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FAMILY INCIDENTS: IMPACTING HOPE OF PERSONS WITH HIV/AIDS

by

Gina Wong-Wylie ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of Master of Science.

in

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Family Incidents: Impacting Hope of Persons with HIV/AIDS** submitted by **Gina Wong-Wylie** in partial fulfilment of the requirements for the degree of **Master of Science** in **Family Ecology and Practice**.

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August 25 [illegible]

Date

We shall not cease from exploration:
and at the end of all our exploring
will be to come from where we started
and know the place for the first time.

•

T. S. Eliot, "Little Gidding"

I have dreamt in my life
dreams that have stayed with me ever after,
and changed my ideas:
they've gone through and through me,
like wine through water,
and altered the color
of my mind.

•

Emily Bronte

In dedication to individuals and families
whose lives are touched by the profound illness of HIV/AIDS.
May you continue to find hope.

ABSTRACT

This thesis presents two separate, yet interconnected studies involving 6 persons living with HIV/AIDS. Collectively, both studies gave voice to *family* meanings and the lived experiences of family incidents that influenced personal hope. Aimed at determining the components within family incidents that enhanced or diminished participants' hope, the preliminary study involved an exploration of the families of persons living with HIV/AIDS. Seven elements were identified to comprise participants' families. They were: (1) *family of origin members*, (2) *health care professionals*, (3) *friends*, (4) *other persons living with HIV/AIDS*, (5) *deceased friends*, (6) *family caregivers*, and (7) *hobbies*. In addition, this preliminary study incorporated a description of family membership criteria: Persons and things perceived to engage in a *reciprocal relationship*, and that were *inspirational influences*, as well as *accepting*, *supportive*, and *health and wellness resources* were in the selected families of persons living with HIV/AIDS. The second study detailed family incidents that affected hope. Critical incident techniques generated 14 *hope-full* and 8 *hope-less* family incidents. *Meaning* was identified as the critical component to influence hope in family incidents. Seven hope-full critical meanings were identified: (1) *emotional support*; (2) *unconditional acceptance*; (3) *mutual support*; (4) *spiritual connection*; (5) *reframing life*; (6) *reframing death*; and (7) *affirmation of worth*. In addition, four hope-less critical meanings were identified: (1) *lacking honesty*; (2) *no emotional support*; (3) *conditional acceptance*; and (4) *reframing death*. Suggestions for future research were proposed. As well, implications for HIV/AIDS health care and social service programs, educational interventions, and counselling endeavours were provided.

Acknowledgements

A poignant analogy of my research journey came to me as I stood on the shore at Ruckle Beach in Salt Spring Island. I looked out towards the gulf islands, into the vast waters on a dark, stormy and rain-filled night-- and imagined myself diving in and swimming across. Through torrential rains, winds, and depths, I somehow emerged on the other side; although I never learned to swim. I conquered the swim-- stroking with my own arms and inertia, but I was propelled by others. It is for them that I send this heartfelt thanks for not only helping me keep afloat, but assisting me with much, much more...

Maryanne Doherty-Poirier was my guide. At times when I was floundering, your endless support and constant words of encouragement kept me going. You illuminated the journey, and not only guided me though, but cultivated the space for me to envision the journeys to come.

Ronna Jevne was and is my reference point; you are the solid, stable rock in the choppy, stormy seas. You provided direction and fostered my capacity to slow down, absorb the surroundings, appreciate the water in which I exist; and to listen to myself and to others.

Dianne Kieren gave me the hope that work and family can gracefully merge. You often took time amidst your busy schedule to offer insight into all my endeavours. I truly admire your sense of personalism and professionalism.

Cathryn Perrier laughed with me and engaged me in many discussions that cultivated my wonderings.

KOR, you are always a part of me.

And of course, the six co-researchers in this research who graciously gave of their time and of themselves; my respect and thanks. It is because of you that this journey has meaning.

I also greatfully acknowledge the financial supports for this research: Doris Badir Graduate Research Fellowship, Mary A. Clarke Memorial Scholarship, and Province of Alberta Scholarship.

Lastly, I extend my thanks for the enduring friendship and unfailing support of my life partner, Douglas Wong-Wylie. You continuously fuel the nourishment of my hope. You swam next to me; anchoring me when I needed, and was my lifeboat at other times. Because of you, I climb more mountains, subside more fears, and conquer more challenges. I live life a little more self-assuredly and permit myself to, once in a while, step outside of my comfortable space. You climb with me and together we feel the sun and wind upon us.

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PROLOGUE

ENDURING INSPIRATIONS

One individual with Thalidomide syndrome has arms that cease at the elbows and a left leg that is negligible. He stands in an upright position using his right leg to hold himself up. His arms are raised and his head is held high. Proudly, he is stretched out--naked, in a display for the world to see the glory of his spirit.

This is a photograph bestowed to me from a friend who died of AIDS. It was his image of hope. These were his thoughts:

> The courage to accentuate the spirit gives me hope. Regardless of our physical condition, there is the courage to put upfront our being, and in so doing, challenge the world to reflect upon the hope and spirit embodied in a less than perfect body. Whatever I may look like eventually as an AIDS patient, I can always project a loving, courageous, decent, and hopeful persona.
>
> --Ben Best, July 19, 1995

I feel strongly that individuals who work with persons living with the HIV/AIDS are most effective when they are driven not through their professional aspirations, but through their passion from an experience of being touched by the soul of a human being who is facing this illness. Ben was one individual who graced me by sharing the beauty within his soul. He has become one of the greatest inspirations to my work with persons living with HIV/AIDS; as well as those who are living day to day, taking care of their children, and nurturing the glory of their spirit through family and friends in the midst of their illness.

The Genesis of this Research

The impetus for this research emerges from my strong conviction that hope is inextricably interwoven within one's psychological, spiritual, and social existence. I believe that hope facilitates the spirit to persevere. The presence of hope accentuates meaning in life, and engenders the will to live in the face adversity. My own convictions of hope were forged through confronting a personal health challenge several years ago. Although not life-threatening, the ill health that I experienced changed my perception of myself, my place in the world, my relationships with others-- and my hope. What struck me the most through this time of adversity was how much others directly and indirectly affected the wholeness of my hope. My hope could be shattered or uplifted through interactions with those around me. As such, my own life has informed me and continues to inform me of the *otherness* that is essential to personal hope.

One of the reasons that I pursued graduate work was to further contribute to research in the area of living with HIV/AIDS. The evolution to the present research study began prior to my graduate work and had its inception at the Hope Foundation of Alberta where I studied under the guidance of Dr. Ronna Jevne. At this time, I became intentional about my own hope-- what it is, what it means to me, and who has the ability to influence it. Then, I had an interaction with a physician who crushed my hope. The doctor treated my health concerns but left my hope impoverished. I began to further question the nature of *otherness* in hope. Specifically, I wondered about patient-doctor interactions and hope. Thus, I combined my interests and embarked on a research project with Dr. Ronna Jevne. From the perspectives of eight individuals with HIV illness, we collected critical incidents of patient-doctor interactions that impacted hope.

Following this research study, I began graduate work in Family Ecology and Practice at the University of Alberta. It was there that my attention shifted to *family members* and their interactions with persons living with HIV/AIDS that impacted hope. Concurrently, my awareness of the subjectivity involved in defining "family" was strengthened in this department. As a result of these influences, and encouragement and support from Drs. Ronna Jevne, Maryanne Doherty-Poirier, and Dianne Kieren, I instigated this thesis research with the evolution of the following questions and understandings guiding the endeavour; the bolded text are the inquiries arising specifically from this evolution which became the focus of this study.

- What things influence personal hope in the face of illness adversity?

Interactions with others affect personal hope.

- Who influences the personal hope of persons living with HIV/AIDS?
  Doctors, family members, friends, health care professionals, counsellors, strangers...
- How is personal hope influenced through *other* in the presence of HIV/AIDS?
  Through contact, conversation, a gesture, interactions, and relationships.
- What components within interactions with physicians impact the personal hope of individuals living with HIV/AIDS?
  Relationship is central and involves the critical components of Authentic/Authoritative, Connecting/Disconnecting, Descriptive/Prescriptive, Welcoming/Dismissing, and Informing/Misinforming (Wong-Wylie & Jevne, 1997).
- **What components within interactions with family members impact the hope of persons living with HIV/AIDS?**
- **From perspectives of persons living with HIV/AIDS, what is "family"?**

The intent of this research is to further unveil the construct of hope as it is influenced through family incidents. In addition, my goals towards this endeavour are to demonstrate the breadth in the variety of family structures and functions prevalent in today's society, particularly for those families affected by the HI Virus. I also hope to enhance my research abilities and to gain insight into the lives of persons living with HIV/AIDS. This goal can assist me in becoming a hope-facilitating and hope-intentional counsellor working in the area of health and illness.

CHAPTER 1

INTRODUCTION

HIV/AIDS Sets the Stage

In 1993 it was estimated that around the globe, 10 to 20 million people were infected with the Human Immuno-Deficiency Virus (HIV), the virus suggested to cause the Acquired Immune Deficiency Syndrome (AIDS) (Haseltine, 1993). Today, in Canada, 14, 836 AIDS cases have been reported (Health Canada, 1997).

Although these HIV/AIDS statistics are staggering, the numbers do little justice to the reality. Behind these figures of HIV and AIDS cases are actual lives; those persons who have died and those who continue to live day by day in the midst of the ravages of this insidious virus. Through nurturing their personal hope, many individuals battling HIV/AIDS continue to persevere in spite of the ruthlessness of the disease. For individuals living with the stigmatizing illness of HIV/AIDS, *hope* is recognized as an essential ingredient to maximizing quality of life with this demanding illness.

Hope and *Otherness*

Hope is thought to reside within oneself as an intrapsychic phenomenon which is strongly influenced by the external world (Lynch, 1965; Marcel, 1942). As Nekolaichuk writes, I too believe that each individual weaves his or her own fabric of hope within the experience of illness but that hope itself "transcends individual experience" (1995, p. 1). This transcendent nature of hope refers to the essence of hope as a "shared experience" generated in the interpersonal realm (Nekolaichuk, 1995, p. 1).

However, prompted by the social stigma of HIV/AIDS, interpersonal relationships often become limited in the lives of persons with this illness. This stigmatizing aspect of HIV/AIDS contributes to persons maintaining the secrecy of their diagnosis (Hall, 1990). Subsequently, HIV/AIDS is an illness that has been described as a lonely battle (Carson, Soeken, Shanty, & Terry, 1990). Stewart (1994) determined that the stigma of

HIV/AIDS often motivated individuals to disclose only to those they considered to be in their family. Thus, in the absence of others, interactions with family members are all the more powerful and essential to the hope of persons living with HIV/AIDS.

Family Members Engender Hope

Past research has underscored the powerful influence that family members have on the hope of persons living with HIV/AIDS. For instance, Bruhn (1984) discussed that interactions within the context of a caring environment impacts hope and wellness. In addition, Herth (1990) studied perceptions of hope from 30 persons who were terminally ill. In her study, "family" was one of the most frequently identified source of hope (Herth, 1990). Consistent with Herth's perspective, Keen's study of the experience of hope in persons living with HIV/AIDS, also identified the family as integral to hope (1994). She wrote, "Families appeared to feather the nest for hope to spring forth" (1994, p.76).

However, amidst the strong recognition of the general importance of "family" to hope, there remains little specific knowledge of family members' influence on hope. Further investigations of hope and its influence from family members will increase our understanding of the elusive construct of hope as it relates to *otherness*. By pursuing this investigation from the perspectives of those living with HIV/AIDS, we are confronting this illness and giving voice to those who are living the experience and "walking the walk". The research inquiry driving this study is, *"What are the components of family interactions that influence personal hope from the perspectives of persons living with HIV/AIDS?".*

Underlying this research are three assumptions: hope has therapeutic value in health and illness, family members influence the hope of persons living with HIV/AIDS, and that the "family" is a subjective distinction. Prior to initiating this research, it was evident that an understanding of the concept of "family" from the perspectives of persons involved in this research was necessary. Thus, the subjective meanings of family were initially sought to further the primary investigation into interactions with family members that influenced hope.

Outlining the Purpose and Objectives

The goal of this study was to identify components that impact the hope of persons living with HIV/AIDS. Whereas there are many components that influence hope, this study was delimited to family incidents.

Objectives of the Study:

This study has two main research objectives:

1. To explore the subjective meanings of "family" from persons living with HIV/AIDS.
2. To analyze hope-influencing critical incident accounts of family incidents that impacted hope from the perspectives of persons living with HIV/AIDS.

Significance of the Research

From the perspectives of individuals diagnosed with HIV, exploring hope-influencing family incidents will contribute to a body of knowledge regarding HIV/AIDS and the family which has not been previously researched. Enhancing our understanding of the critical components of family incidents that impact hope will further elucidate the phenomenon of hope as it is influenced by others. In addition, this research may inform our understanding of the roles that family members play in nurturing the hope of individuals living with HIV/AIDS. Investigating components necessary to engender the hope of persons living with HIV/AIDS will assist to enabling us in understand how we may foster hope. This research of family members' influence on hope can also impact praxis. For instance, implications emerging from this research may improve community HIV/AIDS health care and social service programs, educational interventions, and counselling endeavours.

As the prevalence of individuals living with HIV/AIDS increases (Haseltine, 1993), and the survivorship with HIV increases (Hall, 1990) more and more family members are potential sources of hope. Family members are extremely valuable resources for engendering hope, and for caring and supporting persons infected with this virus.

The Co-Researchers

This study gives voice to six persons living with HIV/AIDS. These individuals share their personal meanings of "family" and their lived experiences of incidents involving family members that significantly influenced their hope. Together, we, as partners planted the seeds and nurtured this study. Thus, we were co-researchers. However, throughout this thesis the term "participants" is employed to represent these six individuals and "researcher" is used to represent myself. The participants' voices, along with my own, run as undercurrents in this thesis. It seems, therefore, most appropriate and adequate to introduce them preserving their presentation of themselves as they shared with me.

These are the six persons who privileged me a glimpse into their lives. Pseudonyms are used to maintain their anonymity:

Susan is a 38 year old, heterosexual, divorced woman with two children. To her knowledge, she has been living with HIV for the last five years of which the last year has been with AIDS. When I asked Susan to describe herself, this is what she shared:

> I am a single parent who loves spending time and doing things with my children. I am quite involved with my children's school and with the community. I really believe in giving back to people and the community. In addition, I am fortunate enough to have the gift of intellect, so I am able to support others who are living with the illness of HIV/AIDS. Lately, however, my health allows my ability to offer help to others less and less. I enjoy hiking in the mountains and reading.

Trevor, a 36 year old, homosexual, single male has been living with HIV for over five years, the last three years has been living with AIDS. He described himself with these words:

> I am a 36 year old gay man. I come from a rural family with many sisters and brothers. I currently volunteer with the HIV/AIDS Society. I am dedicated to helping other people living with HIV/AIDS make the best of their lives. I do speaking engagements, peer counselling, teacher training, and sit on various committees for both provincial and federally funded HIV/AIDS projects. I've been on disability since January of 1993. The year of 1996 was really tough for me. I had several of my close friends pass away. As well, in August of 1996 I was hospitalized for the first time.

Lynn is a 40 year old heterosexual woman living with a common-law husband and her children. To her knowledge, she has been living with HIV for the last five years. She described herself to me:

> I am a very strong person. I have very strong convictions. Despite this, I also value the opinion of those around me. I form my convictions not from only my experiences but also from that of others. I am open to admit that I have more to learn, more to experience, more to see, and more to do to be a complete human being. I think that my experience from birth to now, and especially from my family of origin and growing up in a family of many children has taught me much. Members in my family have many different experiences and opinions. I know that I love and value my brothers and sisters equally and none of them are the same. To me, the most important thing is that I am a human being. I am not complete without other human beings and yet I definitely have a strong identity of my own.

David is a 41 year old male who is bisexual and married with children. To his knowledge, he has been living with AIDS for the last two years. He described himself to me:

> I am a quiet, practical, and very well-intentioned individual. I am tired today. I have learned to deal well with most things in regards to the illness of HIV. I don't deny having the illness. I also do not wish it would go away. I have no regrets about my past. I have worked through much of my confusion. I have learned to not avoid things and to not dwell on things either. I was quite depressed about a year ago and had to work through some major ups and downs. The medications that I have been prescribed, as well as the way I have learned to deal with things, combined with getting rest, have all assisted to maintain me as a person.

Howdy is a 43 year old, single male, and identifies himself as a homosexual male. He received an HIV positive diagnosis and an AIDS diagnosis at the same time three years ago.

> Since June of 1993 I was diagnosed with HIV/AIDS. My CD4 count dropped between 40-50 counts per month to reach a low of 200. Since trying new medications, my CD4 count has increased to 710. I volunteer my ass off to help other people. Some of the things that I have done include: taking peer counselling training; becoming a board member representing the HIV/AIDS Society.

Tom is a 41 year old homosexual male living common-law with a partner and has children from a previous marriage. To his knowledge, he has been living with HIV/AIDS for the last 10 years.

> I am a 41 year old male who is relatively content with his life. I have enough

> stress, I don't need more, but I deal well when it when it is here. I find that I have worked harder at volunteer work than I have ever in a full-time, paying job. I have certain beliefs that no one will shake: one is God, the other is that we all have a right to live our lives and to be happy. No one can shake these beliefs, I would need 100% proof. I am a stubborn, strong-willed person. If you were my friend, you are! There is nothing that I wouldn't do for my friends. I don't find it hard to make friends. I can get around issues so as not allow them to impose on the friendships. I can agree to disagree with my friends.

Preface to the Next Three Chapters

This thesis integrates the perspectives of these participants and delineates the research inquiry: *"What are the components of family interactions that influence personal hope from the perspectives of persons living with HIV/AIDS?"*. This primary investigation begins with a preliminary exploration into the meanings of *family* from the perspectives of the participants. Understanding and documenting the subjective meanings of family addresses the social construction of this institution and emphasizes the researcher's respect for a diversity of family forms and functions. Throughout this thesis, the exploration into family meanings will be referred to as the "preliminary" study while the investigation into the components of family interactions that influence personal hope will be referred to as the "primary" study. Jointly, the preliminary and primary studies form the "research" for this thesis.

In chapter two, the preliminary study into family meanings from participants' perspectives, is discussed in the manuscript entitled, Who's in and who's out: The selected families of persons living with HIV/AIDS. Portions of this study have been presented at the 1997 Canadian Association for Research in Home Economics, Learned Societies Conference in St John's, Newfoundland and at the 1997 Canadian Home Economics Association Conference in Victoria, British Columbia. This study employed a family definition exercise and guided, interactive interviews to explore two specific inquiries into family: (1) identifying the members considered to be in the selected families of persons living with HIV/AIDS, and (2) exploring the significant attributes that determine membership in selected families. Thus, a coherent perspective of the structural as well as the functional components of each participant's family is gleaned from this study. "Family" is not prescribed nor assumed as a monolithic entity; through this study, each participant identified who and what "family" is to him or her.

Chapter three includes a discussion of the acquired perspectives of participants' families and furthers the primary investigation. Following the understanding of who were considered as "family", participants provided detailed information of critical incident (CI) accounts of interactions with family members that impacted their hope. Chapter three includes a presentation of this primary study in the manuscript entitled, A study of interactions with family members: Impacting the hope of persons living with HIV/AIDS. In this study, participants recount 14 hope enhancing and 8 hope diminishing CI accounts with family members. These incidents are analyzed for specific critical components within interactions with family members that instill or erode hope.

Although chapters two and three are both written as self-contained manuscripts, they both contribute to the totality of this research project. A linking exposition connects the two articles, and the discussion section, or chapter four, following the manuscripts enhances the link. As well, chapter four acknowledges both studies and synthesizes and contextualizes their combined applicability to research and praxis. Implications for future research are proposed. Furthermore, implications for community HIV/AIDS health care and social service programs, educational interventions, and counselling endeavours are provided.

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CHAPTER 2

WHO'S IN AND WHO'S OUT: THE SELECTED FAMILIES OF PERSONS LIVING WITH HIV/AIDS

Families are among one of the most prominent institutions within our society. The family manages the provisions of transferring the fundamental human necessities and implements the key socialization processes of bonding, belonging, and caring (Anderson, 1989; Parsons & Bales 1955; Ward, 1994). This institution also acts as a filter and distiller of our experiences and our development as individuals. Furthermore, the family is a network of close ties where intimacy and support through times of adversity may be found.

For individuals confronting an illness adversity, such as a seropositive diagnosis of the Human Immuno-deficiency Virus (HIV), an influx of stressors may develop for those facing the ruthlessness of this illness (Christ & Weiner, 1985; Forstein, 1984; Stulberg & Smith, 1988). The myriad of stressors that HIV or the Acquired Immune Deficiency Syndrome (AIDS) can present to one's life have been identified. Tiblier (1987) outlined the following stressors that an individual living with HIV/AIDS may be confronted with: (1) adjusting to a life threatening diagnosis, (2) dealing with fears of infecting others, (3) accepting one's own sexual orientation, (4) coping with the stigma and discrimination, (5) managing conflict among family members, (6) confronting a time-line push for reconciliation with family members, (7) preparing for loss; (8) shifting family roles, and (9) planning care and negotiating external systems.

Research has clearly demonstrates that significant others, such as those within one's family, assist by buffering the myriad of stressors confronting persons diagnosed with HIV, and that this assistance is meaningful during all stages of the HIV illness (Cohen & Wills, 1985). For instance, Hall (1994) underscored the importance of "family" in lives of individuals with HIV/AIDS by suggesting that family members contribute to the hope of persons living with this illness. As well, Cowels and Rodgers (1991), Jue (1994), Lasher and Ragsdale (1989), Mirken (1992), and Stewart (1994) implicated family members to influence well-being, increase survival, and quality of life for persons with HIV/AIDS. And Destounis (1987) asserted that overall, the "family" is essential to managing the crisis of living with this devastating illness. Consistent with this perspective, Hamilton and Morris (1988) declared that the family is "presently the strongest medicine available to us in the fight against HIV/AIDS" (p. 91). Researchers also suggested that connecting with others, as well as love and support from spouse, family members, or close friends enhances the self-worth of persons living with HIV/AIDS (Jue, 1994; Mirken, 1992). Further to these assertions, Florence, Lutzen, and Alexius (1994) found that persons living with HIV/AIDS who had a network of family support were coping better with the illness than individuals without family support. However, in light of the noteworthy significance of "family" within the HIV/AIDS literature, what has not been well explored is the concept of "family" from the perspectives of persons living with HIV/AIDS. This is the aim of the present study.

The Family as Socially Constructed

A major underlying assumption guiding the present research is that families are socially constructed. Viewing the "family" through the theoretical lens of social constructivism, the family is portrayed as a multifaceted institution. The scope of the family as a system that is not necessarily static nor fixed for everyone, but that is in constant transition for many (Skolnick & Skolnick, 1994) is captured through this view. The underlying premise of social constructivism is that perceptions of reality emerge through a creative sense of selecting, ordering, and organizing information relevant to one's own experiences. According to social constructivist theorists, "family" can mean different things to different people and this meaning can change over time. The concept of family is formulated through one's values, assumptions, and perceptions and is entrenched within the context of one's social, economic, and ideological circumstances (Skolnick & Skolnick, 1994).

In this investigation living with HIV/AIDS is the experience and context underlying the study of "family". The overall purpose of the present analysis was to investigate meanings of family. Since family is socially constructed and idiosyncratic, it is essential to investigate its meanings from a subjective perspective. Thus, from the views of individuals living with HIV/AIDS, meanings of "family" were gathered. This involved a two-fold investigation of the structures and functions of "family": (1) identifying selected family members; in other words, who is considered family, and (2) exploring the significant attributes that determined membership within the selected families of persons living with HIV/AIDS.

Such a study is of vital importance. The incidence of HIV is spreading around the globe and infecting men, women, children, and minority races at alarming rates (Buckingham, 1994). In Alberta alone, in one decade, approximately 2,699 persons tested positive for the HI Virus (Health Canada, Provincial Laboratory, 1996a). As a result, countless family members are, and will continue to be, impacted by members who are living with this illness. Although there are currently new and hopeful anti-retroviral drugs that are being used in the treatment of HIV/AIDS, the complexity of this virus remains, as well as it's terminal nature, the societal stigma, and the increasing prevalence. Research that explores family meanings from perspectives of persons living with HIV/AIDS furthers our understanding of potential networks of care available. This research enhances our knowledge of family configurations while drawing attention to what is important in family within lived experiences of individuals confronting the adversity of HIV/AIDS.

Historical Glimpse: Non-traditional Family Forms

The "family" has gone through many transitions that challenge the traditional, "nuclear" family distinction as a unit "made up of married parents and their children" (Ward, 1994, p. 7). For example, increased divorce rates coupled with declining traditional marriage unions in the 1960's and 1970's ushered in public recognition of non-traditional family types. Moreover homosexual relationships at the time were also testing the boundaries of the term "family" (Kenny, 1993). The strife over homosexual families and non-traditional families has been re-ignited with the strong association between

HIV/AIDS and homosexuality.

Acknowledging homosexual relationships as "family" has continued as a controversial and much debated issue in the 1990's. For example, in a recent discussion about homosexual rights, the Canadian Reform party leader, Preston Manning, stated that the legal definition of marriage should stay focused on "the procreation and nurturing of children" (Edmonton Journal, May 17, 1997). Manning's definition excluded and negated gay and lesbian unions. Canadian scholars challenge such a narrow and static view of the family and advocate against limited definitions for use in policy and practice. For example, Eichler (1988) argued that when family policy is directed towards the betterment and protection of certain "typical" or "normal" families, it nullifies other family compositions that do not conform to the prescribed structure.

Theoretically, Eichler (1988) acknowledged that the family consists of a variety of configurations. She rejected the notion that there are uniform structures and functions that apply to all families. Eichler argued against the tendency to disregard the broad and diverse nature of families and contested the propensity to assume that families are monolithic entities. She referred to this proclivity as the "monolithic bias" (Eichler, 1988).

Defining "Family" in the Context of HIV/AIDS

HIV/AIDS is a demanding and debilitating illness that alters one's life expectations, profoundly impacts family relationships (Bor & Elford, 1994; Macklin, 1989), and thus can challenge one's perception and meaning of family. In the present study, one person living with AIDS shared her experience of angst in coming to terms with her notion of "family". She poignantly articulated the salient qualities that in her perception determined "family":

> I realized in the last year that the family isn't about genetics... it's the relationship that you have with people. Thanks to HIV, I realized this. Who are the people really there for me? My family of origin were stabbing me in the back! [They were] not there for me. We are socialized to believe that family is supposed to be there for each other. [The] family is a very social concept. I have learned what family means and how I define it. I had to ask myself, "In what way does family

> support us [myself and my children], and me them?" It's a relationship that goes two ways, of a real, deep caring.

This manuscript focuses on the family as defined by persons living with HIV/AIDS and specifically identifies and discusses criteria through which individuals are included as members. These criteria elucidate important attributes of family according to persons living with HIV illness.

Levine suggested that HIV/AIDS threatens the "intimacy that ideally undergirds family relationships, while at the same time making them more powerful and necessary" (1994, p. 20). Certainly, HIV/AIDS challenges the traditional and historical concept of family (Bonuck, 1993). Levine challenged a traditional and conventional view of the "family" and offered a more comprehensive definition of this institution. She wrote:

> The family is a network who by birth, adoption, marriage, or declared commitment share deep, personal connections, and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need (1994, p. 5).

According to Levine's definition, families may be comprised of both kinship and non-kinship ties and may also include homosexual relationships (Bor & Elford, 1994). Her definition focused on mutuality and quality relationships rather than biological ties.

Methods

Snowball sampling was employed to elicit persons living with HIV/AIDS for this study. This non-probabilistic procedure is an effective method used to solicit participants who are not easily accessible (Palys, 1992). Through conversations the researcher had with members of an HIV/AIDS agency in Alberta, Canada, one individual living with HIV/AIDS expressed interest in participating in this research project. The individual was invited to participate in the study as a key informant and assisted the researcher to invite interest and subsequently, participation of five other individuals living with HIV/AIDS.

To become involved, participants were required to have oral proficiency in the English language. Participants also had to be 18 years of age or older and not be afflicted with AIDS Dementia. It was also necessary that participants were comfortable discussing aspects of their HIV illness in reference to "family". In addition, participants had to be available for a meeting of one to two hours in addition to a potential subsequent meeting of less than one hour duration occurring within two weeks of the initial meeting. All six participants who were contacted indicated that they met these criteria.

Gathering of Data

Within a constructive-interpretive paradigm, as outlined by Guba and Lincoln (1992), qualitative research methods were used in this study to gain an 'emic' perspective. That is, from the perspective of individuals living with HIV/AIDS, the "family" was investigated. To gain this insight, a family definition exercise (see Appendix D) was developed and piloted with a key informant to determine if modifications were required. The family definition exercise was created to invite participants to respond in their own style. According to Lofland (1971), providing freedom and flexibility to participants is a governing principle underlying qualitative research. The key informant confirmed that the family definition exercise met this criteria and adequately probed family meanings. Thus, no changes to the exercise were suggested.

Following ethical approval of this research, the researcher met individually with each of the six participants. During this first meeting, after signed informed consent as well as demographic information of social, economic, educational, and health histories was obtained, each participant completed the family definition exercise. This exercise first invited the participant to discuss or construct a visual representation of his or her *family of origin*. Secondly, each was invited to describe or visually create his or her *chosen family* and then the *family that influenced health* (participants were encouraged to not provide names).

It was noted that participants uniformly referred to their *chosen family* as the same *family that influenced health* (in a positive sense). There was consensus among all participants that the two systems consisted of the same, identical members. Thus, for clarity and analysis purposes, these two distinctions of family were collapsed and labelled the "selected family". As well, it was noted that all participants chose to visually represent their family. They created "genograms". Genograms are maps that show the configuration of family relationships and allow individuals to identify familial networks (Bor & Elford, 1994).

The family definition exercise was aimed at obtaining a snapshot account of who participants considered to be their family and qualities that were important to determine membership. In addition to providing written or visual representations of one's "family", this exercise included the question:

> Based on your meaning of family, please give reasons as to why you selected those individuals in your *current family* and the *family that influences your health* (this may be a list of important factors that are necessary for an individual to be part of your family or the questions you asked yourself to arrive at this family).

Following the completion of this exercise, guided, interactive interviews were conducted to elicit further insight into families of individuals living with HIV/AIDS.

It became evident during this study that there were positive benefits for participants in creating genograms of their selected family. Participants commented that the process allowed them to consider all members within their selected family; it fostered an holistic appreciation of their existing available supports.

After participants completed the exercise, the researcher verified the information and asked clarifying questions such as *what gender is this family member* and *what is the geographical distance between you and this family member*. More specific questions were asked to enable the investigator to get a richer comprehension of the context and attributes of participants' family of origin and family of selection; in so doing a deeper connection between investigator and participant was created.

Individual confidential meetings with participants occurred at an HIV/AIDS agency in Alberta, Canada. In the first or second session with each participant, interactive interviews were conducted. Participants were asked questions like: "Can you tell me more about who you consider to be in your family," "Is there anything I should be aware of that influences your definition of family," and "Is there something about the HIV experience that makes your relationship with family members especially significant in comparison to having a different illness?". The interviews lasted between 1 to 2 hours and were audiotape-recorded. Key concepts and central information were then transcribed verbatim to maintain integrity of the data and to reduce analytic bias (Field & Morse, 1985). In follow-up meetings and discussions, participants read over and commented on their transcripts before the researcher proceeded with the study.

Analysis of Data

In this study, data gathering and data interpretation occurred simultaneously and interactively within a "dynamic process" (Kieren, 1996, p. 38) and in a "circular fashion" (Kools, McCarthy, Durham, and Robrecht, 1996, p. 316). The constant comparative analysis method as described by Maykut and Morehouse (1994) guided the present analysis. Glaser and Strauss (1967) initially described this method as a process of constant interaction between data gathering and data analysis. Determining the composition of selected families was assessed as each genogram was created by participants. The researcher identified and compared groups of persons that comprised the selected families as data were collected.

To identify attributes determining membership, data were content analyzed. Content analysis involved creating categories and themes extracted from the emerging data. These data sources included: the genograms, other responses to the family definition exercise, interview transcripts, audiotapes of interviews, investigator's field notes, and memos. The process of creating categories of the functional attributes of family members began by reviewing these data of each participant-- allowing the researcher to obtain a contextual and holistic perspective of each individual. Data were then separated and reduced to meaning units. Each meaning unit was transferred onto separate file cards as sentences or short phrases of family attributes. They remained in the words of participants' and were able to stand alone without additional information, except for their relationship to family meanings in the context of HIV/AIDS. The cards were then sorted; each unit of meaning was considered for its relationship to others and was classified with similar statements. If the unit of meaning did not naturally cluster with a previously generated category, a new category was developed. Labels were also given to represent each category as it was formed.

The act of organizing data onto file cards and systematically categorizing the cards in a visual display, allowed the researcher to gain a perspective of the data set in one location (Miles & Huberman, 1994) and facilitated data interpretation. Visualization fosters the drawing of inferences as well as data verification (Kieren, 1996). This analysis procedure coincided with data collection and was repeated until no further associations and categories were detected (Glaser & Strauss, 1967; Maykut & Morehouse, 1994).

In this study, data were reduced to 32 meaning units of descriptive phrases. Examples of descriptors include, "They influence my daily life," and "We have a spiritual bond." The 32 descriptors initially generated 5 thematic categories (e.g. reciprocal relationships, inspirational influences, accepting, supportive, and impacting health and wellness). Themes were examined again to determine whether additional relationships were apparent between and among categories. It was decided that reducing themes further would result in loss of detail. Thus, 5 themes emerged through this data interpretation. Data collection was finalized when no further categories of the attributes of family members as well as no new groups of persons were identified in participants' selected families.

A variety of methods as described by Guba and Lincoln (1992), Patton (1990), and Sandelowski (1986) were employed to establish trustworthiness and confirmability of the data collected as well as the data analysis. These included: memoing, producing field notes, and creating an audit trail. Triangulation among different sources of information enabled data interpretation to be cross referenced (Bibby, 1993; Guba & Lincoln, 1992; Rudestam & Newton, 1992).

In addition, soundness and trustworthiness of the thematic categories were sought by inviting 2 researchers to separately read over the meaning unit on each card and categorize common statements together. Confirmation of thematic categories occurred as similar classifications emerged (Kirk & Miller, 1986). Two different categories were interpreted by each independent researcher. These variant classifications were discussed and categories were reorganized and relabelled until consensus of all themes occurred. Furthermore, thematic labels were semantically refined to best represent and capture the meaning imbedded within each category (e.g. from "Impacting Health and Wellness" to "Health and Wellness Resources"). The thematic categories were also shared with the six participants and two other individuals living with HIV/AIDS. All individuals agreed that the 5 thematic categories represented criteria important in defining family and that the information was meaningful in their present family life.

Results and Discussion

Description of Participants

Of the six individuals living with HIV/AIDS, two females (heterosexual) and four males (three homosexual and one bisexual) were involved in the study. Two participants were single; one was divorced; two were involved in common-law relationships; and one was married at the time the study was conducted. The average age of participants was 40 (range 38-43). All participants were Caucasian. Two had earned a baccalaureate degree from a university. Two did not complete high school; one participant received a high school diploma; and another completed two years of college. An annual income of $10,000 or below was reported by one participant. Three reported between $10,000 and $20,000 and two participants reported incomes above $20,000. Their employment status was as follows: one was full-time employed; two were on long-term disability; one was a recipient of Assured Income for Severely Handicapped (AISH); one received Canadian Pension Plan (CPP); and another was on AISH as well as the CPP. At the time the interviews were conducted, participants had been living with knowledge of their HIV positive diagnosis for as little as 2 years and as long as 10 years. Five of the six participants had been AIDS diagnosed previous to commencement of this study.

Participants' health and well-being in relation to HIV/AIDS was also assessed in this study since HIV illness formed the context through which "family" was investigated.

On a continuum of "excellent", "good", "fair", and "less than fair", one participant chose the descriptor "less than fair" to characterize his current health status. Two participants felt their health was "fair"; two others reported it to be "good"; and one felt his health was "excellent". The last participant attributed his excellent health to the effectiveness of HIV anti-retroviral drugs. In his recent experience, after his white blood cell count (CD4) dipped to very low levels it elevated back to reach near-normal immune system levels. As well, there were minimal traces of the HI Virus detected in his bloodstream. This is an optimistic sign indicating that the virus is not destroying nor taking over the immune system. The amount of virus in the bloodstream is determined through viral load testing. Another participant, who reported his health to be "good" was also living a medical anomaly. While his CD4 count remained relatively low (a poor sign of health), his viral load tests showed that he had extremely low traces of HIV in his bloodstream. He attributed his fortunate health and the medical mystery to his philosophy of dealing with stress:

> I have my theories, no matter how stressed out [I am], I let it out. I will tell somebody off if I need to and release the negative energy.

To best capture the subjective meanings of family from perspectives of persons living with HIV/AIDS, the compositions of selected families will be first discussed. Following this, the thematic categories of significant attributes determining membership in families of persons living with HIV/AIDS will be presented.

Structural Constellation of Selected Families

The genograms representing selected families of the six participants involved in this study were rich sources of information. All individuals in this study identified a wealth of relationships within their selected family. Schematic representations of participants' genograms, illustrating configurations of each family, are shown in Figures 2.1-2.6.

All six participants demonstrated through their genograms that they had broad concepts of "family". As Hamilton and Morris discussed, the broadened definition of family includes kinship as well as non-kinship relations (1988); this became apparent within the present study. In this study, there were 7 different groups included in

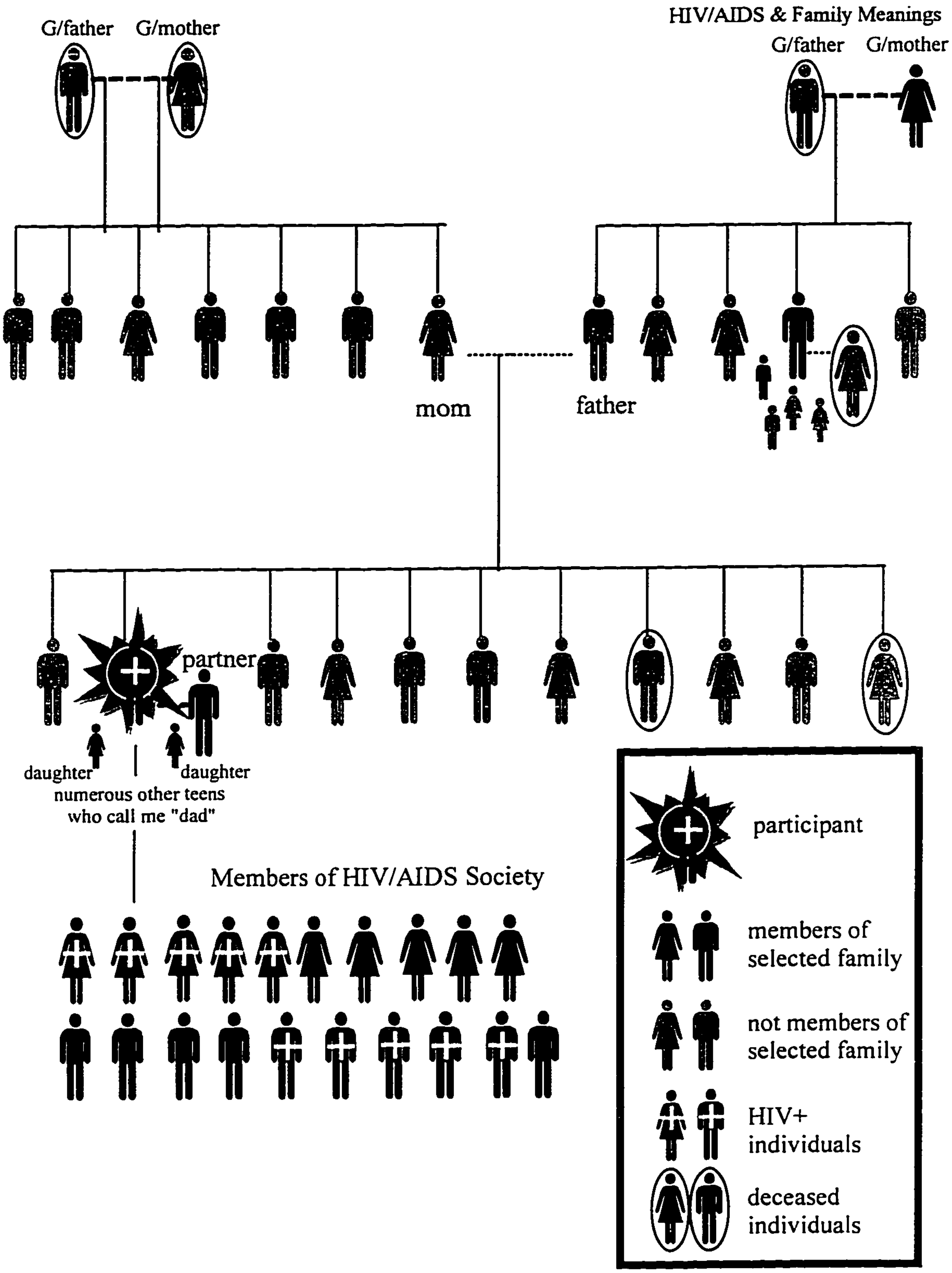

Figure 2.1. Schematic genogram of the *selected family* of a homosexual male living with HIV/AIDS.

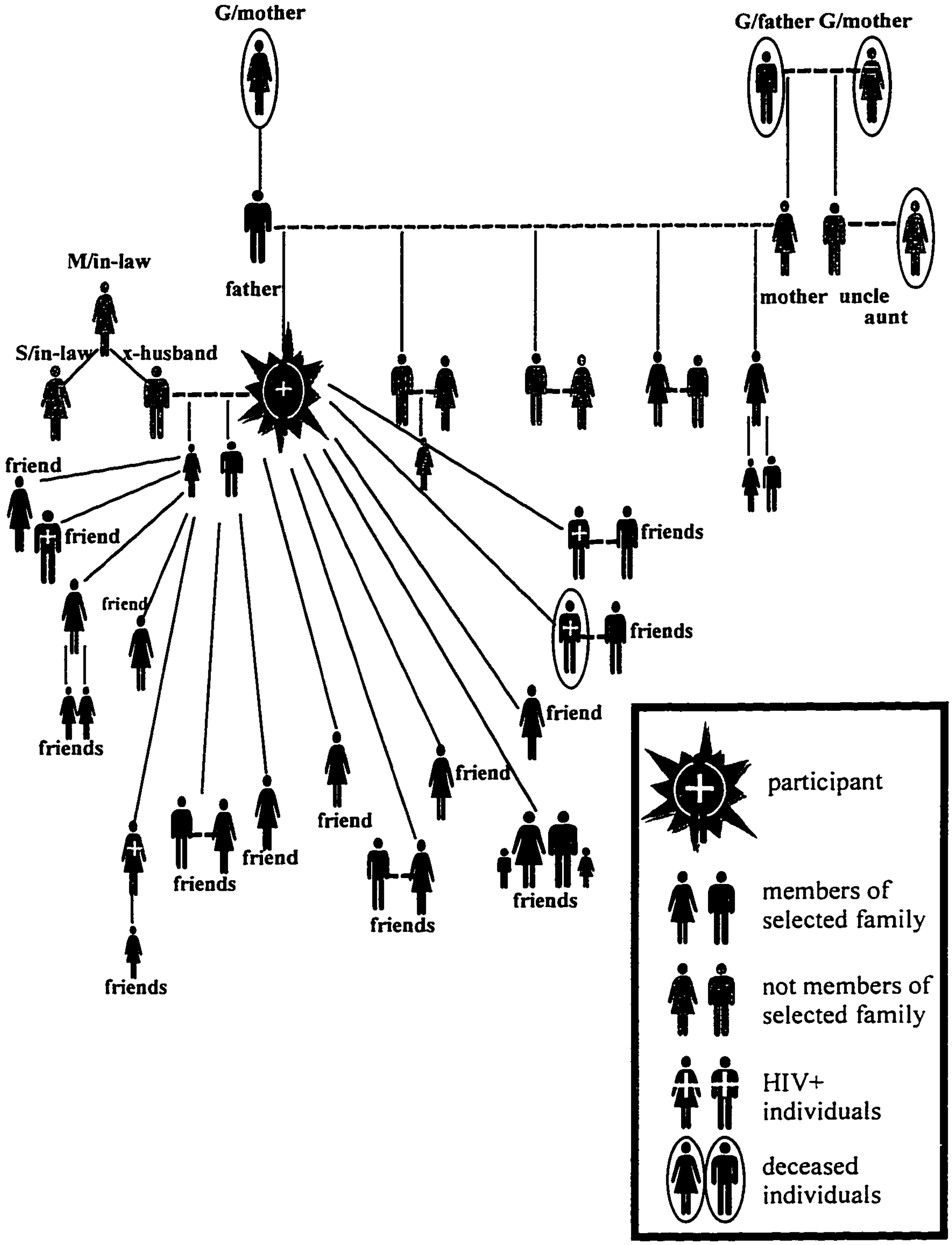

Figure 2.2. Schematic genogram of the *selected family* of a heterosexual female living with HIV/AIDS.

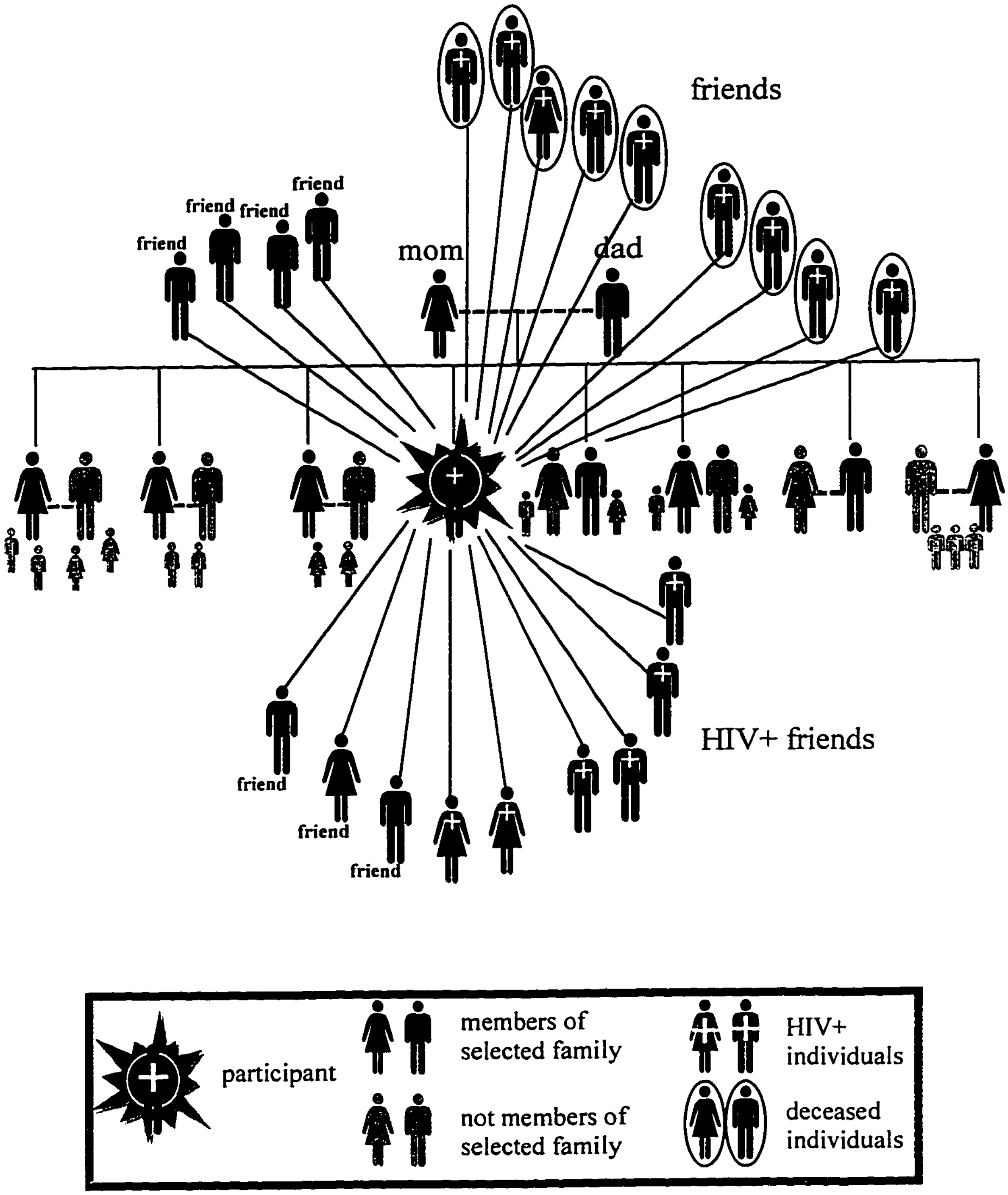

Figure 2.3. Schematic genogram of the *selected family* of a homosexual male living with HIV/AIDS.

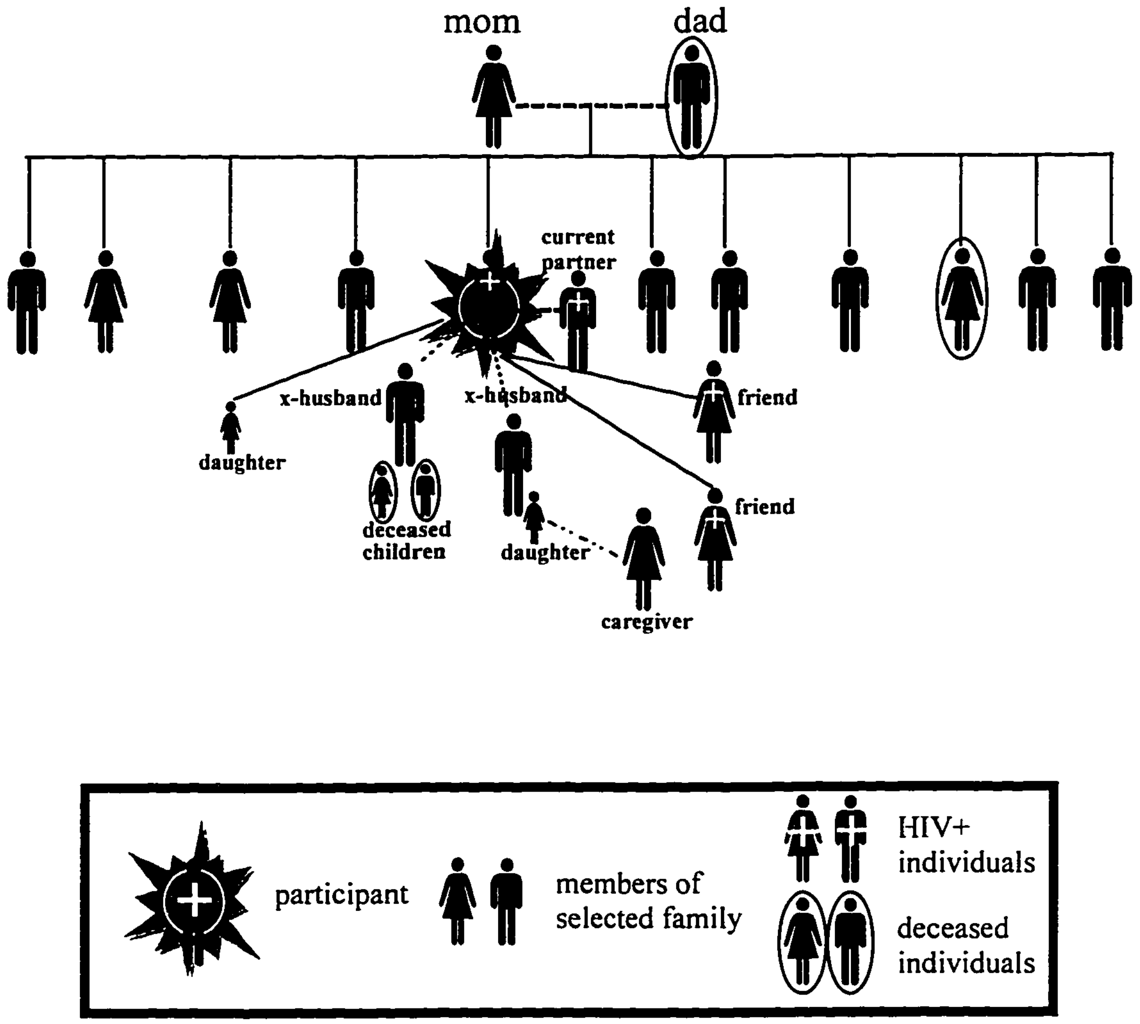

Figure 2.4. Schematic genogram of the *selected family* of a heterosexual female living with HIV/AIDS.

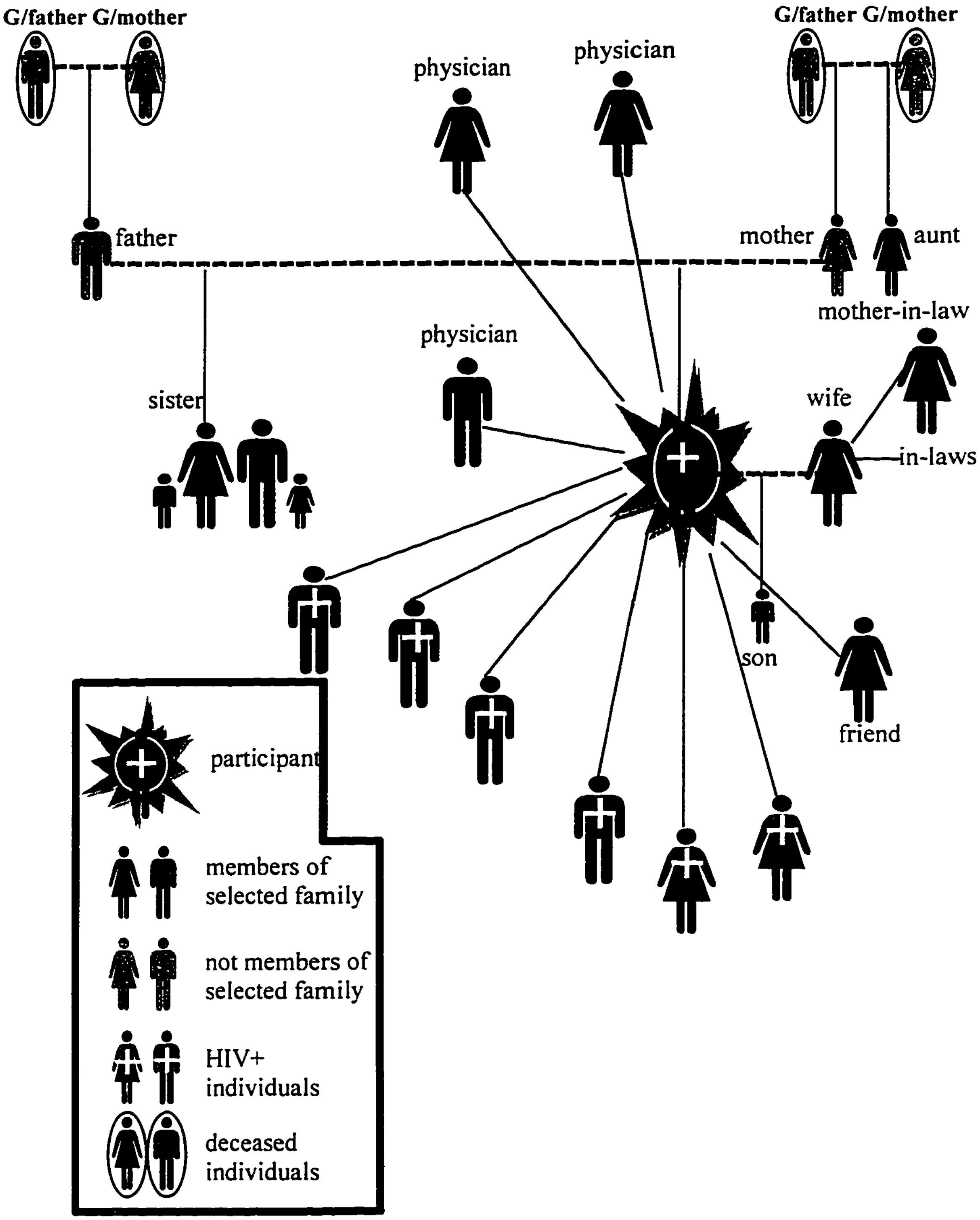

Figure 2.5. Schematic genogram of the *selected family* of a bisexual male living with HIV/AIDS.

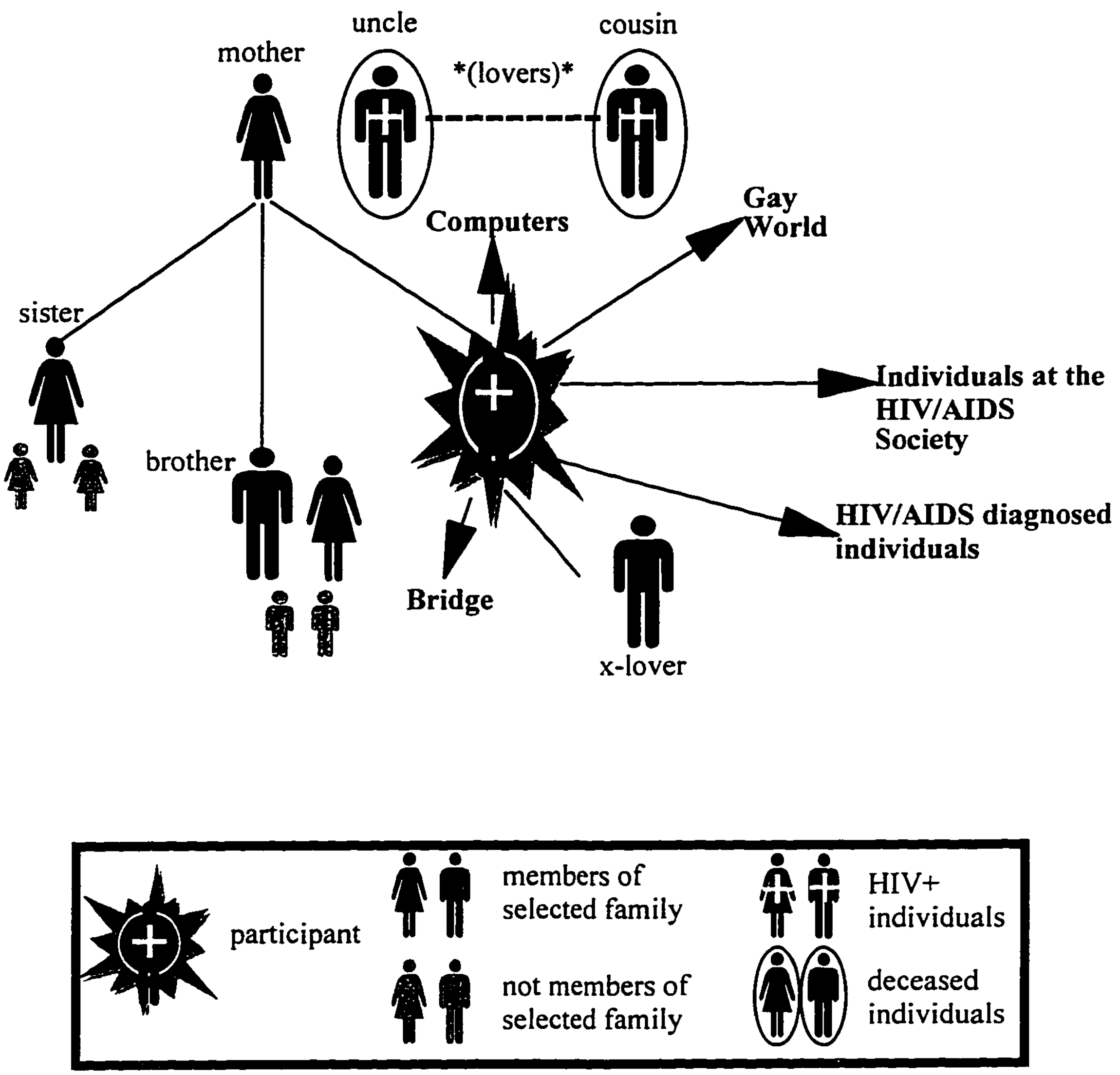

Figure 2.6. Schematic genogram of the *selected family* of a homosexual male living with HIV/AIDS.

participants' selected families. The first of these groups was *family of origin members*. This category involved traditional, nuclear family members of biological and kinship relations [e.g. mother, father, and siblings] and extended kinship relations [e.g. aunts, uncles, grandparents, cousins, etc.,] (Lovejoy, 1989; Stewart, 1994). The other 6 categories of selected family members were non-kinship relations. In this study, *health care professionals*, *friends*, *family caregivers*, *deceased friends*, *other persons living with HIV/AIDS*, and *hobbies* were identified as groups of non-kinship entities and relationships included in the selected family.

Surprisingly, one participant included the hobbies of "computers" and the game "bridge" as selected members of his family (see Figure 2.6). His response raises the awareness that "family" can be more than a cultural and societal distinction; it is a personal and idiosyncratic delineation. This participant focused on the functionality of the family and determined that inanimate entities met his criteria for family. He exemplified through his conception of family that families can be broadly perceived; thus it is imperative to allow for broad distinctions of family to capture subjective realities.

This participant's response pushes the limitations of the concept of family beyond a "human" distinction and raises many questions. For instance, if family members are viewed as entities and persons that meet certain criteria (e.g. dependability, loyalty, and support) might plants, pets, and substances such as coffee be potential members of a family? Likewise, perhaps something like gardening, which can be a healing activity, would also be included within one's family if this was viewed as an important family criteria.

Other groups of selected family members identified in this study concur with previous findings. The literature documents members in the family of choice to include non-kinship relationships of friends, lovers, and other significant people brought together to provide support [e.g. nurses, volunteer caregivers, buddies, etc.] (Hamilton & Morris, 1988; Powell-Cope, 1994). The results from this study affirm a broad distinction of family involving kinship and non-kinship members within the selected families of persons living with HIV/AIDS.

Functional Components of Selected Families

Thirty-two descriptive phrases of factors that determine inclusion into one's selected family were derived from the data. These 32 attributes were sorted and categorized into 5 thematic categories. The most salient feature of the descriptor was focused on to decide its classification. Although attributes fit distinctly into one thematic classification, justification for inclusion of persons into one's selected family was based on 1 or more of the created themes.

The five thematic categories of attributes of family members in selected families of persons living with HIV/AIDS were derived as follows: (1) *reciprocal connections*; (2) *inspiring influences*; (3) *accepting*; (4) *supportive*; and (5) *health and wellness resources.* That is, members selected to be included in the family are perceived to engage in a reciprocal relationship; they also are inspiring influences, accepting, supportive, and are health and wellness resources.

Reciprocal Connections

Levine (1994) discussed family relationships based on emotional qualities of relationality, continuity, and stability. The significance of relationality was particularly evident in this study. The category of *reciprocal connections* represented the equality and special bond between persons living with HIV/AIDS and selected family members. Phrases such as: "They help me, I help them", "We have emotional ties", and "We have a spiritual bond" generated this category (see Table 2.0). A *reciprocal connection* was also evident in one participant's choice of including computers as a member within his selected family. He qualified this inclusion by explaining that computers are a large part of his life; he can use computers to communicate on a regular basis with people nationally and internationally to initiate and maintain reciprocal connections.

Inspirational Influences

It was reported by participants in this study that selected family members had influenced them. "They influence my daily life", "I admire them for raising a family on

Table 2.0
Statements of the Functional Attributes of Selected Families

RECIPROCAL CONNECTIONS	*INSPIRING INFLUENCES*	*ACCEPTING*	*SUPPORTIVE*	*HEALTH/WELLNESS*
They help me, I help them. They selected me. We have emotional ties. We have a spiritual bond. Because of my computer I now have friends internationally and nationally that I talk to regularly.	I admire them for raising a family. I am inspired by the way they live their life committed and being true to themselves. They influence my daily life.	I share with them the intimate details of who I am. They understand me. They accept me and are non-judgemental. They accept me for me.	They indirectly support me by supporting my children. I can go to them. They listen to me. I would call if I wanted to talk. They are the first people I would call with good or bad news. I can count on them. They've just been there for me. They support me emotionally. They support me. They are sources of mental and emotional support to me. They give me emotional support. They've just always been there emotionally, physically, and financially. They directly support me (pick up my meds, groceries, provide emotional and spiritual support). They give emotional support. Playing Bridge is emotional support.	They provide me medical information. They have a positive influence on my wellness. They support me when I'm not well. They are there when I'm not well. They are the first people to see or hear how my health has changed. They are touched but not overwhelmed by what I have to say (in reference to health). I sustain hopeful relationships. Hope is an essential part of maintaining my health and wellness even if I'm unwell.

their own", and "I am inspired by the way they live their life in terms of commitment and being true to themselves" are some examples of statements generating this category (see Table 2.0). Participants talked about feeling inspired and being influenced by others. These impacts confirm deep respect and admiration for those others. Qualities of inspiration, influence, respect, and admiration are important and essential qualities for lasting human relationships.

Accepting Responses

In this study, participants uniformly identified that they perceive HIV/AIDS to be distinguished from any other present day illness because of the associated societal stigma. Accepting oneself was seen as very important and is portrayed in one participant's discussion:

> Because I spent a lot of years hating myself because I was gay, I've worked through the last few years looking at the shame and guilt in my life. I am striving towards being happy with who I am and accepting it and working at it and having the people who are important to me also accept me.

The *accepting* thematic category captures the importance of family members not judging individuals living with HIV/AIDS but being able to provide unconditional acceptance. Phrases such as: "I share with them the intimate details of who I am", "They understand me", "They accept me and are non-judgemental", and "They accept me for me" exemplify the acute nature of acceptance within family relationships (see Table 2.0).

Supportive Links

The *supportive* category contained and could encompass many of the statements of the attributes provided by individuals living with HIV/AIDS of their selected families. Fifteen of the 32 descriptors fell directly into this classification-- while others were better distinguished within categories previously discussed. It is not surprising; as it is not unusual with the presence of any illness, that support is integral to relationships. Hays, Turner, and Coates (1992) discussed the significance of family members providing a wide range of resources to persons living with HIV/AIDS, including tangible and emotional support. When facing an illness such as HIV/AIDS, which remains terminal and socially stigmatizing, support is central and critical within family relationships. Some examples of statements of support are: "They indirectly support me by caring for my children", "I can go to them", "I would call them if I wanted to talk", "They are the first people I would call with good or bad news", "I can count on them", and "They have just been there for me" (see Table 2.0). One participant included the game *bridge* within his family (see Figure 2.6). He explained that this hobby was a vehicle to emotional support. Bridge allowed him "time off" from thinking about his illness and consequently assisted his ability to cope with living with HIV/AIDS.

As Levine (1994) suggested, it is evident that "families are no longer primarily units of production and procreation, they have become instead centres of emotional and social support" (p.4). Supportive long-term relationships are essential to the well-being of persons living with HIV/AIDS (Jue, 1994). Close relationships provide ongoing support, comfort, and a sense of security and stability in a life filled with ambiguity (Jue, 1994).

Social support is a vital resource that greatly influences health (Callaghan & Morrissey, 1993; Green, 1994; Steward, 1993) and is positively associated with psychological health and coping (Green, 1994). Research has demonstrated that support from significant others can buffer the impact of a wide variety of stressors (Cohen & Wills, 1985). It has also been demonstrated that perceived adequacy of support may be more important than actual availability of support (Green, 1994).

Health and Wellness Resources

Within this classification of *health and wellness resources*, distinguishing statements are: "They provide me medical information", and "They support me when I'm not well" (see Table 2.0). In addition, within this category of health and wellness resources, hopeful relationships were noted by participants as an essential component of familial relationships.

> The hopeful relationships are the ones I want to sustain, the hopeless ones-- I get rid of. So, I think hope is an essential part of maintaining my health and wellness even if I'm unhealthy and unwell. I can't sustain hopeless relationships in my life. Negative, hopeless relationships drag me down.

It is not surprising that with an illness such as HIV/AIDS, which can be characterized by constant uncertainty and thoughts about death, that engendering hope is essential in providing health and wellness resources.

Summary and Discussion

In this study, inquiring into the compositions and attributes of the families of persons living with HIV/AIDS combined to create an understanding of the subjective meanings of "family". Bor and Elford (1994), Levine (1994), Miller, Goldman, and Bor (1994), and other family scholars identified HIV/AIDS as a catalyst expanding the definition of "family"; this phenomenon was evident in the present study. Compositions of the selected families of six persons living with HIV/AIDS were presented to demonstrate the array of family configurations and relationships identified in the family. Both kinship and non-kinship relationships comprised these participants' families. Seven groups constituted the selected families of persons living with HIV/AIDS in this study. They were: (1) *family of origin members*, (2) *health care professionals*, (3) *friends*, (4) *other persons living with HIV/AIDS*, (5) *deceased friends*, (6) *family caregivers*, and (7) *hobbies*. The distinction of hobbies included as a family member acutely demonstrates that "family" can be perceived far beyond the traditional delineation of a biological, nuclear, and kinship unit. This study also determined that individuals living with HIV/AIDS perceive members of their families as those who engaged in a *reciprocal relationship*, who were *inspiring influences*, *accepting*, *supportive*, and provided *health and wellness resources*. Identifying the significant attributes determining membership emphasizes functions that family members have in the lives of persons living with HIV/AIDS.

Research leading to a better understanding of the meanings of family to individuals living with HIV/AIDS provides important information to health care professionals, family scholars, social workers, family counsellors, and public policymakers who are attempting to meet challenges of those living with HIV/AIDS in today's society. For example, acknowledging family from a social constructivist perspective is useful and meaningful for policymakers to develop appropriate health benefits, bereavement leave, and hospital visitation rights that would encompass all selected family members. The 10 year partner of a homosexual individual who died of AIDS would not have to mourn in secret for fear of discrimination and job loss.

HIV not only infects individuals: it affects everyone who cares about that person. For each person living with HIV/AIDS, many family members may be involved-- partners and spouses, parents and children, siblings and grandparents, uncles and cousins, friends and caregivers. Their lives may also be profoundly affected by HIV and they are also in need of education, care, and support. Focusing solely on the individual with HIV illness and using a traditional definition of family is inadequate to confront the demands this illness puts on the entire family. Respecting the diversity of family forms is essential to ensure that resources can be made available to family members who are affected by HIV/AIDS. This knowledge of family can assist practitioners in planning and designing more serviceable and worthwhile family bereavement interventions and support groups.

The present research encourages the reexamination of traditional notions of "family". Whether this unit involved in the lives of persons living with HIV/AIDS is termed as a "selected family", "clanship system", the "fictive kin", a "family of function" (Anderson, 1989), an "emergent family" (Tiblier, Walker, & Rolland, 1989), an "out family" (Miller, 1996), the "homosexual family", "family of choice" (Friedman, 1986; Lovejoy, 1989), "health-care family" (Rolland, 1994), or as Margaret Thatcher suggested, a "pretended family" (Miller, 1996), HIV/AIDS and homosexuality continue to stretch the traditional concept of kin to a broader, more diversified family. Investigating kinship and non-kinship relations involved in families of persons with HIV/AIDS enriches our understanding of who is in the "family" and challenges myths and misconceptions about what "family" is and should be. Examining subjective meanings of family from a social constructivist approach underscores the "family" as a multifaceted and dynamic institution within our society.

Eichler (1988) challenged many myths about family by arguing that applying a monolithic approach forces inappropriate assumptions onto families. She asserted advantages of employing a "multidimensional approach" (1988, p. 10) to viewing families and discussed the family as a complex institution that encompasses an array of associations and relationships (Eichler, 1988). As well, Rolland (1994) and other family scholars working in the area of HIV/AIDS promoted use of a broad, comprehensive definition of "family" (Tiblier, et. al., 1989). In their view, the family, both biological and functional, must be the basic unit of care in the treatment of persons living with HIV/AIDS. The family as the foundation to caregiving better equips society to tackle health challenges (Rolland, 1994). Early intervention that acknowledges the family milieu of caregivers is of great benefit and can allow for mobilization of all family resources to assist in care. Families, in all their forms and functions, are evidenced through this study to be significant in the lives of persons living with HIV illness.

Nurses, physicians, counsellors, and other health care professionals can recognize that they may be considered "family" and subsequently plan treatment and care interventions. In addition, health care professionals' grief and bereavement experiences may be better understood considering the context of their roles in the lives of clients. Examining family from a social constructivist approach permits such awareness and underscores the "family" as a multifaceted and prominent institution within our society.

Study Limitations

A limitation of this study was that it did not illustrate fluidity of families. Families are complex with varying arrangements whereby individuals create, dissolve, and re-create supportive and intimate bonds (Levine, 1994). This study captured one snapshot of a person's family. This gives rise to the need for continued research in the area of HIV/AIDS and subjective meanings of family. Additional research needs to be conducted to capture changes in family forms and functions over time: even over the trajectory of the disease.

As well, further studies are needed to glean family perspectives of persons living with HIV illness who represent a variety of backgrounds. Snowball sampling limited this study in that this procedure generated a uniform sample consisting of Caucasians in their late 30's to early 40's. However, in Alberta, this age range does represent the modal category of persons whose illness has progressed to AIDS (Health Canada, Provincial Laboratory, 1996b). Irrespective of this representativeness, the perceptions of "family" from other age groups and races living with HIV/AIDS are not well known and need to be investigated.

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LINKING:
FAMILY PERSPECTIVES AND INTERACTIONS

Exploring the subjective meanings of "family" from the six participants involved in this research enriches the current understanding of who is family and what are important criteria for membership into families. Instead of prescribing or assuming a family structure and functions that would not be meaningful nor appropriate for participants, this researcher respected and acknowledged the diversity of family evolving from participants' perspectives. This preliminary study augments the primary study which investigates interactions with family members that influenced the hope of these participants. Through the preliminary study, an appreciation and understanding of their family perspectives were possible.

The genesis of this research has been presented in the prologue of this thesis. Chapter one outlined the purpose and objectives of the research which emanated from the inquiry: *"What are the components of family interactions that influence personal hope from the perspectives of persons living with HIV/AIDS?"* Chapter two detailed the investigation of participants' family of selection. The following chapter (Chapter three), presents the study which investigates critical incident accounts of hope-influencing family incidents. This chapter, like the previous chapter, is presented as a self-contained manuscript. Chapter four links both manuscripts and offers suggestions for the direction of future research. Additionally, the understandings gleaned from this research are contextualized for praxis within our social world. Implications for community HIV/AIDS health care and social service programs, educational interventions and counselling endeavours are provided in this chapter. The final section, or epilogue, to this thesis consists of my closing thoughts about the research and specifically addresses how I have been personally influenced through conducting this research.

CHAPTER 3

A STUDY OF INTERACTIONS WITH FAMILY MEMBERS: IMPACTING THE HOPE OF PERSONS LIVING WITH HIV/AIDS

Hope, as a verb, is prevalent in our everyday language. "We hope that it works," "I hope your day gets better," and "I hope their daughter gets out of the hospital soon" are just a few examples illustrating the use of *hope* as an action inferring a desire for a positive outcome. However, "All is lost when one abandons hope," "Hope is all that's left," and "The doctors did nothing for my hope," are phrases distinctly using hope as a noun and denotes an essence to life that is vital in the face of adversity.

This delineation of hope as a noun is pervasive in the literature. In this perspective, hope has been described as a life force that heals (Laney, 1969) as well as an eminent protector from death (Dubree & Vogelpohl, 1980). Additionally, Menninger (1963) suggested that hope is a going forward process; others have referred to hope as "a window on the future," "the drive to survive", (Bruhn, 1984, p. 215), and "the voice that yearns to say *yes* to life" (Jevne, 1994, p. 8). Hope has also been considered normal and functional to existence (Kubler-Ross, 1975), as well as "a necessary condition for sustaining life" (Raleigh, 1980, p. 1313-B), and a catalyst to enhancing the quality of life (Beck, Rawlins, & Williams, 1984). Clearly, many scholars attest to the significance and necessity of hope, however a universal consensus as to the constructs of hope has yet to be achieved. That is, the "the domains of hope and how persons maintain hope while confronting adversity are not well-known" (Miller, 1989, p. 23).

Many scholars have attempted to demystify the elusive construct of hope by developing theoretical models. These models have contributed to the field of hope, but collectively perpetuate the complexity and intangible nature of this multidimensional construct. As Nekolaichuk wrote, there is a continuous struggle with the "elucidation of a cohesive and comprehensive hope model" (1995, p. 11).

A variety of perspectives have been proposed in the conceptual frameworks of hope, ranging from unidimensional views to multidimensional perceptions. The elusive nature of hope is evidenced through these multiple interpretations. Some researchers have proposed simpler views of hope and have developed frameworks of hope accordingly: Snyder (1994) and Stotland (1969) represented hope as a unidimensional construct; and McGee (1984) asserted a linear view, capturing hope on a continuum of hopefulness to hopelessness. Other researchers have proposed multidimensional frameworks of hope (Dufault & Martocchio, 1985; Hinds, 1984; Lange, 1978; Nekolaichuk, 1995; Owen, 1989). Such conceptions are more comprehensive than the unidimensional and linear hope models.

In addition to the struggle to elucidate a cohesive framework, there have been inconsistencies within the perceptions of the components that comprise the construct of hope. For example, Cousins (1989) and McGee (1984) described hope as having a cognitive, behavioral, and affective component; while Dufault and Martocchio (1985) viewed hope as having all of these three components, they added affiliative, temporal, and contextual dimensions. Morse and Doberneck (1995), Stotland (1969), and Snyder, Harris, Anderson, Holleran, Irving, Signon, Yoshinobu, Gibb, Langelle, and Harney (1991) discussed hope from a cognitive, goal-directed perspective while others have focused on hope from a behavioral perspective (Averill, Catlin, & Chon, 1990; Menninger, 1959). Thus, hope remains an intangible and elusive construct further perpetuated by the various interpretations and lack of consensus within the views of the components of hope.

Despite these vast differences in the perspectives of hope, the power of hope has not been disputed. A burgeoning of research and resulting literature has underscored its power by asserting and demonstrating the therapeutic value of hope in the face of human adversity (e.g. Bruhn, 1984; Cheren, 1989; Cousins, 1989; Dufrane & Leclair, 1984; Frank, 1968; French, 1970; Jevne, 1990, 1991, 1993; Laney, 1969; Manrique, 1984; Menninger, 1959; Miller, 1989; Miller, Fitzgerald, & Powers, 1988; Orne, 1968; Owen, 1989; Pruyser, 1963; Wakelee-Lynch, 1989; Yalom, 1985). For instance, hope has been proposed as an intrinsic element of life that assists patients to emotionally endure crisis

(Miller, 1989), especially major disabilities or catastrophic illnesses (Mader, 1988). As well, Bruhn (1984) and Buehler (1975) found that hopeful patients followed treatment recommendations and tolerated discomfort better than patients who were not hopeful. That is, in the absence of hope, psychological well-being diminishes and response to therapy and recovery is thwarted (Cousins, 1989; Engel, 1968; Frank, 1975; Lange, 1978). Wolff (1957) declared that hope, like faith and purpose in life, is medicinal and powerfully influences the healing process (Bruhn, 1984; Frank, 1975; Gottschalk, 1985).

In addition, Herth (1990) suggested that the presence of hope is vital for persons who are terminally-ill, regardless of their physical limitations or proximity to death. For individuals living with the Human Immuno-deficiency Virus (HIV), which is not only a life-threatening disease, but is also transmittable and stigmatizing (Tibesar, 1986), hope is integral at all stages of illness. The significant role of hope in lives of those battling this devastating illness is evident through the words of some of the participants involved in the present study.

> Hope is a funny word. I don't really understand it that much. That's probably why you're doing research on it-- cause we don't know what it really means. But if it wasn't for hope, I wouldn't have lasted these 3 years. I would have given up. One of my friends died because hope was lost.
>
> Hope is essential. It is the fabric. I think hope is an essential part of maintaining my health and my wellness even if I'm unhealthy and unwell. No matter how sick I become, hope is so absolutely important.
>
> I know that hope is different things to different people but what I hope out of all this discussion, and what people read into this is that I think hope is real important.

While the significance of hope as an internal process is evident from these participants and in the literature (Lynch, 1965; Marcel, 1962), it has been suggested that the generation of hope stems from relations with others (Jevne, 1992; Pruyser, 1963). Dufault and Martocchio (1985) asserted, from their study of hope involving 35 elderly persons with cancer, that the behaviours of significant others are sources of hope. This "intersubjectivity, collaboration or mutuality" (Stoner, 1988, p. 134) describes an essence of hope. For example, Lynch (1965) and Marcel (1962) discussed that hope is an intrapsychic phenomenon that requires interaction with the external world. Thus, hope is an interior sense but involves relatedness and involvement beyond self (Stoner, 1988).

In past studies involving persons living with HIV or those who have developed Acquired Immune Deficiency Syndrome (AIDS), relationships with significant others have been demonstrated to powerfully influence hope (Keen, 1994; Giacquinta (nee Stewart) 1989; Wong-Wylie & Jevne, 1997). For example, through their exploration of hope in patient-doctor interactions, from perspectives of individuals with HIV/AIDS, Wong-Wylie and Jevne (1997) identified *perceived relationship* as central to patient hope. Within the present study, the relational aspect of hope was also aptly expressed by some participants.

> I know lots of people who died. They just gave up hope. No one showed them where and how to find hope; how to climb inside yourself and find it. I can give hope to others... someone who's newly diagnosed, I tell them, "Hey, I can do this. It's not the end of the world. Just because the virus is inside you, you can go on.".
>
> I think it's really important for people to have hope. It's also important for people to know how easily it's taken away... you know the smallest thing can take away your hope. I don't think other people realize how they can do it with no intent, no intent at all. My sister is one example of how easy it is to take it away. But it's also so easy to give hope.

Given this relational aspect of hope, there have been several researchers who determined the significance of "family" in connection to hope within the lives of persons with HIV/AIDS (Garrett, 1988; Giacquinta (nee Steward) 1989; Lasher & Ragsdale, 1989; Stewart, 1994). For example, connecting and interacting with family and friends was strongly linked to enhancement of hope in Coward's 1994 study. As well, Hall (1990) interviewed 10 persons living with HIV/AIDS and discovered four ways for maintaining hope. In addition to miracles, religion, and involvement in work, Hall found that support from family and friends greatly influenced hope (1990). However, despite this strong evidence of the family's importance to hope, this importance remains inadequately researched. Thus, the intent of this study was to investigate from perspectives of individuals living with HIV illness, incidents between themselves and family members that strongly impacted their hope. The endeavour of this study was to shed more light on the perplexing nature of hope as it is ignited and sapped within interactions involving family members.

For the purposes of this study, hope will be viewed through the "factor structure" derived by Nekolaichuk (1995). Of all the models of hope, Nekolaichuk's multidimensional representation of hope is the most recent and integrative depiction of hope within health and illness. Through qualitative and quantitative methods involving 550 respondents, Nekolaichuk investigated the construct of hope in health and illness and identified hope as an integrative structure involving aspects of *personal spirit*, *risk*, and *authentic caring* (Nekolaichuk, 1995). She asserted that *personal hope* was experienced in these three interconnected realms. Nekolaichuk's "factor structure" of hope captures a unique and dynamic dimension of the human experience and delineated hope as an holistic structure that involved individuals' subjective meanings (Nekolaichuk, 1995). Nekolaichuk's conception was chosen to frame the underlying perspective of hope in this study. Her multidimensional, dynamic, integrative, and holistic "factor structure" of hope (Nekolaichuk, 1995) guides the formulation of this research and undergirds the researcher's perceptions of hope.

The Present Study

There are no studies to date directly exploring family members' influence on the hope of individuals with HIV illness. Currently, the literature includes statements of the importance of family support in the fight against HIV/AIDS (Hamilton & Morris, 1988). As well, the literature documents the significance of supportive reactions and the positive influence that family support has on hope of persons living with HIV/AIDS. Although many researchers suggested that supportive responses from family members contribute to survivorship and quality of life of persons living with HIV/AIDS (Cowels & Rodgers, 1991; Lasher & Ragsdale, 1989), current literature reveals little about the specifics within interactions between persons living with HIV/AIDS and family members that sustain and engender hope.

Considering the increasing prevalence of HIV/AIDS, research linking the phenomenon of hope and interactions with family members is of vital significance. Within the last decade, approximately 2,699 persons have tested positive for the HI Virus in Alberta (Health Canada, Provincial Laboratory, 1996a). Thus, there are countless family members who are, and who will continue to be, potential sources of hope. These family members are extremely valuable resources of care and support for individuals infected with this virus and their impact is clearly evident through the remark of one participant:

> In the end, the important things are those people who are around me-- my family; the people involved in my life. They make life worth living.

From the perspectives of persons living with HIV/AIDS, this research examined interactions with family members that impacted *personal hope* (Nekolaichuk, 1995). Interactions that hindered hope (*hope-less*) and interactions that fostered hope (*hope-full*) were sought in this investigation. Thus, this study enhances our knowledge of the phenomenon of hope while drawing attention to family incidents. By investigating family interactions, our understanding of the direct impact that we can have on those living with HIV illness is furthered.

Methods

Snowball sampling was employed to elicit persons living with HIV/AIDS for this study. This non-probabilistic procedure is an effective method used to generate participants who are not easily accessible (Palys, 1992). Through conversations the researcher had with members of an HIV/AIDS agency in Alberta, Canada, one individual living with HIV/AIDS expressed interest in participating in the research project. The individual was invited to engage as a participant of the study and as a key informant. This key informant assisted the researcher to invite interest and subsequently, participation of five other individuals living with HIV/AIDS.

To become involved, participants were required to have oral proficiency in the English language. Participants also had to be 18 years of age or older and not be afflicted with AIDS Dementia. It was also necessary that participants were comfortable discussing aspects of their HIV illness in reference to "family". In addition, participants had to be available for a meeting of one to two hours in addition to a potential subsequent meeting of less than one hour duration occurring within two weeks of the initial meeting. All six participants who were contacted indicated that they met these criteria.

Critical Incident Technique

The critical incident technique (CIT) was first developed by John Flanagan in 1954. As an aviation psychologist with the U.S. air force, Flanagan developed CIT to collect data of effective and ineffective behaviours for combat leadership. Overall, Flanagan suggested that CIT should be regarded as a flexible set of principles that can be modified and adapted to appropriate any area of research.

CIT however, declined in popularity in the late 1960's when the emphasis of research in social sciences was on quantification and social survey. But with an increased recognition of qualitative research in the early 1980's, CIT was resurrected. It is now an eclectic and versatile technique that has been adapted to meet the demands of a variety of disciplines. CIT is an innovative, exploratory qualitative method of research that generates comprehensive and detailed descriptions from first-person accounts that illuminate a specific content domain.

The CIT has been established as a technique for documenting and understanding human experiences and interactions (Burns, 1956; Flanagan, 1954; Mayhew, 1956; Ronan & Latham, 1974; Sawatzky, Jevne, & Clark, 1994). As well, a wide range of disciplines have capitalized on this highly adaptable technique. In the research areas of *career development* (Dix and Savickas, 1995; Jacobs, 1986; Young, 1988), *counselling research* (Woolsey, 1986), *educational research* (Brookfield, 1992; Care, 1996; Corbally, 1956; Mayhew, 1956), and *nursing* (Minghella & Benson, 1995; Norman, Redfern, Tomalin, & Oliver, 1992; Rutman, 1996; Safren & Chapanis, 1960; Smith & Russell, 1991), CIT has been confirmed as an effective method. CIT also can be effectively utilized for *interaction research*. Poole, Folger, and Hewes (1987) promoted CIT as a useful method for analyzing interpersonal interactions. They favoured this qualitative technique that allows participants to identify and share incidents that in their perceptions fostered or debilitated a specified aim (Poole et al, 1987). Wong-Wylie and Jevne's study of hope-impacting interactions between physicians and persons living with HIV/AIDS is one example of the effectiveness of employing the CIT for interaction research (1997).

In this study, the CIT was utilized to explore family interactions that fostered or debilitated the specified aim of *hope*. Critical accounts of hope-influencing interactions involving persons living with HIV/AIDS and family members were sought. Hope-full and hope-less interactions were recollected by participants and shared to elucidate family interactions that impacted on personal hope. Incidents in this study were generated from six participants. The size of sample within critical incident studies are determined on the basis of the number of CI's generated and not the number of participants involved. The general rule of thumb adhered to in this study was to collect incidents until redundancy appeared and no new information was generated (Woolsey, 1986).

Gathering of Data

Following ethical approval of this research, individual confidential meetings between the principal investigator and each participant occurred at an HIV/AIDS agency in Alberta, Canada. During this first meeting, after signed informed consent as well as demographic information of social, economic, educational, and health histories was obtained, participants identified who was in their family through a family definition exercise. The exercise was designed by the researcher to invite participants to create genograms of their family of origin and their selected family. Genograms are maps that illuminate configurations of family relationships and allow the identification of significant familial networks (Bor & Elford, 1994). Participants' perspectives and meanings of family were further gleaned through interviews.

Following this, participants completed the critical incident recollection exercise designed by the researcher for this study. Here, participants were invited to recount critical incidents of interactions with family members that influenced their hope either positively or negatively.

Figure 3.1 conceptualizes the hope-full and hope-less interactions described in this study (see Figure 3.1). This representation is adapted from Rolland's (1994) model of the Therapeutic Quadrangle which was his conceptualization of the treatment and caregiving system involved in illness. The two Interactional Triangular models presented here represent hope-full and hope-less interactions and include an individual (the participant), the illness of HIV/AIDS, and the identified family member(s). HIV/AIDS is an integral part of incidents; this illness represents the adversity that forms the basis into this investigation of hope. Rolland's conceptualization also included the individual's illness adversity as well as the health care team to formulate his caring quadrangle (1994). Based on his concept of the significant factors involved with persons living with HIV/AIDS, the conception presented in this study focused on the exchange between family members and individuals where HIV illness represented the underlying adversity.

The critical incident recollection exercise invited participants to reflect on incidents involving family members that influenced their hope in a positive or negative way. Most researchers who have used CIT, including Flanagan (1954), have collected incidents which are extreme illustrations of a continuum, in a belief that this results in a more complete description of the phenomenon under investigation (Norman, Redfern, Tomalin, & Oliver, 1992).

There is controversy within the literature as to the continuum of hope and the relationship between hopefulness and hopelessness. Dufault and Martocchio (1985) suggested that hope and hopelessness are not at opposite ends of a continuum, whereas Lynch (1965) pointed to the necessary dialectic existing between the two constructs. McGee (1984) indicated that hopefulness and hopelessness occur in a parabolic relationship and on a linear continuum. Farran, Herth, and Popovich (1995) also addressed this association between hopefulness and hopelessness. Their conclusions concur with the data of the present study as it was found that participants naturally described their experiences of hope in comparison and in relation to hopelessness.

Within the participants' comfort, pace, and style, each incident was descriptively

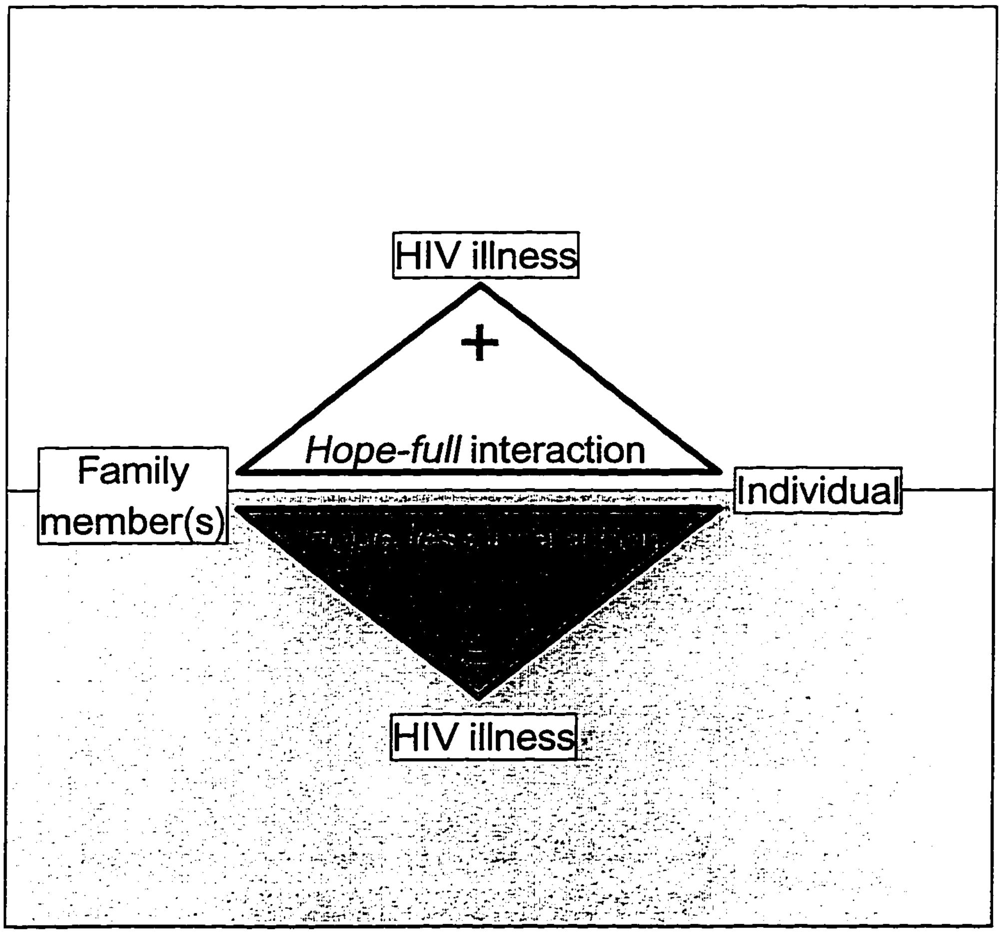

Figure 3.1. Interactional Triangle. Schematic illustration of *hope-full* and *hope-less* interactions.

recounted. The exercise was aimed at obtaining three to five snapshot accounts of interactions with family members that significantly influenced hope. The following words invited participants to share incidents:

> As descriptively as possible, please recount (either written or tape-recorded) 3-5 interactions you had with a family member (based on your own meaning of family), which influenced your hope in some way. The purpose of this exercise is to recall specific interactions that were powerful influences on your hope, and to understand what factors contributed to this impact on your hope. There is no right or wrong procedure: use your way to best accomplish this exercise. The definition of "hope" is based on your own concept.

All participants chose to audio-record the accounts of their interactions with family members. It is unclear why audio-recording incidents was preferred. As participants recounted each incident as a monologue, the researcher listened and remained seated across from the participant. Perhaps this style of audio-recording was perceived by participants to be more interactive than writing accounts.

Following the description of incidents by participants, guided, interactive interviews were conducted and audio-recorded. These interviews focused on eliciting further richness in the descriptions of hope-influencing interactions. Interviews lasted from one to two hours and were audiotape-recorded. Participants were asked questions such as: "Were the two of you alone during each interaction?" "What gestures/actions did the individual use?" "Describe the environment in which the interaction occurred." The interviews focused on the following areas: (a) the participant's hope, (b) length, setting, and mood of each interaction, (c) depth/past relationship with family member, and (d) general impression of the significance of family member's influence on hope.

While engaging within interview sessions, the researcher exercised empathic listening and delivered perception checks to ensure accurate comprehension and respect for the essence of the experience as perceived by participants (Woolsey, 1986). Subsequently, key concepts were transcribed verbatim by the researcher and later provided to participants to ensure referential adequacy.

Data Analysis and Interpretation

The Data

In this study, several different sources of data were used to establish the critical components of hope-influencing interactions. These included audio-recordings of critical incident accounts, interview transcripts, researcher's field notes, researcher's memos and audit trail, and the meta-matrices (Merriam, 1988). A meta-matrix is a large conceptualization of each incident in a time-sequenced representation. The act of organizing data into a visual meta-matrix display enabled the researcher to conceptualize the data in one location (Miles & Huberman, 1994), and facilitated data interpretation. Visualization fosters data coherency and assists the drawing of inferences as well as data verification (Kieren, 1996).

Challenges of the Data

In 1954, Flanagan defined an incident as a clearly demarcated scene, with an obvious beginning and ending. Yet it this study, it was clear that participants were not always sharing one discrete interaction within each CI account, even though they struggled to do so. Participants were, in fact, often summarizing typical examples of interactions. Norman et al. (1992) addressed this phenomenon in their study of high and low quality nursing care that employed CIT. In their study, "getting him up early in the morning," "discouraging him from eating," and "being heavy-handed" were described within one respondent's CI account of low quality nursing (Norman et al., 1992).

Norman et al. suggested that "critical happenings" were recounted by the respondent rather than one single event (1992). The incident appeared to be typical of the care the respondent received, but it was clear that not all critical happenings were present in every interaction (Norman, et. al., 1992). These researchers pointed out that Flanagan was studying interactions between man and machine in 1954 when he determined the criteria of critical incidents. Norman, et al. asserted that interactions between human beings rarely occur in discrete episodes that can be clearly demarcated; and that human beings inevitably describe one incident in light of related incidents exemplifying similar meanings (1992). Thus, these kinds of incidents incorporate typical happenings derived from similar interactions. These researchers proposed a reason for this phenomenon: incidents are difficult to abstract from the chronological temporal flow of human experience and that all of us would likely do the same if asked to share an account of an incident which happened to be typical of many (Norman, et. al., 1992).

As such, I replicated Norman et al.'s (1992) preference for "critical happenings", which are defined as events observed (or experienced) that are meaningful to the participant in the study. "Critical happenings" were evident in the shared accounts of hope-full and hope-less interactions recollected within this study. In 9 of the 22 CI accounts, participants recounted typical actions or events involving family members that were evident over the course of many similar occasions. Thus, an amalgam of happenings with similar perceived meanings were shared within one incident.

An example from this study to illustrate critical happenings within an incident is as follows: One participant described that when she was first diagnosed with HIV, she phoned her x-husband; he drove over and talked with her for six hours. Then, several days later he phoned her to give her information of an HIV/AIDS drug trial that he had investigated. He also lent her his car and fixed her's on many occasions. She commented that he did a lot of little things for her that supported her emotionally. In this incident, critical happenings of "talking for six hours", "finding out drug trial information", and "lending and fixing car" all represented events that combined to enhance her hope. As well, another example of critical happenings involves a hope-less CI account that entailed the critical happening of the deaths of six friends over the last year. The accumulations of these deaths negatively reframed this participant's perception of his own death and consequently sapped his hope.

Wrestling with Data Analysis

Data were first content analyzed using an inductive approach. Cox, Bergen, and Norman (1993) suggested that an inductive classification system is an effective method of

CIT analysis that allows for accurate descriptions of the data. Prior to data analysis, 3 of the 22 incidents collected were removed from the data set and stored for prospective verification of data analysis.

For analysis, each of the incidents was listened to and absorbed as a whole by the researcher (Woolsey, 1986). A diagrammatic meta-matrix was then created to represent each incident. This process of absorption and creation of diagrammatic representations of each interaction allowed the researcher to develop an holistic perspective of the shared accounts.

Following this process, the researcher attempted to reduce the data by employing Miles and Huberman's data reduction technique (1984). Their technique fosters the identification of frequently occurring patterns or themes that cluster into categories and was used to determine common and salient characteristics of hope-influencing interactions between persons living with HIV/AIDS and family members. After extracting, isolating, and listing key phrases of the data, the bracketed information was re-ordered, re-classified, and re-assembled in an attempt to derive coherency from the data. Employing this rigorous technique should have generated findings of critical components in hope-influencing interactions. However, in this stage of the continuous process of data analysis, no conclusive information emerged.

Thus, an alternate system was employed to analyze the contents for critical hope-influencing components. A hierarchical classification system of content analysis was used to break incidents down in four ways: (1) type of experience (e.g. hope-full or hope-less as identified by participants); (2) type of event (e.g. phone conversation, series of deaths, receiving a card); (3) category of event (i.e., specific situation or behaviour during an event such as receiving a hug, providing emotional support to another); and (4) affect of event (i.e., feeling expressed about the incident such as inspired, shocked, anger, etc.,) (Reighart & Loadman, 1984).

Once again, this classification failed to identify the essences of interactions with family members that influenced hope. Incidents were then further restructured and broken down within distinct segments in an attempt to glean concrete, factual information (such as time of day, when during stage of illness the interaction transpired, who was involved, etc.). Incidents were then inspected for meanings and transferred onto an alternate representation under the following headings: general context (background of relationship and circumstances), specific context (what immediately led up to the incident), source (what made the incident hope influencing), agent (who made the difference) and outcome (was hope enhanced or diminished). Then, the researcher went back to the meta-matrices, transcripts, and listened to the audiotapes until a semblance of the data occurred and an intuitive sense of "rightness" and "aha" response (Woolsey, 1986, p. 250) emerged.

Through this analysis process, it was determined that the most prominent hope-influencing detail of interactions was the perceived *meaning* of critical happenings and interactions interpreted by the participant. Other studies substantiate this finding of *meaning* as an integral component to engendering hope. In Norman et al.'s (1992) data analysis, each critical happening derived from incidents pertained to meanings related to positive and negative attitudes towards aspects of nursing care. As well, perceived meaning was found to be a critical dimension of one's *personal hope* (Nekolaichuk, 1995). Nekolaichuk (1995) asserted that hope is "an holistic, interconnection of personal spirit, risk, and authentic caring, grounded by a core theme of meaning" (p. 154). In the present study, *meaning* refers to the personal interpretation that individuals assign to their experiences (Blumer, 1969). Without awareness of the *meaning* of the interactions shared in the present study, the essence of hope's erosion or hope's growth would not be captured. That is, specific elements within interactions themselves (receiving a card, talking on the phone, experiencing the death of friends) were not the purveyors of hope. This initial focus led to the confusion in the data analysis.

The perceived meanings derived from the critical happenings and interactions were the most salient feature related to hope. For example, a certain card sent to a participant by a family member was perceived by the participant to be a demonstration of the family member offering unconditional acceptance. To the participant, this perception of being unconditionally accepted was the catalyst for engendering his hope. As well, what the deaths of six friends from AIDS over the last year meant to another participant was that his own death was imminent; this meaning served to diminish this participant's hope. In contrast, another participant witnessed the death of a friend who had AIDS. The experience demonstrated to her that dying is not horrible, and subsequently increased her hope. In conclusion, analysis of the data with a focus on *meaning*, generated a comprehensive description of the critical components of hope-influencing family incidents.

Soundness and Trustworthiness

Flanagan (1954) noted that determining critical components in CIT analysis requires "insight, experience, and judgement" (p. 344) and is "unavoidably subjective" (Woolsey, 1986, p. 249). However, a variety of methods as described by Sandelowski (1986), Patton (1990), and Guba and Lincoln (1992) were employed to establish trustworthiness of the data collected as well as the data analysis. These methods included memoing, producing field notes, and creating an audit trail. Triangulation among different sources of information derived from conversations with others, brochures, and books enabled interpretations to be cross referenced (Bibby, 1993; Guba & Lincoln, 1992; Rudestam & Newton, 1992).

In addition, the derived categories of critical meanings were applied to the remaining three incidents that were split from the data set prior to analysis. As a result of this splitting of data, categories were examined for accuracy. The critical meanings embedded within the remaining incidents resonated well with the generated categories of critical meanings. Data collection thus was finalized as the split data verified the critical meanings that influenced hope through interactions with family members.

Further soundness and trustworthiness of the categories involved two independent consultants. Flanagan (1954) suggested that when categorization is complete, consultants should be asked to sort incidents into interpreted critical components to determine adequacy of fit. In this study, consultants selected six of the interactions conveyed on the meta-matrix at random and determined whether the interpreted categories of meanings adequately captured the hope-influencing aspect of incidents. Confirmation of critical meanings occurred as consultants easily identified salient meanings in each incident and matched the researcher's analysis.

Accuracy of the derived critical meanings of hope-full and hope-less interactions between persons living with HIV/AIDS and family members were also confirmed through a one hour focus group discussion (Morse & Field, 1995) involving members of an HIV/AIDS Society. As well, all six original participants of the study were contacted and given a summary of the interpretations. No changes were suggested; all agreed that the results resonated with their lived experiences of salient meanings that impacted hope within their family incidents.

Confirmability (Morse & Field, 1995) of the research process is possible through reviewing the researcher's memos, field notes and audit trail. The researcher's assumptions, feelings, impressions, and brainstorming ideas throughout the research were journaled and kept as research memos. As well, field notes were written during and after each meeting with participants.

Results and Discussion

Description of Participants

Of the six individuals living with HIV/AIDS, two females (heterosexual) and four males (three homosexual and one bisexual) were involved in the study. Two participants were single; one was divorced; two were involved in common-law relationships; and one was married at the time the study was conducted. The average age of participants was 40 (range 38-43). All participants were Caucasian. Two had earned a baccalaureate degree from a university. Two did not complete high school; one participant received a high school diploma; and another completed two years of college. An annual income of $10,000 or below was reported by one participant. Three reported between $10,000 and $20,000 and two participants reported incomes above $20,000. Their employment status was as follows: one was full-time employed; two were on long-term disability; one was a recipient of Assured Income for Severely Handicapped (AISH); one received Canadian

Pension Plan (CPP); and another was on AISH as well as the CPP. At the time the interviews were conducted, participants had been living with knowledge of their HIV positive diagnosis for as little as 2 years and as long as 10 years. Five of the six participants had been AIDS diagnosed previous to commencement of this study.

Participants' health and well-being in relation to HIV/AIDS was also assessed in this study since HIV illness formed the context through which hope and family interactions were investigated. One participant chose the descriptor "less than fair" to characterize his current health status. Two participants felt their health was "fair"; two others reported it to be "good"; and one felt his health was "excellent". The last participant attributed his excellent health to the effectiveness of HIV anti-retroviral drugs. In his recent experience, after his white blood cell count (CD4) dipped to very low levels it elevated back to reach near-normal immune system levels. As well, there were minimal traces of the HI Virus detected in his bloodstream. This is an optimistic sign indicating that the virus is not destroying nor taking over the immune system. The amount of virus in the bloodstream is determined through viral load testing. Another participant, who reported his health to be "good" was also living a medical anomaly. While his CD4 count remained relatively low (a poor sign of health), his viral load tests showed that he had extremely low traces of the HI Virus in his bloodstream. He attributed his fortunate health and the medical mystery to his philosophy of dealing with stress:

> I have my theories, no matter how stressed out [I am], I let it out. I will tell somebody off if I need to and release the negative energy.

<u>Hope-Influencing Interactions</u>

Fourteen hope-enhancing and eight hope-diminishing CI accounts were recollected by participants. Data analysis generated *meaning* as the central component of hope-influencing interactions with family members. Categories of critical meanings were derived from the accounts of family incidents that were identified to facilitate or hinder hope.

In terms of quantitative information concerning the 22 CI accounts, the following family members were involved in critical happenings or interactions with participants. In three incidents, other individuals living with HIV or AIDS were identified in hope-full interactions with participants, and six times they were involved in hope-less encounters. One sister was involved in a hope-full incident while three sisters were involved within hope-less exchanges. Five interactions included participants' mothers (two hope-full and three hope-less), while two were with cousins (both hope-full), and two other incidents transpired with life partners who were HIV sero-negative (both hope-full). In addition, other family members who engaged in interactions identified as hope-inspiring included the following persons: HIV sero-negative friend, niece, father, brother-in-law, mother-in-law, x-husband, aunt, uncle, grandmother, and an HIV/AIDS Society employee.

As well, the stages of HIV illness in which the hope-influencing interaction between participants and family members occurred were noted as follows: one happened before the participant was diagnosed with HIV; six transpired immediately following the HIV seropositive diagnosis; six were during the symptomatic stage of HIV; six others transpired after participants received an AIDS diagnosis; two incidents occurred throughout all stages of the HIV illness; and one interaction had an unspecified time of occurrence.

The meanings that were generated from critical happenings and interactions with family members that influenced hope in a positive sense were divided into seven categories. These categories of critical meanings emerged from participants' hope-full family incidents and they were all of equal significance. They are presented as follows in no particular order: (1) *Emotional Support*; (2) *Unconditional Acceptance*; (3) *Mutual Support*; (4) *Spiritual Connection*; (5) *Reframing Life*; (6) *Reframing Death*; and (7) *Affirmation of Worth*. One or more of these critical meanings was identified from each incident as the critical aspect(s) that influenced the participant's hope. These seven categories resounded with the sources of hope identified in Herth's (1990) investigation involving 30 terminally ill adults, and Miller's (1989) research that determined nine hope-inspiring strategies gleaned from 60 persons who were recovering from a serious illness.

In addition, four categories of critical meanings were determined from participants' hope-less CI accounts. These critical happenings or interactions embodied the following critical meanings and are presented in no particular order: (1) *Lacking Honesty*; (2) *No Emotional Support*; (3) *Conditional Acceptance*; and (4) *Reframing Death*. One or more of these critical meanings were identified in each hope-less incident recounted by participants and all meanings were of equal salience.

Figure 3.2 is a schematic representation of all the critical meanings which were derived from the data. The core element of *meaning* is illustrated as central to influencing hope. In the following section, these critical meanings are discussed in further detail. The seven hope-full critical meanings are addressed first. In this discussion, the hope enhancing critical meanings of *mutual support* and *spiritual connection* are described together since both were illustrated within the same incident. However, one meaning is not more nor less critical to influencing hope than other derived meanings. Following this discussion of the hope-full critical meanings, the hope-less critical meanings are presented.

The *Hope-full* Critical Meanings

Emotional support. Social support networks have been strongly linked to psychological well-being (Hays, Chauncey, & Tobey, 1990; Kurdek & Siesky, 1990; Carson, Soeken, Shanty, & Terry, 1990). The amount of emotional support received as well as informational support were identified by Hays et al. (1990) to correspond with hope. In addition, Hall (1990) surmised that terminally ill individuals who are emotionally supported by others, can experience enhanced hope, contentment, and fulfilment even in the last stages of their illness.

Emotional support was identified as a critical meaning within several hope-full incidents recounted by participants in this study. The following example demonstrates one incident consisting of critical happenings involving a friend (whom the participant said is more like a sister):

> After a change in my health due to HIV, I became concerned and frantic. I made a phone call to my friend and over a 3 hour conversation she cried with me and understood how scared I was. Her support was instant and over the course of the

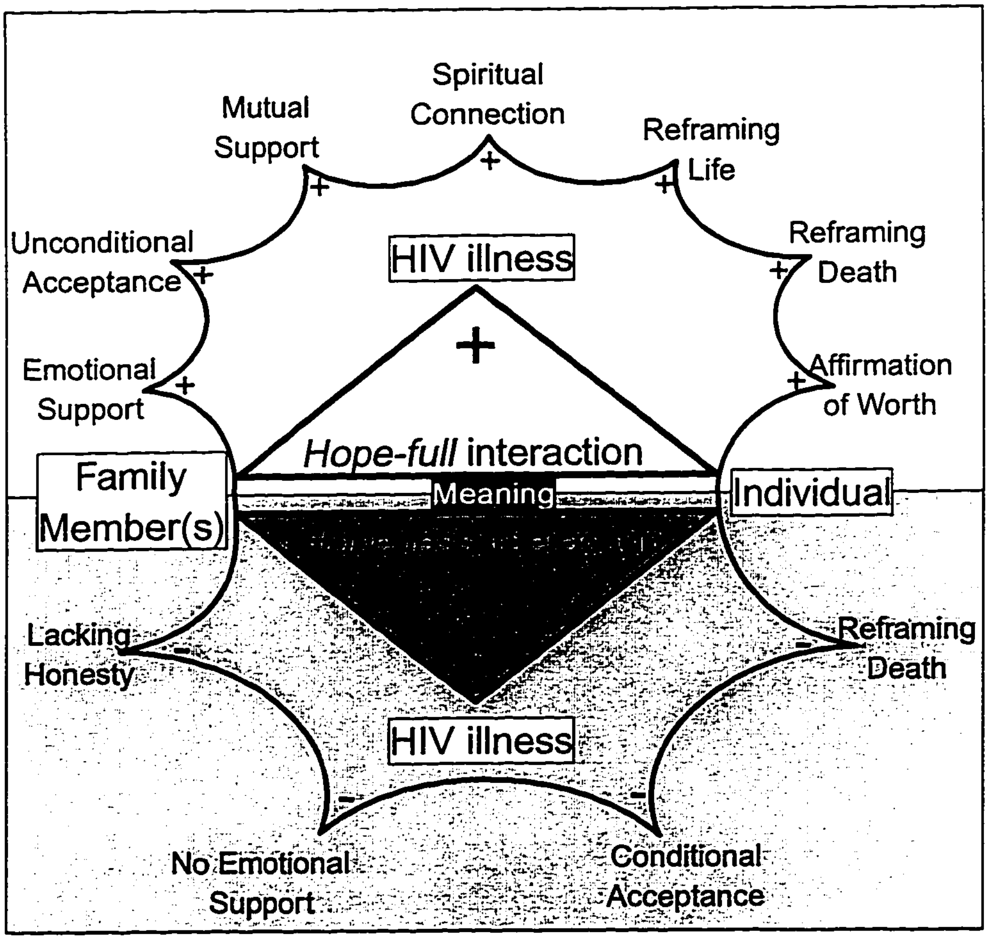

Figure 3.2. Schematic conceptualization of the derived critical meanings of *hope-full* and *hope-less* interactions in relation to the Interactional Triangle.

> next few weeks, she made the effort to give me a hug and to ask me "how's it going" and "what's the latest news?". She provided this support on a daily basis. Then, when I was going in for more tests, she offered to take time off from her work to come with me. In the whole process of going through this, it was so nice to know that there are people out there to talk to and listen. Her support is ongoing.

The significance of *emotional support* in health and illness is substantiated by Hall's study (1990); this researcher determined that emotional support from family members was an essential component for engendering hope. In addition, Carson et al. (1990) conducted an empirical study involving 65 males living with HIV/AIDS. They concluded, using Ellison's Spiritual Well-being Scale (Ellison, 1983) and Beck's Hopelessness Scale (Beck, Weisman, Lester, & Trexler, 1974) that hope was highly correlated with spiritual and emotional well-being (Carson et al., 1990).

<u>Unconditional acceptance.</u> The category of *unconditional acceptance* captures the powerful meaning from incidents that were perceived by participants as hope enhancing. Unconditional acceptance denotes characteristics of respect, trust, and non-judgement. These qualities perceived of incidents were clearly meaningful for engendering hope and were also found as essential for hope in Keen's (1994) investigation of the experience of hope for persons living with HIV/AIDS.

An example of a hope-inspiring incident that demonstrates the critical meaning of unconditional acceptance involves a participant's CI account of disclosing his HIV positive status to his mother over the phone.

> She said, "You are my son. You will always be my son and I love you.". It didn't matter. There was no judgement. You don't have to earn a place in her heart.

The next incident also demonstrates a positive influence on hope arising from a perception of being unconditionally accepted:

> I went home for the week-end to tell my parents I was HIV positive. On Saturday night after supper (this is usually the time when people sit around and gab), there was my mom, my dad, and me at the kitchen table. I just told them: "I am HIV positive and my condition has deteriorated to the point that I should begin medication.". Both my parents started to cry. My father got up from his chair and came around the table to me. He made me stand up.. He gave me a hug and kissed me on the cheek and said, "I love you... I'm sorry I haven't told you this more often. I want you to know that we are here for you whenever you need. And

> we want you to come home more often and whenever you want". My father was unconditional. His impact on my hope was great. To know that they would be there to support me in any way I needed and that he was willing to do that was really great.

Mutual support and Spiritual connection. The poignant connection between *support* and hope in health and illness is evident in the literature. Dubree and Vogelpohl's found that support from others was directly related to hope (1980). Simons (1987) and Wilson-Barnett (1978) have also substantiated the view that external support is therapeutic. And in Miller's (1989) research into the hope of persons who were critically ill, hope was reported by informants to diminish if they lacked support. Further to these researchers' findings of the significance of support from others, "supporting others" was also determined in this study as essential to hope. This concurs with Coward's (1995) assertion that reaching out to give as well as to receive is critical to hope. This reciprocating nature of hope was also recognized in Keen's (1994) investigation.

The critical meaning of *mutual support* derived in this study, represents the significance of an equal relationship, where family members and persons living with HIV/AIDS are interdependent; and where both individuals give and receive support. This is evident as a critical meaning in a participant's CI account which involved a six hour long phone conversation. This participant talked her sister out of suicide and through this ordeal of supporting her sister, she felt she had received support as well.

> This was a critical incident for me because I have felt suicidal many, many times... because of HIV, but mostly because I promised myself I'd never live in the same poverty I grew up in and here I am! This incident allowed me to face suicide. It crossed my mind a hundred times, but to talk to someone who's truly going to carry it out, made me really face the issue. Now I know I'd never put my children and family through that. In the last two years after that phone call, my way of dealing with my thoughts of suicide has changed. They are still there, but my attitude has changed. As a result of this interaction, my sister and I share an incredible spiritual connection. We have a spiritual bond now. This is an important part of my hope to know that I am spiritually connected to another.

Not only does this incident delineate the critical meaning of positively influencing hope through a mutually supportive relationship, it also demonstrates the significant impact of a spiritual connection on hope.

Reframing life. This category was derived from incidents that reframed the outlook of one's own present and future life. This category often refers to "medical hope". Coward (1995) and Hall (1990) reported that the manner in which persons with HIV/AIDS maintained hope included a belief in a treatment that could prologue life. Some of the present day HIV/AIDS anti-retroviral drugs have begun to show efficacy in sustaining life with this illness. Thus, it is not surprising that hope for a medical cure is widely prevalent among those battling life with this illness. Believing in a potential medical cure reframed the outlook on life and enhanced the hope of some participants in this study. This is apparent in the following incident:

> We went out for coffee and I got to know bits and pieces of his story over the course of a couple of months and between bridge games. It was very emotional for him to tell his story. It was a very hopeful encounter for me because he was physically worse off than me. He has been very close to death and began a new HIV/AIDS drug treatment which has since increased his CD4 counts to near normal levels again. He is vigorous and eager to engage life again. This gave me great hope that there is a treatment out there that will make me well again and allow me to work and make money. Mostly, the fact he was in the hospital and they didn't think he was going to make it, and they managed to pull him through the opportunistic infection influences my hope... and that the drug that he is on will be federally approved in the Spring.

As well, another participant shared a *hope-full* account which reframed his life and involved medical hope. This participant's uncle and cousin died from AIDS before the participant was diagnosed with HIV. He discussed that 4 years after they passed away, when he was diagnosed with HIV, he had a "recognition of hope" through recalling that his uncle and cousin were able to live longer due to HIV/AIDS medications.

> It gave me great hope that medications will make me live longer.

Reframing death. This critical meaning was evident in several hope-full interactions. *Reframing death* captures a new optimistic outlook on one's own future death emerging from a family incident. One participant recounted an interaction involving a friend who began his journey with HIV at the same time as she:

> My kids called him "uncle" and called his mom "grandma". We met during an

> HIV/AIDS project and trained together from the very beginning. When he was hospitalized, we visited him everyday in the last 2 weeks before his death. It was very positive to see what it [death] and the process was like for him. To see the support from his family and friends... seldom was there a time that we were visiting that there weren't other people visiting him. It was pretty incredible. In those last 2 weeks of his life he was totally out of it. Yet people would sit there and hold his hand and talk to him as if nothing was wrong with him. It's so cool to know that even if my family of origin isn't there, I know that my chosen family will be there for me. This is so important to me. I know, barring a miracle, that I am going to die from HIV. And he gave me the gift to know that the dying process isn't going to be as scary as I thought. It's going to be okay. It's not that terrible.
>
> It is a huge influence on my hope to know that there are people who support me and my children through all of this. That no matter what happens... whether I live or die, they will be there.

Affirmation of worth. Feelings of rejection and isolation often stems from the social stigma of HIV/AIDS (Sims & Moss, 1991). This stigma is perpetuated by a fear and ignorance of the illness (Clift, Stears, Legg, Memon, & Ryan, 1990). Lippmann, James, and Frierson (1993) also noted that the plethora of stressors in the lives of persons living with HIV/AIDS is exacerbated by the stigma and secrecy involved with HIV illness. Thus, there is no surprise that an interaction that affirms worth is particularly poignant for the hope of individuals living with HIV/AIDS. Feeling accepted and included are all the more powerful and assist to affirm the meaning, value and purpose in the lives of persons with HIV/AIDS (Carson et al., 1990). Herth's (1990) research further supports the category of affirming worth. Herth identified that persons who were terminally ill with cancer were more hopeful when they felt needed, accepted, and acknowledged (1990). As well, Coward (1995) found that helping others who were diagnosed with HIV or AIDS increased one's own sense of worth and engendered a feeling of purpose and hope in life. This is evident in the following CI account within the critical meaning *affirming worth.*

> I am there to answer questions on the phone [at the HIV/AIDS Society] or talk to whoever walks through the door. Whatever position they're in, I'm able to give them help with it. This is hopeful. I can dig up resources and learn about the hope for myself. Through this, I have a more positive attitude and feel better. Being able to support others allows me to find out information for myself and also gives me hope. I thank them. I've received cards, flowers, and thank-yous from people. It's not the cards that are hopeful, it's just being in a position to help. This makes me feel real good.

The *Hope-less* Critical Meanings

Lacking honesty. There is a strong connection between authenticity and fostering hope (Wong-Wylie & Jevne, 1997). Being authentic within interactions requires that one is not deceptive. *Lacking honesty* emerged as one of the four critical meanings derived from CI accounts that diluted participants' hope. There was not a contrasting category of "honesty" found within this data set to demonstrate an impact on hope in a positive sense. That is, family members who were perceived as dishonest sapped hope; but members who were honest were not reported by participants to engender hope. Perhaps, honesty is expected of relationships; and thus, does not impact hope except in its absence. In this study, *lacking honesty* was derived from critical accounts involving family members who were perceived to carry on a facade or who were "two-faced." One participant spoke of the significant negative impact on her hope that emerged from her sister's lack of honesty. She shared that her sister's initial reaction to her diagnosis of HIV was to come to her house and clean and bleach everything for fear and concern that the HIV would be worsened by a bacterial infection. Later, this participant was enrolled in an HIV/AIDS drug trial and had to travel to her sister's city on a regular basis. She stayed at her sister's house; and after she left, her sister again frantically cleaned the house.

> I thought she did this because she was concerned about my health. Then in a telephone conversation, she admitted to me that she frantically cleaned because, "I'm afraid that my husband will get HIV from you and then he'll kill me.". She was actually concerned about herself. It influenced my hope because she wasn't honest and misled me up to that point. It took away from me... I've always wanted to be upfront and honest, but she couldn't be these things.

As well, another participant's CI account strongly supports that perceiving deception and dishonesty from a family member eroded one's hope.

> My mother greets me with a smile when I visit. Then, the minute I walk out the door she's on the phone to the rest of the family and her friends saying, "That fucking faggot was here.". This has a tremendous impact on my hope-- that she could put on this smile and say, "I love you, so nice to see you," and then turn around and do that.

No emotional support. The next incident was revealed by a participant who shared that a heated dispute between herself and her mother prompted a fight with her sister whom the participant often counted on for emotional support. As a result of losing this relationship with her sister, this participant was very upset with her mother. She expressed how despairing this interaction was and how it had dismantled her hope:

> My mother took away the hope, the support... the one person I had to grab on to. I'll never forgive her, never. My mother blew it-- I lost my relationship with my sister because of that fucking bitch. How dare you take away the one person I had to lean on? She was the one support person I knew would always be there. She's the only person I could call when I was feeling suicidal-- there's no one else. It just shattered me. She was my only connection to hope.

Conditional acceptance. This next family incident illustrates the critical meaning of *conditional acceptance*. Resulting in a perception of being conditionally accepted by family members, the following interaction eroded this participant's hope.

> I'm homosexual. This doesn't mean that automatically I'm an enemy. I have chosen what I want. My family of origin always screamed "faggot" at me. They think I got HIV because I'm the "faggot of the family". They associate HIV and homosexuality together and discriminate against me because I'm gay even though I contracted HIV through heterosexual sex. They think of me in a derogatory sense. There's nothing dirty about me. I love the same way they love. I care the same way they care and feel the same way they feel. I wish they would accept me for me.

Reframing death. *Reframing death* emerged as a hope-debilitating critical meaning from incidents with family members. The next two interactions demonstrate hope-less CI accounts of one participant's encounters with family members which negatively altered his perception of death.

> My oldest sister and my youngest sister both talked to me about suicide, although they didn't call it that. They said that they were very selfish but they hoped I would die slowly because they needed the time to prepare. It would upset them most if I died suddenly. This impacts my hope in the reality check that they believe I'm going to die and they believe it's going to be relatively soon. This is realistic, but it also impacts my hope of an easy death-- which was what I was hoping for... I'm hoping to go quickly, without a lot of physical disability and pain beforehand. This is not what they're hoping.

> The accumulation of the deaths of my friends to HIV/AIDS had a negative impact on my hope. The six people were some of the people I got to know when I was first diagnosed with HIV... so I identified with them. I considered us all in the same boat. To see them pass away, one after another, brought home the reality

> that I too will die from this disease, and how fragile a state I am actually in-- like any one of them, I get the right illness [opportunistic infection], I could go. I feel less hope for a long life.

Both these incidents brought "home the reality" of the participant's own death and served to erode his hope. He felt a lack of control over when he would die and how it would happen. Limandri and Boyle (1978) determined that "loss of control" was a precursor to hopelessness. Herth (1990) also distinguished "powerlessness" over one's own life as one of the three hope-hindering categories that greatly threatened hope. For the participant in this study, feeling powerless about his death, which resulted from these critical happenings, smothered his hope.

Particularized Hope

One salient discovery that emerged from this research, in addition to the critical meanings of hope-influencing interactions, was that hope was particularized for each participant in response to the context of their own experiences and surroundings. That is, what individuals perceived as significant in their lives was revealed as they shared their accounts of hope-impacting family incidents. CI accounts therefore, remarking on the ebb or flow of personal hope, unveiled the individual's *personal spirit* (Nekolaichuk 1995). *Personal spirit* in Nekolaichuk's factor structure of hope represented hope as "a holistic, interconnected configuration consisting of the elements of meaning, vibrancy, value, caring, and energy" (1995, p. 84).

The human ecological perspective is a valuable framework to guide the understanding that one's hope is a reflection of personal spirit. In light of this identification of hope as particularized to each individual's circumstances and spirit, it is appropriate to employ a human ecological perspective to engender hope. The human ecological approach encompasses a "scientific and holistic study of human beings, their environments, and human-environmental interactions" (Westney, Brabble, & Edwards, 1988, p. 129). One fundamental assumption of this framework is that humans are interdependent within their surrounding environments (Bubolz & Sontag, 1993). The philosophical undergird of human ecology asserts that individuals cannot be viewed in isolation from their families, their community, the wider society, or the global world. The outer environments in which a person is centred has formative effects on the individual's attitudes, knowledge, beliefs, and behaviours, and therefore impacts one's health (Bubolz & Sontag, 1993) and hope. Human ecology is an appropriate perspective to perceive the interactions that can potentially influence the hope of persons living with HIV/AIDS. Persons need to be considered holistically within the context of their experiences and environments-- and so must hope be considered.

An example to demonstrate the particularization of hope from this study involves "hope for a medical breakthrough". According to the context of what is important to persons living with HIV/AIDS, learning of medical advances in the treatment of HIV/AIDS can be hope enhancing, hope debilitating, or have neither influence depending on the relevance of the news to their lives.

This particularized view addresses the influence that family members can have on an another's hope. That is, in order for family members to be intentional about their impact on the hope of persons living with HIV/AIDS, it is important for family members to have an awareness of what is relevant to them. Developing an understanding of what is critically meaningful to the particular individuals with HIV illness would assist family members to more effectively engender hope.

Summary

In this study, it was revealing that such actions as sending a card, or making a telephone call can ignite another's hope-- not within the action itself, but within the recipient's perception of the behaviour. Family members need to be sensitive not only of their actions but of how their actions may be perceived. This awareness is critical for fostering hope in others.

This research enriched our understanding of the multidimensional construct of hope as it is influenced within family incidents. Managing life with the illness adversity of HIV/AIDS requires hope; family members can assist to engender hope for such persons through engaging in meaningful interactions. The meanings determined as critical to fostering hope in this study were as follows: (1) *Emotional Support*; (2) *Unconditional Acceptance*; (3) *Mutual Support*; (4) *Spiritual Connection*; (5) *Reframing Life*; (6) *Reframing Death*; and (7) *Affirmation of Worth*. Furthermore, the meanings derived as critical in hope-debilitating family incidents were as follows: (1) *Lacking Honesty*; (2) *No Emotional Support*; (3) *Conditional Acceptance*; and (4) *Reframing Death*. These seven hope-enhancing and four hope-diminishing critical meanings derived from this study shed light on what was important to persons involved in this study. The pivotal understanding derived from this study, in terms of the relationality of hope, is that hope is subjectively influenced. The understanding that hope is particularized for persons in family incidents informs our knowledge of the otherness in hope. This study served to increase our awareness of the need to treat persons living with HIV illness with dignity, care, and to take the time to understand where they may be coming from and what is important to them in the context of their lives.

Future Research

Additional research needs to be conducted, particularly from the perspectives of persons living with HIV illness who represent a variety of populations and family contexts. Snowball sampling procedures limited this study by generating a uniform sample consisting of Caucasians in their late 30's to early 40's. In Alberta, this age range does represent the modal category of persons whose illness has progressed to AIDS (Health Canada, Provincial Laboratory, 1996b). However, critical meanings of hope-influencing interactions of other age groups and races are not documented and require investigation.

CIT: Challenges and Benefits

There were several benefits to utilizing CIT as a research method in this study.

- CIT promoted reflectiveness in participants and thus facilitated learning and self-discovery (Parker, Webb, & D'Souza, 1994).
- CIT also generated narratives of hope-inspiring interactions that can be shared as exemplars.

- Additionally, CIT fostered an integration of theory into practice. Rice and Greenberg (1984) stated:

  "Critical incident studies are particularly useful in the early stages of research because they generate both exploratory information and theory or model-building. As such, they belong to the discovery rather than to the verification stage of research (Rice & Greenberg, 1984/ cited in Woolsey)" (p. 252).

By conducting additional research employing experimental and deductive approaches, the resulting seven hope-full and four hope-less meanings identified in this study could be verified and refined to generate theory related to interactions between family members and persons living with HIV/AIDS.

Although there were many benefits to employing this research method, two challenges emerged from this investigation. First, CIT captured snapshot accounts of past interactions that influenced personal hope. Given that hope is "referenced in the future, grounded in the past, and experienced in the present" (Mader, 1988, p. 17), the recollections of hope-impacting family incidents had the potential to be affected through the passing of time between the actual event and the time of recall. That is, present hope may have clouded retrospective accounts of hope. Secondly, a challenge surfaced in regards to the accounts of family interactions. Family incidents are difficult for participants to dissect from their existing relationship with family members. Thus, the nature of the family relationship had the potential to impact one's perception of an interaction as well as flavour recollections of them in the present. Both these challenges however served to further illuminate the complexity of family incidents and the dynamic and integrative nature of hope (Nekolaichuk, 1995).

Nevertheless, these data represented the perceptions of six individuals and served to capture their lived experiences (Norman et al., 1992); therefore, the results from this study are meaningful. It was not "truth" nor accuracy of incidents that were pertinent in this study. The critical accounts were "valid" by virtue of their salience to the participants

(Norman, et al., 1992). Discrete episodes that exist clearly from any influence of time and other events rarely exist in the context of family interactions (Norman et al., 1992). Thus, lived experiences of interactions captured from participants' perspectives, with the awareness of potential influences, remain as rich data.

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CHAPTER 4

CONTEXTUALIZING

In this chapter, the preliminary study and the primary study presented in this research are *contextualized.* That is, the understandings from the studies are synthesized and are applied to praxis within the social world. *Understandings* are the impressions that are left, or the predominant interpretations gleaned from the research (Vaines, 1997). To contextualize understandings of this research, an overview of both studies is first presented. This is followed by a discussion of Human Ecology and Social Constructivism as valuable perspectives to employ for research and praxis. As well, a brief description of understandings that emerged from the studies and their significance within the areas of Family, HIV/AIDS, Hope, and Family Interaction are provided. Furthermore, some of my wonderings that emerged from the research are offered as suggestions for direction of future research. Lastly, to further contextualize, implications of the research are offered for community HIV/AIDS health care and social service programs, educational interventions, and counselling endeavours.

Overview

This research explored the inquiry: *"What are the components of family interactions that influence personal hope from the perspectives of persons living with HIV/AIDS?"* Before delving into this investigation, an understanding of "family" from six participants involved in this research was first obtained. This preliminary study served to preserve participants' meanings of family which were derived through delineating structural and functional components of their selected families. For specific understandings of selected families of persons living with HIV/AIDS in this study, see Table 4.0 blocks A and B.

Following this investigation into meanings of family, participants shared CI accounts of hope influencing family incidents. During the analysis of these data, no

Table 4.0

Summary of *Understandings* and Their Significance

INQUIRIES	*UNDERSTANDINGS*	INFORMED FIELDS
(A) Who do persons living with HIV/AIDS consider as "family"?	Groups of persons included: (1) *family of origin members*, (2) *health care professionals*, (3) *friends*, (4) *other persons living with HIV/AIDS*, (5) *deceased friends*, (6) *family caregivers*, and (7) *hobbies*.	**Family and HIV/AIDS** Specifically determined the created or "selected" families of persons living with HIV/AIDS– structural configurations of family.
(B) What are significant attributes of selected family members for persons living with HIV/AIDS?	Attributes were identified as: *(1) reciprocal relationship, (2) inspirational influences*, (3) *accepting*, (4) *supportive*, and (5) *health and wellness resources*.	**Family and HIV/AIDS** Specifically determined the created or "selected" families of persons living with HIV/AIDS– functional aspects.
(C) In the critical incident accounts shared by persons living with HIV/AIDS of poignant, hope-influencing interactions with family members, what are the critical components in the incidents that **engender** hope?	No specific components in ***hope-full*** incidents were found to be critical to the influence on hope. Instead, critical happenings and their associated critical *meanings* were determined as central. They were: (1) Emotional Support; (2) Unconditional Acceptance; (3) Mutual Support; (4) Spiritual Connection; (5) Reframing Life; (6) Reframing Death; and (7) Affirmation of Worth.	**Hope, HIV/AIDS, and Family Interactions** Specifically identified the hope-engendering critical meanings derived of interactions between persons living with HIV/AIDS and family members.
(D) In the critical incident accounts shared by persons living with HIV/AIDS of poignant, hope-influencing interactions with family members, what are the critical components in incidents that **diminish** hope?	No specific components in ***hope-less*** incidents were found to be critical to the influence on hope. Instead, critical happenings and their associated critical *meanings* were determined as central. They involved: (1) Lacking Honesty; (2) No Emotional Support; (3) Conditional Acceptance; and (4) Reframing Death.	**Hope, HIV/AIDS, and Family Interactions** Specifically identified the hope-diminishing critical meanings derived of interactions between persons living with HIV/AIDS and family members.
(E) Did other relevant information arise from this study?	Persons living with HIV/AIDS recounted hope-influencing interactions and perspectives of "family" from a particularized view. Thus, a contextual and constructivist perspective to view individuals' hope and their "family" is meaningful.	**Human Ecology / Social Constructivism** Specifically recognized that one's "family" and one's hope are influenced through one's experiences and environments. A social constructivist lens is appropriate to consider the "family", and a human ecological lens is relevant to consider the meanings integral to impacting hope in family incidents.

specific components of incidents could be identified as integral to influencing hope. Instead, the understanding emerged that the *meanings* behind participants' CI accounts were the essence to the impact on their hope. That is, how an incident was perceived by participants living with HIV/AIDS, or the meaning they ascribed to interactions with family members, surfaced as the salient feature influencing their hope (for a summary of the critical meanings, see Table 4.0 blocks C and D).

Additionally, this study concluded that a representative or static definition of "family" is not important. Likewise, it is not a rigid nor prescriptive set of critical meanings of hope-influencing family incidents that are significant. In this research, structures of family, their identified functions, and critical meanings of hope impacting family incidents identified were not intended to be developed into "how tos"; instead, their prevalence demonstrates that it is vital to view families broadly and to particularize and personalize family interactions and care. Thus, two pivotal understandings for research and praxis emerged from the studies. They were: (1) a social constructivist approach to regarding families of persons living with HIV/AIDS is meaningful, and (2) a human ecological lens to perceive *meanings* within family incidents that impact the hope of individuals with HIV illness is appropriate.

Although the two studies incorporated within this research were presented as separate investigations, a distinct overlap was evident between family meanings and hope. This overlap emerged in the preliminary study of participants' descriptions of family members. As individuals disclosed attributes of their selected family members, *hope* surfaced in their impressions of these members as health and wellness resources. In other words, one attribute of selected family members, identified in this study, was that they provided *health and wellness resources*; impacting hope was one facet of this resource. This delineation echoes the assertion that family members are significant to the hope of persons with HIV/AIDS. As well, it accentuated the powerful connection that lies between well-being and hope. Thus, researching components of family incidents that influenced hope resonated as a worthwhile endeavour through participants' initial identification of the link between hope and family.

Human Ecology and *Social Constructivism*: Perspectives for Research and Praxis

Human ecology and social constructivism have been expanded in their utility as meaningful conceptual frameworks in this research (see Table 4.0 block E). Both approaches were valuable in assisting the researcher to formulate ideas at various stages of the investigation. Human ecology and social constructivism are not only valuable frameworks for research, they can also be considered as meaningful perspectives to influence praxis. In the following section, a consideration of these approaches for praxis in addition to their application for research are discussed. Furthermore, my wonderings are outlined.

Human Ecology: Application Within Research and Praxis

Human ecology emerged as a valuable conceptualization which framed understandings of the research. For instance, the human ecological approach which embraces world diversity, accommodates multiple views of family generated from this research. In addition, human ecology is an appropriate perspective to guide individuals to be intentional about their impact on the hope of family members who are living with HIV/AIDS. Many assumptions of human ecology are applicable to this endeavour.

For example, an assumption of human ecology is that humans are interdependently connected to their surrounding environments (Bubolz and Sontag, 1993). This holistic perspective in which to regard individuals, acknowledges all contexts including the socio-historical and cultural milieu that a person with HIV/AIDS may be situated within (Bubolz & Sontag, 1993). For family members, employing a human ecological approach to their interactions with persons living with HIV/AIDS would sensitize them to always consider the context affecting the other's hope. Human ecology guides persons to consider cultural, societal, community, and personal experiences of individuals with HIV illness and encourages family members to consider what may be important to the individual to optimize awareness of how an interaction may affect the other's hope.

Another fundamental assumption of human ecology is that people have ability to promote change, emancipate victims of oppression through action, advocate for quality of human life, and improve the human condition (Westney, Brabble, & Edwards, 1988). Evidently, an ethic of caring for people is valued in the human ecological approach. Within this optimistic and compassionate view, all people can work together towards not only considering the environments of those individuals living with HIV/AIDS, but also working on improving the environment to create an atmosphere that is conducive to fostering hope. In addition, with the attitude of compassion and partnership, the human ecological approach stimulates government and non-government community organizations, family members, and all persons to work together in pursuit of the common goal of engendering hope for those facing the devastating illness of HIV/AIDS.

The human ecological perspective also encourages family members to be self-reflective. Vaines suggested that "thinking critically about ourselves connects our story with other living systems and their stories" (1988, p. 19). As such, self-reflectiveness is important for persons to gain an awareness of their own experiences, environments, and hope and thus, have optimal awareness of others. The human ecological framework assists in building a balanced perspective in which to regard oneself and others. It also promotes the constant consideration of meaningful interrelationships. Thus, those who are affected by a family member with HIV/AIDS are encouraged, through this tenet of the human ecological approach, to consistently examine their own assumptions, feelings, experiences, and their own hope.

Human ecology is not only a valuable framework for family members to apply in interactions with persons living with HIV/AIDS; this conceptual perspective can be employed by researchers to guide future research endeavours of family, HIV/AIDS, hope, and family interactions. Human ecology would drive studies to regard family interactions from contexts of individuals as well as from a particularized view of hope.

Social Constructivism: Application Within Research and Praxis

Social constructivism is also a meaningful perspective underlying the present research. This perspective is congruent with human ecology and can be considered as a conceptualization imbedded within the framework of human ecology. For instance, within the scope of human ecology, the assumption that there is world diversity embraces variety in family perspectives. Through the social constructivist lens, families are also perceived as a dynamic and multifaceted institution. One's interpretation of family, from a social constructivist perspective, is created through a personal process of selecting, ordering, and organizing information relevant to one's own experiences. Perceiving families as socially constructed captures the dynamism of this prominent societal institution. In this research, viewing families of persons living with HIV/AIDS from a social constructivist perspective has documented this dynamism. Future studies and current praxis that perceive "family" from a social constructivist lens would capture the breadth of family forms and functions prevalent in society.

Directions for *Human Ecology* and *Social Constructivism*

Wonderings that emerged include:

- How can researchers best employ the human ecological and social constructivist approaches to guide their investigations of family, HIV/AIDS, hope, and family interactions?
- Can social constructivism and human ecology be used as frameworks for practitioners to facilitate increased understanding of the client's family and of the client's hope?
- Given the compassionate and optimistic approach of human ecology, and the subjectiveness involved in perceiving families as social constructions, can these views be adopted as effective approaches for counselling practice?
- Since human ecology focuses on the interrelationship between people and environments, what social supports and resources can be developed in the community to help foster hope?

Relating *Understandings* to Respective Disciplines

The studies presented in this thesis served to inform four separate, yet interrelated fields of research: Family, HIV/AIDS, Hope, and Family Interaction. In this section, research understandings are discussed in terms of their contribution to these disciplines. Additionally, my own wonderings that emerged from conducting this research are offered as directions for future research.

Informing *Family* and *HIV/AIDS* research

This research delineated structural and functional attributes of selected families of six persons living with HIV/AIDS (see Table 4.0 blocks A and B). In terms of the structural understanding of "family" from this study, many different kinship and non-kinship associations were identified in selected families. This insight underscores the need for society to acknowledge and accept a broad range of definitions of family. Further to this insight, this study also derived that embracing a variety of family configurations, based on a key function of caring would benefit those persons and their families who are living with the adversity of HIV illness. That is, all family members, whether blood related or emotionally related, could be encouraged and supported in their involvement of the care of persons living with HIV/AIDS. To this end, this study contests the monolithic bias (Eichler, 1988) of families. Many family scholars asserted the need for an acceptance of a diversity of structures in families; and that family functioning as a network of care is more meaningful than the family purely regarded as a unit of biological relations (Eichler, 1988; Rolland, 1994).

An example that demonstrates that family can be more than kinship associations, and that it can be a personal and an idiosyncratic delineation, was one participant's response that a *computer* and the game *bridge* met his criteria of family. His inclusion of these inanimate entities as "family" further exemplifies the array of diversity that is possible in one's interpretation of this institution. Thus, the assertion of family scholars was further supported in this study; there is need for society to acknowledge and accept that "family" is a social construction (Eichler, 1988; Rolland, 1994; Tiblier, Walker, & Rolland, 1989).

Directions for future *Family* and *HIV/AIDS* research

Future studies of inanimate entities as family members would add to current family literature. Some additional wonderings on this topic of inanimate entities as "family" include:

- Is the inclusion of inanimate entities in one's family a response to facing HIV/AIDS, or would persons who are not confronted by this illness adversity have similar responses if asked to generate their meaning of family?
- Is the identification of inanimate entities as family members by persons living with HIV/AIDS a reflection of technological advances that are facilitating less personal interfacing in society?

Also, another wondering in the direction of family and HIV/AIDS research involves:

- Do structural and functional attributes of selected families delineated in this study resonate with the family perspectives of other persons living with HIV/AIDS who did not participant in this research?

Informing *Hope, HIV/AIDS*, and *Family Interaction* research

Living with HIV/AIDS requires a relentless search for harmony between attachment and loss, hope and despair, and engagement and withdrawal (Andrews, Williams, & Neil, 1993). Some of these issues of living with this illness and some of the repercussions for family members were addressed in this research. Given the myriad of stressors that HIV presents to persons and their family members, hope provides an uplifting focus to researching family interactions in the context of HIV/AIDS. However, no studies to date have explored HIV/AIDS and hope-influencing family interactions. Thus, this investigation served as a catalyst for this direction. This study delved into specific details of family incidents and their influence on the hope of individuals with HIV illness (see Table 4.0 blocks C and D). In addition, as we unveil more of the rich tapestries of families and family interactions, we may continue to foster more insight into this network as a potential source of hope for persons with HIV/AIDS.

Directions for future *Hope, HIV/AIDS*, and *Family Interaction* research

Some wonderings that emerged include:

- Does a family member's personal hope play a role in his or her ability to influence the hope of a member living with HIV/AIDS?
- Can health care professionals, such as counsellors, facilitate their clients to become more intentional of and sensitive to their potential to influence hope in interactions with members living with HIV/AIDS?
- Can health care professionals, recognizing that they themselves may be considered as a member in their client's family, utilize the understandings from this research in their practice and increase their own intentionality around influencing hope?

Conducting further studies in areas of hope, HIV/AIDS, and family interactions would be of great benefit. Understanding possible ways in which we can foster hope and contribute to the well-being of persons with this devastating illness is valuable and has implications for more effective caregiving. Family members are, and will continue to be, powerful facilitators of hope for persons with HIV illness. Studies focusing on this power would add to our knowledge of the connection between well-being and hope and roles of family in this endeavour.

Informing *Hope* research

The present research has shed light on the perplexing nature of hope as it is influenced through *other*. Researching the dynamic and multidimensional construct of hope as it is impacted through family interactions, enhances our understanding of hope as a "shared experience" (Nekolaichuk, 1995, p.1). *Meaning* was identified as central to impacting hope through family incidents in this study. These meanings were reflections of what was poignant in lives of individuals with HIV/AIDS. Therefore, considering context and particular experiences of persons living with HIV illness, in an attempt to understand how their hope may be engendered, emerged as a valuable approach.

This "particularizing" of hope is not to be confused with Dufault and Martocchio's (1985) use of the same concept in describing spheres and dimensions of hope. These authors asserted two spheres of hope, "generalized" and "particularized". Dufault and Martocchio applied these terms within the context of what was "hoped for". That is, whether what was hoped for was on a general or abstract level (generalized), or whether there was a specific object of hope (particularized). In this study, *particularized* hope referred to personal meanings generated from the context of one's life that reflected hope.

Directions for future *Hope* research

My wonderings involve:

- Can we incorporate the understandings from this research to refine a theory of hope (Hall, 1994; McGee, 1984; Nekolaichuk, 1995) or generate a new theory of hope and otherness?
- In regards to the relational aspect of personal hope, what are the meanings that are salient to the hope of persons living with HIV/AIDS in their interactions with individuals who are not considered as "family"?
- If inanimate entities can be characterized as family members, can these things also influence one's hope?
- Even if hope is particular and contextual, what is the universal experience of hope?

Relating the Research to Our Social World

The understandings as well as some of the study techniques used in this research can be effectively implemented for praxis in our social world. For instance, the broad range in definitions of *family* and significance of *meaning* to hope for persons living with HIV/AIDS can be incorporated into HIV/AIDS community endeavours. Overall, understandings from this research provide implications that foster more meaningful HIV/AIDS service delivery. Through this research, suggestions for improving the design and delivery of programs, as well as for the advocacy and support of persons and families affected by HIV/AIDS are proposed. The following is a brief discussion of implications for HIV/AIDS community health care and social service programs, educational interventions, and counselling endeavours.

HIV/AIDS Health Care and Social Service programs

From understandings gleaned from this research, five implications emerged for praxis in HIV/AIDS health care and social services. These implications are briefly outlined in the following section (in no particular order).

First, through this research practitioners working in the area of HIV/AIDS may be prompted to recognize the importance of hope in the lives of their clients. Thus, they may focus on developing wellness strategies that incorporate hope as an essential factor in promoting quality of life and well-being of persons with HIV illness.

Secondly, with emphasis on diversity of family structures, demonstrated as a reality through the preliminary study, program developers need to carefully consider whether their programs are sensitive to such diversity. By accommodating the subjectivity in family meanings, more appropriate and meaningful HIV/AIDS family programs can be implemented.

Thirdly, the previous implication for practitioners to consider the subjectivity involved in defining family, also signifies the potential benefits for health care and social service workers to use the family definition exercise in their work with clients. Inviting individuals to reflect upon and share their meanings of family, would allow practitioners to delve into who and what are important in their clients' life and allow the whole picture of *family* to be incorporated into care and support initiatives. Additionally, through utilizing the family definition exercise with clients, practitioners may be provided with insight that they themselves may be included as a member of their client's family. Thus, this recognition can help to encourage additional emotional support for these professionals. This recognition may also point to the depth of relationships that can develop between practitioners and clients.

A fourth implication generated from understandings of this research is that HIV/AIDS community based health agencies may benefit by providing services that employ a family-centred approach to care. Involving all members in the care of persons living with HIV/AIDS would enable those closest to individuals to assist with optimizing all treatments. An example from the United States, of one such agency that has adopted this perspective of family as a central unit of care, is the Center for Illness in Families in New Haven, Connecticut. Their mission is to provide "collaborative, family-centred approaches to psychosocial needs of families dealing with a range of chronic and life-threatening health problems in children and adults" (Rolland, 1994, p. xiv). Another example of such a facility is the Haemophilia Centre of the Royal Free Hospital in London, England which applies a "family systems" approach to treatment. This perspective of a comprehensive, family-centred approach to care was then adopted within other hospital departments in London (Miller, Goldman, & Bor, 1994). Health organizations within Alberta would benefit from examining and incorporating such a perspective for treatment and care of health challenged persons and their families.

Lastly, a suggestion for HIV/AIDS health care and social service endeavours is to ensure that funds are allocated for maintaining programs that facilitate connections among persons living with HIV/AIDS. As evidenced through this research, other individuals living with HIV/AIDS are integral within selected families of persons with HIV/AIDS. Facilitating and encouraging this support network is essential to well-being and hope of persons living with HIV/AIDS.

HIV/AIDS Educational interventions

The understandings from this research provide three valuable suggestions for HIV/AIDS educational interventions. For example, considering that both kinship and non-kinship relationships are evident in selected families of persons with HIV/AIDS, interventions that target *all* family members would be more meaningful.

A further educational strategy that would be appropriate to maintaining psychological health and wellness of persons living with HIV/AIDS is to educate around the importance of hope in the lives of individuals with this illness. This research promotes the view that family members need to be sensitive to their power to engender or diminish the hope of another; and to also be aware of hope as particularized.

Additionally, educating from real life exemplars, fosters a deeper understanding and compassion of the lived experiences of persons with HIV illness. In the scope of education, critical incidents of family interactions shared in the primary study, can be used during support groups among persons living with HIV/AIDS and their family members. This may help to educate on the significance of hope as well as foster feelings of normalcy and generate reflection into one's hope-influencing family incidents.

HIV/AIDS Counselling endeavours

In the era of HIV/AIDS, counsellors have been thrust into medical, social, and political systems that clients face (Dworkin & Pincu, 1993). In addition, uncertainties of HIV/AIDS and discrimination and prejudice associated with the illness further add to the complexity of counselling (Dworkin & Pincu, 1993). Counsellors can consider understandings from this research for their approaches in counselling. In the following discussion, four implications for counselling practice that emerged through this research are provided.

In 1981 when HIV/AIDS was first recognized as a world epidemic, psychological support for persons confronting HIV illness focused mainly on the individual (Bor, Miller, Goldman, & Kernoff, 1989). Since 1990 there has been a broadening of focus from individuals to concern for individuals as well as impact of HIV on family (Bor et al., 1989). Consistent with this broadening of focus, Dworkin and Pincu (1993) asserted that HIV/AIDS requires counsellors to not only counsel clients but also significant others affected by the illness. Thus, counsellors working in the area of HIV/AIDS would benefit from utilizing a family systems approach to counselling persons living with this illness. Considering the family system within counselling may prompt clients to view their challenges in context of their family. The family may assist in identifying and mobilizing resources (Miller et al., 1994). This approach would also allow counsellors to treat each client in the unique context of their family network and involve members within the care of these individuals.

Employing the family definition exercise, developed within this research, would assist in a family-centred approach to counselling. The construction of family genograms within counselling sessions may help to identify non-traditional relationships existing in families (Miller et al., 1994). Additionally, by gaining insight into persons and types of relationships involved in the client's life, counsellors may be better equipped to facilitate appropriate family support and bereavement services. Furthermore, allowing the client with HIV/AIDS to discuss and update his or her family genograms on a regular basis, can assist the counsellor to monitor changes happening in the client's family life. Miller and Bor (1988) asserted that the changing position of the individual in the family, needs to be taken into account to offer the most effective counselling services.

The third implication for counsellors to consider in their practice to employ the critical incident technique with clients to recount salient experiences. CIT is a valuable counselling tool. This implication emerges from the richness of family incidents generated from use of this method within the present research. This view is likewise supported by the literature (Woolsey, 1986). Inviting clients to specifically share critical incidents of experiences, generates self-reflectiveness in clients, and allows the counsellor to further understand the context of the client's life.

The fourth implication for counsellors working in the area of HIV illness is that employing a social constructivist view to consider families and adopting a human ecological approach to facilitate family members to be sensitive of their impact on the hope of persons with HIV/AIDS would be useful. Through the human ecological perspective, counsellors can encourage family members to interact with persons who are living with HIV/AIDS in an authentic manner which is sensitive to the context of their lives and their hope. Edey and Jevne (1997) discuss the efficacy of implementing a "hope-focused" approach to counselling.

Summary

This research gave increased breadth to the diversity in subjective distinctions of "family" and poignancy of *meaning* for hope in family incidents. It has also served to further illuminate the construct of hope by investigating it's influence through *others*. As we come to regard numbers of persons who have been diagnosed with HIV/AIDS, lives behind the statistics have been captured on a small, but meaningful scale in this research. Some accounts of hope impacting family incidents along with "family" perspectives of Susan, Trevor, Lynn, David, Howdy, and Tom were shared in this research and gave voice to these individuals who are "walking the walk". This research demonstrates that hope is inextricably interwoven within one's psychological, spiritual, and social existence. Family members are central forces in the genesis of this hope. They are significant partners in the dance between life and death and the hope that evolves between these two life events.

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EPILOGUE

CLOSING THOUGHTS

During the course of conducting this research, I have been profoundly affected by the participants of the research and by the research itself. I will share some of these influences as my closing thoughts for this thesis.

The ways that I have been influenced by individuals involved as participants in this research are difficult to articulate. I can recall those times when my perseverance of this research waned. I thought about my discussions with these individuals-- when they shared parts of themselves with me-- and my motivation for continuing the research redoubled. I feel extremely privileged that they allowed me to listen and document their stories of hope interactions and to capture their perceptions of family. Through my connections with them as a researcher, my own hope has deepened. I have also been affected by one participant in this research who shared that she considered me as a member of her selected family. This inclusion warms my soul and I feel greatly honoured. I am further sensitized that we-- whether as a "friend", a "family of origin member", a "health professional", or even a "researcher"-- are all partners in this journey through life and thus play vital roles in each other's lives and to each other's hope.

Conducting this research has facilitated my awareness of the true breadth in the variety of "family" delineations, as well as the complexity involved in the relational aspect of hope. My future endeavour as a researcher and counsellor in the area of health and illness has been informed through this research. I hope to remain attuned to persons' selected families and to remain considerate of my relation to others' hope. These awarenesses will assist my future endeavour as a hope-facilitating and hope-intentional counsellor working in the area of health and illness.

Most acutely however, this research has affected me on a personal level, I notice more of my interactions with others: This assists to engender the wholeness of my own hope. Overall, I have become aware of my ability to influence the hope of others and the significant difference that being hope-intentional can make in my life. I am also alerted to not only those interactions with persons who are living with HIV illness, but also those with my own family, my friends, as well as those with strangers. I am mindful of the power of even the smallest gesture to potentially influence another's hope. I am further informed of the profound connection that exists between human beings, and I have a deeper awareness that we are all networks to each other's hope.

APPENDIX A
Participant Information Sheet

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

Researcher:	**Supervisor:**
Gina Wong-Wylie, Graduate Student, Department of Human Ecology, University of Alberta, Assiniboia Hall 3-67, Telephone: 492-5141	Dr. Maryanne Doherty-Poirier, Assistant Professor, Department of Human Ecology, University of Alberta, Telephone: 492-5769

Participant Requirements:

1. Informants should be male or female (18 years or older).
2. Participants should be comfortable discussing aspects of his/her HIV illness involving interactions with family members.
3. Informants will also be available for a meeting of 1-2 hours and at least one subsequent interview meeting of less than 1 hour (occurring within a two week time frame of the initial meeting).
4. Participants will sign an informed consent form.

If you are interested in participating in this research, please inform the researcher and a meeting will be arranged at your convenience. If you so choose, you may begin your participation in this study immediately (in the case where you are provided this information sheet during a formal meeting with the researcher). During the first meeting, you will be asked to complete a demographic sheet (written or verbal), a family definition exercise, and the recollection exercise where you will discuss (written or verbal) approximately 3 interactions that you had with family members that you feel influenced your hope. All interviews will be audio-tape recorded. The tapes, verbatim transcripts, and all exercises you have completed will be kept in a confidential, locked filing cabinet and destroyed in 5 years time. Strict procedures will be undertaken to ensure your confidentiality. No identifying information (names, etc.) will be used in any documentation of the research. You will be given a code number and a pseudonym. You may refuse to answer any questions and terminate your participation at any time before or after involvement in the study without any consequence (all information you provided will be destroyed).

Contact Gina Wong-Wylie at 492-5141 or Dr. Maryanne Doherty-Poirier at 492-5769 should you have any questions or concerns.

APPENDIX B
Written Informed Consent Form

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

Principal Investigator:	**Supervisor:**
Gina Wong-Wylie, Graduate Student, Department of Human Ecology, University of Alberta, Assiniboia Hall 3-67, Telephone: 492-5141	Dr. Maryanne Doherty-Poirier, Assistant Professor, Department of Human Ecology, University of Alberta, Telephone: 492-5769

Research Purpose:

The purpose of this research project is to investigate interactions with family members that influenced the hope of persons living with HIV/AIDS.

When participating in this project, you will be asked to complete a family definition exercise and discuss/write approximately 3 interactions that you had with family members (based on your own definition of the family). These accounts are of those that you feel influenced your hope in *some* way. Subsequently, I will talk with you to further understand your perceptions of each interaction with your family members. The information that you share will be used for research and educational purposes only and may be presented at professional conferences, or workshops, and through published works. This information will be kept in a locked, confidential filing cabinet for 5 years. After this time, all materials will be destroyed. Files will be identified by code numbers only; no names of persons or identifying information will be included.

As a study participant, you are being asked to be involved in four specific ways:

1. To be available for a meeting of 1-2 hours and at least one subsequent interview meeting of less than 1 hour (occurring within a two week time frame of the initial meeting).
2. To complete a background sheet about yourself (detailing information about your age/ sex / employment / income / stage of HIV illness, etc.).
3. To complete an exercise about the topic of family.
4. To write/discuss specific times when you had an interaction (conversation or meeting) with a family member that you felt had great impact on your hope.
5. To be involved in at least one subsequent interview that is less than one hour. During this interview, you will be asked to discuss hope and the experiences which you wrote about. The interview will be audio-taped and later transcribed verbatim by the researcher.

Your involvement as a participant in this study is your own choice. This means that you:

* May refuse to do any writing involved with the research / you may opt to audio-record exercise responses and verify the written re-storying of your shared accounts in a subsequent meeting.
* May verify your transcriptions and representations of your experiences at least once to ensure their accuracy.
* May refuse to answer any question(s) and/or discuss any topic(s) during the interview.
* May stop the interview at any point in time.
* Will be given potential counselling resources and assistance will be provided by the researcher in contacting professional counsellors if you desire.
* Can withdraw from the research project at any time either before or after consent of participation, either by

informing the researcher or the thesis supervisor (Dr. Maryanne Doherty-Poirier). The information that you have given the researcher prior to your withdraw will be used only with your permission. If you decline this permission, the researcher will destroy all written materials and erase audio-recordings of interview conducted and destroy all verbatim transcripts of the interview.

The researcher may use anonymous excerpts from writings and interviews when presenting the research. These accounts of the study will not include your name; rather, you will be identified by a fictitious name which you may choose or will be assigned at the discretion of the researcher.
As a participant of this study, you will have a chance to ask any questions concerning this study. These questions will be answered to your satisfaction prior to beginning and throughout your involvement in the study.

There are no known risks to individuals participating in this study. It may, however, be emotional to recount experiences related to your illness as well as interactions with family members. Although there are no known direct benefits of involvement in this study, it is anticipated that you may find it helpful talking to the researcher about your experiences with family members and how these interactions have influenced your hope. By being involved in this study, you may help to emphasize the importance of family by creating an understanding of your interactions with family members that have enhanced or sustained your hope.
There is no financial compensation to informants who decide to participate in this research project.
I, ________________________certify that I have read (or have been read) and fully
(Print Name)
understand the above consent form. I agree to participate as a volunteer for this research project.
I have a copy of this entire consent form to keep.

____
(Participant's Signature)

____
(Signature of Witness)

____
(Date)

____
(Researcher's Signature)

APPENDIX C
Demographic Sheet

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

Code #_________
Special Instructions: (e.g., not phoning after certain hours)
____
____

General Information:
Age_______Sex_______
Ethnic background (e.g.,Irish)____________________
First Language_____________________
Languages Spoken___________________________________
Place of birth______________________
Highest education obtained_________________________

Current Partner Identification:
Single___ Married___ Common-law____ In committed relationship___
Separated__ Divorced__ Other (specify)_______________

Sexual Orientation:
Bisexual___ Heterosexual___ Homosexual___ Other (specify)___________

Sources of Income:
AISH___ Long term disability___ CPP___ Social Assistance___
Part-time employment___ Full-time employment___
Volunteer_____ Other (specify)__________________________

Levels (include all sources):
less than $5 000___ $5 000- $10 000___
$10 000- $20 000___ $20 000- $50 000___
more than $50 000___ not specified___

Number of children:___ Age(s):___________ Sex:_________
Number of brothers: ____ Number of sisters: ____ Are your parents still alive? ____

Illness:
Date of HIV diagnosis______________
Opportunist Infection diagnosis____________(put N/A if not-applicable)
In your view, what is the status of your health at this time:
(Please check one)
EXCELLENT___ GOOD___ FAIR___ LESS THAN FAIR___

Please give a brief description of yourself:

APPENDIX D
Family Definition Exercise

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

(Written/or Audio-recorded exercise)

(1) Please identify (You are not required to give names):

(a) Who is in your family of origin. Please draw a diagram with the paper and markers supplied.

(b) Who do you consider to be in your family with regard to the management of your health? Please draw a diagram with the paper and markers supplied.

(2) Based on your above response, please give reasons as to why you selected those individuals in your *current family* and the *family that influences your health* (this may be a list of important factors that are necessary for an individual to be part of your family or the questions you asked yourself to arrive at this family).

(3) Do the family members involved in the management of your health live in the same house? city? province? country?

APPENDIX E

Critical Incidents Accounts: Recollection Exercise

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

As descriptively as possible, please recount 3-5 interactions you had with a family member (based on your own meaning of family), which influenced your hope in some way. The purpose of this exercise is to recall specific interactions that were powerful influences on your hope, and to understand what factors contributed to this impact on your hope. There is no right or wrong procedure: use your way to best accomplish this exercise. The definition of "hope" is based on your own concept. You may wish to consider the following example. Both recount the same incident, however the latter is written in the present tense and captures feelings and depth of the situation.

(1) "When I was eight I was on a beach with my two older brothers one bright sunny morning. We were barefoot and walked backwards so that we could look at our footprints. It was cold and windy so we stuffed our hands into our pockets. I kept thinking how much I wanted to be big like them."

(2) "I am eight years old and I feel small in comparison to my two older brothers. I can feel the wet, cold sand beneath my toes as we walk. We walk backwards, looking at the prints we make and our shadows. My shadow is the smallest. My next oldest brother turns to me and gives me the biggest smile. It makes me feel warm inside. A deep breath brings forth the cool air into my lungs and the strong scent of the sea. I see my brothers stuff their hands into their pockets as though they are cold. I do the same. Perhaps my hands are also cold, or am I just copying them?"

Please use both sides of the sheets of paper INCLUDE: a) Page number
b) Your code number
c) Recollection Number (#1, #2, #3)

APPENDIX F

Interview Guide

Research Study Title:
Family Incidents: Impacting Hope of Persons with HIV/AIDS

- Repeat the date, time, and place, participant code number, interview number, etc.
- Can you tell anything more about who you consider to be in your family (refer to Family Sheet)?
- Is there anything that I should be aware of that influences your definition of the family?
- How did you feel recalling those interactions with family members?
- Is there anything you can tell me to further capture the interactions that you have recounted?
- Can you give me a description of what you think an interaction with a family member that enhances or sustains your hope would be like?
- Do you feel that the means through which the family members you discuss suspect that you became HIV positive affect the way that they interact with you? How?
- Is there anything that you can tell me that can allow me to understand your hope story further?
- Complete this sentence: "With regard to my health and illness and interactions/relationships with family members, hope is ______________? "With regard to my health and illness and interactions/relationships with family members, hopelessness is ______________?
- Is there anything else that I need to know about you to help me understand more about how your hope may be influenced through interactions with family?
- Is there any part of the interactions between yourself and the family members that you've discussed that you would like to comment on or that we have missed?
- For each incident told, what was the approximate length of time of the interaction lasted? At what point of time in your stage of HIV did the interactions take place?
- Were the two of you alone during each interaction?
- Is there something about the HIV experience that you think makes interactions with family members especially significant, or would you feel the same if you had another illness (Cancer)?
- In each recollection, I would like to get a sense of who you are talking about when you are talking about your family member. What characteristics describe them? What is their demeanour? What gestures/actions did the individual use? Describe the environment in which the interaction occurred? What was the general mood of the time?
- Describe your past relationship with each family member that you discuss in your interactions.
- What were some of the actual words spoken between the two of you? What impression did these words (and actions) leave on you?
- Of those family members that you discuss, what understanding did they have of your fears and your hopes?
- What words did or do you want to hear?? Were you able to communicate what you wanted?
- Do you discuss the impact that your family has on your hope with anyone?

Concluding Remarks:

> Conclude interview with a statement about getting in touch if something in the interview comes up and they would like to change or add something.

> Make it clear for them to get in touch with me and ask if I can get in touch with them for verification

> Ask if they know anyone else who would like to get involved, encourage them to let them know about it. Thank them.

***Note:** This interview guide is not to lead discussion. Interviews will unfold at pace and guidance of participants.

APPENDIX G
Resource Sheet for Participants

CALGARY
STD Clinic
319-2nd Ave. S.W.
Telephone: 297-6562

EDMONTON
STD Clinic
3rd Floor, Executive Bldg.
10105-109 Street
Edmonton, Alberta
T5J 1M8
Telephone: 427-2834

FORT MCMURRAY
Health Unit
9921 Main Street
Telephone: 743-3232

* For toll-free access, refer to your AGT telephone directory for the listing under Government of Alberta Information and RITE line assistance. Ask for the number for the STD clinic closest to your area as listed above. For STD/AIDS information, call the toll free **STD/AIDS Information Line at 1-800-772-2437**.

AIDS NETWORK OF EDMONTON SUPPORT SERVICES
#201, 11456 Jasper Avenue
Edmonton, Alberta
Telephone: 488-5742

LIVING POSITIVE SOCIETY PEER COUNSELLOR SUPPORT
#201, 11456 Jasper Avenue
Edmonton, Alberta
Telephone: 488-5768

KAIROS HOUSE I
Telephone: 454-2906

KAIROS HOUSE II (families)
Telephone: 473-5957

24 hr. CRISIS (Suicide/Distress Line)
Telephone: 428-HELP (4357)

EMERGENCY SOCIAL SERVICES
Telephone: 427-3390

Mental Health Therapists
427-4449

University of Alberta Hospital
492-9503/ HIV Psychologist

UofA Hospital
492-6098/S.Worker

Gina Wong-Wylie

Curriculum Vitae

PERSONAL INFORMATION

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Date of Birth: September 25, 1971

EDUCATIONAL BACKGROUND

September 1997: Admitted to the University of Alberta, Ph.D. program in the department of Educational Psychology, Counselling.

1996-1997: Completed a M.Sc. at the University of Alberta in the department of Human Ecology, Family Ecology & Practice.
Thesis title- Family incidents: Impacting hope of persons with HIV/AIDS.

1989-1994: Completed a B.A. at the University of Alberta in Linguistics.

REFEREED PUBLICATIONS

Wong-Wylie, G., & Jevne, R. (1997). Exploring hope: Interactions between physicians and HIV seropositive individuals. Qualitative Health Research, 14, 31-49.

Published Abstract

Wong-Wylie, G., & Jevne, R. (1996). The influence on hope of physician/patient interactions with persons living with HIV/AIDS, International Journal of Psychology, 31, 346.

Manuscripts

Wong-Wylie, G., Doherty-Poirier, M., & Kieren, D. (in-progress). Who's in and who's out: The selected families of persons with HIV/AIDS.

Wong-Wylie, G., Doherty-Poirier, M., & Jevne, R. (in-progress). Interactions with family members: Impacting hope of persons with HIV/AIDS.

REFEREED CONFERENCE PRESENTATIONS

Wong-Wylie, G., & Doherty-Poirier, M. (1997). Created families: Perspectives from persons living with HIV/AIDS. Learned Societies Conference, Canadian Association for Research in Home Economics, St. John's, Newfoundland.

Wong-Wylie, G., & Doherty-Poirier, M. (1997). The critical incident technique (CIT) and family interaction research. Learned Societies Conference, Canadian Association for Research in Home Economics, St. John's, Newfoundland.

Wong-Wylie, G., & Doherty-Poirier, M. (1997). Creating families of support: Perspectives from persons with HIV/AIDS. Canadian Home Economics Association Conference, Victoria, British Columbia.

Wong-Wylie, G., & Jevne, R. F. (1996). The influence on hope of physician/patient interactions with persons living with HIV/AIDS. XXVI International Congress of Psychology, Montreal.

Submitted Abstract

Wong-Wylie, G., Doherty-Poirier, M., & Jevne, R. (in-review). Hope influencing: A critical incident study of interactions between persons with HIV/AIDS and family members. Fourth International Qualitative Health Research Conference, Vancouver, British Columbia.

NON-REFEREED PUBLICATIONS

Wong-Wylie, G. (1997). Instilling hope: The patient-doctor relationship. V.I.P., AIDS Network of Edmonton Newsletter, June.

Wong, G. (1995). Smart sex: Using your brain to protect your body. Canadian AIDS, VIII, 4-5.

AWARDS

1997-1998:	*Honorary University of Alberta Ph.D. Scholarship (renewable)*
1997-1998:	*Province of Alberta Graduate Fellowship*
1997:	*Province of Alberta Graduate Scholarship*
1997:	*Mary A. Clarke Graduate Memorial Scholarship*
1996-1997:	*Walter H Johns Graduate Tuition Scholarship*
1996:	*Mary Louise Imrie Graduate Student Award*
1996:	*Doris Badir Graduate Research Fellowship*

MEMBERSHIPS

- Canadian Home Economics Association (CHEA)
- Alberta Society for the Promotion of Sexual Health (ASPSH)
- Academic Women's Association, UofA (AWA)

OTHER CREATIVE AND SCHOLARLY ACHIEVEMENTS

- Developed a two day workshop for the Hope Foundation of Alberta, **Exploring hope workshop: "Women Living HIV Positive"**.

- Co-facilitated **Exploring Hope Workshop** to Canadian Federation of University Women at their Annual Provincial Meeting of Executives in Alberta.

- Developed/implemented a Youth HIV/AIDS Public Health Promotion campaign entitled, **Using Your Brain to Protect Your Body**, Alberta.

- Facilitated a graduate seminar entitled, **Coping and Problem Solving: Single mothers living with HIV/AIDS and dependent children**, University of Alberta .

- Invited lecturer for Fam 412, **Hope for families' in the age of HIV/AIDS**, University of Alberta, HECOL 602, **The publishing process: A students' perspective**, University of Alberta.

- Department of Human Ecology graduate student representative, **FGSR Council**, and Graduate student representative, **FGSR Appeals committee**, University of Alberta.

- Trained as a **Peer Educator**, a **Student Orientation Services** (SORSE) leader, an **AIDS Network of Edmonton** volunteer, in *ethical* and *bereavement* issues in support of individuals living with HIV/AIDS, and certified as a **Distress Line Listener**, The Support Network.