded.

The literature search was supplemented by material obtained from local and national agencies which act as a clearing house in disseminating information. In addition, a personal diary was made available through contact with the local AIDS network. The diarist who was ascribed the pseudonym of Frances, wrote about her own, and her family's involvement in a brother's fight with AIDS, over a period of twenty-one months. Frances's first-hand account was considered valuable for several reasons. First, it was written as events unfolded, rather than retrospectively. Secondly, it was not written with a research objective in mind, and therefore it was quite spontaneous. Thirdly, as direct access to the diarist was still possible, this represented an ongoing resource for obtaining more precise details regarding the experience and a means of clarifying queries with respect to meanings of words, and expressions used.

Eighty four separate studies and accounts were uncovered. (These are listed separately in Appendix 2). They constituted an eclectic selection of anecdotal and instructional material, government reports and empirical research, which stemmed primarily from medical and academic disciplines. From these a mixture of qualitative research (Brown & Powell-Cope, 1991, 1992; Matocha, 1990; Siegl, 1992), autobiographical material (Frances, unpublished; Haque, 1989; Peabody, 1986), reviews (Lovejoy, 1989, Tiblier, Walker & Rolland, 1989) and instructional literature (Martelli, Peltz & Messina, 1987; Pohl, Kay & Toft, 1990) were considered central and fundamental to the study. They provided rich and detailed description from the perspective of living with AIDS in the family. They also covered a relatively long period of time which encompassed the established parameters of AIDS, i.e., from diagnosis to death. Consequently they became the core material. The remainder were used as supplementary to that core.

DOUBLE ABCX MODIFIED.

Having identified the core and supplementary accounts, the task of synthesis was undertaken. Upon reading and re-reading the core studies, the first problem in using the double ABCX model was uncovered. The studies made it evident that there are several stages to the family member's experience of living with AIDS. Unfortunately, however, no agreement as to the number of stages, or the appropriate labels to describe the stages could be found. For example, Matocha (1989) and Pohl, Kay and Toft (1990) used four stages, whereas Siegl (1992) used six. The diversity in labeling the stages is suggested in the following three examples. Lovejoy (1989) referred to crisis, transition, acceptance and anticipatory mourning, whereas Pohl, Kay & Toft (1990) used numbers of weeks following diagnosis plus the stability of health, and Siegl (1992) named the stages suspecting, taking it in, going along with the changed reality, sweeping along with the symptoms, beating down the denial and learning to live with it. It was therefore clear that the double ABCX model had to be adapted to the multi-stage experience of living with AIDS in the family, but how many stages are appropriate?

The decision to use four stages was prompted by the re-current recognition among researchers that the stages in the family members experience seemed to mirror, or parallel the disease stages which the patient experiences (Bartlett & Finkbeiner, 1991; Bennett, 1988; Britton & Zarski, 1989; Chekryn, 1989; Eidson, 1988; Expert Working

Group on Integrated Palliative Care, 1989; Flaskerud, 1987; Grieg, 1987; Lovejoy, 1989; Needle et al., 1989; Siegl, 1992; Stulberg & Buckingham, 1988; Tiblier, Walker & Rolland, 1989). The four disease stages, Early, Progressive, Advanced and Terminal, which patients experience, were outlined in a bio-medical model of the AIDS trajectory, from diagnosis to death. Each stage has been determined according to clinical and therapeutic markers in the pathology and accompanying therapeutic regimen (Expert Working Group on Integrated Palliative Care, 1989). The determination that the disease has progressed from one stage to another becomes known to both patient and family members through the attending physician. Therefore the medical pronouncement of diagnosis and treatment stages serves as an objective marker of the pathology, and for the qualitative shift in the experience of patient and family. Although it is noted here that a family member's response is subjective and may not represent a crisis or correspond precisely with these objective markers, the use of these stages was crucial to the study since they provided a way to combine the disease, its stages, and the family experience. Therefore the four bio-medical stages were adopted as the most likely markers of the experience of living with AIDS in the family.

INFLUENCE OF THE BIO-MEDICAL MODEL

Diagnosis represents the marker in the Early Stage and provides the initial physiological declaration and framing of the illness. Diagnosis is normally confirmed when a patient has contracted one of two opportunistic infections; Pneumocystis Carnii

Pneumonia, or Kaposi Sarcoma (Grieg, 1987). Individuals thus diagnosed have experienced major and irreversible damage to their immune system. Diagnosis is accompanied by short infrequent periodic bouts of illness, and active response to pharmatherapeutic treatment. Although socially diagnosis is often perceived as "the beginning of the end" (Tiblier et al.,1989), aggressive medical therapy is offered, and those diagnosed often resume normal activities.

The marker for the Progressive Stage is the distinguishable decrease in response to aggressive treatment, indicating that the immune system can no longer cope. This is accompanied by an increased occurrence and intensity of opportunistic infections. The patient has episodic bouts of illness which sometimes necessitate hospitalization, and relatively fewer periods of stable health and relief from symptoms. The disease at this stage is characterized by slow but progressive impairment, persistent fatigue, gradual and progressive weight loss, and some behavioral changes due to mental impairment. Bouts of illness are longer with shortened intervals between. Each new infection attacks different physiological systems. The most common examples are: mucositis, esophagitis, colitis, and hepatitis, which effect the gastrointestinal system, tuberculosis which attacks the respiratory tract, and various forms of cancer of the skin and immune system. However, the occurrence and the development of these diseases shows individual variation (Allen, 1988). Medical treatment is continued, activity is slow and partial, but periods of improvement are still possible.

The marker for the Advanced Stage is the withdrawal of aggressive treatment. At this point infections are constant and the symptomatology is worsening. The patient experiences a marked loss of daily functioning, normal bodily functions and personal dignity, and increased periods of hospitalization, as the cumulative effects of the infections take hold. The likely onset of neurological manifestations stemming from deterioration of the central nervous system may cause excessive fatigue, incoherent speech, incontinency, blindness and dementia. Aggressive treatment is no longer seen as viable, nor effective at this stage.

The marker for the Terminal Stage is that death is imminent, and treatment is totally palliative i.e., for the purpose of pain relief. The patient may be barely conscious, or unconscious. Therefore, the experience relates more to the physiological and emotional "letting go of life," (Davies, Chekryn-Reimer & Martens, 1990; Kubler-Ross, 1987; Rolland, 1987).

Having adopted four stages, uncovering (and naming) the family member's experience became the central task of the research. The double ABCX model was used at each stage to synthesize the data accordingly. One additional problem remains to be discussed. Using both phases, that is, pre- and post-crisis phases of the double ABCX model, was not feasible. As the studies were not longitudinal and prospective, or undertaken prior to diagnosis there was no valid way to differentiate pre- and post-crisis, i.e., pre- and post-diagnosis variables in the data. Therefore only the post-crisis phase (post-AIDS diagnosis) of the model was used. This decision is the logical consequence of defining the phenomenon beginning with the diagnosis of AIDS. The four stages, therefore, are elaborations of the post-crisis phase of the Double ABCX model.

As a result, the biomedical marker at each stage was taken to represent the crisis which family members adapt to throughout the ensuing stage. Whether or not this subjective reaction to the biomedical crisis is actually present is an empirical question. From the definitions and relationships presented earlier the answer depends upon the interaction of several variables. In addition, since the majority of existing data are invariably collected retrospectively, lack of memory, and changed perception over time, is bound to play a significant role. The likelihood of resolving this problem in a synthesis of existing studies is very low.

PROCEDURES

The procedures employed in synthesizing the present study draws together strands from grounded theory, meta-ethnography, concepts in the double ABCX framework, and the stages of the biomedical model. The initial analysis was conducted in two parts, according to the type of material being analyzed. In the first part, only core material already organized into stage models was used. Each piece of core material was divided according to the four biomedical stages. At each stage, material was scrutinized and coded according to its fit with the post-crisis concepts of the double ABCX model. All coding was conducted by use of the comparative method of analysis (Glaser & Strauss, 1967). In the event that the information matched two or more categories, it was recorded accordingly. The individual findings with respect to each item of material were then recorded under a core matrix consisting of four stages (early, progressive, advanced and terminal) and the headings of the variables in the post-crisis stage of the double ABCX model (crisis, stressors, resources, perception, coping and adaptation). The coded items were analyzed further for material considered similar or repetitious.

On completion of the initial analysis, the supplementary material was examined. Since this material was not organized according to stages, this second analysis required a preliminary scrutinization to match information to a stage. This was done by identifying phrases such as "when a patient is first diagnosed" or, "the decision to terminate treatment." Having established the stages according to these markers, information was scrutinized, coded and recorded and incorporated with the core matrix material.

The combined matrix of core and supplementary material was checked for items that had common links and such items were combined. Items were then selected, re-coded and recorded under "realities" or "management" respectively. The components of "realities" constituted the pile up of stressors, and those of "management" were: a) the existing and new resources; b) coping; c) perception of crisis pile up and resources, and d) adaptation.

The findings at each stage constituted the substance of the experience according to the disease trajectory (a term borrowed from Strauss and Glaser, 1975) and the realities and management of living with AIDS in the family. These findings were subsequently studied for the quality of life which they represented for family members and they were assigned to the model presented in chapter four.

CHAPTER THREE

THE STRESS OF LIVING WITH AIDS IN THE FAMILY

The purpose of this thesis was to review the diverse literature and extract material to answer the research questions, by applying the double ABCX framework. The realities which family members of AIDS patients face, and the strategies employed in the management of these realities will be presented as they apply to each stage.

EARLY STAGE

> *June 18th 1989.... It was Mum and Dads' Anniversary yesterday, but G was unable to come. He was in the hospital again for tests and he's become so thin and tired. The doctor wants to talk to us about the results when G can handle it. I'm afraid of what I'm dreading most. I guess we have to wait until he can tell us himself.*
>
> *June 21st 1989....G got the test results and its AIDS, so now what? Mum and Dad are devastated and I am numb. I am really anxious for some answers. I went to visit, but it depresses me to see all those yellow diamonds. I guess we are categorized now.*
>
> (taken from the diary of Frances, unpublished).

Diagnosis provides the initial framing of the illness labelled AIDS (Tiblier et al., 1989). The two diary entries written before and after the news was confirmed mark the change in perception which had taken place. Despite the prior suspicions and fears which had led Frances to believe that something was radically wrong, it is the diagnosis which unequivocally substantiated AIDS as a reality for her, and set a marker for a *cataclysmic stage*.

REALITIES.

A person with AIDS and his or her family share one thing in common. Once a diagnosis of AIDS is confirmed, life for the remaining family members changes irrefutably. Smith (1988) writes, that "A person with AIDS wakes up and retires each day, confronted with the realities of the disease; involved family members face the same daily prospect. A life threatening illness modifies the values and perspectives of all those who are most closely related to the person diagnosed with AIDS" (Smith, 1988, p. 136). The family will never seem the same again. Frances defined the difference as a change in categorization, in which the family's status in society was transformed from that of normal to abnormal. Her diary entry confirmed that this definitive change in categorization acted as a catalyst for the eruption of disparate stressors which she recorded as perceptions, experiences, interactions and emotions among her brother, parents, siblings, husband, children and herself. These disparate stressors represented the components of the new reality which family members experienced from this point on.

CRISIS

As stated previously, each stage begins with a crisis. The crisis in the early stage was identifiable by the diagnosis of AIDS as a confirmed disease (McMillan, 1988). The crisis as defined here carries meaning and implies a changed reality. In her diary entry it also marked a shift from doubts to certainty for Frances . For those unaware that anything was wrong, the news that a family member has been diagnosed with AIDS represents a tremendous shock (Pohl, Kay & Toft, 1990; Siegl, 1992). This was the case for a mother, who defined her reaction to learning of the diagnosis, as unreal.

> That first day was just unreal when I found out. They asked me at the hospital what was wrong with Michael. I said that he had pneumonia. They asked what kind. When I took out the paper from the clinic that we had just been to a few days before and showed it to the nurse, she said, "Oh, he has AIDS!" That was the first I heard about it. That was a real shock to me.
> (Gregory & Longman, 1992, p.345).

In this example the circumstances of finding out intensified the mother's shock. Even for those family members who suspected, finding out represented the first of a series of reactions which are experienced as painful. The pain was captured in cognitive, emotional, physical, and behavioral manifestations in Haque's autobiographical account of her conversation with her brother.

> "What are you telling me?" "I have AIDS." I couldn't swallow; I could hardly talk. This couldn't be happening. I spoke softly. I began to cry quietly. "Oh, John, it can't be true." So our journey began.
> (Haque, 1989, p. 230).

In characterizinging the experience of receiving the diagnosis a mother of an AIDS patient described it as pain:

> The pain of finding out was like a knife being forced into the heart and then twisted..... I cried for month's, everytime I'd turn around you'd think about it.
> (Siegl, 1992., p.48).

PILE UP

The realities of AIDS encompasses three elements, the crisis, existing and new stressors, and pile up. From the moment of finding out, family members abruptly began to experience new stressors, released as a result of the crisis. These compound with existing stressors to substantiate further the painful reality of AIDS.

AIDS, like many types of chronic illness usually causes anatomical and physiological changes, alternating periods of stability and crisis, need for care, low probability of improvement, decreased life span and significant changes to self-concept (Koch-Hattem, 1987). Therefore the realities of AIDS comprised stressors similar to those experienced by others facing a chronic and terminal illness, such as cancer and Alzheimer's disease, and additional stressors which related specifically to the disease of AIDS (Atkins & O'Rawe Amenta, 1991; Raveis & Siegel, 1990; Pearlin, Semple & Turner, 1988). Similar ones at this stage include shock, and fear, particularly of the unknown (Lovejoy, 1989; Pohl, Kay & Toft, 1990), a sense of betrayal, concern over unfinished business, death, and overwhelming feelings of loss (Strawn, 1987; Tiblier et al., 1989). Differences were associated with the unique bio-psychosocial features of AIDS which acutely affected families. In a study which used the double ABCX model as a framework to compare family adaptation to AIDS and other terminal illnesses, Atkins & O'Rawe Amenta (1991) found that the families of AIDS patients had more rules prohibiting emotional expression, lower levels of trust and more anxiety than other families.

The realities of AIDS represent a convolution of familial and bio-psychosocial stressors. These were associated with the unpredictability of the illness, the relatively young age of those affected, a high mortality rate, infectiousness, and an associated social stigma resulting from societal discrimination and fears (Frierson, Lippman & Johnson, 1987). Primary exposure to these issues on an ongoing basis created constant anxiety, feelings of powerlessness, and loss of control. In an account of AIDS caregiving, a caregiver perceived the source of her anxiety as two stressors, which never went away.

> We wake with it and go to sleep with it; we live with it for days, for weeks at a time. This overwhelming blend of fear and uncertainty is anxiety.
>
> (Pohl, Kay & Toft, 1990, p. 64).

As a result the psychosocial consequences of AIDS at this stage were often considered to be more devastating than the physical illness itself (Strawn, 1987). The feelings expressed by a partner of an AIDS patient describe the form of the devastation.

> AIDS has screwed up our lives, its robbed us of everything we took so long to build. AIDS only compounds our feelings of powerlessness, our sense that life is unmanageable and out of control. We wonder why did this damned disease have to enter our lives?
>
> (Pohl, Kay & Toft, 1990., p. 58).

The *biomedical realities* of AIDS at this stage were classified according to a patients symptomatology. Diagnosis of AIDS is clinically substantiated by one of two infections, Pneumocystis Carnii

Pneumonia or Kaposi Sarcoma (Caring Together, 1989). As these infections cause acute problems, the individual was often diagnosed in hospital. Upon recovery he, or she returned home, weaker, but relatively active (Cates et al., 1990).

From the point of diagnosis, the progression of the illness sets the parameters of the bio-medical realities. As the health of the patient was relatively good at this point, chronologically speaking this was longest stage in the AIDS trajectory. For Frances the early stage lasted twelve months in a disease trajectory (Strauss & Glaser, 1975) of twenty one months. In her diary entry on June 29th 1990, she recorded a conversation with her brother's doctor; "he said it's been a year now and we should start preparing ourselves." The doctor's comment suggested that clinical evidence established that the early stage lasts approximately twelve months, but no additional literature was found to substantiate this. Comparative measurement of stressors for each of the stages suggested that this stage was the most cognitively assiduous one. In the absence of research to validate this observation, it is hypothesized that unless the family has managed a previous AIDS death, the experience is new and therefore evokes numerous alien stressors which were all dealt with in this period.

An overwhelming reality for family members facing these new stressors was uncertainty. In unstructured interviews of 53 family caregivers of people with symptomatic HIV infection or AIDS, Brown & Powell-Cope (1991) found that uncertainty was a reality which pervaded all aspects and stages of AIDS, and exerted a profound influence on the experience of those involved. In a study of caregivers a partner described how uncertainty was manifest.

> "Things are all messed up now, I never know whats happening. The days are all wrong, and I'm never in control of my time anymore. I don't know what will happen next. I'm not even sure what is happening right now."
>
> (Pohl. Kay & Toft, 1990, p. 60).

Feelings of uncertainty were expressed in questions as to what next, how the illness will manifest itself, why and when infections will occur, and how much time is left (Frances, unpublished). One caregiver asked "Will he live for ten days, ten months, or ten years?" (Pohl, et al.,1990, p.65). Brown & Powell-Cope (1991) found that uncertainy arises from the perpetual and unpredictable change accompanying the symptomatology of AIDS. Frances (unpublished) found the effects of uncertainty particularly stressful. In a diary entry on October 10th., she wrote "confusion is a daily thing, and sometimes its very hard to maintain peace."

Confusion and uncertainty were compounded by the relative newness of the disease and its constantly developing therapeutic regimen. This invariably resulted in a lack of current information regarding new developments and treatments. Frances (unpublished) found the Doctor's lack of knowledge stressful when she accompanied her brother for medical treatment.

> "We went to the hospital today. The doctor talked to me for about 20 minutes, but obviously his information was not up to date."
>
> (January 28th 1990).

It is assumed here that her knowledge in some aspects of the disease was more advanced than the doctor's. Additional stressors therefore resulted from a lack of definitive clinical information concerning prediction of disease progression, transmission, treatment, nursing care, justification for invasive diagnostic procedures and future outcomes (Chekryn, 1989; Francis, unpublished). Consequently there were no valid guidelines to assist in the early stage day-to-day management decisions which family members had to make (Cowles & Rodgers, 1991). This resulted in an inability to anticipate and comprehend new infections, therapeutic measures and outcomes. The realities of this situation were manifest in a family member's perception of himselfor herself and the situation. On January 25 1990, Frances wrote,"I really feel now that I'm the loser"...."I need some self esteem".

The realities of AIDS were reinforced by hard and painful hospital visits (Frances, unpublished; Lovejoy, 1989; Tiblier et al., 1989). Family members experience societal ignorance, homophobic intolerance, fear and frustration endorsed through the bureaucracy of the establishment, and acted out by clinical staff. The inability to obtain the resources she needed resulted in one mother expressing her anger at the doctor for the way she was treated.

> Why can't we get experimental drugs? And why doesn't the lung specialist talk to me in words I understand? Is it my imagination or is he avoiding me?
> (Pohl et al., 1990, p. 56).

In addition, preventative hospital procedures such as isolation gowns, and yellow triangles, which mark the rooms of contagious patients, acted to isolate, physically and emotionally, family members from their relative, and remind them that he or she is no longer "normal" (Flaskerud, 1992; Frances, unpublished; Lovejoy, 1989; Peabody, 1986). Those involved with out-patients contended with frequent appointments, extended waiting periods, and endless delays for tests and results (Peabody, 1986). Family members perceived themselves as being managed by the illness, as they monitored blood counts, absorbed complex medical information, coped with "a sea of drugs" (Frances, unpublished), and negotiated for new drug regimens (Brown & Powell-Cope, 1991; Flaskerud, 1987; Tiblier et al., 1989). Frances provided an example of some of the stressors she dealt with on one day.

> G has to see a Urologist, then the Doctor phoned and G's blood was 1 instead of 4, so now he needs a transfusion. That was yesterday - today G is threatening suicide again.
> (January 28th 1990).

Research which addressed the AIDS trajectory from a phasic perspective reports that although relative health is possible towards the end of the early stage, the severity of the patient's symptoms and suffering increases (Caring Together, 1989; Tiblier et al., 1989; Matocha, 1989). As a result, additional realities for family members involved keeping pace with new and recurring infections and symptomatologies while witnessing their toll manifested in a changed body image, physical debilitation, disfigurement, loss of weight and dignity. In her autobiographical account of the experience, of having a son diagnosed with AIDS a mother summed up these bio-medical realities, by writing "It is not easy to watch your son waste away in front of your eyes" (Peabody, 1986, p. 46).

Research on the impact of AIDS on the gay man's homosexual and heterosexual families has led others to conclude, that in addition to the *bio-medical realities, familial realities* are played out in the system with whom the AIDS individual interacts (Lovejoy, 1989). In an article which used secondary analysis from case studies, Tiblier et al., (1989) speculate that family identity following an AIDS diagnosis will never be perceived in the same way again, and the family immediately begins to adapt to that loss. This was not confirmed by studies using primary data. However, Moynihan et al., (1988) and Rolland (1987), who drew on literature relating to different terminal diseases, suggested that the diagnosis of a relatively young person's chronic disease and likely premature death, represents a non-normative stressor in the individual and family life cycle.

In the early stage, when AIDS most often is figuratively, and in many cases, literally, "brought home," by the diagnosis, family members feel forced to provide emotional, instrumental, and physical care (Cates et al.,1990; Pearlin et al., 1988). O'Donell & Bernier (1990), define this new phenomenon, in terms of a "re-entry of parents as caregivers." They agree with others who speculated that additional stressors resulted from the developmental conflicts of reintegrating an adult child into the family, coping with chronic illness, and issues of homosexuality (Cates et al., 1990; Lovejoy, 1989). However, no additional research was found to substantiate this.

According to some writers, the *familial realities* of AIDS at the early stage ranged from ongoing friction to total lack of interaction of its members, resulted in interpersonal relationship changes and family disruption (Cowles & Rodgers, 1991; McDonnell, Abell & Miller, 1991). They suggested that an AIDS diagnosis represented an untimely death of a family member to a socially unacceptable disease. Consequently, for some family members the diagnosis precipitated a personal crisis of values and beliefs (Lovejoy, 1989).

Researchers who studied the family's experience, reported that for those unaware of, or unable to accept the source of the disease, the diagnosis represented a "double whammy" of stressors; those associated with diagnosis of a terminal disease, and others related to lifestyle held responsible for contraction of the disease (Chekryn, 1989; Siegl. 1992; Strawn, 1987; Stulberg & Buckingham, 1988). However these findings relied upon data from subjects who predominantly represented the homosexual lifestyle. It is regretted here that despite current reports of AIDS affecting male and female heterosexual people and young children, the dominant research and cultural images of AIDS still equates contraction of the disease with male homosexuality. In light of such reports, research which recognized the current epidemic shift, and distinguished AIDS stressors according to contraction from different sources, would have enriched this analysis.

Irrespective of the method of contraction, it was a commonly held view that moral judgements regarding promiscuity and other transmission behaviors impose unique *social realities* on families experiencing AIDS. These were manifest in stigma and resultant shame (Chekryn, 1989; Macks, 1988; Stulberg & Buckingham, 1988). Stigma develops from the discrepancy between social expectations perceived as normal, and abnormal (Goffman, 1963). AIDS related stigma was attached to a new and different epidemic involving aesthetic and repellant "Leper-like" characteristics, (Herek, 1990), contagion, sexuality, death and dying, and unacceptable cultural lifestyle (Giacquinta, 1989; Moynihan et al., 1988). These traditionally avoided subjects induced a societal fear, panic, moral righteousness, homophobia, rejection and ignorance (Strawn, 1987; Stulberg & Buckingham,1988). Consequently, family members experienced feelings of shame on learning of the diagnosis. In their discussion paper, Stullberg & Buckingham (1988) provide an example of how AIDS stigma affects the family's ability to continue one of its basic functions.

> When the social worker suggested to the father that the best thing he could do for his son, who had AIDS, would be to take him back to his hometown to be cared for by the family, the father replied, "Oh I couldn't possibly. I mean, he has AIDS. What would we say to people?"
>
> (Stullberg & Buckingham,1988, p. 357).

Family members experienced *attached stigma* , once their involvement with AIDS became public (Herek, 1990). This was invariably manifest in social isolation, rejection, and other negative responses. A mother described one form of isolation and rejection within her own family.

> We were so close before Al got AIDS. Then there was no contact, whatsoever with the cousins. They never even sent a note.
>
> (Giacquinta, 1989, p.31).

Another mother described her experience of attached stigma as it applied in the workplace.

> They forced me at work to be very quiet about him having AIDS. They threatened my job. My job was secure as long as I didn't tell anybody.
>
> (Gregory & Longman, 1992. p. 339).

Societal practices and behaviors expressed in these types of hostile reactions intensified personal uncertainty and discomfort, concern for personal vulnerability, feelings of shame, and challenged personal and moral values, cultural and religious ideals. Thus the stigmatization represented a more devastating reality than the disease itself (Strawn, 1987).

The fear of stigmatization invariably evoked a climate of family denial and secrecy surrounding the diagnosis of AIDS. In unstructured interviews of family members, Giacquinta (1989) found that individuals with AIDS routinely requested non-disclosure of the diagnosis from friends and other family members. Although this strategy enabled the person with AIDS to cope, evidence suggested that having a secret presented family members with additional and ambivalent stressors. For example on August 25th.1989, Frances wrote:

> I am aching to be able to be honest with someone, almost anyone. I hate having to lie about G's illness. I can't seem to feel trust or support in anyone.

In this case ambivalence was inherent in her need to tell someone, to alleviate some of the stressors, together with fear, manifest through distrust, of the reactions of those she told. Stressors inherent in having a secret at the early stage included: inability to label the disease appropriately, knowing who to tell, remembering who knew and who did not, inability to seek certain information, make changes, and guarded interaction in social and familial relationships (Stulberg & Buckingham, 1988). Keeping the secret compounded the fears, isolation and deprivation of support (Zlotnik, 1987). Alternately, seeking appropriate help meant telling a world marred by societal homophobic attitudes, AIDS hysteria, stigmatization and rejection (Lovejoy, 1989). Consequently, it is suggested here that the ambivalence and moral dilemma imposed by secrecy at this point had a profound effect on the realities and management of AIDS at this stage.

It was commonly accepted that isolation and loss were key concepts in understanding the impact of AIDS on family members (Gregory & Longman, 1992; Sherr, 1989; Strawn, 1987). Loss was defined as a state of being deprived of, or being without something one has had (Rando, 1984). Losses took different forms and were tangible, i.e., physical, or intangible, i.e., symbolic. The predominant loss in the early stage was a loss of control over the diagnosis, pathology, disease process, symptomatology, psychosocial restrictions, therapeutic regimen, economic deprivation, clinical and hospital staff and protocol, and the dependence of the person diagnosed with AIDS (Cates et al.,1990; Flaskerud, 1990; Frierson et al., 1987; Herek, 1990; Sherr, 1989).

From the family member's perspective an AIDS diagnosis of another family member also represented a non-sequential loss of tangible and symbolic family assets. The effects of loss were felt within the family structure, and relationships held in future family roles, and represented a loss of hopes, dreams and expectations (Hill, 1958; Moynihan et al., 1988; Rolland, 1987; Strawn, 1987). According to Gregory & Longman (1992), who studied the suffering of mothers of sons with AIDS, for those women the diagnosis and subsequent loss served as a catalyst for a loss of sense of self and personhood.

MANAGEMENT

Family management at this phase was a process of *Living with the knowledge of an AIDS diagnosis.* It involved the use of mechanisms designed to quell the emotionally painful realities of the diagnosis. These mechanisms provided time, and protected family members from the shock and painful truth, while they rapidly assimilated and tested the realities for similarities and discrepancies to "the norm" (Cates et al., 1990).

COPING.

Family members countered the realities of the disease by taking control, and getting on with living with the knowledge of an AIDS diagnosis. To take control family members assimilated knowledge, reorganized their cognitions, and regulated their emotions and actions regarding the disease, the individual with AIDS, other family members, and society as a whole. Taking control in this way enabled them to reduce the effects of the realities of the diagnosis, to make sense of what was happening, and to have clearer choices and decisions regarding what to do, and how to proceed (Brown & Powell-Cope, 1991; Matocha, 1990).

In qualitative studies regarding family members experiences of having a loved one diagnosed with AIDS, several researchers found that family members took control at the early stage by "not letting the truth hit home," which they invariably maintained through denial (Dietz & Hicks, 1989; Matocha, 1990; Siegl, 1992). It was generally agreed that denial was commonly used as a coping strategy in all terminal illnesses. From research with dying patients, Kubler-Ross, (1969) reports that denial provides a healthy way of coping. The researcher pointed out, that in the same way that we cannot look at the sun all the time; neither can we face death all the time. "Sometimes it is necessary to put away consideration of death to pursue life" (Kubler-Ross, 1969, p. 35). Faced with the diagnosis, denial selectively protected the user against the overwhelming pain emanating from the realities which he or she was not ready to deal with. In the following example when a sister talked about telling others, she indicated two benefits of "not letting the truth hit home."

> Telling others was a painful task because it reinforced our reality, and there was the fear of judgement, stigma and rejection.
>
> (Haque, 1989, p. 232).

Whereas another sister admitted to her knowledge of the diagnosis but tried to prevent the truth hitting home by disproving it ."There's been a mistake. They got the blood samples mixed up" (Pohl, Kay & Toft, 1990, p 66). In this way she coped by maintaining denial.

In the early stage denial provided time to get used to the diagnosis and its implications, work through feelings, devise means of dealing with the crisis, and cope with day-to-day living (Lazarus & Folkman, 1984; Martelli et al., 1987). In an autobiographical account, a sister explained some personal benefits of coping this way.

> We found denial was a helpful coping mechanism because it allowed us some relief from the anxiety ......It permitted us to direct our energy toward going on with our lives. It is not possible to deal with death and sorrow every day.
> (Haque, 1989, p. 233).

She used denial to take care of herself, while she provided care for her brother.

It is suggested here that family members utilize denial selectively throughout the disease trajectory, to accommodate the bio-medical realities of each stage. For example, in the early part of this stage, they maintained the diagnosis was a mistake, and denied its existence. Later on as the disease took hold they ceased denying the diagnosis, choosing instead to deny certain aspects of the illness, such as its terminal prognosis. Family members demonstrated denial when they insisted that the AIDS test be repeated over and over again, pretended that the person was not sick, acted as if nothing had happened physically or emotionally withdrew, or made plans for the future which may never be carried out (Martelli et al., 1987;

Matocha, 1990; Pohl et al, 1990). Their denial was also expressed in anger, depression, use of impersonal words when describing the patient's illness, and/or avoidance of the health care system (Lovejoy, 1989). One manifestation of denial particularly synonymous with AIDS was secrecy (Lovejoy, 1989 ; Matocha, 1990; Siegl, 1992). Where the diagnosis was likely to evoke undefendable stigma, and introduce more stressors, anecdotal reports suggested that the choice to restrict information of the diagnosis, by maintaining secrecy, represented a viable short-term coping strategy at this stage (Frierson, et al., 1987; Martelli et al., 1987). Unfortunately, despite the importance of their suggestions no empirical research was found to support this claim. However, as noted earlier, keeping the secret also represented a stressor. Pohl et al. (1990), suggested that family members moved beyond the feelings of the early stage by sharing information of the diagnosis with someone, despite their fear of reactivating more stressors. It is noted here, and substantiated by the following example, that making the decision of when and whom to tell about the diagnosis greatly enhanced the management of AIDS. In an autobiographical account the sister of a family member wrote:

> Once those significant to us knew and accepted his illness, one burden was lifted, which decreased our anxiety.
> (Haque, 1989, p. 232).

Making decisions to share the secret, and taking control in this way, signalled a change in attitude, and a resultant lightening of some stressors. When family members came to grips with sharing the information, they no longer denied the diagnosis (Pohl et al., 1990). Consequently, this change provided the catalyst for setting new patterns regarding how family members managed the remaining realities of the AIDS trajectory. These included keeping busy, spending money "now rather than later" and taking physical care of the patient. Giving up time, social relationships and, in some cases, money, to become involved, and taking care of self, were all used as early stage coping strategies (Brown & Powell-Cope, 1991; Lovejoy, 1989; Matocha, 1990; Giacquinta, 1989). Taking care of self involved physical, psychological and spiritual acts for maintaining personal health, such as exercise, medication, physical contact, meditation, emotional self-examination, positive self-talk, and spiritual and religious rituals (Lovejoy, 1989; Siegl, 1992; Tiblier et al., 1989). This type of coping was expressed in accordance with the personality of each family member. Those who used non-expression of thoughts and feelings took control by bottling it up, putting on a brave face, disbelief, rationalization, denial, depression and social and verbal withdrawal (Peabody, 1986; Siegl, 1992). Alternately, those who "gave vent to feelings" used endless questioning and rehashing of the past, getting angry, blaming, and crying. (Flaskerud, 1992).

RESOURCES.

Family members used resources to gain control and maintain hope (Tiblier et al., 1989). At the early stage, these resources represented knowledge and support. Reports suggested that family members attempted to quell the painful realities of AIDS through relentless pursuit of concrete knowledge and information which they could trust (Kelly & Sykes, 1989; Kazarus & Folkman, 1984; Lovejoy, 1989; Pohl et al., 1990; Sosnowitz & Kovacs, 1992). A mother described the form which her information seeking took.

> After you know for sure, then you read everything you can get your hands on. At least I did....You listen to everything on the radio [and] television. Whatever's coming, if you hear something, you try to get a hold of it. You are constantly looking for information
>
> (Siegl, 1992, p.60).

The literature provided several examples of how family members read anything, and everything, in their attempts to make sense of the situation, increase hope regarding a possible cure, learn how to cope physically and emotionally with the disease and deny the inevitability of death (Frances, unpublished; Siegl, 1992). However, issues of secrecy and confidentiality pertaining to AIDS restricted the pursuit of knowledge to readily accessible written, and audio-visual information and information hotlines (Boland & Conviser, 1992).

Reports suggested that information-seeking served several purposes. These included identifying available choices, helping to make informed decisions and maximizing effective problem-solving techniques (Lovejoy, 1989). In so doing it reduced the effects of the bio-psychosocial realities that the diagnosis evoked (Frierson & Lippman, 1987; Greif & Porembski, 1988; Martelli et al., 1987; Moynihan et al., 1988; O'Donnell & O'Donnell, 1987; Pohl et al., 1990), and provided a valuable form of confidential support, which Haney (1988) suggested was one means of empowering people. Information also helped to normalize the experience and gave the individual permission to grieve (Schoen & Schindelman, 1988). Clinicians suggested that family members needed to have misinformation corrected, and receive accurate information in a timely manner (Lovejoy, 1989). This was confirmed by (Siegl, 1992, p. 61) who found that untimely information providing "gory details" of numerous diseases, and future possible complications, sometimes prematurely, increased the stressful reality of AIDS by supplying facts that were considered to be overwhelming.

The major type of information sought at this stage concentrated on "what to expect" regarding the basic facts of the disease. Family members wanted to know the route of transmission, likely prognosis, possible treatments and their rationale, and the potential for contracting the disease through involvement with the person having AIDS (Lovejoy, 1989; Frierson et al., 1987; Siegl. 1992). Matocha's (1990) study of AIDS patients and their partners, two to six weeks after diagnosis confirmed this.

> Paul needed specific information during this initial phase. He needed to know what to expect in the future for Alan and himself, side effects of medications, what kind of plans could be made for their immediate future, how Alan's disease would progress, and what symptoms Alan might exhibit.
> (Matocha, 1990, p.100).

In gathering information about the disease, family members were also looking for information that would alter their perception of AIDS as incurable, and maintain hope. In her study Siegl (1992, p. 61) provided an example of one mother's attempt to use information to increase hope."We hoped, and we looked for, and we were quite diligent in our reading everything, and trying to get the doctors to do this, that, or the other thing" It was assumed here that the mother was searching for information which related to possible cures.

Towards the end of this stage facts alone did not suppress the sadness, fear, shock and other early stage emotions, or highlight the most appropriate responses (Pohl, et al.,1990). A few family members expressed a need for interpersonal support, to work with their feelings, and share their burden (Kelly and Sykes, 1989; Pohl et al., 1990). This was often sought from trusted friends, family members, and telephone counselling. The latter was particularly beneficial since it provided a confidential form of support which the researchers considered to be a means of enhancing the clarity and perspective of the realities (Pohl et al., 1990).

PERCEPTION.

According to Gregory & Longman (1992, p. 353), perceived orderliness and controllability in life are essential to survival. The authors suggested that in the face of turmoil, such as an AIDS diagnosis, the individual's ability to impose order is severely challenged. Therefore to create order out of the turmoil, family members reconstructed the subjective meanings associated with the realities of AIDS to represent a more positive perception. For example several family members tried to see the diagnosis as an opportunity to bring the family together and care for someone who had been estranged. Doing this allowed family members to interpret the experience in ways that preserved their sense of competency and self-esteem which was essential for coping and adaptation. This may be especially hard to achieve in the case of AIDS which carries both a negative cultural meaning, and the perception of a death sentence (Strawn,1987). Since either one of these exerts numerous stressors on the situation, the prospect of the joint effect on the family member's perception could be potentially catastrophic.

The subjective quality, or "meaning" attributed to each stressor in the early stage was expressed in terms of thoughts and feelings. At the beginning of the early stage, when family members experienced shock, perception was most often expressed in negative thoughts and feelings which related to being out of control, helpless, feeling unreal, threatened, and overwhelmed by the news (Frierson et al. 1987; Martelli et al. 1987; Peabody, 1986; Siegl, 1992). In the absence of successful treatments, the overall outlook was frightening and was perceived as negative. Strawn (1987) suggested that guilt and shame are common components of the experience which shaped a family member's perception, particularly at the commencement of this stage.

Perception fluctuated in accordance with the length of time since the news broke, the existing pathology, the coping strategies used, and the resources that were available. Consequently, as the news began to take hold, family members struggled with the negative and positive aspects of the diagnosis in order to give new meaning to the situation (Siegl, 1992). At any point in this stage, a family member's perception could be divided between hopelessness and hope, depending upon the extent of their denial or acceptance of the diagnosis. As family members gained more experience and knowledge of the disease and its implications, and increased their abilities to handle these aspects, their perceptions of the situation varied tremendously from devastation, hopelessness, confusion and uncertainty to a new level of control manifest in denial, hope, and belief that the problem would be overcome. A sister described the hope she experienced at Easter when she was caring for her brother:

> Easter is always filled with hope, and we clung to each other with hope for a cure and miracles.
>
> (Haque, 1989, p. 231)

In this case, the sister's perception was evaluated and enhanced by means of a spiritual endorsement at the time of a celebration. From knowledge of family interactions it is suggested here that the level at which the realities of AIDS are perceived relies upon an interdependent process comprised of each family member's subjective evaluation of the problem at any moment. Perception is therefore evolving constantly and idiosyncratically and it is defined by each family member according to a set of personal, objective, cultural and subjective definitions. In the autobiographical account of her son's struggle with AIDS, a mother provides an example of evolving perception shortly after diagnosis in a conversation between her and her husband who is a doctor.

> His chances of surviving aren't good, they told me." His father-eyes glisten but his voice is calmly professional.... "He waited so long to get help....he was so sick when admitted." " At least every day he lives is a good sign. I think we should get more opinions," I said, find out what's being done in research on AIDS.... If he pulls through this ....I hesitate as the tears of uncertainty and anguish surface. "If he pulls through, were
>
> (Peabody, 1986, p. 19)

In this example the father's perception was defined by the bio-medical realities, and reinforced by resources gained from his professional knowledge. He coped with his pain by preparing himself, and defining the situation as hopeless at that moment. The mother was partly influenced by her husband's perception and behavior at that moment, and her perception momentarily matched that of her husband, as hopeless. However, she managed to change her perception to hopeful, by exploiting the coping mechanism of getting informed. This example depicts the complex transitory and idiosyncratic nature of perception, and may explain why no measurement nor studies of perception could be found. Consequently, no definitive account of perception could be attributed to the early stage.

ADAPTATION

In order to adapt at this stage family members attempted to situate the AIDS diagnosis within their lives and come to terms with living with the knowledge of an AIDS diagnosis. The process involved constant assimilation and adjustment to the situation. Family members who adapted, learned to accommodate to the diagnosis, and make choices regarding re-establishment of a sense of order and structure, in a world made chaotic by the diagnosis (Gregory & Longman, 1992). The outcome of this stage fluctuated back and forth on an adaptation continuum between bonadaptation as acceptance, and maladaptation as fervent denial of the diagnosis.

PROGRESSIVE STAGE

> *July...good memories, 4th of July barbecue, visits to the city, and times to laugh.We tried to live in the present and enjoy each day, although we envisioned the future which had death as its finality.*
> *September... still upbeat. John was still feeling good and friends gave him a birthday party. It took energy to enjoy the celebration and not focus on next year when he might not be here.*
> *October... John's energy level was decreasing. He lost a few pounds. He was still working, but it was becoming a struggle.*
> *Late in October...another crisis, more respiratory problems and extreme fatigue. He was better by the end of the week.*
> *November...Thanksgiving and another crisis. John called me that morning crying and telling me he thought he was dying. He had difficulty breathing. I remember the panicky feeling I had as the reality of death was getting closer. Later that day his breathing problem vanished, and he joined us for Thanksgiving dinner.*
> *December..A few days before Christmas, John called and said he was having fun making cookies with friends. On Christmas Eve, he was so fatigued he was unable to attend church services. Boxing Day we watched his higher level of energy and better mood, it was easy to deny this illness-at least for a while.*
> *January .. a sad but rich experience on New Year's Day. John and I talked for the first time about his eventual death.*
> *One week later...another opportunistic infection of tuberculosis, and he started on a new medication to reduce his respiratory symptoms. He was excited and again, active and hopeful. The conversation of New Year's Day was put aside.*

Extracts from an autobiographical account of a sister's two year experience of having a brother with AIDS.
(Haque, 1989. p.233-234).

The progressive stage of AIDS is distinguished by the erratic course of the illness at this point. The alternating periods of health and illness recorded in Haque's (1989) autobiographical account of caring for her brother who had AIDS, are representative of a *chaotic stage*. Her experience of this stage was likened to "being on a see-saw, on which the family struggled for balance, when the good days brought hope and the bad days erased it" (Haque, 1989, p. 235).

REALITIES.

Despite the eruption of alien stressors in the previous stage, family members attempted to live in the present by resuming the business of regular life, establishing a new equilibrium, coming to terms with several aspects of the situation and beginning to take new forms of action (Pohl et al. 1990). Although some stressors still existed around the diagnosis, new stressors evolved from waiting for the next opportunistic infection and the deterioration in health which it manifested. Consequently, this period was often labelled the "roller coaster phase" of the disease (Brown & Powell-Cope, 1992; Cates et al., 1990; Peabody, 1986; Siegl, 1992; Stullberg & Buckingham, 1988). Writers used this metaphor to describe the emotional impact of the frequently violent unpredictability of AIDS, which they defined in terms of alternating periods of stability and crisis.

CRISIS.

The crisis which identified the progressive stage was the sudden and simultaneous change in the disease pathology, increased occurrences and severity of opportunistic infections, and a marked deterioration in health. This sudden change was particularly problematic for family members because it followed a relatively steady period of several months, in which the person with AIDS had been free of symptoms and able to resume a semblance of "normal life."

PILE UP.

The progressive stage represented an agitated and cognitively busy stage, which was much shorter than the early stage. Although no studies had quantified the stages, in autobiographical reports of Haque (1989), and Frances (unpublished) who dated their experience, indicate that this stage lasted for approximately five months. In that time the bio-medical realities of AIDS fluctuated to the extent that one day seemed hopeful, and the next seemed overwhelmingly hopeless (Cowles & Rodgers, 1991). Studies found that the bio-medical realities are idiosyncratic to the person with AIDS and depend upon the type of opportunistic infection, the level of multi-system deterioration, and the availability of treatment (Britton & Zarski, 1989; Caring Together, 1987; Eidson, 1988; Grieg, 1987; Kiecolt-Glaser & Glaser, 1988). The problems which occurred, such as pneumonia, diarrhea, skin lesions, fungal infections, anorexia and mal-absorption were invariably acute, and usually required hospitalization. Throughout the times of increased infections, those infected were neither able to work, socialize nor care for themselves. Fatigue was intense, activities were reduced to a minimum, and social isolation was compounded at these times. Active treatment continued throughout this stage, for as long as there was some positive response in the patient's health. However, weight loss and fatigue were ongoing and behavioural changes due to neurological, or mental impairment became obvious (Brown & Powell-Cope, 1992; Flaskerud, 1992; Haque, 1989; Lovejoy, 1989; Matocha, 1989; Peabody, 1986; Siegl, 1992; Tiblier et al., 1989).

These problems created a profound effect. Involved family members experienced ongoing upheaval, with sudden changes, and fluctuating stressor pile ups on a daily basis. Although these may have been bio-medically induced, the stressors reflected the emotional upheaval of perpetual uncertainty (Brown & Powell-Cope, 1992; Flaskerud, 1992; Lovejoy, 1989; Matocha, 1989; Siegl, 1992). The sister of an AIDS patient wrote that "the roller-coaster effect on one's emotions is incredible." (Haque, 1989, p.236). Alternate periods of health and sickness increased uncertainty with regard to the future and prevented enjoyment of any relatively calm periods (Brown & Powell-Cope, 1991). Family members therefore lived with the constant uncertainty of what would happen next, and when it would occur.

It was also suggested that ongoing fears associated with aspects such as, contracting the disease, the patient's deterioration, death and dying, how much time was left, and the inability to care for the person with AIDS added to the pile up at this time (Cowles & Rodgers, 1991). Uncertainty, first identified in the early stage, remained as a constant stressor, but its focus changed (Brown & Powell-Cope, 1990). It was not so much the reality of the diagnosis which was questioned at this stage as the outcome over time, and how it should be managed. This was expressed in questions such as "should I make funeral arrangements?" (Frances, unpublished), do we need to change our insurance policies? who will have power of attorney? (Pohl et al., 1990). It was also manifested in interactions with the person with AIDS. This was the case for one partner who recalled his experience in this way.

> I would never bring it up... he [person with AIDS] did bring it up several times. He gave me a list of names of what personal items he wanted to go to them when he died. That was the most difficult thing for me to do. I had to sit there and look at someone who is dying and discuss his death. I had never done that in my life.
>
> (Matocha, 1989 p.121).

These examples suggested that the issue of death was being covertly and in some cases overtly addressed at this stage.

Unfortunately no research dealt specifically with when and how family members began to address "death issues". Anecdotal and autobiographical material suggested that despite attempts to remain hopeful of a cure, family members were constantly aware of the terminal nature of the disease, and had begun to think about the death of the person with AIDS, by this stage. In light of this, and based on family stress theory, it was assumed that once a family member recognized the incurability of the disease, there would be a profound effect on the meaning subsequently attributed to any new stressors that arose.

As stated earlier, research and anecdotal reports suggested that family members had either begun, or were often forced to share the secret of the diagnosis by the progressive stage (Brown & Powell-Cope, 1992; Giacquinta, 19 89; Matocha,1989; Siegl, 1992; Martelli et al.,1987). Although secrecy was a major issue in AIDS, little was found about its operationalization, maintenance, or the process of sharing it with others. However it was noted that the effects of telling others presented additional stressors for some family members. Haque (1989, p. 232) wrote that "telling others [about the diagnosis] was a painful task because it reinforced our reality, and there also was the fear of judgement, fear and rejection".

Giacquinta (1989) found that stifled family communication patterns among family members contributed to the pile up of stressors at this stage, and helped to maintain a climate of secrecy between family members. She provided the following example from her observations and interviews of 45 AIDS family members, regarding the effects of AIDS on families.

> My husband Bud, and I have never talked about Hal's AIDS or gayness. Bud's reaction to Hal's diagnosis is anger, I'd guess. There are all these walls there so I can't get to my husbands feelings. I imagine that the gayness is why he is so quiet, but I really shouldn't say. I have no way of knowing what goes on inside my husband's head. Furthermore, I don't tell Hal how I'm feeling... I feel that I don't want him to know that he's not going to make it.
>
> (Giacquinta, 1989, p. 32).

In this example, fear of anger, negative coping strategies, stressors associated with aspects of homosexuality, homophobia, and premature death and dying, were all given as reasons for maintaining a climate of secrecy among family members. Research which assessed the psychological repercussions of AIDS on family members found a difficulty between some family members in addressing homosexuality. Frierson et al. (1987) found that in virtually all of 50 interviewees, communication patterns tended to be easier among siblings, and difficult between AIDS patients and their fathers. The researchers suggested that as fathers traditionally have problems in accepting a homosexual son, it was the issue of homosexuality rather than the AIDS diagnosis which represented the major stressor. What remains unknown is whether it was specifically the issues, as suggested, or the pattern of family communication that existed prior to the diagnosis, that was responsible. Research which addressed communication patterns in families with AIDS would have been helpful here, since communication represents an important resource in the management of family events (Hill, 1958), and the management of grief post-death (Piemme & Bolle, 1989).

As the progressive stage advanced, "keeping the peace" in interpersonal and family struggles, and "keeping pace" with new information and ongoing mental and physical deterioration, presented family members with additional stressors (Frances, unpublished; Peabody, 1986). In their instructional material, Rowe, Plum and Crossman (1988) suggest that a family member's reaction to being told of the diagnosis is idiosyncratic. Reaction represented a composite of each person's perception, and resources, and the application of these to all the stressors which the person associates with AIDS. The way in which the family members act out their reactions invariably caused additional family interaction problems, and imposed additional stressors. Frances (unpublished) recorded several examples of family relationship stressors in the progressive stage, and the effect which these had on her perception of the realities of AIDS.

> June 29th to August 27th. Everyday is different and upsetting. G wants a holiday. I am not sure he can cope. His ideas are so selfish. Me only.... I need to know what will happen to the rest of us....
>
> C [niece of the diarist, and daughter of G] has been typical, grad, exams and irresponsibilities.... Dad was admitted to psychiatric care -boy this is an ongoing agony....Thoughtless relatives arrive....P [husband] and I are no longer communicating....T [sister] is slowly losing it....Its tough keeping our family together... our ties seem to be fraying....I seem to be caught in the middle again, is there no end to the bad stuff?....Mum and Dad seem to be waiting for me to come to some wonderful conclusion....I'm still waiting for answers to the chaos.

Not all family members were aware of the diagnosis (O'Donell and Bernier, 1990), or offered care. O'Donell and Bernier (1990) point out that in some instances, family members first find out about their relative's diagnosis when he, or she dies. Where AIDS was contracted through lifestyles of homosexuality, additional stressors associated with unacceptable relationships, i.e., same sex partners were evoked (Lovejoy, 1989). Stressors arose when members of the family of origin were confronted with a gay lover and gay friends, who had invariably provided primary support to this point (Horsley, 1991; Stullberg & Buckingham, 1988). Issues of homophobia which may have been tolerated at a distance, became reignited and severely tested on face to face contact with such unconventional family members. In addition, major conflicts began to arise over feelings of jealousy and resentment, decisions regarding who would care, and how this was to be achieved (O'Donnell & Bernier, 1990). As the deterioration became more obvious, the uncertainty regarding who would care for the person with AIDS became an additional stressor at this point (Chekryn, 1989). Relationships can be so strained at this point that family members struggle with the ambivalence of wanting to end the relationship, and the guilt of leaving when the diagnozed individual is sick, weak and helpless (Martelli, Peltz & Messina, 1987; Tiblier et al.,1989; Pohl et al.,1990).

Towards the end of the progressive stage when the seriousness of the disease had become self-evident, family members who were involved in care experienced a loss of peace of mind. A friend of a person with AIDS who later became a lover said, "There's always a threat hanging over you; there's always a little bit of tension, its always in the back of your mind" (Brown & Powell-Cope, 1992, p. 13). Consequently, the feeling of living in limbo and not knowing what will happen from one day to the next, increased physical and emotional fatigue, dependence on health-care practitioners and lack of solutions, all represented new and ongoing stressors (Frances, unpublished; Peabody, 1986; Tiblier et al.,1989). In addition, the person's cumulative physical losses had begun to destroy family members' long-term hope of recovery by this point (Peabody, 1986; Pohl, Kay & Toft, 1990; Tiblier, 1987).

MANAGEMENT

The realities of AIDS at the progressive stage were two dimensional; symptomatic and asymptomatic. Consequently, the management at this stage constituted keeping a constant vigilance, interpreting subtle symptoms and comparing these to the experience of what currently represented the norm. Having distinguished the current reality, family members made choices and acted accordingly. As the bio-psychosocial progression of the disease at this stage was constantly changing, management represented a constantly active process of "thinking on ones feet", and spontaneous actions as each new stressor occurred.

COPING

Reports and studies of the experience of having a family member diagnosed with AIDS suggested that coping with the constant impact of alternating periods of health and deterioration in the progressive stage was a complex and stressful process (Brown & Powell-Cope, 1989; Matocha, 1989; Peabody, 1986; Siegl, 1992). Although many of the early stage coping methods and strategies remained evident, new ones developed as family members continued their attempt to "take control" through the reorganization of cognitions, emotions and actions of all those involved. Family members determined the current reality, as either symptomatic or asymptomatic. As a result coping strategies at this stage were three dimensional, two sets of strategies for dealing with the different realities, symptomatic and asymptomatic, and a third set for dealing with personal needs. Family members attempted to maintain a semblance of balance of control over the realities at this stage by using these strategies interactionally. One particular strategy that was noted was "keeping busy". A mother of an AIDS patient explains why.

> I finally had to ask [her son] if there was something I could do, because I felt so helpless.
>
> (Siegl, 1992, p. 70).

In the asymptomatic phases of this stage, family members felt helpless and counteract by watching and waiting for new symptoms, and providing care. Frances recorded her brother's symptoms at the beginning of each diary entry. Aug 7th...."G's blood is 1. and he is sleeping hours.... Aug 27th....G has been in for more blood. Sept 6th.... G in hospital again, blood dropping again, more transfusions. Family members also watched for signs of improvement. In one journal account of her son's struggle with AIDS, Peabody wrote:

> My fingers have been crossed night and day and I hardly dare to hope. What is happening? Peter has felt vastly better the last two or three days...we wonder what has caused this improvement, could the [new] drug be working so soon? We must enjoy it while we can.
>
> (Peabody, 1986, p. 119).

When family members were able to take care of the situation it enabled them to regain some control, and increased their hope of reverting the physical deterioration. In the context of AIDS, taking care included "being involved" in what was going on and "being there", for the person with AIDS. A friend of an AIDS patient described "being there" in the following ways.

> Everyday I would come in and bathe him...most of the time I would have dinner with him. I'd be with him sometimes until twelve or one o'clock. On the nights he was really bad off, I would spend the night with him. "
>
> (Matocha, 1989, p.39).

Family members found they were able to maintain an increased physical and verbal presence by generally assisting with care. It provided them with opportunities to keep "talking it out" with the person with AIDS. At the same time family members learned all they could by "keeping tabs" on the current and likely future symptoms and preventative therapies. They sought new resources, performed small acts of compassion, such as driving the patient to the hospital, buying groceries and providing economic support for new drugs (Frances, unpublished; Matocha, 1989; Peabody, 1986; Pohl et al., 1990). One mother felt that preparing meals for her son was the best way to cope and keep her son healthy as well. For example she described how she did this. "I tried home cooking, cooked stuff and froze it and [took] it over to him" (Siegl, 1992, p. 83).

Keeping busy in the symptomatic phase usually involved a more intensive form of giving caring, which was loosely defined as informal caregiving. Family members seemed to adopt gradually to this role as the disease progressed. Caregiving at the progressive stage was an intermittent role which family members coped with as best they could. In their book, entitled *Caring for a Loved One with AIDS*, which was developed from a study of AIDS caregivers, Brown and Powell-Cope (1992) provide an example of caregiver coping when the person with AIDS is symptomatic.

> In the never ending struggle to manage the constantly changing symptoms, caregivers reported that they would reuse or revise the strategy they used for the last symptom. If it didn't work, they would discard that strategy entirely and come up with new ideas.
> (Brown and Powell-Cope, 1992, p. 26).

Family members assessed and dealt with their own needs in both asymptomatic and symptomatic phases. Frances wrote in her diary "I need something good for me." It was suggested that in caring for a person with AIDS family members have an ongoing need to establish and re-establish their autonomy, which they can achieve by taking time out (Martelli, et al., 1987). Taking time out to attend to personal needs, was a different form of keeping busy, as it usually involved engaging in activities away from the person with AIDS (Matocha, 1989). Some examples of this included setting up a personal support system and participating in organizations which provided AIDS support for others. Parents who took time out in this way expressed a need to be involved and to give back to society (Siegl, 1992). From in-depth interviews with 10 family members of AIDS patients, Cowles and Rodgers (1992) found evidence that involvement in what was termed "AIDS work" was one of the primary mechanisms used for coping. The researchers suggested:

> Although they attributed their motivation to become active in work that would benefit those with AIDS to their own personal experience and their increasing knowledge of the nature of the disease, it is also possible that the companionship they found in this work directly benefitted them.
> (Cowles and Rodgers, 1991, p. 11).

Family members felt the need to "carry on" at this point irrespective of whether the person with AIDS was symptomatic or asymptomatic. Although partners questioned their role in the relationship they rarely gave up at this stage (Martelli et al., 1987). Carrying on involved coping with uncertainty, and fast moving change (Brown & Powell-Cope, 1992; Siegl, 1992). Family members had two methods for carrying on, "fighting it" and "going along with the changed reality" (Siegl, 1992). Those who chose "fighting it" continued to use secrecy, selective denial and "keeping emotions in check."

Family members who admitted to the diagnosis went along with the disease and experienced the same problems as the person with AIDS. A mother described it this way: "They were on a roller coaster and so were you. When they were up, you were up. When they were down, you were down" (Siegl, 1992. p.6). To overcome these effects they coped by taking effective actions, seeking outside help, beginning to grieve, and making decisions for the future. As they no longer denied the presence of the illness they carried on by fighting the disease in any way they could. Physical attempts to fight the disease focussed on caring, whereas emotional and cognitive attempts to "carry on" continued through: "venting emotions", such as getting angry. Martelli et al., (1987) suggested that a family members' anger had several focii. These included anger at the disease, "why did it have to strike here?"; at the government, or God, "why did they, or he, let it happen?"; at the news media for describing the disease as fatal; at the family for being so narrow minded; at the doctors for not showing more concern, and anger at the patient for his or her irresponsibility. Family members invariably channelled their anger cognitively through "becoming knowledgeable" regarding prevention, symptomatology and seeking cures for each new disease. The mother of a daughter with AIDS said "I read, I look at TV......I guess what I'm looking for is a cure" (Matocha, 1989, p.138).

Coping still relied on selective denial and hope (Lovejoy, 1989; Siegl, 1992; Tiblier et al., 1989, Martelli et al., 1987). Denial at this stage focussed on reducing the severity of the symptomatology, and refuting the situation as hopeless and terminal. In Siegl's (1992, p. 77) study, a mother talked about her way of coping with the likelihood of her son's death: "I knew it was going to happen, but I refused to let myself believe [that] it was." Denial therefore assisted in the maintenance of hope. Hope at the progressive phase centered on a miracle drug to halt, or slow down progression and ensure long-term health and avoidance of premature death. Family members maintained hope at this phase by making things normal, intellectualizing, shifting priorities and responsibilities, keeping busy, and planning for the future. (Lovejoy, 1989; Pohl, Kay & Toft, 1990). This enabled them to maintain coping to the end of the progressive phase when hope of a cure became increasingly difficult to imagine.

RESOURCES.

The resources which family members acquired were those which provided new and specific information, reassurance, and a sense of stability (Flaskerud, 1992; Peabody, 1986). Writers suggested that the information most required at this stage related to identification of possible forthcoming infections, and the avoidance of contagion. (Flaskerud, 1992; Lovejoy, 1989; Matocha, 1989; Peabody, 1986; Siegl, 1992). Evidence for these findings was superficial and anecdotal.

Family members noticeably turned to support at this phase. The type of support they sought was dependant upon the level of secrecy which they maintained. Where family members were not limited by secrecy, they gained support through a variety of relationships and support networks. In addition to close family members and friends, they relied upon health care staff, support groups, religious affiliations, individual and family counselling, and community resources which catered specifically to AIDS (Diary; Flaskerud, 1992; Lovejoy; 1989; Peabody, 1986; Pohl, Kay & Toft, 1990; Siegl, 1992; Tiblier, 1987).

Researchers suggested that the benefits derived from these types of support networks included: new relationships based on truth; positive role models; exchange of information from personal experience; reduction of fear and anxiety, identification of central issues of concern and problem solving approaches, time to self, and "hope from those who know the system" (Kelly & Sykes, 1989; Newmark & Taylor, 1987; Pohl et al., 1990; Matocha, 1989). Those who actively sought new means of support found their relationships were strengthened by resources such as emotional support and small acts of kindness (Matocha, 1989), a shared history (Siegl, 1992), "unloading" (Siegl, 1992, Pohl et al., 1990), a sense of rapport with health care staff (Flaskerud, 1992; Tiblier, 1987), and improved communication patterns.

In the progressive stage family members relied more heavily on support provided through groups (Bowes & Dickson, 1991; Kelly & Sykes, 1989; Newmark & Taylor, 1987; Sosnowitz & Kovacs, 1992). Again, evidence to substantiate the use and value of such groups is currently unavailable, but writers suggested that the resources which these groups offered were numerous. Most especially they provided security within a non-stigmatized environment in which to determine the realities of AIDS. Bowes & Dickson (1992) wrote that support groups provide a safe place to say "AIDS". They acted to reduce the feelings of fear, loneliness, powerlessness and abandonment which were prevalent at this phase. This was achieved through the recognition that each group member was associated with a family member diagnosed with AIDS. Support group members provided a balanced opinion based on common experience, assurance, acceptance, help, and a safe environment in which to vent emotions and channel hostility into positive action (Flaskerud, 1987; Kelly & Sykes, 1989; McCann & Wadsworth, 1992). They also provided opportunities for empowerment through a sense of connectedness and sharing of problems, conflicts, and experiences. Some functioned as substitute kin, friends and neighbors (Lopez & Gretzel, 1987). All these aspects were considered beneficial resources at the progressive stage when self respect, encouragement, practical advise, friendship and the strength to carry on was vital (Haney, 1988).

Family members who still maintained secrecy at this point, generally relied upon support from counselling, or other forms of psychologic and spiritual help provided by community based organizations which offered confidentiality (Boland & Conviser, 1992). Additional beneficial resources not effected by issues of confidentiality included: hobbies and interests disassociated with AIDS; intra-personal techniques to enhance inner strength such as spiritual enrichment through prayer, meditation and visualization; physical unloading through exercise, laughter and keeping busy, over-eating, and the use of medications such as anti-depressants, cigarettes, alcohol, and other drugs (Frances, unpublished; Lovejoy, 1989; Matocha, 1989; Peabody, 1986; Siegl, 1992).

PERCEPTION

Although each family member's perception of the situation may be idiosyncratic, anecdotal material relating to the progressive stage indicated that perception was heavily influenced by the progression of the disease and the physiological, psychological and pathological state of the patient. In a study of eight family members who acted as caregivers to individuals with AIDS, Matocha (1989) found that the caregiver's "hope for life" expanded when the health of the person with AIDS stabilized. Whenever caregivers observed their loved ones with a severe illness return to normal living, this nourished an inner strength. Consequently, they adopted a belief that while there was life there was hope. In the absence of empirical research on perception, it was assumed that the perception of the realities of AIDS was controlled by this belief at times when the family member was well, but also reflected, and was reflected in, the growing uncertainty associated with this stage (Brown & Powell-Cope 1992). Consequently perception oscillated at any moment between those who perceived that "AIDS could be overcome" (Frances, unpublished) to those who felt overpowered by the irresolute problems and belief that it was hopeless, and that AIDS was overwhelming. An example of the latter was provided by Peabody in the following extract from her book.

> I feel so discouraged these days, all the tests seem so futile. They are always negative. I have a sickening dread that at this rate he won't live beyond June.
>
> (Peabody, 1986, p. 83).

ADAPTATION

Adaptation at this stage involved adjustment to an illness in which the person with AIDS was hospitalized for part of the time with a life threatening illness and for the rest of the time he, or she was well and returned to work. Family members who adapted positively at this stage learned to balance the realities of AIDS with the need to ensure that life went on (Brown & Powell-Cope, 1991). They enjoyed the periods when the person with AIDS was well, and did the best they could when the person was ill. Being balanced allowed them to acknowledge the diagnosis and admit that "AIDS was a fact of their lives" (Pohl et al., 1989, p. 81), but not to submit to the realities by constantly dwelling on them, or by giving up hope prematurely.

ADVANCED STAGE.

> ***He's tired all the time, he can't make his own food half the time, and he gets sick like that, and when he does whether he's in hospital or not, it takes constant brain power. You are constantly thinking and worrying about him...helping him speak with the doctors and just work everything out. Other people who are in a caregiving situation in a hospital can shut it off after eight hours. I can't ever shut it off; I have no way ever of shutting it off. I'm not sure I'd wish to if I could-but I have to live with it twenty-four hours a day, seven days a week. Life has become consumed by***

> ***AIDS. If there were only some way to getting other folks to cross the threshold and see what it's like: that there is no easy way of doing this. [Caregiving] is the hardest thing I have ever done in my life. Nothing ever prepared me for this. Sometimes I wonder if I will ever recover.***
>
> Extracted from interviews with AIDS caregivers presented in Caring for a loved one with AIDS (Pohl, Kay & Toft, 1992, pp.22-23).

The advanced stage was distinguished by a total absence of periodic health, and constancy in the deterioration and decline of the person with AIDS. Consequently, this stage was one of getting on with life, and *constant caregiving*, as family members faced the irreducible reality that the disease was winning and the person with AIDS would not recover. The curtailment of aggressive treatment which was experienced in this stage marked an end to the family member's "emotional roller coaster" and initiated some noticeable changes.

REALITIES

The reality of AIDS at this stage was described as devastating (Pohl et al., 1990). Uncertainty associated with intermittent periods of health, and resumption of relatively normal life and work, represented a thing of the past. The manifestations of this were portrayed as an increased loss of control, personal deprivation and role overload (Pearlin et al., 1988). Consequently, involvement with an AIDS patient at this phase involved living with compounding stressors which collectively represented a chronic level of distress (Pohl et al., 1990).

In addition, the active therapy which previously maintained the person with AIDS was no longer effective. Deteriorative spells and stressor pile ups relating to disease symptomatology were persistent. Family members who had until then devised ways to cope and maintain hope regarding long-term prognosis were forced to acknowledge that AIDS was relentless and the disease was winning.

As a result there was a marked change in perception regarding the outcome of the diagnosis. At the early and progressive stages family members had remained optimistic and focussed on aspects of the living process, with strong hopes for a cure, and plans for future survival. By contrast at the commencement of the advanced stage their perception changed to acquiescence to the unalterable and unstoppable progression of the disease. The advanced stage therefore represented the commencement of the dying process and the "beginning of the end" for all those involved.

CRISIS.

The crisis, which identified the advanced stage in objective terms, is the clinical recognition of the immutable course of the disease symptomatology, and deterioration in health, to the point that active treatment is withdrawn. It is recognized here, that this clinically determined reality may well have been expected at this stage, and therefore, may not in subjective terms necessarily represent a major shock or crisis for the family member. It may be the pile up of deterioration, the withdrawal of aggressive treatment, and the repercussions of both of these, which represent in subjective terms, the new crisis for family members.

PILE UP

In the advanced stage the person with AIDS is confined to home, and is invariably very ill and gradually becoming bedridden. Health has deteriorated to the extent that the patient is often hospitalized for long periods. A progressive loss of sight, increased incidences attributed to developing dementia, cessation of appetite, and a total lack of energy, are among the bio-medical realities of AIDS at this stage. Family members still monitor new symptoms and watch and wait for evidence of advancing deterioration.

Monitoring symptomatology involves constantly watching out for new opportunistic infections, recurrences of old ones, and signs of worsening physical and emotional deterioration. According to Tiblier, Walker & Rolland (1989), watching the deterioration was like witnessing a slow death. The development of each new infection exacerbated existing feelings of helplessness and loss of control. Constant "signposts" of handicap, worsening deterioration and reduced hope of recovery from this point on were symbolically reinforced in the use of walking sticks, wheelchairs and hospital beds at home (Peabody, 1986). Fears at this phase included, overlooking an important symptom, what will happen next, the implications of communicating the truth to the patient and the community, and personal adequacy with respect to the strength to carry on (Pohl et al., 1990). Ambivalence resulted from expressing what they thought and felt, versus respecting the sick persons feelings. These stressors were intensified by a lack of guidance, information, and practical help in the management of these aspects. Family members expressed the feeling of "providing care in a vacuum," which compounded the demands placed on those who become major caregivers (Brown & Powell-Cope, 1992).

As family members invariably become the major informal caregiver to an AIDS patient, this role has invariably been used as a model to study the family experience of AIDS (Boland & Conviser, 1992; Brown & Powell-Cope, 1991; Cowles & Rodgers, 1991; Dietz & Parker Hicks, 1989; Giacquinta, 1989; Greif & Porembski, 1989; Hepburn 1990; Martelli et al., 1987; Matocha, 1990; Siegl, 1992). No studies were found regarding family members who offered intermittent care at this point, and only one article mentioned non-caregiving family members. The latter piece of research compared symptoms linked to the post-traumatic stress syndrome of 19 female family members who provided care for three or more weeks, with those of 24 female family members who did not serve as caregivers. In the study, those who did not become caregivers experienced more symptoms that those who became the primary caregivers (Trice, 1988).

The role of primary caregiver is ascribed apparently to the person who assumes many of the caregiving duties in addition to coordinating their management (Brown & Powell-Cope, 1992). It is important to point out that participants in AIDS family research were invariably selected because they were perceived as occupying this role. Therefore the realities discussed here equate to that role. At this point, it is not known if the same realities are experienced by family members who either provide intermittent care, or do not provide any physical care.

Primary caregivers provided different types of help, including: symptom management, assisting in personal care, such as bathing, managing the household, maintaining social activities, interacting with the health care system and making advocacy decisions when necessary. A major stressor for many caregivers was getting the sick person to eat (Matocha, 1990; Pohl et al. 1990). This concern was addressed in an account of the typical daily responsibilities provided by a mother of a son with AIDS.

> The most important thing about all this is making sure that he eats well-balanced meals, and getting him up for exercise,....making sure he gets his medicines, trying to keep his mouth clean-its a lot of little details.
> (Brown & Powell-Cope, 1992, p. 24).

As the number and level of stressors intensified with each infection, so too did the physical effort involved in caring. Stressors involved in dealing with the worsening symptomatologies included relentless fears, personal health deterioration, exhaustion, loss of control, independence, time, sleep, and family and social commitments due to the continued demands of caring, or hospital visiting (Lovejoy, 1989; Tiblier et al., 1989). The constant supervision and increased involvement in care evoked patient/caregiver dependency issues, and disruption of relationship equilibrium resulted (Kelly & Sykes, 1989).

Caregiving by this stage was constant. Repetitious and worsening infections and multi-system failures invariably evoked neurological manifestations. The latter involved dementia, blindness, extreme fatigue, debilitation and cumulative deterioration. Family members were horrified by the disease and limited by what they could do. They worried about leaving the person with AIDS alone. One wife explained.

> I try not to leave him all alone. He's already feeling low and alone. Understand me, I try to be here and comfort him as much as possible.
>
> (Matocha, 1989, p. 150).

Caregiving was also exhausting and demanding, and family members often feel unsuited to the task. One partner explained how stressful it was.

> It just wipes you out, and it makes you sicker than a dog. Vomiting, high fever, shaking, its just awful....I was having to deal with it , and I was having to take care of him. I was having to wonder if he was going to have a heart attack during all this shaking....I was just like a home health care nurse. I'm just not suited to that...But he needed me, and I wanted to be there for him. I swallowed and did it.
>
> (Matocha, 1989, p167-168).

The constant involvement in care deprives the caregiver of personal time and space and intensifies social isolation. In addition the attendant life strains in having several roles, for example, housekeeper, caregiver and breadwinner, evoked new stresors and took their toll by this point. A wife of an AIDS patient said:

> I worry about Albert with me on the job. I wonder what he is doing and how he is feeling. That's the truth. I feel like pretty soon I'll quit work altogether so I can stay home with him. We'll make it somehow .
>
> (Matocha, 1989, p. 153).

Primary caregivers were forced to quit their jobs. Socializing and attendance at support groups became almost non-existent due to lack of time and physical exhaustion, and friends and relatives distanced themselves at this stage (Motacha, 1989). The resentment this caused was directed at those who did not offer help, as noted in the following statement of a woman who was the sole caregiver to her husband.

> Neither family come forward. I hope now they don't come around....I really don't want to have nothing to do with them. They don't have enough sympathy in their hearts to call us and say, "Hey, is there something that you need?"
> (Matocha, 1989, p.156).

Although it was noted in her case that the lack of family support helped to keep the secret of AIDS from others the reduced contact with family friends and co-workers proved particularly stressful, since personal relationships constituted a valuable resource at this time.

Existing feelings of fear, anger, uncertainty, sadness, loss of control and exhaustion intensified and changed at this stage. Fears related to the ugliness of the disease, abandonment by health-care givers, family and friends, personal adequacy, health and sanity, and death and the dying process. Anger focussed on those who did not understand the horrific nature of AIDS, and heath-care professionals who provided treatment such as pain medication too late. In addition, anyone who was dispassionate towards the person with AIDS, or failed to offer help to the caregiver was subjected to outbreaks of anger.

The focus of uncertainty at this point was twofold; "how long" will this go on, and "is it him or the disease"? (Brown & Powell-Cope, 1992). Not knowing how long, induced feelings of being trapped and frustration from an inability to plan for an immediate, or long-term future, since one day they are told that death is imminent, and the next the person with AIDS rallied (Frances, unpublished). In addition, as the disease progressed and the cumulative effects and side-effects of the drugs took their toll, family members also struggled with the uncertainty of whether the behavior and problems they encountered related to the disease, or the person with AIDS.

The cessation of aggressive therapy in this stage gave way to despair, and family members experienced stressors associated with "facing the truth". Facing the truth involved acknowledgement that "time is running out and the patient was dying (Brown & Powell-Cope, 1992; Frances, unpublished; Haque, 1989; Matocha, 1989). Acknowledgement of this compounded the loss of control at preventing the inevitable. Family members prepared for the oncoming death, and watched helplessly as the physical and mental effects took over. Sadness was intensified as decisions were made regarding future life support, and funeral arrangements. Guilt was intensified with thoughts of "wanting it to end quickly" (Siegl, 1992).

MANAGEMENT.

In the previous stage family members' emotions passed through a range of extremes. Now that the realities, and their resultant effects had become more predictable and constant, the management of the advanced stage became one of making changes to cope with this. The comparative degree of emotional calm was offset by constant physical demands. An overview of the family members' role at this point indicates one of constant caregiving. Caregiving, giving care, or becoming a caregiver, which are terms used indeterminately in the literature, involved numerous tasks which required urgent attention.

Family members employed mechanisms, strategies and resources which enabled them to keep going and lead a semblance of normal life, while facing the truth. Keeping going included taking care of both the person with AIDS and their own needs. Facing the truth involved accepting both the prognosis and realization that nothing more could be done and preparing for the death of the person with AIDS. Therefore family members began a new stage of living with the terminal reality of AIDS at this point.

COPING

Family members at this stage used a variety of coping mechanisms interchangeably in order to keep going and maintain a semblance of normal life and functioning in the face of chronic impairment, worsening deterioration, termination of active medical support and the inevitability of death. These included re-regulation, living one day at a time, living within limits, keeping going, living life to the fullest, taking care of self and preparing for the future.

One partner of an AIDS patient used a strategy of "not crowding the future in the remaining days," so that he could keep each day more manageable (Matocha, 1989, p. 172). He explained the motivation for his choice.

> Now you see, you want to continue to live your life normally. By normally I mean having your disagreements, you know. But at the same time, you want to have as much good feeling as you can because you don't know how much longer you're going to be able to have that.
>
> (Matocha, 1989, p. 172).

The caregiver in this example was taking care of himself, as well as taking care of his partner. He took care of his current feelings while facing the inevitability of worsening deterioration and the possibility of imminent death. In this way his regulation of the situation enabled him to cope. However, coping at the advanced stage involved constant structuring and restructuring of plans to meet the patient's and caregiver's needs (Bennett, 1988). Once the decisions regarding treatment and care were put in place, family members waited to see what would happen next, and dealt with it as well as possible at that time (Siegl, 1992). When hospitalization was necessary, established routines became upset, as forced dependency caused by physical deterioration, or hospital routines compromised established coping strategies (Bennett, 1988). Family members kept going by a process of re-regulation. As the stage progressed, and family members faced more and worsening problems, they controlled the situation by re-evaluating the realities and re-regulating the management on a daily basis. Consequently they learned to cope by "living one day at a time" (Matocha, 1989; Pearlin et al., 1988; Siegl, 1992). One wife desribed her need to regulate caregiving to one step at a time.

> I have to take one step at a time. I can't push myself to do too many things at once, because if I do, I am going to mess up in one of the areas.
> (Matocha, 1989, p. 154).

As the days passed and the deterioration intensified, caregivers became increasingly flexible, and adopted new coping mechanisms and strategies as and when they recognized the necessity to do so.

Generally, the worsening pathology affected the need for increased openness (Brown & Powell-Cope, 1992). In order to keep going at this stage family members told more people about the diagnosis. However, to protect themselves from the stressors of disclosure, they remained selective regarding whom they told, or what they said, as the following example shows.

> The people that are probably closest to me know that there has been some problems. I haven't gone much further than that.
> (Brown & Powell-Cope, 1992, p. 45).

> Although John's illness was not a secret, I realized I was not entirely open with everyone. I did not tell my ten year old because I thought she might be afraid of closeness with her uncle. I told her it was cancer.
> (Haque, 1989, p.232).

Choosing to say it was cancer rather than admit it was AIDS was a way of maintaining control, but eliciting the physical and emotional help which family members needed to cope. Telling more people reduced the isolation and stressors associated with keeping the secret. It opened up more avenues of support both for the person with AIDS and the family members themselves.

There was some evidence that relationships between the person with AIDS and his, or her primary caregiver changed at this stage (Martelli et al., 1987; Siegl, 1992). Both a strengthening and a lessening of closeness was reported in caregiver's accounts of the experience. Relationship closeness was operationalized as the subjective amount of change in the level of conversation about AIDS, as perceived by a caregiver. Whether this change came about as a reaction to caregiving, or was adopted as a form of coping with the oncoming death, was not clear. Equally, the following example does not indicate what the relationship was like prior to this stage, but this wife credited her sick husband with helping her to cope. She explained how this was achieved.

> I have my days when I don't feel good and sure. I come in here, and I be evil. That lets him know that I am being me....That makes him sometimes want to talk to me and ask the same way. He can't support me as far as money, but he can as far as conversations concerned. It relieves me of my pressure.
>
> (Matocha, 1989, p.153).

In this example the caregiver perceived "talking it out" as a valuable form of coping. Whereas the following description of a wife who cared for her husband Charlie, suggested a different form of coping in the relationship.

> Charlie had become cold and phlegmatic, like seaweed, we never talk. Our relationship seems shipwrecked on the shoals of his indifference, and a part of his coping mechanism is to get drunk. This has made things even worse. It was nice when we did talk, but life goes on.
>
> (Pohl et al., 1990, pp. 89, 95).

In this relationship, the couple were using distancing and selective denial as a means of coping.

In this relationship, the couple were using distancing and selective denial as a means of coping.

Family members kept going and maintained self control through the use of cognitive and emotional discipline which kept the situation manageable. Pohl et al. (1990) suggest this form of coping modulates the mind and emotions and thereby helps in the healing process. One obvious manifestation of this at the advanced stage was "reframing" (Siegl, 1992), in which family members make deliberate attempts to identify the positives in the situation. Siegl (1992) suggested that family members had the need to see AIDS as not entirely negative. Consequently, they searched for the positive aspects of the experience, such as a closer relationship with the person with AIDS, an increased spiritual awareness, and the opportunity to give back to society. In Longman's (1992) study, a mother who cared for her son focussed on the positive aspects of giving back in a self-help group.

> Helping other mothers who are going through what I was going through, right now is what keeps me going. If I weren't able to help somebody else, seeing what may be ahead for them, and help them talk out whatever they are feeling now, I wouldn't be able to make it.
>
> (Gregory & Longman, 1992, p. 346).

Although this may seem like selective denial of her own situation, giving something back to society from her own experience, concentrating on other peoples' problems, and the companionship this afforded, undoubtably helped this mother to cope (Cowles & Rodgers, 1991).

activities which did not include the person with AIDS. Caregivers took time out in solitude, or attended events which took their mind off what was happening. On October 30th Frances wrote: Tomorrow is Grey Cup and I am going to have a good day. Matocha (1989) suggested that taking time out enabled the caregiver to regain mental strength. She provided the following example of a wife who coped in this way.

> We just can't function too good without being with each other. It makes him feel better to have me with him, and the same with me too. At times though, when he's not with me---I don't mean to sound harsh or bad when I say this, but my mind can be a little more at ease when I can be alone. I'm only human. Sometime I need that little space just to get myself together.
> (Matocha, 1989, p. 155).

All these coping strategies enabled caregivers to live and let live, feel better about what they were doing and cope with current and future stressors. Additional strategies were "reducing expectations", and "being selective" (Siegl, 1992). As hope for recovery decreased family members reminded themselves that the best laid plans may not work out. They constantly re-regulated their hopes and expectations to fit more adequately the current experience, and the remaining time prior to death. Selectivity involved narrowing the focus of involvement, by adjustment of schedules, setting goals, choosing to deny, or ignore the most painful aspects of the disease, and concentrating only on those things that were urgent, important, or had positive meaning. These strategies helped to prevent role overload, reduced the painful effects of facing the truth, and helped to keep going (Brown & Powell-Cope, 1991; Frances, unpublished; Matocha, 1989; Siegl, 1992).

Although family members may have thought about death prior to this point, there was evidence to suggest that they dealt more actively with impending death at the advanced stage.

> That horrible feeling inside 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.
>
> (Siegl, 1992, p. 81).

It is often at this stage that family members started making physical and emotional preparations for death, such as funeral planning (Frances, unpublished). Confronted by a shortened life, family members prepared for the death by making the most of the present, and living life to the fullest. They attempted to complete unfinished business, and began the process of saying goodbye (Dietz & Parker Hicks, 1989; Matocha, 1989). Some examples of this were reminiscing together, completing projects, and crowding in as many good memories as possible. For example, Frances (unpublished) accompanied her brother to Las Vegas, (which was an unfulfilled dream for him), even though his level of sickness limited what they could do. This strategy was both diversionary and satisfying at the time, but it also provided Frances with a memory which helped her cope with her grief after her brother died. Therefore coping at this stage also involved "starting to let go", and learning to deal with emotions regarding death.

RESOURCES.

As the illness progressed and the person with AIDS needed more care, being less secretive at this stage enabled caregivers to seek more resources. From their retrospective interviews of caregivers, Brown and Powell-Cope (1989) found that family members sought resources which reduced the physical and emotional magnitude of the situation. At this stage they relied heavily on those which offered them compassion, support, trust and constructive assistance. These were provided through psychological and medical interventions and personal, familial economic and legal support.

If care was in the home at this stage, family members relied on resources which offered physical care to the person with AIDS, and respite for themselves, from the increased burden of caregiving. Resources which offered relief enabled them to "take a break", by physically removing themselves from the situation. A partner who was the primary caregiver felt that "one of the biggest things that a person who is taking care of somebody, no matter what the situation is, whether they are bedridden, whether they are an invalid, whether they are terminally ill, is to have some kind of interest outside the home, it provides a change of environment " (Matocha, 1989, p. 174). This partner intermittantly removed himself by going home to his family. This was particularly significant, because although he had not maintained contact with them previously , he found their support, and being cared for by them on his visits, provided an invaluable resource at the time. At this stage many caregivers relied upon others to provide respite care, either through formal caregivers such as hospital care, home-care nurses and social agencies, or informal care such as buddies, family members and friends. Ten family caregivers in Chekryn's (1989) study perceived the homecare nurse as an invaluable teacher who came in and formally taught them how to do things, whereas a Buddy, that is, a volunteer, offered informal support to the person with AIDS. In research which studied caregiving of people with AIDS, Matocha (1989) found that in addition to providing physical and social support over time a Buddy could also become emotionally attached to the person with AIDS, and therefore provide the most heuristic form of support.

If the person with AIDS was admitted to hospital, family members required different types of resources, such as provincial or federal economic resources, which enabled them to make regular visits. One interviewee in Matocha's (1989) study found her knowledge of the social system enabled her to gain economic support, and this proved to be an invaluable resource at the time.

In research which studied the needs of informal caregivers who supported gay men with HIV disease, McCann and Wadswoth (1992) found a disparity existed between people's recognition of a need for certain resources and their willingness to ask for it. The researchers found that only a minority of the 125 interviewees had asked for the resources they needed. Little is known about how, or why resources are accessed, but the assumptions in the family stress framework remind us that in order to be utilized, resources have to be perceived as valuable by the recipient (McCubbin & Patterson, 1983).

The reluctance to access resources, together with the constant demands of caregiving, isolation and restricted time, prevented family members from continuing with many of the resources previously found helpful (Bennett, 1988). Therefore resources which provided emotional respite without the need to remove themselves physically from the home were more evident. These included: involvement in hobbies, humor, journal writing, having fun with friends, maintaining family traditions, religious, spiritual and other forms of self-care. Exercise, adequate sleep, nutrition, regular eating habits, stress reducing techniques, and maintaining hope were also mentioned (Greif & Porembski, 1988; Lovejoy, 1989; Matocha, 1989; Moffatt, 1986; Peabody, 1986; Siegl, 1992). Family members found relationships which deepened were also an important resource at this stage (Cowles & Rodgers, 1991; Haque, 1989; Siegl, 1992; Matocha, 1989). Those who reported a close personal relationship either with the person with AIDS, or with another human being, found this resource invaluable (Chekryn, 1989).

PERCEPTION

Although there were no studies of perception at the advanced stage, extracts from accounts of family members who were closely involved with a person with AIDS at this point, indicated that the struggle to fight the disease was perceived as "all but lost," but hope was not completely relinquished (Flaskerud, 1987; Matocha, 1989; Siegl, 1992).

As the focus of family management shifted, perception in the advanced stage was invariably one of resolution and hopelessness.

However, many family members made changes to overcome this before the stage terminated. Therefore perception at this stage could be anywhere between pessimism and optimism.

> "Despite your optimism and hope that you keep in your heart. you know you cannot control the disease or its progression... no matter what your efforts are. So it becomes hopeless to agonize about the disease......you have no control here.
> (Martelli, Peltz & Messina, 1987, p133).

Cognitive resolution gradually evolved from knowledge of the pathology, lack of recovery, level of deterioration and degeneration, and medical confirmation that therapeutic control of the disease was now futile. As available resources failed to change this perception and the illness became all consuming, it was impossible to deny the diagnosis or maintain that the patient would survive. In his book Martelli suggests that :

> As it becomes harder to deny that you are witnessing your partner's physical and mental deterioration, it is no longer possible to perceive that it is not happening. The pain is great as you realize that you may soon lose a person who has been intensely valuable to you.
> (Martelli, 1987, p. 168).

Family members, therefore, perceive the situation according to its personal effect. In the literature, perception was described as a feeling of being overwhelmed (Brown & Powell-Cope, 1992), a tremendous loss (Giacquinta, 1989; Gregory, 1992), and something which is uncontrollable (Matocha, 1989). Peabody (1986) perceived accepting the inevitability of her son's death as the the hardest thing she had ever done. The effect for Frances was manifested in personal doubts of her capabilities. On November 24th she wrote:

> "This AIDS is not easy, it's tough love and everything is so overwhelming. I'm not sure if I am ahead of the game, or even if my concerns count."

However, family members also believed that they still had a job to do. Chekryn (1989) found that family members perceived it as their responsibility to care for the sick member, until death. Therefore in order to cope with the pain and loss at this stage they altered their perception of the task, to one of "caring for the shell of a body", rather than the person known previously (Chekryn, 1989, p. 31). In their endeavors to stick it out, and do the best they could, while they could, family members also looked for ways to reframe their perception to something more positive (Siegl, 1992). A sister provided an example of this in her narrative of caring for her brother. On the first occassion her brother wanted to move apartments at the advanced stage.

> I wondered if the decision to move was realistic since we knew he would not be there for long. Then I realized it was a good decision because John was still living, and he had needs which could be met by a change in environment.
>
> (Haque, 1989, p. 236).

This example also demonstrated how a family members perception could change depending upon its focus. In this case John's sister perceived the long-term future as hopeless, but the immediate situation of living as hopeful. From evidence in a later entry, she relied upon positive perception as a constant resource. "It was

Mother's Day, and another occassion to celebrate more time with John, as well as say goodbye" (Haque, 1989, p. 237).

As family members came to terms with their inability to change the situation and made new meanings out of their life, they changed their perception of their ability to care, believing that they would not have done it any differently, and took pride in their achievement. One man described his new perception of himself at this stage.

> I have developed certain strengths and abilities in different kinds of ways that are being called into play....I am real proud of myself.
>
> (Brown & Powell-Cope, 1992, P. 50).

ADAPTATION

By the end of the advanced stage family members had been living with major changes for a while and AIDS had become a part of their everyday reality. Family members at this stage, adapted to the reality of incurability. They recognized the ineradicable nature of the disease and their inability to control this, despite attempts to prove it otherwise. From their own experience, and studies of AIDS caregivers, Pohl et al., (1990) found that family members at this stage did not deny, or avoid the reality of AIDS, or its deepening hold on the infected person. They moved through that fact as part of the daily routine, much as anyone would drive at night through fog. The researchers provided an example of adaptation at this stage. "The pain and fear are still there yet they seem familiar. We're used to it. We know it inside out. We wish it were different, but we know that wishing changes nothing" (Pohl et al., 1990, p. 95). Family members therefore accepted the inevitability of death, relinquished their battle to save life, and concentrated their efforts on the quality of the life remaining.

Family members who adapted had developed the ability to live in the present and to make the most of each occassion when the person with AIDS was present. By the end of this stage they had also begun to take care of the future, by establishing memories, putting their affairs with the person with AIDS, in order, as well as, beginning to say goodbye. In her account of her experience of having a brother with AIDS, Haque wrote:

> There were exchanges of love and affection...My daughter cross-stitched a heart which said, "I love you," and she wrote a note telling him what a good uncle he had been to her. We were all saying good-bye in our own way.
> (Haque, 1989, p. 237).

Matocha provided an example of how two partners had prepared for the forthcoming death of one of them:

> They put their affairs in order, made their wills., and labelled items in the house which were to be given to others. Making these plans helped [the caregiver] move on to the next stage.
> (Matocha, 1989, p. 171).

These and other examples found in the studies indicated that family members adapted successfully at this stage. What is not known, however, is how representative these findings are, compared to the general population when faced by an AIDS diagnosis in the family. Given the realities as outlined in this stage, and the short time available to manage them, the probability that this sample is representative seems to be low. However, in the absense of more research this hypothesis remains unproven.

TERMINAL STAGE

> *I had to leave my job in March and stay home with him continually. The only time I got out of the house was either to run to the store real quick, which was right next door, or run to the mailbox, and otherwise I just couldn't leave the house much unless I had somebody there to stay with him. When he went into a coma, I was right there beside him. I stayed on his right side of the bed and held his hand the whole time I was going through this, and I just watched him turn colours....Just watched the whole process. I watched him suffer so much. He lost so much weight he was about 45 pounds. I saw him having the aches and pains in the legs and arms and shoulders and tailbone area. Most of the time he was on his back. He couldn't turn either to one side or the other. He just suffered so much. His eyes didn't close all the way, but every once in a while his left eye would blink and a little tear would fall out of it, ... during this whole time I was wondering when. I just felt like my heart was just ripping out. I just felt as if my heart was breaking. It felt like a real pain in my heart. Here I am with my only child lying here dying, and me watching every second of it. I would just cry out. There was nothing I could do.*

Extracts from a mother's narrative of the final 10 days before her son died. (Gregory & Longman, 1992, p. 343).

The terminal stage represented the final and most highly emotional and spiritual stage in the AIDS trajectory. Dated accounts of the family experience suggested to the researcher that this stage may be a few days to a month in duration (Haque, 1986). However, no conclusive evidence was found to support this observation.

The terminal stage was distinguished by a total ineffectiveness of any form of therapeutic intervention. Death was considered inevitable and imminently apparent. Treatment was aimed at providing comfort and compassionate care only. Consequently for family members, this represented the *relinquishment stage* , which involved engaging in the physiological and emotional "letting go of life," (Davies, Chekryn-Reimer & Martens, 1990; Kubler-Ross, 1987; Rolland, 1987).

REALITIES.

By the terminal stage the patients' deterioration had progressed to the point that he, or she could not function normally, and the inevitability of death could no longer be denied. With the withdrawal of active treatment, family management at this phase was one of "waiting for death", and comprised of taking care of the physiological and sentimental tasks prior to the occurrence of death.

While in the previous stage, family members cared for the person with AIDS and still maintained hope of keeping him or her alive by any means they could, in the terminal stage this is no longer the case. Hope for a miracle cure was unrealistic given the amount and severity of symptoms and deterioration. At this stage the person with AIDS could not be left alone. He, or she was likely to be blind, experiencing dementia, bedridden and totally dependent upon a 24 hour care system. Termination of treatment accelerated the death, and it was just a matter of time before this occured. Therefore the reality for the family members at this stage was physically and emotionally exhausting. Confronted with giving 24 hour care and preparing for death with the uncertainty of not knowing when, meant that family members resorted to living one moment at a time.

CRISIS

The crisis which identified the terminal stage was the clinical decision that nothing more could be done. This finality was usually confirmed in a meeting with the physician, although reports of the experience suggest that both the family members and the person with AIDS were previously aware of it (Haque, 1989; Matocha,1989; Siegl, 1992). Family members described being aware that their loved one was "not going to make it" (Siegl, 1992), and recognizing that further medical attempts were futile, recovery was not possible, and palliative care offered the only feasible option at this stage.

PILE UP

The person with AIDS was invariably in hospital, or at the home of a family member by this stage. Family members experienced two major sets of stressors, those associated with short-term care of the patient, and the long-term care after the death occured. Short-term care involved planning and coordinating round the clock monitoring of care. As the days passed Frances recorded visiting the hospital almost every evening until 3 or 4 in the morning. Another family member spent so much time caregiving that she described herself as an "AIDS recluse" (Matocha, 1989, p. 157).

At this stage the horror of the disease became immensely stressful. Those involved in caregiving were physically and emotionally pushed to their limits by the general failure of every bodily system, blindness, dementia, total incapacitation and depletion of life. One mother described her experience.

> He got so 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. He'd couldn't feed himself, so I started feeding him. I watched him die every day, before my eyes, everyday something less that he was able to do.
>
> (Siegl, 1992, p. 85).

Family members maintained a 24 hour care surveillance to ensure that the person with AIDS was never left alone. This, together with dealing with hospital staff and the effects of treatment withdrawal, caregiving demands, isolation, fear of death and dying, all contributed to the pile up of stressors. Social contacts and relationships diminished further as the AIDS vigil controlled their lives (Matocha, 1992). In addition, the anxiety of contamination and contagion returns to the forefront, as family members provided physical care such as toileting and changing dressings. In an autobiographical account of caring for her brother, a sister who was a nurse noted.

> Despite the assurance that good hand washing techniques were the only precautions necessary to prevent contagion, there was still some anxiety and periodic thought of whether we were absolutely safe. It did not prevent or change John's care, but it took more of our emotional energy to deal with these feelings
>
> (Haque, 1989, p. 238).

In addition to witnessing the physical withdrawal of life, two family members noted the emotional withdrawal of the person with AIDS. Frances wrote in her diary.

> G has withdrawn from everyone, he hasn't wanted to go for a smoke so we haven't left the room. I just keep praying and hoping God is listening. I think I'm prepared.
> (Frances, unpublished, February 14th, 1991).

For a partner this withdrawal constituted an additional loss:

> Its the loss of the relationship. Of the person I love and his presence to me. Its not an interactive relationship anymore. He responds to me or to changes in a way that is different....I don't have that important relationship anymore.
> (Brown & Powell-Cope, 1992, p. 11).

The breakdown in communication, uncertainty, constant demands of being on the alert, taking care of a totally dependent patient, keeping him, or her comfortable, surrendering control to the disease, extreme feelings of sadness and the emotional task of letting go of the dying person, were all held responsible for high incidences of burnout at this stage, and problems associated with post traumatic stress disorder, following the death (Trice, 1988). Uncertainty stemmed from an inability to anticipate the extent of time remaining, and how and when the patient would die. Stressors evolved from knowing that time was limited, and from the uncertainty regarding when to say goodbye. Family members often found themselves out of synchrony with the patient and the medical profession regarding this issue. They tried to either keep the patient alive, and failed to say goodbye, or prematurely buried their loved one (Brown & Powell-Cope, 1991; Pohl, et al., 1990; Tiblier et al., 1989). Sosnowitz and Kovacs (1992) suggest that family member's reactions at this stage are more based in emotion than founded on fact, and their panic and fear of the death may cause them to give up too soon.

If the person had not made a "living will" family members became involved in surrendering control to the disease by making life and death decisions regarding resuscitation techniques. A mother who cared for her son explained.

> He was in a coma. The Doctor had asked if we wanted our son put on life-support systems. We had already decided no. I didn't even hesitate....I really felt that we basically gave him the last gift that we could give him- the gift of not letting him be in pain anymore.
>
> (Matocha, 1992, p. 79).

In his account of the terminal stage, one interviewee recalled having made an earlier decision to refuse life support an hour before his partner died.

> They [the doctors] came in and told me I could change my mind and put David on a respirator. I said, "No way".
>
> (Martelli et al., 1987, p. 180).

The pile up of stressors became so acute at this stage that family members began to wish that it would all end, and this induced more stressors in the form of guilt. In her autobiographical account, a sister recorded the ambivalence of these feelings at the terminal stage.

> I remember arriving one day at John's apartment after I finished work to stay with him and relieve another friend. I had had a busy day. I had to arrange for my daughter's care and now I had to watch my brother die. I cried and vented my anger and frustration to my friend so that John would not be subjected to these feelings. Part of me was wanting the journey to end, for it to be all over, but the other part didn't want to say good-bye. As a nurse who cared for dying patients I had validated their feelings, yet it was difficult for me to accept those feelings within myself.
>
> (Haque, 1989, p. 238).

In preparing for a family member's death crucial decisions regarding the patient and the family had to be made (Tiblier et al., 1989). Stressors evolved from dealing with children unable to understand when a parent was dying, and concerns over who would look after them (Frances, unpublished; Tiblier et al., 1989). Decisions regarding where the patient will die, the use of life saving efforts, wills, memorials, the type of burial, property distribution and other legal aspects all contributed to pile up at this time (Bartlett & Finkbeiner, 1991; Brown & Powell-Cope, 1990; Frances, unpublished, Siegl, 1992).

Making this type of preparation evoked excessive fears for those experiencing their first death. Family member's fear of death related to their own death, as well as that of the AIDS patient. "Facing the death of a close loved one forces us to face our own deaths. The dying person is a symbol of what every person fears and knows he must someday face" (Anonymous, 1970). Family members fear of public exposure, rejection, abandonment, and embarrassment, losing friends, money and employment after death also contribute to the pile up of stressors at this point.

MANAGEMENT

By the terminal phase the deterioration of the person with AIDS has progressed to the point that he, or she cannot function normally, and the inevitable reality of death could not be denied. With the withdrawal of active treatment family members are reduced to living in a climate of uncertainty as they wait for death to occur. In order to manage the situation family members live from moment to moment, as they care for the person with AIDS and prepared for a future in which he, or she is missing. The wife of a person with AIDS who was close to death, explained why she felt this was necessary.

> "By now I know what I can do. I've already seen how far I can push myseif. So, that's how far I go. Staying in control is very important. I have to take it a step at a time. I can't push myself to do too many things at once, because if I do, I am going to mess up in one of the areas.
>
> (Matocha, 1990, p. 154).

COPING

Family members coped at this stage by keeping busy. They constructed and revised plans for the impending death of a loved one (Brown & Powell-Cope, 1992). This involved taking physical care of the person with AIDS, and emotionally preparing for his, or her death. In order to achieve this they established a 24 hour physical care plan, and simutaneously prepared themselves to face all aspects of the loss. From their observations of family members involved in the terminal care of people with AIDS, researchers reported that family members developed the ability to maximize the present, while preparing for the future. Despite the necessity to provide comfort to the dying person, they also managed the sentimental work involved in the preparation for death (Brown & Powell-Cope, 1991; Tiblier, 1987; Lovejoy, 1989).

It was suggested that letting go of the fight to combat the disease and of hope for recovery, and instead making preparation for death, are all part of the "anticipatory grief process" which family members experience (Haque, 1989; Lovejoy, 1989; Rando, 1984; Raphael, 1983; Tiblier et al., 1989). This area of AIDS research is relatively uninvestigated, and evidence regarding the anticipatory grief process with respect to AIDS family members mainly relied on anecdotal data. It is not known when the anticipatory grief process begins, or how beneficial this is in preparing family members for the moment of death and the bereavement which follows.

It was noted that anticipatory loss was a gradual process. Although it may have commenced at diagnosis, it appeared more evident and intensely stressful at the terminal phase, particularly when the person with AIDS began to withdraw emotional investment in others. However, writing as a nurse who had extensive experience with death and bereavement, Haque (1989) recorded the following in the terminal stage of her brother's illness.

> Some grief preparation can be done before our loved one dies, but only after death can we experience the intensity and depth of those feelings to fully grieve the loss. Anticipatory grief does not diminish the pain, emptiness, and loneliness of post-mortem grief, but it does allow us to prepare for death and say our good-byes.
>
> (Haque, 1989, p. 239).

Family members had to prepare themselves both for a death, and a future in which their loved one is missing (Worden, 1983). Researchers found that family members put their own lives on hold and maximized the time left. Despite the stress and horror associated with this stage they maximized their time by being there for their loved one, sharing time and secrets with them (Matocha, 1989), and "giving all they can" (Siegl. 1992). Parents in Siegl's (1992, p. 92) study found that being there provided a means of "giving him what he needed and getting what they needed". Having ceased looking for miracle cures they ensured that the time left was comfortable and filled with love and support.

Writers also noted that family members worked hard to respect the patient's wishes for current living and future arrangements following their death (Siegl, 1992). Haque (1989) described the efforts her family made to respect her brother's wish to die in his own home.

> John wanted to stay in his apartment, but he was running out of money for rent and nursing care. Some of the medical expenses were covered by public assistance but our family still had to use some of our own money, and our resources were limited. We had to make tentative plans to move him to my home, but decided to tell John closer to the time of the move to decrease his anticipation. John never knew about this plan because he died on July 2 in his own apartment with his friend, Ken, near his bedside.
>
> (Haque,1989, p. 239).

For those who had not aready done so, respecting the person's wishes after the death included exploring spiritual questions, planning the funeral, preparing memorials, purchasing burial plots and settling estates. These strategies provided a way of taking care of the present and the future, by laying down good feelings and memories, completing unfinished business, giving permission to let go of life, and saying goodbye (Brown & Powell-Cope, 1992; Siegl, 1992). As the inescapability of death sank in, caregivers who talked with the person with AIDS about his, or her death, reported a positive spiritual uplifting (Siegl, 1992). In some cases the caregiver and the person with AIDS functioned as a team to prepare for death. In making decisions such as when to withdraw life support, they described an enrichment of inner strength and an ability to meet the demands of the impending death.

> He's talking about his funeral and you don't want to discuss such a thing. ...You work at it , and finally you accept it.... 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.
>
> (Siegl, 1992, p. 88)

An additional coping mechanism was bringing the family together. This strategy involved pursuing reconciliation, trying to settle unfinished business and unresolved issues, holding family gatherings and trying to reunite the family (Lovejoy, 1989; Siegl, 1992). If rifts existed in their son's relationships with family members, parents in Siegl's (1992) study, worked to ensure that these were resolved. In a diary entry on the final evening of her dying brother's life, Frances recorded how she and another brother, who had previously been estranged from the family, visited together.

> My brother [P] came to the hospital and we talked most of the night. G never spoke, but we had a cry together. We tried to leave, 5.00 5.30 5.45. I just left there and he was alone.
>
> (March 2-3 1991).

A final and accutely obvious method of coping was the continuance of reframing, which had been used in previous stages to create a positive value, meaning, or purpose from the experience (Pohl, Kay & Toft, 1990). In Matocha's study, one wife who gave up part of her life in order to care for her husband believed that AIDS had ordained her life.

> "I always wanted to have a child but I never did....now I think to myself that --I'm not going to say it was a punishment, but I think the Lord has made it so I would never bear kids because of what I'm going through now.
>
> (Matocha, 1989, p. 151).

As death drew closer, creating meaning provided a reason for the dying person's suffering and purpose on earth, and eased the family member's anticipatory grief. Those who coped this way believed that the death was not in vain. Some time after her son's death, a mother in Siegl's (1992) study, provided the following retrospective insight.

> "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" .
>
> (Siegl, 1992, p. 93).

RESOURCES

Resources at the terminal stage can be classified as external support and personal inner peace. In her autobiographical account Haque (1986) wrote:

> The emotional and physical exhaustion we all felt as we continued caring for John would have been unbearable had it not been for the network of supportive people with whom we could talk, cry, or vent anger.
>
> (Haque,1986, p. 238).

Family members required someone who was supportive to both the person with AIDS and themselves. This was invariably provided by health professionals (Lovejoy, 1989). Family members needed to receive accurate information about the patient's condition, and aspects of care such as avoidance of contamination. They sought reassurance that the patient was comfortable, and validation of their approach to nursing care (Haque, 1989). Aside from providing the necessary physical help, health care professionals also offerred compassion and support, and represented someone who was not afraid of death (Haque, 1989). This resource was invaluable, as fears, anxieties, and the need to talk about death, increased in this stage (Brown & Powell-Cope 1992).

As time was limited to pursue resources outside the home, family members relied on selective contact with family, friends, religious leaders, doctors and people who were associated closely with the care of the patient. They required someone to listen to them and provide love and acceptance (Flaskerud, 1987; Haque, 1989). Flaskerud (1992) purports, that AIDS threatens a family member's meaning of life, hope, self-identity and self-worth. Therefore family members need resources which address the spiritual dimension of their lives and re-establish a sense of value, direction, purpose and inner peace (Flaskerud, 1992, p. 265). Sussman (1989) suggested that the giving of oneself that is required could lead to a profound spiritual growth. He wrote that:

> The care and treatment of the family member with AIDS will be for some a transforming experience resulting in deepened consciousness and a commitment to serve, whereas for others it may leave emotional scars, which require therapy.
> (Sussman, 1989, p. 237).

However, no empirical research was found to confirm this.

The use of coping mechanisms such as "being there right to the end", positive thinking, creating meaning, saying goodbye, and letting go, all represented positive resources in the struggle for inner peace. Siegl (1992, p. 87) suggested that "being there" was an invaluable resource to fathers who often found this the only way they could participate in their son's care. It is noted here that unfortunately very little is known about the experience of male non-homosexual family members. Existing studies invariably interviewed females and male homosexual partners. Although they provided some insight, it is not known how the experience of these groups correlates with that of male hetrosexual family members.

Family members also developed personal strength and inner peace from increased communication, reconciliation and forgiveness with the dying person. They gained reassurance from knowing that he, or she was comfortable and at peace, and continued to draw comfort from hope. Hope was realistic at this stage, and remained something which bought time. Family members described it as "foolish silly human hopes" (Siegl, 1992, p. 93), that their loved ones would not suffer a violent nor accutely painful death (Frances, unpublished; Peabody, 1986).

Although studies have not addressed the effects of inner peace, Brown & Powell-Cope (1991) suggested that caregivers may find that the experience of caregiving provides a positive effect which acts as a resource in itself. Their study of AIDS caregivers at the terminal stage, found that although the person with AIDS was conscious and able to hear, he or she might lose the ability to speak, move or see. At this time caregivers found that being present at the bedside provided them with an important resource. The long hours gave them time to lose themselves in thought. They reviewed and evaluated the experience and their relationship with the dying person. Parents reminisced events of the child's life, and loved ones regretted arguments. As the caregiver remembered his or her past and the good parts of life with the sick person, the memories provided a positive effect in the form of comfort (Brown & Powell-Cope, 1991, p. 15). This idea of a positive effect as a long-term resource was confirmed by a partner in another study when he said.

> I think terminal illness makes people realize how vulnerable you are as a person, as a human being. It makes you more, your humility, it brings you down to earth a little bit, and it shows you where you're human.
>
> (Matocha, 1989, p. 173).

PERCEPTION

Family members at this stage acknowledged that the disease was winning. Once they had recognized there was a deadline they noted a changed perception. For Haque (1989, p. 231) the terminal stage represented "the beginning of making every minute more precious because there was a deadline now for John's time with us".

Studies suggest that there was a changed sense of time. The perception of what is important in life narrowed, and life took on an unreal feeling, as caregivers stopped paying attention to the normal markers of how time progresses. They felt suspended in time. The difference between days vanished, and they described the experience as "looking back into a blurr" (Brown & Powell-Cope, 1991, p. 18). Reports of perception were both negative and positive. A partner who assessed himself and his experience negatively, said:

> I can handle myself being sick, but I have a hard time taking care of someone I love and seeing them suffer. That's just, it turns me inside out....I get mean, angry I would like to be able to escape sometimes and be crazy and free. That's the word - free. But I'll never be free again. I don't live anymore. I'm living his life. I can't make any decisions anymore. I can't seem to do anything right anymore.
>
> (Matocha, 1992, p. 76).

However, not all family members perceived the terminal stage this way. In another study a caregiver was suprised and pleased that he and his partner with AIDS had been able to talk to one another and change their viewpoints. Consequently, he perceived this stage as positive when he wrote:

> Its a strange time for us right now. It's almost a very spiritual time. We're dealing with some life and death issues and finding our own spirituality there, its been a real path
> (Brown & Powell-Cope, 1991, p. 17).

ADAPTATION.

Adaptation at this stage involved accepting that the disease had won, and that the family members had done a good job, but they did not stand a chance. Achieving acceptance and participating in these activities, however, did not mean that family members had reached a sense of completion at this point. In Siegl's (1992) study, a mother whose son was in the terminal stage of AIDS made reference to a temporary form of adaptation prior to the death.

> "Its going to be pretty terrible when the time does come, and we'll probably still be accepting after. I guess its kind of different, like right now we're accepting that it's going to happen, and after we'll have to accept that it has.
> (Siegl, 1992, p. 91).

Although this thesis only addresses the AIDS trajectory prior to the point of death, it is important to acknowledge here that death will mark an additional crisis for family members, and the commencement of the bereavement process. Literature which addresses the post-death period and grief process suggests that adaptation following the death of an AIDS family member represents another autonomous process which can take many years to achieve (Pheifer & Houseman, 1988; Piemme & Bolle, 1990; Rando, 1984; Raphael, 1982).

CHAPTER 4

CONCLUSION

The previous chapter represents a synthesized account from selected literature of the realities which family members of people diagnosed with AIDS faced, as well as their phasic attempts to manage them with equanimity. In the absence of a cure, the diagnosis of AIDS equates with terminal illness, and the two are regarded as synonymous. The current estimated life expectency for the diagnosed individual is variable, and dependent on factors of the symptomatology, effectiveness of new antiviral drugs, alternate therapies and the diagnosed individuals themselves. Analysis from dated accounts in this research provides a mean of approximately 15 months from diagnosis to death (Frances, unpublished; Haque, 1989; Peabody, 1986). Other anecdotal sources suggest periods of six months to five years (Moffat, 1986). For the family members of people with AIDS, this period represents living a new life, or living with AIDS. Living with AIDS comprises of a death sentence for one of its members, and for other family members numerous stressful bio-psychosocial realities which pile up and call for various management techniques designed to overcome the effects of these problems.

In this thesis the progression, or trajectory of the patient's illness has been shown to influence the experience of family members: to create crisis, regulate the parameters of the experience, and set the shape of its course. Several accounts of the experience of living with AIDS use the analogy of a journey through life and death which those who are infected and their family members embark upon (Pohl et al, 1990; Moffatt, 1986; Peabody, 1986). By adopting the analogy, and describing the journey of living with AIDS, this summary recognizes the AIDS trajectory first as the pathological route of the disease, and second, its corresponding influence on the experiential journey for family members. The route is therefore diagrammatically depicted as a combined lifeline, for the patient and the quality of life for the family member. It has four bio-medical markers which represent land marks, or signposts to different parts of the journey. A holistic overview of the total journey suggests that each signpost confronts family members with a new reality, or crisis and redirects them on a qualitatively different course from the previous one. In so doing the bio-medical AIDS trajectory takes away control, and subjects the family members to new and existing challenges to which they respond and adapt. Throughout each stage family members call upon new and existing mechanisms to manage the situation and sustain a semblance of control and adaptation, prior to the confrontation of a subsequent signpost.

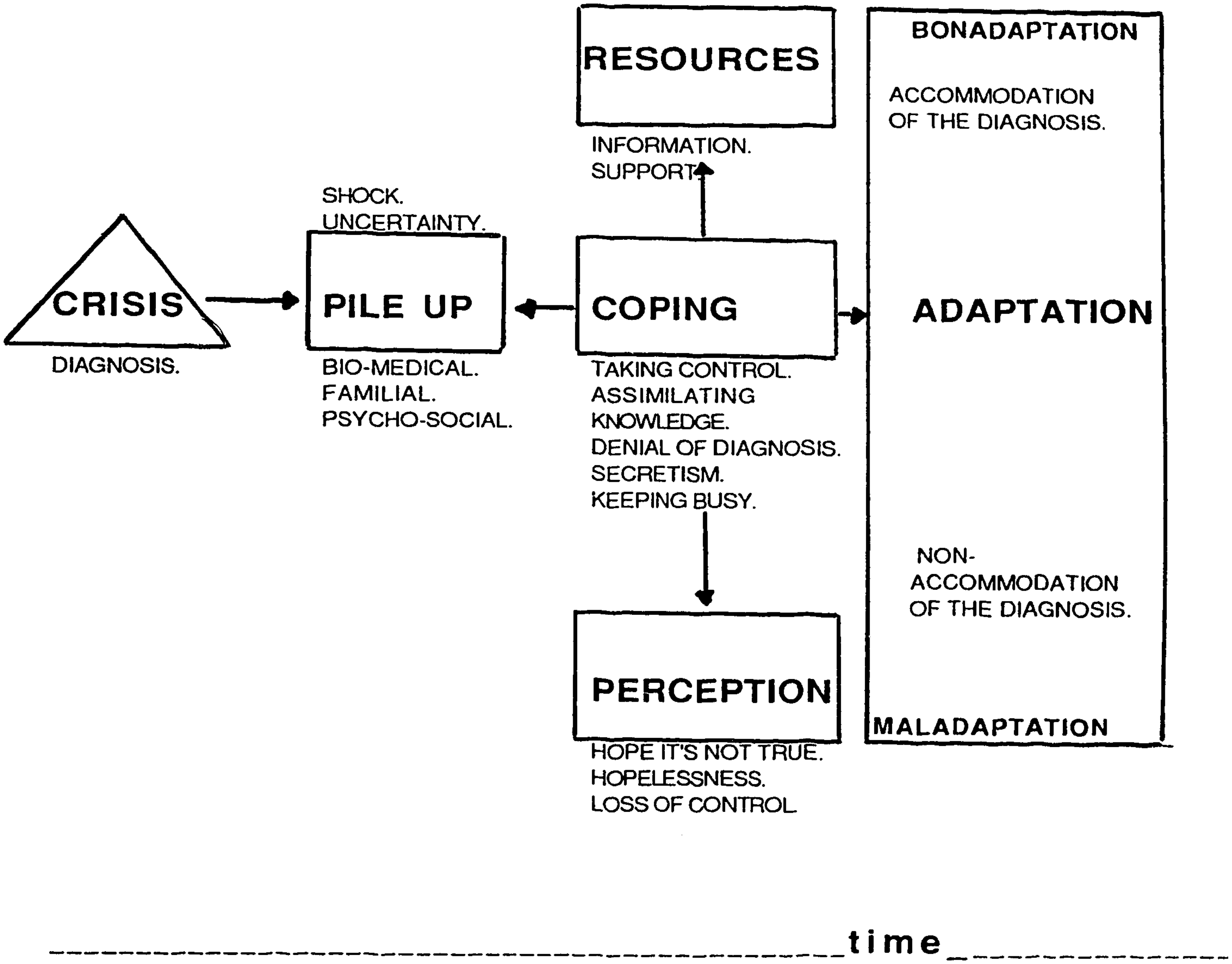
Diagnosis provides clinical confirmation of the disease and commencement of the early stage. For Frances (unpublished) the duration of this stage was an approximated twelve months in a total journey of twenty-one months. At its commencement, the diagnosed family member is relatively sick with new opportunistic infections that invariably necessitate hospitalization. However, active medical treatment affords recovery, maintains relatively stable health, and the diagnosed individual normally resumes a normal working life for the remainder of this stage. The shape of the the lifeline at this stage is therefore depicted as a short negative slope followed by an almost equally positive incline. This remains relatively static throughout the remainder of the stage.

For the family, the ill-health and subsequent diagnosis of one of its members represents a *cataclysmic stage* (see Fig. 4.1) which is extremely emotional and painful. The confirmation creates an intense shock response which acts as the catalyist for change in their circumstances and in their perception of life. Irrespective of prior suspicions or warnings of AIDS, hearing the painful truth penetrates directly to the heart of family members. The initial shock response of the family members is manifest in anger, anxiety, denial, disbelief, distrust, guilt, fear, and sadness. From the moment of diagnosis, it is as if a cascade of new problems and challenges is released. Family members face a pile up of stressors which emanate from bio-medical, psychological, sociological and familial sources. Dominant issues include noticeable weight loss, fear of contagion, death and dying, stigma and shame, homophobia and a non-normative family death. The constant exposure to these at the early stage, creates anxiety, fear of judgement and rejection, a feeling of powerlessness, uncertainty and loss of control.

It is noted that the pervasive sense of uncertainty, a psychological stressor which characterizes the AIDS trajectory (Brown & Powell-Cope, 1991), is intensified at the early stage by a lack of answers. Uncertainty regarding verification, prognosis, and contagion represents a major component of pile up at this stage. Obtaining answers and resources is obstructed by the dearth of definitive information, medical bureaucracy, and societally imposed

Figure 4.1

CATACLYSMIC STAGE: LIVING WITH THE KNOWLEDGE OF AIDS IN THE FAMILY



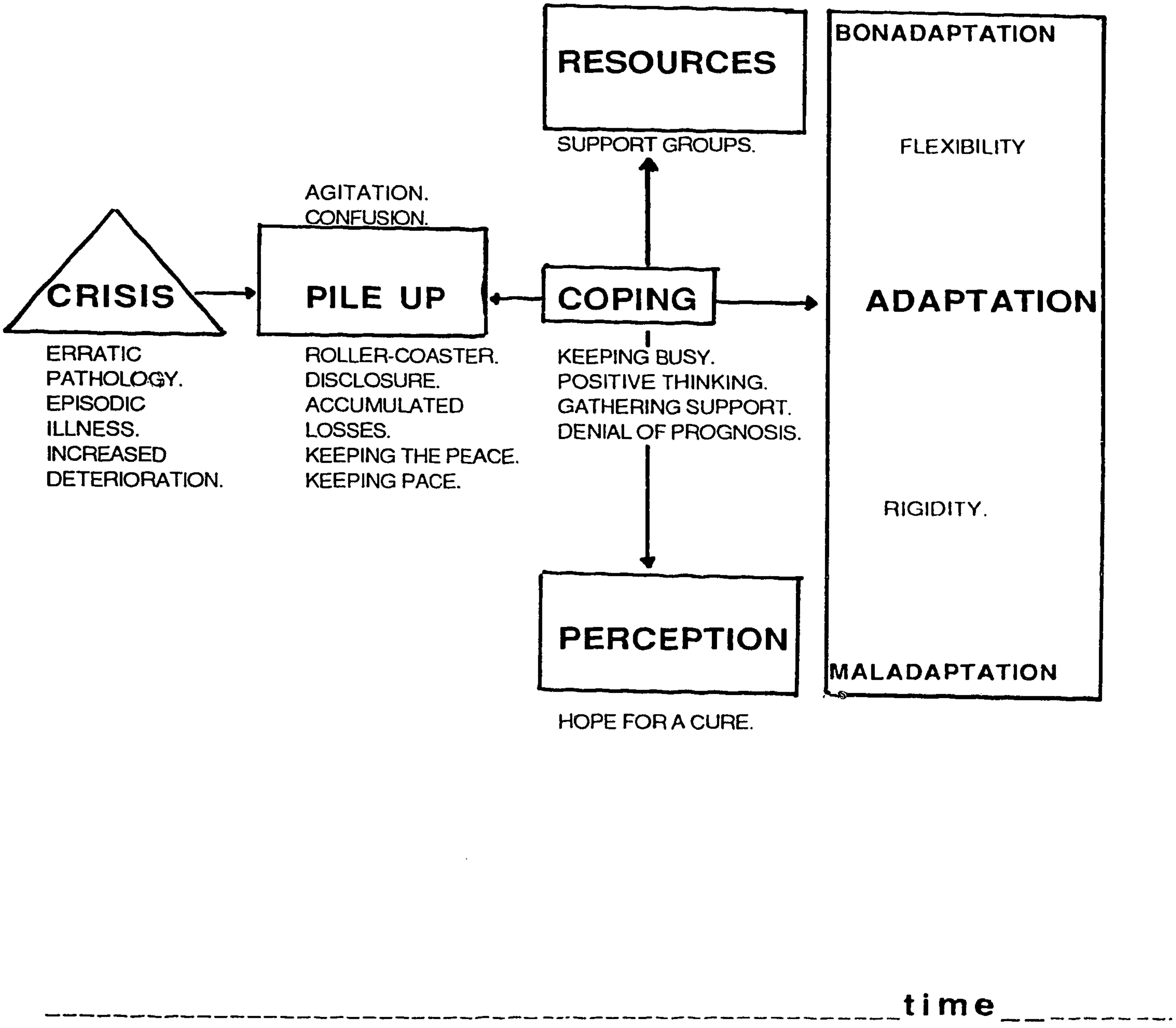
stigma. Family members perceive the situation as hopeless, themselves as helpless and out of control, and their lives as managed by the illness.

Management throughout this stage involves confronting the realities of the diagnosis, by assimilating knowledge and coping methods which maintain denial and secrecy. This management style, which is implemented selectively throughout the early stage, affords time whilst evidence is sought which refutes or substantiates the diagnosis. It also restricts the choice of resources and coping mechanisms to personal and cognitive endeavors, along with confidential sources of information and support. Towards the end of the stage, when re-occurrence of opportunistic infections and assimilation of the realities is advanced, family members use less denial and secrecy, and rely more on an intense hope that a cure will soon be found. Consequently, family members who adapt at this stage have re-asserted some control, made readjustments and accommodated the diagnosis into their family management patterns, which are now designed for *living with the knowledge of AIDS in the family*.

The progressive stage is distinguished by the intensely erratic course of the disease and the patient experiences alternating short periods of health and longer periods of acute sickness, with accumulating debilitation and weight loss, For family members this is a *chaotic stage*, (see Fig. 4.2) which for Frances (unpublished) lasted approximately five months. In this time new developments, and severity, of infections intensify, and remain active longer. Active therapy re-establishes shorter periods of relative normality, but

Figure 4.2

CHAOTIC STAGE: LIVING WITH AIDS AS A FACT OF FAMILY LIFE



deterioration is cumulative and highly evident towards the end of this stage. The shape of the patient's lifeline and the family member's quality of lifeline is therefore depicted as a series of long descending lines, followed by shorter ascending ones which subsequently gravitate to a lower level by the termination of this stage.

For the family members the changed pattern of pathology confirms the diagnosis, but perpetuates the uncertainty regarding what to expect next, and the long-term prognosis. The analogy of the emotional roller coaster is often attributed to this stage, as family members watch and wait for new infections, and lurch from periods of calm to instability in ever quickening succession. Pile up comprises of existing early stage stressors, fears and uncertainties regarding terminal aspects of the disease, and repercussions of divulging the diagnosis to others, particularly when the issue of homosexuality is involved. Living with AIDS at this stage represents a loss of peace of mind as perception oscillates between hope and hopelessness for long-term recovery. Living in limbo, maintaining a vigilance, interpreting the signals, keeping pace with symptoms and therapies, keeping the peace in family relationships, providing intermittent care, and the effects of accumulated losses all contribute to the constant state of agitation.

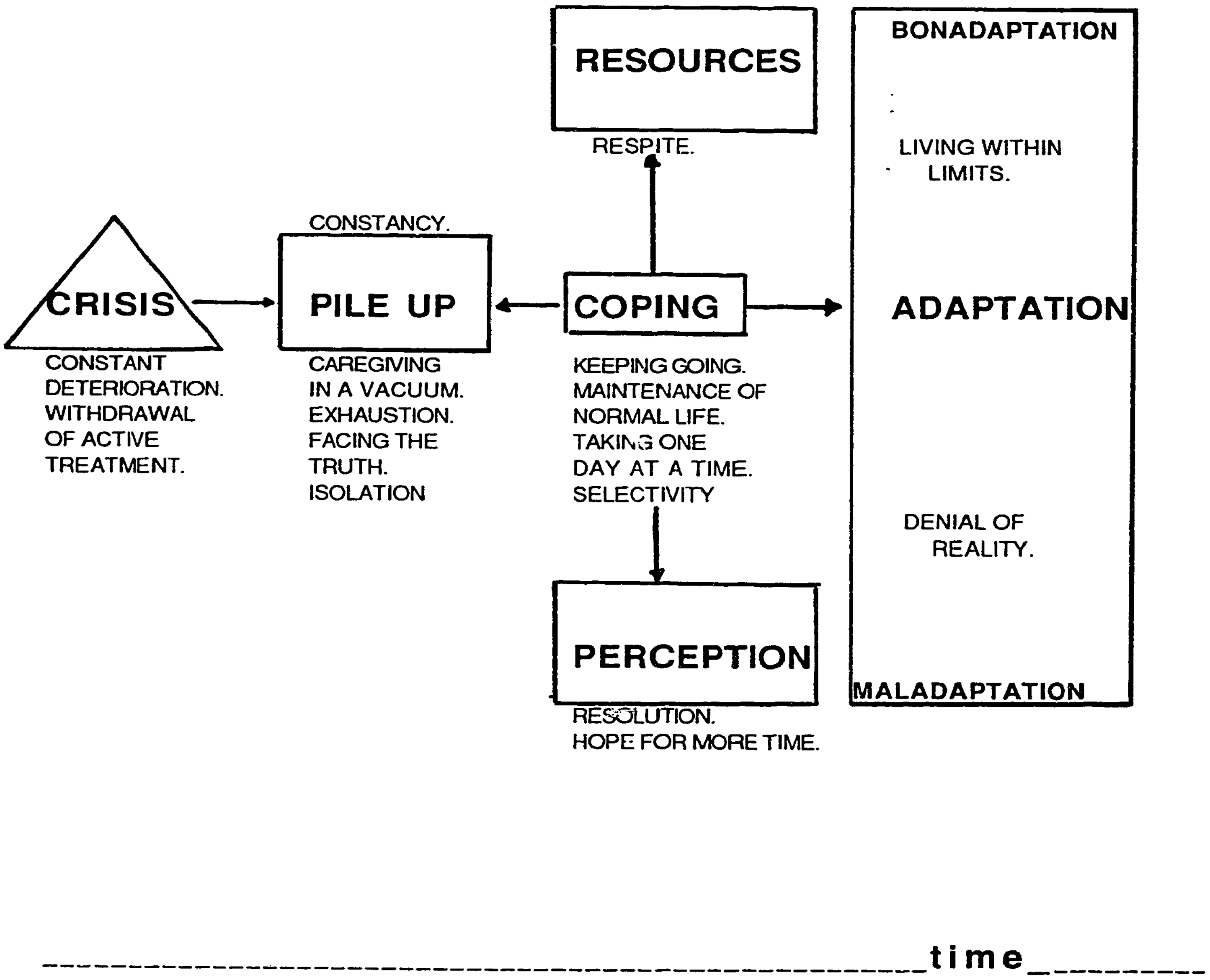
Management throughout this stage involves taking care, of both an individual with AIDS, who can be symptomatic or a-symptomatic and the family members themselves. Coping strategies involve keeping busy, through being involved, telling others, gathering support, inventing new strategies, venting emotions and giving time to others. Denying the severity of symptoms, or inevitable terminability, and the search for a cure, remains the mainspring of hope for life. With the instigation of new resources, such as support groups, and cognitive opportunities for empowerment, such as positive thinking, family members ostensibly adapt by perceiving their environment as less threatening and by developing the ability to be flexible. This enables them to carry on *living with AIDS as a fact of family life.*

The advanced stage is distinguished by a constancy in deterioration which is devastating, and the withdrawal of active therapy. This stage marks the "beginning of the end" for the infected individual, who may have become progressively blind, incontinent, disabled, and demented. The combined effect of persistent infections, irreducible impairment, and an ineffective therapeutic regimen over this approximate three month period, accounts for a progression which is relentlessly downward. Consequently, the shape of the lifeline is depicted as a steep negative slope (see Fig. 4.3) .

For the family members, the bio-medical constancy, together with the curtailment of therapy heralds an acutely active *constant caregiving stage* which becomes chronically exhausting and isolating. Family members designated to provide primary care, invariably did so in a vacuum of inadequacy and isolation, which they perceived as personal and societally induced. In addition to the existing accumulated stressors from previous stages, primary caregivers became consumed by AIDS and suffer from chronic levels of deprivation, role overload, fear, anger, helplessness, distress, uncertainty and loss of control over the progression and inevitability

Figure 4.3

CONSTANT CAREGIVING STAGE: LIVING WITH THE TERMINAL REALITIES OF AIDS IN THE FAMILY



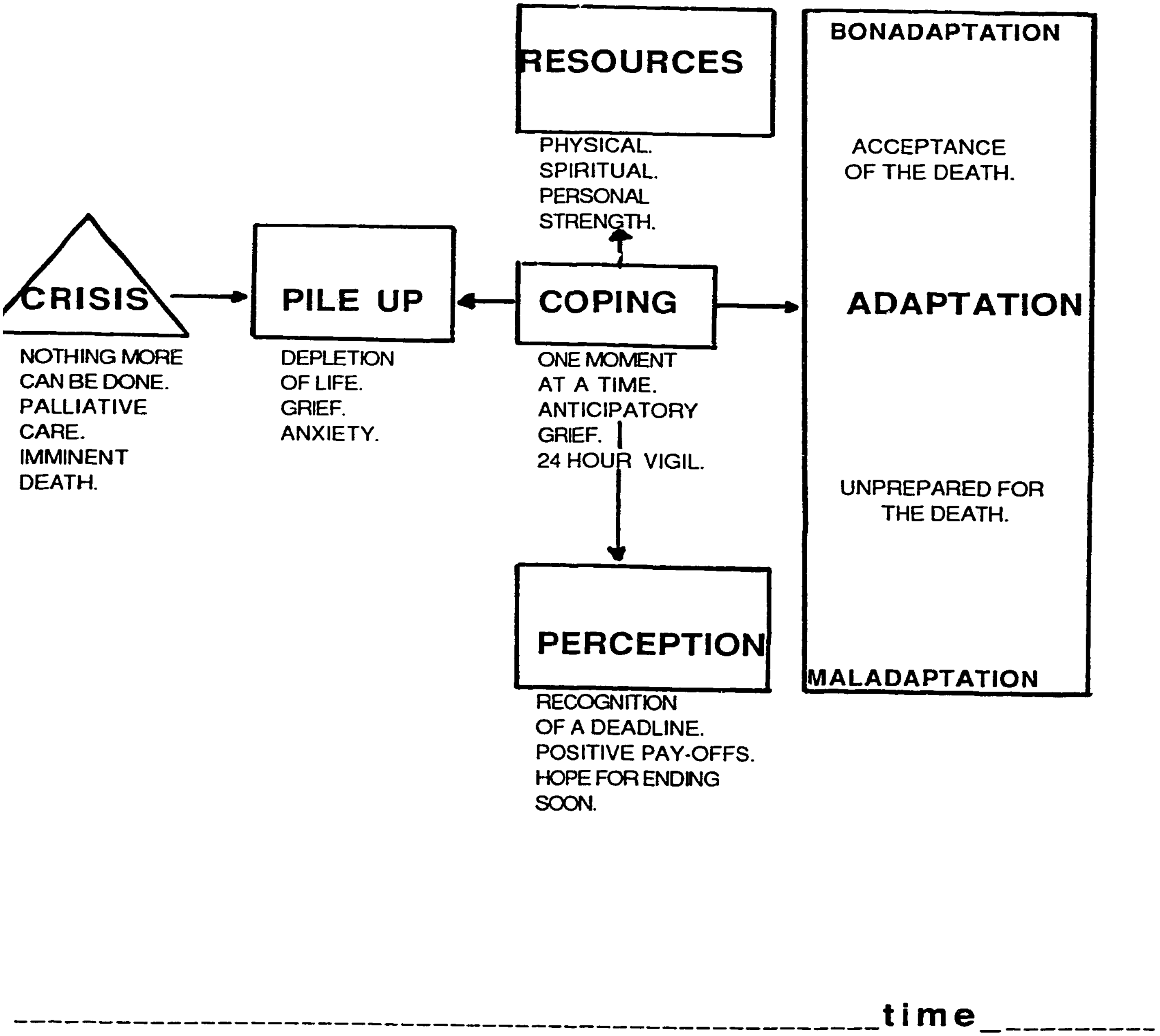
of death. Additional uncertainty centres on the source of behavioral manifestations which are displayed by the diagnosed individual, and how much time remains before the inevitable death occurs.

Management at this stage is orchestrated by the restraints of reactive and pro-active living. Coping involves constant monitoring and re-regulation of existing structures, routines and strategies for caregiving and self preservation. Family members learn to live within self and AIDS imposed limits. They take one day at a time, elicit more support, reduce their isolation and discomfort, and face the truth that time is running out. They seek resources which offer constructive physical and emotional respite, and restrict their efforts in order to concentrate on important activities and relationships, in preparation for letting go of the individual with AIDS. As perception changes to recognition that the fight against the disease is all but lost, they counter the effects by thinking positively. Family members ultimately adapt by living in the present, and pinning their hopes on more time, and concentrate on *living with the terminal realities of AIDS in the family*

The terminal stage is the *relinquishiment stage* (see Fig. 4.4) which is distinguished by the instigation of care that is palliative, or entirely comfort orientated. By this point the ravages of the disease have taken their toll. The individual with AIDS is bedridden, considerably affected by dementia and totally dependent. Death is imminently apparent and may occur in a period of days to approximately four weeks. The life-line at this point is therefore short and relatively level, as the person with AIDS coasts towards death. Accordingly, the quality of life for the family members also

Figure 4.4

RELINQUISHMENT STAGE: LIVING WITH IMMINENT DEATH DUE TO AIDS IN THE FAMILY



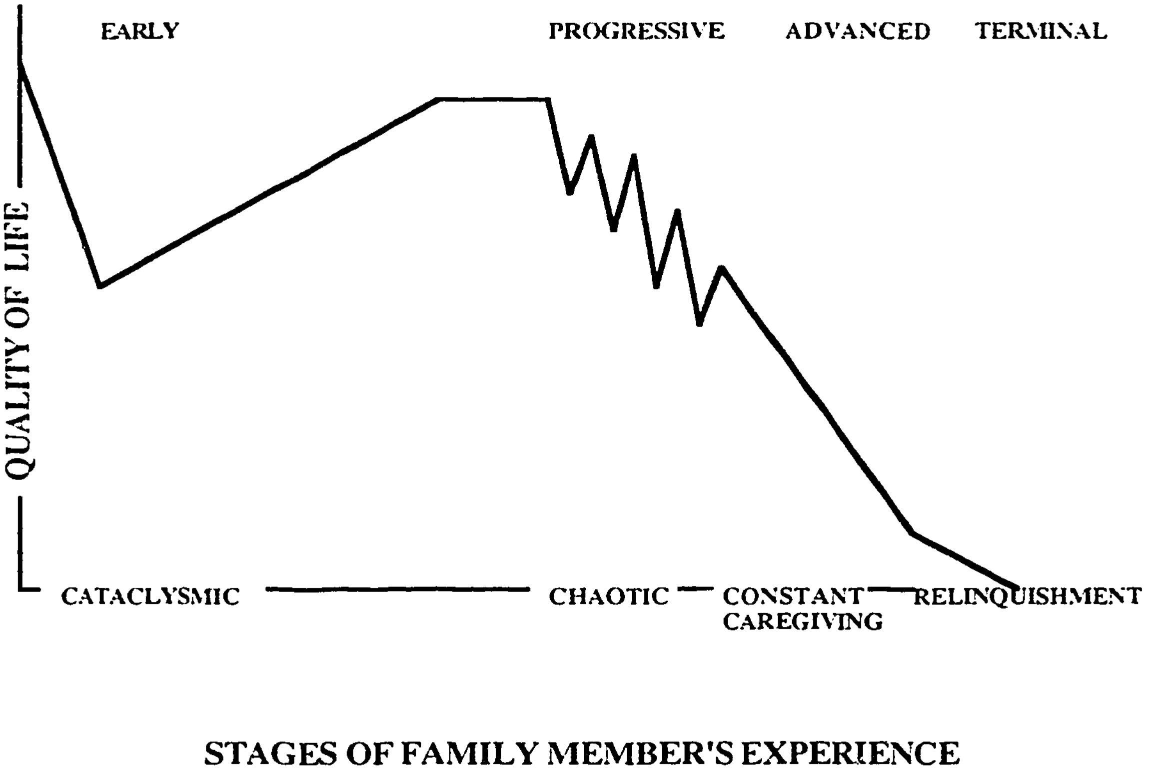
shifts. Although this is the shortest stage in the AIDS trajectory, relinquishing represents a profoundly emotional and spiritual stage as family members witness the physical depletion of life and simultaneously negotiate their emotional withdrawal. Grief is intense, and anxiety regarding contamination, contagion, and death and dying returns. Uncertainty is manifest in the inability to predict when death will occur, and the orchestration of letting go of the dying person.

Management at this stage is dictated by the urgency and emotionality of living in the shadow of impending death. Coping involves maintaining a twenty-four hour vigil, and engaging in the final stages of anticipatory grief. Family members maximize the time left by living from moment to moment, providing physical and emotional comfort for the dying individual, respecting his or her wishes, physically and emotionally uniting family members, saying good-bye and letting go. They rely on personal strength and selective contact with professionals and close relationships to provide the physical and spiritual resources required to sustain them. Perception at this stage represents a changed sense of time and values, which develops from the recognition of the deadline. Although perception is designated as both negative and positive, the realities are such, that the existing hope for many is for it to all end soon. Adaptation constitutes acceptance that death is an integral part of living with AIDS, and recognizes the beneficial aspects of *living with imminent death due to AIDS. in the family.*

Figure 4.5 represents the interlinkage between the family member's quality of life, and the person with AIDS lifeline in a qualitative shift through each of the four stages outlined above. What is clear is the overall downward slope. This represents the relatively rapid deterioration in life from the moment of diagnosis to death.

Figure 4.5

A SYMBOLIC REPRESENTATION OF THE STRESS OF LIVING WITH AIDS IN THE FAMILY



In the *cataclysmic stage*, one observes the line has a sharp downward slope after the shock of the diagnosis. This is followed by an upswing, indicating the relative return to regular activities, and given future events, relative stability in the quality of life. The shape and direction of the lifeline in the *chaotic stage* reflects the "roller coaster pattern" which was evident in the disease trajectory of the person with AIDS, and correspondingly in the family member's quality of life. In the *constant caregiving stage* when aggressive treatment is withdrawn, the lifeline represents the steep decline and rapid deterioration. At the *relinquishment stage*, prior to the moment of death, the line is almost horizontal. This period was described as "coasting" referring both to the state of near death of the person with AIDS, and the family member's almost total emersion in attending to the final moment.

The dramatic shifts from stage to stage in the quality of life of the family members suggests a comparison to the earlier work of Strauss and Glaser (1975). Although beyond the scope of this thesis, this work would benefit comparison with the quality of life for living with other chronic illnesses such as Alzheimer's disease, rheumatoid arthritis, and multiple sclerosis, and promote a more encompassing synthesis.

IMPLICATIONS FOR USE AND SUGGESTIONS FOR FUTURE RESEARCH.

This study integrated the bio-medically determined stages of AIDS with psychosocial realities and management of each, categorized according to the double ABCX framework of family stress. The integration provides a more holistic yet succinct approach to further understanding of living with a family member diagnosed with AIDS and offers invaluable knowledge for utilization in interventions and future research. Before addressing these aspects, however, it is important to add a caveat with respect to the notion of stages.

The danger of developing a stage model is that it leaves an impression that family members universally experience living with AIDS according to the progression of the model. I wish to dispell implications of this nature. Currently given the absence of a cure for AIDS, it is certain for an individual diagnosed with AIDS that following clinical confirmation, a four stage trajectory towards death will occur. However, although they live with the same disease, this is not the case for family members. Their experience of, and response to, the trajectory, is likely to be unique. Therefore, providing a two dimensional, four stage representation of living with AIDS, involving specific categories of realities and management, in no way implies that all family members did, will or should experience the journey homogeneously. As unique individuals we are all subject to numerous cognitions and emotions which effect our response to the realities we encounter. As a result not all family members have the same feelings, or experience them as acute, and lasting. Equally feelings may come and go throughout the trajectory, or be replaced by others which are similar. For example some may use anger as a response to disguise feelings of fear. Consequently, in utilizing this material it is important to remember that what is described here represents a general representation of the experience, at each stage, in terms of the bio-psychosocial realities faced by family members of individuals diagnosed with AIDS, together with their attempts to manage them.

The value of these generalities lies in the ability to provide practitioners with sufficient guidelines to anticipate reactions, needs and vulnerabilities to the realities of AIDS, and assist in the conceptualization of interventions and treatment of families thus affected. For example, knowing the stages and what can be expected within each provides a basis grounded in research. From this basis, additional models can be developed as tools for assessment of family members, and checklists can be assembled which enable practitioners to provide reassurance that certain responses such as fear and isolation are normal. In this way they can allay family members fears of non-normalcy, or loss of control. In addition, resources such as information, and programs intended to support people at certain stages of the AIDS trajectory can be more precise in timing, content and format to the characteristics of the particular stage currently being dealt with. For example, knowing when to offer different types of information, what topics to address at different stages, when to provide more physical support, and what important issues, which may not have been addressed in previous stages, should be checked out.

Timely access to support is important. As bio-medical stages only suggest an approximate point in the disease trajectory, it is not inevitable that the family member's psychosocial stage will always correspond to this. Practitioners, such as physicians, nurses, therapists, social workers, family educators and clergy can use the model to identify the psychososcial stage that is being experienced by family members. Furthermore, in order to offer opportunities to empower the family members with responsibility for their own journey, practitioners need to establish which realities they currently require assistance with, and forewarn them of those which may yet come. A Q-sort could be developed to assist in this. Since a Q-sort relies on statements which indicate measurable degrees of acceptance or rejection (Cornell, 1974; Skorupka & Bohnet, 1982), data collected in this synthesis, could be used to formulate these. Assessment of each family member using the Q-sort will ultimately provide the practitioner with the necessary information to design a psychosocial intervention plan. Flaskerud (1992) has already noted that such a plan can be personalized to meet the specific needs of individuals and families, as they move through the various stages of living with AIDS in the family. However, the quality of the Q sort will depend on the quality of the research which needs to be done to test and validate the model's applicability to AIDS.

It is suggested here that before data from this synthesis is used in the development of a Q-sort it should be validated in future empirical research. Some suggestions for the direction of research follow. These pertain in particular to design, data source and sampling. Current available research is biased by designs which are retrospective and samples which are drawn almost exclusively from a homosexual population. In addition there is relatively little data which gives access to the experience in the depth and richness required by this model. Therefore, to establish the extent to which these findings can be generalized to the AIDS trajectory future studies should be conducted using a longitudinal and ethnographic approach. The richest data for the development of this model was the diary. More extensive use of the diary is recommended.

A diary allows access to personal experience. It is capable of covering a long time frame without economic, or time burdens placed on the researcher. It is cost effective without the ethical problems of intruding into a persons life on a daily basis. It would also allow the researcher to answer with more certainty the issues and daily realities of living with AIDS monitored against the health of the individual with AIDS. For example, it could record when uncertainty, hope, and anticipatory grief begin, and plot their development through time. It would also provide a further understanding of their effects within the family and the roles which resources, coping and perception play in adaptation. For example, the diarist would be encouraged to write of the use of secrecy, selective denial, returning to religion after a lapse, or attending a new support group; how these strategies and resources were perceived over time, and how did this effect adaptation by the end of a stage? This method would also test for negative cases and may provide pointers regarding the causes for the differences which could be tested later by other empirical methods.

Ethnographic research would also fill some of the gaps in the existing AIDS family research data, which were noted throughout chapter three. Studies which require family members to complete a diary provide prospective data from the point of diagnosis, and follow the person forward, rather than relying on retrospective data which may have been processed over the interceding period, and thereby altered by time. Diaries can be used to record specific variables, such as the developments of new infections or instances of stigma, and the resources and perception which were used to overcome their effects. Comparative information could be obtained by studying diarists who represent different sexes, ages, ethnic backgrounds, family roles and relationships. It is also important to examine differences in responses in cases where AIDS was contracted by different routes, e.g., homosexual behavior, heterosexual relations, IV drug abuse and blood transfusions. For example, does a family member of a haemophiliac experience stigma in the same way as a family member of a homosexual? Do family members who provide primary care perceive the realities, or manage them differently from others in the same family? How does the perception of children of adults with AIDS differ from that of adults or between siblings? What effect does age, gender, personality, or religious belief have on the process over time? Do any of these factors have a significant role in the amount of uncertainty, fear, isolation and hope which were found to be ongoing in this study? Studies which incorporate these differences in samples are considered invaluable and urgently needed, given increased reports of "tainted blood", and incidences of HIV infection in young children and heterosexual adults. These studies are made all the more essential given, health-care cutbacks, which all necessitate increased family involvement in care. Hopefully such studies would shed increased light on the issues involved for all families living with AIDS. It is important to provide practitioners with ideas for management interventions, and to offer those who study the family a greater insight into family relationships and more techniques for coping with the unique stress encountered by people living with AIDS in the family.

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APPENDIX 1

FOUNDATIONS OF THE DOUBLE ABCX MODEL

FOUNDATIONS OF THE DOUBLE ABCX MODEL

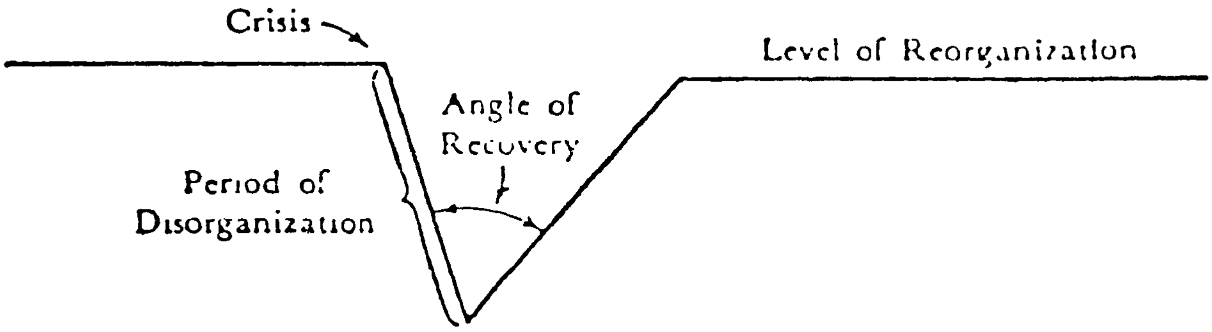
It is generally accepted in family studies literature that Hans Selye popularized the concept of stress as early as 1936 (Appley & Trumbull, 1986). In his medical conceptualization stress was seen as a physiological and psychological transaction occurring between individuals and their environments which was potentially harmful to health and well-being. The application of this to the family situation, as opposed to the individual, was developed later through the models of Koos (1946), Hill (1958), and McCubbin and Patterson (1983).

In 1946 Earl Lomon Koos created the first family stress model; the Profile of Adjustment to Trouble. The model, which he presented in his major publication "Families in Trouble" (1946), was created from an extended case study which focussed on the troubles of 62 low-income families in New York. Koos studied family troubles to establish "how families solve problems, what internal stresses are set up and what changes take place due to a family's action or inaction" (Koos1946). He subsequently defined troubles as "situations outside the normal pattern of life which create a sharpened insecurity, or block the usual patterns of actions and call for new ones" (1946, p. 9). Troubles created a demand for new patterns of behavior which may be constrained by cultural and social barriers operating against the family. They arose from several sources and included acute and chronic illness, financial mis-management, unemployment, sexual incompatibility and family death.

The study conclude that families eventually adjusted, but the level of disorganization and recovery rate varied from family to family, and among different types of problems. "What might be an exigency in life to one family could well be trouble for another" (Koos, 1946, p.9). A family's sensitivity and adjustment to trouble was determined multifactorially by numerous simultaneous interacting factors, including previous experiences. Well organized and successful experiences with troubles tested and strengthened families, whereas totally disorganized and unsuccessful experiences were detrimental (Koos,1946).

Koos's work provided the basic foundation for family stress theory; that families react to a situation and become involved in a process of adjustment over time. His simplistic model represented the process of family disorganization and reorganization over time (See Figure A 1.1).

Figure A.1.1. **The Koos Profile of Adjustment to Trouble.**



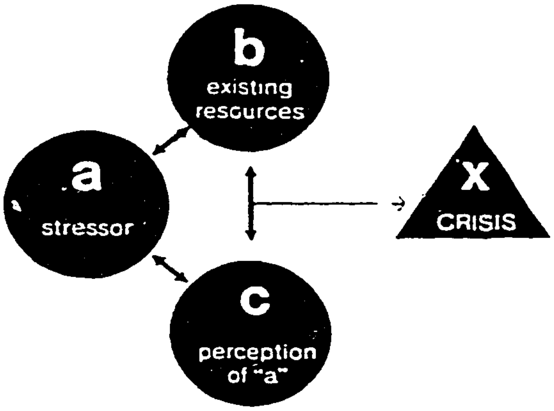
Source: Koos (1949), Families in Trouble, p.108.

According to the model, families can finish the process of adjustment at approximately the same, a lower, or a higher level of interaction relative to where the trouble began; thereby recognizing a family's potential for positive recovery from its experience.

In 1958 Reuben Hill further advanced the understanding of family stress by proposing the ABCX model. It was developed from his study, Families Under Stress (1958), which focussed on war-induced separation and reunion of 135 Iowa families. Hill's fascination regarding how some families thrive in the face of crises, whereas others do poorly, motivated his study of the inherent family characteristics of successful adjustment and the conditions and processes involved. His choice of families separated by war allowed him to study a common external stressor of a prescribed length, and two adjustment periods per family; separation and homecoming. Although family crises seem similar to Koos's troubles, Hill defined them as unanticipated bigger jolts. He wrote that "death and taxes we always have with us, but if death, taxes, unemployment and infidelity hit at once, most families are stricken with panic." Crisis situations "create a sense of sharpened insecurity upon the family, or block the usual patterns of actions and call for new ones." (Hill, 1949, P.9).

Having confirmed that adjustment to the impact of problems varied among families even when faced with the same situations, Hill subsequently used the case study method to investigate those who thrived. He concluded that survival was determined by five factors within the family and the potential crisis situation. These were: the number of hardships entailed in the event, the resources used, the definition the family made of the situation, the family itself, and the adjustment to each situation (Hill,1958, p.143). These findings were developed into the diagrammatic form of the ABCX model (see Figure A. 1.2).

Figure A 1.2. **The ABCX Model**



Source: Adapted from: McCubbin & Patterson, 1983, Family stress and adaptation to crisis:
A double ABCX model of family behavior. In D. H. Olsen & B. C. Miller (Eds.), Family Studies Review Yearbook, Vol. 1 (p. 91).

The ABCX model (Hill, 1958) greatly enhanced researchers' understanding of family adjustment to change. It depicts the family, which is comprised of several individuals, as a reactor to a stressor or stressor event, and a manager of existing resources. Therefore it explains how a family combats and controls the change, or adjustment process within its system, using different theoretical constituents, or independent variables. The variables are; a stressor or crisis provoking event (a), existing family resources for meeting crisis (b), and the perception or definition the family made of the event (c). The interaction of (a) with (b) and (c) is perceived as an ongoing adjustment to the situation, which is ultimately held responsible for affecting the outcome. Arrows between the variables indicate that the adjustment process is circulatory and interdependent, and either results in the reduction of the stressor effect, or a crisis (x).

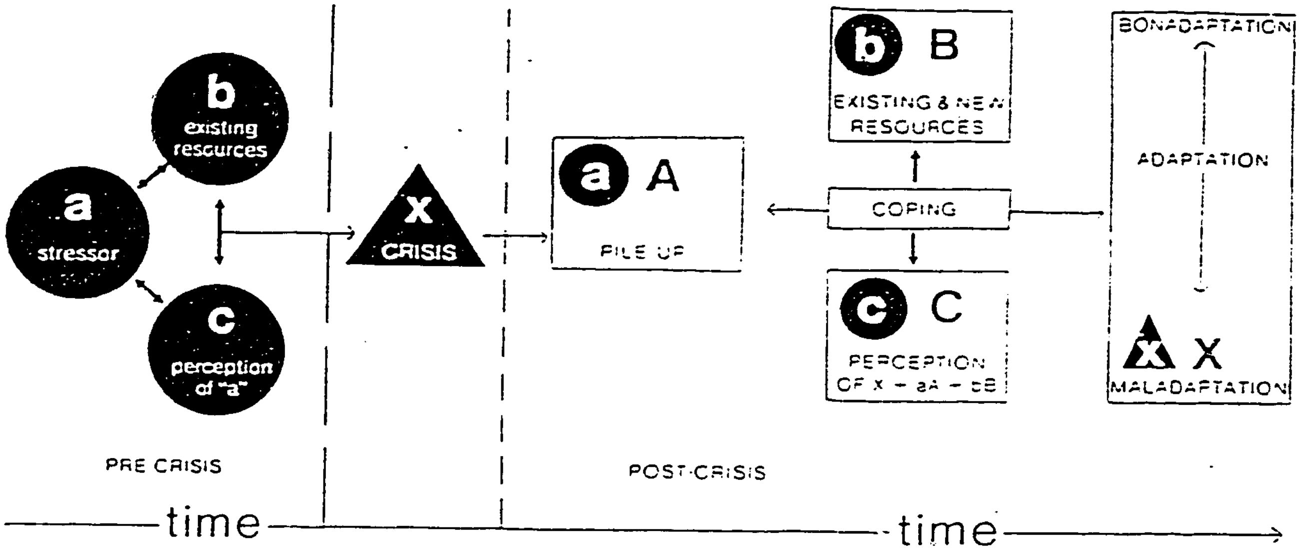
Hill's contribution succeeded in combining Selye's work with that of family sociologists and social workers studying susceptibility to family crisis. A major attribute of the model was its simple explanation of the complex processes involved in responding to stress and this was missing in Koos's model. The ABCX conceptualization provided researchers and practitioners from diverse disciplines with a compact model to understand and study the processes of change and the differences existing among families with respect to outcome.

Additional comparisons between the two models reveal four conclusions. Firstly, where the Koos model depicted a process of disorganization and reorganization following crisis, the ABCX model portrays crisis as the outcome of the family change process. This ultimately resulted in the ABCX model becoming known as the pre-crisis model (McCubbin & Patterson,1983). Secondly, both models depict a process of family level adjustment to something which is stressful. It is only the definition of the stressful situation, as either a problem, or possible crisis situation, which makes the crucial difference. Thirdly, in terms of outcome, the ABCX model offers an ongoing adjustment, or crisis; whereas the Koos model offers varying levels of re-organization ranging from negative to positive family adjustment. Therefore, from a family educational and developmental perspective, the ABCX model appears to be more restrictive.

Hill's three variable, pre-crisis ABCX model dominated family stress research for many years. Researchers continued Hill's work on normative and non-normative family life cycle events (Drabeck, Key, Erickson & Crowe, 1975; McCubbin, Dahl & Hunter, 1976; McCubbin & Olsen, 1980; Neugarten & Hagestad, 1977; Russel, 1974), and desired or unpleasant events (Hill, 1973; Hill & Joy, 1979; Lewis & Pleck, 1979; McCubbin Cauble & Patterson, 1982; Moen, 1979). They also clarified and gave empirical support to the ABCX model, by redefinition, re-measurement and elaboration, of its intervening variables (Burr,1973; Boss, 1977; Cobb, 1976; McCubbin, Hunter & Dahl., 1975; McCubbin, Patterson & Wilson,1979; McCubbin, Boss, Wilson & Dahl, 1981; Olsen, Portner & Bell, 1978). These findings suggested that although normative and non-normative stressor events represent an inevitable part of the family life cycle, crisis is not a definitive outcome. Many families avoided crisis, and adapted successfully to the experience. Consequently, there was a major shift of focus in family stress research from family vulnerability to crisis, to one of regeneration and resilience following a demand for change. Crisis had become redefined as the family's inability to restore stability in the face of continuous pressure to make changes in family structure and interaction patterns.

Hamilton McCubbin and Joan Patterson developed the third family stress model; the double ABCX (see Figure A 1.3), which was published in an article entitled "Family Stress and Adaptation to Crises" (1983).

Figure A 1.3. The Double ABCX Model.



Source: McCubbin and Patterson, 1983, p.91

They built on previous knowledge of the family stress framework (McCubbin, Boss, Wilson, & Lester,1980; McCubbin & Patterson, 1981; McCubbin Larsen & Olson, 1982) together with cognitive, psychological (Haan; 1977), and sociological theories (Antonovsky, 1979; Mechanic, 1974; Pearlin & Schooler, 1978). These supported their hypothesis that crisis avoidance is made possible by the management of existing resources and the redefinition of the stressors involved. Family stability and the resistance to systemic change was thought to be maintained in this way. McCubbin and Patterson (1983) confirmed this in a longitudinal study of 216 families with fathers held captive, or unaccounted for in the Vietnam War. They concluded that over time, the family's adaptation to a stressful situation was influenced by four interdependent post-crisis variables, or factors. These were: the pile up of additional stressors; acquisition of new resources; modification of family perception to the total crisis situation, and the role of family coping. McCubbin and Patterson (1983) suggested that the interaction of post-crisis variables impacts with life cycle stressors and strains, and the psychological intrafamilial and social factors which are inherent in the management and outcome of adaptation.

Consequently, they modified the ABCX model by extending it to include and make more explicit, the post-crisis management phase. The replication of the ABCX can be seen in figure A 1. 3. The components of the post-crisis phase are conceptualized as the Pile Up of Stressors (aA); Existing and New Resources (bB); Coping, a separate entity or state juxtaposed to crisis; Perception of Crisis, Pile Up and Resources (cC); and Adaptation at three levels; Bonadaptation, Adaptation and Maladaptation, or Crisis (xX). The Double ABCX model and its components were discussed in greater detail in the main body of the thesis.

McCubbin and Patterson had successfully combined their work with that of Koos (1949) and Hill (1958) and extended it to explain more adequately the family management of stressful situations. In addition to refining and encompassing the process and variables in the adjustment to trouble (Koos, 1949) and pre-crisis phase (Hill, 1958), they had identified extra variables in the post-crisis management of stressful situations and, in particular, highlighted coping as an integral part of the process.

Irrespective of its complexity relative to previous models, McCubbin & Patterson's two stage double ABCX model advanced knowledge by providing clear, valuable and positive information. Current researchers and family practitioners now recognize that transitions, or catastrophes do not necessarily create crises, or major upheavals in family functioning. Unlike earlier models which stressed family vulnerability and dysfunction, the double ABCX offers an holistic model for studying how families might manage stressful events successfully (Boss, 1986). This type of knowledge is particularly beneficial in the identification of appropriate educational and supportive strategies for AIDS families.

Since the introduction of the double ABCX model, McCubbin and his contemporaries continued to publish using the double ABCX model (Comeau, 1985; Olsen, Lavee, McCubbin & Patterson, 1985; Lewis & Looney, 1984; McCubbin, Barnes, Larsen, Muxem, & Wilson, 1983; McCubbin & McCubbin,1987). In "Family Assessment Inventories for Research and Practice," McCubbin & McCubbin (1987), suggest a further refinement to the ABCX model, by adding the variable of family structure. However the addition of this variable did not change the basic components of the original formulation, which are considered most suitable for research to discover the stress of living with AIDS in the family.

APPENDIX 2

CORE AND SUPPLEMENTARY MATERIAL

CORE AND SUPPLEMENTARY LITERATURE

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