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THE IMPACT OF AIDS ON THE LIFE CYCLE OF YOUNG GAY MEN

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ABSTRACT

Objectives: Explore and describe the impact of premature life-threatening illness, stigma, multiple loss of significant others, decreased vocational choice and mobility, and decreased financial security among young gay men living with AIDS. It was hypothesized that young gay men with AIDS and the elderly experience similar physical, social, and psychological changes, but the cognitive adaptation to these changes are hindered by the non-normative timing of these events.

Methods: Thirty-two self-identified gay men with AIDS between the ages of 22 to 44 years were recruited from an out-patient clinic in Montreal. These participants were asked to complete a comprehensive questionnaire, which assessed the respondent's daily stress, impact of HIV, health-related quality of life, ways of coping, multiple loss, dependency on informal and formal supports, and preparation for death. Quantitative methods were used to analyse the data.

Results: The hypothesis was confirmed. Respondents reported relatively low levels of health-related quality of life, significant concern over health and financial security, considerable multiple loss, increased dependency on informal and formal supports, proportionally greater use of active coping strategies, and significant concern about discrimination.

Conclusions: A comprehensive method of intervention which addresses all of the biopsychosocial aspects to care is proposed. It is suggested that a coordinated multidisiciplinary approach to clinical and research endeavors should be adopted to address the multidimensional obstacles facing young gay men with AIDS.

RÉSUMÉ
IMPACT DU SIDA SUR LE CYCLE DE VIE DES JEUNES GAYS

Objectifs: D'évaluer et de décrire l'impact d'être atteint d'une maladie mortelle. aussi stigmatisée que peut l'être le sida, pertes multiples des personnes significantes. moins de choix et mobilité occupationel, et moins de sécurité financiel chez les jeunes hommes gays séropositifs. L'hypothèse était que les jeunes hommes gays qui l'on a diagnostigué le sida et les personnes âgées ont les expériences physiques, sociales. and psychologiques similaires, mais l'adaptation cognitif aux changements est encore plus difficile à cause des événements prématurer.

Méthodes: Trente-deux hommes gays identifié par seul même qui l'on a diagnostigué le sida et âgés de 22 à 44 ans étaient choisi d'une clinque médicale pour les patients externes à Montréal. Les participants été demandé de complèter un questionnaire compréhensif qu'évalue leurs tracas/facteurs de stress et plaisirs/événements positifs. impact due VIH sur leur vie sociale et personelle, leur bien-être physique et psychologique, stratégies d'adaptation, leur pertes multiples, leur dépendence sur les supports institutionelles et familiales, et leur préparation pour le mort. Les méthodes quantitatives étaient utilisé pour l'analyse des résultats.

Résultats: L'hypothèse était confirmé. Les respondents décriraient un niveau de bien-être physique and psychologique relativement bas. concernes de santé physique et finances étaient significantes. les pertes multiples des personnes significantes étaient considérable. et dépendence sur les supports institutionelles et familiales était élèver. proportionellement plus des stratégies d'adaptation actives étaient utilisé. et une concerne significante au discrimination étaient démonstrer.

Conclusions: Une méthode d'intervention compréhensive est proposer pour s'addresser à touts les aspects biopsychosocial de soins. Il est aussi suggérer q'une approche multidisiciplinaire soi adopter pour mieux évaluer les problèmes de cliniques et recherches qui sont directements responsives aux besoins multidimensiels des jeunes hommes gays séropositifs.

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1.0
INTRODUCTION

The onset of the AIDS epidemic in the early 1980's forced health care professionals and society to simultaneously confront issues of entrenched discrimination and devise new ways of providing compassionate care for those infected and affected by the disease. The stigma ascribed to persons living with AIDS (PLWA) is overwhelming and creates a lonely state of social isolation. The PLWA must struggle with isolation, structural discrimination, and emotional issues associated with a life-threatening illness. "The terror this disease engenders affects every aspect of the person's life and results in serious personal, social, occupational, and financial difficulties" (Dane, p. 305, 1989).

For many persons living with HIV/AIDS (PLWHA), the disease is incorporated into their personal identity, and becomes difficult to separate from their sense of self. An understanding of the subjective and collective experience of PLWHA is essential for devising new prevention strategies and developing dynamic interventions that are responsive to the needs of persons living with a presently incurable disease.

The widely acknowledged tragedy of HIV/AIDS is that its victims are impaired by physical limitations, and social and psychological stresses at such a young age. The loss of large numbers of people in the most productive period of their lives is felt by PLWA, their partners and families, and society. It is estimated that the cumulative cost to Canada in lost productivity due to AIDS disability and death will be $30-billion by the year 2010 (Gibbon, 1996). The economic repercussions of AIDS is too extensive to be exmained in its entirety in this present discussion. However, the economic indicators often provide valuable ammunition to compel politicians to allocate the necessary resources for continued research, and implementation of prevention and intervention programs.

1.1 RESEARCH ISSUE

In order to improve the biopsychosocial care of young gay men living with AIDS, it is necessary to evaluate how this disease impacts the normative transitions and expectations in the person's life cycle. By assuming a life-course perspective, the analysis of the experience of young gay men living with AIDS avoids becoming too narrowly defined by specific pyschological and social theories, and hence will seek to provide a more comprehensive paradigm.

The majority (78.7%) of those infected with HIV and dying of AIDS in Canada continue to be men who have sex with men (MSM) (Health Canada, 1996). This demographic trend is evident in the composition of HIV/AIDS clinics throughout the country. This study is concerned with the impact of AIDS on the gay community. This focus was a function of my personal and professional interest in the life cycle disruptions experienced by young gay men living with AIDS, and the more logistical concern of accessibility to adequate numbers of participants for the research project. The emphasis on gay men does not seek to diminish the devastating impact of HIV on Third World nations, women, children, and heterosexual men.

The following paper examines whether the premature exposure to AIDS among young gay men challenges their expectations of current and future normative life cycle experiences and phases. It is believed that this early encounter with severe illness, stigma, multiple loss of significant others, decreased vocational choice and mobility, and decreased financial security, creates a source of considerable stress and anxiety. As we develop through life, and age into the latter part of our life cycle, we can expect deteriorating physical health, increasing cognitive limitations, multiple loss of significant others, fixed incomes due to retirement from the work force, and reminescence/life review due to anticipated illness and death. However, confronting a life-threatening illness, such as AIDS, as a young adult demands flexible coping skills to adapt to the accelerated changes normally experienced more gradually by older adults.

1.2 OBJECTIVE OF RESEARCH

This paper includes a comprehensive analysis of the interplay between the biological, social, and psychological aspects to AIDS in an effort to address the multi-faceted dimensions of the impact of AIDS on young gay men. These three components to AIDS will serve as a parallel outline for an examination of the experience of older adults in the literature review.

It is believed that AIDS forces young gay men to address developmental issues prematurely, which produces greater psychological distress and taxes their coping resources. Whereas older adults have had a lifetime of opportunity and experience to adapt their coping skills and psychological perspectives to accept impending physical decline, younger adults do not. It is believed that young gay men living with AIDS experience similar physical challenges to older adults, but the psychological, familial, and social reactions to physical ill health and the prospect of death are much different due to non-normative expectations.

The analysis of the literature will be followed by a review of the research hypotheses and the methodology of the study. This cross-sectional study uses quantitative methods to analyse the data accumulated from thirty-two patient questionnaires. The analysis of research data is grouped into descriptive analysis and analysis of relationships. Finally, the clinical and social policy implications are discussed in the context of summarizing the findings.

1.3 EPIDEMIOLOGY

The epidemiological data are essential for documenting the different trends in the transmission of HIV and evaluating the impact of prevention efforts targeted at certain sub-populations. The sociodemographic profiles of PLWA permits social researchers to identify sub-populations requiring continued attention and those groups lacking adequate social and financial resources. This epidemiological analysis seeks to portray the current AIDS epidemic at a global and local level, and also seeks to justify my selection of young gay men as the research focus of this project. It is important to acknowledge that epidemiological findings in the field of HIV are distorted and often grossly underestimated due to the shame, discrimination, and delayed reporting associated with the disease.

AIDS has devastated many communities in the world, which have already been plagued with poverty, discrimination, and disease. “AIDS is not an equal opportunity disease. It systematically exploits those already experiencing subjugation” (Aggleton, June 1997). The global context of HIV/AIDS paints a very different demographic trend than does the local context of Canada. Table 1.1 portrays the distribution of AIDS cases across the world (Mann & Tarantola, 1996). The most important element of this table is the stark over-representation of AIDS cases in Sub-Saharan Africa (81.1% of the 10,375,000 total) of which there is almost an equal distribution of cases between men and women. In contrast, North America only represents 4.3% (449,000) of the total world AIDS cases and men constitute 84.6% of this amount. In summary, AIDS in the world is primarily a heterosexually transmitted disease, however it continues to disproportionately affect men who have sex with men (MSM) in most industrialized nations in North America and Western Europe.

Table 1.1
Cumulative AIDS Cases for the World as of January 1, 1996

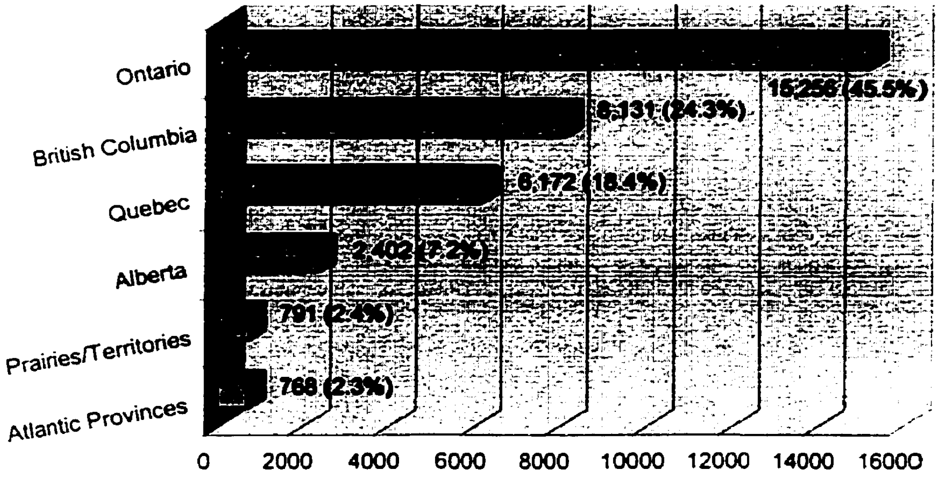
	Adults	Men	Women	Children	Total
North America	443,000	380,000	63,000	7,000	449,000
Western Europe	193,000	161,000	32,000	3,000	195,000
Oceania	9,000	8,000	1,000	<1,000	9,000
Latin America	518,000	414,000	104,000	62,000	579,000
Sub-Saharan Africa	6,367,000	3,032,000	3,335,000	2,046,000	8,413,000
Caribbean	133,000	80,000	53,000	27,000	160,000
Eastern Europe	7,000	7,000	<1,000	<1,000	7,000
SE Mediterranean	12,000	10,000	2,000	<1,000	12,000
Northeast Asia	12,000	10,000	2,000	<1,000	12,000
Southeast Asia	332,000	221,000	111,000	206,000	537,000
TOTAL WORLD	8,024,000	**4,321,000**	3,703,000	2,351,000	**10,375,000**

Mann & Tarantola (1996)

The face of AIDS in Canada is somewhat different than that of the rest of the world. Similar to the global presentation, the majority of HIV cases are largely (95.4%) concentrated in major urban centers (i.e., Toronto, Vancouver, Montreal, and Calgary) (Health Canada, 1996). Table 1.2 on the next page illustrates the over-representation of AIDS cases in Eastern Canada (64.2% of the 33,520 total). The HIV-positive test results for Quebec are believed to be under-estimated due to different methods of reporting. However, recent research in Vancouver shows alarming epidemic levels of HIV transmission among IV drug users (Hogg, 1997). The HIV prevalence rate in Canada is 1/800 versus 1/380 for the United States (Archibald, 1997).

The gay communities of North America have suffered massive losses of young men. Death due to AIDS in the United States constituted 3.0% of total deaths in 1994, however, "in the 25 to 44 age group, the biggest single killer is now AIDS," and more so among men (Economist, p. 144, 1996). Health Canada (1997) reported that MSM represent 78.7% of the total AIDS cases for adult males in Canada (n=13,739). The table in Appendix 1 portrays the distribution of AIDS cases by exposure category and year of diagnosis for adult males between 1979 and 1997. It demonstrates the following trends in the incidence of AIDS in Canada: (1) a gradual decrease among gay men (81.1% to 71.4%); (2) an increase among intravenous drug users (2.0% to 14.3%); (3) an increase among persons from endemic countries (3.1% to 7.1%), and; (4) a decrease in health-related exposures (blood transfusions, etc.). Despite these important trends, the majority of PLWA in Canada continue to be gay men.

Table 1.2
Cumulative 10-Year HIV+ Reports in Canada, by Province (1985 to 1994)



Health Canada (1996)

The finding that 69.5% of gay men living with HIV in Canada are between the ages 20 to 39 years reflects the 'young' characteristic of HIV-affected populations (Health Canada, 1996). Table 1.3 below presents the age distribution of HIV cases by exposure category. This disease continues to predominantly affect people in the prime of their life. The delay in HIV reporting also implies that many of these figures would be even higher for the younger generations.

Table 1.3
Cumulative 10-Year (November 1, 1985 to December 31, 1994) HIV+ Test Reports in Canada, by Age Group and Exposure Category

	Exposure Category									
Age Group	MSM	MSM/ID	IDU	HC/E	B/B	Perinatal	Other	Unknown	Total	%
<15	9	0	3	3	68	94	13	245	435	1.3
15-19	94	9	26	33	39	0	12	268	481	1.4
20-29	3,167	146	378	298	151	44	145	4,970	9,259	27.6
30-39	4,222	116	555	341	119	3	204	6,810	12,370	36.9
40-49	1,859	29	173	138	70	1	68	3,155	5,493	16.4
50+	576	3	17	58	116	1	39	1,246	2,056	6.1
Unknown	693	18	59	55	82	8	49	2,462	3,426	10.2
TOTAL	**10,620**	**321**	**1,211**	**926**	**645**	**111**	**530**	**19,156**	**33,520**	-
TOTAL (%)	**31.7**	**1.0**	**3.6**	**2.8**	**1.9**	**0.3**	**1.6**	**57.1**	-	**100.0**

Health Canada (1996)

The preceding review of the epidemiology of HIV/AIDS was intended to provide a general overview of the trends in transmission across different nations, exposure categories, genders, and ages. HIV continues to present a significant risk to young gay men between the ages of 20 to 39 years in Canada, and despite gradual decreases in HIV incidence among MSM since 1992 (Health Canada, 1997), the gay community persists with its disproportionate representation in HIV clinics across the country. This persevering trend is one the reasons for dedicating this research to young gay men.

2.0
LITERATURE REVIEW

2.1 LIFE CYCLE THEORIES

(a) Sociological versus Psychological Approaches

There are two principal paradigms of development over the life cycle: (1) the psychological (intrapsychic) approach, which was popularized by the life span perspective, and (2) the sociological approach embraced by the life course perspective. Whereas the former regards development over the life span as primarily individual psychic phenomena, the latter emphasizes the change of the social person according to age-related transitions, which have been "socially created, socially recognized, and socially shared" (Hagestad & Neugarten, 1986). As previously mentioned, this paper will integrate the two paradigms to offer a more holistic examination of life cycle development. The sociological dimension of life cycle frameworks will be addressed first in order to present a more macro picture of development. The psychological paradigm is examined in the following section on *Identity Formation.*

(b) Life Course Perspective

The life period is divided into age systems, which create predictable and socially recognized "turning points." These socially constructed age-related periods provide us with a general idea as to what we can expect in terms of experiences, roles and status. Age-related norms also act as social controls (Neugarten, 1976). "An early socialized and thus highly normative system of values, estimates of life span changeability, and their timings are influenced by accumulated experience and knowledge across the life span" (Heckhausen, Dixon, & Baltes, p. 119, 1989). The social construction of normative expectations is deeply rooted in historical, political, and social time, and thus the age periods of the early 1900's are much different than current life stages. The changing roles of women in society, the gay rights movement, and the extended life span and quality of life due to improved medical technology are just some of the factors influencing the perception of the age-appropriateness of behaviour and events. For example, old age was defined as 60 years and over in the literature prior to 1980, whereas current research categorizes old age into two groups defined by physical limitations. Age stages are usually defined by changes in family roles (i.e., marriage, widowhood, etc.) and economic changes (i.e. entering work force and retirement) (Neugarten, 1976; Newman & Newman, 1995).

There seems to be general agreement among theorists that there are six major phases of the life span: childhood (including infancy), adolescence, young adulthood (22 to 44 years), middle adulthood (45 to 64 years), and old age (65+ years). Old age is often broken down into the "young old" and the "old old" to distinguish between the diverse experiences of persons in this age range (Skolnick, 1986; Arnstein, 1984).

Young Adulthood

This present research study is concerned with men in young adulthood. This period of early adult life is defined by several biopsychosocial experiences and expectations. First, it is expected that during this time the body is in peak condition with few ailments and chronic complaints. Health-relevant goals and preventive efforts become more salient over the latter part of the adult life span. Young adults fear the "possible selves" of old age, which include being too ill to maintain independence, and losing mental capabilities (Hooker & Kaus, 1994) Younger male adults, in particular, perceive the young body as better able to deal with illness, toxins, and physiological abuse from lifestyle choices (Backett & Davison, 1995).

Second, many young men believe that a future orientation and concern about lifestyle patterns and chronic illness is boring, and "un-youthful" (Backett & Davison, 1995). Third, this period is associated with establishing an occupation, which is consistent with adult interests and values (Glueckneuf & Quittner, 1983; Levinson, Darrow, Klein, & Levinson, 1976; Turner & Helms, 1976). During this stage, adults devote a good portion of their disposable income to 'having a good time,' such as frequent social excursions or large purchases (e.g. a car). Many young men have unrealistically high expectations of high economic earnings, which may be difficult to achieve (Mumford, 1977). Fourth, the attainment of interpersonal intimacy through a relationship based on similarity, reciprocity, and compatibility is considered to be a hallmark of early adulthood (Lowenthal & Weiss, 1976).

Fifth, one study (Carstensen & Turk-Charles, 1994) analysing the salience of emotion across the life span noted that young adults reported more sensation seeking, emotional instability, and less control over affective responses. This finding parallels other research studies documenting greater use of problem-focused coping in early adult age (see section on *Coping Response Patterns across the Life Span, p. 25*). This tendency to have a lesser degree of control over one's emotional state has important implications for young men living with AIDS.

Finally, early adulthood is characterized as a period of "affirmation" during which the confirmation of social status as an adult and full independence is sought (Medley, 1980). In terms of the subjective perception of self, it has been reported that "from early to middle adulthood the self is described less in extreme idealizations and more in pragmatic institutional transitions relating to career and family – more emphasis is on qualification, concreteness, and on anchoring a focus on greater complexity and centextualization" (Labouvie-Vief et al., p. 412. 1995). An ability to think in terms of complexity and transformations across personal, social, and political time is believed to develop with the maturity of later adulthood.

Status and Roles

Status and roles change across the life span in response to the development of the individual. "Status is treated as a position in a social structure and role as a pattern of activity intrinsic to that position and expected of one who occupies it" (Rosow, p. 63, 1985). Status and role are often mentioned in unison, and quite rightly so, since role represents the dynamic component of status. Throughout the life cycle, we engage in a continuous process of changing roles through status accretion (i.e., new positions are added), status succession (i.e., new roles replace ones outgrown), and status attrition (i.e., loss of roles) (Rosow, 1985).

The social processes of role acquisition and loss are an essential component of any analyses of the development of the individual across time, and the subsequent psychological reactions to these social changes. PLWA suffer gradual status attrition through the loss of work roles, physical fitness role, family and partner role, etc. These lost roles are not being replaced and the new roles acquired may be unfulfilling and without significant status or meaning. This tenuous social situation can cause considerable distress and confusion as to their social and personal expectations of their role in society.

Timing of Events

Having events occur "on schedule" has been reported to reduce stress via two influential factors. First, anticipatory socialization and rehearsal socially prepare individuals for scheduled events (Arnstein, 1984). Second, when a transition occurs on time, the person has a set of peers who can provide social support and a sense of "all in the same boat at the same time" (Hagestad and Neugarten, pp. 41, 1986; Brim and Ryff, 1980; Seltzer, 1975). We live and interact in a social environment amongst persons of all ages, and therefore we develop a keen sense of normative age expectations of behaviour and the timing of events. This predictability creates reassurance and social constancy, but also may create distress and anxiety when the events or behaviour do not coincide with socially prescribed rules. "It is more often the timing of the life event, not its occurrence, that constitutes the salient or problematic issue... the events are anticipated and rehearsed, the 'grief work' completed, the reconciliation accomplished without shattering the sense of continuity of the life cycle" (Neugarten, 1976). This conclusion is very significant when addressing the anxiety and distress experienced by persons living with AIDS. The physical deterioration, stigma due to physical illness/weakness, leaving the work force, lack of financial security, and increasing dependency on others arrives prematurely and disrupts the sense of continuity and predictability in the life cycle.

(c) Life Span Perspective: Identity Formation

The majority of developmental theories focus on the individual and his/her ability to master certain tasks or conflicts at different points in the life span. There are numerous life span development theories, which have been proposed in the field of psychology, but most of these are rooted in the work of Erik Erikson (1959). Erikson was unique in that he integrated the seemingly disparate fields of child and adult development. Whereas many theorists proposed that human development occurred primarily in the beginning stages of life, which set a fairly rigid personality blueprint for later life, Erikson purported that development continued throughout every stage of our life span.

Erikson (1959) proposed an eight-stage model of human development, which entailed the resolution of a phase specific developmental task. Each phase is described in terms of two extremes - successful versus unsuccessful outcomes - and a realistic resolution of the task is often achieved by balancing the two extremes. The eight phases of identity formation are grouped into child and adult development. In ***childhood and adolescence,*** the individual is confronted with resolving basic trust versus mistrust, autonomy versus. shame/doubt, initiative versus guilt, industry versus inferiority, and identity versus identity diffusion. In ***adulthood,*** an individual struggles to resolve intimacy versus isolation, generativity versus stagnation, and integrity versus despair (Erikson, p. 15, 1959). Each successive step presents a potential crisis, because the individual is expected to change the manner in which he/she relates to their social environment, and this reorientation represents a radical change in perspective.

Since this present research study is only concerned with the impact of a curtailed life span due to AIDS among young adults, the last three stages of adult development will only be discussed. "A healthy personality actively masters his environment, shows a certain unity of personality, and is able to perceive the world and himself correctly (Erikson, p. 51, 1959)." When a person is diagnosed with an AIDS-defining illness, their sense of psychological and physical self is challenged by premature physical decline. The search for a new balanced sense of self demands a lot of psychological energy. Not only is the person with AIDS confronting issues of identity and intimacy as a young adult, but they are also compelled to explore a method of contributing to the next generation or society (i.e., generativity versus stagnation), and achieving a sense of integrity or wisdom before death (i.e., integrity versus despair) because of an early threat to physical existence.

Tasks of Adulthood

Healthy development assumes that an older adolescent resolves issues relating to sexual identity. However, for many men and women who identify themselves as gay, social stigma and psychological resistance means that sexual identity continues to play a central role in adult development (discussed in greater detail in the next section on *Homosexual Identity Formation*). Intimacy requires that the person develop a relationship based on mutual psychological and sexual love. This phase will see the individual shift from the self-absorption of childhood and adolescence to the "expansiveness of generosity" and the ability to relate warmly with others (Allport, 1961) in adulthood. Generativity was originally based on the parental need to guide and care for their offspring. In the context of this research study, generativity is defined as contributing to the next generation or society by assuming activities in the community, such as volunteering or mentoring. Allport (1961) refers to this phase of adult maturity as self-extension, which involves developing interests in vocational, moral, and civic responsibilities.

Integrity represents the pinnacle of adult maturity, and the essence of this developmental task is captured in the excerpt below.

> It is the acceptance of one's own and only life cycle and of the people who have become significant to it as something that had to be and that, by necessity, permitted of no substitutes. It thus means a new different love of one's parents, free of wish that they should have been different, and an acceptance of the fact that one's life is one's own responsibility... The lack or loss of this accrued ego integration is signified by despair and an often unconscious fear of death...Despair expresses the feeling that the time is short, too short for the

> attempt to start another life and try out alternate roads to integrity (Erikson, p. 98, 1959).

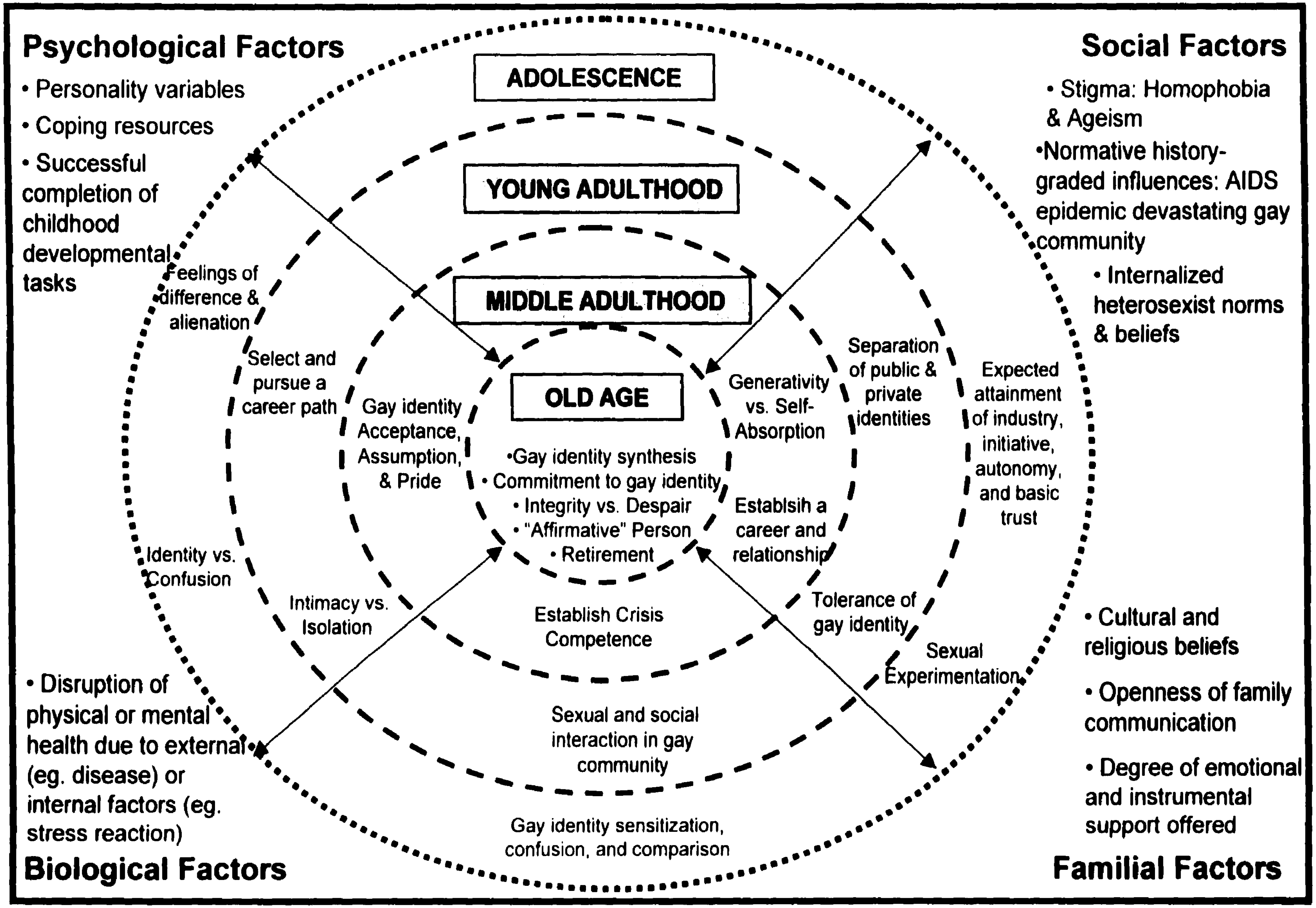
Ideally, integrity is considered to be the final stage of adult development. It has also been referred to as self-actualization; a developmental task only accomplished by a segment of the population. This phase of maturity is of utmost importance to PLWA because it involves the acceptance of death. The ability to tolerate the end of the life cycle requires an ultimate acceptance and integration of past achievements, failures, and regrets. Allport (1961) suggests that this final stage of integrity requires the development of emotional security, realistic perceptions and a knowledge of self, and finally establishing a unifying philosophy of life. These tasks, not normally resolved as a younger adult, are necessary components of therapeutic interventions with PLWA.

Homosexual Identity Formation

An examination of life cycle development would be incomplete without a discussion of identity formation as it pertains to persons who self-identify themselves as gay. The literature is primarily heterosexist, and ignores the unique experiences of young men and women 'coming-out.' All of the theories discussed above are based on observations and analyses in heterosexual populations. Despite the apparent research bias and inadequacy in representing all segments of our population, these theories offer an essential base from which to work, and provide a more comprehensive perspective than some of the research exclusively dedicated to studying identity formation in the gay community. The methodology of these more pertinent studies is often weak due to small sample sizes attributable to the fear associated with identifying oneself as gay. Another interesting bias in these studies is the over-representation of persons with higher socioeconomic status (D'Augelli & Patterson, 1995).

Figure 2.11 offers a graphic representation of identity formation from a gay sensitive perspective. This paradigm integrates the sociological and psychological paradigms discussed earlier with the current literature proposing models of homosexual identity formation. The external factors exerting strong influence on the development of the young adult through to older age are indicated in the outer box. These influential factors act to assist, contain, and sometimes restrain the individual through adult development. These factors include: (1) ***psychological***

Figure 2.11
Identity Formation from a Gay-sensitive Perspective



factors (personality, coping resources, and the successful completion of childhood tasks); (2) ***physical factors*** (disruption of physical or mental health due to external or internal factors); (3) ***familial factors*** (cultural and religious beliefs, openness of family communication, and degree of emotional and instrumental support offered); and (4) ***social factors*** (stigma, normative history-graded influences, and internalized heterosexist norms and beliefs). "The life span approach portrays the developing individual as embedded in a complex matrix of social and contextual influences that interact over time" (Baltes, 1987)

The above paradigm is useful in contextualizing the following discussion of homosexual identity formation. 'Homosexuality' is a clinical term, which is often resisted because of its medically oriented definition, but is used in direct reference to older literature. There appears to be a general consensus regarding the definition of what it means to be gay, which is as follows: an awareness of same-sex attractions, involvement in same-sex acts, self-designation as gay, disclosure of sexual identity to significant others, and some involvement in the gay culture (Gonsiorek & Rudolph, 1991; Troiden, 1979; Cass, 1984; Chapman & Brannock, 1987; Colgan, 1987; and Macdonald, 1982). The inadequacy of this definition is its inability to account for the mass diversity in the gay culture. The formation of an identity as a 'gay' individual is quite diverse and is best represented on a continuum. As acknowledged by Troiden (1979), the process of becoming gay is not linear, but rather a horizontal spiral. There are many men and women who identify themselves as gay, but have not yet been able to 'come-out' to family and friends because of a fear of rejection.

There are many versions of the basic models of homosexual identity formation initially put forward by Troiden (1979) and Cass (1984). Troiden presents a simpler four stage model, whereas Cass adds somewhat more detail in her six stage model. The following discussion of gay identity formation is based on the integration of both models to form a six stage model. The first stage in adolescence has been referred to as *sensitization* or *pre-coming out*. Both of these labels imply a sense of awareness of same-sex feelings, feelings of alienation and differentness, and subsequent confusion and anxiety. The second stage is often labelled *identity confusion*, *identity comparison*, or *incongruence*. This period of altered perceptions of self can lead to internal turmoil and self-imposed isolation. The rates of suicide among gay adolescents undergoing this emotional upheaval is alarmingly high (D'Augelli & Patterson, 1995).

The third phase of development is referred to as *identity assumption*, *identity tolerance*, or "*coming-out,*" and is marked by an increasingly more positive self-image as a gay person. In conjunction with acknowledging social, emotional, and sexual needs, the individual will seek out interaction with the gay community in search of role models and positive relationships. Even though the individual self-identifies as gay, there often appears to be a double life, in which the person evades stigma by remaining 'heterosexual' in social and familial environments.

The fourth stage of identity formation is labeled *identity commitment* or *identity acceptance*. The stage comprises of increased contact with the gay community, which normalizes and destigmatizes the gay identity. There is a fusion of sexuality and emotionality, which enables the individual to establish intimate relationships and disclose sexual orientation to heterosexual others. There appears to be decreasing anxiety, as there is an increasing acceptance, rather than tolerance, of the 'homosexual' self-image. This phase parallels Erikson's intimacy versus isolation stage. Traditional models of adult development assume that the 'right' or 'complete' relationship demands monogamous long-term relations. This focus on monogamy may not be appropriate in the context of gay identity acquisition. It is argued that gay men will place greater importance on the quantity of sexual interaction, while lesbians will emphasize the quality of the interaction (Berger, 1984). This observation may be an artifact of socialized gender norms rather than sexual orientation differences. The excerpt below explains a unique sexual culture in the gay community.

> Gay men are also interested in long-term relationships. However, they are less likely than lesbians to be sexually exclusive, and there is less consensus among gay men about the importance of sexual exclusiveness. In comparison, to lesbian relationships, gay men often find partners in the context of a more active, competitive social scene that involves multiple short-term relationships (Newman & Newman, p. 533, 1995).

The final stage of gay identity formation is referred to as *identity pride*, *identity synthesis*, or *commitment*. As these labels signify, this phase involves the integration of personal and public sexual identities. Cass (1984) describes an initial stage of rejection of heterosexuals and heterosexual values espoused generally by society. There is an expression of anger towards the social system for devaluing the importance and value of the gay identity. This strong activism and dichotomy between the heterosexual and homosexual worlds gives way to a greater congruency between the personal and public identities.

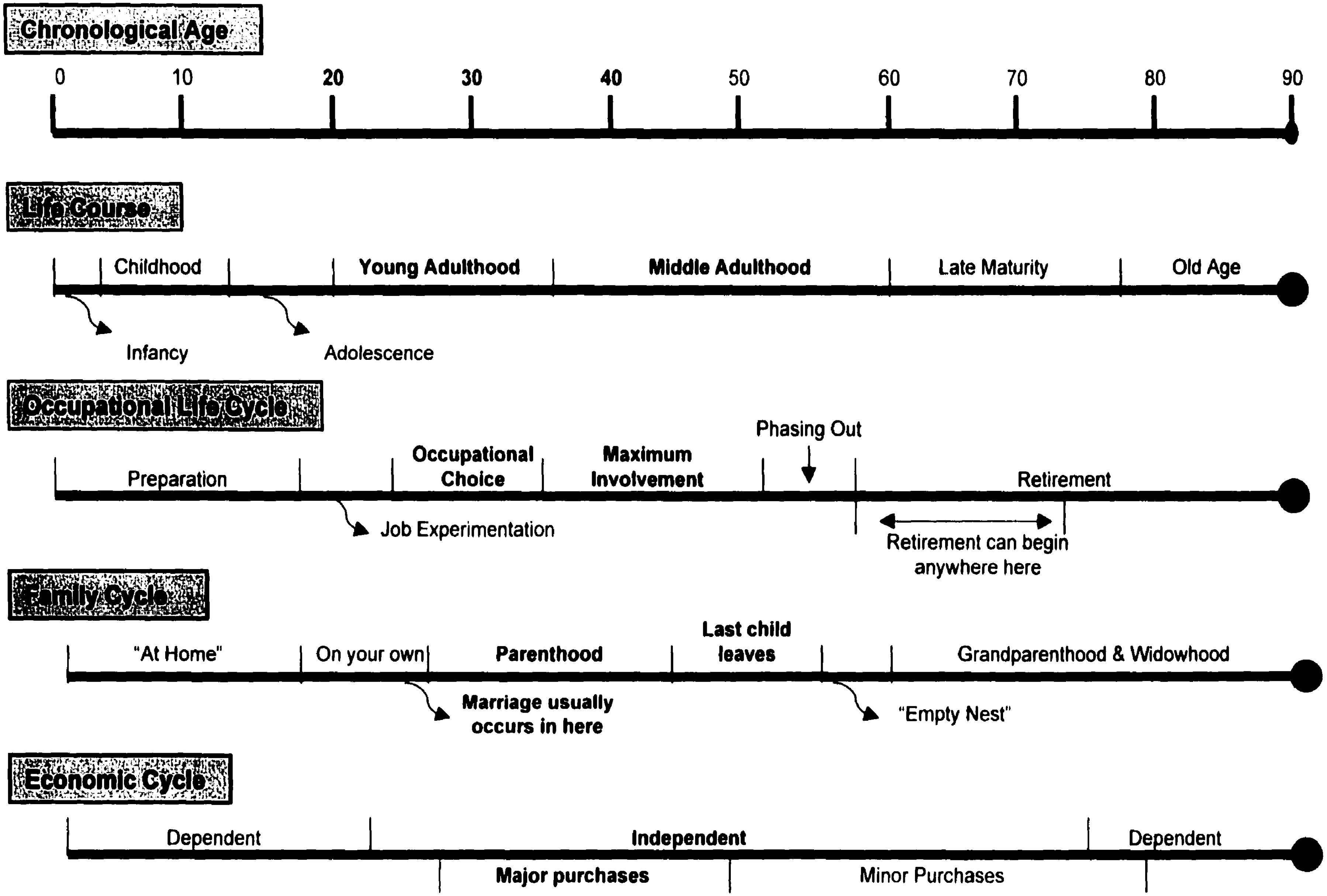
An individual's network of gay friends has often been referred to as a surrogate family (Ross, 1995; Plummer, 1981; D'Augelli & Patterson, 1995; and Troiden, 1979). Due to familial and social alienation, many gay individuals will rely on the gay community as main sources of formal and informal support. "Gay acculturation leads to the creation of family, of an intimate environment in which traditional holidays may be celebrated. Social support will buffer or prevent stress, and in stigmatized communities, the need for such support to protect against marginalization, discrimination, or rejection is high" (Weston, p. 424, 1991). In addition to benefits of social support, Jacobs and Tedford (1980) found that higher self-esteem was reported among those respondents attaching greater importance to membership in the gay community.

Identity formation is a life span process, which requires personal strength as well as a supportive social environment. As mentioned previously, a supportive family can enhance development, while a historical influence, such as AIDS, may increase shame, guilt, disgust (Troiden, 1979; D'Augelli & Patterson, 1995). There are inherent difficulties in researching the actual prevalence of homosexuality, because of the stigma and shame associated with the label. This stigma prevents social researchers from achieving a truly representative sample. It is important to note that the models of gay identity acquisition fall short of describing the development of the individual into old age. There is an acknowledgement that development continues throughout the life span, but it has yet to be described in detail. Figure 2.11 attempts to provide a complete framework of identity formation and adult development with the unique realities of the gay culture in mind.

(d) Different Life Cycles

There is an integration and sequencing of phases of work and family, which constitute the life course. There are several different life course trajectories, which are marked by periods of overlapping transitions (i.e. beginning or closing of an event or role relationship) (Newman & Newman, 1995). Figure 2.12 on the next page was derived from Atchley (1975) and provides a view of the age-linked changes in occupational, economic, and family careers. It "allows you to map the convergence of transitions across the occupational and family trajectories, illustrating periods of potential harmony and potential conflict between the demands in the two trajectories.

Figure 2.12
MULTIDIMENSIONAL DEVELOPMENTAL TIMELINE



The pattern of the life course is influenced by the historical era" (Newman & Newman, p. 520, 1995).

A noticeable omission in this illustrative trajectory is the family life cycle for the gay adult. The period of "on your own" will be extended, and intimate relationships will not produce children. However, changing social beliefs, new fertility technology, and loosening adoption regulations are now changing that childless reality. Introduce the historical influences (Turner-Henson & Holaday, 1995; Weekes, 1995), such as the gay rights movement and the AIDS epidemic, into this model, and these trajectories will shift independently and in relation to each other. The conflict between events and role transitions may increase because of opposing normative transitions. AIDS and/or job-related discrimination may interrupt or halt the normal transitions of the young adult into initial job experimentation, establishment of a career, and enjoyment of financial independence marked by major purchases. It is crucial to incorporate the dynamic nature of these trajectories into the life course perspective, as it will better reflect the transformative nature of the social environment.

(e) **Coping Patterns across the Life Span**

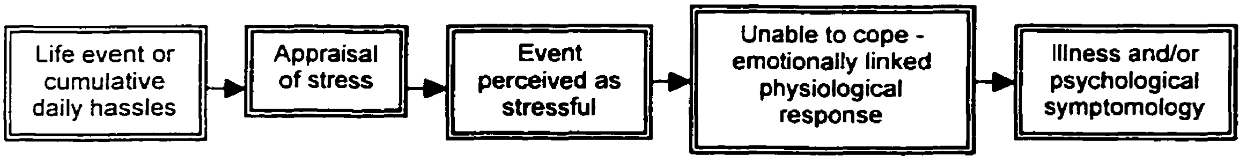
As with most research of the life span, research of coping and stress in the life cycle is plagued by methodological limitations. There are few research studies in life span development, which attain large and representative samples. In addition to this limitation, most of the data collected from different age samples within a population are cross-sectional, and therefore do not observe the changes of individuals across time. It is uncertain whether changes that occur in research samples are due to age-graded coping differences, or indeed due to shifts in the environment or cohort effects (Costa and McCrae, 1982). It is often impossible to tease out the interaction between the shifting interactions between the individual and the social environment. This inherent limitation in life cycle research is very important for understanding the true complexity of developmental psychology, and critically reviewing the literature.

Stress Process

Lowenthal & Chiriboga (1973) describe a time-dimensional model of stress, which includes: (1) ***infancy and childhood stress*** influences successive stages of adulthood; (2) ***cumulative/chronic and multiple concurrent stress***, such as poverty; (3) ***precipitating stress*** involving recent changes or loss in roles and status, which may be voluntary/involuntary or scheduled/off-schedule (eg. illness, bereavement, and loss of income); and (4) ***anticipatory stress*** (eg. anticipating physical deterioration). This model is crucial for understanding the complexity and intensity of the stress experienced by a PLWA. A PLWA potentially experiences all four of these components through developmental stress (issues of sexual orientation), chronic stress of poverty and discrimination, precipitating stress of premature illness and potentially death, and anticipatory grief associated with serious illness. This magnitude of stress can be overwhelming for individuals with or without excellent coping skills. The next section examines coping across the life span and presents research documenting optimal coping strategies.

Figure 2.13 of the stress process was adapted from Cohen and Wills (1985) and is useful for following this discussion. In order to mobilize coping resources, the individual must have experienced an event or cumulative daily hassles, which were perceived to be significant to well-being and taxing or exceeding available resources (Lazarus, 1980). There has been considerable debate about whether significant life events (Holmes & Rahe, 1967; Dohrenwend & Dohrenwend, 1974) or cumulative daily hassles (Coyne & Lazarus, 1980; Kanner et al., 1981) predict increases in psychological and physiological symptoms. Initially, it was argued that life events, despite being a distal measure of stress, were a greater predictor of psychological and physical distress (Holmes & Rahe, 1967; Holmes & Masuda, 1974; Schroeder & Costa, 1984).

Figure 2.13
The Stress Process



Since these early research studies, results now indicate that daily hassles, as a proximal measure of stress, are better predictors of physical and mental health (Ross, 1990; DeLongis, Folkman, & Lazarus, 1988; Monroe, 1983; Burks & Martin, 1985; Kanner, Coyne, Schaefer, & Lazarus, 1981; DeLongis, Coyne, Dakof, Folkman & Lazarus, 1982). "Hassles are irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment" (Kanner, Coyne, Schaefer, & Lazarus, p. 3, 1981). With further replication and validation of studies, it was discovered that it is the chronically high frequency of hassles, rather than intensity, that is most highly correlated with greater symptomology (Kanner, Coyne, Schaefer, & Lazarus, 1981). Life events continue to be useful for assessing the potential contributing factor for increasing daily hassles. However, hassles or the lack thereof, can also act as critical mediators during the occurrence of a major life event. Therefore, an individual without financial concerns (i.e. daily hassle) might be better able to cope with the death of a spouse (i.e. major life event). Similarly, a person who is diagnosed with a life-threatening illness (i.e. major life event) will experience a massive onslaught of new hassles, such as health, family, and financial concerns.

Despite being less vigourously studied and offering less conclusive evidence of positive affect on mood and health, uplifts or positive life events are worthy of mention. Folkman et al. (1995) recently studied the impact of positive meaningful life events in the context of coping with HIV/AIDS following many years of neglect in the literature. Positive meaningful events are defined as "events that touch on valued beliefs and goals, are appraised as beneficial, and evoke positive emotion" (Folkman et al., p. 5, 1995). Uplifts, positive events in daily living that generate positive emotions, were correlated with reduced distress in samples of adults (Kanner, Coyner, Schaefer, & Lazarus, 1981) and adolescents (Kanner, Feldman, Weinberger, & Ford, 1987). Lazarus, Kanner, & Folkman (1980) described three methods by which positive events may act as coping functions. ***Breathers***, such as a vacation or coffee break, temporarily free the individual from a stressful experience and also provide an enjoyable 'diversionary activity.' Positive emotions (e.g. excitement, challenge, or hope) may also serve as ***sustainers***, which help motivate a person to persist in what might be an aversive activity. Finally, positive emotions or events may function as ***restorers***, which facilitate the individual's recovery from harm or loss by rejuvenating resources or developing new ones. In the context of HIV, positive events, such as social activities and respite, can be extremely important in replenishing depleted resources.

Coping Process

It has been documented extensively (Brandtstadter & Renner, 1990; Folkman, Lazarus, Pimley, & Novacek,1987; Felton & Ravenson, 1987; Mages & Medelsohn, 1979), that there is a gradual progression from active coping (i.e., assimilative coping) to emotion-focused coping (i.e., accommodative coping) over the life-span in an effort to adapt to the increasing uncontrollability of life events, such as retirement, loss of friends, and declining physical health. "Physical, environmental, and social limitations that typically accompany aging limit the range of attainable outcomes, reduce action-outcome contingencies for important areas of life, and thus undermine feelings of competence and control" (Brandtstadter, 1994).

A brief introduction to the basic classification of coping strategies will help contextualize the somewhat obscure theoretical concepts, which are so readily referred to in the literature. Coping is a process characterized by dynamic changes in the shifting of the person-environment relationship (Folkman et al., 1987). "Shifts may result from coping efforts that are directed outward toward changing the environment, or efforts that are directed inward toward changing the meaning of the event. Any shift in the person-environment relationship leads to a reappraisal of what is happening, its significance, and what can be done" (Folkman & Lazarus, 1988). Coping typically refers to those adaptational activities requiring effort, and are not those continuous daily activities carried out in relating to the environment. Originally, Folkman & Lazarus (1980) constructed a binary division model of coping: ***problem-focused coping*** (directed outward – altering the source of stress in the environment) and ***emotion-focused coping*** (directed inward – regulating stressful emotions), which was recognized by numerous other researchers. This simplistic division was abandoned to welcome a more accurate model of assessment. Although there are many different labels ascribed to coping mechanisms, an eight scale coping model as refined by Folkman and Lazarus (1988) is presented here. The coping scales are comprised of the following: (1) ***confrontive coping*** – aggressive efforts to alter the situation, which may involve hostility and/or risk-taking; (2) ***distancing*** – cognitive efforts to detach oneself and to minimize the significance of the situation; (3) ***self-controlling*** – efforts to regulate one's feelings and actions; (4) ***seeking social support*** – seeking informational support, tangible support, and emotional support; (5) ***accepting responsibility*** - acknowledging one's own role in the problems with an effort to 'put things right;' (6) ***escape-avoidance*** – wishful thinking and behavioural efforts to avoid the problem (e.g. substance abuse); (7) ***planful problem-solving*** – deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem; (8) ***positive reappraisal*** – creating positive meaning of event by focusing on personal growth (also contains a spiritual dimension).

It seems that the success (i.e. a positive affect in psychological and physiological health) of these coping strategies is dependent on the type of situation (McCrae, 1984; Folkman & Lazarus, 1980; and Folkman & Lazarus, 1986). Problem-focused coping is associated with better outcomes when the situation is changeable. As we age, situations, such as declining health and retirement, are less changeable, and therefore efforts to change the environment are futile. In contrast, younger adults with good health have greater success at changing their circumstances.

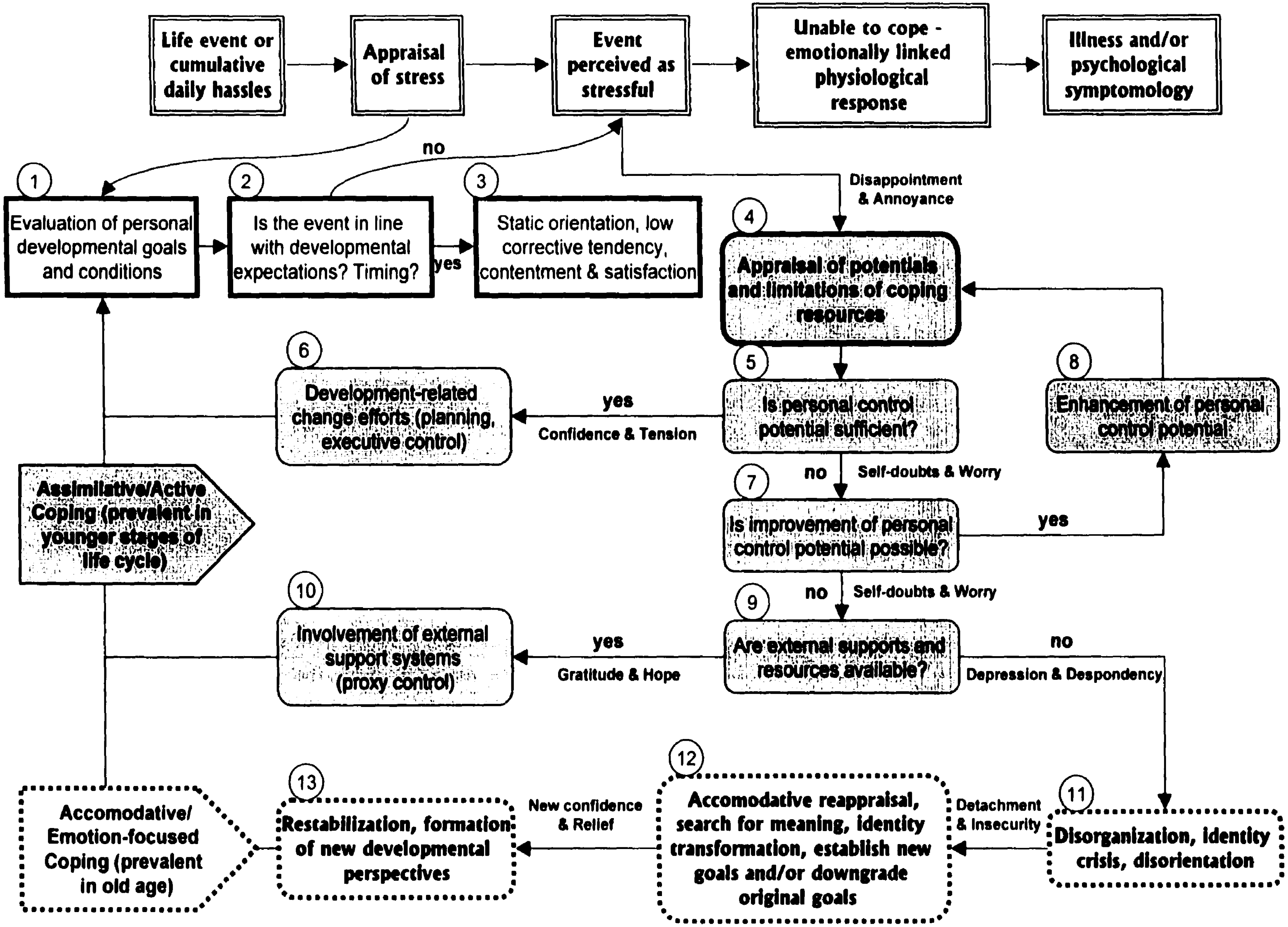
On the contrary, emotion-focused coping is correlated with better well-being and health when the situation is not amenable to change (Folkman & Lazarus, 1980; Folkman et al., 1986). In one study by Felton, Ravenson, and Hinrichsen (1984) of chronically ill adults, it was found that information seeking (emotion- and problem-focused coping) was related to positive affect, while avoidance, blame, and emotional ventilation were related to negative affect, lowered self-esteem, and poorer adjustment to illness. One common theme throughout all of the studies on coping is that escape-avoidance and wishful thinking are associated with poorer psychological and physical health in both young and older samples and in all types of situations.

Most gay men living with AIDS are in the early to middle adult stage of their life cycle (i.e. aged 22 to 44). It is during this period of the life span that adults adopt strategies to exert control over their social and physical environment as a method of coping with stress (Korniewicz, O'Brien, & Larson, 1990; Leserman, Perkins, & Evans, 1992; Namir, Fawzy, & Alumbaugh, 1987; Nicholson & Long, 1990; Siegel and Krauss, 1991; Wolf et al., 1991). Unfortunately, the relentless progression of the disease continues despite the adoption of intensive coping strategies (i.e., planful problem-solving and seeking social support), and therefore advocating for a mix of active and accomodative coping styles may be useful.

Figure 2.14 was adapted from the work of Brandtstadter and Renner (1990). It is a complex representation of the entire coping process at a single point in time. These two typologies were chosen to illustrate the dynamic nature of the stress and coping processes. The upper section describes the stress process, which involves: (1) the presence of either cumulative developmental stress, chronic stress, precipitating stress, or anticipatory stress; (2) the appraisal or recognition of stress; (3) the realization that the stress cannot be managed by existing resources; (4) inability to cope causes an emotional and physiological response (fight or flight reaction); and (5) continuing inability to cope creates illness or psychological symptomology (Cohen & Wills, 1985).

There are several potential points of intervention/prevention in this stress process. First, if the person recognizes the event as stressful, but determines that it is consistent with development goals (eg. premature parenthood), then the complete stress reaction can be prevented – positive reappraisal (**stage 1 to 3 on diagram**). Second, if the stress is incongruent with development

Table 2.14
COPING RESPONSE PATTERNS ACROSS THE LIFE SPAN



goals and expectations, then the individual seeks to analyse and enhance their sense of personal control (**stage 4, 5, and 8 on diagram**). An individual with adequate personal control will proceed with greater confidence, yet tension, in shifting developmental goals - active problem-solving - (**stage 6 on diagram**). Third, an individual with insufficient personal control and perceived inability of enhancement may then attempt to recruit assistance and support from informal (friends, partner, and family) and/or formal (therapist) networks - seeking social support - (**stage 9 and 10 on diagram**). If this "proxy control" is available and capable of assisting in the resolution of overwhelming feelings of stress, then the person can resume a state of homeostasis once again. Depression and despondency are believed to occur with the failure to achieve psychological balance independently or with the help of others (**stage 11 on diagram**). Fourth, it is at this crucial point that the individual engages in a process of self-reflection and review. Ultimately, there is a reappraisal of the stress through a search for meaning, identity transformation, and the creation of new goals or original goals being downgraded – cognitive restructuring/positive reappraisal - (**stage 12 on diagram**). The psychological and physiological state of the individual is restabilized and there is a new framework of developmental perspectives that are in sync with their social and biological reality (**stage 13 on the diagram**).

2.2 AGING THEORIES

This section on aging is intended to emphasize the parallel losses that occur among the elderly and PLWA. Although many of the biological, social, and psychological losses that occur with age and AIDS are very similar, there is one crucial difference: ***timing***. The losses of social roles and physical strength, albeit stressful, are expected and socially scheduled for persons in old age. Young persons living with AIDS-related illnesses experience significant life-changing events prematurely (non-normative crises) without the essential life experience or social framework of normative expectations required to cope.

(a) Physical Changes

Old age represents the culmination of the life span. Birren and Renner (1977) propose the following definition of aging: "Aging refers to the regular changes that occur in mature, genetically representative organisms living under representative environmental conditions as they advance in chronological age" (p. 4). Aging is not purely a biological process, but the social and behavioural aspects of aging are equally influential and important to the subjective experience of older adults.

In terms of the biological process of aging, Newton, Lazarus, and Weinberg (1984) reported that 86% of persons over age sixty-five in the United States have one or more chronic illnesses, such as heart disease, hypertension, diabetes, and arthritis. However, increasing medical technology means that many of these illnesses are becoming treatable, preventable, or at least subject to partial remission from intensive treatment. This new technology does not undermine the increased stress associated with health maintenance in older age (Folkman and Lazarus, 1988). The increased incidence of chronic disease also increases the risk of being more seriously affected by the contraction of other illnesses, such as pneumonia (Skolnick, 1986).

In addition to chronic illnesses, there are several biological changes, which are reported to occur as we age: (1) gradual hearing loss (five times more likely among persons aged 65 to 79); (2) decreased visual acuity and increased chance of developing cataracts; (3) gradual deterioration of taste and smell; (4) increased risk of developing Alzheimer's disease (depicted by profound intellectual decline, confusion, and memory loss); (5) fluid intelligence (i.e. ability to manipulate new information to solve problems) gradually decreases with age, whereas crystallized intelligence (i.e. ability to use prior information, such as vocabulary or general information) remains constant or even improves in late life; (6) short-term memory decreases with age, whereas long-term memory remain stable; and (7) decreased coordination between visual and motor functions (Newman & Newman, 1995; Skolnick, 1986; Specht & Craig, 1982; Horn & Donaldson, 1976; Turner and Helms, 1976).

(b) Social Changes

Multiple Loss

In this present context of aging and PLWA, multiple loss is used to describe the high number of losses of friends, family members, and partners experienced by older adults (*AIDS-related losses will be discussed later*). The deaths of friends and family members can virtually lead to a complete diminution of the individual's support network. Kastenbaum (1977) coined the term "bereavement overload" in reference to older adults who experience the loss of many friends and family members within a short period of time. The ability to engage in the lengthy process of bereavement is continually interrupted by a new death. "One's resources, energies, adaptability, and function, the intimacies of relationships upon which depended, family and friends, are continually being depleted and lost" (Newton, Lazarus, & Weinberg, p. 242, 1984). At a time when the body is losing physical stamina, there is an inevitable confrontation with a declining support network. The lack of social support has an important impact on the psychological and physiological health of the individual (Cohen & Wills, 1985).

Retirement

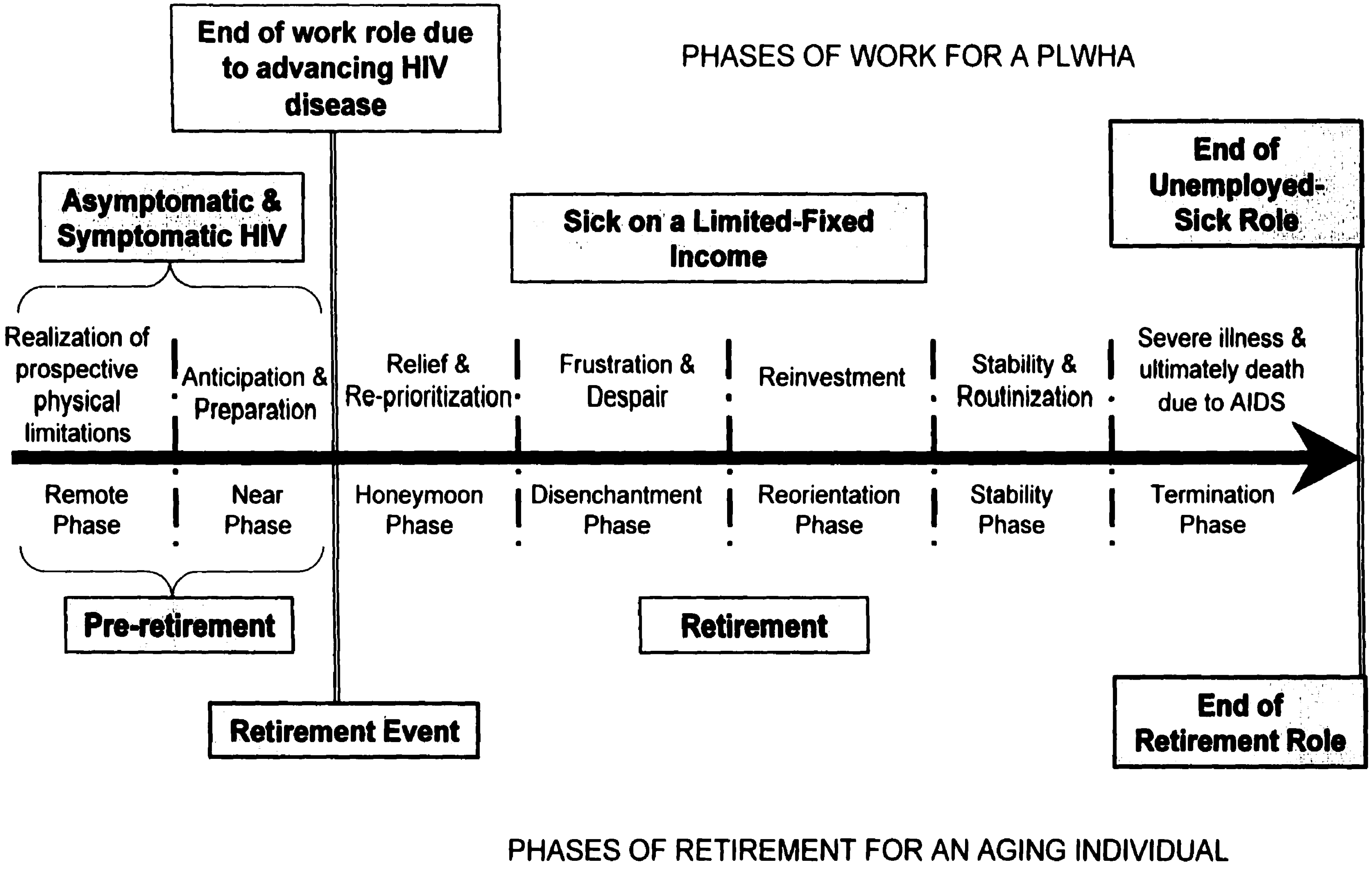
Although the loss of the work-role due to retirement requires some psychological adjustment, it is generally personally and socially expected, and prepared for well in advance. "Preparation for retirement should be a life-span process, beginning with enhanced awareness of the eventuality of the event and the consequent need for planning in childhood and adolescence, even before the assumption of a work role" (Datan & Thomas, p. 218, 1984). This early socialization of the retirement process eventually leads to the internalization of a social clock, which mentally prepares the individual for late-life role changes.

The significance of work in the self-concept of the individual is highly subjective and quite diverse among different populations. However, older adults in Canada have been socialized with neo-puritan Western values, which value the work ethic and emphasize productivity over 'personhood' (Strauss, 1977). For older persons whose intelligence and work greatly accounted for their sense of self-esteem, the loss of work status can be devastating. There are five main issues that must be dealt with upon retirement: (1) ***Loss of finances and living on a fixed income***. A 25%-30% reduction in income after retirement can be expected among the elderly in the Western world (Newman & Newman, 1995). Poverty is of grave concern for 38% of older persons (Chappell, 1994), who have been widowed or who are unattached. (2) ***loss of self-esteem***; (3) ***loss of work-oriented social contacts***; (4) ***loss of meaningful tasks***; and (5) ***loss of a social reference group***.

Atchley (1976) described the retirement process in seven phases. Figure 2.21 illustrates this retirement process, and also proposes a similar process experienced by those persons stopping work due to AIDS-related disability and illness. This seemingly linear process is intended to provide a framework for analysing the psychological and social impact of losing the work role. There is considerable individual diversity in this process, and some persons may skip some phases all together depending on their coping mechanisms, social support, and other resources.

Figure 2.21

Phases of Retirement for an Older Adult and Work Stoppage for a PLWA



The ***pre-retirement phase*** involves the realization of the upcoming retirement event and subsequent preparation. This phase can be extended over several years, and may involve anxiety or excited anticipation. The actual retirement event often leads to a ***honeymoon period*** in which the person may schedule a vacation and celebrate the free time available. For PLWA, the actual work stoppage may bring a sense of relief and a re-prioritization of values may take place. Work-related demands may be perceived as threats to physical health, and therefore a new system of values may be developed. Following the initial period of relief and enjoyment, there is usually a phase of ***disenchantment***. The frustration and despair associated with being on a limited fixed income (losing financial independence), and losing an important social role can endure for a considerable amount of time, and may never end for some persons. The ***re-orientation phase*** is an essential part of developing ego strength and integrity. It involves discovering new activities that provide fulfilling new roles, and indeed making a purposeful effort to reinvest in a new way of life. Following this difficult period of self-reflection, there is a general phase of ***stability*** and a routinization of new activities and roles. The final phase of ***termination*** is reflected by general social disengagement due to serious illness and disability before death.

As mentioned at the beginning of this section of "*Aging*," the major difference between retirement in old age and work stoppage as a young adult due to AIDS-related illness is the timing of the event in the life cycle. Leaving the work force prematurely may mean that the individual will remain at the disenchantment phase for a longer length of time struggling to find meaning in new activities and establishing new priorities.

Role Changes

Rosow (1985) provides an excellent examination of the function of status and roles throughout the life cycle. He proposes that older adults are "tenuous," because they have been designated definite social positions without roles or only vague or insubstantial ones. There is a reduction in the status set of the entire cohort of older adults due to a gradual loss of roles without the replacement or succession of new ones. Major status losses start occurring with retirement, widowhood, failing health, and drastically reduced income. The loss of roles has several important affects on the elderly: (1) exclusion from significant social participation and the devaluation of their contributions; (2) old age has an unstructured and undelineated set of social expectations, which leads to a lack of ascribed social duties, obligations and responsibilities; and (3) deprivation of their social identity.

As illustrated previously in Figure 2.12, the family life cycle shifts throughout the life span. In late life, role realignment within the family is often necessary. Increasing physical and/or cognitive limitations may mean that adult children are expected to care for their ailing parents. "Whether families are able to negotiate the role reversal wherein the adult child serves as parent or principal caregiver to aging parents is dependent on the pattern and quality of earlier family ties as well as on the capacity of the adult child to achieve 'filial maturity.'" (Newton, Lazarus, & Weinberg, p. 246, 1984). The vulnerability often experienced by older adults can be further worsened by the unidirectional caregiving relationship. An older person limited by physical or cognitive disability lacks the fulfillment of reciprocity in the family relationship due to dependency.

With increasing geographical distance between family members and the changing role of women in the work force, the sick elderly are now being placed in institutional settings. The institutionalization of the elderly increases alienation, loneliness, and stigma associated with old age. The lack of family support and community involvement can act as obstacles to the resolution of late-life developmental tasks (i.e., generativity and integrity), and may increase death anxiety and general distress. Contrary to the suggestions of disengagement theory advocates, Neugarten (1973) found an overall positive relationship between social engagement and life satisfaction, and therefore encourages social interaction among the elderly with younger generations.

(c) Psychological Changes

Important factors that affect adjustment and satisfaction in old age are health status, level of cognitive functioning, financial resources, education, social support network, amount of stress, and the extent to which developmental tasks were resolved in earlier life through the use of adaptive coping mechanisms. "If an individual reaches old age without having to confront major life crises, he or she will have failed to develop adequate coping mechanisms and thus will be ill-equipped to meet the demands of growing old" (Newton, Lazarus, & Weinberg, p. 258, 1984).

As discussed earlier, Erikson (1959) suggested that the older adult is presented with the developmental tasks of attaining generativity and integrity. Generativity refers to investing in guiding and contributing to the welfare of the next generation, whereas integrity involves the emotional integration of life experiences. Wisdom is often thought to be synonymous with integrity because it involves "the reconciliation of earlier goals and dreams to achievements actually accomplished, reevaluation and reconceptualization of earlier life experiences in light of later ones, and the revision of one's sense of self in a way that is compatible with those experiences" (Newton, Lazarus, & Weinberg, p. 243, 1984). This process of self-reflection and reminiscence leads to the pinnacle of maturity and self-respect, which inevitably leads to a desire to pass on life's lessons to the next generation. Despite the frightening reality of aging (i.e. realizing one's own mortality and vulnerability), the ego strength developed through the acquisition of integrity brings a sense of security and peace. "Those older adults who achieve this degree of acceptance of their death appreciate that the usefulness of their contributions does not necessarily depend on their physical presence" (Kubler-Ross, 1972).

The concept of integrity and generativity has been indirectly confirmed by several studies. In particular, Ryff (1989) studied 171 older adults with a mean age of 73.5 years, and found that older persons defined successful adaptation to aging as the ability to accept change. There was also a strong emphasis placed on the importance of being a caring and compassionate person with established positive relationships with family and friends. The value placed on being a 'good person' took precedence over individual goals, which was alternatively viewed as a top priority by the younger population. Cartensen & Turk-Charles (1994) confirmed the above finding in their study of 83 persons aged 20 to 83 years. They found that older adults devoted greater cognitive resources to processing emotional material, and there was a shift towards attaining proximal goals, such as regulating emotion. Neugarten (1976) also suggested that this increased emotional investment in old age, referred to as interiority, occurs as there is a gradual change in perspective from 'time since birth' to 'time left to live.' It is believed that this shift in time-perspective is related to the 'personalization' of death.

Life Stress and Daily Hassles

Despite the common-sense hypothesis that old age attracts an onslaught of major losses (i.e. declining health, loss of work role, and loss of friends and loved ones) and fewer gains, there has been repeated evidence to the contrary (Lazarus & DeLongis, 1983; Holmes & Masuda, 1974; Felton & Revenson, 1987). As one would expect, the type of hassles experienced by individuals varies according to age and role patterns. In a large comparative age study of 246 persons, Folkman et al. (1987) found that older adults report fewer work-related hassles, but a greater number of hassles concerning health, home maintenance, and environmental and social issues. The events experienced by the older sample were perceived to be less changeable (also reported by Brandtstadter & Renner, 1990). Participant reports indicated a lesser number of hassles, which was explained by the researchers as being a function of their effective coping strategies. "The use of emotion-focused forms of coping such as distancing and positive reappraisal helped short circuit the stress process, so that incidents that might otherwise have been hassles were neutralized" (p. 182). The finding of concern, centering on issues relating to health, physical abilities, and economic well-being, was duplicated by Holahan, Holahan, & Belk (1984) in their study of 64 elderly adults.

A study by Lewinsohn et al. (1991) reported no age differences in symptoms of depression in a very large sample of 4,617 adults over the age of fifty. However, depression was associated will ill heath, inactivity, reduced independent-living skills, and cognitive dysfunction. The fact that older adults report fewer major life events and micro-stressors was also confirmed. Therefore, the precipitating stress of serious illness and disability in older age may be more predictive of psychological health than chronic or cumulative stress. A recent Canadian study based on the National Population Survey suggested that depression steadily decreases with age until the ages 70 to 74 years (especially for males) at which point it increases (Wade & Cairney, 1997). I would propose that this increase is most likely associated with increased physical limitations, which hamper social activity and independent living.

The timing and duration of stressful events combined with the anxious anticipation of its effects can act to mediate the impact on psychological health. It is not the occurrence of stress per se, but how it is coped with that affects health and well-being. The development of alternative and age-appropriate coping mechanisms in response to the increasingly uncontrollable aversive events in old age has been observed repeatedly in development research (Brandtstadter & Renner, 1990; Folkman et al., 1987; McCrae, 1982; and Vaillant, 1977). Brandtstadter & Renner (1990) developed a complex coping model *(refer to Figure 2.14)* to describe the age-graded differences in coping from data collected over an eight year period in a large sample of 890 older adults. Those individuals engaging in the adaptation of goals according to environmental constraints reported greater life satisfaction, less emotional strain, and lower developmental deficits (also reported by Nurmi, Pullainen, and Salmela-aro, 1992). The tenacious goal pursuits associated with better psychological health in younger age become a detriment in old age. The recognition that health-related problems of older age are an uncontrollable fact of life actually contributes to a greater sense of personal control by equipping the person with knowledge and psychological preparation (Brandtstadter and Rothermund, 1994).

(d) Older Gay Men

Older gay men are burdened with the combined negative stereotyping and prejudice associated with being a member of two subjugated populations. The stigmatized depiction of aging gay men as being lonely, depressed, oversexed or asexual, and living in isolation of friends and family, is one that systematically erodes an individual's self-esteem (Friend, 1991; Berger, 1984; Laner, 1978; Kelly, 1977). This section is intended to highlight the psychological and social issues specifically facing older gay men.

Gay men from the older generations have been reared and socialized in a historical era dominated by a rhetoric of traditional family values, which were considered to be synonymous with heterosexual monogamy. The two polar reactions to this heterosexist discourse are developing internalized homophobia on one side of the spectrum, and challenging social norms and affirming one's sexual identity on the other. Friend (1991) proposed that "affirmative" gay men are better equipped to cope with old age, because they have developed "crisis competence" through combatting rigid gender role definitions in the past. It is suggested that early experiences with discrimination, social alienation, and depleted financial resources better prepare gay men for the harsh realities of aging. Skills for managing the loss of family and independent living are more likely to be a part of a gay man's repertoire (Friend, 1987).

There are two principal studies, which set out to test the validity of the negative stereotypes of older gay men. Berger (1980) disproved these stereotypes in his sample of 112 gay men by uncovering low rates of serious depression and anxiety, and favourable rates of life satisfaction (74.5% versus 62.0% in the general population). There was a positive association between psychological adaptation, good health, and sexual satisfaction. The age distribution of the sample extended to as low as forty years of age, and therefore this large diversity in age prevents the generalizability of results to older gay men. Pope and Schulz (1991) more recently studied 87 gay men aged 40 to 77 years, and found that 91% of the total respondents continued to be sexually active. These two studies disprove the negative societal perceptions of older gay men, but both of these samples cannot be considered truly representative due to the large spread in age.

The ability to effectively cope with social alienation is believed to be another task of early adulthood for young gay males (Friend, 1987). The development of "crisis competence" in early adulthood may buffer the stressful process of aging, however there are several stumbling blocks that prevent such a smooth transition. First, accelerated aging - experiencing oneself as old at an earlier age than one's chronological age - has been identified, with debate, in the gay community (Bennet & Thompson, 1991; Friend, 1980; Laner, 1978; Minnegrode, 1976). The increased value placed on youth and beauty, especially in the sexual marketplace, in the gay culture tends to depreciate the potential contributions of older gay men in the community and accelerate the social and behavioural components of aging (Friend, 1987). It is important to note that Laner (1978) and Berger (1984) did not uncover any conclusive evidence of accelerated aging in their samples of gay men.

Second, the effects of ageism and homophobia are compounded, thus creating a hostile social environment. Government and private benefit plans are designed for the heterosexual population, and thus neglect the needs of gay partners who may be seeking equitable health care services, life insurance policies, advanced directives, and pension benefits (Kus, 1990). "Thus, the process of aging for the male homosexual is seen as 'exceptionally stressful' due to a lack of legal supports and sanctions binding in nature, lack of children as a focal point in middle and old age, and the emphasis on youth and physical attractiveness in the homosexual community" (Francher and Henkin, 1973).

2.3 STIGMA

In this present discussion, stigmatized groups shall be referred to by the following definition: "social categories about which others hold negative attitudes, stereotypes, and beliefs, or which, on average, receive disproportionately poor interpersonal or economic outcomes relative to members of society at large because of discrimination against members of the social category" (Crocker and Major, p. 609, 1989). A comprehensive theoretical model was developed by Goffman (1963) to define three types of stigma associated with (1) ***physical abnormalities*** (physical illness or disability); (2) ***blemishes of individual character*** (homosexuality, unemployment, etc.); (3) ***tribal stigma*** (race, nation or religion). This typology is useful in highlighting the multifaceted aspects of AIDS-related discrimination. Jones et. al (1984) developed a similar typology of stigma specifically tailored to illness. Table 2.31 below represents an integration of both of these models. A comparative assessment of PLWA and the elderly is made according to eight social dimensions of stigma. The graphic layout emphasizes the mutidimensional aspects and intensity of AIDS- and age-related stigma.

AIDS is unpredictable, life-threatening, very disruptive, concealable, changes the physical appearance of the individual (i.e. wasting or skin lesions), and is deeply intertwined with moral issues of lifestyle choices. PLWA are subject to discrimination on the basis of *appearance* (wasting or visible marks*)*, *sexual orientation*, *inability to work* (dependence on medical welfare or disability benefits), *lifestyle choices* (multiple partners and IV drug use), and often by *race* (a great proportion of those infected with AIDS belong to minority groups) (Lapierre, 1990; Lawrence & Husfeldt, 1990; Weitz, 1990).

Table 2.31
Social Dimensions of Stigma

Dimensions of Stigma	Description	PLWA	Elderly Individual
Concealability	Uncertainty and fear involved in trying to hide one's physical illness and/or disabilities	✓	
Course/predictability	Condition is irreparable and subject to fluctuating periods of health and ill-health	✓	✓
Peril	Having a contagious disease, which may put others at risk. Generally, there are many misconceptions about what constitutes high risk behaviour (eg. casual contact)	✓	✓
Disruptiveness	Degree to which the illness impedes on social interaction and communication	✓	✓
Aesthetic qualities/ Abominations of the body	Person is perceived as being disfigured or deformed, because of physical manifestations of the illness (eg. skin lesions, coughing, and wasting).	✓	✓
Origin	Person is perceived as being responsible for contracting the illness (blame).	✓	
Blemished character	Illness represents immoral behaviour such as, homosexual behaviour, promiscuity, or IVDU.	✓	✓
Tribal stigma of race	Assumes the person is from an inferior or infected lineage (eg. the Haitian community).	✓	✓

Adapted from Jones et al. (1984), and Goffman (1963)

Similarly, older adults are subject to an "ageist" (Grant, 1996) social environment, which places emphasis on youth and beauty, and discriminates according to physical appearance and chronological age (Stones & Stones, 1997; Bennett & Eckman, 1993; Crocker & Major, 1989; Hummert, 1990; Montepare & Lachman, 1989). Newton, Lazarus, and Weinberg (1984) reveal the multiple negative stereotypes faced by older adults: physically weak and unattractive, conservative, rigid, weak, dependent on others to meet their needs, passive, and lacking personal acceptability. All of these 'faulty' characteristics are in opposition to the Western "culture of narcissism" (Achenbaum, p. 144, 1985), which values independence, rapid change and innovation, youth, and beauty. Death and aging are uncomfortable topics in Western culture and are therefore dealt with by denial or prejudice. Ageism deprives many older adults, particularly those from low-income and minority groups, of access to equitable health care, social services. and self-enrichment activities. The stigma exacerbates the financial difficulties and reduces the employment prospects for those whose savings and other assets have become inadequate (Butler. 1975).

AIDS is one of the only life-threatening illnesses which views its victims as deserving and being subject to divine punishment (Weitz, 1990). The "just world hypothesis" (Adam & Sears. 1996) is often used to describe this justification of 'divine punishment' in the examination of "bad" behaviour. The overwhelming social blame and self-blame for contracting HIV can contribute to a negative self-image. Chapman (1997) found a strong correlation between perceptions of self and self as perceived by others. More disturbing is the finding that the self as perceived by others has a strong impact on psychological health. In her relatively small sample of thirteen HIV-positive persons, she found that 70% of them reported a desire for more physical contact. despite receiving similar amounts of touch as that of a comparative HIV negative group. The "dying leper syndrome" (Tsoukas, 1988) is a term which has been used to describe the experience of living with AIDS; a disease that breeds fear of contagion, and evokes feelings of shame among its victims.

Herek and Capitanio (1993) conducted a large comparative survey of one sample of White. English-speaking Americans (n = 538), and another of African-Americans (n = 607). A total of 47.8% of all respondents believed that they were likely to become infected with HIV from sharing a glass of water with someone who is HIV-positive. Whereas the White sample reported more negative opinions of PLWA and were more likely to blame them for becoming infected, the African-American sample indicated a greater fear of contagion, and even supported the quarantine of PLWA. On a more micro level, Weitz (1990) found that almost her entire sample of gay men with AIDS encountered rejection by at least one family member and some by their seronegative partners upon learning of their diagnosis. In addition to this interpersonal alienation, participants had been subjected to considerable discrimination within their work settings and health care settings (also reported by Tindall & Tillett, 1990).

The stigma associated with homosexuality and HIV frequently compels individuals to conceal both their sexual orientation and diagnosis from family, friends, and colleagues, and therefore adopt a dual identity. The division between personal and private identities can become laborious to maintain, and therefore distance is often used to maintain the secret (Newman & Newman, 1995; Weitz, 1990; Herek, 1995). The distance can further weaken relations with family and friends, and thus limiting the availability of social supports.

2.4 PEOPLE LIVING WITH HIV/AIDS

(a) "Premature Aging"

Mages and Mendelsohn (1979) coined the term "premature aging" following the observations of the psychosocial reactions of a sample of young women who were diagnosed with metastatic breast cancer. The phrase was developed to describe the experience of young women confronting the following challenges prematurely: physical decline, increased dependency on others, multiple social losses, stigmatization, and increased need for life review. These young women were confronted with an uncontrollable and aversive event that threatened their physical and psychological sense of self, and responded with intense anxiety and distress. In contrast, a group of older women with the same prognosis reacted with less anxiety because of the age-expected norms of developing a life-threatening illness later in life. Siegel (1984) replicated a similar study which compared the values and time-orientation of two samples: one sample of seventy-two women who underwent a radical mastectomy for breast cancer, and a normative sample of fifty women with no history of life-threatening illness. The younger women in the mastectomy sample were more concerned with death and the uncertainty of their future life span, and placed a greater emphasis on living in the present. However, the older women in the sample were less distressed with the uncertainty of their future life span. Respondents in the normative sample reported greater concerns with family commitments and future plans.

This concept of "premature aging" is used in this paper to describe the experience of gay men living with AIDS at a remarkably young age. "AIDS is a chronic disease of the young, causing physical decline and social losses that are usually not encountered until older ages" (Kalichman, p. 97, 1995). Gay men living with AIDS encounter three main sources of stress which have been identified as being an integral part of "premature aging:" (1) ***physical changes***: declining health intertwined with unpredicatble and alternating episodes of physical crisis and stability; (2) ***social changes***: multiple deaths of friends and lovers to AIDS, loss of employment due to disability, rejection or distancing by family and friends, living with stigma and discrimination, and role loss; (3) ***psycholgical changes***: quality of life, stress and related symptomology, and need to derive new coping strategies to confront the unpredictability of events.

The following sections will address the biological, social, and psychological aspects of AIDS, which objectively, not subjectively, parallel the different dimensions of aging. Figure 2.41 illustrates all of the the factors influencing a PLWA at the micro level (physical and psychological health), meso level (family, partner, and community), and the macro level (formal regulations and attitudes in social environment) in a condensed format. All of the issues being addressed in the subsequent sections are summarized in Figure 2.41, and as such serves as a useful guideline throughout the discussion.

(b) Adaptation to Illness Progression

Weiss (1976) recommends that a crisis event should be differentiated from a developmental/adaptational task, due to its suddenness, time-limited nature, and severity. The immediate mobilization of energy to cope with a crisis state can exhaust an individual's resources quite quickly. A severely taxing situation requires that the extreme stress be temporary, so that the individual may return to a pre-crisis state, or so that the individual may engage in a process of establishing a new life organization and stable identity (also referred to as the "transitional state"). The individual may perceive the new social and personal identity as inadequate and lead to a "permanent deficit state." Living with HIV/AIDS is not a temporary or fleeting stress. It is a constant presence in the person's physical, psychological, and social life. The ability to incorporate an incurable (as of yet) and highly stigmatized illness into one's existing identity, without destroying one's sense of self-worth, is extremely challenging and may demand extensive use of formal and informal supports.

While there are numerous studies indicating variations of the psychosocial stages of illness and dying, those models proposed by Kubler-Ross (1969) and Sourkes (1982) were selected, because they seem to have withstood the test of time and critical review. In addition, a general diagnostic stage model by Holosko and Taylor (1994) is included to highlight the major illness stages recognized by the medical system in Canada. All of these models are illustrated in Figure 2.42 for comparative purposes. These stages are not linear and may alternate according to illness relapses and remissions, but they are useful for identifying the major illness-related crises and events which require psychological adjustment. The health professional may be meeting

Figure 2.41
FACTORS AFFECTING A PERSON LIVING WITH AIDS

PHYSICAL HEALTH

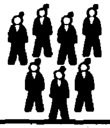
PSYCHOLOGICAL WELL-BEING

PYSCHOSOCIAL TYPOLOGY OF ILLNESS (Rolland, 1987)
- Timing in life cycle: normative expectations of ill health are for old age
- Onset (acute or gradual) affects adaptation
- Course (constant vs. relapsing) affects adaptation
- Degree of incapacitation: Impairment of cognition, sensations, energy production, disfigurement, and medical causes of stigma affects adaptation abilities

AIDS:
- Usually occurs in young adulthood when maximal health is normative
- The onset of AIDS is gradual, its course constant and relapsing, and its incapacitation can be severe.

Some Opportunistic Infections:
- Kaposi sarcoma (disfigurement & stigma), CMV retinitis (blindness & stigma), pneumocystis pneumonia, tuberculosis, & MAC (energy reduction), PML, meningitis, toxoplasma gondii, syphilis & AIDS-related dementia (cognition & stigma), wasting (disfigurment & stigma), thrush, and shingles (skin rash incurs stigma and disfigurement).

- Tolerance for uncertainty and ambiguity
- Coping resources (ability to mobilize social support resources important)
- Increased daily stressors or "hassles"
- Self-esteem & body image
- Sense of personal control over disease process
- Loss of important social roles and ascribed status
- Social Isolation: socially-imposed or self-imposed
- Tenacious goal pursuit vs. flexible goal adjustment
- Death-anxiety
- Fear of physical decline and dependency
- Lifestyle patterns (athletic, workaholic, active social life, IV drug use)
- Self-blame (AIDS as a punishment - internalized social beliefs)
- Feeling contaminated and a fear of infecting others
- Lack of financial security
- Hope vs. despair/depression
- Degree of commitment to gay identity
- Degree of "crisis competence" established



PARTNER & COMMUNITY

- Bereavement overload (continual onslaught of multiple loss)
- Caregiver burden
- Role ambiguity (increasing dependency with advancing HIV)
- Available quality support resources
- Availability of HIV- & gay-sensitive services

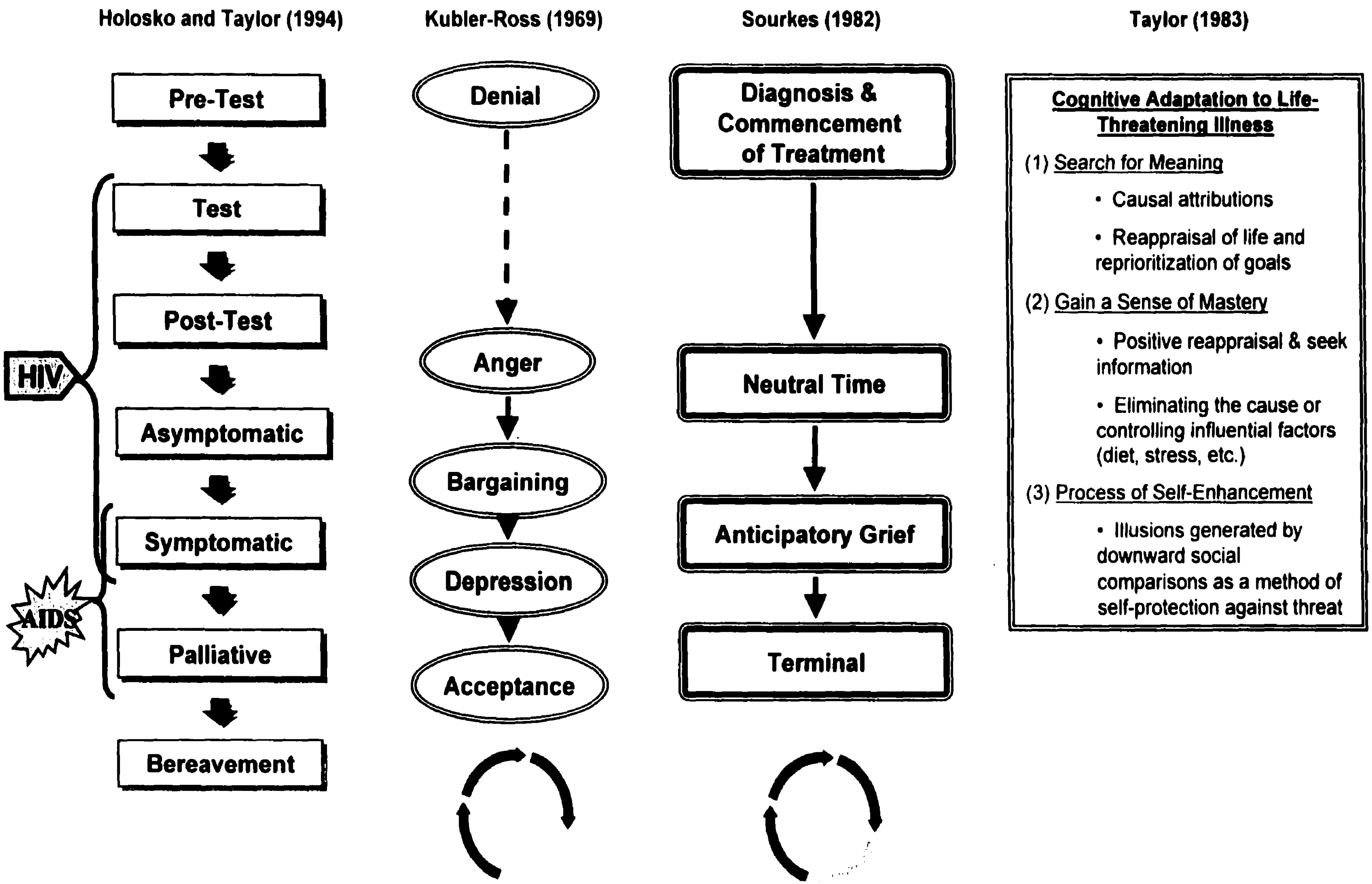
SOCIAL ENVIRONMENT

- Degree of homophobia and AIDS-related fear/misinformation in society
- Discrimination in employment and housing
- Lack of flexible employment opportunities & inadequate governmental assistance programs
- Availability & increasing costs of life-saving medications
- Anti-discriminatory laws and regulations
- Existence of a national AIDS strategies

FAMILY

- Instrumental and emotional support
- Cultural or religious beliefs re: sexual orientation and AIDS
- Rejection because of fear of contagion or disapproval
- Tolerance for potentiality of role reversal with advancing HIV disease
- Degree of rigidity in family interactions

Figure 2.42
BIOPSYCHOSOCIAL STAGES OF HIV INFECTION



Cognitive Adaptation to Life-Threatening Illness

(1) Search for Meaning

- Causal attributions
- Reappraisal of life and reprioritization of goals

(2) Gain a Sense of Mastery

- Positive reappraisal & seek information
- Eliminating the cause or controlling influential factors (diet, stress, etc.)

(3) Process of Self-Enhancement

- Illusions generated by downward social comparisons as a method of self-protection against threat with a client with AIDS (symptomatic phase with fluctuating asymptomatic periods) for the first time, but the initial crisis of diagnosis and the first onset of symptoms may have been equally traumatic and worthy of attention.

Kubler-Ross (1969) and Sourkes (1982) outline very similar psychosocial stages. Upon learning of a diagnosis, Kubler-Ross suggests that most individuals enter a state of ***denial*** to protect their emotional well-being from threat. This period of ***diagnosis and commencement of treatment***, according to Sourkes, is an "emotional shock wave" (p. 46) during which "existence is stripped to the essence" (p. 51). The next phase of, "***neutral time***," is characterized by ***anger*** and deep uncertainty. A circular interplay between hope during remissions and anger during relapses, complicates how the individual perceives the threat of the illness: chronic or life-threatening. "An 'ill-defined illness' connotes a suspended limbo when death looms as a potentiality or is imminent. The stress of waiting for an event which is inevitable, yet whose time of arrival is unknown, is enormous" (Sourkes, p. 56, 1982). The existential question, "Why me?" and the associated anger is particularly difficult for families and health care professionals to cope with because it is seemingly directed randomly at various targets. Kubler-Ross (1969) described an additional phase of ***bargaining*** with God for divine intervention and reprieve in exchange for 'good behaviour,' which takes place during this period of chronicity.

Following a variable duration of denial and anger, the individual begins a process of grieving for illness-related losses (body image, work, financial security, family dynamics, etc.), referred to as ***reactive depression***, and the upcoming loss (separation from loved ones through death), known as ***anticipatory depression/grief***. Anticipatory grief is defined as "grief expressed in advance when loss is perceived as inevitable" (Aldrich, p. 4, 1963). The sense of living on "borrowed time" encourages the individual to engage in a process of organizing priorities and life goals, coming to terms with past achievements and perceived failures, and coping with the upcoming physical and emotional separation from loved ones. Unexpected remission may introduce new hope and temporarily interrupt this grieving process and development task of developing integrity. Sourkes notes that the risk of early protective "family disengagement" may interfere with the normal feelings of relief and excitement associated with remission or the asymptomatic phase. The unpredictable cycle of remissions and relapses puts the patient and family on an emotional roller-coaster ride.

Finally, when death is imminent and irrefutable, the patient and family enter the palliative or terminal phase of the illness. This phase is marked by ***acceptance*** and a "turning inward…a pulling back from the external world. The patient's sphere of concerns constricts markedly to include only the most essential and intimate: control of pain, and communication with those closest" (Sourkes, p. 84, 1982). Kubler-Ross remarks that acceptance should not be confused with being content. On the contrary, this stage is almost devoid of feelings, a time of increased sleep, and realizing that the struggle is over. This acceptance of death can be devastating for partners and families who are not in sync with the emotional and physical reality of the patients. In comparing this experience with the process of aging, it is evident that they share an emphasis on life review and an inward orientation. However, older adults do not generally emotionally disengage from the social sphere, but instead use this time to self-reflect on their past and contemplate existential issues.

The final phase of bereavement applies to the loved ones left behind by the deceased. The bereavement process seems to parallel the stages of grief for a person living with a life-threatening illness (i.e. shock, disbelief, numbness, anger, depression, and finally acceptance). "Death ends a life, but it does not end a relationship, which struggles on in the survivor's mind toward some resolution, which it never finds" (Andersen, p. 77, 1966).

In concluding this section on the psychosocial aspects of life-threatening illness, a cognitive model of adaptation to life-threatening illness developed by Taylor (1983) following her clinical observations of cancer patients is also presented. This model is illustrated in Figure 2.42, and seeks to provide three effective methods of cognitively adapting to a new state of uncertainty and threatened health. First, she suggested that an individual ***searches for meaning*** to better understand why illness has occurred and what its impact has been. She claimed that 95% of her respondents reported developing causal attributions. Patients most frequently attributed their illness to lifestyle factors (i.e. stress, diet, smoking, or family genetics) which allowed them to regain a sense of personal control. Identifying these contributing factors provided an incentive to reprioritize goals and reappraise life circumstances.

Second, ill-patients were determined to ***gain a sense of mastery*** over their body and uncontrollable situation. This sense of control was attained through the use of causal attributions, and the belief that a positive attitude could change the course of the illness. A total of 37% of respondents reported this belief of control. Stress management techniques were used to relax the mind and enhance positive, motivating thoughts. Third, the process of ***self-enhancement*** was used to restore weakened self-esteem and body image. The use of "healthy denial" is believed to provide individuals with a break in the crisis to rejuvenate energy resources and regain hopeful vision. Patients developed illusions of better health and coping by making downward comparisons (i.e., comparing oneself to someone who is sicker). She emphasizes that these cognitive adaptations to illness are only adaptive when the illness is in its chronic stage. If the individual is facing the terminal phase of illness, and is being repeatedly battered by relapses of life-threatening illness, then the "healthy denial" and causal attributions may not improve emotional well-being. Recurrent illness can undermine one's sense of control and create a crisis or "learned helplessness" (Seligman, 1975; Wortman & Brehm, 1975). "When efforts at control are exerted in an environment where no control exists, controlling efforts will lead to poorer rather than more successful adjustment. A sense of mastery may be fine so long as nothing happens to undermine it " (Taylor, p. 1169, 1983). There can be intense disappointment and anguish associated with recurring illness following active attempts to change 'bad' lifestyle patterns and adhere to complex or physically exhausting treatments (e.g. antiretroviral medication regimes for AIDS patients).

(c) Physical Changes

In the context of the psychosocial typology of a chronic illness, AIDS is classified as a gradually progressive and relapsing illness which eventually incapacitates the person in its late stages (Rolland, 1987). As mentioned previously, the medical, psychological and social issues facing a PLWA are condensed in Figure 2.41 for a simplified multidimensional perspective. The uncontrollable and unpredictable course of AIDS can lead to an emotional state of uncertainty during periods of reasonably good health. "The unrelenting continuous assaults of the disease. which generally require long and frequent hospitalizations, leads to physical and emotional exhaustion both for the person with AIDS and for those caring for him or her" (Buckingham and Stulberg, p. 359, 1988).

The "primary infection" stage represents the first six months of HIV infection, which may or may not coincide with the medical diagnosis (Coates, 1997). Medical tests in this early phase indicate an immediate and drastic drop in CD4+ count, a dramatic increase in viral load count, and a reduced immune response to HIV. Symptoms during the primary infection period include flu-like symptoms, such as fatigue, swollen glands, persistent diarrhea, and low-grade fevers. It is during this initial stage of HIV infection that the disease is very infectious. Many individuals suffering from primary infection will mistake the symptoms for the flu, and therefore there is a high risk of unknowingly transmitting a very infectious strain of HIV (Coates, 1997).

As the HIV infection progresses, persons can expect to develop AIDS-related complex (ARC): disruptive and irritating symptoms and illnesses, but do not pose an immediate risk to life. ARC includes the following infections: oral thrush, oral hairy leukoplakia, herpes zoster. constitutional symptoms (i.e. chronic diarrhea, weight loss, night sweats, fever, fatigue), generalized lymphadenopathy (nodules in the armpits, groin, and neck), and idiopathic thrombocytopenia (bleeding from gums, rectum, and urine). Even though the person may experience one or all of these infections, this stage is considered to be relatively "asymptomatic" and without major life-threatening infections (Bartlett & Finkbeiner, 1991).

Once the CD4+ count markers drop below 200, there is a greater risk for developing opportunistic infections, and hence AIDS. AIDS is recognized to be the final stage of HIV infection. AIDS-defining illnesses are potentially life-threatening infections which may incapacitate the individual in various forms. These infections all require intensive treatment which may be treated in in-patient units or day hospital centers. Table 2.43 presents the majority of AIDS-defining illnesses and their relative risk.

Medical professionals actively advocate changes in lifestyle (i.e. exercise, good diet, cessation of alcohol, smoking, or drug habits, and decrease stress) for the purposes of bolstering the person's immune system strength and psychological health. The inability to prove the scientific effectiveness of alternative treatments, such as herbal remedies and massage, seems irrelevant if there is a strong placebo effect. Despite all of these efforts, an individual in 1991 had a 74% chance of dying within 2 years of the diagnosis once developing full-blown AIDS (Bartlett & Finkbeiner, 1991).

Table 2.43

AIDS-related infections and AIDS-defining illnesses

AIDS-DEFINING ILLNESS	SYMPTOMS AND FREQUENCY
Pneumocystis pneumonia (PCP)	80% of people will develop the dry cough, shortness of breath, and fever associated with PCP if preventive medication is not taken
Kaposi's Sarcoma (KS)	Second most common AIDS-defining illness, which is indicated by purplish-black cancerous lesions on the skin
Cytomegalovirus Infection (CMV)	80-90% of people will develop CMV which can lead to blindness, hepatitis, or pneumonia
Mycobacterium Avium	30-50% of people will develop MA in either the intestine, liver, lungs, or blood
AIDS Dementia Complex	30-50% of people will develop the Alzheimers-like disease indicated by memory loss, apathy, inability to concentrate, and inability to control arms and legs
Herpes Simplex	10-25% of people will develop serious herpes lesions
Wasting Syndrome	Dramatic weight loss (often the initial AIDS-defining diagnosis)
Toxoplasmic Encephalitis	10-15% of people will eventually get headaches, seizure, and fever associated with toxo.
Candidal Esophagitis	15-25% of people will have painful difficulty swallowing
Cryptococcal meningitis	8%-15% of people will eventually develop the severe headache, stiff neck, and potential brain damage associated with meningitis
Cryptosporidial diarrhea	3-8% of people will develop severe diarrhea for over one month
Tuberculoisis	Coughing, blood in sputum, shortness of breath, fever, and weight loss
Lymphoma of brain and other parts of the body	Symptoms include seizure, impaired function of arm, leg, and speech

Bartlett and Finkbeiner (1991)

Antiretroviral Therapies (ARTs) or Triple Combination Therapy

A discussion of the AIDS virus in the present context of rapid medical and pharmaceutical advancements would be incomplete without a discussion of the new antiretroviral therapies (ARTs). ARTs were introduced by the pharmaceutical industry in the past five years to slow the progression of HIV, and ultimately halt its progression. A cure has not been uncovered, but for some PLWA, there is a reasonable hope that HIV can be suppressed to low-risk levels and to undetectable (not absent) amounts of viral load. Appendix 2 portrays the HIV viral replication cycle and describes how the new prothease inhibitors or triple combination therapy (AZT, 3TC, and DDC or saquinavir) interrupt the replication of further HIV infected cells in the body.

The evidence demonstrating the success of ARTs is scarce at the moment, but new promising findings are expected to be revealed at the 12th World AIDS Conference in Geneva, Switzerland (June 28 to July 3, 1998). Presently, the majority of research in Canada is dominated by the B.C. Centre for Excellence in HIV/AIDS in Vancouver. Veugelers et al. (1997) found that the survival time in an untreated group of HIV patients was estimated to be 9.7 years, and increased to 11.8 years for a sample who had full access to treatment. It was estimated that

17.8% of the sample (n=554) would survive 20 years of HIV infection. Similarly, Hogg et al. (1997) reported that the death rate for persons on ARTs declined from 18.9 to 6.8 deaths per 1,000 participants, with the greatest reduction experienced by those participants with CD4+ counts less than 100 (69.3 to 23.1 per 1,000 participants). It seems that the introduction of ARTs has coincided with reductions in mortality rates, and therefore confirms our clinical observations of physical improvement among patients taking ARTs in the local HIV clinics.

The introduction of routine viral load testing in mid- to late-1996 in Canada has helped physicians better assess the timing of administering triple combination therapy. Viral load tests measure the amount of HIV in the blood by measuring RNA, a part of HIV that the virus needs to reproduce (*Loads of Information. Guidelines on using viral load measure for monitoring health*, 1996). There are various opinions about when to first start administering ARTs, ranging from starting treatment in primary infection to starting therapy with the development of AIDS-related illnesses. *AIDS Clinical Care* (1996) suggested the following guidelines for the use of viral load measurements as clinical indicators: a viral load measure of 10,000 copies/mm^3 is correlated with a low risk of worsening disease, a viral load measure of 10,000 to 100,000 copies/mm^3 is associated with a medium risk of disease worsening, and finally a viral load measurement of 100,000 copies/mm^3 or greater is correlated with a high risk of disease progression. The *Sixth Annual Canadian Conference on HIV/AIDS Research* in May 1997) was host to a large number of debates regarding the optimal time for starting ART. While the early administration of ARTs in primary infection stage can potentially suppress HIV at a non-dangerous level for a long length of time, there was contradicting arguments claiming that early treatment can lead to viral mutation, and therefore resistance to treatment. The secondary transmission of resistant HIV strains can be damaging to public health efforts to prevent the ravaging impact of HIV (Coates, 1997). "These (ARTs) require complex monitoring and adjustment to avoid drug resistance and cross resistances" (Linsk and Keigher, 1997). Ultimately, the decision to start ARTs is quite subjective and is made by the patient with the medical advice of his/her treating physician.

(d) <u>Social Changes</u>

AIDS pervades every aspect of one's being, and as such has multiple social impacts for gay men living with AIDS, including change or termination of employment, loss of many friends and partners to AIDS, role changes, confronting heterosexist laws and regulations, and coping with discrimination based on health status and sexual orientation. This section is presented in condensed format in Figure 2.41 under partner and community, social environment, and family.

Multiple Loss

Similar to older adults, gay men living with AIDS lose incredibly high numbers of friends and partners to AIDS. Rando (1984) described a normal process of mourning as including three phases: (1) The ***avoidance phase*** involves recognizing the loss. (2) The ***confrontation phase*** involves reacting to the separation, recollecting and re-experiencing the deceased, and relinquishing old attachments to the deceased; and (3) The ***accommodation phase*** involves readjusting to a new world without forgetting the deceased and reinvesting in life. She also suggests that death from an overly lengthy illness may complicate mourning and contribute to denial and holding-on. Marcotte (1996) hypothesized that multiple loss of friends to AIDS may also complicate mourning, and in addition to denial and holding on, the mourner may also experience survivor guilt. He found, in his small Montreal qualitative sample of six gay men with AIDS, that all of the men experienced complicated mourning. There seems to be two major factors contributing to complicated bereavement. First, society's intolerance and unsympathetic attitude towards bereaved gay partners and friends creates an environment of hostility in which secrecy is often the only answer. The lack of validation of the significance of the death and the lack of available social supports isolates the individual in a time of greatest need. Second, the repetitive loss of significant others over a brief period of time does not give a person adequate breathing space and time to cope with the death properly (Biller and Rice, 1990). This type of multiple loss mimics the "bereavement overload" (Kastenbaum, 1977) experienced by older adults. The unrelenting loss of friends to AIDS in the gay community "is particularly devastating and frightening" in the gay community because it represents the potential threat they are facing themselves (Lehman and Russell, p. 180, 1985).

It has been reported that the intensity of grief increases as the number of deaths of friends due to AIDS escalates, and this has also been correlated with higher levels of depression (Biller and Rice, 1990; Dean, Hall and Martin, 1988; Folkman et al., 1996; Kemeny et al., 1995; Sikkema et al., 1995; Saunders, 1990). However, there seems to be one dominant loss that is most significant to the individual (Marcotte, 1996). Because of frequent rejection by family members and social discrimination due to sexual orientation and seropositive status, the gay community often acts as a "surrogate family" for its members. The lack of recognition and devaluation of these significant and numerous losses can be very damaging to psychological health (Folkman et al., 1996; Saunders, 1990; and Biller & Rice, 1990).

Work-Related Issues

In addition to the decreased size of the support network due to AIDS-related deaths, people living with AIDS confront the grim reality of not being able to continue work due to physical limitations (Kalichman, 1995) and/or discrimination in the workplace (Tindall & Tillett, 1990). The uncertain and unpredictable nature of symptom progression makes it very difficult for a person with AIDS to undertake and maintain secure employment. This work stoppage has incredible social and personal costs. Since the psychosocial process of stopping work for a person with AIDS was already compared to the experience of retirement in the prior section on "*Aging*," it will not be re-examined here in detail. Please refer to Figure 2.21 for the comparative model. PLWA are cornered into government assistance programs, which provide low fixed incomes (Leigh et al., 1995, Schneider, 1989) and erode the person's self-esteem. These financial strains contribute to a battery of chronic, daily stressors concerning financial security. Similarly, older persons are also limited by limited, fixed incomes (Krause and Baker, 1992; Herzog, House and Morgan, 1991; Krause, 1987; Peterson, 1979).

An occupation is a primary means of accumulating financial resources, but it also acts as a social indicator and provides people with a certain self-image through work-related socialization. It is one of the key indicators in determining socioeconomic status and, as such, defines where the individual belongs in the social structure. In response to the following question, "what most describes you as an individual?" the majority of people initiate the response with a description of their occupation (Mumford, 1977). "Most males are socialized to feel that their work is a central part of their identity. Young adults who fail to enter this mainstream of the work force because they are competitively disadvantaged must seek employment in the secondary labour market, where employment is less stable and wages are low" (Specht & Craig, pp. 226 & 228, 1982). The wages and working conditions of this secondary labour market (i.e. minimum wage positions) do not offer many incentives over government income support programs, which provide security and coverage of medical costs. The bureaucratized and rigid nature of income support programs prevents any flexibility in integrating part-time work with government assistance, and therefore provides few options for a PLWA.

The *Third International Conference on the Biopsychosocial Aspects of HIV Infection* in June 1997 offered some new research findings concerning current issues for PLWHA in the light of the new combination therapies. McConachy, Grubb, & Ezzy (1997) found that finances, health and health maintenance, and treatments and therapies were of most concern to her sample of 120 gay men with HIV/AIDS. Concerns about finances were intertwined with concerns about returning to work, drug treatments, and housing. With the advent of ARTs, people are contemplating returning to work after a long absenteeism and are concerned with job retraining. One of her respondents remarked, "Money is running out but my life isn't – how to get a balance between work, income, and health" (p. 11). Golan (1997) also noted that improved health led to increased stress and uncertainty relating to the renegotiation of relationships, employment and goals.

Financial Security and Poverty

Poverty continues to be one powerful commonality of experience, which binds PLWA. The absolute poverty of PLWA in Third World nations is quite severe, and the relative poverty of PLWA in industrialized nations is also quite significant. Whether AIDS disproportionately affects marginalized groups due to associated behavioural patterns, or whether poverty is a result of the discrimination and lifestyle changes associated with being diagnosed HIV positive, remains debatable. However, one conclusion is clear: the financial subjugation of PLWA is extreme and impacts every aspect of their personal, social, and professional lives. Krause, Jay, and Liang (1991) reported that increased financial strain among the elderly leads to decreased feelings of control and self-worth, which in turn contributed to increased symptoms of depression. The study also confirmed a common finding that low household income was correlated with poorer health. This study of an elderly sample is included to highlight the potential impact of low incomes on the psychological and physical well-being of PLWA.

As life-prolonging medications remain prohibitively expensive to many people in North America, and the majority of people in Third World nations, these financial concerns are bound to only become worse. Table 2.44 portrays the staggering costs of AIDS, which include the more formal costs of AIDS associated with lost participation in the work force and the cost of health care. The total cost of AIDS in Canada was estimated to be $10-billion in 1995, and is predicted to increase to an alarming total of $30-billion by 2010 (Gibbon,1996). It is in the public and private interest to devote the appropriate amount of funds to research, prevention, and care and treatment through effective medication insurance schemes.

Table 2.44
The Cost of AIDS in Canada

Year	Number of PWA (cumulative)	Human capital cost per person	Total human capital cost	Direct medical cost	Total cost per capita	TOTAL COST
1995	16,000	$500,000	$8-billion	$2-billion	$330	$10-billion
2000	30,000	$500,000	$15-billion	$3-billion	$580	$18-billion
2010	60,000	$500,000	$30-billion	$6-billion	$1,000	$30-billion

Gibbon (1996)

Catherine Hankins (1990), an epidemiological researcher in the field of HIV, carried out a study on HIV infection among Quebec women giving birth to live infants to investigate the relationship between poverty and seroprevalence of HIV. The results of the study indicate a strong correlation between high seroprevalence and low revenue among her sample of 988 women aged 15 to 44 years. Mothers living in poorer regions (20% to 40% below the provincial median) had the highest rates of HIV infection at 46.4 per 10,000 births. There were virtually no reported HIV cases in families with incomes 40% above the provincial median. There are a total of nine postal code regions concentrated in eastern and northern Montreal, which have high rates of HIV (primarily St. Michel, Montreal North, and Park Extension). These regions are "...the poorest in the city. Together, they have a population of 145,000 and a 17% unemployment rate" (Hustak, p. A3, 1996). These grim statistics depict the poor economic security of the people living in these regions, especially for those living with HIV/AIDS.

The relationship between poverty and the high prevalence of HIV/AIDS can be conceptualized in three ways: (1) living in a poorer region with associated behavioural patterns, such as IV drug use, prostitution, and sexual contact without protection predisposes the person to contracting HIV, or (2) PLWA may experience a decrease in income and income security subsequent to diagnosis because of unstable employment due to physical disability or work-related discrimination, or (3) a lower socioeconomic status prior to being diagnosed with AIDS worsens the degree of economic deprivation following AIDS-related illnesses. It could be concluded that scenario three, poverty as a cause and result of HIV infection, appears to offer the most complete explanation. Living in a low-income area provides fertile ground for the contraction of AIDS and living with this illness also places the victim at high risk for experiencing poverty.

Role Changes

The onset of AIDS marks the beginning of alternating periods of health associated with hopeful uncertainty, and periods of opportunistic infections which threaten one's emotional and physical well-being. As the healthy peers of PLWA remain actively involved in the work force, financially independent, and socially active, the PLWA is being faced with increased social isolation due to deteriorating health. Similar to older adults, PWA have been ascribed status obligations, but because of illness and status loss due to stigma, they are unable to perform the associated roles (i.e. career, family, and social obligations) (Rosow, 1985). There appears to be a gradual role attrition with disease progression, and without social support and community involvement, there risks being no replacement of roles (e.g. volunteer in the community). This general role loss creates a "tenuous" situation, which threatens the person's sense of self.

In addition to role loss, there is a general shift in family dynamics to accommodate the new role of the sick member. The partners of men with AIDS are forced to constantly adapt to the roller-coaster symptoms, and prepare for the gradual mental and physical deterioration to come. If the partner is also HIV positive, there may be a powerful self-identification process that takes place. The partner may see his own grim future reflected in that of his partner's, which may create great distress. "By the terminal stages of AIDS, responsibility for decision-making and implementation is likely to have shifted in large part, often completely, from the person with AIDS to the caregiving partner. The shift in responsibility usually occurs in increments as the disease progresses" (Folkman, Chesney, & Christopher-Richards, 1994). The partner rarely discusses his own fears and distress for fear of upsetting their loved one, and the emotions associated with the caregiver burden are often kept silent because of guilt and shame (Folkman et al., 1996).

The constantly re-adjusting family constellation of roles according to the physical condition of the family sick member threatens the mutuality and reciprocity that exists in relationships. At a time when partners need mutual support the most, relationships are under the greatest threat of dissolving. A "partner of persons with AIDS struggle to adapt to the patient's changing role and function. The patient can no longer offer the same level of physical or emotional support, and roles and responsibilities shift" (Christ, Moynihan, and Silver, p. 382, 1988). Kelley et al. (1983) conceptualized interdependence as "ongoing chains of mutual influence between two people" (p. 65). The balance between dependency and independence is thought to empower the self and the other. Due to socialization of roles from a very early age, dependency seems to be less accepted by men, because they are not socialized to accept passivity and dependency like their female counterparts (Moss, 1960). Dependency in men can counteract the fulfillment of their social roles. The developmental tasks of adulthood, intimacy and generativity, can be best realized through communal relationships that are based on reciprocity and mutuality.

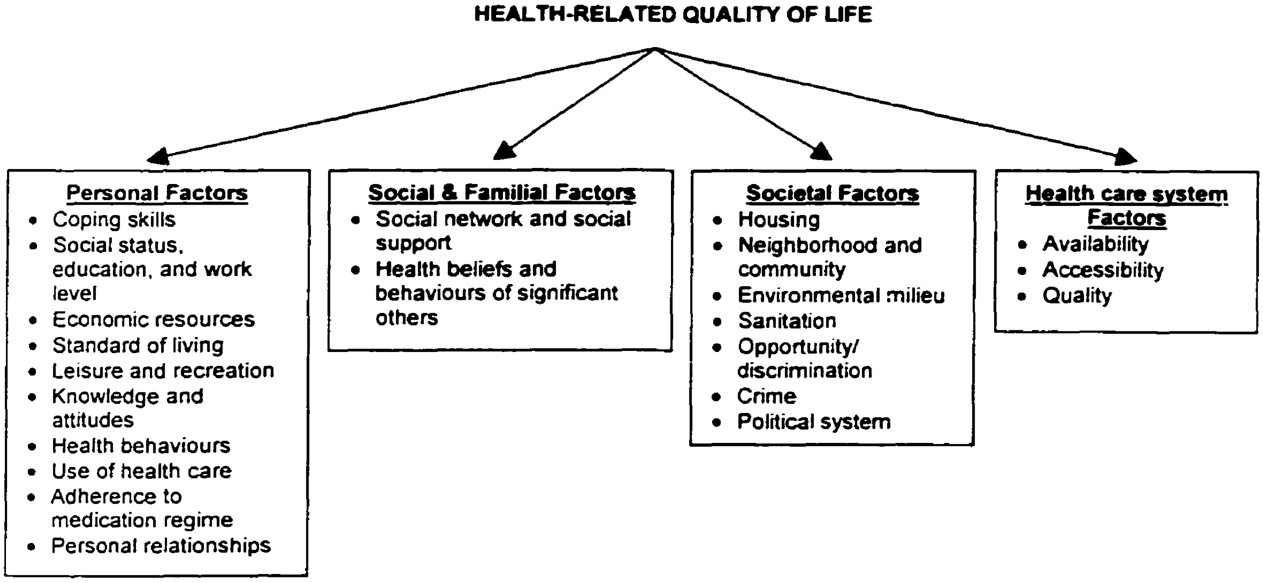
Townsend (1981) describes a three-dimensional model of dependency of which a PLWA potentially satisfies all three components. First, ***structured dependency*** (i.e. reliance on the state) is the result of loss of work and/or retirement. Second, ***physical dependency*** is defined as a functional incapacity or inability to carry out the essential activites of daily living. Third, ***behavioural dependency*** is often preceeded by physical dependency, and occurs when an individual must rely on others to fulfill self-care tasks. Western culture values independence, mastery, and activity as strengths and perceives reliance on others as weaknesses. Aging parents of PLWA are also launched into a state of flux. The parents of gay men with AIDS may be confronted with the dual disclosure of sexual orientation and HIV status for the first time. If the family does not reject the adult child and the alienation in the family is not to severe, parents, most probably the mother, may begin to assume the caretaker role again. "A time of role reversal is expected, when children will care for dying parents. When parents instead find themselves watching their child face death, a sense of tragic absurdity prevails" (Sourkes, 1982). At a time when the adult child was expecting to care for his aging parents, the roles are reversed, and it is the young adult requiring parental care once again. This change of roles threatens the adult need to assume financial and personal independence from their family of origin. The stigma and distance within the family may create a tenuous environment, which may be quite destructive. It is for these reasons, that many gay men with AIDS will turn to their "surrogate family" of partner and friends for more intimate and unconditional support.

(e) Psychological Changes

Quality of Life

There have been numerous attempts by researchers to operationalize the concept of quality of life to increase the validity of the global measurement. For the purposes of this present study the definition proposed by Croog and Levine (1989) will be used to highlight the nature of health-related quality of life. Croog and Levine conceptualized that health related quality of life includes performance of social roles, physiological status (including physical function and symptoms) emotional status, cognitive functioning, and sense of well-being. Outlined in Figure 2.45 are the four groups of factors that are believed to influence health status and quality of life (Bergner, 1985).

Figure 2.45
Components of Health-related Quality of Life



Quality of life assessments are effective in evaluating treatments and interventions (i.e. drug trials and psychosocial interventions), assessing individual needs of a client (similar to a diagnostic test), and evaluating policy options for purposes of formulating social and medical service delivery plans for specific groups of patients or communities (Wu & Lamping, 1994). There have been several HIV specific studies investigating the association between quality of life and physical and psychological health status. Lubeck & Fries (1992) found that lower health-related quality of life for HIV patients was associated with advanced disease, critical life events, and drug relapse. Valentine, Hedge, and Pinching (1993) also documented that psychological factors, including social support, coping, perceived stress, and self-rated physical health, were most strongly associated with quality of life in their sample of 92 HIV-positive clinical-trial participants. Zander et al. (1993) used the *Medical Outcomes Survey* (MOS-HIV) questionnaire to measure health-related quality of life, and they found that physical and psychological symptoms were related to quality of life. In a large national study in the United States of 520 HIV-positive persons, Wachtel et al. (1992) indicated that persons with HIV infection had considerably lower quality of life scores compared to other chronically ill adults. The study also suggested that the MOS survey was a reliable measure of quality of life, and was very sensitive to changes in circumstance.

Perhaps more significant, Kaplan et al. (1995) revealed that the quality of life in a sample of 514 HIV positive men was associated with psychological symptoms. It was also established that quality of well-being scores were significant prospective predictors of death over a median follow-up time of 30 months. One of the few studies of its kind, Ragsdale and Morrow (1990) studied quality of life at different stages of HIV infection in a cross-sectional sample of 95 HIV positive respondents. They determined that the impact of HIV on the physical and psychological health of respondents was greatest during the AIDS-related complex (ARC) stage prior to developing AIDS, and lowest in the HIV positive only group. It was suggested that this finding was a product of the uncertainty during the ARC stage of HIV. "It may be that uncertainty experienced by ARC diagnosed subjects produces degrees of anxiety, depression, anger, and somatization which decline (at least temporarily) on reception of a diagnosis of AIDS, thus moderating (the physical and pyschological) symptoms" (p. 358). Chuang et al. (1989) also found that level of psychosocial distress was highest among those persons with ARC in their sample of 65 gay and bisexual men. It was also proposed that the uncertainity and fear of the unknown pain and suffering to come with AIDS can present a greater threat to psychological health than confronting issues of death and dying, once in the terminal stage of AIDS.

In light of the new advances in the treatment and prevention of AIDS-defining illnesses, I would propose that the uncertainty experienced by persons with AIDS in 1998 is very similar to the extreme uncertainty of the ARC stage in 1990. The protease inhibitors have introduced a new hope for suppressing disease progression, but the possibility of viral mutation or resistance to medications always lurks in the background. The revitalized energy and hope associated with antiretroviral treatments is somewhat tainted by the uncertainty of potential unknowables. The media and many medical professionals emphasize the successful suppression of viral replication, which make HIV a chronic rather than terminal disease. Unfortunately, resistance to medications and/or intolerable side-effects are now being observed in some patients on ARTs. As Peter Aggleton (1997) stated at the *Third International Conference on the Biopsychosocial Aspects of AIDS*, "It is not the beginning of the end , but the end of the beginning."

Sexuality

Sexuality is deeply intertwined with feelings of self-esteem and body image. Intimacy has the power of boosting a person's body image through physical touch and emotional closeness. AIDS differs from other serious illnesses in that, for a majority of persons, it was contracted as a result of sexual lifestyle, and may be a source of guilt or unresolved conflict (Dupras, Morisset, & Pharand, 1997). There are several reasons why some PLWA do not have sexual contact: (1) fear of infecting others, (2) fear of disclosure of seropositive status due to potential rejection, (3) not interested or a lack of arousal due to side-effects of medications; (4) no partners available, (5) feeling unattractive, (6) too physically ill; and (7) fear of reinfection (Turner, 1995; Gochros, 1992; Adam & Sears, 1994). Ross and Ryan (1995) also suggested that a sick person with AIDS may engage in a self-quarantine. The self-imposed social isolation (Barrett, 1995) is an attempt to cope with internalized discourses of blame and guilt expressed by society.

Factors associated with Psychological Distress

The discrimination and subsequent alienation and rejection experienced by PLWA evokes feelings of shame, guilt, and anger. Because of these strong feelings of self-imposed and society-imposed blame, PLWA may go to extreme lengths to keep their diagnosis secret. This intricate web of secrecy inadvertently hinders their social support system, which is already limited. "The onset of AIDS also may force disclosure of previously disguised drug-use in drug-addicted patients (or homosexuality), which may weaken familial support" (Nichols, p. 765, 1985). PLWA face the daily challenge of coping with overwhelming uncertainty in addition to the psychosocial stresses associated with being stigmatized and feared. Moulton et al. (1987) studied the impact of self-blame among a sample of 103 persons with AIDS and ARC, and found that attributing the cause of the disease to the self was significantly correlated with dysphoria, including depression, anxiety, and negative mood, in PLWA. However, attributing self-responsibility for improvement does not have negative psychological effects and is positively associated with positive health behaviour changes.

The omnipresent threat of relapse and death creates an environment laden with sadness and uncertainty. "There is a sense of being suspended in space and time, without defined movement in either a forward or backward direction" (Sourkes, p. 56, 1982). No matter how much you try to abandon the illness, the threat of dying is ever-present and creating enormous stress for the patient and the family. A few AIDS patients described this feeling of uncertainty as. "...feeling like a 'walking time bomb,' 'just waiting for the next medical crisis or explosion' to occur" (Christ, Moynihan, and Silver, p. 384, 1988). This awful state of uncertainty contributes to a loss of personal control. The illness seems to take on a life of its own and the patient feels a lack of control over its direction. The physical and mental deterioration is frustrating and heart-wrenching for the patient and the family. "Convalescence, attendant care, medical equipment, and medication regimens are overwhelming issues for many patients. These issues fuel patient's fears of loss of independence and serve as constant reminders of the patient's fragile, vulnerable health" (Napoleone, p. 379, 1988).

The loss of function and disfigurement is a disturbing reality for AIDS patients. Opportunistic infections, such as Kaposi's sarcoma, leave visible lesions on the face, and increase social isolation and chances of losing employment due to HIV status. Diseases of the central nervous system, such as AIDS dementia, are the most disturbing to patients because it destroys their mental capacity to remember and control emotions. This loss of function elicits intense feelings of anger and sadness.

Helplessness and despair are evoked by the physically debilitating and life-threatening nature of the illness, the lack of medical treatment or cure, the severe economic impact of the disease, the difficulties in planning for the future, and the impact on intimate and family relationships (Thompson, Nanni, & Levine, 1996; Macks, 1988). Many patients experience a period when they become especially fatalistic and disinterested in life. This is a normal response to a diagnosis, which connotes no hope for survival and is associated with such negative consequences. The following excerpt captures these feelings of helplessness.

> Fearing the symptoms of an incurable illness can evoke intense feelings of helplessness and hopelessness...they may feel depressed by their helplessness and may withdraw or regress. Some patients may talk about suicide, a common response among AIDS patients that is usually related to their anger, fear of being isolated, and concerns about being unable to manage the disease (Christ, Moynihan, and Silver, p. 384, 1988).

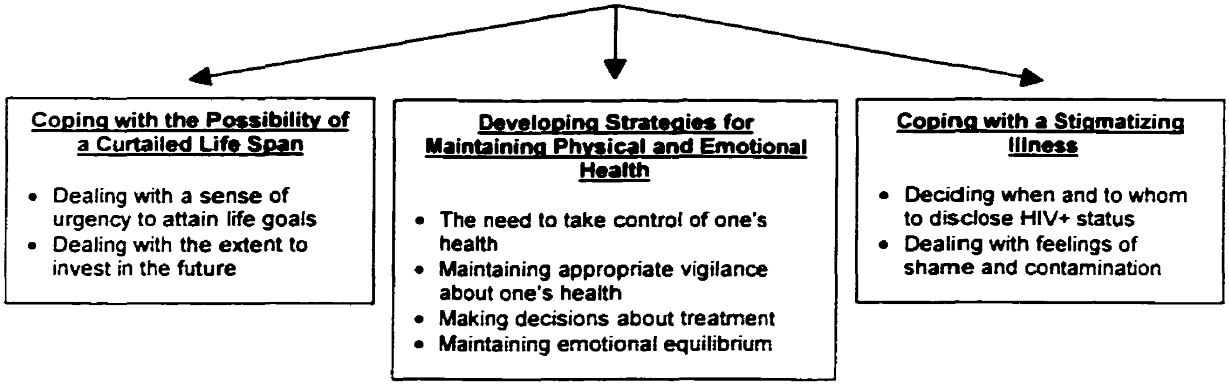
Kubler-Ross (1969) proposed that anger and depression are normal psychosocial reactions to life-threatening illness. Reactive and anticipatory depression may be triggered by feelings of anger and shame turned inwards. There are concurrent and past factors that may influence the person's susceptibility to psychological symptomology, such as substance abuse, past history of mental health problems, low self-esteem, financial difficulties, discrimination, and complicated mourning due to multiple loss of significant others (Kalichman, 1995).

There has been a lot of variance across studies investigating the prevalence of psychiatric disorders among PLWHA. Woo (1988) reported that the prevalence of mental health problems in HIV patients is as follows: (1) 17% of persons with AIDS met the criteria for depression; (2) 50% of hospitalized HIV patients experience adjustment disorder; and (3) up to 70% of those people with HIV disease will develop organic mental disorder, such as delirium and dementia. In general, the rates of depression among an HIV-positive population range from 4% to 38% whereas the normal rate of depression for the general population is 5% (Rabkin & Gewirtz, 1992). Lyketsos et al. (1993) studied 1809 HIV positive men without AIDS over an eight year period. They found that 21% of participants were classified as depressed at the first assessment. Depressed respondents had lower CD4+ counts and more AIDS-related symptoms. Depression did not independently predict a poorer outcome and shorter time to death. Burack (1993) conducted a similar longitudinal study of 66 months among a smaller sample of 330 homosexual and bisexual men. They found that 20% of the men were classified as being depressed overall at the baseline survey. The respondents who were depressed were significantly more likely to experience a decline in CD4+ count, but again depression did not correlate with early AIDS diagnosis or earlier mortality. It is difficult to draw any clear conclusion from these research studies, because the composition of the samples vary by risk behaviour (i.e. substance abuse) and stage of illness. Despite this lack of clarity and diverging results, it does seem that the prevalence of depression, as expected, is slightly higher in the HIV-positive population.

Coping Strategies

Coping resources can facilitate the adaptation to feelings of loss addressed in the above section. Siegel and Krauss (1991) developed an HIV-specific adaptational model based on their sample of 55 HIV positive gay men. There are three adaptive tasks of HIV positive gay men, which are illustrated in Figure 2.46. Outlining these cognitive and behavioural tasks is very useful for contextualizing a discussion of the different coping strategies observed in the HIV-positive population.

Figure 2.46
Adaptive Tasks for Seropositive Gay Men



Coping with the Possibility of a Curtailed Life Span

- Dealing with a sense of urgency to attain life goals
- Dealing with the extent to invest in the future

Developing Strategies for Maintaining Physical and Emotional Health

- The need to take control of one's health
- Maintaining appropriate vigilance about one's health
- Making decisions about treatment
- Maintaining emotional equilibrium

Coping with a Stigmatizing Illness

- Deciding when and to whom to disclose HIV+ status
- Dealing with feelings of shame and contamination

There is a general consensus among researchers that extreme expressions of denial, anger, depression, and suicidability are maladaptive ways of coping with HIV-related stress, because they are negatively associated with good physical and psychological health (Nyamathi & Servellen, 1989). A large proportion of studies analysing the coping patterns of HIV-positive persons consistently document that escape-avoidance coping, such as substance abuse and refusing to discuss HIV-related issues, is significantly associated with low self-esteem and psychological and physical symptomology (Wolf et al., 1991; Leserman et al., 1992; Nicholson & Long, 1990; Namir, Wolcott, Fawzy, & Alumbaugh, 1987; Korniewicz, O'Brien, & Larson, 1990; Barrett, 1995; Goodkin et al., 1992). However, there is varying agreement about the clear identification of adaptive coping techniques for HIV-related stress.

It seems that the appropriateness of coping strategies differs across the different disease stages. The benefits of social support are believed to have a buffering effect on stress across all disease stages, however those persons who are debilitated by AIDS-defining illnesses and requiring social support the most, are unfortunately the least likely recipients of support (Wolf et al., 1991; Namir et al., 1987). It seems that people will avoid persons experiencing mental and physical distress because of discomfort and fear of 'saying the wrong thing.' In addition, people who are feeling ill and fatigued may not have the energy to actively seek support from others.

The literature consistently reports a positive association between active-behavioural coping (i.e., seeking informational, tangible, and emotional support, and making changes to positively affect symptoms) and positive mood and self-esteem (Namir et al., 1987; Nicholson & Long, 1990; Wolf et al., 1992; Leserman et al., 1992; Byers, 1993; Kornieweicz, O'Brien, & Larson, 1990). The ability to positively influence symptoms through diet changes, decreasing stress. or maintaining a good medication regime, contributes to greater feelings of personal control. It seems that being equipped with knowledge regarding HIV and its symptoms also provides people with much needed feelings of control over their illness. However, sustained and persistent control beliefs in the very late stages of AIDS can interfere with coming to terms with death and life review processes (Reed, Taylor, & Kemeny, 1993). Some studies suggest that active-cognitive coping may lead to obsessional or ruminative thoughts about HIV, which are not associated with positive mood (Wolf et al., 1991, Namir et al., 1987).

Pollock (1986) refined Kobasa's (1979) term, hardiness, to apply specifically to those people with chronic illness. Hardiness, also referred to as a fighting spirit, is comprised of three psychological dimensions: commitment, challenge, and control. In early and asymptomatic stages of HIV disease, a fighting spirit positively contributes to better psychological health via better coping strategies (Byers, 1993; Solomon and Temoshok, 1987; Leserman et al., 1992).

Since life events alter social situations continually, coping mechanism are also subject to change. Clear conclusions are difficult to attain in coping research because coping constructs are unstable by nature.

3.0
RESEARCH HYPOTHESES

The overall objectives of this study are the following: (1) determine whether a sample of gay men diagnosed with AIDS aged 22 to 44 experience a "premature aging" effect (i.e., declining health, financial strain, social status & social network losses); (2) identify the type, frequency, and intensity of daily hassles and uplifts experienced by this population; (3) examine the coping styles of the sample; (4) examine the sample's exposure to discrimination; (5) determine the amount and impact of multiple social losses; (6) assess the degree of dependency on formal and informal support networks since being diagnosed with AIDS; and (7) measure the sample's preparation for death by examining the completion rate of advanced directives.

3.1 DESCRIPTIVE HYPOTHESES

H_1 Low annual incomes and a high percentage of respondents relying on government income support programs.

H_2 A large number of losses of friends and partners to AIDS.

H_3 A large proportion of participants will have completed advanced directives in preparation for disability and death.

H_4 A significant amount of participants will report having required additional tangible and emotional support from formal and informal support networks since being diagnosed with AIDS.

H_5 High frequency and intensity of daily hassles concerning health and finances.

H_6 High frequency and intensity of daily uplifts concerning social activities with friends.

H_7 A large proportion of participants feeling uncertain about their future.

H_8 A large proportion of participants feeling a loss of control.

H_9 A significant proportion of participants concerned about stigma and/or discrimination.

H_{10} Relatively low levels of physical quality of life.

H_{11} Relatively low levels of psychological well-being.

H_{12} Comparatively more active/problem-solving coping strategies.

3.2 RELATIONSHIP HYPOTHESES

H_{13} No correlation between income levels and education levels.

H_{14} Annual income positively associated with the frequency of hassles regarding finances for basic needs and leisure activities.

H_{15} Annual income positively associated with health-related quality of life.

H_{16} Number of loss of friends and partners to AIDS positively associated with bereavement grief and lower levels of psychological well-being.

H_{17} Frequency and intensity of hassles negatively associated with health-related quality of life.

H_{18} Frequency and intensity of uplifts positively associated with health-related quality of life.

H_{19} PLWA sharing health and finances as top concerns with the elderly.

H_{20} PLWA reporting increased frequency and intensity of hassles relative to the elderly.

H_{21} Feelings of lack of control and uncertainty positively associated with lower levels of health-related quality of life.

H_{22} Active coping styles positively associated with health-related quality of life. increased vigour and increased self-esteem

H_{23} Escape-avoidance coping positively associated with the frequency of hassles and negatively associated with health-related quality of life and self-esteem.

H_{24} Health-related quality of life negatively associated confrontive and accepting responsibility coping.

H_{25} Positive reappraisal positively associated with health-related quality of life.

H_{26} Seeking social support as a coping strategy positively associated with health-related quality of life and self-esteem.

H_{27} Number of months in a committed relationship positively correlated with health-related quality of life.

4.0
METHODOLOGY

4.1 SAMPLE

The results presented in this paper are derived from a cross-sectional sample of thirty two self-identified gay men aged twenty-two to forty-four with an AIDS diagnosis. The sample was recruited from the Immunodeficiency Program at the Montreal Chest Institute, Royal Victoria Hospital in Montreal, Canada. The 22 to 44 age range was selected to represent the young and middle adulthood stages of the life span. The respondents were also selected on the basis of their illness progression. Participants must have been diagnosed with an AIDS-defining illness in the past to be eligible for the study. The AIDS diagnosis criterium was established to achieve a group of men who had already experienced a life-threatening illness. It was also decided that patients having an active social service dossier at the time of the recruitment would not be actively approached for the study to avoid authority/coercion bias. Because the investigator was the clinic social worker, she was responsible for the psychosocial care and treatment of those patients who requested or were referred to social services. If the patient volunteered his participation on the basis of advertising at the clinic, then he would be accepted.

The sampling population included all patients who were registered with the Immunodeficiency Program at the Montreal Chest Institute, Royal Victoria Hospital in the fiscal year of 1995 to 1996. The sampling element is the individual patient at the clinic. The total number of patients registered with the clinic (i.e. HIV negative partners, HIV positive persons without AIDS, and persons with AIDS) in the 1995/1996 fiscal year was 759 patients. The population parameters were specified as patients who had received an AIDS diagnosis (as defined by the World Health Organization- i.e. having had an opportunistic infection), were self-indentified gay men, and between the ages of 22 to 44. The total number of AIDS patients, the sampling frame, was operationalized using the patient data base. There was a total of 217 patients in the clinic who were eligible on the basis of their AIDS status. Participants ranged from clinically stable to those experiencing current active infections. However, patients being hospitalized for major infections or receiving day hospital treatments who were too ill or weak to complete a questionnaire of approximately 45 minutes were not approached. Table 4.11 below indicates that there was a total of 166 hospital admissions for AIDS patients in 1995/1996 with an average hospital stay of 21.9 days. In addition, there was a total of 232 individuals receiving AIDS-related treatments in the day hospital.

Table 4.11
Summary of Patient Statistics for the Immunodeficiency Program at the Montreal Chest Institute, Royal Victoria Hospital for the 1995/1996 Fiscal year

	TOTAL
Number of new patients	230
Number of HIV- patients	9
Number of HIV+ patients	303
Number of AIDS patients	217
Total number of admissions for HIV patients	19
Average length of stay (days) for HIV patients	13.7
Total number of admissions for AIDS patients	166
Average length of stay (days) for AIDS patients	21.9
Number of individual patients receiving major day hospital treatments (aerosolized pentamadine, IV pentamadine, transfusion, chemotherapy, IV CD8 infusion, IV foscarnet, IV gancyclovir, IV rhogam, IV ampho B, IV other	232

The total recruitment aim for this study was forty participants to reflect a 10% allowable error with an associated confidence level of 84%. However, this total sample size was not attained due to time limitations and a patient population that was inundated with numerous recruitment requests for other research studies. The final sample size of thrity-two particpants reflects a 12% allowable error with an associated confidence interval of 86%.

A purposive effort was made to achieve a sample that is reflective of the language composition of the clinic, which is approximately 60% francophone respondents and 40% anglophone respondents. These estimates of language composition were determined on the basis of an analysis of patient database summaries.

4.2 SAMPLING PROCEDURES

Prior to initializing recruitment efforts, a proposal for this research study was presented to the Montreal Chest Institute Ethics Committee for review. The study was approved on December 19, 1996, and the recruitment phase ensued shortly thereafter and lasted until July 1997. It was agreed that all patient consent forms were to be kept in a locked filing cabinet.

Quota sampling and snowball sampling methods were used to recruit participants. The general clinic population was broken down into stratas, and the persons satisfying the inclusion criteria were then approached by their physician or treating nurse. In addition, word of mouth from friends and other patients was also an effective recruitment method. The advertisement at the clinic reception desk also reminded people of the study at each visit. There were several factors that prevented the investigator from adopting random sampling techniques: (1) limited staff availability, which prevented staff from meeting patients at their clinic visits any time of the week; (2) there were an insufficient number of volunteers to cover the research demands whilst the investigator was not at the clinic; (3) inadequate funding to cover the transportation costs to the hospital for those patients willing to come during non-scheduled appointment times.

The research study was advertised throughout the clinic and the medical team at the clinic was largely responsible for recruitment. The team of nurses and physicians was given a list of the inclusion criteria, and they approached patients individually. If the patient agreed to talk with the researcher, then she would meet with the patient and explain the purpose of the study, the study requirements, and the rights of the research participant to decline participation at any time. It was also stated that participation in the study was to remain confidential, and the results of the questionnaires were to be anonymous. The investigator was not ethically permitted to approach patients directly due to a potential authority-based coercion bias. Some respondents were constrained by time limitations, and therefore may not have had adequate time to complete the entire questionnaire at the clinic. These participants were given the opportunity to complete it at home. However, the necessity for the questionnaire to be completed in the same day of commencement was emphasized to the respondents in order to avoid bias across instruments.

The duration of the recruitment phase was seven months (January to July 1997), and a total of forty persons were approached to fill out the questionnaire. A total of two people declined participation (5.0% refusal rate), which was considered very positive in this research flooded environment. However, out of the thirty-eight persons who consented to participate in the study, only thirty-two (84.2%) of them returned the completed questionnaire to reception. Of those thirty-eight consenting people, seven of them contacted the investigator prior to physician contact requesting further information and participation. Word of mouth and the advertisement in the clinic seemed to be the main sources of information about the study for these men.

4.3 INSTRUMENTS

All of the respondents were asked to complete a detailed informed consent form before commencing the self-administered questionnaire. Please refer to Appendix 2 for the study's questionnaire. The objective of the study was explained and the right of the research participant to ask questions and leave the study at any time was emphasized. The questionnaire was reviewed with each respondent and any questions or concerns were clarified. If completed at the clinic. I was available for queries while the questionnaire was being filled out by the respondents. The questionnaire was pre-tested on 5 patients and was estimated to take approximately 45 minutes to one hour to complete.

The questionnaire was designed to assess the biological, social, and psychological changes that occur with AIDS. As such, it was designed to evaluate the daily stresses, specific AIDS-related concerns, health-related quality of life, and the coping strategies adopted to deal with the aforementioned stress. In addition, certain sociodemographic information was also collected.

The *Combined Hassles and Uplifts Scale* (Folkman & Lazarus, 1989) measures daily hassles which involve irritating, frustrating, and distressing occurences experienced on a day-to-day basis, and daily uplifts which tend to buffer or provide a breather from the negative impact of the hassles. The participants were asked to rate a total of 54 individual items as either or both a hassle and/or an uplift on a 4-point Likert scale ranging from "none or not applicable" to "a great deal." This scale assesses events appraised by the person as stressful and enjoyable (i.e. subjective not objective measures), and therefore the items have a reasonably high degree of face and content validity (Folkman & Lazarus, 1989). The individual questions of both scales can be grouped into seven main components: family and friends, work, finances, lifestyle issues, health, home maintenance, environmental, political, and social issues. This instrument was selected because of its extensive use among diverse populations, including the elderly.

The frequency of the hassles scores have been found to be quite stable over time, suggesting that hassles scores have both trait and state characteristics. Kanner et al. (1981) re-tested the scale over a 9 month period and found that the reliability or stability of the frequency of hassles was quite good (r=0.79), whereas the stability of the intensity of hassles was lower (r=0.48).

The *Impact of HIV Scale* (Lamping, Sewitch, Clark, & Ryan, 1990) measures HIV-related concerns and distress in the past month. The 40-item instrument has a 5-point Likert scale ranging from "not at all" to "a lot." The variables can be generally grouped into six components: personal factors, loss of autonomy, health-related issues, interpersonal issues, death and dying, and concrete concerns (financial, legal, etc.). As this instrument extensively measures subjective

HIV-related concerns, it has considerable face and content validity. This instrument has been standardized with a Montreal sample of gay men, and therefore was disease specific and culturally appropriate.

The Ways of Coping Scale (Folkman & Lazarus, 1988) measures the degree to which the participant uses different styles of coping on a 4-point Likert scale ranging from "not used" to "used a great deal." A total of 73 items are used to assess the respondent's coping mechanisms in relation to a stressful event named by the respondent at the beginning of the scale. The instrument has been classified into the following eight sub-scales: *confrontive coping* (6 items; e.g. "stood my ground and fought for what I wanted"), *distancing* (6 items; e.g. "went on as if nothing had happened"), *self-controlling* (7 items; e.g. "I tried to keep my feelings to myself"), *seeking social support* (6 items; e.g. "talked to someone to find out more about the situation"), *accepting responsibility* (4 items; e.g."realized I brought the problem on myself"), *escape-avoidance* (8 items; e.g. "wished that the situation would go away or somehow be over with"), *planful problem-solving* (6 items; e.g. "just concentrated on what to do next- the next step"), and *positive reappraisal* (7 items; e.g. "changed or grew as a person in a good way").

The face validity and construct validity of the *Ways of Coping Scale* are considered to be very good (Folkman & Lazarus, 1988). The instrument has confirmed the existence of two prominent coping processes: emotion-focused and problem-focused. This instrument was chosen because of its extensive use in large age-graded populations in both the United States and Canada, and its impressive reputation. Because the questionnaire measures coping processes, which, by defintion, are subject to change, traditional test-retest estimates of reliability are inappropriate. Tests measuring the internal consistency of the scale have shown that the Cronbach's alpha coefficient range from a fairly low score of 0.61 for the distancing scale to 0.79 for the positive reappraisal scale, which are considered higher than other instruments measuring coping processes (Billing and Moos, 1981).

The Medical Outcomes Survey (MOS): SF-36 (Ware, 1991) is a 36-item instrument for measuring health status from the patient's point of view. The survey measures the following eight health concepts, which are relevant across age, disease, and treatment groups: (1) limitations in physical activities because of health problems; (2) limitations in usual role activities because of physical health problems; (3) bodily pain; (4) general health perceptions; (5) vitality (energy and fatigue); (6) limitations in social activities because of physical or emotional problems; (7) mental health (psychological distress and well-being). Again this research instrument was used because of its vigourous testing in different patient populations and with varying age groups. This scale also had the added benefit that it was already standardized for a French-Canadian population. Estimates of reliability range from 0.76 to 0.90 on the eight sub-scales in a large sample of 9,332 persons in the general U.K. population, to 0.78 to 0.93 in a sample of 3.445 persons with one or more chronic conditions (Ware et al., 1993). The 'social functioning' scale is the one most prone to variation. McHorney. Ware, and Raczek (1993) assessed the validity of the SF-36 instrument with psychometric and clinical standards. They found that the physical functioning and mental health scales are relatively pure. It appears that these two scales are most sensitive to the clinical symptoms of medical and psychiatric conditions. It is suggested that a comprehensive assessment of the burden of disease on quality of life requires multidimensional factors, which include variations in disability, personal evaluations of health, and general well-being. The SF-36 instrument provides this multidimensional assessment of health-related quality of life with excellent validity.

In addition to the standardized instruments above, a battery of other questions (i.e., *Basic Profile Information*) were formulated to assess the following information: (1) socioeconomic status; (2) number of losses of significant others to AIDS; (2) religious denomination and commitment to religion; (3) time since receiving an HIV and AIDS diagnosis; (4) CD4+ count, which represents the number of white-killer blood cells present in the body (<250 = a very weakened immune system, and 600 to 1000 = healthy immune system); (5) preparation for disability and death, which is assessed with three "yes/no" questions addressing the completion of advanced directives. The maximum score for preparedness is three and the minimum score of preparedness is six. (6) The degree of role shifting and potential dependency, which is assessed with seven "yes/no" questions addressing the increased need to seek emotional or tangible support from informal (i.e. partner, friends, and family) and formal supports (i.e. CLSC and community organizations). The scale ranges from a score of 7 (maximum dependency) to a score of 14 (minimum dependency). This section of questions appears to have good face validity and content validity.

All of the instruments above, with the exception of the *Basic Profile Information*, are standardized, and were professionally translated into French by the McGill University Translation office.

5.0
DESCRIPTIVE ANALYSIS

5.1 PROFILE OF SAMPLE

This sample of thirty-two self-identified gay men has an average age of 35.9 years with the minimum age being 27 years and the maximum age being 44 years. The sample is fairly homogenous being predominantly white (87.5%, n=28). However, the sample is also represented by two Latin American respondents, one Afro-Caribbean participant, and one person marked "other" without further specification. The language composition of the sample parallels that of the medical clinic with 56.3% (n=18) of participants speaking French as their mother tongue, and the remainder (40.6%) speaking English. As expected, religious denomination reflected the language composition of the sample with 62.5% (n=20) identifying themselves as Roman Catholic, 18.8% reporting being Christian, and an additional six persons (18.8%) indicating "no religion." A good proportion of the sample (43.7%, n=14) reported that religion or spirituality was at least somewhat more important in their life since being diagnosed with AIDS.

The mean amount of time since receiving an AIDS diagnosis was 2.7 years (SD=1.6) for the entire sample. Therefore, the majority of the sample had already outlived the life expectancies of a PLWA (i.e. average of 2 years until death following an AIDS diagnosis) statistically defined in 1991 (Bartlett and Finkbeiner, 1991). The vast majority of respondents (65.6%, n=21) have been living with HIV since 1991 or earlier. The mean CD4+ count for this sample is 201.8 (SD=226.1).

There are fourteen men (43.8%) who indicated that they were in a stable relationship, and the remainder portion (56.3%) reported being single at the time of completing the questionnaire. Those persons who were engaged in a long-term same-sex relationship reported being with their partner for an average of 38.8 (SD = 54.7) months.

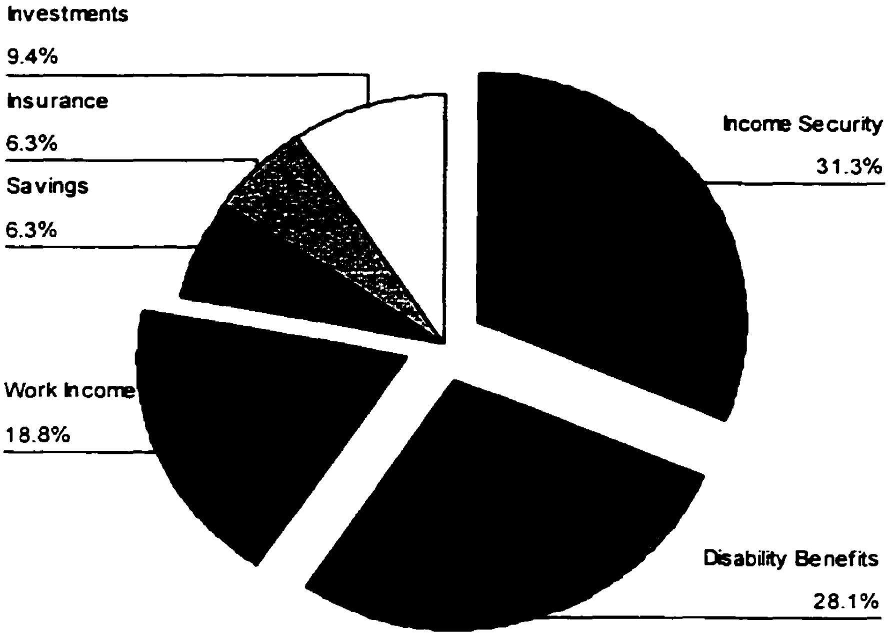
5.2 DESCRIPTIVE HYPOTHESES

H_1 Low annual incomes and a high percentage of respondents relying on government income support programs. <u>CONFIRMED</u>

The overall economic status of the sample is quite depressed, and thus confirmed the first hypothesis. While a large percentage of men (56.3%, n=18) had completed university education, a disproportionate amount of the sample was represented by persons earning less than $30,000 per year (81.3%, n=26). The number of respondents earning less than $10,000 per year (34.4%)

paralleled the number of participants receiving income security benefits (31.3%). Graph 5.21 below illustrates the source of income received by the participants in this study. The graph clearly shows that only 18.8% of the sample received work-related income, while the remainder struggled with fixed incomes from government disability benefits (28.1%), savings (6.3%), and investments (8.7%).

Graph 5.21
Sources of Annual Income



As expected from the low fixed incomes of the sample, the majority of men (62.5%) reported sharing their place of residence with at least one other individual. A large segment of the sample (56.3%) rented their residence, while four persons rented a room in AIDS-related accommodations, such as a hospice (6.3%) or shared an apartment complex for PLWA (12.6%). A total of 21.9% of respondents (n=7) reported owning their own home.

H_2 A large number of losses of friends and partners to AIDS. ***<u>CONFIRMED</u>***

The mean number of friends and partners lost to AIDS was very high at 9.6 (SD=11.5) persons. The multiple loss was staggeringly high for some of the respondents, reaching as much as 50 losses of significant others to AIDS. The open-ended question asked respondents to recall how many significant others they have lost to AIDS. It was also suggested that they write down the person's initials to help them remember the accurate number of losses, but these names were not recorded. Some respondents wrote an endless list of friends and partners they have grieved for since the beginning of this epidemic.

H_3 A large proportion of participants will have completed advanced directives in preparation for disability and death. <u>PARTIALLY CONFIRMED</u>

As mentioned previously in the *Methodology* section, a basic scale was constructed to assess the respondent's preparedness for death by asking whether the respondent had completed three types of advanced directives, including a mandate, power of attorney, and funeral arrangements. Table 5.22 below indicates the number of participants who reported having completed each type of advanced directive. The mean preparedness for death is 4.3 (SD=1.3) on a scale where the maximum preparedness is three and the minimum is six. A large percentage of the sample (62.5%) completed a mandate, which confirmed the hypothesis. A significant portion had completed power of attorney forms (53.1%), and funeral arrangements (37.5%), but the percent endorsement for these last two items was not as overwhelming as expected.

Table 5.22
Respondents Reporting the Completion of Advanced Directives

Type of Advanced Directive	% Endorsement
Completed a Mandate	62.5% (n = 20)
Completed Power of Attorney	53.1% (n = 17)
Completed Funeral Arrangements	37.5% (n = 12)

H_4 A significant amount of participants will report having required additional tangible and emotional support from formal and informal support networks since being diagnosed with AIDS. <u>CONFIRMED</u>

The degree of dependency on others was also assessed in the "*Basic Profile Information*" section of the questionnaire. A crude scale was formulated to evaluate whether the respondents sought additional tangible and emotional support from informal and formal support structures since being diagnosed with AIDS. The percentage of persons endorsing the seven items on the scale is presented in Table 5.23. The results confirm the hypothesis. A very large percentage (93.8%) of respondents reported requiring additional support from friends. In addition, over half (62.5%) of the men still turn to the parents for tangible or emotional support, but few (n=5) turn to other family members. In terms of formal support systems, almost half (46.9%) of the sample received support from community organizations and over a third (34.4%) required greater tangible support (i.e. meals on wheels, home maintenance, monitoring medication intake, and medical assistance) from CLSCs (Community Health Care Centres). The mean degree of dependency was 10.3 (SD=1.5) on the scale which ranged from a possible minimum dependency score of fourteen to a maximum score of seven.

Table 5.23
Respondents reported seeking tangible and emotional support from the following sources since being diagnosed with AIDS

Source of Support	% Endorsement
Friends	93.8% (n = 30)
Parents	62.5% (n = 20)
Other family members	15.6% (n = 5)
Partner	56.3% (n = 18)
Siblings	56.3% (n = 18)
Community Organizations	46.9% (n = 15)
CLSC (Community Health Care Centres)	34.4% (n = 11)

5.3 DAILY HASSLES AND UPLIFTS

The frequency of daily hassles has been shown to be a better indicator of health than the severity of hassles (Folkman and Lazarus, 1989). In this sample, the mean number of hassles per day is 20.0 (SD=9.3) out of a maximum of 54, and the mean severity of hassles is 1.5 (SD=0.6) on a 4-point Likert scale ranging from 0 to 3. Similarly, the frequency of daily uplifts is a better indicator of mental health than the actual intensity of uplifts. In this sample, the mean number of uplifts per day is 23.5 (SD=9.5) out of a maximum of 54, and the mean intensity of uplifts is 1.5 (SD=0.6) on a 4-point Likert scale ranging from 0 to 3. The respondent was able to mark any individual item as either a hassle or an uplift, or both a hassle and an uplift if applicable. For example, many participants indicated that their medical care was both a hassle and an uplift.

H_5 High frequency and intensity of daily hassles concerning health and finances. *CONFIRMED*

An analysis of the percentage of persons endorsing each item and its corresponding mean intensity was calculated for the combined *Hassles and Uplifts Scale*. Table 5.31 below lists the top ten daily hassles for the sample, which, as hypothesized, center on issues related to health and finances. Physical appearance, physical abilities, and effects of medication are all AIDS-related issues. Daily stresses regarding political and social issues may reflect the stigmatized status of PLWA and the subsequent interest in following political efforts to ease the obstacles of bureaucratic and discriminatory laws and regulations. The daily hassle of paperwork may be associated with the demands of filling out forms for income security or disability benefits.

Table 5.31
Top Ten Daily Hassles

RATING	Hassle Item	% Endorsement	SD	Mean Severity	SD
1	Enough money for necessities	84	0.37	1.88	1.10
2	Your health	81	0.40	1.59	1.10
3	Enough money for emergencies	78	0.42	1.81	1.26
4	Paperwork	75	0.44	1.28	1.02
5	Physical abilities	72	0.46	1.13	0.91
6	Physical appearance	72	0.46	1.22	1.01
7	Enough money for extras	72	0.46	1.50	1.19
8	Political & social Issues	63	0.49	1.16	1.11
9	Medical care	63	0.49	1.06	1.08
10	Effects of medication	59	0.50	1.06	1.16

H_6 High frequency and intensity of daily uplifts concerning social activities with friends. ***CONFIRMED***

Table 5.32 below lists the top ten uplifts for this group of 32 men. There seems to be less variation and disagreement in this sample when considering uplifts. There is an interesting dichotomy between the nature of the uplifts. As hypothesized, the sample reports deriving pleasure from social interaction with partner and friends, but, alternatively, a sense of contentment also comes from spending time alone at home cooking and enjoying basic home entertainment.

Table 5.32
Top Ten Daily Uplifts

RATING	Uplift Item	% Endorsement	SD	Mean Severity	SD
1	Eating at home	97	0.18	1.84	0.81
2	Home entertainment	97	0.18	2.16	0.68
3	Recreation and entertainment outside the home	94	0.25	2.06	0.88
4	Friends	88	0.34	2.09	1.09
5	Amount of free time	88	0.34	1.97	1.06
6	Time alone	81	0.40	1.50	0.98
7	Cooking	78	0.42	1.66	1.07
8	Intimacy	75	0.44	1.50	1.08
9	Being organized	72	0.46	1.41	1.16
10	Your physical appearance	63	0.49	1.00	0.98

5.4 AIDS-RELATED CONCERNS

H_7 A large proportion of participants feeling uncertain about their future. CONFIRMED

This scale was used to assess the specific HIV-related concerns among this sample. Table 5.41 indicates, not surprisingly, that the top two concerns are dealing with the effects of a curtailed life span. As hypothesized, uncertainty about the future (84%) and not being able to realize life goals of (78%) are of utmost concern to these young men and are rated with great intensity (mean=3.1, SD=1.4 and mean=3.3, SD=1.6 respectively). The other concerns center on the fear of physical deterioration, current antiretroviral treatments, and psychological symptoms. such as depression and anxiety. The anxiety associated with disclosure of seropositive status is expressed by 65% of the men. The fear of losing physical autonomy is represented in the concern of not being able to care for oneself in the future. Even though a large percentage of the sample had already completed some basic advanced directives, such as a mandate and power of attorney. there continued to be concern over concrete planning for the future (65%).

Table 5.41
Top 10 Items of HIV-related Concerns

RATING	Item of Concern	% Endorsement	SD	Mean Severity	SD
1	Feeling uncertain about the future	84	0.37	3.06	1.41
2	Not being able to realize life goals	78	0.42	3.31	1.64
3	Side-effects of medication	75	0.44	2.44	1.29
4	Getting sick or sicker	75	0.44	2.44	1.29
5	Feeling depressed	75	0.44	2.59	1.32
6	Feeling anxious	72	0.47	2.84	1.48
7	Concern about not being able to Care for myself	69	0.47	2.53	1.41
8	Feeling Isolated	69	0.47	2.25	1.22
9	Telling Others	65	0.48	2.13	1.07
10	Planning for my future care (Living will, power of attorney, etc.)	65	0.48	2.31	1.28

H_8 A large proportion of participants feeling a loss of control. CONFIRMED

H_9 A significant portion of participants concerned with stigma and/or discrimination. CONFIRMED

The majority of the sample (59%) reported being concerned with a loss of control, and expressed this concern with great intensity. The mean score for feeling a loss of control is 2.4 (SD=1.6) on a 5-point Likert scale ranging from 0 to 5. Just under half of respondents (44%) endorsed the item of concern dealing with the fear of being discriminated against with a mean intensity of 2.0 (SD=1.4).

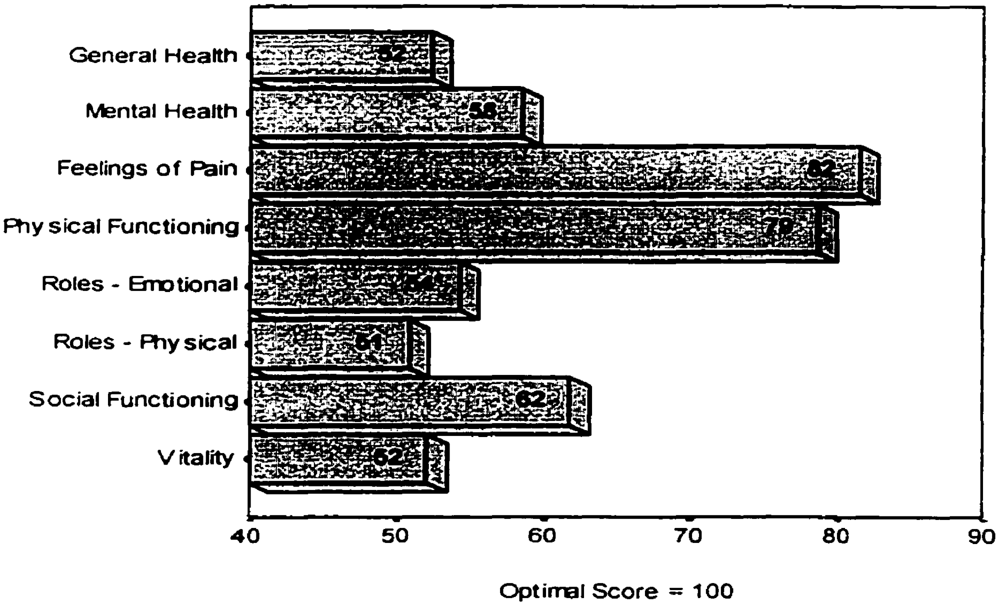
5.5 HEALTH-RELATED QUALITY OF LIFE

H_{10} Relatively low levels of physical quality of life. CONFIRMED

H_{11} Relatively low levels of psychological well-being. CONFIRMED

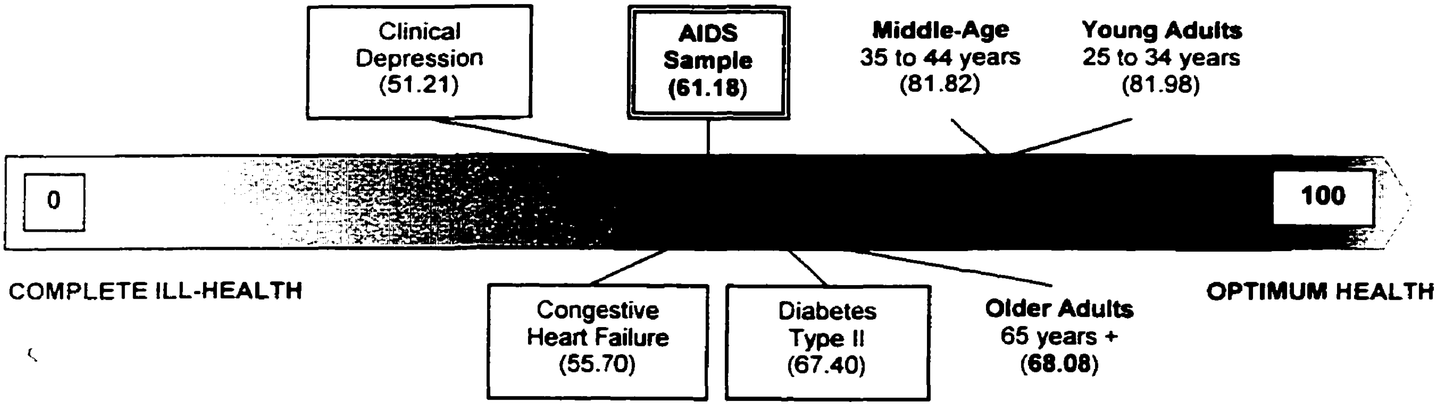
The SF-36 measures health-related quality of life across eight biopsychosocial dimensions. Graph 5.51 below illustrates the overall mean scores for the eight sub-scales, which are rated out of a possible optimal health score of 100. Feelings of pain and physical functioning appear relatively high compared to the low levels of general health, mental health, degree of vitality, social functioning, and role disruption as a result of physical and emotional problems. Therefore, the above hypotheses were confirmed by the results indicating that this sample has relatively low levels of mental health and general health.

Figure 5.51
Health-related Quality of Life Indicators



The mean overall score for health-related quality of life across all eight dimensions of physical and psychological health is 61.8 out of a total of 100 for this sample. Contrasting quality of life scores were collected from various studies with diverse age and patient populations from Ware's (1993) comparative list of SF-36 results. Figure 5.52 below illustrates the location of this sample's quality of life score in relation to older and younger adults, and other patient populations, including persons with clinical depression, congestive heart failure, and type II diabetes. The overall quality of life of this sample more closely resembles someone of old age, and those patients with severe diabetes and congestive heart failure.

Figure 5.52
Health-related Quality of Life Compared by Age Group and Chronic Illnesses



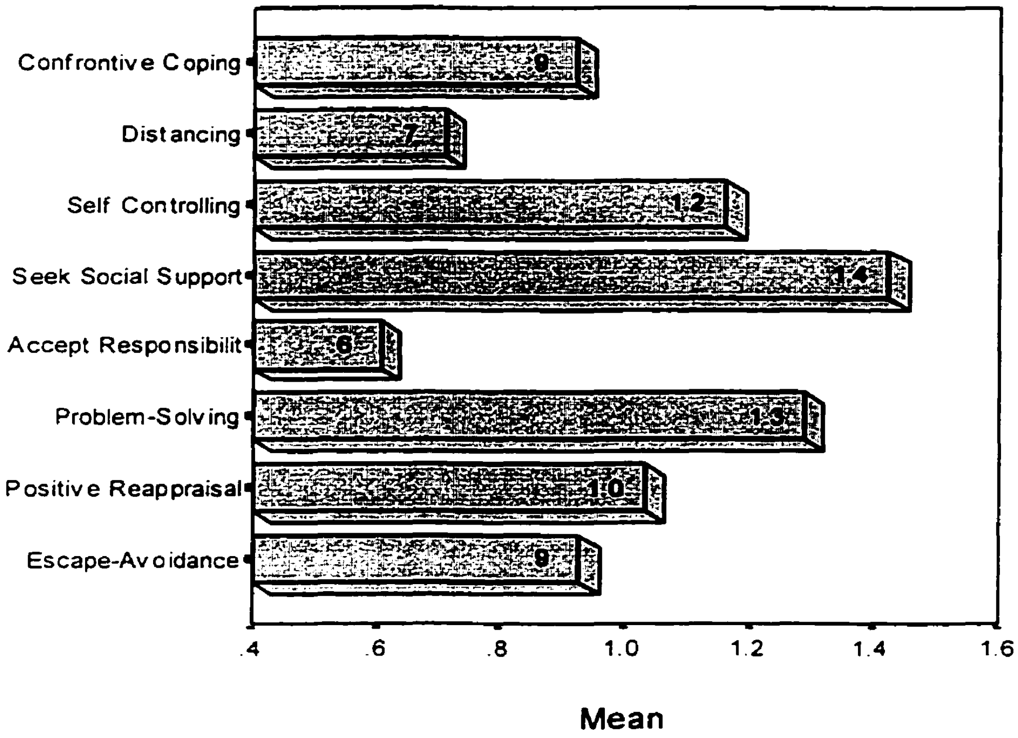
5.6 WAYS OF COPING

The *Ways of Coping* scale measures the person's coping strategies in relation to a particular stressful event across 73 items. The respondent was instructed to write an open-ended account of an event or experience that was stressful in the past week. The qualitative responses can be grouped into seven main categories: (1) *Relationships* with friends and/or partner (25%, n=8). There were a few men who discussed sadness regarding a recent break-up with a long-term partner. (2) *AIDS-related limitations or illnesses* were reported by seven men (22%), who wrote specifically about certain illnesses and physical inabilities; (3) Issues relating to *antiretroviral medications* were reported by five men (16%). The stress was associated with the following factors: anxiety regarding recent resistance to a medication regime, increasing viral load, a lack of information of the medication effects, or financial ability to pay for the medications. (4) *Work-related issues* were indicated by a total of five men (16%). One respondent wrote, "I am learning to cope with the fact, I'm unable to work, and my enthusiasm for wanting to work and leading a normal life has made me feel low." (5) *Financial difficulties* were alluded to in the above named stresses indirectly, but were directly indicated by three men (9%). (6) *Isolation and loneliness* were reported by two men (6.3%). One respondent simply wrote, "staying in my room," while another man wrote, "Je me pose beaucoup de questions à savoir pourquoi une personne qui le voudrait s'intéresserait à moi." (7) *Housing problems* were indicated by two men (6.3%) who spoke of longstanding problems with their landlords.

H_{12} Comparatively more active/problem-solving coping strategies. ***<u>CONFIRMED</u>***

Similar to the health-related quality of life measure, this scale measures the individual's coping processes across eight sub-scales. The mean intensity of each scale is calculated along a 4-point Likert scale ranging from 0 to 3, and is presented in Graph 5.61 below. This sample uses active coping methods, such as seeking social support (18%), and planful problem-solving (17%), relatively more than emotion-focused strategies, such as accepting responsibility (8%), escape avoidance (11%), distancing (11%), confrontive coping, and self-controlling coping (12%).

Graph 5.61
Mean Intensity Scores for the Eight Coping Scales



In addition to the eight coping sub-scales calculated above, the individual responses for the 73 items were also rated by percent endorsement and mean intensity. The top ten coping items adopted by this sample are presented in Table 5.62 below. Unlike the high relative use of active coping methods, the top ten individual coping items were an interesting mix of items from the planful problem solving, seeking social support, escape avoidance, and self-controlling coping scales. A very large proportion of respondents (94%) indicated that they talked to someone about their feelings and tried to analyse the problem. Self-controlling methods of coping are evident in the "stiff upper lip" (84% endorsement) item and the item reporting efforts to prevent emotional interference (78% endorsement). Positive reappraisal of stressful events was also used by 81% of respondents in attempt to change the psychological effects of the event. Another important finding is that 78% of respondents indicated using wish fantasies to cope with the stress.

Table 5.62
Top Ten Coping Items

RATING	Coping Item	% Endorsement	SD	Mean Intensity	SD
1	I talked to someone about how I was feeling	94	0.25	1.84	0.95
2	I tried to analyse the problem in order to understand it better	94	0.25	1.91	0.89
3	I maintained my pride and kept a stiff upper lip	84	0.37	1.56	0.98
4	Just concentrated on what I had to do next	81	0.40	1.63	1.04
5	I told myself things that helped me feel better	81	0.40	1.34	0.97
6	I wished I could change what had happened or how I felt	78	0.42	1.41	1.19
7	I tried to keep my feelings from interfering with other things too much	78	0.42	1.28	0.99
8	Talked to someone to find out more about the situation	75	0.44	1.53	1.16
9	Tried not to burn my bridges, but leave some things open	75	0.44	1.16	0.95
10	I had fantasies or wishes about how things might turn out	75	0.44	1.41	1.19

6.0
ANALYSIS OF RELATIONSHIPS

6.1 RELATIONSHIP HYPOTHESES

* A significance level of $p<0.05$ is used as a cut-off point for significant relationships in this section.

H_{13} No correlation between income levels and education levels. CONFIRMED

As hypothesized, there is an independent relationship between annual income and educational attainment ($r=-0.134$, $p<0.464$). It seems that education levels, already indicated as being relatively high for this sample, are not related to increasing financial status. Financial resources existing prior to having AIDS may have been related to education level, but past financial information was not gathered in the questionnaires.

H_{14} Annual income positively associated with the frequency of hassles regarding finances for basic needs and leisure activities. NOT CONFIRMED

Annual income reported by respondents in the *Basic Profile Information* of the questionnaire is not significantly associated with an increased number of hassles relating to any of the finance items on the *Hassles and Uplifts Scale*. However, lower annual income is related to increased concern over financial difficulties ($r=-0.456$, $p<0.009$) on the *Impact of HIV Scale*. As expected from the basic premise of the hypothesis, financial worries decrease as annual income increases. In addition, concern over financial difficulties is significantly associated with all of the daily financial hassle measures, including money for necessities ($r=0.597$, $p<0.001$), money for education ($r=0.449$, $p<0.010$), money for emergencies ($r=0.573$, $p<0.001$), and money for extras ($r=0.593$, $p<0.001$).

H_{15} Annual income positively associated with health-related quality of life. NOT CONFIRMED

Contrary to the hypothesis, annual income is not associated with general health ($r=-0.041$, $p<0.825$) or mental health ($r=0.190$, $p<0.298$). A strange anomaly exists in the positive relationship between income and role disruption as a result of physical problems ($r=0.395$, $p<0.025$). The results indicate that the disruption of social roles as a result of physical problems increases as annual income increases. It seems that concern over financial difficulties plays a more significant role in general health ($r=-0.384$, $p<0.030$), mental health ($r=-0.375$, $p<0.034$), and vitality ($r=-0.431$, $p<0.014$) than does annual income. Despite the independent relationship between income and health-related quality of life, the general hypothesis stating that increased financial difficulties are related to decreased health was confirmed. In addition, greater financial concerns are significantly associated with an increase in the frequency of daily hassles (r=0.463, p<0.008).

H_{16} Number of losses of friends and partners to AIDS will be positively associated with bereavement grief and lower levels of psychological well-being. PARTIALLY CONFIRMED

As hypothesized, the number of losses of friends and partners to AIDS is correlated with concern over the grief of these losses (r=0.495, p<0.004). However, the actual number of losses reported by the respondents is not significantly related to any of the quality of life measures with a highest significance level of p<0.191 on the eight sub-scales. Alternatively, increased concern expressed over the grief of the losses is very much associated with decreased mental health (r=-0.665, p<0.001), vitality (r=-0.654, p<0.000), social functioning (r=-0.541, p<0.001), general health (r=-0.445, p<0.011), and role disruption as a result of emotional problems (r=-0.412, p<0.019). In addition, bereavement grief, not the actual number of losses, is associated with increased feelings of isolation (r=0.565, p<0.001 for grief versus r=-0.051, p<0.783 for number of losses).

H_{17} Frequency and intensity of hassles negatively associated with health-related quality of life. PARTIALLY CONFIRMED

The frequency of daily hassles (mean=20.0 per day) reported by this sample is only negatively associated with only three of the quality of life sub-scales, including mental health (r=-0.473, p<0.006), general health (r=-0.452, p<0.009), and vitality (r=-0.454, p<0.009). The severity of daily hassles is not associated with any of the quality of life measures in either direction. Multiple regression analyses uncovered that the frequency of daily hassles, individually, are better predictors of mental health than intensity of hassles by explaining 24% of the variance at p<0.020 significance. Whereas, the number and severity of daily hassles combined have an improved explanatory influence in general health by explaining 29% of the variance at p<0.007 significance level. Regression analyses also revealed that "health" impacts the frequency of hassles reported in the sample. General health, social functioning, and mental health explain 33.5% of the variance in the frequency of daily hassles at a significance level of p<0.009.

H_{18} Frequency and intensity of uplifts positively associated with health-related quality of life.
NOT CONFIRMED, WITH ONE EXCEPTION

The number of daily uplifts is only significantly correlated with the physical functioning sub-scale on the health-related quality of life instrument ($r=0.422$, $p<0.016$). The intensity of uplifts is not associated with any other quality of life measures with a minimum significance value of only $p=0.170$. However, multiple regression analyses revealed that the frequency and severity of uplifts together account for 46.5% of the variance ($p<0.001$) in vitality, 33.3% of the variance ($p<0.003$) in physical functioning, and 27.7% of the variance ($p<0.009$) in general health scores.

H_{19} PLWA sharing health and finances as top concerns with the elderly. *CONFIRMED*

The t-test was used to examine the difference between the intensity of daily hassles in this sample and the elderly. The comparative data on the elderly were extracted from Folkman and Lazarus (1989). From the top ten hassles listed in the *Descriptive Analysis* section, only enough money for necessities (t-value=-3.55, $p<0.010$) and enough money for emergencies (t-value=-2.39, $p<0.010$) are significantly different from the elderly group. With statistical confidence, it can be noted that this sample shares the elderly's daily hassles regarding health, paperwork, physical abilities, enough money for extras, physical appearance, political or social issues, medical care, and effects of drugs and medications.

H_{20} PLWA reporting increased frequency and intensity of hassles relative to the elderly.
CONFIRMED

The frequency of daily hassles is significantly higher in this sample than in the elderly population (t-value=-6.90, $p<0.010$). However, the mean intensity of the daily hassles is not found to be statistically different between the two groups with a t-value of –1.58 and significance of $p>0.100$.

H_{21} Feelings of lack of control and uncertainty positively associated with lower levels of health-related quality of life. *CONFIRMED*

Loss of control and uncertainty about the future were assessed by a 5-point Likert scale in the *Impact of HIV Scale* and evaluates the degree to which the item has been a concern in the past month. Loss of control is significantly negatively correlated with every dimension of the quality of life scale. However, feeling a loss of control is most significantly associated with lower levels of vitality ($r<-0.682$, $p=0.001$), mental health ($r<-0.651$, $p=0.001$), social functioning ($r=-0.604$, $p<0.001$), general health ($r=-0.561$, $p<0.001$), and physical functioning ($r=-0.515$, $p<0.003$). Weaker, but still significant, relationships exist with the other sub-scales of pain (-0.462, $p<0.008$), and role disruption as a result of physical problems ($r=-0.428$, $p<0.015$) and emotional problems ($r=-0.466$, $p<0.007$). Further analyses indicate that escape-avoidance coping and self-controlling coping together, account for 47.4% of the variance in feeling a loss of control ($p<0.001$). Respondents using these coping strategies are more prone to feeling out of control.

A significant inverse relationship exists between being concerned about the uncertainty of the future and general health ($r=-0.762$, $p<0.001$), mental health ($r=-0.633$, $p<0.001$), vitality ($r=-0.601$, $p<0.001$), social functioning ($r=-0.542$, $p<0.001$), and physical functioning ($r=-0.367$, $p<0.039$). The other sub-scales, including pain and role disruption, are not related to the degree of uncertainty expressed by the respondents.

Multiple regression analyses reveals that "loss of control" and "uncertainty" about the future are powerful predictors of quality of life indictors. These variables combined explain 61.2% of the variance ($p<0.001$) in general health, 54.1% of the variance ($p<0.001$) in vitality scores, and 53.5% of the variance ($p<0.001$) in mental health scores. Alternatively, mental health, general health, and vitality as a set predict an overwhelming 65.7% of the variance ($p<0.001$) in uncertainty about the future and 46.5% of the variance in loss of control ($p<0.001$).

H_{22} Planful problem-solving coping style positively associated with health-related quality of life, increased vitality and increased self-esteem. NOT CONFIRMED

Planful problem-solving is not associated with any of the quality of life indicators. None of the correlation coefficients even approach significance. The relationship with vitality almost reaches total independence ($r=-0.087$, $p<0.636$). The hypothesized negative relationship between planful problem-solving coping and loss of self-esteem was also not confirmed with an almost non-existant correlation coefficient of 0.017 and $p<0.928$ significance. Further analysis using multiple regression revealed that together five health-related quality of life indicators, including general health, mental health, social functioning, physical functioning, and role disruption as a result of physical problems, explained 41.3% of the variance in planful problem-solving coping scores with a significance level of $p<0.012$.

H_{23} Escape-avoidance coping and self-controlling coping positively associated with the frequency of hassles and negatively associated with health-related quality of life and self-esteem. ***<u>PARTIALLY CONFIRMED</u>***

Both escape-avoidance coping and self-controlling coping are not associated with increased frequency of daily hassles with respective insignificant correlation coefficients of r=0.325, p<0.159 and r=0.298, p<0.09. However, escape-avoidance coping strategies, such as drug use, are negatively related to mental health (r=-0.521, p<0.002), social functioning (r=-0.542, p<0.001), general health (r=-0.417, p<0.018), and vitality (r=-0.492, p<0.004). Self-controlling coping is highly negatively correlated with all dimensions of quality of life, except for pain. The strongest inverse relationships exist with social functioning (r=-0.665, p<0.001), mental health (r=-0.623, p<0.001), vitality (r=-0.582, p<0.001), and physical functioning (r=-0.530, p<0.002). Both self-controlling and escape-avoidance coping are correlated with increased feelings of anger with respective correlation coefficients of r=0.529 (p<0.002) and r=0.457 (p<0.009). In addition, self-controlling coping is also associated with feelings of self-blame and guilt (r=0.400, p<0.023).

Both escape-avoidance and self-controlling coping are positively correlated with concern regarding a loss of self-esteem (r=0.483, p<0.005 and r=0.622, p<0.001 respectively). A regression model reveals that these two coping methods account for 39.9% of the variance in loss of self-esteem with a significance of fit of p<0.001.

H_{24} Health-related quality of life negatively associated confrontive and accepting responsibility coping. ***<u>NOT CONFIRMED</u>***

Both confrontive coping and accepting responsibility are neither positively or negatively associated with any of the health-related quality of life sub-scales with p-values not even nearing a significance of p<0.05. Actually, these two coping strategies failed to be associated with many other measures, including loss of self-esteem, anger, and self-blame.

H_{25} Positive reappraisal positively associated with health-related quality of life. ***<u>PARTIALLY CONFIRMED</u>***

Positive reappraisal is the only coping strategy to be positively correlated with health-related quality of life. However, reappraising a stressful situation in a positive light is only significantly associated with the general health perception sub-scale with a correlation coefficient of 0.400 at p<0.026 significance. It is not negatively or positively associated with any other quality of life measure. In addition, it seems that positive reappraisal has a significant positive relationship with the severity ($r=0.406, p<0.023$), not frequency, of daily hassles, and frequency ($r=0.465, p<0.008$) and intensity ($r=0.407, p<0.023$) of daily uplifts.

H_{26} Seeking social support as a coping strategy positively associated with health-related quality of life and self-esteem. <u>NOT CONFIRMED</u>

Contrary to this hypothesis, seeking social support as a coping method is not related to any sub-scale measure of health-related quality of life. Further, it is not positively associated with self-esteem. A regression model also revealed that general health, mental health, and physical functioning did not play a role in seeking social support. Only 10.6% of the variance in seeking social support is explained by the three quality of life measures with $p<0.365$ significance level.

H_{27} Number of months in a committed relationship positively correlated with health-related quality of life. <u>NOT CONFIRMED</u>

This hypothesis was not confirmed. The number of months in a committed relationship is not associated with increased general health ($r=-0.152, p<0.407$) or mental health ($r=0.089, p<0.627$). The number of months in a committed relationship is not negatively associated with loss of self-esteem and feeling isolated, as common-sense would suggest.

6.2 <u>OTHER FINDINGS</u>

<u>Hassles and Uplifts</u>

As expected, the frequency and severity of daily hassles had a significant positive correlation ($r=0.714, p<0.001$), and the frequency and intensity of daily uplifts did as well ($r=0.773, p<0.001$). However, a strange perfect positive relationship ($r=1.00, p<0.001$) exists between the severity of daily hassles and the intensity of daily uplifts. The number of daily uplifts is also positively correlated with the severity of hassles ($r=0.766, p<0.001$) and the frequency of daily hassles ($0.407, p<0.021$).

The severity, not the frequency, of daily hassles reported by a respondent is positively correlated with three forms of active coping: seeking social support ($r=0.521, p<0.002$), planful problem–solving ($r=0.445, p<0.011$), and positive reappraisal ($r=0.406, p<0.023$). It appears as though people who confront their problems more actively are more likely to experience their hassles as severe, or, alternatively, the severity of their hassles encourages them to cope with stressors actively. These three forms of coping together account for 33.5% ($p<0.011$) of the variance in the severity of daily hassles scores, but do not significantly predict the variance in the frequency of hassles. Alternatively, the number and severity of hassles combined explain 52.2% of the variance ($p<0.010$) in the seeking social support coping sub-scale.

When considering the impact of these active coping methods on the frequency and intensity of daily uplifts, it is evident that seeking social support exerts the greatest predictive impact by explaining 26.7% of the variance ($p<0.002$) in the intensity of uplifts.

Ways of Coping and Health

Escape-avoidance coping and self-controlling coping styles seem to exert the greatest negative impact on health and well-being. Multiple regression analyses indicate that these two coping styles combined predict 41.3% of the variance in mental health ($p<0.001$), 46.5% of the variance in social functioning ($p<0.001$), and 36.2% of the variance in vitality ($p<0001$).

The degree to which a person adopts an active coping style seems to be, in part, explained by the health and well-being of the individual. A set of three quality of life indicators, including physical functioning, general health, and mental health, predict 36.3% of the variance in positive reappraisal, only 25.5% of the variance ($p<0.039$) in planful problem-solving. These health variables do not significantly explain the variance in seeking social support as a coping strategy (10.6% variance, $p<0.365$)

Quality of Life Indicators across Age Groups and Patient Populations

Even though the previous *Descriptive Analysis* section established that the overall health-related quality of life of this sample most closely resembles that of the elderly, persons with congestive heart failure, and persons with type II diabetes, there are a few finer points of comparison to mention. This sample is not statistically different from the elderly on three health-related quality of life sub-scales, including general health (t-value=1.35, $p>0.100$), vitality (t-value=1.29, $p>0.100$), and role disruption as a result of physical problems (t-value=1.05, $p>0.100$). The elderly have significantly lower scores of physical functioning and bodily pain, and significantly higher scores of social functioning, mental health, and role disruption as a result of emotional problems. This sample is statistically different from all of the younger samples across all of the eight quality of life sub-scales, except for bodily pain.

In the context of comparing this sample's overall quality of life score of 61.18 to that of other patient populations, an interesting distribution of relationships occurs. The mental health scores of this sample are significantly lower than persons with congestive heart failure (CHF).

type II diabetes, and recent acute myocardial infarction (AMI), and significantly higher than persons with depression. However, this group of men with AIDS shares similar scores on physical functioning and general health with all of the other patient populations with t-values less than 1.64 ($p>0.100$). The sub-scale scores for role disruption as a result of physical problems and vitality are not significantly different between this group, persons with recent AMI, clinical depression, and type II diabetes. This sample shares similar scores on four quality of life sub-scales with the clinical depression group, whereas they only share significantly similar results on three scales with the rest of the patient groups.

Ways of Coping across Age Groups

The mean scores of the individual eight coping styles for this sample were statistically compared to those scores collected by Folkman and Lazarus (1989) in an elderly (ages 65 to 74 years) sample of males and a middle-aged (ages 35 to 45 years) population of males. This sample most closely resembles the elderly group in coping styles reflected by similar scoring on four coping sub-scales versus sharing similar measures with the middle-aged group on only two of the scales. This sample and the elderly seem to similarly use confrontive coping, seeking social support, escape-avoidance, and planful problem-solving coping methods to the same degree to deal with stressful events. This sample uses significantly more positive reappraisal (t-value=-2.75, $p<0.01$), and significantly less distancing (t-value=3.07, $p<0.01$), self-controlling coping (t-value=2.45, $p<0.05$), and accepting responsibility (t-value=3.95, $p<0.001$) in comparison to the elderly. The younger sample of middle-aged adults uses significantly more confrontive coping (t-value=2.76, $p<0.01$), seeking social support (t-value=2.26, $p<0.05$), self-controlling coping (t-value=2.38, $p<0.05$), accepting responsibility (t-value=4.47, $p<0.010$), and planful problem-solving (t-value=2.35, $p<0.05$). However, this sample of young men with AIDS uses relatively greater positive reappraisal coping techniques than does the middle-aged sample (t-value=-3.09, $p=<0.01$).

Discrimination and Disclosure

The concern about being discriminated against was assessed in the *Impact of HIV Scale*, and the resulting scores indicate no relationship between fear of discrimination and mental health ($r=-0.063$, $p<0.731$). Upon further analysis, the positive relationship between concern about discrimination and questions about sexual identity ($r=0.358$, $p<0.044$) is revealed. The concern about sexuality is also positively related to self-blame and guilt ($r=0.430$, $p<0.014$). Related to secrecy and fear of discrimination is the issue of disclosure. Concerns about who to tell and what to tell others about one's HIV positive status and/or sexuality is significantly correlated with feeling isolated (r=0.396, p<0.025), feeling depressed (r=0.427, p<0.015), and self-blame and guilt (r=0.481, p<0.005).

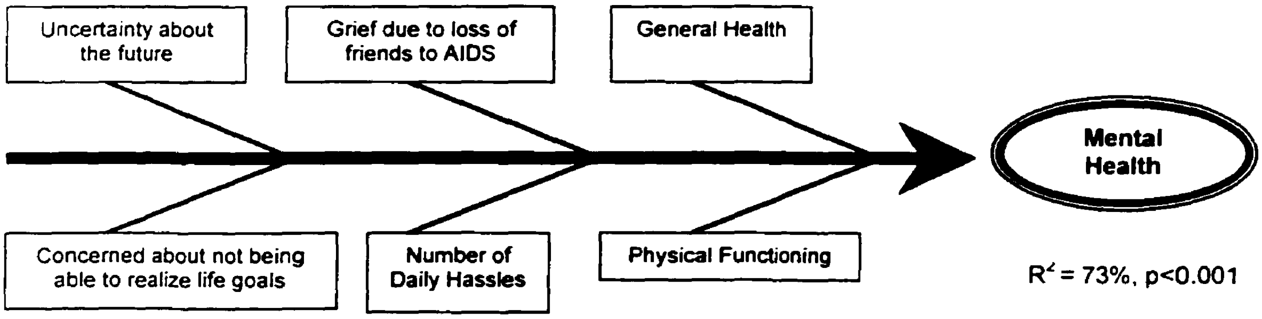
Body Image and Sexuality

Physical appearance was listed in both the top ten lists of hassles and uplifts. Respondents indicating that they were concerned about feeling less physically attractive on the *Impact of HIV Scale* were significantly more likely to have lower physical functioning (r=-0551, p<0.001), poorer general health (r=-0.570, p<0.001), and poorer mental health (r=-0.490, p<0.004). In terms of the respondent's sexual life with HIV, it was revealed that physical functioning and general health together account for 26.3% of the variance (p<0.012) in the item of concern about "problems with my sex life" in the *Impact of HIV Scale*.

6.3 REGRESSION MODELS

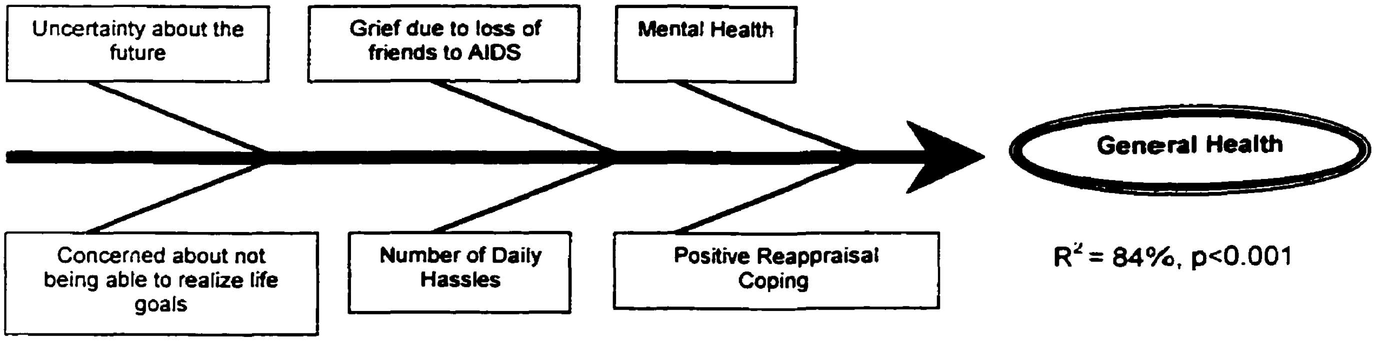
In summarizing the results of this study, I have constructed two path diagrams to illustrate the main influential factors related to the mental health and the general health of the individuals in this sample of young gay men with AIDS. These variables were grouped as a set and used in multiple regression analyses to explain the variance in mental health and general health. Figure 6.31 depicts the combining influence of six variables, including uncertainty about the future, not being able to realize life goals, grief due to loss of friends to AIDS, number of daily hassles, general health, and physical functioning, on the mental health status of individuals. This set of variables account for 73% of the variance in mental health scores with a significance of fit of p<0.001.

Figure 6.31
Mental Health Path Diagram



The regression model for general health is illustrated in Figure 6.32 below. The six variables that were combined for the purposes of analyses are much the same as above, except that physical functioning and general health were removed, and positive reappraisal coping and mental health were added. This set of variables explains a total of 84% of the variance in general health status of the individual with a significance of fit of $p<0.001$.

Figure 6.32
General Health Path Diagram



$R^2 = 84\%$, $p<0.001$

7.0
CONCLUSIONS AND IMPLICATIONS

7.1 LIMITATIONS OF STUDY

The internal validity of the study was potentially threatened by the influences of ***self-selection bias***. Persons who volunteer their participation for research may be doing so to contribute to enlarging academic knowledge, which may originate from a background in university education. The over-representation of university educated men (56.3%) may be a function of this self-selection bias, and hence skew some of the interpretations of the results. D'Augelli and Patterson (1995) established that persons of higher educational status have traditionally over-represented a lot of the research that has been conducted in the gay and AIDS communities due to self-selection bias. In addition, the data gathered in the questionnaires are based on self-assessment and have not been objectively measured.

There was also potential ***researcher bias*** involved in the physician's decision to approach a patient for participation in the study. The physician may have assumed that certain types of people were not suitable or willing to participate in the study, and as such, bias the composition of the sample. The internal validity is also affected by the exclusion of persons who were very ill and/or weak. In no way am I advocating for pressuring fatigued and weakened patients to participate in studies, but the absence of this very sick population would affect the results. In particular, health-related quality of life and coping strategies are presumed to change in the terminal stages of an illness.

The ***instrumentation*** of the study may have also weakened the internal validity of the research. Due to the lengthiness of the questionnaire, it was not possible to include individual instruments measuring respondent's perceptions of social support, depression, self-esteem, and personal control. These variables were assessed with one-item questions in the *Impact of HIV Scale*. The inclusion of four additional instruments would have made the questionnaire too burdensome for participants, and potentially have limited participation. The variables including, depression, loss of control, uncertainty, feeling angry, and low self-esteem, were not measured with a multidimensional assessment instrument, and therefore the conclusions regarding these items are limited.

The instruments assessing the objective health status of the individual could have also been improved. Further permission from the hospital ethics committee could have enabled me to consult the medical charts to confirm the respondent's report of their last CD4+ count results. The disparity, or lack thereof, between the results documented in the chart and the respondent's perception of the results would have been interesting to study. At the time of constructing the questionnaire, viral load tests were not readily available to all patients as there was a $100.00 charge for testing at a different hospital site. Since that time, viral load testing is now being extensively used by HIV clinics around Canada. The viral load measures would have provided a more accurate assessment of the stage of HIV infection and the respondent's future risk of contracting AIDS-related illnesses.

The external validity of the study is threatened by the ***lack of random sampling***, the relatively ***small sample size***, the ***quota and snowball sampling*** method limits, and the ***lack of longitudinal analyses***. This research study intended to explore and describe the experience of young gay men with AIDS, and as such did not seek to make sweeping generalizations about causal relationships. The next step is to increase the sample size and attain a comparative elderly sample in the community for the purposes of making more conclusive comparisons between the experiences of the elderly and PLWA. In addition, random sampling, and longitudinal analyses versus the present cross-sectional analysis, would enable a researcher to make broader generalizations and inferences.

The external validity may also be weakened by the nature of the ***recruitment methods***. Because I was not recruiting people directly, the factors influencing the recruitment of patients was not completely standardized. While some physicians were enthusiastic about the study and active in the recruitment of respondents, others were not. As a result, there was a disproportionate amount of patients coming from certain clinic physicians. Even though each physician was given a list of inclusion and exclusion criteria, there were several occasions when these guidelines were ignored. In addition, some physicians would make educated guesses as to the patient's age, sexual orientation, and potential willingness to participate in the study. Consequently, many patients were not approached about the study. The low refusal rate of the study indicates that greater team participation and adherence to guidelines would have helped increase the final sample size.

The ***racial composition*** of the sample was predominantly white. There were two factors influencing this result. The physicians often assumed persons of minority status were heterosexual, and were uncomfortable with confirming their assumption. Persons from diverse cultural backgrounds tend to resist identifying themselves as gay because of the strong stigma attached to the homosexual label in their community. As a result of these biases, there is a lack of diversity in the sample. It would have been very interesting to have greater cultural representation in order to make cross-cultural comparisons regarding health, mental health, sources of stress, discrimination, and finances.

Multidisciplinary team research can work very effectively when there is cooperation and a mutual understanding of the study's purpose and goals. The study was explained at several team meetings, but unfortunately the physicians were often not present. The goal is to make psychosocial research of interest and importance to every health care discipline. I should have gone directly to the physician meetings to encourage participation and interest. The clinic physicians tend to focus their research energies on drug trials. The goal would be to demonstrate that psychosocial research has the potential for complementing existing medical research protocols. The nurses, in particular, are very useful for establishing large-scale recruitment because their profession is becoming more and more concerned with the psychosocial aspects of care. It is difficult to get full participation from the staff when they are often burdened with excessive work in an environment of continuing budget cuts. The potential benefits of successful multidisciplinary research include developing truly comprehensive care and treatment packages for the patient population being served, and establishing new links between health care disciplines.

Initially, this research project intended to incorporate both qualitative and quantitative methods of data collection. Due to time limitations, the scheduled interview sessions with ten participants were postponed indefinitely. From the total sample of 32 participants, only two men declined to participate in the one-and-a-half hour follow-up semi-structured interview. This incredibly high acceptance rate leads to the interpretation that these men were interested in talking about their experiences with AIDS despite the time requirements and lack of financial reimbursement for their time. With greater funding and increased involvement from other professionals specializing in geriatrics, this study has a lot of potential for future investigations. The qualitative interviews would considerably contribute and complement the data already collected in the questionnaires. This study was designed to explore the phenomenon of premature aging among young gay men with AIDS, but it also had the intention of driving biopsychosocial research into the experiences of PLWA forward.

7.2 SUMMARY OF FINDINGS AND IMPLICATIONS

The premature occurrence of illness among PLWA, and its subsequent social and psychological effects are noted frequently by clinicians and academics. However, there has yet to be a study analysing the divergences and similarities between the experiences of gay men with AIDS and the elderly. This research project was established to further explore and describe the impact of AIDS on the life cycle development of young gay men. The study investigated the social, psychological, and physical effects of AIDS among this sample. The major findings are summarized below, and the implications of this research for clinical social work and social policy are intertwined in the summary of the results presented in Figure 7.21.

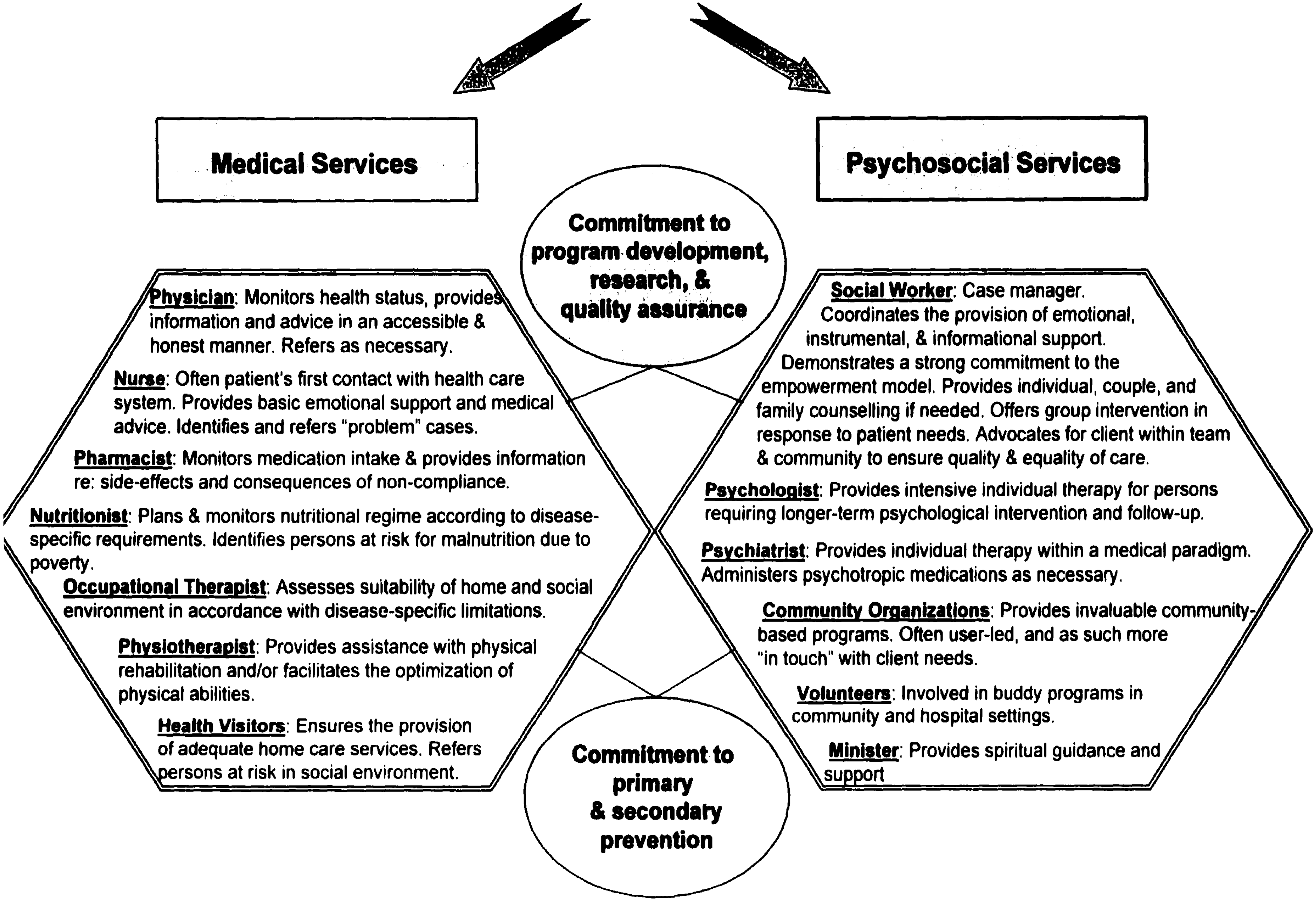
(a) Physical Changes

Health-related Quality of Life

This sample of young gay men has been living with AIDS for an average of 2.7 years with mean CD4+ counts of 201.8. This entire group of men had already confronted at least one life-threatening opportunistic infection prior to enrolling in this study. Relative to other age groups, the findings indicate that this sample most closely resembles the elderly across eight quality of life indicators in comparison to similarly aged men (18 to 44 years) without any illness. This sample reported comparable levels of pain to the general population between the ages of 18 to 44 years, but significantly less pain than the elderly. Despite the overall similarities to the elderly, this sample experienced significantly lower levels of mental health and social functioning, and the degree to which emotional problems impacted on social roles was more severe. The elderly population indicated a lesser degree of physical functioning than this sample, but reported similar levels of general health, vitality, and role disruption as a result of physical limitations. An interesting finding was revealed when comparing the quality of life results to that of other patient populations. This sample reported lower levels of mental health in relation to all of the other patient groups, including persons with congestive heart failure, recent acute myocardial infarction, and type II diabetes, but slightly higher mental health scores than persons with clinical depression. These findings parallel the results found by Wachtel et al. (1992) in their research of quality of life status (also assessed with the *MOS-SF-36* survey) among HIV positive persons. This sample resembled persons with clinical depression in terms of physical functioning, social functioning, general health, and the degree to which physical problems interfered with social roles.

Figure 7.21

MULTIDISCIPLINARY APPROACH TO THE CARE AND TREATMENT OF PLWHA



Medical Services

Psychosocial Services

Commitment to program development, research, & quality assurance

Physician: Monitors health status, provides information and advice in an accessible & honest manner. Refers as necessary.

Nurse: Often patient's first contact with health care system. Provides basic emotional support and medical advice. Identifies and refers "problem" cases.

Pharmacist: Monitors medication intake & provides information re: side-effects and consequences of non-compliance.

Nutritionist: Plans & monitors nutritional regime according to disease-specific requirements. Identifies persons at risk for malnutrition due to poverty.

Occupational Therapist: Assesses suitability of home and social environment in accordance with disease-specific limitations.

Physiotherapist: Provides assistance with physical rehabilitation and/or facilitates the optimization of physical abilities.

Health Visitors: Ensures the provision of adequate home care services. Refers persons at risk in social environment.

Social Worker: Case manager. Coordinates the provision of emotional, instrumental, & informational support. Demonstrates a strong commitment to the empowerment model. Provides individual, couple, and family counselling if needed. Offers group intervention in response to patient needs. Advocates for client within team & community to ensure quality & equality of care.

Psychologist: Provides intensive individual therapy for persons requiring longer-term psychological intervention and follow-up.

Psychiatrist: Provides individual therapy within a medical paradigm. Administers psychotropic medications as necessary.

Community Organizations: Provides invaluable community-based programs. Often user-led, and as such more "in touch" with client needs.

Volunteers: Involved in buddy programs in community and hospital settings.

Minister: Provides spiritual guidance and support

Commitment to primary & secondary prevention

The relatively low levels of mental health functioning indicate the need for training social workers in the field of HIV to identify persons at risk for depression and suicide. The severe social implications of AIDS, including discrimination, stigma, blame, and shame, place PLWA at greater risk for developing mental health problems. Social workers should also be involved in mobilizing formal support networks, such as community health care assistants in the CLSCs, to help reduce the degree of social disruption as a result of physical limitations by assisting with self-care tasks, medical monitoring, home maintenance, and paperwork tasks. Community organizations also have a role to play in offering home care assistance for PLWA with low levels of general health and vitality through direct tangible support and emotional support provided through volunteer buddy programs.

Health Concerns

This sample reported numerous daily hassles and concerns regarding their health and medical care. An overwhelming majority (81%) reported that their health was a daily hassle, and 63% remarked that their medical care also represented a daily stress. A total of 75% of the sample indicated being concerned about getting sick or sicker and 69% of men reported being concerned about not being able to care for themselves. Despite the improvements in medical health among PLWA since the introduction of triple combination therapy, a majority of the sample (59.4%) remain concerned about losing their mental abilities and developing dementia in the future. These findings parallel the results of recent research conducted by McConachy (1997) and Golan (1997) among PLWHA.

Daily health concerns are expressed with great intensity by a large percentage of the sample. It is important to sensitize medical professionals, including social workers, about the anxieties and fears of PLWA. In addition to educating the different disciplines as to the experiences and concerns of PLWA, it is also essential to provide some suggestive interventions to reduce feelings of helplessness among professionals. This group of men have already experienced the fear and vulnerability of an opportunistic infection prior to their improved health status. It is important to validate their fears and provide honest and accruate information about the risks of developing certain illnesses. There continues to be half of respondents concerned about where and from whom to get accurate and honest information about HIV. This need for information and confusion about where to access the material needs to be addressed by multidisciplinary HIV/AIDS teams. Pamphlets and fact sheets with information about the course of HIV infection and its potential complications should be provided to patients and their significant others free of charge. Medical information should be presented in accessible language with colourful pictures to depict the virus at work in the body. If there are preventive treatments available, such as prophylactic therapy for pneumocystis pneumonia, they should be discussed with the patients to reduce feelings of loss of control and helplessness. Information and assistance regarding behavioural lifestyle changes, such as diet changes, exercise, stress reduction, substance abuse, hygiene, diet, and stress should also be presented to PLWA to maximize feelings of control over the maintenance of health.

Antiretroviral Therapies

According to Rolland's (1987) psychosocial typology of chronic illness, AIDS is defined as a gradually progressive and relapsing illness, which eventually incapacitates the person in its late stages. The roller-coaster nature of AIDS-related symptoms and illnesses makes predicting the course and severity of the infection nearly impossible. The media and some medical professionals now portray HIV as a well-established chronic illness. However, for some PLWA, the ARTs and medical advances are too late for beneficial effects, too complex and burdensome, or just ineffective due to resistance or intolerance of medication regimes. AIDS has become more controllable, but it remains an incurable disease that demands close surveillance.

In this sample, 75% of men reported being concerned about the side-effects of medications, and 59% of respondents indicated that the effects of the medications are a daily hassle. The speed at which medical developments in HIV are occurring is enough to confuse anyone. One respondent commented on the lack of information regarding the benefits and negative side-effects of starting triple combination therapy. It is important to furnish patients with accurate and honest information about the side-effects of medications, the risks of intolerance and resistance, and alternative medical options. A quarter of this sample documented their concerns over the complexity of the medication regimes and the financial burden associated with starting these long-term drug protocols.

It is essential that PLWA have adequate financial resources to cover the cost of medication insurance down-payments in order to avoid non-compliance of triple combination medication therapies. Social workers can use their community organization skills to fundraise a private medication fund for PLWA. Most of the pharmaceutical companies have a certain portion of their revenues set aside for 'goodwill,' and are often more than happy to receive positive press about their involvement in HIV. Larger charities and corporations should also be approached for funding a slush fund for medication.

In addition, local community health centers should be involved in monitoring the medication intake of PLWA in the community. Nurses and social workers can become jointly involved in developing a weekly written medication schedule and provide weekly pill boxes to help people remember the timing of medication intake. Recently, a large pharmaceutical company invested in a pilot study of 'timing' machines for PLWA to help people manage the complex scheduling of medications. The small hand-size machines are programmed by the pharmacist and beep each time a person is required to take a pill. This system seemed to be very effective, and should be offered on a larger scale. Basic alarm watches also provide the basic reminders for persons who may have suffered from cognitive limitations, or who may be generally distracted by the onslaught of new hassles.

Coates (1997) emphasized the need for clinical professionals in the field of HIV to educate people as to the risks of secondary transmission. Triple combination therapy reduces the person's susceptibility to illness and the infectiousness of HIV. Without the moderating effects of triple combination medications, HIV may be transmitted in its highly infectious stages (i.e. during primary infection and AIDS), which has very serious public health implications. For persons taking triple combination therapy unreliably, there is a higher risk of developing virus mutation and hence resistance to medications. These resistant strains of HIV can be passed on to a person with serious effects on their physical health. It is important to educate people as to the risks of non-compliance and unreliable intake of ARTs, which include threats to their own health and that of others (e.g. passing on resistance strains of HIV to persons with whom they practice unsafe sex). Prevention efforts should continue at the micro level of care and treatment of PLWA.

(b) Social Changes

Multiple Loss

There seems to be three influential factors affecting the high numbers of losses of friends and lovers to AIDS. First, the gay community represents a surrogate family to many persons with AIDS because of societal and family rejection, and therefore the losses are very significant. Second, a large segment of this sample (62.5%) reported sharing their residence with at least one other person, and many of these men were living in AIDS hospices or apartment complexes for

PLWHA. The finding that the majority of men (56.3%) in this sample are in long-term relationships with a same-sex partner means that their partners are also at risk for a significant future loss.

The grief associated with multiple losses of friends to AIDS - not the actual number of losses - is related to lower levels of mental health, which endorses past studies (Biller and Rice, 1990; Dean, Hall, and Martin, 1988; Folkman, Chesney, Collette, Boccellari, & Cooke, 1996; Kemeny et al., 1995; Sikkema, Kalichman, Kelly, & Koob, 1995; Saunders, 1990). Since the number of losses and the grief experienced as a result of these losses were highly correlated, I would suggest that the bereavement overload (Kastenbaum, 1985) experienced by PLWA complicates the mourning process. This conclusion parallels Marcotte's (1996) suggestion that multiple loss in a short period of time and survivor guilt contribute to complicated mourning.

For many seropositive partners of PLWA, witnessing the physical decline of their lovers involves powerful self-identification. The partners will see themselves and their future fate in the experience of their dying partner. The emotional pain associated with the loss of a partner or close friend to AIDS is worsened by the lack of societal validation of these losses. All too often, the heterosexual community and family members will not acknowledge the significance of the loss. The isolation and secrecy preceding and following the death of a gay partner or close friend poses a threat to the mental health of the bereaved individual. It can be inferred that AIDS has become a social reality for the gay community due to the history graded influences of the current gay generations, but the emotional and social devastation resulting from multiple loss can never be fully normalized.

There are several strategies for facilitating the grieving of losses and healing the emotional pain experienced by PLWA in the gay community. Community organizations can become involved in establishing AIDS memorials or murals dedicated to the deaths of loved ones. The importance of keeping a person's name recorded in a respectful public memorial cannot be underestimated. Several community organizations advertise losses in their newsletters with poems and commentaries. In addition, bereavement support groups, art therapy, and annual camp excursions are all useful interventions for persons experiencing multiple losses.

Individual counselling is suggested for persons with complicated mourning, which is often manifested in the form of anger, guilt, self-imposed isolation, and depression. The bereavement phase, defined by Holosko and Taylor (1994) and outlined in Figure 2.42 earlier, changes the social work focus from the dying AIDS patient to the grieving partner, family, and friends. However, many persons who have been recently bereaved, such as the men in this sample, are also dealing with the uncertainty of their own health. Therefore, the clinician needs to attain a fine balance between addressing their bereavement-related depression and the anticipatory grief related to their own physical decline. Bereaved individuals need help coping with disbelief, acute grief, preoccupations with the deceased, anger, guilt, somatic responses, family role adaptation, and the lack of social support. The entire multidisciplinary team should be trained to identify persons at risk for depression and suicide as the result of a recent onslaught of losses. Family counselling can also complement individual therapy by helping family members of the bereaved understand the significance of the death, and encourage them to validate the loss. Family members of the deceased may also need assistance in accepting their relative's pre-death decision to leave financial and meaningful belongings to their bereaved gay partner and not the family.

Socioeconomic Status: Finances and Education

The sample was over-represented by the university-educated (56.3%) and persons with annual incomes under $20,000 (62.5%). There was no association between education levels and income, which is normally present in the general population (Statistics Canada, 1995). The majority of respondents (59.4%) were receiving low fixed incomes from government support programs, such as medical income security and disability benefits. These results parallel the findings of a local research project conducted by Hankins (1990), which revealed that the highest rates of HIV infection in the Montreal area were in poorer regions with incomes 20% to 40% below the provincial median. A finding worthy of special attention is that the top ten daily hassles for this sample were dominated by stress about adequate money for necessities (84% endorsement), emergencies (78% endorsement), and extras (72% endorsement). This group of men had very limited financial security.

The relationship between poverty and health was researched in the elderly by Krause, Jay, and Liang (1991). It uncovered that the impact of low incomes on health was significant. In this sample, concern about financial difficulties seems to be a better indicator of the number of reported financial hassles and general health than actual annual income. However, higher incomes in this sample are associated with increased role disruption as a result of physical problems. I would propose that persons with higher income levels are most probably remaining in the work force, and therefore physical ailments cause the greatest social disruption due to active social involvement. Concern about financial difficulties is associated with lower levels of mental health, general health, and vitality, and is significantly correlated with a greater frequency of daily hassles overall, and more specifically to finances. Causal relationships cannot be established, but the relationship between poverty and health can be conceptualized in two ways: greater financial concerns negatively affect mental and physical health, and/or lower levels of physical health and psychological functioning contribute to greater financial concerns due to inability to work.

There are several important implications for clinical social work and social policy. Income support programs should adapt to the changing nature of HIV/AIDS and encourage back-to-work incentive programs for persons experiencing improved health due to ARTs. The government should encourage a reasonable amount of financial support from families if offered, because it eases the burden on the government. Social workers should advocate for the free provision of basic life-saving medications, such as the prothease inhibitors. PLWA on income security and disability benefits should not have to struggle to cover the cost of monthly down-payments for government insurance plans. Greater access to triple combination therapies and increased compliance while on the medication regimes will positively impact public health efforts to limit the transmission of infectious and resistant strains of HIV. In addition, as the health of PLWA improves due to increased access to triple combination medications, there will be a decreased reliance on government programs, and greater involvement in the work force. The increased work force participation will reduce the predicted loss in productivity of $30-billion by the year 2010 due to AIDS-related deaths in Canada (Gibbon, 1996), and increase feelings of self-esteem and self-worth among PLWA.

In addition to ensuring that PLWA have access to basic life-prolonging medications, it is important to secure other basic necessities, such as food, housing, and clothing. The government should be lobbied for increased financial subsidies for housing programs for PLWHA, including apartment complexes for those persons who remain autonomous and hospices for those persons requiring regular formal assistance with self-care tasks. Social workers should gauge when to apply for residence in an HIV accommodation, and should recognize the fine balance between too much segregation of PWA and complete integration. Excessive or repeated exposure to discrimination and rejection in the general population, family of origin, or certain cultural communities may indicate a need for finding HIV-specific housing, which provides unconditional acceptance and security.

Linking PLWA to community organizations, which offer food and clothing donations, or items at a reduced rate, is also another tangible avenue of support. Christmas fundraisers are often very effective for accumulating clothing, food, children's toys, and some second-hand furniture. Meals-on-wheels programs are also offered by some regional community health centres and a few non-profit organizations at a low cost to ensure proper nutritional intake on a reduced income.

Hospital-based and community-based social workers can offer monthly educational seminars focused on providing people with a list of community resources and eligibility criteria for government benefits. These seminars can also be used to assist PLWA in formulating a budget on a limited fixed income. These educational workshops provide a dual purpose of alleviating the individual case load of the social worker, and reducing the burden of bureaucratic paperwork on the PLWA. A list of resources and benefits in simple language can empower a PLWA to seek assistance independently, and it also enables social workers to devote more time and energy to individual, couple, family, and group therapy for persons requiring special attention.

Work-Related Issues

The unpredictable course of AIDS combined with the daily task of maintaining optimal health, together place incredible demands upon a PLWA. Many PLWA often decide to stop work because of the inflexibility of adapting work hours due to physical limitations, or increasing fears of being discovered and being subject to discrimination in the workplace (Kalichman, 1995; Tindall & Tillett, 1990). Figure 2.21 outlined the phases of retirement for an elderly person and compared those to the general stages of stopping work due to AIDS-related limitations.

The general improvement of health in the recent past for PWA is attributed to antiretroviral medications and medical advances. There is great uncertainty regarding the duration of these medical improvements, which complicates the smooth transition through the phases of work stoppage. The disenchantment phase may be considerably longer, and the reorientation and stability phases may be more difficult to achieve due to the uncertainty of whether their health will improve to a level at which full-time work is possible again (Atchley, 1976). Work not only supplies necessary money for basic living needs, but it also positions a person in the social structure, and provides a social reference group and self-esteem. A small portion of the sample (18.8%) continues to work, and that number can be expected to grow with the increasing effectiveness of medications.

Fear of discrimination and inability to maintain a full-time position often forces people into the secondary labour market in which their rights to equal treatment and sick leave are neglected. Many companies force their employers to subscribe to group insurance schemes, and due to fear of breeches in confidentiality, PLWHA may avoid seeking reimbursement for medication costs. The group of working poor men are particularly susceptible to non-compliance to medication regimes because of unreliable access to medications.

The implications for clinical social work and social policy are numerous. First, there is a substantial need for flexible income-support programs, which encourage gradual back-to-work incentive programs with continual emotional and tangible support from welfare officers. The government should incorporate part-time work opportunities for persons wanting a gradual transition into the work force. During this transitory phase, PLWA can assess their physical and emotional abilities to handle work-related obligations and responsibilities after years of work absenteeism due to illness. Nolan (1997) claimed that her entire sample of HIV-positive men reported fears and insecurities of returning to work due to a lack of up-to-date skills and a fear of losing government disability benefits. The government must structure income support programs to better reflect the reality of AIDS. PLWHA should be offered the opportunity to join subsidized job-retraining programs, which incorporate training in new technologies, such as computers and the internet. In terms of confidentiality in the workplace, the government should ensure that persons registered in group insurance plans are permitted to enroll with the government medication insurance plans without penalty.

There is a significant need for individual counselling for persons stopping work and for those persons choosing to return to work. For those persons stopping work due to physical limitations, social workers can offer informational support about government benefit programs. Emotional support can be directed towards facilitating the person's transition through the phases of work stoppage, especially the disenchantment and reorientation phase. For persons returning to work or presently working, social workers should offer informational support about worker rights in regards to confidentiality and discrimination. Emotional support and insight therapy is effective in dealing with insecurities about skills, fear of burn-out and over-exertion, and conflict resolution to deal with delicate situations of discrimination or disclosure.

Role Changes and Increased Dependency on others

A portion of this research was devoted to investigating the role changes that occur as a result of being diagnosed with AIDS. It was hypothesized that dependency on informal and formal support networks increases when a person is diagnosed with AIDS due to physical limitations and emotional needs. During a period in the life cycle when men are expected to be autonomous from family and gradually care for aging parents, the roles are reversed and parents are once again involved in their children's care. Contrary to my expectations, 62.5% of the sample turned to their parents and 56.3% to their siblings for additional emotional and tangible support since being diagnosed with AIDS. Despite the alienation and rejection often present in families due to moral disagreement over their adult child's lifestyle choices, there continues to be a large percentage of gay men relying on their families of origin for support. As hypothesized, almost the entire sample (93.8%) of men turned to their friends for additional support since being diagnosed with AIDS. The proportion of men depending on formal support networks, such as community organizations and community health services (CLSCs), for support was slightly lower but still significant with relative percentages of 46.9% and 34.4%. In relation to this increasing dependency on others, a large group of men (62.5%) expressed concern about a reduced ability to provide care for others.

There are several avenues of intervention for social workers. Tangible support can be offered by mobilizing formal support mechanisms, such as a CLSC, community organization, or hospice, to provide respite for caregivers to ease caregiver burden. Montgomery, Gonyea, and Hooyman (1985) studied the relationship between objective and subjective caregiver burden in 80 elderly adults. They found that higher levels of subjective burden were associated with younger age (conflicts with other roles) and financial insecurity. Objective burden seemed to be alleviated when there was assistance with concrete tasks, such as bathing, dressing, transportation, nursing care, and errands. These results confirm the importance of respite for caregivers. Special attention should be given to partners and friends who have suffered multiple losses, and who are themselves HIV-positive. The risk of reactive depression due to multiple losses and anticipatory depression in response to identifying with the physical deterioration of their friend/lover should be recognized by health care professionals.

Reciprocity in a relationship is extremely important for maintaining the emotional well-being and self-esteem of both the caregiver and the person being cared for. Due to socialization of roles from a very early age, dependency seems to be less accepted by men because they are not socialized to accept passivity and dependency like their female counterparts (Moss, 1960). Dependency in men can counteract the fulfillment of their adult developmental tasks of intimacy and generativity, which can be best realized through communal relationships that are based on reciprocity and mutuality. Social workers should offer couple and family counselling to help maximize reciprocity in their relationships without placing guilt on either party involved. Townsend (1981) describes a three-dimensional model of dependency, which includes structured dependency (i.e. reliance on the state), physical dependency, and behavioural dependency. The dyad in the caregiving relationship should be assisted in achieving some degree of interdependence across the stages of the disease. Dependency can be minimized by offering formal support through respite and assitance with home maintenance and self-care tasks. Hospital-based and community-based social workers can form support groups to address the unique needs of family caregivers, gay friends, and/or lovers providing caregiving for a PLWA.

Individual counselling for PLWA should focus on the feelings associated with role reversals in families and dependency in intimate relationships. Counselling should work towards developing a sense of emotional interdependence. It is important to resist an overemphasis on being independent because it can lead to disillusionment, frustration, and to emotional disequilibrium. The unpredicatble nature of AIDS means that families and partners risk premature disengagement from the relationship due to defence mechanisms inherent in anticipatory grief (Sourkes, 1982). Many PLWA have rebounded from near death with the assistance of new medications and return to relationships to discover their partners have difficulty reinvesting in a reciprocal relationship due to deeply rooted dependency. Individual and couple counselling can help people rediscover the intital attributes that they found attractive about each other, develop a new image of each other, and simultaneously learn to deal with the uncertainty of future physical illness.

(c) Psychological Changes

Discrimination, Stigma, and Body Image

The typologies of stigma delineated by Goffman (1963) and Jones et al. (1984) were combined and presented in Table 2.31 for the purposes of comparing the stigma experienced by the elderly and PLWA. It was concluded that AIDS is subject to stigma across all of the individual components including: the degree of concealability, the predictability of the course of the illness, the degree of peril, the degree of disruptiveness, the aesthetic qualities or abominations of the body, the origin or cause of disease, the perception of a blemished character, and the tribal stigma of race.

A total of 44% of the sample reported being concerned about being discriminated against, which demonstrated the harsh social reality for gay men with AIDS. Fear of being discriminated against was significantly related to concerns and questions about sexuality. It seems that concern about AIDS-related discrimination is worsened when the person is also questioning their sexual identity, and is not fully 'out of the closet.' The stigma associated with being gay and having AIDS contributes to feelings of shame, contamination, guilt, and fear of disclosure. In this sample, 65.6% reported being concerned about who to tell, what to tell, and how to tell. Fear of disclosure was significantly associated with feelings of isolation, depression, self-blame, and guilt.

The stigma associated with AIDS sparks feelings of insecurities regarding physical attractiveness. A total of 59.4% of men in this sample indicated that they felt less physically attractive since being diagnosed with AIDS and the same amount of men reported being concerned about problems in their sex life. A negative body image can compel a PLWA to self-quarantine themselves for fear of rejection or fear of infecting others. Fatigue, physical illness, and side-effects of medications may also dampen the person's sexual interests and energies (Turner, 1995; Gochros, 1992; Adam and Sears, 1994; Dupras, Morisset, & Pharand, 1997; Ross & Ryan, 1995). In this sample, physical functioning and general health together account for 26.3% of the variance in concerns about sexual problems.

There are several important implications for the social work profession. Discrimination on a macro level can be targeted at the micro level by providing educational lectures to school children and university students training to work in the medical professions. Students should be encouraged to acknowledge and confront their own biases and prejudices. In addition, PLWA of different backgrounds should be invited to speak of their experiences. The personalization of the experiences of PLWA and gay men eliminates the mystery and confusion about what they look like or what kind of persons they are. Recent research by Herek (1997) found that discrimination, fear of contamination, and blame is greatly reduced when a PLWA is introduced and allowed to speak informally in a public forum. It was also suggested that anti-discrimination messages be tailored to the cultural groups being addressed because of culture-specific beliefs about HIV/AIDS. Herek (1997) suggested that issues regarding fear of infection and support for quarantine should be discussed with African Americans, whereas white populations should address issues relating to blame and moralistic lifestyle judgements.

Social workers involved in community activism should continue to advocate on a systemic level for increased protection against discrimination for PLWHA and gay men, and equal rights for gay partners in bureaucratic institutions, such as hospitals. In addition, support groups in the gay community can help normalize experiences with discrimination, rejection, alienation, and self-imposed isolation. Individual counselling can be offered to help remove self-blame, shame, and guilt, which will help reduce feelings of anger. Informational support and role playing can assist people in developing effective disclosure techniques, which can help minimize the social alienation that can occur with disclosure.

Body image and sexual activity are improved by facilitating physical contact and intimacy, and enhancing subjective perceptions of physical attractiveness. This may seem unorthodox, but establishing a dating service for PLWA provides an opportunity for meeting other people in a similar predicament and without fear of rejection. This type of service may not suit everyone, but several of my patients at the clinic have inquired about such services in the past. A simple method of enhancing body image is by providing free access to exercise facilities for PLWA either through community organizations, or through subsidized memberships at the YMCA. Recruiting volunteers from the community to offer free haircuts and facials are also simple, but effective, interventions that can be organized by social workers or patients themselves. The "*Look Good, Feel Good*" program was developed by non-profit cancer organizations to help women with cancer revitalize their low self-esteem and weakened body image. This type of program should be adapted to the needs of gay men with AIDS, and should be offered in hospital and community settings by social workers and trained volunteers.

Psychological Correlates

There are several factors that are negatively correlated with mental health, including uncertainty, not being able to realize life goals, loss of control, helplessness, loss of self-esteem, anger, shame, depression, and anxiety. All of these factors are considered to be important AIDS-related concerns for 59.4% of the respondents. The most alarming finding is that 50% of the sample reported thoughts of suicide in the past month. Serious suicidal ideation and suicide attempts were not assessed in the questionnaire.

It is important for social workers to differentiate between reactive depression and anticipatory depression (Kubler-Ross, 1969). The development of clinical depression in PLWA may reflect a previous history of mental illness, a predisposition to mental health problems, a lack of social support, lack of effective coping strategies, or associated problems of substance abuse. Some degree of depression in response to losses already experienced and those yet to come is a normal part of grieving when diagnosed with a life-threatening illness. It is essential for social workers to tease out the persons at risk for prolonged clinical depression and those at high risk for suicide from those persons engaged in a normal grieving process. 'Starting from where the client is' becomes the key phrase when dealing with any person suffering from a life-threatening illness.

Social workers can facilitate the coordination of health and social services, and assist in the care and treatment of PLWA through collaborative and integrative efforts with other health disciplines, rather than continuing with competitive and disjointed efforts. Some PLWA experiencing severe anxiety and depression can benefit from psychotropic medications, and the value of the psychiatrist at these times should not be underestimated. Social workers can reduce feelings of loss of control and uncertainty in PLWA by providing informational, tangible, and emotional support. Mobilizing supportive resources and maximizing existing support networks can buffer the effects of chronic stress. Working jointly with the client to identify behavioural patterns that require change in order to maximize health (i.e. diet, stress, exercise, drugs, alcohol, cigarettes, etc.) also empowers a PLWA. Supporting any desired change through organizing treatment programs and allocating adequate resources for the program are invaluable interventions for vulnerable persons. Involvement and interest in alternative forms of therapies, such as herbal medicines, massage, yoga, progressive muscle relaxation, and guided imagery should be encouraged rather than dissuaded. PLWA can derive some sense of control and connection with their physical body by adopting some of these techniques. The actual effectiveness of alternative therapies is controversial, but the placebo effect cannot be underestimated.

Hassles and Uplifts

Lowenthal and Chiriboga (1973) defined three types of stress: infancy and childhood stress, cumulative/chronic stresses, and precipitating stress. This sample was subject to the adolescent stress of 'coming-out' in a social environment of stigma. They are confronted with the chronic stress of physical and financial limitations, and complex and expensive medication regimes. Finally, they are likely to experience the precipitating stress of recent losses of friends or lovers to AIDS and opportunistic infections. History-graded influences, such as AIDS and the gay rights movement, also positively and negatively impacted this generation of gay men (Turner-Henson & Holaday, 1995; Weekes, 1995).

This study was concerned with the current daily hassles and uplifts of this sample, because they were previously documented to be accurate predictors of mental and physical health (Kanner, et al., 1981). This study confirmed that the frequency of daily hassles, not the intensity, is related to lower levels of mental health, vitality, and general health. The severity of hassles failed to be associated with any of the measures of health. These findings parallel those found by Lazarus, Kanner, and Folkman in 1980. The number of hassles per day explains 24% of the variance in mental health, whereas the frequency and intensity of hassles as a set are a better predictor of general health by explaining 29% of its variance. Regression analyses also revealed that general health, social functioning, and mental health explain 33.5% of the variance in the frequency of hassles reported by the sample. Therefore, it could be concluded that the relationship between daily stress and health is bi-directional.

Folkman, Moskowitz, Ozer, and Park (1995) suggested that daily uplifts can act as sustainers of positive mental health, breathers from stress, or restorers of energy. An increase in the number of daily uplifts reported by this sample is related to higher levels of physical functioning, but is not associated with any other quality of life measure. The intensity of uplifts did not play any role in the quality of life measures. However, regression analyses revealed that the frequency and intensity of uplifts as a set significantly explained vitality and physical functioning.

In the context of age-graded comparisons of daily hassles, it seems that this sample has significantly more hassles than the elderly, but their hassles are rated with equal intensity. This group of young men with AIDS are considerably more stressed about money for basic necessities and emergencies than the elderly, but they share an older adult's daily stress over health, physical abilities, enough money for extras, physical appearance, medical care, side-effects of medications, political and social issues, and paperwork.

Many of the individual hassles described in this section have already been addressed in the previous sections on finances, discrimination, and quality of life, and therefore the associated implications are not repeated. The association between daily stress and health emphasizes the need for social workers and other health professionals to evaluate past, precipitating, and systemic stress when making a comprehensive assessment.

Coping Strategies

Siegel and Krauss (1991) delineated three adaptive tasks for seropositive gay men. First, coping with the possibility of a curtailed life span involves reprioritizing of life goals and re-investing in the future. Second, developing strategies for maintaining physical and emotional health through lifestyle changes, maintaining emotional equilibrium, and monitoring health changes. Third, coping with a stigmatizing illness entails dealing with issues of disclosure, feelings of shame and contamination. Siegel and Krauss (1991) derived their model of adaptation for PLWA from Taylor's (1983) tri-dimensional adaptational framework formulated from her observations of cancer patients. The three cognitive-adaptive tasks for a person with a life-threatening illness include a search for meaning, gaining a sense of mastery over the illness, and engaging in a process of self-enhancement.

This sample seemes to be trying to accomplish these tasks through three methods of coping: seeking social support, planful problem-solving, and positive reappraisal. Whereas planful problem-solving is primarily assimilative/problem-focused coping, positive reappraisal and seeking social support involves both assimilative and emotion-focused techniques (accomodative). Positive reappraisal coping was the only coping method to associate with higher levels of general health. It seems that the physical functioning, general health, and mental health together explain a considerable amount of the variance in planful problem-solving and positive reappraisal, but not in seeking social support. Although seeking social support from formal and informal networks is associated with higher levels of self-esteem and control, it is not related with better health. Health status does not seem to affect the person's ability to seek support. However, lower levels of health seem to hinder a person from adopting positive reappraisal and planful problem-solving coping methods.

It is important to note that escape-avoidance and self-controlling coping are associated with significantly lower levels of health across most measures of quality of life, and predict lower levels of self-esteem by 40%. These two coping styles are also related to increased anger and self-blame/guilt. These coping strategies are independent of the frequency and intensity of hassles, but are considerably related to worse health outcomes.

In terms of comparisons across different age groups, it seems that this sample most closely resembles the elderly in coping styles by sharing four types of coping, including confrontive coping, planful problem-solving, seeking social support, and escape-avoidance. This group of men uses more positive reappraisal and less distancing, self-controlling coping, and accepting responsibility than do the elderly.

These results are fairly mixed, but there are two clear conclusions: social workers should encourage positive reappraisal in person's with a positive health status, and both escape-avoidance and self-controlling coping should be minimized in all situations. Reappraising a crisis situation as a growth experience is often tied into a spiritual dimension. It may be difficult for some gay men to subscribe to structured religions because of its overt intolerance and rejection of homosexuality, but a significant number of this sample (47.3%) of men reported increased importance of sprituality and/or religion since being diagnosed with AIDS. The spiritual need to search for meaning is an important part of any intervention. Ministers often form a part of an HIV/AIDS multidisciplinary team and should be consulted regularly.

Social workers should work jointly with clients to evaluate the negative impact of escape-avoidance coping techniques, such as drug use and wish fantasies, and self-controlling strategies, such as suppressing emotions and reactions. Although seeking emotional, tangible and informational support is not related to any health measures, it should be encouraged because it boosts self-esteem and feelings of control. If certain patients are lacking support networks, these support systems should be mobilized. Planful problem-solving is not destructive to a person's health, but it is not necessarily beneficial either. Social workers should channel the young adult's coping need to change the environment into more accessible goals, such as monitoring and managing symptoms, and improving quality of life. Accepting responsibility is used more often by the elderly, and can be used effectively with this population to encourage a person to take responsibility for their illness, medication regimes, and lifestyle choices. It is important to ensure that taking responsibility is not interpreted or expressed as blame. Distancing is also used by the elderly to a greater extent, and should not be equated with denial. A certain amount of distancing from the actual severity of a desperate situation can be useful for maintaining hope. There is a fine balance to achieve between hoplessness and despair due to complete acceptance, and urealistic hopeful expectations, which can lead to repetitive disappointment (Kubler-Ross, 1969). Social workers can assist PLWA in finding emotional equilibrium on this continuum.

Life Cycle Disruption

AIDS impacts a multitude of life cycles, including that of the family, occupation, and economic (Atchley, 1975). There is a complete disruption in the personal and social representations of the individual with AIDS. For this sample of young gay men, the resolution of adult developmental tasks - attaining independence from family, developing a fulfilling career, establishing intimate relationships, attaining financial independence, and maintaining optimum physical health – was dramatically interrupted by AIDS. The premature occurrence of serious illness, physical limitations, multiple losses of significant others, loss of financial security, and loss of roles and status inhibit a smooth transition through the life cycle. Instead of coping with intimacy and the desire to contribute to the next generation through generativity, these men are coping with basic survival needs such as physical, emotional, and financial security. "Just as the individual is planning and fulfilling life goals, the open horizons of the future are sharply delimited" (Sourkes, pp. 1982). The final task of late adulthood, integrity vs. despair, is an essential part of integrating past failures, regrets, and successes into a crystallized self which accepts the finitude of death without overwhelming anxiety.

The disruption of the life cycle due to AIDS may represent a complex and intangible force to be dealt with, but individual and group counselling can be used as effective interventions. Social workers and health psychologists should regularly consult with each other in order to develop mutually complementary interventions. Psychotherapy should focus on the person's thoughts and feelings associated with their inability or delay in achieving certain traditional tasks of adulthood. A plan of action should be formulated with the client to identify those efforts needed to adapt tasks and adopt flexible goal pursuits according to the new physical and social realities.

The resolution of the three primary psychosocial tasks of adulthood – intimacy, generativity, and integrity – can be achieved in the context of AIDS with informal and formal support. A fear of intimacy can develop out of AIDS-related fears, such as disclosure, contamination, and rejection, and can lead to self-imposed isolation. Social workers can help clients resolve these fears, and establish healthy intimate relationships. Generativity can be achieved by encouraging clients to become involved in their family or community by speaking in schools, enrolling in a "big brother" program, volunteering in community organizations, or offering their patient representation on hospital committees. Life review therapy is essential for facilitating the lengthy process of critically reviewing and accepting past regrets, perceived failures, and anger towards others. Social workers can offer more informational and tangible support regarding the completion of advanced directives in preparation for disability and death. Discussing mandates, power of attorney, and funeral arrangements can be terribly uncomfortable for both the professional and client, but if done tactfully, it can replenish the person with feelings of control and resolution.

7.3 OVERALL CONCLUSION

This paper intended to explore and describe the impact of premature life-threatening illness, stigma, multiple loss of significant others, decreased vocational choice and mobility, and decreased financial security among young gay men living with AIDS. It was hypothesized that young gay men with AIDS and the elderly experience similar physical, social, and psychological changes, but the cognitive adaptation to these changes are hindered by the non-normative timing of these events. It was established that uncertainty about the future, concern about not being able to realize life goals, grief due to loss of friends to AIDS, frequency of daily hassles, general health, and physical functioning significantly predict this sample's overall level of mental health. This detailed investigation into the commonly referred to tragedy of early death and disability among gay men with AIDS established that a comprehensive biopsychosocial perspective and multidisciplinary approach to the care and treatment of persons with AIDS are essential components to the success of any pyschosocial intervention. Ultimately, it is hoped that this research will provide ample incentive for other social researchers to embark on more expansive studies investigating the phenomenon of premature aging among all persons with HIV and AIDS.

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APPENDICES

APPENDIX 1

EPIDEMIOLOGICAL DATA

Table A1

Number of AIDS Cases reported by exposure category and year of diagnosis for adult males in Canada (cases diagnosed up to March 31, 1997)

	Year of Diagnosis													
	1979-1992		1993		1994		1995		1996		Jan-Mar 1997		Cumulative	
Exposure Category	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Men who have sex with men	7,085	81.1	1,211	76.1	1,143	76.4	920	73.1	446	69.1	10	71.4	10,815	78.7
Injection drug use	175	2.0	69	4.3	80	5.3	76	6.0	57	8.8	2	14.3	459	3.3
MSM/IDU	355	4.1	88	5.5	91	6.1	68	5.4	34	5.3	0	0.0	636	4.6
Heterosexual contact:														
(a) endemic country	272	3.1	60	3.8	41	2.7	41	3.3	35	5.4	1	7.1	450	3.3
(b) sexual contact with a person at risk	193	2.2	70	4.4	71	4.7	71	5.6	40	6.2	0	0.0	445	3.2
Occupational exposure	0	0	0	0	1	0.1	0	0	0	0	0	0	1	0.0
Recipient of blood	113	1.3	10	0.6	5	0.3	6	0.5	6	0.9	0	0	140	1.0
Recipient of clotting factor	180	2.1	14	0.9	20	1.3	19	1.5	9	1.4	0	0	242	1.8
No identified risk factor	361	4.1	69	4.3	45	3.0	57	4.5	18	2.8	1	7.1	551	4.0
TOTAL	**8,734**	**100**	**1,591**	**100**	**1,497**	**100**	**1,258**	**100**	**645**	**100**	**14**	**100**	**13,739**	**100**

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APPENDIX 2

QUESTIONNAIRE

For office use only	
DATE: ____________ day / month / year	**CODE:** ____________

THE IMPACT OF AIDS ON THE CONTINUITY OF THE YOUNG ADULT LIFE CYCLE OF GAY MEN

- *Thank you for participating in this study.*
- *This questionnaire evaluates your health, general well-being and coping styles.*
- *Your answers to the following questions are essential to the success of the study.*
- ***ANSWER EVERY QUESTION** by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.*
- *Please remember that all the information that you provide is **strictly confidential**.*

PART ONE: HASSLES AND UPLIFTS

HASSLES are irritants -- things that annoy or bother you; they can make you upset or angry. **UPLIFTS** are events that make you feel good; they can make you joyful, glad or satisfied. Some hassles and uplifts occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, others have a strong effect.

The following section lists things that can be hassles and uplifts in day-to-day life. You will find during the course of a day some of these things will have been only a hassle for you and some will have been only an uplift. Others will have been both a hassle and an uplift.

Please think about how much of a hassle and how much of an uplift each item was for you today. Please indicate on the left-hand side of the page (under "HASSLES") how much of a hassle the item was by circling the appropriate number. Then indicate on the right-hand side of the page (under "UPLIFTS") how much of an uplift it was for you by circling the appropriate number.

Remember, circle one number on the left-hand side of the page <u>and</u> one number on the right-hand side of the page for <u>each</u> item.

Day of the week (circle one): Sun Mon Tue Wed Thu Fri Sat

How much of a hassle was this item for you today?	How much of an uplift was this item for you today?
HASSLES	**UPLIFTS**
0 = None or not applicable 1 = Somewhat 2 = Quite a bit 3 = A great deal	0 = None or not applicable 1 = Somewhat 2 = Quite a bit 3 = A great deal

0	1	2	3	1. Your child(ren)	0	1	2	3
0	1	2	3	2. Your parents or parents-in-law	0	1	2	3
0	1	2	3	3. Other relative(s)	0	1	2	3
0	1	2	3	4. Your spouse/partner	0	1	2	3
0	1	2	3	5. Time spent with family	0	1	2	3
0	1	2	3	6. Health or well-being of a family member	0	1	2	3
0	1	2	3	7. Sex	0	1	2	3
0	1	2	3	8. Intimacy	0	1	2	3
0	1	2	3	9. Family-related obligations	0	1	2	3
0	1	2	3	10. Your friend(s)	0	1	2	3
0	1	2	3	11. Fellow workers	0	1	2	3
0	1	2	3	12. Clients, customers, patients, etc...	0	1	2	3
0	1	2	3	13. Your supervisor or employer	0	1	2	3

How much of a hassle was this item for you today?

HASSLES

0 = None or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

How much of an uplift was this item for you today?

UPLIFTS

0 = None or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

0 1 2 3	14. The nature of your work	0 1 2 3
0 1 2 3	15. Your work load	0 1 2 3
0 1 2 3	16. Your job security	0 1 2 3
0 1 2 3	17. Meeting deadlines or goals on the job	0 1 2 3
0 1 2 3	18. Enough money for necessities (e.g., food, clothing, housing, health care, taxes, insurance, etc...)	0 1 2 3
0 1 2 3	19. Enough money for education	0 1 2 3
0 1 2 3	20. Enough money emergencies	0 1 2 3
0 1 2 3	21. Enough money for extras (e.g., entertainment, recreation, vacations, etc...)	0 1 2 3
0 1 2 3	22. Financial care for someone who doesn't live with you	0 1 2 3
0 1 2 3	23. Investments	0 1 2 3
0 1 2 3	24. Your smoking	0 1 2 3
0 1 2 3	25. Your drinking	0 1 2 3
0 1 2 3	26. Effects of drugs and medications	0 1 2 3
0 1 2 3	27. Your physical appearance	0 1 2 3
0 1 2 3	28. Time alone	0 1 2 3
0 1 2 3	29. Exercises	0 1 2 3
0 1 2 3	30. Your medical care	0 1 2 3
0 1 2 3	31. Your health	0 1 2 3
0 1 2 3	32. Your physical abilities	0 1 2 3
0 1 2 3	33. The weather	0 1 2 3
0 1 2 3	34. News events	0 1 2 3
0 1 2 3	35. Your environment (e.g., quality of air, noise level, greenery, etc...)	0 1 2 3
0 1 2 3	36. Political or social issues	0 1 2 3

How much of a hassle was this item for you today?

HASSLES

0 = None or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

How much of an uplift was this item for you today?

UPLIFTS

0 = None or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

0	1	2	3	37. Your neighborhood (e.g., neighbors, setting, etc...)	0	1	2	3
0	1	2	3	38. Discrimination (e.g., work, housing, social)	0	1	2	3
0	1	2	3	39. Conserving (gas, electricity, water, gasoline, etc...)	0	1	2	3
0	1	2	3	40. Pets	0	1	2	3
0	1	2	3	41. Cooking	0	1	2	3
0	1	2	3	42. Housework	0	1	2	3
0	1	2	3	43. Home repairs	0	1	2	3
0	1	2	3	44. Yardwork	0	1	2	3
0	1	2	3	45. Car maintenance	0	1	2	3
0	1	2	3	46. Taking care of paperwork (e.g., paying bills filling out forms, etc...)	0	1	2	3
0	1	2	3	47. Home entertainment (e.g., TV, music, reading)	0	1	2	3
0	1	2	3	48. Amount of free time	0	1	2	3
0	1	2	3	49. Recreation and entertainment outside the home (e.g., movies, sports, eating out, walking)	0	1	2	3
0	1	2	3	50. Eating (at home)	0	1	2	3
0	1	2	3	51. Church or community organizations	0	1	2	3
0	1	2	3	52. Legal matters	0	1	2	3
0	1	2	3	53. Being organized	0	1	2	3
0	1	2	3	54. Social committments	0	1	2	3

PART TWO: IMPACT OF HIV

Below is a list of problems that you, like many others with HIV infection, may be facing. For each of these problems, please circle your answer to indicate how much you have been bothered by this problem during the past month. **Circle one on each line**

How much have you been bothered by this problem during the past month?

		Not at all	A little	Moderately	Quite a bit	A lot
1.	Not knowing where to go for help	☐	☐	☐	☐	☐
2.	Fear of infecting others	☐	☐	☐	☐	☐
3.	Questions about sexual identity	☐	☐	☐	☐	☐
4.	Being discriminated against	☐	☐	☐	☐	☐
5.	Feeling helpless	☐	☐	☐	☐	☐
6.	Feeling anger or frustration at the health care system	☐	☐	☐	☐	☐
7.	Rejection by others close to me (e.g., family or friends)	☐	☐	☐	☐	☐
8.	How and where to get honest, up-to-date information about HIV	☐	☐	☐	☐	☐
9.	Feeling isolated	☐	☐	☐	☐	☐
10.	Problems in my sex life	☐	☐	☐	☐	☐
11.	Financial difficulties	☐	☐	☐	☐	☐
12.	Feeling angry	☐	☐	☐	☐	☐
13.	Getting sick or sicker	☐	☐	☐	☐	☐
14.	Self-blame, guilt	☐	☐	☐	☐	☐
15.	Drug/alcohol use	☐	☐	☐	☐	☐
16.	Grief due to loss of friends to AIDS	☐	☐	☐	☐	☐
17	Fear of dying	☐	☐	☐	☐	☐
18.	Feeling depressed	☐	☐	☐	☐	☐
19.	Spiritual needs	☐	☐	☐	☐	☐
20.	Reduced ability to provide care for others	☐	☐	☐	☐	☐
21.	Telling others (e.g., who to tell, what to tell)	☐	☐	☐	☐	☐
22.	Housing problems	☐	☐	☐	☐	☐
23.	Concern about not being able to care for myself	☐	☐	☐	☐	☐
24.	Legal problems	☐	☐	☐	☐	☐

How much have you been bothered by this problem during the past month?

		Not at all	A little	Moderately	Quite a bit	A lot
25.	Planning for my future care (e.g., living will, life support, power of attorney)	☐	☐	☐	☐	☐
26.	Feeling uncertain about the future	☐	☐	☐	☐	☐
27.	Loss of employment	☐	☐	☐	☐	☐
28.	Concern about confidentiality	☐	☐	☐	☐	☐
29.	Rejection by caregivers	☐	☐	☐	☐	☐
30.	Side effects of HIV medication	☐	☐	☐	☐	☐
31.	Having pain	☐	☐	☐	☐	☐
32.	Feeling less physically attractive	☐	☐	☐	☐	☐
33.	Feeling lonely	☐	☐	☐	☐	☐
34.	Losing or not having life insurance	☐	☐	☐	☐	☐
35.	Loss of control	☐	☐	☐	☐	☐
36.	Thoughts about suicide	☐	☐	☐	☐	☐
37.	Feeling anxious	☐	☐	☐	☐	☐
38.	Fear about loss of mental abilities or dementia	☐	☐	☐	☐	☐
39.	Not being able to realize life goals (e.g., establishing intimate relationships, completing my education, obtaining career goals)	☐	☐	☐	☐	☐
40.	Loss of self-esteem	☐	☐	☐	☐	☐

PART THREE: GENERAL HEALTH STATUS

This part of the questionnaire asks for your views about your health. This information will help us understand how you feel and how well you are able to do your usual activities.
Please check the answer that most applies to you.

1. In general, would you say your health is:

   ☐ Excellent
   ☐ Very Good
   ☐ Good
   ☐ Fair
   ☐ Poor

2. Compared to one year ago, how would you rate your health in general now?

   ☐ Much better now than one year ago
   ☐ Somewhat better now than one year ago
   ☐ About the same as one year ago
   ☐ Somewhat worse now than one year ago
   ☐ Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does you r health now limit you in these activities? If so, how much? ***Check one box on each line.***

		Yes, Limited A Lot	**Yes, Limited A Little**	**No, Not Limited At All**
a.	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b.	**Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf**	☐	☐	☐
c.	Lifting or carrying groceries	☐	☐	☐
d.	Climbing **several flights of stairs**	☐	☐	☐
e.	Climbing **one flight of stairs**	☐	☐	☐
f.	Bending, kneeling, or stooping	☐	☐	☐
g.	Walking **more than a kilometer**	☐	☐	☐
h.	Walking **several blocks**	☐	☐	☐
i.	Walking **one** block	☐	☐	☐
j.	Bathing and dressing yourself	☐	☐	☐

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? ***Circle one answer on each line.***

a.	Cut down on the **amount of time** you spent on work or other activities	YES	NO
b.	**Accomplished less** than you would like	YES	NO
c.	Were limited in the **kind of work or other** activities	YES	NO
d.	Had **difficulty** performing the work or other activities (for example, it took extra effort)	YES	NO

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? ***Circle one answer on each line.***

a.	Cut down on the **amount of time** you spent on work or other activities	YES	NO
b.	**Accomplished less** than you would like	YES	NO
c.	Didn't do work or other activities as **carefully** as usual	YES	NO

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family friends, neighbors, or groups? ***Check one box.***

☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

7. How much bodily pain have you had during the past 4 weeks?

☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all
☐ A little bit
☐ Moderately
☐ Quite a bit
☐ Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. ***Check one box on each line.***

How much of the time during the past 4 weeks -

		All of the time	**Most of the time**	**A good bit of the time**	**Some of the time**	**A little of the time**	**None of the time**
a.	Did you feel full of pep?	☐	☐	☐	☐	☐	☐
b.	Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c.	Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d.	Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e.	Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f.	Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
g.	Did you feel worn out?	☐	☐	☐	☐	☐	☐
h.	Have you been a happy person?	☐	☐	☐	☐	☐	☐
i.	Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc...)? ***Circle one number.***

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

11. How TRUE or FALSE is <u>each</u> of the following statements for you? ***Check one box on each line.***

		Definitely True	**Mostly True**	**Not Sure**	**Mostly False**	**Definitely False**
a.	I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
b.	I am as healthy as anybody I know	☐	☐	☐	☐	☐
c.	I expect my health to get worse	☐	☐	☐	☐	☐
d.	My health is excellent	☐	☐	☐	☐	☐

<u>PART FOUR</u>: WAYS OF COPING

Please describe a situation or event in the past week that you believe to have been particularly stressful/difficult.

____

____

____

Please read each item below and indicate, by **checking** the appropriate box, to what extent you used it in the situation you have just described above.

		Not used	**Used somewhat**	**Used quite a bit**	**Used a great deal**
1.	Just concentrated on what I had to do next - the next step.	☐	☐	☐	☐
2.	I tried to analyze the problem in order to understand it better.	☐	☐	☐	☐
3.	Turned to work or substitute activity to take my mind off things.	☐	☐	☐	☐
4.	I felt that time would make a difference - the only thing to do was wait.	☐	☐	☐	☐
5.	Bargained or compromised to get something positive from the situation.	☐	☐	☐	☐
6.	I did something which I didn't think would work, but at least I was doing something.	☐	☐	☐	☐
7.	Tried to get the person responsible to change his or her mind.	☐	☐	☐	☐
8.	Talked to someone to find out more about the situation.	☐	☐	☐	☐

		Not used	**Used some-what**	**Used quite a bit**	**Used a great deal**
9.	Criticized or lectured myself.	☐	☐	☐	☐
10.	Tried not to burn my bridges, but leave some things open.	☐	☐	☐	☐
11.	Hoped a miracle would happen.	☐	☐	☐	☐
12.	Went along with fate; sometimes I just have bad luck.	☐	☐	☐	☐
13.	Went on as if nothing had happened.	☐	☐	☐	☐
14.	I tried to keep my feelings to myself.	☐	☐	☐	☐
15.	Looked for the silver lining, so to speak; tried to look on the bright side.	☐	☐	☐	☐
16.	Slept more than usual.	☐	☐	☐	☐
17.	I expressed anger to the person(s) who caused the problem.	☐	☐	☐	☐
18.	Accepted sympathy and understanding from someone.	☐	☐	☐	☐
19.	I told myself things that helped me to feel better.	☐	☐	☐	☐
20.	I was inspired to do something creative.	☐	☐	☐	☐
21.	I tried to forget the whole thing.	☐	☐	☐	☐
22.	I got professional help.	☐	☐	☐	☐
23.	Changed or grew as a person in a good way.	☐	☐	☐	☐
24.	I waited to see what would happen before doing anything.	☐	☐	☐	☐
25.	I apologized or did something to make up.	☐	☐	☐	☐
26.	I made a plan of action and followed it.	☐	☐	☐	☐
27.	I accepted the next best thing to what I wanted.	☐	☐	☐	☐
28.	I let my feelings out somehow.	☐	☐	☐	☐
29.	I realized I brought the problem on myself.	☐	☐	☐	☐
30.	I came out of the experience better than when I went in.	☐	☐	☐	☐
31.	I talked to someone who could do something concrete about the problem.	☐	☐	☐	☐
32.	I got away from it for awhile; tried to rest or take vacation.	☐	☐	☐	☐
33.	I tried to make myself feel better by eating.	☐	☐	☐	☐
34.	I tried to make myself feel better by drinking.	☐	☐	☐	☐

		Not used	Used some-what	Used quite a bit	Used a great deal
35.	I tried to make myself feel better by using recreational drugs (e.g. cocaine, crack, marijuana).	☐	☐	☐	☐
36.	I tried to make myself feel better by using prescribed mood-altering drugs (e.g. Valium, Halcion, Xanax).	☐	☐	☐	☐
37.	I took a big chance or did something risky.	☐	☐	☐	☐
38.	I tried not to act too hastily or follow my first hunch.	☐	☐	☐	☐
39.	I found new faith.	☐	☐	☐	☐
40.	I maintained my pride and kept a stiff upper lip.	☐	☐	☐	☐
41.	I rediscovered what is important in life.	☐	☐	☐	☐
42.	I changed something so things would turn out all right.	☐	☐	☐	☐
43.	I avoided being with people in general.	☐	☐	☐	☐
44.	I didn't let it get to me; I refused to think too much about it.	☐	☐	☐	☐
45.	I asked a relative or friend I respected for advice.	☐	☐	☐	☐
46.	I kept others from knowing how bad things were.	☐	☐	☐	☐
47.	I made light of the situation; I refused to get too serious about it.	☐	☐	☐	☐
48.	I talked to someone about how I was feeling.	☐	☐	☐	☐
49.	I stood my ground and fought for what I wanted.	☐	☐	☐	☐
50.	To feel better, I had sex with my primary partner.	☐	☐	☐	☐
51.	I took it out on other people.	☐	☐	☐	☐
52.	I drew on my past experiences; I was in a similar situation before.	☐	☐	☐	☐
53.	I knew what had to be done, so I doubled my efforts to make things work.	☐	☐	☐	☐
54.	I refused to believe that it had happened.	☐	☐	☐	☐
55.	I made a promise to myself that things would be different next time.	☐	☐	☐	☐
56.	I came up with a couple of different solutions to the problem.	☐	☐	☐	☐
57.	I accepted it, since nothing could be done.	☐	☐	☐	☐

		Not used	Used somewhat	Used quite a bit	Used a great deal
58.	I tried to keep my feelings from interfering with other things too much.	☐	☐	☐	☐
59.	I wished that I could change what had happened or how I felt.	☐	☐	☐	☐
60.	I changed something about myself.	☐	☐	☐	☐
61.	I daydreamed or imagined a better time or place than the one I was in.	☐	☐	☐	☐
62.	I wished that the situation would go away or somehow be over with.	☐	☐	☐	☐
63.	I had fantasies or wishes about how things might turn out.	☐	☐	☐	☐
64.	I prayed.	☐	☐	☐	☐
65.	I had anonymous sex to feel better.	☐	☐	☐	☐
66.	I had non-anonymous sex with someone else to feel better.	☐	☐	☐	☐
67.	I prepare myself for the worst.	☐	☐	☐	☐
68.	I went over on my mind what I would say or do.	☐	☐	☐	☐
69.	I thought about how a person I admire would handle this situation and used that as a model.	☐	☐	☐	☐
70.	I tried to see things from the other person's point of view.	☐	☐	☐	☐
71.	I reminded myself how much worse things could be.	☐	☐	☐	☐
72.	I jogged or exercised.	☐	☐	☐	☐
73.	I meditated or used imagery.	☐	☐	☐	☐

PART FIVE: BASIC PROFILING INFORMATION

The following questions are important for analyzing general trends. We wish to remind you that your answers are **completely confidential** and will not be used to personally identify you.
Please check the box for the item that applies to you.

1. What is your type of residence?

   ☐ Rent an apartment, condominium, or home
   ☐ Rent an apartment partially subsidized by the government
   ☐ Belong to a shared apartment complex for people living with AIDS
   ☐ Stay in an AIDS hospice
   ☐ Belong to a cooperative
   ☐ Own a home or condominium

2. How many people usually live in this household (including yourself)? ________

3. Please write the first three digits of your postal code (for example, H2K). __________

4. What language do you use most often?

   ☐ French
   ☐ English
   ☐ Other - please specify: ____________________

5. To what race or ethnic group do you feel you most closely belong?

   ☐ White
   ☐ African Canadian
   ☐ Hispanic
   ☐ Asian
   ☐ Other - please specify: ____________________

6. What is your current 'relationship' status?

   ☐ Single
   ☐ Common Law (currently in a relationship)
   ☐ Widowed
   ☐ Separated
   ☐ Divorced
   ☐ Other - please specify: ____________________

7. How many months have you been involved in a committed relationship? ______ **months**

8. What is the highest level of schooling that you have completed?

- ☐ No formal schooling
- ☐ Less than high school
- ☐ Completed high school
- ☐ Some college (CEGEP)
- ☐ College (CEGEP) graduate
- ☐ Some university
- ☐ University graduate
- ☐ Post graduate degree

9. What is your main source of income?

☐ Income security benefits (i.e. welfare)	For how long? _____ months
☐ Unemployment insurance benefits	For how long? _____ months
☐ Disability benefits	For how long? _____ months
☐ Income from work	For how long? _____ months
☐ Savings	For how long? _____ months
☐ Insurance (private and group)	For how long? _____ months
☐ Investments (mutual funds, RRSPs, savings)	For how long? _____ months
☐ None	For how long? _____ months

10. What is your approximate annual income?

- ☐ less than 10,000$
- ☐ 10,000$ - 19,999$
- ☐ 20,000$ - 29,999$
- ☐ 30,000$ - 39,999$
- ☐ 40,000$ - 49,999$
- ☐ 50,000$ - 59,999$
- ☐ 60,000$ - 69,999$
- ☐ 70,000$ - 79,999$
- ☐ 80,000$ - 89,999$
- ☐ 90,000$ - 99,999$
- ☐ more than 100,000$

11. To what religious denomination do you belong?

- ☐ Christian- please specify: ____________________
- ☐ Jewish
- ☐ Roman Catholic
- ☐ Muslim
- ☐ No Religion
- ☐ Other- please specify: ______________________

12. How <u>actively</u> involved are you in your religion?

- ☐ Not active
- ☐ A little active
- ☐ Fairly active
- ☐ Very active

13. Has your faith in religion changed <u>since</u> you were diagnosed with AIDS?

- ☐ Significantly less important
- ☐ Less important
- ☐ Slightly less important
- ☐ Stayed the same
- ☐ Slightly more important
- ☐ More important
- ☐ Significantly important

14. Have you or are you in the process of completing the following items?

		Yes	**No**
a.	Living will/Mandate	☐	☐
b.	Power of attorney	☐	☐
c.	Funeral arrangements	☐	☐

15. How many of your partners, friends, or family members have died from AIDS-related illnesses? ***Marking down the initials of the persons you have lost may help you remember.***

____

16. Have you required more **physical or emotional support / assistance** from the following persons or resources, since you were diagnosed with AIDS?

		Yes	No
a.	Family members		
	i. Siblings	☐	☐
	ii. Parents	☐	☐
	iii. Other (Specify) ____________	☐	☐
b.	Friends	☐	☐
c.	Partner	☐	☐
d.	CLSC (community medical clinic)	☐	☐
e.	Volunteer organizations (e.g., Maison Plein Coeur, AIDS Community, Care of Montreal, Fondation Aide Directe SIDA Montreal, Centre Pierre Henault)	☐	☐

17. What is your birth date? ________ month ________ year

18. What is your approximate **CD4$^+$** count now (to the best of your knowledge)? ____________

19. Please indicate the date (to the best of your knowledge) that you were diagnosed with **HIV**.

________ **month** ________ **year**

19. Please indicate the date (to the best of your knowledge) that you were diagnosed with **AIDS** or having a **opportunistic infection**.

________ **month** ________ **year**