A PERSON-SITUATION STUDY OF COPING WITH A LIFE-THREATENING ILLNESS: QUALITATIVE ANALYSIS OF COGNITIONS AND BEHAVIOURS IN GAY MEN WITH THE ACQUIRED IMMUNE DEFICIENCY SYNDROME

by

Dennis John Haubrich

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Graduate Department of Social Work
University of Toronto

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ABSTRACT

A Person-Situation Study of Coping with a Life-threatening Illness: Qualitative Analysis of Cognitions and Behaviours in Gay Men with the Acquired Immune Deficiency Syndrome

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Set within the professional context of social work in health care, this study examines the nature and characteristics of coping in a purposive sample of six gay men with the acquired immune deficiency syndrome (AIDS). Based on the illness-related cognitions and behaviours reported by the subjects, the study develops a process model of coping in order to identify a knowledge base for social work in health care.

As a specialized field of practice, social work in health care is primarily concerned with the facilitation of coping with illness and health-related issues with individuals, groups, and communities. Consistent with social work's historic practice focus on the person and situation, the study conceives coping with AIDS as a function of a stressful transactional relationship mediated by cognitive appraisal processes.

Using a qualitative research method, the study identifies 11 interrelated person-situation transactions that depict coping with AIDS as a process of adaptive compromise in relation to three cumulative phases in the illness
continuum. Body vigilance, fatalistic preoccupation, and reconstructed autonomy were the characteristic features of coping portrayed by the subjects.

The study concludes that personal autonomy is intrinsic to coping in situations that impose a process of adaptive compromise. Adherence to the principle of personal autonomy in the facilitation of coping with AIDS is articulated in guidelines for social workers in health care.
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The men who participated in this study were pioneers in coping with AIDS. It is to them to whom I am most indebted. They were my teachers on a journey previously not taken. My hope is that I have adequately represented them.

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Finally, I wish to dedicate this work to the memory of my friend, Michael Ward, who died of AIDS-related complications in 1991, and to the memory of my beloved CAP, Charles Arthur Patterson, who died February 20, 1996.
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CHAPTER ONE
INTRODUCTION

The study of coping spans diverse conceptions, methodologies, and contexts. This study on coping in gay men with the acquired immune deficiency syndrome (AIDS) is imbedded in the disciplinary context of social work in health care. As a specialized field of practice, social work in health care is primarily concerned with how individuals, groups, and communities cope with assaults to health status and social well-being. Since the essence of social work is its practice, social work is predominantly concerned with the facilitation of coping and the amelioration of conditions that impede the process of adaptation to life demands.

The study of coping is the study of personal and social phenomena related to stressful life events that exceed pre-existing psychosocial capability. This study examines the nature and characteristics of coping in the context of gay men who have been diagnosed with AIDS. This is not a study of prescriptions for coping, but of discovery and exploration of how coping can be understood as a process of contextually-based person-situation transactions.

A Frame of Reference for Knowledge Development in Social Work

Transactional theory of the person-in-situation is of central interest to social work since the profession has always stood at the juncture of person and situation, and is cognisant of their interdependence (e.g., Hearn, 1969; Germain,
The intent of the study is to develop a person-situation transactional view of coping as a knowledge base for social workers in health care. This approach to knowledge building is referred to as 'specialty from a common framework,' articulated by Gordon and Schutz (1972):

A social work specialization must be concerned with 'some interface between persons and their environments' for the purpose of making people's transactions with their environments more conducive to their own development and to the amelioration of the environment for others. The immediate cause of the mismatch between coping capability and environment may lie primarily with a person's limited coping ability or with the unfavourableness of the impinging environment, and interventive efforts may be more concerned with one side of the interface in question than the other. But as long as a dual focus is used to achieve a better match between coping capability and environment, and if efforts to improve coping capabilities or the environment are not ignored, a social work specialization may be identified (p. 423).

Development of a specialized knowledge base for social work of the person-environment interface is required where practice requires knowing more about a particular environment and how individuals cope with that environment. Within this framework, coping is an interface concept that mediates the relationship between persons and their environments.

**AIDS and Gay Men**

AIDS, the acronym for the acquired immune deficiency syndrome, is a biomedical construct defined by the presence of opportunistic infections, cancers, and/or neuropathies in an individual that indicates an immune system compromised by infection with HIV, the human immune deficiency virus.
HIV is acquired through blood and semen sources of infection, specifically by: 1) unprotected sexual contact with an infected partner, 2) use of an infected intravenous needle, 3) receipt of infected blood or blood products, and 4) through an infected mother to her newborn.

HIV infection is identified by serologic evidence of antibodies to the virus. The infection has an extended asymptomatic period prior to the development of symptoms that are biomedically indicative of AIDS (Curran et al., 1985). The syndrome is the illness stage of the infection and eventually leads to mortality. While medical treatment to promote longevity is now more effective, to date (1996), there is no treatment to eradicate the virus from an infected individual.

The first cases of the acquired immune deficiency syndrome were reported in homosexual men and intravenous drug users in the United States in mid-1981 (Centers for Disease Control, 1981). In the course of seeking its etiology, the behaviours associated with these population groups suggested a transmissible agent as the cause of the syndrome. By early 1983, occurrences of AIDS among persons with hemophilia and recipients of blood transfusions further confirmed the transmissible agent hypothesis (Centers for Disease Control, 1982). In the following year, a variously-named retrovirus, now known as HIV, the human immune deficiency virus, was shown to be the cause of AIDS (Barre-Sinoussi et al., 1983; Gallo et al., 1984; Levy et al., 1984).

Among gay men, AIDS was initially identified by the presence of pneumocystis carinii pneumonia (PCP), a protozoan infection usually seen in individuals whose immune systems have been compromised, and by the presence
of Kaposi's sarcoma (KS), a vascular cancer associated with previously damaged immunity. Later it was found that HIV infection could also affect the central nervous system and cause chronic meningitis, encephalopathy, and dementia.

By 1985, in San Francisco, the prevalence of HIV infection among gay men was estimated to be at least 50%, and AIDS was the leading cause of death among single men who lived there, aged 25 to 44 years (Curran et al., 1985). While the prevalence of HIV infection is now more diversified, the disease remains endemic within gay male communities and is the leading cause of death in this population group in North America.

Organization of the Study

Chapter Two of this study reviews the research traditions in which the concept of coping has emerged as a field of inquiry, and identifies the basis and requirements for its theoretical construction as a person-situation transactional process.

Chapter Three operationalizes the transactional conception of coping through the design and specification of a qualitative research methodology that addresses the person-situation process dimensions of coping in a sample of gay men with AIDS.

Chapter Four profiles the illness-related cognitions and behaviours of the study sample and presents a composite portrait of coping of six gay men with AIDS.

Chapter Five reports the methodological process of abstraction,
conceptualization, and classification of the subjects' illness-related cognitions and behaviours. The chapter identifies and describes the coping processes engaged in by the subjects.

Chapter Six, Research Findings and Conclusions, presents the transactional process model of coping derived from analysis of the research data and articulates a knowledge base for social work in health care based on the study's findings.
CHAPTER TWO
REVIEW OF THE LITERATURE

This chapter addresses the question "what is coping?" as it has evolved in various theoretical and research traditions. The dominant preoccupation of the coping literature is with the link between forms of life stress and coping as a function of adaptation (Coelho, Hamburg, and Adams, 1974). This chapter reports the major theoretical and methodological formulations of coping and articulates a person-situation transactional process model of coping derived from this literature. The literature review features coping with illness as its central theme with particular reference to gay men with AIDS.

Dictionary Definition of Coping

Since coping is an everyday term, the concept first warrants attention to its dictionary definition. The verb "to cope" as defined in The Oxford English Dictionary has four interrelated features:

1) Coping is an action, an activity referred to as "copeage, the action of coping." The words used to define coping suggest embattlement: "to strike, to come to blows, to join battle, to fight."

2) The activities that describe coping imply that it is a relational concept: "to encounter, to engage, to face, to meet, to come into contact with, to touch."

3) Coping is defined in contextual terms as occurring in "the shock of battle, a fight, a field," and as having to do with "blows, dangers, difficulties, a
situation or problem, hostile or friendly."

4) The words used to define coping imply mastery: "to contend with, to deal with, to manage (competently), to be or prove oneself a match for" (Simpson and Weiner, 1989, p. 904).

Implicit in these definitional features of the concept are four assumptions relevant to this study:

1) Coping is an activity that requires conscious effort as opposed to predetermined or automatized behaviour.

2) Coping is undertaken in relation to a novel situational demand which is of varying intensity and duration, usually noxious.

3) Coping serves resistive and protective functions.

4) The association of coping with mastery implies that it is a value-laden concept defined by socio-cultural beliefs and expectations.

The theoretical, methodological, and value issues inherent in these assumptions are addressed in this literature review.

Theoretical and Research Formulations of Coping

The literature on coping is found in three interrelated research traditions: 1) psychosomatic medicine, 2) life event research, and 3) crisis intervention theory. Irrespective of diversities in their conceptions of coping, these traditions share a common paradigm that relates forms of life stress to the onset of illness or forms of maladaptation (e.g., Dohrenwend and Dohrenwend, 1974; Kobasa, 1979; Rabkin and Struening, 1976).
Psychosomatic Medicine

The contribution of psychosomatic medicine to the study of coping primarily evolved through the development of psychoanalytic theory which focuses on the relationship between personality traits or conflicts and types of disorders (Wittkower, 1974). Psychoanalytic theories of coping share a common focus on the role of ego defences in the management of life stress and psychosocial functioning. Originating with Anna Freud (1946), research on ego defences has focused on the development of hierarchical classifications of ego defences in which coping refers to functionally adaptive defences, followed by neurotic modes of defence, also hierarchically arranged, and finally, at the bottom, psychotic levels of defence or ego failure (Haan, 1969, 1977; Menninger, Mayman, and Pruyser, 1963; Vaillant, 1977). Haan (1980), for example, argues that coping is qualitatively different from defensive actions: "People will first attempt to cope, but, failing to cope, they will move to use defensive strategies; if these fail, they will retreat to self-chosen fragmentation (p. 115)."

The core conceptual issue posed by ego theorists is the distinction between coping as adaptive, and defences as maladaptive (Haan, 1963, 1969, 1977; Kroeber, 1963). By contrast, Murphy (1974), Vaillant (1976) and White (1974) provide illustrations of how individuals fluctuate between and intermix defences and problem-solving efforts in order to manage threatening situations. As such, to equate coping with what is normative and preferred is a cultural ideal imbedded in Western individualism. The situation of a person facing an irreversible threat, for example, is not one to be mastered. Further, to equate
coping with mastery and functionally adaptive defences confines its conception to the value judgement of an observer and limits understanding of a broader range of cognitions and behaviours that people engage in to cope with stressful life events.

This study, therefore, does not make a sharp distinction between coping and ego defences. For example, the defence mechanisms of denial and avoidance in the context of illness are generally considered ineffective since the person who denies or avoids does not engage in illness-related problem-solving (Lazarus and Folkman, 1984). However, denial and avoidance have been reported to be functional to coping when the objective situation is unchangeable (Breznitz, 1983a, b) and in differential phases of illness in which they facilitated recovery (Cohen and Lazarus, 1983; Hackett and Cassem, 1975; Hackett, Cassem, and Wishnie, 1968).

**Life Event Research**

The field of life event research was derived from the establishment of an assumed causal link between life events and illness (Brown and Birley, 1968; Brown, Harris, and Peto, 1973; Cochrane and Robertson, 1973; Dohrenwend, 1973a, b; Dohrenwend and Dohrenwend, 1974; Holmes and Rahe, 1967; Kaplan, 1970). Life event research focuses on coping as an intervening variable between a stressful life event and the onset of illness or maladaptation, including conceptualizations of illness itself as a stressful life event.
Three types of coping can be discerned in the life event literature: 1) psycho-physiological, 2) psychological, and 3) social. While conceptually distinctive, these perspectives are not always clearly demarcated from each other; however, they share in common an individualistic conception of coping, one that neglects social structural analysis (Gerhardt, 1979; Mechanic, 1974).

**Psycho-physiological Coping**

The psycho-physiological perspective views coping as a faulty reaction of the body to life changes and associated adaptive requirements which, in turn, lower body resistance and enhance the probability of disease (Holmes and Masuda, 1974; Kagan and Levi, 1971; Levi, 1974). This perspective is derived from animal experimentation research which defines coping as acts that attempt to reduce psycho-physiological disturbance (Miller, 1980; Selye, 1956; Ursin, 1980). By contrast to the adaptive view of coping held by the ego theorists, this 'flawed' view of coping includes illness behaviour as compatible with coping, irrespective of the presence of disease (Mechanic and Volkart, 1961; Rahe, 1974).

This study does not make a distinction between illness behaviour and coping. While it does not equate coping with mastery, it does not view coping to be inherently flawed. It assumes that all thoughts and behaviours are purposively directed to managing life tasks, all be they culturally and situationally contextualized, as well as resource dependent.
Psychological Coping

The psychological view of coping dominates the coping literature. First elaborated by Lazarus (1966; Lazarus and Opton, 1966), this view of coping holds that subjective factors located in the individual determine what it is that people do in coping with stressful life situations. Among subjective variables, the psychological perspective holds that cognitive appraisal is the intervening variable between person and situation and is the central determinant of coping (Cohen and Lazarus, 1980; Cox, 1978; Lazarus, 1966; Lazarus, Averill, and Opton, 1970, 1974; Lazarus and Folkman, 1984; Lazarus and Launier, 1978).

The role of cognitive appraisal in coping is a key component of this study's theoretical framework and is elaborated in the person-situation transactional conception of coping presented later in this chapter.

Social Coping

The social coping perspective construes coping as active attempts to influence the environment in order to change or ameliorate a situation. Social coping is differentiated from psychological coping by a distinction between manipulation of the environment and manipulation of cognitions about the environment (Cobb, 1976; Mechanic, 1970). The social coping perspective argues that psychological coping alone is an insufficient means of managing stressful situations (Brown, Bhrolchraín, and Harris, 1975). In particular, this research has established the positive role of social support in the mediation of life stress.

Psychological and social coping share common ground in two types of etiological agents: 1) loss events and 2) chronic problems, both of which are relevant to the study of gay men with AIDS. Loss events deprive an individual of previously held objects and social roles which provoke grief (psychological) and mourning, its social expression (Averill, 1975; Simos, 1979). Second, management of chronic problems requires resources external to an individual's psychological repertoire and therefore requires social action (Gerhardt, 1979).

The intermix of psychological and social coping is made further apparent through the distinction made by several authors between two functions of coping: 1) problem-solving and 2) the regulation of emotional distress (Cohen and Lazarus, 1980; Hamburg, Coelho, and Adams, 1974; Lazarus, 1974, 1975; Lazarus, Averill, and Opton, 1974; Lazarus and Folkman, 1984; Lazarus and Launier, 1978; Mechanic 1962; Murphy, 1974). While these functions are reported to be mutually facilitative, they may also interfere with each other as when denial of a situation prohibits social coping (Katz et al., 1970; Hackett and Cassem, 1975).

This study views coping as comprising both psychological and social variables in a complex interplay that invariably impact upon health status and social well-being.
Crisis Intervention Theory

Coping with crisis was first scientifically studied by Lindemann (1944) who described the loss and grief experiences among survivors and relatives of victims of a tragic nightclub fire (the Coconut Grove, Boston, 1942). Drawing upon Lindemann’s work as well as Erikson’s (1950) classic formulation of developmental crises in the life cycle, Caplan (1974) was the first to formulate crisis intervention theory for the helping professions. Caplan defines crisis as a situationally-based state of psychological disorganization and social ineffectiveness. The perspective emphasizes the novelty of a crisis situation in which psychosocial demands exceed an individual’s pre-existing coping ability. By definition, the person in crisis is in a deficient state to competently manage the situation without external assistance. Based on the notion that all crises are time-limited, the goal of crisis intervention is to restore the individual to optimal psychosocial functioning and reintegration as soon as possible (Golan, 1978).

The crisis intervention literature is imbedded in social constructions of help and dependency in which psychological and social competence in coping is the desired outcome (Brickman et al., 1982). The perspective is relevent to this study in that it focuses attention on the dynamics of what people actually think and do in relation to a novel and noxious situation. However, its view of coping is limited in that it confines coping to the crisis component of a situation and assumes a restorative state through the imposition of problem-solving strategies.

While this study assumes that a diagnosis of AIDS as a life-threatening and stigmatized disease precipitates a crisis, the duration and characteristics of
coping are not confined to crisis components in the illness trajectory. Further, the study does not impose a prescribed view of what an individual should think or do in relation to life-threatening situational demands.

A Person-Situation Transactional View of Coping

Apart from diversities in conceptualizations of coping among its research traditions, it can generally be stated that coping is a volitional attempt to deal with self and situation in their interdependence (Perlman, 1975). This relational view of coping has its origins in the concept of transactionalism and is theoretically developed in the field of stress research (Mason, 1975a, b; Phillips and Orton, 1983).

This study was conducted with the presupposition that there is a transactional relationship between a person and a situation in which coping is a transactional variable.

Originated by Dewey and Bentley (1949), transactionalism is an epistemological theory of scientific inquiry in which transactionalism refers to systems of description that deal with aspects or phases of action without final attribution to "elements" or other presumptively detachable or independent "entities" (p. 108). The transactional level of inquiry assumes that prior knowledge of a person or situation alone is inadequate and that key person and situational variables must be designated relationally (Coyne and Lazarus, 1980). An assumed correspondence between stable characteristics of the person or situation and the actual coping process often does not hold (Cohen and Lazarus,
Person and situational variables co-exist in a unitary system characterized by circular reciprocal influence (Dewey and Bentley, 1949; Riegal and Meacham, 1978; Watzlawick, Beavin, and Jackson, 1967).

A transactional description of a person in situation employs the dynamics of process and its relationship to its situational context as the units of analysis. The boundaries of the process and its relevant context are determined by the purposes of analysis (Coyne and Lazarus, 1980).

This study sought to identify the illness-related cognitions and behaviours of gay men with AIDS in the situational contexts in which they were reported.

The transactional model of coping employed by this study is cognitive-phenomenological, and is cogently described by Coyne and Lazarus (1980):

...the person appraises what is being experienced and uses this information in coping to shape the course of events. This appraisal of the significance of an ongoing relationship with the environment for one’s well-being leads to coping processes consistent with personal agendas. The effects of the coping are in turn appraised and reacted to as part of the continuous flow of psychological, social, and physiological processes and events. Stressful commerce with the environment thus involves extensive psychological mediation and reciprocal feedback loops, which cannot be reduced to stimulus and response terms. The nature of stress phenomena therefore requires that any comprehensive model of it be developed within a transactional, process-oriented perspective (p. 145).

The cybernetic system model of stress developed by Cox and Mackay (1976; Cox 1978) describes a transactional view of coping in which cognitive appraisal is its essential feature. The system is shown in Figure 1. The model holds that stress and coping are individually perceived phenomena rooted in psychological processes. Second, feedback loops in the system means that the model is cyclical rather than linear.
Figure 1

A Cybernetic System Model of Stress

Actual capability → Perceived capability

Actual demand → Perceived demand

Cognitive appraisal → Imbalance

Imbalance = Stress

Emotional experience → Stress response

Stress response → Psychological response

Psychological response → Cognitive defence

Stress response → Behavioural response

Source: Cox and MacKay (1976); Cox (1978).
The system process is described in five stages:

**Stage One**

The first stage addresses the sources of demand. Howarth (1978), for example, identifies four categories of demand: 1) biological, 2) developmental, 3) social, and 4) phenomenological. Sources of demand are assumed to be both internally- and externally-based. Internally generated demands such as psychological and physiological needs, as well as their fulfillment, are included as determinants of coping.

In coping, the sources of demand are compounded by situational factors which qualitatively inform the person-in-situation. Lazarus and Folkman (1984), for example, identify six situational factors that influence cognitive appraisal in coping: 1) novelty, 2) predictability, 3) event uncertainty, 4) temporal factors, such as imminence, duration, and uncertainty, 5) situational ambiguity, and 6) the timing of stressful events in relation to the life cycle. These factors play a key role in the study of gay men with AIDS. The study assumes that the source of demand, AIDS, as well as related situational factors of the study population, influence cognitive appraisal processes.

**Stage Two**

Stage two of the model is constituted by cognitive appraisals of the demand and of the ability to cope. Stress in this model is the consequence of an imbalance between perceived demand and perceived capability to meet the
demand. Ongoing cognitive appraisals of the demand and of the ability to cope are viewed as the central determinants of coping within the circular system. Cognitive appraisals of demand and capability are operationalized in Chapter Three, Research Design and Methodology.

**Stage Three**

In stage three the subjective experience of stress and accompanied physiological changes precipitate coping, i.e., cognitive and behavioural attempts to reduce or ameliorate the demand. This view of coping is further elaborated by Lazarus and Folkman (1984), who define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping, in their definition, includes anything a person thinks and does in an effort to manage a demanding situation. This inclusive view of coping is the one adopted in this study.

**Stage Four**

Stage four, the feedforward component in the system, considers the perceived and actual consequences of coping efforts and functions. In fact, subjective stress may only occur when the person's failure to meet the demand is important (McGrath, 1976; Sells, 1970). The threat of failure to cope, perceived or actual, undermines or alters an individual's beliefs and commitments (Lazarus and Folkman, 1984).
The feedforward component of the model accentuates two themes in the coping literature relevant to this study: 1) the severity of threat in a demand situation, and 2) anticipatory coping in relation to a signalled event or series of events.

Anderson (1977), Janis and Mann (1977), Menninger (1954), and Wheaton (1959), for example, report that the greater the perceived level of threat the more likely the individual will engage in primitive, defensive emotion-focused coping and that initial problem-solving is more likely to be ineffective.

Anticipatory coping refers to preparatory coping responses, both emotion- and problem-focused, to a signalled event (Lazarus and Folkman, 1984). For example, people with illnesses which include anticipated losses often begin to grieve these losses prior to their occurrence (Mages and Mendelsohn, 1979; Moos and Tsu, 1977). In anticipatory coping the individual is allowed some freedom in the selection of what to attend to, how, and when (Folkman, Schaefer, and Lazarus, 1979; Lazarus, 1975; Lazarus and Cohen, 1977; Lazarus and Launier, 1978).

Stage Five

The fifth stage in the system is the presence of feedback loops which function to influence coping processes and outcomes in each of the previous four stages of the model. The feedback dimension of the model exemplifies three tenets of transactionalism originally proposed by Dewey and Bentley (1949) and outlined by Pervin and Lewis (1978):
1) No part of the system is independent of the other parts of the system or of the system as a whole.

2) All parts of the system have a constant reciprocal relationship; one part does not simply act on another part.

3) Action in any part of the system has consequences for other parts of the system.

The five stages in the model comprise a dynamic cybernetic system in which stress and coping are intervening variables that reflect person-situation transactions (Cox, 1978). Thus, in order to consider the dynamic relationship of the person in situation, coping must be considered from a transactional standpoint (Benner, 1982). Spiegal (1971) summarizes this position as follows:

If the field is transactional, then all of its parts are interdependent. No one of its parts could be omitted without destroying the whole field, for all are conceived as being in functional relation with all others in an exclusive system of relationships. It is not that the whole is greater than the sum of its parts. Rather, the whole is a way of exhibiting the functional relation between parts. Whole and parts are complementary and indispensable to each other (p. 41).

The study assumes that coping occurs in a transactional field in which analysis into separately and independently existent parts has no fundamental status (Bohm, 1980). A transactional field has two fundamental properties. One, it is contextual, in this case gay men with AIDS. Both person and situation are contextual. Second, a transactional field is constituted by processes in which person-situation encounters unfold in a dynamic constellation. Lazarus and Folkman (1984) identify three key features of process in coping:

1) Coping is what the person actually does (e.g., see Table 1).
Table 1

General Coping Strategies

1) Seek more information about the situation (rational-intellectual)

2) Talk with others to relieve distress (shared concern)

3) Laugh it off; make light of situation (reversal of affect)

4) Try to forget; put it out of mind (suppression)

5) Do other things to distract self (displacement)

6) Take firm action based on present understanding (confrontation)

7) Accept, but find something favourable (redefinition)

8) Submit to and accept the inevitable (fatalism)

9) Do something, anything, however reckless, impractical (acting out)

10) Negotiate feasible alternatives (if X, then Y)

11) Reduce tension by drinking, overeating, drugs (tension reduction)

12) Withdraw socially into isolation (stimulus reduction)

13) Blame someone or something (disowning responsibility)

14) Seek direction from an authority and comply (compliance)

15) Blame yourself, sacrifice or atone (self pity)

2) Coping occurs in a particular context and is responsive to contextual requirements.

3) How what is done changes as person-situation encounters unfold, including those united by a common theme such as the AIDS illness trajectory.

The dynamics of coping is change.

This study examines the illness-related cognitions and behaviours in the particular context of gay men with AIDS. The study views all illness-related cognitions and behaviours as constituting coping. From a transactional perspective, the study seeks to identify the sequence of person-situation encounters as an individual's cognitions and behaviours unfold following an AIDS diagnosis. The study does not seek to attribute value to what a person actually does, it simply seeks to conceive and describe a process of person-situation encounters in a contextualized illness trajectory, gay men with AIDS.

Literature on Gay Men with AIDS

The contextual features of AIDS among gay men are twofold:

1) AIDS bears the stigma of a sexually transmitted disease that is epidemiologically associated with men who have sex with men.

2) Men who have sex with men is socially constructed as a stigmatized behaviour in society.

These themes dominate the early literature on gay men with AIDS (Altman, 1984; Kayal, 1985; Patton, 1985) and is evident in analyses of early media reports on the disease (Albert, 1984, 1985).
The literature on coping among gay men with AIDS can be subsumed under three categories: 1) first-person accounts, 2) nonintervention studies, and 3) clinical intervention literature.

**First-person Accounts**

First-person accounts report the subjective experience of coping. Ferrara (1984), for example, details his personal experiences as a gay man with AIDS, highlighting the importance of support from friends and counselling, the demands of physical decline, treatment problems, fear of pain and death, and the search for hope. First-person accounts of coping are generally characteristic of early literature on an illness, for example, Rollin (1976) on breast cancer, and Cousins (1976) on collagen disease. Personal accounts serve an educative and self-therapeutic function, and generally depict coping as a process of adaptation.

**Nonintervention Studies**

Nonintervention studies of coping identify the sequelae of psychosocial demands and corresponding coping modes, frequently constructed in stage models. Stage models of coping focus on irreversible loss or loss of commitment as a precipitating event that is met with cycling fluctuations in efforts to regain control or disengagement such as denial and avoidance (Horowitz, 1982; Klinger, 1977; Shontz, 1975; Wortman and Brehm, 1975).

Diagnosis with a life-threatening, debilitating illness is generally construed as a crisis (Moos and Tsu, 1977), is followed by a period of exacerbated thoughts
and emotions about life/death concerns which Weisman and Worden (1976-1977) refer to as the period of 'existential plight,' and, in the face of impending mortality, leads to a declined physical and/or mental state in which capability and autonomy are compromised. The dialectics of living or dying are the featured characteristics in coping with a life-threatening illness (Pennington, 1981).

Nonintervention studies of gay men with AIDS highlight illness-related events and issues, and report the psychological status of the study population usually related to stages in the illness. Nichols (1985) identified three stages of situational distress in the AIDS illness trajectory: 1) the crisis of diagnosis, 2) a transitional state, post-diagnosis comparable to Weisman and Worden's (1976-1977) period of existential plight, and 3) a physical and/or mental deficiency state, with the frequent addition of another stage, preparation for death. It is difficult to assign more precise stages to the AIDS illness trajectory since the syndrome is highly variable in morbidity and expected mortality.

Compared to people with other illnesses, gay men with AIDS have been reported to manifest more significant mood disturbances and lower self-esteem, the latter particularly in situations of diminished or low social support (Donlou, Wolcott, Gottlieb, and Landsverk, 1985; Woods, 1985). In a study that distinguished between coping and defences, Alumbaugh (1985) reported coping to be consistently associated with lowered mood disturbance, high self-esteem, and satisfaction with support. The defence of avoidance was associated with depression, low self-esteem, low quantitative support, and low satisfaction with support. A similar finding by Hirsch (1985) found that lowered mood
disturbance in gay men with AIDS was associated with their ability to positively compare themselves to those who were physically and socially less fortunate.

Consistent with these findings, this study assumes that what people think and do in coping with a life-threatening illness is dependent upon the availability and use of internal and external resources. These studies are, however, limited in that they equate coping with outcome and, therefore, neglect its process dimensions.

**Clinical Intervention Literature**

The clinical intervention literature on coping with illness disseminates ways in which coping can be facilitated through the provision of information and psychotherapy (Cohen and Lazarus, 1980). Intervention studies on gay men with AIDS focus on two themes, psychotherapy and social advocacy, generally within a crisis intervention framework (e.g., Baumgartner, 1985; Furstenberg and Olson, 1984; Isaacs, 1985; Lopez and Getzel, 1984; Morin, Charles, and Malyon, 1984; Tresse, 1985). While different in focus, these interventions share an assumed dependency on the help of others in order to cope, particularly in crisis situations.

This study includes, but does not limit coping to crisis components of the illness and to help-seeking behaviour as does the intervention literature.

Together, the scientific and professional literature on coping in gay men with AIDS is limited to reports on psychological and social support status. While illness phases are identified, the process of coping is not.
Implications of Transactionalism for the Study of Coping

In a transactional conception of coping the essential task is the identification of the processes that occur between person and situation at their points of engagement (Pervin, 1978). Traditional coping research has been predominantly concerned with the individual as the fundamental unit of analysis in which the specific context of coping, i.e., the particular person-situation configuration, is treated as a static phenomenon. A transactional, process-oriented study of coping focuses on what people actually think and do in relation to a specific situational context over a period of time. This type of research is referred to as ipsative-normative (Broverman, 1962; Marcell 1977). It is ipsative in that it focuses on intraindividual comparisons, i.e., it observes the same person again and again, comparing the person with himself or herself at different times and under different conditions. It is normative, i.e., interindividual, in that it compares person with person in relation to common situations over time. Ipsative-normative research recognizes variability both within and between persons, while at the same time it seeks to identify normative patterns among people under similar conditions. It requires that data collection be sufficiently systematic and situationally-specific to allow intraindividual data to be compared interindividually.

The requirements of a transactional process research design for the study of coping in gay men with AIDS are operationalized in Chapter Three.
CHAPTER THREE
RESEARCH DESIGN AND METHODOLOGY

Research Design

This is a qualitative research study, appropriate to the collection and explication of data which are personal, subjective, socially-sensitive, and process-oriented. The study examines the nature and characteristics of coping with a life-threatening illness from a person-situation transactional perspective. The exemplar for the study is gay men living with AIDS.

The study is descriptive of the lived experience of gay men with AIDS, and focuses on discovery and understanding of the coping activities engaged in by the subjects in relation to the psychosocial demands imposed by the illness. The study construes coping as a process of what the person actually thinks and does in relation to a subjectively perceived situation. The qualitative research methods selected to represent this theoretical construction of coping are grounded theory (Glaser and Strauss, 1967) and phenomenology (Heidegger, 1962; Taylor, 1971). Grounded theory methodology focuses on the construction of theory obtained from systematic data collection of a lived experience. From a grounded theory perspective, the study sought to identify what the subjects actually thought and did in relation to their respective situations. Second, the study is phenomenological in that it sought to identify the personal meaning of a lived experience. Personal meaning of a lived experience refers to the individual's cognitive appraisal of a situation as previously imbued by cultural practices and
personal history (Heidegger, 1962). Analysis of the data sought to systematically represent the subjects' lived experience in coping with AIDS.

In design, the study intended to develop complete and extensive personal-situational portraits of the ways a small sample of subjects are coping with a life-threatening illness. A person-situation conceptual model of coping with illness is derived from these portraits for application in social work in health care.

In-depth, audio-taped interviews using a pre-tested, semi-structured interview schedule is the method used for data collection.

Sixteen gay men with AIDS consented to be interviewed. The transcribed texts of their interviews served as the basis to select a smaller sample for in-depth qualitative data analysis.

A sample of six was selected for the textual analysis based on their approximate representation of three transitional phases in the course of a life-threatening illness: 1) the period of diagnosis, two subjects, 2) the period of "existential plight" (Weisman and Worden, 1976-77), two subjects, and 3) the period of "living or dying" (Pennington, 1981), two subjects. Together the six subjects constitute the equivalence of a study of two subjects throughout three transitional phases in a life-threatening illness trajectory.

Theoretical Framework for the Study

The focus of the study is on coping conceived as a person-situation transactional process. In contrast to static, cause-and-effect models of research, a transactional approach requires that person and situation be considered as two
components of a unitary behavioural system in an ongoing process of reciprocal influence (Kahle, 1979; Magnusson and Endler, 1977; Nuttin, 1977).

Since the study is conducted from within the professional context of social work in health care, selection of the person-situation transactional paradigm as the study's conceptual frame reflects social work's historic practice focus on the person-in-situation.

Acceptance of the person-situation transactional system as the primary unit for data collection and analysis has implications for research methodology:

what counts is not...subjectivity or objectivity, but the fit, the tensions, the capacities and limitations of the system to maintain itself or to change, and the dialectics of this process. ...The "objective" is created and recreated by the "subjective" and vice versa in a continuing interplay. ...(Thus) we "know" neither the "objective" person nor the "objective" situation. We "know" only the interaction (Raush, 1979, pp. 102-103).

In a transactional approach the essential task is the identification of the processes that occur between person and situation at the point of engagement. This approach to the person-situation relationship takes into account two assumptions:

1) There are a variety of events occurring simultaneously both within and outside the person.

2) An event can only be understood as part of a sequence, phase, or pattern (Pervin, 1978).

Within this framework, coping is conceived as a constantly changing person-situation transaction mediated by an individual's cognitive appraisals. An individual's cognitive appraisals determine what is at stake in any given person-
situation transaction, as well as what resources, internal, external, or both that the individual has, to deal with a personal-situational demand (Lazarus and Folkman, 1979; 1984).

The study conceives coping with AIDS as an individually perceived and experienced phenomenon, encompassing a series of events in an individual life history whose course of life is substantially altered by the concrete realities of the disease. At any point in time in the illness trajectory, the individual must manage the personal and situational demands presented by the disease. In order to identify both the common and idiosyncratic in an individual's thoughts and behaviours in relation to a life-threatening illness, the most suited method of study is the intensive analysis of a series of individual subjects (Mages and Mendelsohn, 1979).

The Research Question

Coping is anything a person thinks and does in relation to a perceived demand. Using gay men with AIDS as the exemplar, the question for research, therefore, is:

"What are the illness-related cognitive and behavioural coping processes that occur between a person and a situation at their points of engagement?" The question assumes that the experience of coping with an illness is the function of a psychosocial relationship of some duration between a person and a situation, each with their distinctive characteristics.
Research Methodology

Development of the Research Instrument

An interview schedule (Appendix A) was developed to serve as a consistent base and guideline for the data collection process, and was designed to elicit the data necessary to obtain a complete, personal account of the participants' thoughts, actions, and feelings toward their situations. The interview topics selected were based on a review of literature on coping with a life-threatening illness, including literature on how gay men cope with AIDS, as reported in Chapter Two.

The Interview Schedule was organized in seven sections:

1) Discovery and Diagnosis
2) Medical Information
3) Medical Treatment
4) Lifestyle
5) Relationships with Others
6) Self
7) Questions to Validate the Purpose of the Interview

Section 1, Discovery and Diagnosis, obtained information about how the participants discovered that they had AIDS, the impact that this information had on them, and how they dealt with this information.

Section 2, Medical Information, elicited information on the participants' knowledge of medical treatment and how they made decisions about medical treatment, including alternative therapies.
Section 3, Medical Treatment, elicited the participants' experiences in undergoing medical treatment, the problems they encountered, and how they dealt with these problems.

Section 4, Lifestyle, obtained the participants' general patterns of activity both before and after diagnosis, as well as their assessments of how they were coping with their life situations.

Section 5, Relationships with Others, obtained the participants' perceptions of how their illness has affected their relationships with their families and friends.

Section 6, Self, elicited the impact that AIDS had on the participants' views of themselves. Coping with an altered sense of self was the central theme in this area of questioning.

Section 7, Questions to Validate the Purpose of the Interview, determined the candour and completeness of the information provided by the participants.

The specific questions in Sections 1 to 6 were designed to reflect five essential elements of the coping process derived from the paradigm formulated by Lazarus and Folkman (1984):

1) Situation

The coping process occurs in a situation in which the participants face an event that has occurred or one that they anticipate will occur.

*E.g.*, Interview Schedule question 1.1: Would you tell me what symptoms you first developed that indicated to you there was something wrong with your health?
e.g., Interview Schedule question 5.5: Is there anyone you haven’t told whom you feel you need or want to tell?

2) Awareness

Awareness refers to the information that the participants have about their situation at any point in time in the illness trajectory.

e.g., Interview Schedule question 1.7: Would you share with me, in as much detail as you are able to remember, how you eventually found out that you had AIDS?

3) Cognitive Appraisals

There are two types of cognitive appraisal: i) primary, and ii) secondary.

Primary appraisals are the participants’ assessments of the significance of their situations for their well-being.

e.g., Interview Schedule question 1.8: At the time of your diagnosis, what did being told that you have AIDS mean to you?

Secondary appraisals are the participants’ assessments of their ability to deal with their situations, as well as their assessments of the options that they have available to them.

e.g., Interview Schedule question 3.10: Are there ways in which you have been able to influence the course of your illness? Probe: What have you done?

4) Responses

Responses are the participants’ thoughts and actions as a result of their appraisals. There are two types of responses to situational demands: i) internally-directed, and ii) externally-directed.
Internally-directed responses are palliative, i.e., focused on the management of emotions.

e.g., Interview Schedule question 1.11: How did you handle your feelings at this time?

Externally-directed responses focus on problem-solving.

e.g., Interview Schedule question 1.12: Was there anything you did at this time that was helpful to you?

5) Cognitive Reappraisals

Cognitive reappraisals are the participants' perceived consequences of their response efforts, both internally- and externally-directed.

e.g., Interview Schedule question 1.13: How do you feel about your situation now, compared to how you felt at the time of your diagnosis?

Additional questions were devised in order to elicit variations in an individual participant's experiences. The interview questions were purposely constructed in an open-ended format to maximize the participants' freedom and fullness of expression.

Study Site

The city of San Francisco, an American epicentre of the AIDS epidemic among gay men at the time of data collection, was the site selected for the study. Data were collected from April to September, 1985. At the time of the study it was estimated that over 50% of gay men in San Francisco were infected with HIV (Curran et al., 1985).
In relation to the study site, the investigator was appointed as a research associate at the AIDS Clinical Research Center in the Department of Dermatology, School of Medicine, University of California, San Francisco (Appendix B).

**Ethical Review**

The thesis proposal, Interview Schedule, the Request for Voluntary Participants (Appendix C), the Consent to be a Research Subject (Appendix D), and the Biographical Information form (Appendix E) were submitted for ethical review both to the University of Toronto Review Committee on the Use of Human Subjects and to the University of California, San Francisco, Committee on Human Research. Both committees approved the study.

**Access to the Study Population**

As a research associate at the AIDS Clinical Research Center, the investigator was able to access the study population by contacting AIDS-related medical and social service providers. When contacted, potential referral sources were offered a personal interview with the investigator to obtain information about the study and were sent copies of the Request for Voluntary Participants to be made available to their service users.

Participants were recruited over a four month period. During this time, 18 men agreed to be contacted by the investigator. Three men were referred by a hospital-based social worker and three by a community-based primary care
physician. The remaining 12 men were referred by men who had completed the interview schedule and had recommended it to others. Snowball sampling was the most effective means of obtaining a sample from this study population.

**Informed Consent**

All 18 men participated in an exploratory interview with the investigator. Two men declined to participate in the study after the exploratory interview, one citing that he thought the experience would not be psychologically good for him, and the other because of his advanced physical deterioration.

The exploratory interview was a pivotal step in establishing informed consent. Since the investigator did not have any previous relationship with potential study participants, the exploratory interview not only clarified the purpose of the study, but also afforded the opportunity for the beginning development of psychological comfort between the participant and the investigator. Potential participants were encouraged to ask any questions or express any reservations that they might have about the study or the investigator.

In establishing informed consent, the participants were informed that they were free to decline to answer any interview question, as well as to ask for the reason why a particular question was asked. They were also informed that, for whatever reason, they were free to withdraw from the study at any time without any jeopardy to their medical care.

All 16 participants agreed to audio-tape recording of the interviews and
were informed that they would be given a transcribed copy of their interviews to keep.

Each participant signed and was given a copy of the Consent to be a Research Subject, along with a copy of The Experimental Subject’s Bill of Rights, University of California, San Francisco (Appendix F).

The exploratory interview, as well as all subsequent interviews, was guided by the principle of respect for the psychological state and physical condition of the participants.

Pre-test of the Interview Schedule

In the initial weeks of recruitment, three participants who had established informed consent were selected to pre-test the interview schedule.

There were several purposes to pre-testing the interview schedule:

1) To verify the schedule’s adequacy, i.e., its content and scope, and thereby to correct omissions and delete redundancies;

2) To test the specific interview questions for their salience, clarity, order, and efficacy in eliciting information on the participants’ experiences;

3) To identify any negative psychological impact that the interviews or specific questions might have on the participants, and

4) To further the psychological attunement of the investigator to the participants’ sensitivities and their situations.
The Pre-test Subjects

The pre-test subjects were selected for their variations in primary diagnosis, current physical condition, medical treatment, and time since diagnosis. However, not all combinations of these were possible.

Pre-test subject 1 was 34 years old, diagnosed with PCP, three months earlier. The onset of his illness had been sudden and acute. He required hospitalization and intensive medical care.

Pre-test subject 2 was 24 years old, diagnosed with KS, one and a half years earlier. He had never been hospitalized, but had pursued an active treatment regimen, including participation in several experimental treatment protocols.

Pre-test subject 3 was 32 years old, diagnosed with KS a year earlier. He had elected not to undertake any medical treatment, but had been actively engaged in alternative therapies.

It took from three to five hours in two to three sessions for the pre-test subjects to complete the interview schedule. All chose to be interviewed in their homes, and each determined the time and length of the interviews.

The pre-test subjects reported that while the interview questions were found to be adequate in content and scope, they had, at times, caused them psychological distress. This reinforced the importance of informing participants of potential psychological discomfort precipitated by the interview questions. In addition, the pre-test subjects reported that the interviews had a positive effect in that it helped them to clarify their thinking about themselves and their
situations.

The pre-test interviews were tape-recorded, transcribed verbatim, and then reviewed to check the salience, clarity, and order of the questions. As a result, some questions were reworded or their sequence modified. Open-ended questions were helpful in avoiding any implicit assumptions about the participants' experiences, as well as allowing participants to express what was relevant for them.

Procedures for Data Collection

Excluding the pre-test subjects, 13 participants completed the revised interview schedule. Throughout the interviews, ethical responsibilities dictated that precedence be given to the personal needs and wishes of each participant in completing the schedule. All the participants chose to be interviewed in their homes and each determined the time and length of the interviews. Although all of the participants were asked the same questions in the same order, their responses varied considerably in length. A participant's level of fatigue frequently determined the length of an interview. However, the duration and number of interviews were largely dependent on how much a participant had to say.

Although participants were asked to respond to specific sets of questions, the overall effect of the interviews was biographical. The interview experience parallels that described by Levinson (1978):

A biographical interview combines aspects of a research interview, a clinical interview and a conversation between friends. It is like a structured interview in that certain topics must be covered, and the main purpose is research. As in a clinical interview, the interviewer
is sensitive to the feelings expressed, and follows the threads of meaning as they lead through diverse topics. Finally, as in a conversation between friends, the relationship is equal and the interviewer is free to respond in terms of his own experiences. Yet each party has a defined role as a sustained work task, which imposes its own constraints. What is involved is not simply an interviewing technique or procedure, but a relationship of some intimacy, intensity and duration. Significant work is involved in forming, maintaining, and terminating the relationship. The recruiting of participants, the negotiation of a research contract, and the course of the interviewing relationship are phases within a single complex process (p. 15).

All the participants completed the interview schedule in two to five sessions over a two to five week period. Interviews ranged from one and a half to three hours.

The audio-tapes of the interviews were transcribed verbatim within six months of data collection and the tapes were destroyed. Participants were sent a copy of their transcript to keep. Each transcript ranged from two to three hundred pages in length, typewritten and double-spaced.

Selection of the Study Sample

Given the voluntary nature of the participation, it was recognized that the sample could not be representative of gay men with AIDS. Further, the volume of data produced from transcripts of the interviews with each participant was so extensive that a reduction in sample size was necessary for qualitative data analysis. Therefore, the study sought a smaller purposive sample.

Two subjects, designated as A-1 and A-2, were selected based on their representation of coping with AIDS two months, post-diagnosis. Two subjects, designated as B-3 and B-4, were selected based on their representation of coping
with AIDS six months, post-diagnosis, and two subjects, designated as C-5 and C-6, were selected based on their coping with AIDS three and a half years, post-diagnosis.

Although they met the temporal conditions for sample selection, two participants who had completed the interviews were excluded from the study, one because he no longer believed that he had AIDS, and the other because he had been an intravenous drug user and therefore had more than one risk factor.

Analysis of the Research Data

Data analysis sought to identify the cognitive and behavioural processes that occur between a person and a situation at their points of engagement, using a phenomenological qualitative research method. As described by Dreyfus (1979):

A phenomenological description of our being-in-a-situation suggests that we are always already in a context or situation which we carry over from the immediate past and update in terms of events that in the light of this past situation are seen to be significant. We never encounter meaningless bits in terms of which we have to identify contexts, but only facts (emphasis added) which are already interpreted and which reciprocally define the situation that we are in. Human experience is only intelligible when organized in terms of a situation in which relevance and significance are already given (p. 288).

Given this dictum, two methodological assumptions guided the analysis of the participants' interview texts:

1) The participants' self-reported cognitions and behaviours, i.e., the "facts," are presented from within a situational context in which they have already been interpreted by a participant.

2) The participants' self-reported "facts" both define and are defined by
their situational contexts.

Qualitative analysis of the research data consisted of a multiple stage process that formed the subjects' self-reported cognitions and behaviours into activity units for interpretation and abstraction based on commonality in function, situation, and temporal context, post-diagnosis. The abstractions of the data were then grouped in order to specify the types and functions of coping processes engaged in by the subjects in relation to the temporal contexts in which they first occurred. The stages of data processing and analysis are detailed in Chapters Four and Five.

The Problem of Interpreter Bias

The initial challenge to the investigator was to leave interpretation in abeyance and to rely on the concrete expression of the "facts" as reported by the participants. Validity was given to the participants' expressions and explanations of their perspectives, thus creating contexts that were, at times, fundamentally different from those of the investigator.

The use of a multiple stage approach to data analysis, as described by Benner (1982), helped to diminish interpreter bias:

Multiple stages of interpretation allows for bias control by confronting the interpreter with contradictions, conflicts or surprises that cannot be accounted for by an earlier or later interpretation. This is based on the assumption that actions and practices, while not necessarily rational, are constituted by meaningful patterns and practices.

The intent is to go systematically from the whole to the parts and back to the whole. A constant shifting between the whole case and discrete coping and emotion episodes and self-reported characteristics provide the confirming and/or disconfirming
evidence for the study's interpretations (p. 54).

This multiple stage approach to data analysis retained the candour, both common and idiosyncratic, of each participant's self-reported thoughts and actions, past, present, and anticipated. There was no inherent value attached to what the participants reported thinking and doing. In everyday use, the word "coping" is too frequently associated with "doing well" or "managing," otherwise one is designated as "not coping." Analysis of the data sought representation and understanding, rather than judgement or prescription.

Processing and analysis of the data focused on what the participants reported thinking and doing in relation to their respective situations, following a qualitative research method that abstracts concrete data to the conceptual stage. This is presented in Chapter Five. Interpretations and abstractions of the participant's thoughts and behaviours were conceptualized as a series of person-situation transactions that resulted in a three phase, interrelated process model of coping in the context of gay men with AIDS.

Limitations of the Study

The study is limited by at least four factors: 1) its temporal context, 2) the sample size and characteristics, 3) the reliability of the data, and 4) by the theoretical bias of the investigator.

Temporal Context

The study data were collected in 1985, i.e., in the first half of the first
decade of the AIDS epidemic. While gaining in understanding, knowledge of the epidemiology of AIDS and the natural history of the disease were limited by comparison to today's understandings. Stigmatization of people with AIDS was at its peak, particularly through its social-epidemiological associations with male homosexual behaviour. Medical treatment was less efficacious, and AIDS support services, while available, were in their early developmental stages.

From a coping perspective, there was, existentially and socially, more at stake for a person living with AIDS in 1985. People were less likely to know that they were infected with the virus prior to being diagnosed with AIDS. Once diagnosed, their expectations for longevity were considerably less than they are today. Given the social epidemiology of AIDS among gay men and paucity in understanding of risk factors and behaviours in 1985, there was greater potential for social stigmatization and discrimination of people who contracted the disease or who were thought to be at risk. Stigmatization of people with AIDS was also endemic within gay communities (Altman, 1984; Morin and Batchelor, 1984; Patton, 1985).

While knowledge of the disease, and corresponding medical treatment and social care have undergone significant developments, and while many people with HIV disease are known to live longer, AIDS remains a life-threatening and stigmatized disease as it was in 1985.

The Sample Size and Characteristics

The study sample was indeed small and is not representative of gay men
with AIDS. In addition, the study sample is limited by two distinguishing features:

1) The subjects were volunteers. They were personally motivated to participate in the study, either to help others understand what it is like to be living with AIDS or to further clarify their own thinking in relation to their illness.

2) Of the study participant pool, the sample of men selected were the most articulate, expressive, and reflective in their responses to the interview questions. These qualities of their interviews were factors that influenced the selection of the sample.

Reliability of the Data

The study data are self-reported and retrospective, and therefore are limited by the subjects' lack of recollection of events, thoughts, feelings, and behaviours, as well as by the self-selected screening of information.

Second, the interview questions were reported by the study participants to have a clarifying and integrating effect. As such, there is no clear way of determining the influence of the interviews on what the subjects reported thinking, feeling, and doing.

Theoretical Bias of the Investigator

The study is limited by the adherence of the investigator to a particular conceptualization of coping which informed both its data collection and analysis. The study sought to examine coping as a function of a relationship between a
person and that person's situation. This is contrary to the view of coping as an intrapsychic process or as a pre-determined trait or style of the individual. This perspective on coping, however, is congruent with social work's practice focus on the person-in-situation as its unit of attention.
CHAPTER FOUR

PRESENTATION AND PROCESSING OF THE RESEARCH DATA

This chapter profiles the six subjects and presents their illness-related cognitions and behaviours derived from the interview transcripts. The process by which the data are identified, reduced, and grouped is described. The cognitions and behaviours reported by the subjects are then contextualized in a composite portrait in order to elucidate their meaning, purpose, and function in relation to the demands posed within the AIDS illness trajectory.

Description of the Study Sample

The six men who formed the study sample ranged in age from 32 to 38 years of age. They had at least two or more years of college or university and had been employed in positions appropriate to their level of education. They identified themselves as gay and acknowledged this as an important component of their lives. They had a clear understanding of the purpose of the research, and were expressive and articulate in response to the interview questions.

Apart from these commonalities, the six subjects reflected diversity in race, ethnicity, culture, religion, physical well-being, and social support, although all reported having at least one source of "unconditional" support, i.e., a friend, partner, or family member(s).
Stages of Data Processing

Stage One

The interview transcripts were first read and studied as a whole in order to describe the person-in-situation circumstances of each subject. The descriptions that follow profile each subject as an individual within the context of a unique life history and situational circumstances at the time of the research interviews.

Profile of Subject A-1

A-1 was 37 years old, Anglo-American, university-educated, and held a senior management position with a bank. He lived with his male partner for the past seven years in a non-monogamous relationship. He described himself as promiscuous. Even though he had begun to practice safer sex, he suspected that he was already HIV positive.

A-1 was referred to the study by a social worker of an out-patient hospital AIDS clinic. He initiated the contact with the investigator stating that he thought the interviews might help him deal with the issues he was currently facing.

The first of five weekly interviews took place eight weeks after he was diagnosed and hospitalized for PCP. Although he had recovered from PCP, he was still easily fatigued and frequently reported times of severe depression.

A-1 presented himself as worried and anxious about the future. His concerns were for himself, his partner whom he identified as having difficulty
dealing with his diagnosis, and for his parents and siblings with whom he had always maintained close ties. He regarded himself as fortunate to have their love and support.

During the administration of the interview schedule, A-1 attempted to return to work, but had difficulty managing his fatigue and faced incidents of workplace discrimination. He consequently went on long-term disability and looked for ways to make use of his time. He thought of volunteering to help other PWAs (PWA is an acronym for a person or people with AIDS).

Profile of Subject A-2

A-2 was 37 years old, an African-South American immigrant to the United States. He was a health care professional.

He had lived alone for the past four years after the termination of an assumed monogamous relationship with another man. He was not sexually involved with anyone since this relationship, and reported being completely shocked by his diagnosis.

A-2 was referred to the study by another participant. Although he agreed to be contacted by the investigator, he was initially apprehensive about participation in the study, citing the importance of his anonymity as well as restrictions resulting from his weak physical condition. Nevertheless, he decided to participate as he saw participation as an opportunity to examine the issues arising from his illness.

The first of three weekly interviews took place eight weeks after he had
been diagnosed and hospitalized for PCP. At the first interview he was bedridden with PCP and said he was very depressed about his situation. His immediate concern was recovering from PCP.

While his parents and siblings were aware of his situation and were supportive of him, he had asked them not to come and see him until he had recuperated from the pneumonia and regained some of the weight he had lost.

During the course of the interviews, A-2’s physical condition improved considerably and he reported that he was less depressed.

He was dissatisfied with the quality of medical care he had received, and reported incidents of what he saw as medical incompetence and discrimination. Given his professional background, he discerned the kinds and quality of help available to him and sought better medical care.

Profile of Subject B-3

B-3 was 32 years old, Hispanic-American, university-educated, and was a bank accountant. He said he came to San Francisco after graduating from university to escape his parents and to find his freedom as a gay man. He lived alone and had never had a long term sexual relationship. His primary source of social contact and support was his best friend. In addition, he had a sibling who lived in the Bay area who was both aware of and worried about his situation.

B-3 said that he suspected for some time that he might have AIDS and had considered the consequences. He had made financial plans prior to his diagnosis. Several months prior to developing PCP he found out that he was HIV
positive.

B-3 was referred to the study by his primary care physician who thought B-3’s participation might benefit him. B-3 described himself as being "stuck," not knowing what to do with his time. Having resigned from his employment, he was on long-term disability.

B-3 completed the interview schedule in three weekly interviews, six months after he had been diagnosed and hospitalized for PCP. He did not give any particular reason for participation in the study, although he reported that the interviews had helped him to look at his situation.

A primary concern of B-3 was to keep his parents from discovering that he has AIDS. He said he would commit suicide rather than tell them.

Profile of Subject B-4

B-4 was 33 years old, Anglo-American. He had completed two years of college and had worked previously as an office manager. He was unemployed at the time of his diagnosis and since has been living on state disability.

B-4 lived with a roommate, a nurse whom he described as his primary source of information and support.

Although B-4 had adopted safer sex practices, he viewed his past sexual behaviour as having put himself at risk for AIDS.

B-4 reported that he had had a number of health problems in the year prior to his diagnosis. He initially attributed these problems to frequent cocaine use until he developed KS lesions on his face.
B-4 was referred to the study by another participant. He said he wanted to participate in the study in order to contribute to others' understanding of what it was like to live with AIDS.

The first of two weekly interviews took place six months after his diagnosis. Although B-4 described himself as having dealt with his diagnosis, several of the interview questions triggered tearful reactions.

Recently B-4 had returned home to see his parents, from whom he said he was estranged. At that time he told them that he was gay and that he had AIDS. Although he said that they were unresponsive, he felt he had done his duty. He reported having a sibling to whom he is very close and who is very supportive of him.

Although he generally maintained a positive attitude and felt he was dealing with his illness responsibly, B-4 reported having times when he was negatively preoccupied with his illness.

He volunteered to help other PWAs and attended a peer support group once a week.

Profile of Subject C-5

C-5 was 38 years old, Anglo-American, college-educated, and had been self-employed in a business partnership at the time of his diagnosis. He sold his share of the business shortly after he was diagnosed and was living on state disability.

Initially diagnosed with KS, C-5 had been living with the disease for over
three and a half years. He had recently suffered his first bout of PCP from which he was recovering, and also reported that he now had over 400 KS lesions on his body. He thought that his death was imminent.

Though geographically distant, C-5 maintained close ties with his parents and siblings from whom he said he had unconditional support.

C-5 was referred to the study by another participant. When contacted by the investigator C-5 indicated that, given his deteriorating physical condition, he was uncertain about his ability to complete the interview schedule, but wanted to try. He completed the interview schedule in two sessions.

In recent months C-5 had become involved in a new relationship. Given his physical condition, he now questioned the realism of this commitment and was concerned about the grief his death would cause his new partner.

Profile of Subject C-6

C-6 was 38 years old, Anglo-American, university-educated, an aspiring writer who supported his artistic pursuits working as a word processor. He has lived on state disability since his diagnosis with KS over three and a half years ago. He currently lived alone, but was looking for someone with whom to share the rent.

C-6 described himself as being in good health. He said he was still hoping to find a lover, but saw his AIDS status as an obstacle to achieving this. He planned to go back to university in the fall to start graduate studies.

C-6 was referred to the study by another participant. He was eager to
participate, and was particularly interested in receiving a copy of his transcript for his own personal writing. C-6 completed the interview schedule in five weekly sessions. The final interview took place in hospital where he was being treated for an opportunistic infection. Although hospitalized, he said he wanted to complete the interviews.

C-6's primary concern was that he had not told his mother that he had AIDS. Although his mother knew he was gay, they had never discussed his sexuality. He feared her reaction. Both of his siblings knew of his situation and have been supportive.

**Stage Two**

After development of the person-in-situation profiles the interview transcripts were re-read to identify each subject's past, current, and anticipated illness-related thoughts and actions.

A corollary to the question, "what is coping?" is coping with "what?" The identification of "what" each subject reported thinking and doing, past, present, and anticipated, together generated 924 discrete cognitions and behaviours (A-1=159, A-2=173, B-3=132, B-4=135, C-5=135, and C-6=190). Each of the 924 items was recorded on a card and identified by subject. These items constituted the unit of analysis in stage three of data processing.

**Stage Three**

In the third stage of data processing the 924 items were clustered
according to their commonality in meaning, purpose or function as reported by two or more subjects. Idiosyncratic items, i.e., activities reported by one subject, were retained. This process reduced the 924 items to 152.

The 152 grouped and idiosyncratic items were put in envelopes, each specifying an activity and coded according to the reporting subject(s).

Together the 152 items constituted the self-reported illness-related cognitions and behaviours of the study sample and are the unit of analysis in stage four of data processing.

Stage Four

In the fourth stage of data processing each of the 152 items were grouped according to the temporal situation of the subject in which an activity was reported. Three temporal situations are portrayed by the six subjects: 1) pre-diagnosis, temporal situation A, 2) the time period immediately following diagnosis, temporal situation B, and 3) the subjects' temporal situations at the time of the interviews, temporal situation C.

The three groups of activities are presented in three tables. Table 2 lists the self-reported cognitive and behavioural activities of the six subjects prior to diagnosis. Table 3 lists the subjects' self-reported cognitions and behaviours associated with having been diagnosed with AIDS, and Table 4 lists the subjects' self-reported cognitions and behaviours that depict their current adjustments to living with AIDS. Items in a table are identified by the reporting subject and by the temporal situation of the subject at the time of the interviews. The variation
in verb tense of the items listed correspond to the past, present, and anticipated cognitions and behaviours reported by the subjects at the time of the research interviews.
Table 2

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Pre-diagnosis

<table>
<thead>
<tr>
<th>Self-reported Cognitive and Behavioural Activities</th>
<th>Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Had felt invincible about his health</td>
<td></td>
</tr>
<tr>
<td>Had felt negative about his health</td>
<td></td>
</tr>
<tr>
<td>Has been practicing safer sex</td>
<td></td>
</tr>
<tr>
<td>Compared himself to a stigmatized stereotype of a PWA</td>
<td></td>
</tr>
<tr>
<td>Saw himself as being at risk</td>
<td></td>
</tr>
<tr>
<td>Was aware of physical symptoms</td>
<td></td>
</tr>
<tr>
<td>Did not suspect/think it was AIDS</td>
<td></td>
</tr>
<tr>
<td>Compared his symptoms to non-AIDS-related illnesses</td>
<td></td>
</tr>
<tr>
<td>Compared his symptoms to the common profile of a PWA</td>
<td></td>
</tr>
<tr>
<td>Suspected/thought symptoms were AIDS-related</td>
<td></td>
</tr>
<tr>
<td>Was concerned about his health</td>
<td></td>
</tr>
<tr>
<td>Avoided dealing with his symptoms</td>
<td></td>
</tr>
<tr>
<td>Gave himself a farewell fling</td>
<td></td>
</tr>
<tr>
<td>Used alcohol</td>
<td></td>
</tr>
<tr>
<td>Had (safer) sex</td>
<td></td>
</tr>
<tr>
<td>Saw doctor(s)</td>
<td></td>
</tr>
</tbody>
</table>

Temporal Situations:  
A = 2 months, post-diagnosis  
B = 6 months, post-diagnosis  
C = 3½ years, post-diagnosis
Table 3

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Immediately, Post-diagnosis

<table>
<thead>
<tr>
<th>Self-reported Cognitive and Behavioural Activities</th>
<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subjects</td>
</tr>
<tr>
<td>Asked doctor how long he had to live</td>
<td>0</td>
</tr>
<tr>
<td>Summarized his life</td>
<td>0</td>
</tr>
<tr>
<td>Initial disclosure of diagnosis</td>
<td>0</td>
</tr>
<tr>
<td>Suppressed negative emotions</td>
<td>0</td>
</tr>
<tr>
<td>Denied</td>
<td>0</td>
</tr>
<tr>
<td>Slept to tune it out</td>
<td>0</td>
</tr>
<tr>
<td>Used sleeping pills/tranquillizers</td>
<td>0</td>
</tr>
<tr>
<td>Got strong for others</td>
<td>0</td>
</tr>
<tr>
<td>Didn’t want to talk about it</td>
<td>0</td>
</tr>
<tr>
<td>Used humour</td>
<td>0</td>
</tr>
<tr>
<td>Confronted negative emotions</td>
<td>0</td>
</tr>
<tr>
<td>Lost hope/gave up/did nothing</td>
<td>0</td>
</tr>
<tr>
<td>Isolated himself</td>
<td>0</td>
</tr>
<tr>
<td>Pitted himself</td>
<td>0</td>
</tr>
<tr>
<td>Wanted to die</td>
<td>0</td>
</tr>
<tr>
<td>Cried</td>
<td>0</td>
</tr>
<tr>
<td>Cried in the research interview</td>
<td>0</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>0</td>
</tr>
</tbody>
</table>

Temporal Situations:  
A = 2 months, post-diagnosis  
B = 6 months, post-diagnosis  
C = 3½ years, post-diagnosis
Table 3 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Immediately, Post-diagnosis

<table>
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<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Subjects</td>
<td>1</td>
</tr>
<tr>
<td>Plans to exercise control over the timing of his death</td>
<td>●</td>
</tr>
<tr>
<td>Sought attribution for having contracted AIDS</td>
<td>●</td>
</tr>
<tr>
<td>Didn't let any guilt in</td>
<td></td>
</tr>
</tbody>
</table>
Table 4
Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

<table>
<thead>
<tr>
<th>Self-reported Cognitive and Behavioural Activities</th>
<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Subjects</td>
<td>1</td>
</tr>
<tr>
<td>Accepted the fact/reality</td>
<td>●</td>
</tr>
<tr>
<td>Stopped self-mourning</td>
<td></td>
</tr>
<tr>
<td>Decided to do things his way/takes control</td>
<td></td>
</tr>
<tr>
<td>Hopes</td>
<td>●</td>
</tr>
<tr>
<td>Views himself as stigmatized</td>
<td>●</td>
</tr>
<tr>
<td>Struggles with past beliefs</td>
<td></td>
</tr>
<tr>
<td>Recognizes stigmatization by others</td>
<td>●</td>
</tr>
<tr>
<td>Protects himself from discrimination/abuse</td>
<td>●</td>
</tr>
<tr>
<td>Camouflages</td>
<td></td>
</tr>
<tr>
<td>Doesn't take it personally</td>
<td></td>
</tr>
<tr>
<td>Up front about having AIDS and being gay</td>
<td></td>
</tr>
<tr>
<td>Struggles with others' fear of intimacy/HIV infection</td>
<td></td>
</tr>
<tr>
<td>Struggles with his anger toward others</td>
<td>●</td>
</tr>
<tr>
<td>Learns to be patient with others</td>
<td>●</td>
</tr>
<tr>
<td>Relies on others for personal care</td>
<td>●</td>
</tr>
</tbody>
</table>

Temporal Situations:  
A = 2 months, post-diagnosis  
B = 6 months, post-diagnosis  
C = 3½ years, post-diagnosis
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

<table>
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<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Acknowledges the support of family/friends</td>
<td></td>
</tr>
<tr>
<td>Keeps notes/written schedule</td>
<td></td>
</tr>
<tr>
<td>Talked to other PWAs who have/had the same opportunistic infection(s)</td>
<td></td>
</tr>
<tr>
<td>Initially attended a support group for PWAs</td>
<td></td>
</tr>
<tr>
<td>Compares himself to PWAs who are socially less fortunate</td>
<td></td>
</tr>
<tr>
<td>Compares himself to other PWAs re: disease progression</td>
<td></td>
</tr>
<tr>
<td>Avoids/limits contacts with other PWAs</td>
<td></td>
</tr>
<tr>
<td>Cognisant of mortality</td>
<td></td>
</tr>
<tr>
<td>Intellectualizes</td>
<td></td>
</tr>
<tr>
<td>Tries to be realistic</td>
<td></td>
</tr>
<tr>
<td>Vigilant about time left</td>
<td></td>
</tr>
<tr>
<td>Made a will</td>
<td></td>
</tr>
<tr>
<td>Stopped planning future goals</td>
<td></td>
</tr>
<tr>
<td>Read about dying and death</td>
<td></td>
</tr>
<tr>
<td>Views his illness/dying as an opportunity, a maturing process</td>
<td></td>
</tr>
<tr>
<td>Went back to work</td>
<td></td>
</tr>
<tr>
<td>Quit work</td>
<td></td>
</tr>
</tbody>
</table>
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

| Self-reported Cognitive and Behavioural Activities | Temporal Situations
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subjects</td>
</tr>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Arranged financial means of support</td>
<td>•</td>
</tr>
<tr>
<td>Reaches out for support</td>
<td>•</td>
</tr>
<tr>
<td>Regularly attends a support group for PWAs</td>
<td>•</td>
</tr>
<tr>
<td>&quot;Talks it out&quot; with friends</td>
<td>•</td>
</tr>
<tr>
<td>Seeks expert advice</td>
<td>•</td>
</tr>
<tr>
<td>Couple counselling</td>
<td>•</td>
</tr>
<tr>
<td>Used a physical health professional for psychotherapeutic means</td>
<td>•</td>
</tr>
<tr>
<td>Used the research interview for psychotherapeutic means</td>
<td>•</td>
</tr>
<tr>
<td>Seeks treatment information</td>
<td>•</td>
</tr>
<tr>
<td>Places trust/faith in his physician</td>
<td>•</td>
</tr>
<tr>
<td>Does not put total faith in doctors</td>
<td>•</td>
</tr>
<tr>
<td>Complained about the side effects of medical tests/treatment</td>
<td>•</td>
</tr>
<tr>
<td>Seeks better medical care</td>
<td>•</td>
</tr>
<tr>
<td>Chose to participate in experimental drug trials</td>
<td>•</td>
</tr>
<tr>
<td>Stopped experimental drug trials</td>
<td>•</td>
</tr>
<tr>
<td>Decided not to take medical treatment</td>
<td>•</td>
</tr>
</tbody>
</table>
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

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<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Selectively controls disclosure of diagnosis</td>
<td></td>
</tr>
<tr>
<td>Disclosed diagnosis/sexual orientation to his parents</td>
<td></td>
</tr>
<tr>
<td>Shuts his parent(s) out</td>
<td></td>
</tr>
<tr>
<td>Takes initiative in helping others to talk about it</td>
<td></td>
</tr>
<tr>
<td>Has talked about his dying with his partner/family</td>
<td></td>
</tr>
<tr>
<td>Maintains supportive relationships with his parents/family</td>
<td></td>
</tr>
<tr>
<td>Limits the information he gives his family about his illness</td>
<td>*</td>
</tr>
<tr>
<td>Distinguishes between his reality and others' reality</td>
<td>*</td>
</tr>
<tr>
<td>Values relationships differently</td>
<td>*</td>
</tr>
<tr>
<td>Has made new kinds of friends</td>
<td></td>
</tr>
<tr>
<td>Abstains from sex</td>
<td></td>
</tr>
<tr>
<td>No longer makes sexual advances</td>
<td></td>
</tr>
<tr>
<td>No longer looks for a love relationship</td>
<td></td>
</tr>
<tr>
<td>Positively compares present quality of life to past quality of life</td>
<td></td>
</tr>
<tr>
<td>Takes one day at a time</td>
<td>*</td>
</tr>
</tbody>
</table>
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

<table>
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<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Lives each day to the fullest</td>
<td>●</td>
</tr>
<tr>
<td>Values quality time</td>
<td>●</td>
</tr>
<tr>
<td>Enjoys nature</td>
<td>●</td>
</tr>
<tr>
<td>Looks for ways to make use of time</td>
<td>●</td>
</tr>
<tr>
<td>Thinks about volunteering to help other PWAs</td>
<td>●</td>
</tr>
<tr>
<td>Procrastinates</td>
<td>●</td>
</tr>
<tr>
<td>Likes to spend time alone</td>
<td>●</td>
</tr>
<tr>
<td>Tries to like/love himself</td>
<td>●</td>
</tr>
<tr>
<td>Nurtures himself</td>
<td>●</td>
</tr>
<tr>
<td>Artistic and creative expression</td>
<td>●</td>
</tr>
<tr>
<td>Spends/buys</td>
<td>●</td>
</tr>
<tr>
<td>Plans to travel</td>
<td>●</td>
</tr>
<tr>
<td>Travelled</td>
<td>●</td>
</tr>
<tr>
<td>Fights to live</td>
<td>●</td>
</tr>
<tr>
<td>Positively compares himself to PWAs who have given up</td>
<td>●</td>
</tr>
<tr>
<td>Relies on inner strength</td>
<td>●</td>
</tr>
<tr>
<td>Draws strength from past beliefs</td>
<td>●</td>
</tr>
<tr>
<td>Believes in a better life after death</td>
<td>●</td>
</tr>
<tr>
<td>Prays</td>
<td>●</td>
</tr>
</tbody>
</table>
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

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</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Subjects</td>
<td>1</td>
</tr>
<tr>
<td>Focuses on his spirituality</td>
<td></td>
</tr>
<tr>
<td>Tries to maintain a positive attitude</td>
<td></td>
</tr>
<tr>
<td>Controls negative thinking</td>
<td></td>
</tr>
<tr>
<td>Tries not to think about...</td>
<td></td>
</tr>
<tr>
<td>Strives for normality</td>
<td></td>
</tr>
<tr>
<td>Talks less about his illness</td>
<td></td>
</tr>
<tr>
<td>Partied after finding out that he tested negative for cytomegalovirus (CMV)</td>
<td></td>
</tr>
<tr>
<td>Misses doing things he used to do</td>
<td></td>
</tr>
<tr>
<td>Manages an altered financial situation</td>
<td></td>
</tr>
<tr>
<td>Manages physical limitations</td>
<td></td>
</tr>
<tr>
<td>Tries to protect himself from others’ illnesses</td>
<td></td>
</tr>
<tr>
<td>Improved nutrition/eats well</td>
<td></td>
</tr>
<tr>
<td>Takes vitamins</td>
<td></td>
</tr>
<tr>
<td>Exercises</td>
<td></td>
</tr>
<tr>
<td>Stopped using alcohol and marijuana</td>
<td></td>
</tr>
<tr>
<td>Believes in alternative approaches to health/illness</td>
<td></td>
</tr>
<tr>
<td>Meditates/uses visualization</td>
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</tbody>
</table>
Table 4 (Continued)

Self-reported Cognitive and Behavioural Activities of Gay Men with AIDS: Current Adjustment to Illness

<table>
<thead>
<tr>
<th>Temporal Situations</th>
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<tbody>
<tr>
<td>A</td>
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<table>
<thead>
<tr>
<th>Self-reported Cognitive and Behavioural Activities</th>
<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focuses on healthy parts of his body</td>
<td>•</td>
</tr>
<tr>
<td>Focuses on affected parts of his body in a loving way</td>
<td></td>
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<tr>
<td>Uses alternative physical therapies</td>
<td>• • •</td>
</tr>
<tr>
<td>Uses herbal remedies</td>
<td>• •</td>
</tr>
<tr>
<td>Listens to relaxation tapes</td>
<td>•</td>
</tr>
<tr>
<td>Uses marijuana to reduce stress, relax, sleep</td>
<td>• • •</td>
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<tr>
<td>Seeks involvement in a love relationship</td>
<td>•</td>
</tr>
<tr>
<td>Recent involvement in a love relationship</td>
<td>•</td>
</tr>
<tr>
<td>Practices safer sex</td>
<td>• • •</td>
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<tr>
<td>Grieves the multiple deaths of friends due to AIDS</td>
<td>• • •</td>
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<tr>
<td>Volunteers to help other PWAs</td>
<td>• • •</td>
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<tr>
<td>Externalizes/politicizes the disease</td>
<td>• • •</td>
</tr>
<tr>
<td>Participates in AIDS-related community development and education</td>
<td>• • •</td>
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<tr>
<td>Sees himself as having a positive effect on others</td>
<td>• •</td>
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<tr>
<td>Plans future goals</td>
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</tbody>
</table>
Stage Five

In the fifth stage of data processing a composite portrait of the six subjects was developed which describes and contextualizes, in narrative form, the functions of the subjects' illness-related cognitions and behaviours in the situations in which they were reported to occur. The composite portrait described below is based on the items listed in Tables 2, 3, and 4. It describes what the six subjects shared in common, but also retains what was idiosyncratic to each subject’s thoughts and behaviours. Together the subjects portray living with AIDS from pre-diagnosis to three and a half years, post-diagnosis.

A Composite Portrait of the Six Subjects

Prior to diagnosis each subject became aware that there was something wrong with his health. Four of the men reported having persistent infections accompanied by weight loss and fatigue (A-1, A-2, B-3, B-4). C-5 and C-6 initially discovered purplish lesions on their skin.

All of the subjects were personally aware of the risk for AIDS among gay men, and described themselves as being informed about the disease. Since becoming aware of the risk for AIDS, A-1 and B-4 said they had adopted safer sex practices. The other subjects did not report whether or not they practiced safer sex.

No subject initially appraised his physical symptoms as AIDS-related. B-3, the only subject who knew he was HIV-positive, said upon getting shingles, "Shingles! My grandmother had shingles." B-4 said that while he had considered
his symptoms as AIDS-related, his physician was always giving him explanations other than AIDS. Three subjects (A-2, B-4, C-6) compared themselves to what they perceived to be a stigmatized stereotype of a PWA, someone with whom they did not personally identify. Irrespective of how they appraised their symptoms, all subjects reported being worried about their health and vigilant about what was happening to them physically.

The routes to a definitive diagnosis with AIDS varied from individual to individual. Not suspecting that their symptoms were AIDS-related, A-2 and C-5 reported being completely shocked by the diagnosis. Those who did come to suspect that they might have AIDS reported having to struggle with the possibility, looking for ways to avoid dealing with it (B-4), drinking (B-3), partying, going on a "farewell fling" (A-1, B-3).

All of the men recounted the moment at which they were told that they had AIDS, and that it meant that they were going to die: "I asked the doctor how long I had to live" (A-1, A-2, B-4, C-6); "I summarized my life" (C-6).

Three subjects (A-1, A-2, B-3) required hospitalization for treatment of PCP. The acuteness of this opportunistic infection heightened their awareness of the potential imminence of their mortality, as well as their dependence on others for personal care.

After diagnosis all subjects reported an immediate need to tell someone. The reason for these disclosures of diagnosis, as well as the selection of the person to whom they chose to disclose, varied from individual to individual: out of a sense of social obligation, to seek support or advice, or for no expressed
reason. Nevertheless, all of the men recounted who they first told and the situation in which they did this. They described themselves as having to "get strong" for others when disclosing their diagnosis. They reported trying to protect others from psychological pain and discomfort. A-1 said he used humour in an attempt to ease the distress he was causing others.

For all subjects, the period immediately following diagnosis was dominated by the management of negative emotions arising from the knowledge that they had a life-threatening and stigmatized disease. The men reported suppressing their emotions (A-1, A-2, B-3, B-4), denied (A-2, B-3, C-6), didn't want to talk about it (B-3, C-5), slept to tune it out (A-2, B-3), or, for a period of time, used sleeping pills and tranquilizers to help them sleep and manage their anxiety (A-1, B-4).

Confronting negative emotions arising from their diagnosis precipitated loss of hope, giving up, and doing nothing, accompanied by self-imposed social isolation (A-1, A-2, B-3, B-4). This time was variously described as a period of self-pity (A-1, A-2), of wanting to die (A-2, B-3), and contemplation of suicide (A-1, B-3, B-4).

Crying (A-2, B-4, C-5) and "trying" to cry (A-1, B-3) were reported at this time. While all subjects said they had cried, it was not initiated by or restricted to any one point in time in their illness trajectories. They reported having cried for themselves, for the pain they were causing others, and because of the deaths of friends due to AIDS.

Three men cried in the research interviews (A-1, B-4, C-6). In these
instances an interview question triggered a grief response in relation to someone or something that had not yet been considered.

One aspect of this period was seeking attribution for how they had become infected, i.e., how?, why?, and from whom? All subjects struggled to reconcile themselves with a pre-held stigmatized stereotype of a PWA. C-5 simply said, "I didn't let any guilt in."

All subjects identified a point in their illness trajectory when they accepted their situation and began "doing things my way." Three subjects (A-2, B-3, B-4) reported that this particular time marked the end of initial self-mourning and self-isolation, and the beginning of hope, e.g., "beating the odds" (B-3).

All of the men described AIDS as a stigmatizing disease, imposed by internalized, socio-cultural beliefs (A-1, A-2, B-3), and exhibited by the attitudes and behaviours of others toward them. They reported having to protect themselves from discrimination or abuse by attempting to camouflage visible signs of the disease (A-2, B-3, C-5, C-6), and by avoiding situations where they would feel vulnerable. When discrimination occurred, A-1, B-4, and C-5 said, "I didn't take it personally." B-4 and C-6 had decided to be "upfront" about having AIDS and being gay, while C-6 said, "After three and a half years, I still struggle with others' fear of intimacy and getting AIDS." All subjects shared an awareness of the potential for discrimination or abuse in their interactions with others.

Misunderstanding and discrimination were cause for subjects to struggle with their anger toward others (A-1, A-2, B-4). While, at times, they reported feeling justified in their anger, they also reported needing to learn to be more
patient with others' reactions to them (A-1, A-2, C-6).

Reliance on friends and family for personal care was a function of incapacitating illness caused by PCP (A-1, A-2, B-3). A-1 and A-2 reported keeping notes to remember when to take medications, remind them of what they had done, or what they had yet to do. C-6 said he kept a diary which helped him to remember the questions he wanted to ask his doctor.

Talking to other PWAs who had or have the same opportunistic infection helped subjects to acquire more understanding of their particular disease (A-1, C-5, C-6), and in one instance, gave a subject hope (A-1). However, when a positive comparison to another PWA was not possible, contact with other PWAs had a negative effect. A-1 and A-2 said that attending a support group for PWAs made them more fearful and worrisome about their future and they decided not to return. Seeing other PWAs who were socially less fortunate provided consolation, whereas seeing someone whose illness was further progressed generated fear and sadness (A-1, A-2, B-4, C-6).

All subjects reported having to remind themselves to be realistic about their situations. They were cognisant of their mortality; however, when they felt well, this awareness was more intellectual than tangible (A-1, B-3). A-1 and A-2 began reading about dying and death shortly after diagnosis. B-4 and C-6 viewed their dying as an opportunity for growth and maturation. Making a will illustrated a subject's acknowledgment of his mortality (A-2, B-3).

Four of the men reported having a constricted view of time (A-1, A-2, B-3, B-4). Time was viewed as "time left." Three subjects said they had abandoned
future goals (A-1, A-2, B-3).

Four of the men decided to return to work after diagnosis (A-1, B-3, C-5, C-6). Returning to work represented an effort to get on with living. However valued work had been, subjects now questioned its intrinsic worth, particularly given the potential deleterious effects of work-related stress, and the discriminatory attitudes and behaviours of fellow employees. Deciding to quit work and to go on disability were described as acts of self-care.

All subjects reported reaching out to others for information and support. Help- and information-seeking was an intermittent, but ongoing feature of dealing with their illness. However, the frequency of "reaching out" and to whom, varied from individual to individual. The function of reaching out to others was to seek information, understanding, and advice. "Talking it out" with friends was a particular feature of illness-related problem-solving reported by A-1 and C-5.

All subjects reported having consulted people whom they regarded as "experts" in the AIDS field. B-4 and C-5 regularly attended a support group for PWAs. A-1 and his partner were in couple counselling to deal with the relationship issues arising from the diagnosis. A-2 and C-6 reported using a physical health professional for psychotherapeutic purposes. A-2 said he regularly "let it all out" with one of his nurses when he was in the hospital. C-6 said that his acupuncturist was a psychotherapist to him.

Participation in the research also was reported to be therapeutic. A-1 and A-2 said the interviews helped them to clarify their thinking about what they were facing.
All subjects reported keeping themselves apprised of available treatment options through their doctors, the media, and heresy, including alternative and experimental therapies. Four subjects said they primarily relied on their doctors for treatment information and advice (A-1, B-3, C-5, C-6), although this did not mean that they placed total faith in what their doctors said (A-2, B-4, C-5, C-6). A-2, for example, once had to be hospitalized because he had been overmedicated. B-4 had decided to do alternative medicine until such time that he needed Western medicine. C-5 and C-6 had been in experimental drug trials which they stopped because of negative side effects and ineffectiveness. All subjects who had undergone medical treatment complained about side effects.

All the men reported being selective in whom they told they had AIDS in order to protect themselves from discrimination or to protect others from distress. For B-4 and C-5, telling their parents that they had AIDS also meant telling them they were gay. B-3 and C-6 had still not told their parents. B-3 said he feared that his parents would "take over" and not allow him his autonomy. C-6 feared his mother's reaction since she had never accepted the fact that he was gay.

In an effort to deal with others' discomfort, four subjects reported taking initiative in helping others to talk about their illness (A-1, A-2, B-3, C-5). A-1 and A-2 said they have spoken to their families and partner (A-1) about dying. These subjects, as well as C5, reported maintaining supportive relationships with their families; however, this meant limiting the information they gave about their health in an effort to protect them from distress (A-2, C-5).
All of the men reported valuing relationships differently as a result of their illness. B-4 and C-5 said that this shift in values resulted in their making "new kinds" of friends. No longer making sexual advances (B-4, C-5), abstaining from sex (B-3, B-4), and no longer looking for a "love" relationship (B-3, B-4) illustrates a revaluation of intimacy and sexual relationships. B-4 said that he discerns his relationships by distinguishing between "my reality" and "their reality." In coming to value others, as well as himself, for "what's on the inside," B-4 now views his quality of life, particularly his relationships with others, more positively.

Cognisant of the inevitability of their situations, four subjects reported "taking one day at a time" (A-2, B-3, C-5, C-6). With the exception of B-3 who described himself as "being stuck" and "needing to do something," all of the men reported trying to live each day to the fullest, taking time to enjoy nature, and spending their time in ways that were important to them. Having given up their professional careers, A-1 and B-3 reported looking for ways to make use of their time and were thinking about volunteering to help other PWAs. However, B-3 said he procrastinates doing anything. Given his struggle to find a sense of purpose and the uncertain quality of his remaining life, B-3 said he was planning to exercise personal control over the timing of his death.

Cognisant of how they spend their time, A-2 and C-6 reported taking time to be alone and enjoying time by themselves. A-1, B-4 and C-6 spoke about the importance of liking, loving, and accepting yourself for "who you are" irrespective of being "damaged goods" (A-1). All subjects reported taking time to nurture themselves, to give importance to their own wants and needs, irrespective of
others'. Four subjects had returned to artistic and creative modes of expression that they had previously enjoyed: water colours (A-2, C-5), playing the piano (B-3), and writing music (C-6). If they were able to afford it, they spent their money buying or doing things they wanted (A-1, A-2, C-5), travelling (B-4, C-5, C-6) or planning to travel (A-1, A-2, C-5).

After coming to terms with the implications of their illness, all of the men reported fighting to live, forcing themselves to want to go on with their lives. A-2 and C-5, for example, compared themselves positively to other PWAs whom they saw as having given up. Subjects' will to live was sustained by a reliance on "an inner strength" (B-3, B-4, C-5), past beliefs (A-2, B-4, C-6), and a belief in a better life after death (A-2, B-4, C-5). Four subjects reported that they prayed for inner strength (A-1, A-2, B-3, C-6). Recognizing their physical deterioration, B-4 and C-5 said that they now focused on developing their spirituality.

In an effort to sustain their will to live, all subjects spoke of the importance of maintaining a positive attitude, although there were constant threats to this. For example, C-6 said his positive attitude about his illness was sustained after testing negative for cytomegalovirus (CMV) which, if positive, would have likely cost him his vision. After finding out, he said he went out and partied all night.

All of the men said that they strived for some degree of normality in their lives. B-4 said he now talks less about his illness: "Its a piece of the pie, but not all of the pie." Subjects try not to think about having AIDS all of the time or to worry about what lies ahead. They reported having to control negative thinking. Nevertheless, there were losses and reminders to contend with: missing things
they used to do (A-2, B-3, C-5), having to manage living on a reduced income (B-3, B-4, C-5, C-6), finding themselves having to rest more (A-2, B-4, C-5, C-6), or devising other ways to manage their physical limitations, such as maintaining a schedule or reducing levels of activity.

All subjects engaged in various measures to protect their health: A-2 and B-3 avoided contact with people they knew had infections; four subjects reported improving their nutrition (A-1, B-4, C-5, C-6), took vitamins (A-1, B-4), exercised regularly (B-4, C-6), and refrained from use of alcohol or marijuana (A-5). C-5 and C-6 stopped treatment in experimental drug trials because they viewed them as having an adverse effect on their health.

B-4 and C-6 said they believed in alternative approaches to health. They meditated and used visualization to focus on healthy (B-4) or affected (C-6) parts of their bodies in positive and loving ways. Three subjects were engaged in alternative physical therapies such as acupuncture and therapeutic massage (B-4, C-5, C-6). A-1 and B-3 used herbal remedies.

B-3 and B-4 said they frequently smoked marijuana to reduce stress, and to promote relaxation and sleep. B-3 said that he often listened to relaxation tapes.

C-5 and C-6 reported that they were having sexual relations again, practicing safer sex. C-6 said he hoped to find someone to fall in love with, while C-5 was in a new "love" relationship.

C-5 and C-6, who had lived with AIDS for three and a half years, reported grieving the multiple deaths of friends due to AIDS.
C-5 and C-6 spoke about externalizing their illness through political action, community development initiatives, and public education. They, as well as B-4, volunteered to help other PWAs. B-4 and C-5 saw themselves as having a positive effect on others.

Only C-5 and C-6 reported planning future goals.

The composite portrait of the six subjects illustrates two key features of coping:

1) Coping is context-dependent, i.e., what people think and do to manage a situation is determined by the interdependence of person and situational factors. In context, these men held, in common, dual stigmatized identities. They were gay men, and they were gay men with AIDS. This context illuminated the qualities of their coping.

2) Coping is a change process, in this case, set within phases in a life-threatening illness trajectory. The common process of the six men was one of coming to terms with having to live a redefined existence characterized by inevitable change. The self-reported cognitions and behaviours of the subjects portray the dynamics of this change process.

These two key features of coping, context and change process, are the focus of data analysis presented in Chapter Five.
CHAPTER FIVE

ANALYSIS OF THE RESEARCH DATA

In this chapter, the illness-related cognitive and behavioural activities reported by the subjects are classified, interpreted, and abstracted in two stages of analysis of the data according to their combined functions, situational features, and temporal contexts. This process identified 11 categories of person-situation coping transactions engaged in by the subjects.

Stage One Analysis of the Data

In the first level of data abstraction, the items listed in Tables 2, 3, and 4 are formed into units for analysis based on their functional, situational, and temporal commonality. This process integrated the activities, creating 52 activity units for analysis.

An activity unit may consist of one or more items. Each activity unit has combined functional, situational, and temporal features. Interpretation of each activity unit addressed the questions: what are the subjects thinking and doing?, for what?, and for whom? Interpretations are provided in functional, situational, and temporal terms. The subjects' cognitions and behaviours are described in person-situation relational terms. Each abstraction of an activity unit denotes a situationally-based cognitive process, behavioural activity, or both, reflecting the subjects' coping with AIDS, past, present, and anticipated. Together the 52
first-level abstractions portray coping with AIDS as a complex set of person-situation transactions.

**Analysis of Activity Units: Pre-diagnosis [Table 2]**

**Activity Unit 2.1**

Had felt invincible about his health (B-4)

Had felt negative about his health (C-6)

**Interpretation.**

These subjects held presuppositions about their health prior to diagnosis, derived from their past experiences with illness. During the time prior to diagnosis, when they were worried about their health, these suppositions either offered hope or precipitated negative thinking. Although, in their current situations, they both hoped and were resigned to an adverse situation, these previously held suppositions no longer served a function and were relinquished.

**Abstraction.**

Relinquishment of a previously held supposition about self-concept.

**Activity Unit 2.2**

Has been practicing safer sex (A-1, B-4)

**Interpretation.**

Given the risk of AIDS among men who have sex with men, these subjects adopted safer sex behaviours prior to diagnosis to protect themselves from HIV
infection. When they thought they already were infected, these behaviours functioned to protect others from contracting the virus.

Abstraction.

Protection of self and others from HIV infection.

Activity Unit 2.3

Compared himself to a stigmatized stereotype of a PWA (A-2, B-4, C-6)

Saw himself as being at risk (B-3)

Interpretation.

Comparing perceptions of self to others in a perceived stigmatized category drew conclusions about self-concept: "I am not this," or its antithesis, "I am possibly this."

Abstraction.

Reevaluation of self-concept based on an external, stigmatized stereotype.

Activity Unit 2.4

Was aware of physical symptoms (A-1, A-2, B-3, B-4, C-5, C-6)

Did not suspect/think it was AIDS (A-2, C-6)

Compared his symptoms to non-AIDS-related illnesses (A-1, B-3, B-4)

Compared his symptoms to the common profile of a PWA (A-1, B-3, B-4)

Suspected/thought symptoms were AIDS-related (A-1, B-3, B-4, C-6)

Interpretation.

Physical symptoms, either sporadic or ongoing, precipitated a cognitive
process: 1) symptom recognition, 2) comparison to an AIDS diagnosis, and 3) self-appraised negative health status, AIDS-identified in four subjects. This cognitive process precipitated seeking medical help.

**Abstraction.**

Negative self-appraisal of health based on physical symptoms.

**Activity Unit 2.5**

Was concerned about his health (A-1, A-2, B-3, B-4, C-5, C-6)

**Interpretation.**

Irrespective of whether subjects thought their physical symptoms were AIDS-related, subjects became concerned about their symptoms and reported being negatively preoccupied with their health.

**Abstraction.**

Negative preoccupation.

**Activity Unit 2.6**

Avoided dealing with his symptoms (B-4)

Gave himself a farewell fling (A-1, B-3)

Used alcohol (B-3)

Had (safer) sex (A-1)

**Interpretation.**

Prior to diagnosis, these subjects engaged in avoidant activity in order to escape the thought that they had AIDS.
Abstraction.
Avoidance or escape.

Activity Unit 2.7
Saw doctor(s)

Interpretation.
Seeing doctors served two functions: 1) symptom- and AIDS-related information-seeking, and, if prescribed, 2) medical treatment, conventional or experimental.

Abstraction.
Diagnostic help- and information-seeking.

Analysis of Activity Units: Immediately, Post-diagnosis (Table 3)

Activity Unit 3.1
Asked doctor how long he had to live (A-1, A-2, B-4, C-6)
Summarized his life (C-6)

Interpretation.
Immediately, post-diagnosis, these subjects queried the projected imminence of their mortality. In summarizing his life, C-6 is an exemplar of closure to a previously held existential identity.

Abstraction.
Relinquishment of a previously held existential identity.
Activity Unit 3.2

Initial disclosure of diagnosis (A-1, A-2, B-3, B-4, C-5, C-6)

Interpretation.
In telling someone your situation, the situation is interpersonally recognized. Subjects' existential situations were disclosed and socially validated.

Abstraction.
Seeks attuned recognition from others for a newly acquired existential identity.

Activity Unit 3.3

Suppressed negative emotions (A-1, A-2, B-3, B-4)

Denied (A-2, B-3, C-6)

Slept to tune it out (A-2, B-3)

Used sleeping pills/tranquilizers (A-1, B-4)

Interpretation.
In the period immediately following diagnosis, these subjects cognitively controlled their negative emotions and sought temporary means of escape.

Abstraction.
Inner-directed control of negative affect.

Activity Unit 3.4

Got strong for others (A-1, A-2, B-3, B-4, C-5, C-6)

Didn't want to talk about it (B-3, C-5)
Used humour (A-1)

**Interpretation.**

Subjects put up a front to protect others and themselves from discomfort and distress, and to control the content of their social interactions.

**Abstraction.**

Outer-directed control of negative affect.

**Activity Unit 3.5**

Confronted negative emotions (A-1, B-3, B-4, C-5)

Lost hope/gave up/did nothing (A-1, A-2, B-3, B-4)

Isolated himself (A-1, A-2, B-3, B-4)

Pitied himself (A-1, A-2)

Wanted to die (A-2, B-3)

Cried (A-1, A-2, B-3, B-4, C-5, C-6)

Cried in the research interview (A-1, B-4, C-6)

**Interpretation.**

These activities are the antithesis of the control of negative affect. Subjects face a pre-destined mortality. This recognition precipitates a period of self-mourning as well as ongoing intermittent grief.

**Abstraction.**

Self-mourning, grieves the loss of a previously held existential and social identity.
Activity Unit 3.6

Suicidal ideation (A-1, B-3, B-4)

Plans to exercise control over the timing of his death (B-3)

*Interpretation.*

These subjects initially considered suicide as the means to deal with what they considered to be an intolerable situation. For B-3, suicidal ideation is his way of maintaining personal autonomy and control over his situation.

*Abstraction.*

Self-protection from an intolerable threat.

Activity Unit 3.7

Sought attribution for having contracted AIDS (A-1, A-2, B-3, B-4, C-6)

Didn’t let any guilt in (C-5)

*Interpretation.*

Subjects sought meaning and explanation for having contracted AIDS. They engaged in self-other comparisons in an attempt to reconcile themselves with a stigmatized stereotype of a PWA.

*Abstraction.*

Reconciliation with a stigmatized stereotype of a PWA.
Analysis of Activity Units: Current Adjustment to Illness (Table 4)

Activity Unit 4.1

Accepted the fact/reality (A-1, A-2, B-3, B-4, C-5, C-6)

Stopped self-mourning (A-2, B-4)

Interpretation.

Subjects reconciled themselves with their existential situations. In coming to terms with their prognosis, A-2 and B-4 stopped a self-identified period of self-mourning.

Abstraction.

Reconciliation with a new existential situation.

Activity Unit 4.2

Decided to do things his way/takes control (A-1, A-2, B-3, B-4, C-5, C-6)

Interpretation.

Subjects assert their autonomy, power, and instrumentality.

Abstraction.

Autonomous action.

Activity Unit 4.3

Hopes (A-1, A-2, B-3, B-4)

Interpretation.

Subjects hope for respite from sickness and death.
Abstraction.

Hopes for respite.

Activity Unit 4.4

Views himself as stigmatized (A-1, A-3, B-3)

Struggles with past beliefs (B-3)

Interpretation.

As a consequence of having contracted AIDS, these subjects now view themselves negatively, shamefully, reflecting a pre-existing internalized, moral conception of their sexuality. Homosexuality and death as punishment are linked.

Abstraction.

Internalization of a stigmatized stereotype.

Activity Unit 4.5

Recognizes stigmatization by others (A-1, A-2, B-3, B-4, C-5, C-6)

Protects himself from discrimination/abuse (A-1, A-2, B-3, B-4, C-5)

Camouflages (A-2, B-3, C-5, C-6)

Doesn't take it personally (A-1, B-4, C-5)

Up front about having AIDS and being gay (B-4, C-6)

Struggles with others' fear of intimacy/HIV infection (C-6)

Interpretation.

Subjects devise behavioural and cognitive-defensive ways to protect
themselves from discrimination. They recognize the propensity for others to
denigrate them for their sexuality, to be uncomfortable with their existential
status, or to shun physical proximity for fear of HIV infection.

Abstraction.

Self-protection from denigration by others.

Activity Unit 4.6

Struggles with his anger toward others (A-1, A-2, B-4)

Learns to be patient with others (A-1, A-2, C-6)

Interpretation.

These subjects strive to manage their social expression of anger.

Abstraction.

Learns to manage anger.

Activity Unit 4.7

Relies on others for personal care (A-1, A-2, B-3)

Acknowledges the support of family/friends (A-1, A-2, B-3)

Keeps notes/written schedule (A-1, A-2, C-6)

Interpretation.

When sick, these subjects relied on instrumental supports.

Abstraction.

Sickness-related external reliance.
Activity Unit 4.8
Talked to other PWAs who have/had the same opportunistic infection(s) (A-1, C-5, C-6)
Initially attended a support group for PWAs (A-1, A-2)

  Interpretation.
  These subjects sought AIDS- and illness-related information from other PWAs. However, for A-1 and A-2, seeing and talking to other PWAs whose illness was further progressed, generated fear for their own futures.

  Abstraction.
  Peer-based information-seeking.

Activity Unit 4.9
Compares himself to PWAs who are socially less fortunate (A-1, B-4, C-6)
Compares himself to other PWAs re: disease progression (A-1, B-3, B-4, C-6)

  Interpretation.
  These subjects view their situations positively by comparison to other PWAs. They appraise their current situation relative to other PWAs.

  Abstraction.
  Positive self-appraisal compared to other PWAs.

Activity Unit 4.10
Avoids/limits contact with other PWAs (A-1, A-2)
Interpretation.

This behaviour is a consequence of having attended a support group for PWAs. The experience induced fear and depression rather than perceived support.

Abstraction.

Social distancing from other PWAs whose illness is further progressed.

Activity Unit 4.11

Cognisant of mortality (A-1, A-2, B-3, B-4, C-5, C-6)

Intellectualizes (A-1, B-3)

Tries to be realistic (A-1, A-2, B-3, B-4, C-5, C-6)

Vigilant about time left (A-1, A-2, B-3, B-4)

Made a will (A-2, B-3)

Stopped planning future goals (A-1, A-2, B-3)

Read about dying and death (A-1, A-2)

Views his illness/dying as an opportunity, a maturing process (B-4, C-6)

Interpretation.

These activities reflect preoccupation with the fact of their mortality, expressed perceptually and behaviourally. Subjects struggle with the question, "Am I living or dying?" with outcomes in "being stuck" (B-3) or in getting on with living, albeit in a new context. A perceived imminent mortality can be an opportunity for internal growth and externally-directed constructive action. However, in all subjects, existential identity is reconstructed.
Abskamm

Reconstruction of existential identity.

Activity Unit 4.12

Went back to work (A-1, B-3, C-5, C-6)
Quit work (A-1, B-3, C-5, C-6)
Arranged financial means of support (A-1, B-3, B-4, C-5, C-6)

Interpretation.

These actions are subjects' concrete expressions of coming to terms with their new situation with respect to work. Subjects expressed concerns about the deleterious effects of the stress of work and workplace discrimination on their physical health and psychosocial well-being. It raises the question of the value of work, particularly within the social context of having a life-threatening and stigmatized disease. The meaning of work, as they once knew it, is altered. Work as a value is relinquished; nevertheless, it is mourned.

Abstraction.

Relinquishment of work, a behavioural expression of self-concept.

Activity Unit 4.13

Reaches out for support (A-1, A-2, B-3, B-4, C-5, C-6)
Regularly attends a support group for PWAs (B-4, C-5)
"Talks it out" with friends (A-1, C-5)

Interpretation.
These activities represent an active search for recognition and understanding from others.

Abstraction.

Seeks attunement with others.

Activity Unit 4.14

Seeks expert advice (A-1, A-2, B-3, B-4, C-5, C-6)

Couple counselling (A-1)

Used a physical health professional for psychotherapeutic means (A-2, C-6)

Used the research interview for psychotherapeutic means (A-1, A-2)

Interpretation.

These actions represent externally-directed problem-solving measures taken in relation to the particular features of their situations.

Abstraction.

Situation-specific help-seeking.

Activity Unit 4.15

Seeks treatment information (A-1, A-2, B-3, B-4, C-5, C-6)

Interpretation.

Treatment-related information-seeking is an ongoing activity in the AIDS illness trajectory.

Abstraction.

Treatment-related information-seeking.
Activity Unit 4.16

Places trust/faith in his physician (A-1, B-3, C-5, C-6)
Does not put total faith in doctors (A-2, B-4, C-5)
Complained about the side effects of medical tests/treatment (A-1, A-2, B-3, C-5, C-6)
Seeks better medical care (A-2)
Chose to participate in experimental drug trials (C-5, C-6)
Stopped experimental drug trials (C-5, C-6)
Decided not to take medical treatment (B-4)

Interpretation.

In the context of enforced dependency on medical care and ambiguous treatment efficacy, subjects discriminate the competence of their physicians, and consider this factor in making decisions about their medical care and treatment. Medical tests and treatment are viewed negatively because of their adverse side effects. Subjects seek to satisfy themselves that at least they have the best available medical care.

Abstraction.

Discerns medical care and treatment options.

Activity Unit 4.17

Selectively controls disclosure of diagnosis (A-1, A-2, B-3, B-4, C-5, C-6)
Interpretation.

Controlling disclosure of diagnosis is a form of protection, directed toward themselves or others whom they seek to protect.

Abstraction.

Social protection of self or others.

Activity Unit 4.18

Disclosed diagnosis/sexual orientation to his parents (B-4, C-5)

Shuts his parent(s) out (B-3, C-6)

Interpretation.

In this context, having contracted AIDS is a consequence of being gay, the latter previously not disclosed to parents.

Abstraction.

Seeks attuned recognition from parent(s) or maintains secrecy.

Activity Unit 4.19

Takes initiative in helping others to talk about it (A-1, A-2, B-3, C-5)

Has talked about his dying with partner/family (A-1, A-2)

Maintains supportive relationships with his parents/family (A-1, A-2, C-5)

Limits the information he gives his family about his illness (A-2, C-5)

Interpretation.

These are other-directed activities intended to help significant others deal with their discomfort, and provide consolation or protection from emotional
distress. These activities recognize that one's grief is shared with others.

Abstraction.
Supportive, protective attunement with others.

**Activity Unit 4.20**
Distinguishes between his reality and others' reality (B-4)

Interpretation.
This is a cognitive distinction that establishes a self-protective boundary between the self and others. B-4 makes this distinction to deal with others' misunderstanding of his reality.

Abstraction.
Self-attunement and other-estrangement.

**Activity Unit 4.21**
Values relationships differently (A-1, A-2, B-3, B-4, C-5, C-6)

Has made new kinds of friends (B-4, C-5)

Interpretation.
These reflections and actions represent a revaluation of relationships with others, focusing on substantive rather than frivolous dimensions. In some instances, this has resulted in the relinquishment of some relationships and embarkment on others.

Abstraction.
Revaluation of relationships.
Activity Unit 4.22
Abstains from sex (B-3, B-4)
No longer makes sexual advances (B-4, C-5)
No longer looks for a love relationship (B-3, B-4)

Interpretation.
Relinquishment of previous activities and pursuits that denote sexual intimacy and fulfilment.

Abstraction.
Relinquishment of sexual intimacy.

Activity Unit 4.23
Positively compares present quality of life to past quality of life (B-4)

Interpretation.
A conclusion that his present quality of life is more positive and meaningful than it had been prior to diagnosis. B-4 now focuses on the internal-spiritual dimensions of himself and others, a positive comparison to his former focus on the external-physical aspects of himself and others.

Abstraction.
Positive revaluation of quality of life.

Activity Unit 4.24
Takes one day at a time (A-2, B-3, C-5, C-6)
Interpretation.

This stance implies recognition of temporal uncertainty about longevity and related future events, and serves as a means of managing this phenomenon.

Abstraction.

Manages time.

Activity Unit 4.25
Lives each day to the fullest (A-1, A-2, B-4, C-5, C-6)
Values quality time (A-1, A-2, B-4, C-5, C-6)

Interpretation.

These subjects maximize their use of time, as well as discern how their time is spent. These standards imply a restricted view of time.

Abstraction.

Maximizes use of time.

Activity Unit 4.26
Enjoys nature (A-1, A-2, B-4, C-5, C-6)

Interpretation.

These subjects identify a conscious appreciation of the natural world, reflecting a sort of wonderment and personal sense of oneness with the natural order. There appears to be solace in this communion with nature and a recognition that "I am part of this."
Abstraction.
Seeks attunement with the natural order.

Activity Unit 4.27
Looks for ways to make use of time (A-1, B-3)
Thinks about volunteering to help other PWAs (A-1, B-3)
Procrastinates (B-3)

Interpretation.
These activities reflect the difficulties experienced by subjects in the meaningful use of time after stopping employment, and raises the question of "what to do?" in the context of their existential situation. These subjects are now looking for ways to fill the void left by the absence of work and are thinking about undertaking activities that would be helpful to other PWAs.

Abstraction.
Seeks an other-, outer-directed purpose.

Activity Unit 4.28
Likes to spend time alone (A-2, C-6)
Tries to like/love himself (A-1, B-4, C-6)
Nurtures himself (A-1, A-2, B-3, B-4, C-5, C-6)
Artistic and creative expression (A-2, B-3, C-5, C-6)
Spends/buys (A-1, A-2, C-5)
Plans to travel (A-1, A-2, C-5)
Travelled (B-4, C-5, C-6)

**Interpretation.**

Together these self-fulfilling and expressive activities reflect a revaluation of self-concept. It means, "I am of value and I am worthy of fulfilling myself."

**Abstraction.**

Self-fulfilling activities.

**Activity Unit 4.29**

Fights to live (A-1, A-2, B-3, B-4, C-5, C-6)

Positively compares himself to PWAs who have given up (A-2, C-5)

Relies on inner strength (B-3, B-4, C-5)

Draws strength from past beliefs (A-2, B-4, C-6)

Believes in a better life after death (A-2, B-4, C-5)

Prays (A-1, A-2, C-6)

Focuses on his spirituality (B-4, C-5)

Tries to maintain a positive attitude (A-1, A-2, B-3, B-4, C-5, C-6)

Controls negative thinking (A-1, A-2, B-3, B-4, C-5, C-6)

Tries not to think about... (A-1, A-2, B-3, B-4, C-5, C-6)

Strives for normality (A-1, A-2, B-3, B-4, C-5, C-6)

Talks less about his illness (B-4)

**Interpretation.**

Subjects exercise a conscious decision to assert their will to live, externalized in self-help activities, by contrast to other PWAs whom they perceive
as having given up. The reported means used to sustain the will to live are forms of cognitive control strengthened, in part, by existential-spiritual beliefs in a higher order, and externalized in efforts to maintain normality in day-to-day living. Inherent in these activities is an acceptance of their situation, as well as a resolve to live within the confines that it imposes.

**Abstraction.**

Will to live.

**Activity Unit 4.30**

Partied after finding out that he tested negative for cytomegalovirus (CMV) (C-6)

**Interpretation.**

This particular activity is an exemplar of celebration of relief from realistic worry and fear: "I could have been worse off."

**Abstraction.**

Celebrates respite.

**Activity Unit 4.31**

Misses doing things he used to do (A-2, B-3, C-5)

**Interpretation.**

Irrespective of time duration, post-diagnosis, grieving is an enduring dimension of these subjects' experiences.

**Abstraction.**

Grieves the loss of previous abilities and activities.
Activity Unit 4.32

Manages an altered financial situation (B-3, B-4, C-5, C-6)

Interpretation.

For these subjects, adjustment to a reduced income restricts previously enjoyed activities associated with cost.

Abstraction.

Financial adjustment.

Activity Unit 4.33

Manages physical limitations (A-1, A-2, B-3, B-4, C-5, C-6)

Interpretation.

Day-to-day activities are paced in order to conserve energy and manage fatigue.

Abstraction.

Self-conservation.

Activity Unit 4.34

Tries to protect himself from others’ illnesses (A-2, B-3)

Improved nutrition/eats well (A-1, B-4, C-5, C-6)

Takes vitamins (A-1, B-4)

Exercises (B-4, C-6)

Stopped using alcohol and marijuana (A-1)

Believes in alternative approaches to health/illness (B-4, C-6)
Meditates/uses visualization (B-4, C-6)

Focuses on healthy parts of his body (B-4)

Focuses on affected parts of his body in a loving way (C-6)

Uses alternative physical therapies (B-4, C-5, C-6)

Uses herbal remedies (A-1, B-3)

Listens to relaxation tapes (B-3)

Uses marijuana to reduce stress, relax, sleep (B-3, B-4)

Interpretation.

These are conventional and alternative activities undertaken to prevent illness, and improve physical health and mental well-being.

Abstraction.

Self-care and nurture.

Activity Unit 4.35

Seeks involvement in a love relationship (C-6)

Recent involvement in a love relationship (C-5)

Practices safer sex (C-5, C-6)

Interpretation.

Reported by subjects in temporal situation C, these activities represent a renewed interest in intimacy and love, part of a renewed interest in seeking self-fulfillment in living with others.

Abstraction.

Seeks intimate attunement with another.
Activity Unit 4.36

Grieves the multiple deaths of friends due to AIDS (C-5, C-6)

Interpretation.

This activity reflects the gay context of AIDS characterized by the multiple loss of friends to the disease. In outliving their friends, subjects in temporal situation C are not only facing the imminence of their own mortality, but, as well, are left to grieve the loss of others known to them.

Abstraction.

Grief, complicated by multiple loss, precipitating further mourning.

Activity Unit 4.37

Volunteers to help other PWAs (B-4, C-5, C-6)

Externalizes/politicizes the disease (C-5, C-6)

Participates in AIDS-related community development and education (B-4, C-5, C-6)

Sees himself as having a positive effect on others (B-4, C-6)

Interpretation.

These activities reflect self- and other-enablement. These subjects view themselves as models to educate and help others, externalized in community activity. They view their individual experiences in living with the disease as something beyond themselves, and they act to make an impact.

Abstraction.

Self- and other-enablement.
Plans future goals (C-5, C-6)

Interpretation.

Exclusive to subjects in temporal situation C, there is a renewed interest to plan for an aspired future, albeit under constricted and certain conditions. It is, however, the antithesis of stagnation.

Abstraction.

Aspires to future goals.

Interpretation of the activity units advances the subjects’ cognitions and behaviours to their first level of abstraction. First level abstractions reflect the substance of the subjects’ thoughts and actions within their situational and temporal contexts as interpreted by the investigator.

The first level abstractions of the data are presented in Tables 5, 6, and 7. Abstractions in each table are identified by the reporting subject and by the temporal situation of the subject at the time of the interviews.
Table 5

First Level Abstractions of Self-reported Cognitive and Behavioural Activities Employed by the Subjects in Coping with AIDS: Pre-diagnosis

<table>
<thead>
<tr>
<th>First Level Abstractions of Self-reported Cognitive and Behavioural Activities</th>
<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Relinquishment of a previously held supposition about self-concept</td>
<td></td>
</tr>
<tr>
<td>Protection of self and others from HIV infection</td>
<td></td>
</tr>
<tr>
<td>Revaluation of self-concept based on an external, stigmatized stereotype</td>
<td></td>
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<tr>
<td>Negative self-appraisal of health based on physical symptoms</td>
<td></td>
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<tr>
<td>Negative preoccupation</td>
<td></td>
</tr>
<tr>
<td>Avoidance or escape</td>
<td></td>
</tr>
<tr>
<td>Diagnostic help- and information-seeking</td>
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</tbody>
</table>

Temporal Situations: A = 2 months, post-diagnosis  
                    B = 6 months, post-diagnosis  
                    C = 3½ years, post-diagnosis
Table 6

First Level Abstractions of Self-reported Cognitive and Behavioural Activities Employed by the Subjects in Coping with AIDS: immediately, Post-diagnosis

<table>
<thead>
<tr>
<th>First Level Abstractions of Self-reported Cognitive and Behavioural Activities</th>
<th>Temporal Situations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Subjects</td>
<td>1</td>
</tr>
<tr>
<td>Relinquishment of a previously held existential identity</td>
<td>⬤</td>
</tr>
<tr>
<td>Seeks attuned recognition from others for a newly acquired existential identity</td>
<td>⬤</td>
</tr>
<tr>
<td>Inner-directed control of negative affect</td>
<td>⬤</td>
</tr>
<tr>
<td>Outer-directed control of negative affect</td>
<td>⬤</td>
</tr>
<tr>
<td>Self-mourning, grieves the loss of a previously held existential and social identity</td>
<td>⬤</td>
</tr>
<tr>
<td>Self-protection from an intolerable threat</td>
<td>⬤</td>
</tr>
<tr>
<td>Reconciliation with a stigmatized stereotype of a PWA</td>
<td>⬤</td>
</tr>
</tbody>
</table>

Temporal Situations:  
A = 2 months, post-diagnosis  
B = 6 months, post-diagnosis  
C = 3½ years, post-diagnosis
Table 7

First Level Abstractions of Self-reported Cognitive and Behavioural Activities Employed by the Subjects in Coping with AIDS: Current Adjustment to Illness

<table>
<thead>
<tr>
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<th>Temporal Situations</th>
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<td>Subjects</td>
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<tr>
<td></td>
<td>A</td>
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<tr>
<td>Edent</td>
<td>1</td>
</tr>
<tr>
<td>Reconciliation with a new existential situation</td>
<td>•</td>
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<tr>
<td>Hopes for respite</td>
<td>•</td>
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<tr>
<td>Internalization of a stigmatized stereotype</td>
<td>•</td>
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<tr>
<td>Self-protection from denigration by others</td>
<td>•</td>
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<tr>
<td>Learns to manage anger</td>
<td>•</td>
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<tr>
<td>Sickness-related external reliance</td>
<td>•</td>
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<tr>
<td>Peer-based information-seeking</td>
<td>•</td>
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<tr>
<td>Positive self-appraisal compared to other PWAs</td>
<td>•</td>
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<tr>
<td>Social distancing from other PWAs whose illness is further progressed</td>
<td>•</td>
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<tr>
<td>Reconstruction of existential identity</td>
<td>•</td>
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<tr>
<td>Relinquishment of work, a behavioural expression of self-concept</td>
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<tr>
<td>Seeks attunement with others</td>
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</tr>
<tr>
<td>Situation-specific help-seeking</td>
<td>•</td>
</tr>
</tbody>
</table>

Temporal Situations:  

A = 2 months, post-diagnosis  
B = 6 months, post-diagnosis  
C = 3½ years, post-diagnosis
Table 7 (Continued)

First Level Abstractions of Self-reported Cognitive and Behavioural Activities Employed by the Subjects in Coping with AIDS: Current Adjustment to Illness

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<tr>
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<td>A</td>
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<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Treatment-related information seeking</td>
<td>●</td>
</tr>
<tr>
<td>Discerns medical care and treatment options</td>
<td>●</td>
</tr>
<tr>
<td>Social protection of self or others</td>
<td>●</td>
</tr>
<tr>
<td>Seeks attuned recognition from parent(s) or maintains secrecy</td>
<td></td>
</tr>
<tr>
<td>Supportive, protective attunement with others</td>
<td>●</td>
</tr>
<tr>
<td>Self attunement and other- estrangement</td>
<td></td>
</tr>
<tr>
<td>Revaluation of relationships</td>
<td>●</td>
</tr>
<tr>
<td>Relinquishment of sexual intimacy</td>
<td></td>
</tr>
<tr>
<td>Positive revaluation of quality of life</td>
<td></td>
</tr>
<tr>
<td>Manages time</td>
<td>●</td>
</tr>
<tr>
<td>Maximizes use of time</td>
<td>●</td>
</tr>
<tr>
<td>Seeks attunement with the natural order</td>
<td>●</td>
</tr>
<tr>
<td>Seeks an other-, outer-directed purpose</td>
<td>●</td>
</tr>
<tr>
<td>Self-fulfilling activities</td>
<td>●</td>
</tr>
<tr>
<td>Wills to live</td>
<td>●</td>
</tr>
<tr>
<td>Celebrates respite</td>
<td></td>
</tr>
</tbody>
</table>
Table 7 (Continued)

First Level Abstractions of Self-reported Cognitive and Behavioural Activities Employed by the Subjects in Coping with AIDS: Current Adjustment to Illness

| First Level Abstractions of Self-reported Cognitive and Behavioural Activities | Temporal Situations |
|---|---|---|---|---|---|---|
| | A | B | C |
| Subjects | 1 | 2 | 3 | 4 | 5 | 6 |
| Grieves the loss of previous abilities and activities | • | • | • | | | |
| Financial adjustment | | • | • | • | • | • |
| Self-conservation | • | • | • | • | • | • |
| Self-care and nurture | • | • | • | • | • | • |
| Seeks intimate attunement with another | | | | • | • | |
| Grief, complicated by multiple loss, precipitating further mourning | | | | • | • | |
| Self- and other-enablement | | • | • | • | | |
| Aspires to future goals | | | | | • | • |
Stage Two Analysis of the Data

In order to identify the essential person-situation coping transactions engaged in by the subjects, the 52 abstractions of the data (Tables 5, 6, and 7) were grouped according to their commonality in function and process. The abstractions were grouped across temporal situations A, B, and C in order to identify continuities in the types of coping transactions engaged in by the subjects. This process reduced the 52 abstractions to 11 groups. Interpretations and summary abstractions of the 11 groupings sought to identify the essential features of coping with AIDS portrayed as an interrelated set of person-situation transactions.

Group One

Negative self-appraisal of health based on physical symptoms (2.4)

Negative preoccupation (2.5)

Interpretation.

The onset of potential AIDS-related symptoms, as appraised by the affected individual, precipitates the beginning of negative preoccupation or worry, a cognitive activity that continues intermittently throughout the illness trajectory. In any one of the temporal situations portrayed by the subjects, worry is the consequence of a perceived threat, either current or anticipated. Worry is a cognitive attempt to problem-solve, behaviourally expressed in help- and information-seeking, avoidance and escape, or through cognitive control of negative affect.
Summary abstraction.
Worry.

Group Two
Avoidance or escape (2.6)
Inner-directed control of negative affect (3.3)
Outer-directed control of negative affect (3.4)
Learns to manage anger (4.6)
Social distancing from other PWAs whose illness is further progressed (4.10)

Interpretation.

The experience of negative emotions is managed by deliberate cognitive control, behaviourally expressed through avoidant activity, social distancing, and by masking negative emotions in the presence of others. Control of negative affect serves a self- and other-protective function. It is a sporadic, but recurrent cognitive activity in the illness trajectory, precipitated by worry and self-appraised negative events, either current or anticipated.

Summary abstraction.

Control of negative affect.

Group Three
Revaluation of self-concept based on an external, stigmatized stereotype (2.3)
Internalization of a stigmatized stereotype (4.4)
Positive self-appraisal compared to other PWAs (4.9)
Revaluation of relationships (4.21)

Positive revaluation of quality of life (4.23)

Interpretation.

Revaluations are situationally-based cognitive activities which revise an individual's self-concept, including appraisals of social relations and quality of life. In the context of AIDS, revaluations of self-concept include the assimilation of a stigmatized social identity. Among the subjects, this process precipitated positive social comparisons to a stigmatized stereotype of a PWA with whom subjects did not personally identify. The process of assimilating a stigmatized identity demystifies the subject's previously held stereotype; however, it leaves him vulnerable to those stereotypes held by others.

Summary abstraction.

Revaluation of self-concept.

Group Four

Relinquishment of a previously held supposition about self-concept (2.1)
Relinquishment of a previously held existential identity (3.1)
Relinquishment of work, a behavioural expression of self-concept (4.12)
Relinquishment of sexual intimacy (4.22)
Financial adjustment (4.32)

Interpretation.

Accompanying revaluations of self-concept and social identity are processes associated with "letting go" or relinquishment. Subjects relinquish
previously held suppositions about themselves, their existential and social identities, and associated social practices. Quitting work, related financial adjustments, forgoing sexual intimacy are concrete expressions of relinquishment.

**Summary abstraction.**

Relinquishment.

**Group Five**

Protection of self and others from HIV infection (2.2)

Self-protection from an intolerable threat (3.6)

Self-protection from denigration by others (4.5)

Social protection of self or others (4.17)

**Interpretation.**

Among the subjects, activities associated with the social and physical protection of self are based on principles of care and positive regard for both self and others. The fact that HIV is transmissible under certain conditions carries the potential for infected individuals to be seen as a personal and social threat accompanied, in some instances, by social denigration. Further, HIV infected individuals face the certain prospect of physical deterioration resulting in death. Subjects often withheld information about their diagnosis or physical condition in order to protect themselves or others from psychological pain or discomfort.

**Summary abstraction.**

Self- and other-protection.
Group Six

Diagnostic help- and information-seeking (2.7)
Sickness-related external reliance (4.7)
Peer-based information-seeking (4.8)
Situation-specific help-seeking (4.14)
Treatment-related information-seeking (4.15)
Discerns medical care and treatment options (4.16)

Interpretation.
Help- and information-seeking is a continuous feature of the AIDS illness trajectory. The help and information sought is situation-specific reflecting the unique features of the person-in-situation. Discernment of the quality of medical care and available treatment options is a key feature of help- and information-seeking in this context.

Summary abstraction.
Help- and information-seeking.

Group Seven

Seeks attuned recognition from others for a newly acquired existential identity (3.2)
Seeks attunement with others (4.13)
Seeks attuned recognition from parent(s) or maintains secrecy (4.18)
Supportive, protective attunement with others (4.19)
Self-attunement and other-estrangement (4.20)
Seeks attunement with the natural order (4.26)
Seeks intimate attunement with another (4.35)

**Interpretation.**

The seeking of attunement with others and with the natural order is a self-initiated activity that attempts to overcome subjects’ perceived sense of separateness and differentness from others. The process of attunement assumes that separate individuals can come to share the same feelings. It asks others to empathically assume the subject’s position and accurately perceive the subject’s needs and feelings. The antithesis of attunement in subjects’ experiences is estrangement from others.

**Summary abstraction.**

Attunement with others or estrangement.

**Group Eight**

Self-mourning, grieves the loss of a previously held existential and social identity (3.5)
Grieves the loss of previous abilities and activities (4.31)
Grief, complicated by multiple loss, precipitating further mourning (4.36)

**Interpretation.**

The onset of grief, precipitated by a definitive diagnosis of AIDS, is marked by an intense period of negative self-absorption with one’s plight and inevitable fate. What is immediately incumbent upon a gay man with AIDS is the loss of his previously held existential identity and the mourning of his stigmatization.
Following this period of preoccupation with one's fate, grief in the AIDS illness trajectory, while intermittent, is both immediate and anticipated in relation to actual and future losses in physical and social abilities. In the gay context of the disease, a PWA's grief is further complicated by the loss, due to AIDS, of partners, friends, and acquaintances, precipitating further grief and mourning.

**Summary abstraction.**

Complicated grief.

**Group Nine**

Reconciliation with a stigmatized stereotype of a PWA (3.7)

Reconciliation with a new existential situation (4.1)

Reconstruction of existential identity (4.11)

**Interpretation.**

Preoccupation with one's fate as a definitive period in the AIDS illness trajectory is terminated by the achievement of conciliation, a self-acceptance of the fact of one's existential situation. There is new found self-cohesion in the reconciliation of self with situation, spurring the beginning of self-directed, legislative actions in relation to the illness. For the subjects, the process of conciliation demystifies the "otherness" of a PWA as a stigmatized stereotype.

**Summary abstraction.**

Conciliation.
Group Ten

Self-fulfilling activities (4.28)
Self-conservation (4.33)
Self-care and nurture (4.34)

Interpretation.

The issue of the self's attitude toward itself in the context of gay men with AIDS is complicated by internalized social constructions of AIDS as metaphors of homosexuality and death. With the achievement of conciliation, subjects began to deliberately engage in activities that reflect self-situation cohesiveness and self-esteem. Among the subjects, self-valuing activities were reported to take initiative and effort, and are part of asserting one's will to live.

Summary abstraction.

Self-valuation.

Group Eleven

Autonomous action (4.2)
Hopes for respite (4.3)
Manages time (4.24)
Maximizes use of time (4.25)
Seeks an other-, outer-directed purpose (4.27)
Wills to live (4.29)
Celebrates respite (4.30)
Self- and other-enablement (4.37)
Aspires to future goals (4.38)

Interpretation.

The achievement of conciliation marks the beginning of reconstructed autonomous actions that reflect the individual's will to live with hopes and aspirations confined by the destined course of the disease. How the subject appraises his self-in-situation is the key determinant of his coping. In coming to see the illness as beyond themselves, subjects sought to be helpful to others affected by the disease.

There is no map for this life course except for the self-cohesion and integrity of the individual.

Summary abstraction.

Self- and other- focused autonomous actions.

At the second stage of analysis, the data are reduced to 11 interrelated categories depicting 11 person-situation transactions engaged in by the subjects in coping with AIDS.

In a final ordering of the study's findings, the 11 transactions were grouped according to the temporal situation in which a transaction was first reported to occur: 1) pre-diagnosis, 2) immediately, post-diagnosis, and 3) current adjustment to illness. Table 8 lists the person-situation coping transactions relative to the temporal situation in which they became activated.
Table 8
Person-Situation Coping Transactions in Gay Men with AIDS

<table>
<thead>
<tr>
<th>Temporal Situations</th>
<th>Pre-diagnosis</th>
<th>Immediately, Post-diagnosis</th>
<th>Current Adjustment to Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person-Situation Coping Transactions</td>
<td>1) Worry</td>
<td>7) Attunement with others or estrangement</td>
<td>9) Conciliation</td>
</tr>
<tr>
<td></td>
<td>2) Control of negative affect</td>
<td>8) Complicated grief</td>
<td>10) Self-valuation</td>
</tr>
<tr>
<td></td>
<td>3) Revaluation of self-concept</td>
<td></td>
<td>11) Self- and other-focused autonomous actions</td>
</tr>
<tr>
<td></td>
<td>4) Relinquishment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5) Self- and other-protection</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6) Help- and information-seeking</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chapter Six presents the model of coping derived from these person-situation transactional categories, and addresses the implications of the study for social work in health care.
CHAPTER SIX
RESEARCH FINDINGS AND CONCLUSIONS

This chapter presents the model of coping derived from classification and analysis of the research data. The implications of this model for the practice of social work are discussed, with particular reference to the field of health care.

The study findings identify a knowledge base for social work in health care from a person-situation paradigm which features coping as a transactional process. The facilitation of coping as an activity of social workers is discussed in the particular context of gay men with AIDS.

A Transactional Process Model of Coping in Gay Men with AIDS

The model is grounded in the subjects' illness-related cognitions and behaviours reported during the course of the research interviews. The model consists of three temporally-based, illness-related phases represented by the six subjects: 1) pre-diagnosis, 2) immediately, post-diagnosis, and 3) current adjustment to illness.

Temporal Situation One: Pre-diagnosis

In the pre-diagnostic situation, the onset and awareness of physical symptoms marks the beginning of "body vigilance." Body vigilance refers to those person-situation transactions that reflect a subject's awareness and appraisal of his physical well-being relative to his current situation.
Body vigilance is a continuous feature in the AIDS illness trajectory. The appraisal and persistence of physical symptoms, as well as efforts to deal with these, disturb the pre-existing continuity of the individual's sense of self-situation cohesion. In order to manage the psychosocial demands posed by physical symptoms, six cognitive and behavioural coping transactions are activated in the pre-diagnostic situation: 1) worry, 2) control of negative affect, 3) revaluation of self-concept, 4) relinquishment, 5) self- and other-protection, and 6) help- and information-seeking.

In the pre-diagnostic situation, subjects were faced with persistent physical symptoms. This threat to well-being was further complicated by the perceived threat of having acquired a disease stigmatized by its social-epidemiological associations with male homosexual behaviour. For these men, AIDS was a metaphor of their homosexuality. Within the social construction of a stigmatized PWA stereotype, subjects sought to socially distance themselves, while at the same time, they began to re-evaluate their self-concept relative to their appraisal of personal risk for AIDS. They worried and tried not to worry. They sought help and information upon which to appraise their situations. The visibility of symptoms and the subjective experience of illness precipitated the beginning of relinquishment, the "letting go" of preconceived conceptions both of self and of situation.

The appraised degree of threat to the continuity of the pre-existing self-in-situation determines the intensity of body vigilant activities in the pre-diagnostic situation as well as in subsequent temporal situations in the illness continuum.
Temporal Situation Two: Immediately Post-diagnosis

A definitive diagnosis of AIDS personified the subjects' existential threat and PWA stereotype, and marked the beginning of an intense preoccupation with their fate. "Fatalistic preoccupation," the period immediately following diagnosis, is characterized by grief for the previous existential self, and by the social validation of a redefined existence through selective disclosure of diagnosis to others.

The immediate response of subjects to the diagnosis of AIDS was grief. Grief, in this phase, is a cognitive and behavioural struggle to assimilate the personal reality of one's impending demise. The subjects' grief was further complicated by stigmatized sexual behaviours and stereotypes that are epidemiologically associated with the disease. Self-selected social distancing and isolation, accompanied by intense cognitive and emotional responses to life/death concerns, were characteristic of this period. Efforts to interpret social relationships and the immediate world sought psychological attunement with others or recognized its antithesis, i.e., the acknowledgement of estrangement and the potential for discrimination and denigration by others.

As subjects achieve conciliation with their situations, fatalistic preoccupation as a distinctive period in the illness continuum ends; however, its features, grief and the seeking of attunement with others, as well as body vigilance continue intermittently in the next temporal phase of the illness.

Grief, in this context, is anticipated as well as actual. Subjects were left to anticipate further threats and losses to their physical and social autonomy.
They also grieved the deaths of friends and acquaintances to AIDS, experiences which further heightened their own sense of mortality.

Fatalistic preoccupation was the most vulnerable period reported by subjects in their experience of the illness. They faced a destined life course, complicated by the task of internalizing a stigmatized stereotype derived from socially constructed features of AIDS as a disease of gay men. Through fatalistic preoccupation, AIDS became integrated into a new definition of self-in-situation. Its outcome was a reconstructed sense of autonomy as an embraced personal value.

Temporal Situation Three: Current Adjustment to Illness

Conciliation, the acceptance of the facts of one’s existential situation, marked the beginning of coping transactions that depicted a reconstructed sense of personal autonomy. "Reconstructed autonomy" refers to cognitions and behaviours that are self-legislating within the physical and social confines that the disease imposes. The ability to be self-legislating is the true measure of personal autonomy. The essence of this process is the ability to make choices within a reconciled and destined life course.

Reconciled with their existential situations, subjects engaged upon a course of action that was dominated by a reconstructed sense of self-in-situation, guided by the principle of autonomy as its core value. Since the demand for body vigilant activities and fatalistic preoccupation continue in the third temporal phase, the challenge to maintain a sense of integrity in relation to one’s
existential and social situations is persistent.

Self-valuation and self- and other-focused autonomous actions were the means to the management of enforced physical and social dependencies imposed by the illness. Self-valuating activities frequently were reported by subjects to take considerable effort, particularly when subjects felt negatively about themselves and their situations. The stigmatization of AIDS as a disease of homosexuality was a perceived threat to the subjects’ self-esteem, managed by physical and social camouflage.

Subjects’ autonomous choices and actions were imbued with regard and care for others as well as for themselves. While the subjects strove to maintain their personal autonomy, they were deeply concerned about any hurt and pain they might cause others, and sought a life purpose which included the desire to help others understand and cope with the illness. Inspired by hope and the will to live, the subjects’ task in the third temporal phase was the management of a destined life course.

The three temporal situations represented by the subjects reflect a cumulative process of coping with AIDS in three sequential phases: 1) body vigilance, 2) fatalistic preoccupation, and 3) reconstructed autonomy. Figure 2 portrays the model of coping derived from classification and analysis of the subjects’ self-reported, illness-related cognitions and behaviours.
Figure 2

A Transactional Process Model of Coping in Gay Men with AIDS

Temporal Phase 1
Body Vigilance
- Worry
- Control of negative affect
- Revaluation of self-concept
- Relinquishment
- Self- and other-protection
- Help- and information-seeking

Temporal Phase 2
Fatalistic Preoccupation
- Attunement with others or estrangement
- Complicated grief

Temporal Phase 3
Reconstructed Autonomy
- Conciliation
- Self-valuation
- Self- and other-focused autonomous actions

Person-Situation Transactional Field

- Person-situation coping transactions
Description of the Model

The model is multi-cyclical. The outside circle portrays the context of coping, i.e., the person-in-situation as a transactional field. A transactional field is characterized by a dynamic process of reciprocal influence between a person and a situation.

Within the person-situation transactional field, the three phases in the illness, 1) body vigilance, 2) fatalistic preoccupation, and 3) reconstructed autonomy, are displayed in three interconnected, sequential, inner circles. Each circle consists of an interrelated set of person-situation coping transactions.

In each temporal phase, a set of cognitive and behavioural coping transactions become activated in order to manage the current person-situational demands posed by the illness. Once activated, these coping transactions continue intermittently, in a cumulative pattern, in varying combinations, intensity, and duration, reflecting the changing conditions, content, and particular features of the person-in-situation configuration. Arrows show the direction of movement in the model.

The result is a kaleidoscopic model of coping set in three, recurring, cumulative phases. In each phase of the illness, cognitive and behavioural coping transactions are directed toward an "adaptive compromise" between a person and a situation as appraised and managed by the individual.

Adaptive Compromise: The Outcome of Coping

The process of adaptive compromise (White, 1974) is the quintessential
feature of coping in this context. The continuum of physical and psychosocial threats, demands, and losses imposed by AIDS diminishes the PWA's capacity for personal autonomy. The coping process is one of adaptive compromise. It is adaptive in that the struggle to manage the loss continuum is imbued with the value of personal autonomy. It is a compromise in that the loss continuum impairs physical and psychosocial capability in a deteriorating process.

Adaptive compromise reflects the relative state of personal autonomy in a person-situation field. Personal autonomy is the seminal value of all persons and is the object of coping. It is, however, culturally defined and is subject to cultural norms and conditions.

Possible Implications of the Model for the Practice of Social Work

This inquiry into coping in gay men with AIDS is set within the professional context of social work in health care. As a specialized field of practice, social work in health care is primarily concerned with the facilitation of coping with illness and health-related issues with individuals, their significant others, and the communities in which they live.

The study examined coping from a person-in-situation perspective, social work's distinctive conceptual unit of attention and practice focus. The study viewed the person-in-situation as a transactional field and focused on the mediation of cognitive appraisal processes as the determinant of what it is that people do to cope with a life-threatening and stigmatized illness.

The study gave significance to the reliability of subjective human
experience in self-reported data, based on the assumption that personal meaning shapes the reality of one's life and informs how one's fate is understood and managed.

The study identified 11 categories of person-situation coping transactions in a temporally-based process model. The implications for the practice of social work derived from this model identify a knowledge base for the facilitation of coping as the practice focus of social workers in health care.

The study findings pose two questions of relevance to social work:

1) What is coping, as derived from social work's person-situation conceptual framework?

2) What are the requirements for the facilitation of coping in the particular context of gay men with AIDS?

**What is Coping?: A Knowledge Base for Social Work in Health Care**

The essential features of coping identified in this study comprise a knowledge base for social workers in health care. Within the broader context of coping with illness, these features of coping are limited by the physical and psychosocial characteristics of AIDS in gay men and by the nature of a small purposive sample.

Nine features of coping identified in the study inform social work's knowledge base:

1) Coping is purposive.

Within the context of threats to life purpose, coping is directed toward the
maintenance of personal autonomy through self-legislated cognitive and behavioural activities. Personal autonomy is the hallmark of coping. Adherence, in principle, to the value of personal autonomy is integral to the facilitation of coping.

2) Coping has an outcome.

In the context of a chronic, debilitating illness, coping is inevitably characterized as a process of adaptive compromise in relation to actual and anticipated losses to physical and psychosocial well-being. As the outcome of coping, adaptive compromise is the measure of the degree of personal autonomy in an illness situation, an outcome that changes through disease progression.

3) Coping is contextual.

In the context of illness, coping is comprised of three dimensions: i) the physical and psychosocial demands of biomedical aspects of the disease, ii) the social and behavioural characteristics of affected populations, and iii) the social constructions of disease as portrayed in the human experience of illness. Each of these contextual dimensions bear heavily upon the nature, scope, and intensity of the person-situation coping transactions identified in this study.

4) Coping is a process.

Coping is a continuum of cognitive and behavioural person-situation transactions that reflect adaptation. The temporally-based features of the 11 person-situation coping transactions identified in this study reflect the phasic nature of coping. Body vigilance, fatalistic preoccupation, and reconstructed autonomy are cumulative phases in an illness-related adaptive process.
5) Coping is a cognitive and behavioural response to threat.

The threat is either actual, anticipated, or both. The severity, imminence, and duration of the threat are factors which determine the qualities of coping efforts.

AIDS poses actual and anticipated threats along two dimensions in the illness continuum. The life-threatening features of the disease pose persistent threats to physical well-being and psychosocial capability, factors which inform the individual's self-concept and autonomy. Second, as a socially stigmatized disease, AIDS poses threats to social esteem and attunement with others.

6) Coping is a function of a person-situation relationship.

From this perspective, coping occurs in a transactional field in which a person and a situation, each with distinctive features, are engaged in a process of reciprocal influence and adaptation over time. This is contrary to the view of coping as a function of an individual's intrapsychic processes, traits or styles.

7) Coping is unique to person and situation.

As an individual human experience, coping is imbedded in systems of personal beliefs and commitments, particularly in culturally-derived valuations of self and others. Beliefs and commitments constitute what a person values, and reflect the substance and uniqueness of personhood. The value of personal autonomy is maintainable only to the extent that an individual is able to adhere to his or her beliefs and commitments. In illness some beliefs and commitments may no longer serve a coping function and, therefore, are relinquished.
8) Person-situation coping transactions are mediated by cognitive appraisal processes.

Coping is precipitated by an event, or series of events, appraised by the person as threatening the pre-existing integrity and continuity of the person-in-situation. Cognitive appraisals of the meaning of the event, as well as cognitive appraisals of personal and situational resources to deal with the event, determine the distinctive features of coping transactions in any given person-in-situation.

9) Coping is learning.

A redefined existence requires the acquisition of knowledge and skill to manage the new demands inherent in person-situation transactions. For all subjects, the illness placed unprecedented physical and psychosocial demands upon their pre-existing capacities and resources. Thus to cope, in unprecedented day-to-day terms, inevitably means to learn.

The Facilitation of Coping: The Social Work Task

The tasks of the social worker in the facilitation of coping in gay men with AIDS are implicit within the 11 person-situation coping transactions identified in the study.

1) Worry

Worry is the mirror of what a person values and of what is at stake in any given person-situation transaction. What a person worries about is the subjective measure of what is problematic to that individual's coping. The content and scope of a person's worry reveals the anticipated threats to the
intactness and integrity of the person-in-situation.

Worry reflects the value of personal autonomy. Attunement to an individual's worry is the key to being present to that person. The vulnerabilities to personal autonomy portrayed through worry define the parameters for the assessment of coping and establish the priorities for its facilitation.

2) Control of Negative Affect

The control of negative affect is a persistent demand upon a person who is coping with a life-threatening illness. Control of negative affect is a consequence of worry that helps to contain person-situation intactness and the maintenance of psychosocial functioning. While the social worker may need to facilitate the expression of negative affect as a cathartic activity, its containment is essential to the maintenance of hope and aspiration to future goals.

The epitome of control of negative affect is denial. In the context of a life-threatening illness, both denial of fact of illness and denial of implication of illness offer psychological respite from life-death concerns. Denial is dysfunctional to coping only when it prohibits problem-solving and help- and information-seeking. To be unable or unwilling to engage in illness-related problem-solving indicates a need for help and supportive attunement with others.

3) Revaluation of Self-concept

Revaluations of self-concept are derived from an individual's ongoing appraisals of self-in-situation. At any one point in time in the illness trajectory, the person's self-concept reflects the personal meaning of the illness. Among gay men with AIDS, revaluations of self-concept encompass both the life-threatening
and stigmatizing qualities of the disease. Combined, these components of the illness create a metaphorical equation between homosexuality and death that, if internalized, taxes one's self-esteem.

The social work task in this category is twofold: 1) at the level of the individual, to address the deleterious effects of AIDS upon an individual's self-worth, and 2) to systematically address the social constructions of the disease as reflected in discriminatory social policies and practices.

4) Relinquishment

The losses associated with AIDS are multiple, progressive, past, and anticipated. In the situation of a life-threatening illness, loss precipitates both grief and worry. The person grieves the loss of a former identity and worries about how to maintain personal autonomy as a consequence of loss.

There are two types of loss associated with illness: 1) those that are imposed by the physical and psychosocial realities of the disease, and 2) those that are self-selected. Relinquishments that are self-selected reflect shifts in what is now important to the person and assist in the reconstruction of personal autonomy.

Beyond demonstration of empathic attunement with the person's relinquishments and associated grief, the task of the social worker is to address the question of "what is important to this person?" and focus on the elements of personal autonomy that are retained or that can be reconstructed.

5) Self- and Other-protection

Self- and other-protective activities are attempts to thwart the physical and
psychosocial assaults imposed by illness. The principal mechanism for self- and other-protection among gay men with AIDS is camouflage. To camouflage means to devise physical and social ways to disguise or evade the negative psychological and social ramifications of the illness.

Selective disclosure of diagnosis and the withholding of personal illness information from others are elements of camouflage that serve protective functions in social relationships. Questions of disclosure: to whom?, what?, when?, how?, under what circumstances?, and with what repercussions?, are salient to the facilitation of coping in this category.

6) Help- and Information-seeking

Illness creates enforced dependencies on others for help and information. Help- and information-seeking behaviours occur in situations of self-appraised personal vulnerability, enmeshing the PWA in power-imbalanced relationships with service providers and sources of information and support.

The dictum that knowledge is power is requisite to the facilitation of coping. The knowledge base of AIDS is multidisciplinary and multiservice, casting the social worker in social brokerage and advocacy roles associated with accessing help and information.

7) Attunement with Others or Estrangement

In the context of AIDS, attunement with others or its antithesis, estrangement, are precipitated by the disclosure of HIV status. The endemic nature of AIDS among men who have sex with men further exacerbates the stigmatization of homosexuality and carries with it the potential for estrangement
from others. Moral constructions of AIDS and their personification impair coping by imposing oppressive conditions upon an autonomous adaptive compromise. A prerequisite to the capacity for attunement with a PWA requires that the social worker address his or her own internalized moral constructions of illness and sexuality.

The elements of attunement are the capacity to listen, unconditional positive regard, and the ability to accurately reflect the PWA’s perceived personal-situational reality. There is, as a corollary task, the need to address the social policy and interpersonal contexts that impose restrictions to attunement and support from others.

8) Complicated Grief

Grief is a process of cognitive and behavioural reactions to perceived loss that are culturally expressed through mourning. A person with a life-threatening illness grieves the anticipated loss of one’s self and one’s world. Among gay men with AIDS, this grief is further complicated by the loss of partners, friends, and acquaintances to the disease. The pervasiveness of physical and psychosocial loss among gay men with AIDS complicates the grief process in that it does not allow for restitution. As such, the PWA experiences acute episodes of grief in what is a chronic grief continuum. Further, in some instances, oppressive social situations restrict expressions of mourning and impede the grief process.

There is no clear map to the facilitation of coping with grief in this context. However, to listen to another in grief is its most powerful therapeutic tool. To be heard marks the beginning of healing and transformation.
9) Conciliation

In the context of a life-threatening illness, conciliation is the process whereby the person incorporates a redefined existence into the self. Among PWAs this process includes assimilation of a stigmatized identity. Conciliation reflects the level of one’s acceptance or resignation to one’s self-in-situation. The goal of conciliation is a reconstructed sense of personal integrity in attunement with others and the natural order.

In the facilitation of coping, conciliation raises the question of "what is resolvable?" and directs the social worker to where the PWA wants conciliatory problem-solving to occur. The outcome of conciliation is a reconstructed sense of personal autonomy which reflects the dimensions of adaptive compromise imposed by the illness.

10) Self-valuation

The valuation of self is integral to the pursuit of life goals. Illness is invariably an assault to self-image and curtails the individual’s ability to engage in activities that enhance the valuation of self.

Among gay men with AIDS, the valuation of self is complicated by the propensity for self-denigration for being gay and/or for having contracted the disease. The subjective attribution of illness contains the indicators of self-blame which impede the valuation of self.

Affirming the self-worth of the person and supporting activities that are self-valuing are integral to the facilitation of coping.
11) Self- and Other-focused Autonomous Actions

The maintenance and maximization of personal autonomy is the guiding principle in the facilitation of coping. Personal autonomy is the preeminent value in the process of adaptive compromise. The ethic of personal autonomy includes regard for others which finds its expression in service to others, particularly those of like kind.

In their reconstruction of personal autonomy the men of the study considered their regard for others in their decisions, actions, and life plans. To consider others enables the self. Personal autonomy, therefore, is not exclusive of others, but is a clear expression of "I am not alone in this."

To facilitate coping means to build interpersonal alliances that enable people to understand, help, and support each other in ways that respect the life course and dignity of personhood.

Possible Implications of the Study for Further Research

The implications of the study for further research are interrelated and two-fold: 1) the applicability of the model to the practice of social work in the present context of AIDS and other life-threatening illnesses, and 2) the value attached to personal autonomy in coping with a situation that imposes a compromise which threatens, if not diminishes, personal autonomy.

Applicability of the Model to the Practice of Social Work

The study of coping is integral to the practice of social work. Since an
objective of practice is to facilitate coping with life demands and conditions, social work requires systematic understanding of the particular contexts in which both coping and practice occur.

This study examined coping in the context of gay men with AIDS from a transactional theory perspective that is congruent with social work's historic practice focus on the person-in-situation. Further study is required to examine the representation of the model and its processes in the present context of coping among gay men with AIDS, as well as with other infected populations, and to consider the broad range of diversities both within and across infected populations as these impact on coping with the disease. Comparative studies are required to identify the unique features of coping with AIDS related to person and situational characteristics, process, temporal and socio-cultural contexts, and in relation to other life-threatening illnesses. These variables form a complex interplay which informs the knowledge base for social work in health care.

This study is relevant to two types of contemporary social work practice: 1) case management approaches, articulated in forms of community care (e.g., Challis and Davies, 1986), and 2) radical critique perspectives (Dominelli, 1996), such as anti-racist social work (Dominelli, 1988; Ahmed, 1990), empowerment (Kleffer, 1984), feminist social work (Marchant and Wearing, 1986; Hanmer and Statham, 1988; Domenelli and McLeod, 1989), Marxist social work (Corrigan and Leonard, 1978), and structural social work (Goldberg Wood and Middleman, 1989; Moreau, 1979). Radical critique perspectives share, in common, a recognition of the social divisions and structural inequalities among people that
are oppressive of personal autonomy, whereas case management approaches seek to impose a culturally prescribed view of coping that may curtail autonomous actions and thereby diminish participatory competence in social life (Dominelli, 1996; Kieffer, 1984).

The men of this study are testimony to the value of personal autonomy in managing a life-threatening and stigmatized disease caught in the metaphorical trappings of "homosexuality equals death" (Sontag, 1988).

**The Value of Personal Autonomy**

Social work promotes the value of personal autonomy in its practice through the principle of self-determination. In this study personal autonomy was the measure of the subjects' integrity in coping with AIDS. Their existence was theirs to be defined, willed to live, and compromised to live in the context of available resources and systems of beliefs and commitments. Adherence to the value of personal autonomy in the facilitation of coping requires systematic study of factors which promote and impede personal autonomy in situations where this value is threatened. Given that personal autonomy is a seminal value in coping with stressful life conditions, further research needs to attend to its determinants, operationalization, measurement, and facilitation.
REFERENCES


APPENDIX A

AIDS Clinical Research Center
University of California, San Francisco

Dennis J. Haubrich

INTERVIEW SCHEDULE

1. Discovery and Diagnosis

   Preamble: I would like to begin the interview by asking you some questions about how you first discovered and were eventually told that you had AIDS or an AIDS-related illness.

   1.1. Would you tell me what symptoms you first developed that indicated to you there was something wrong with your health?

   1.2. When did you first notice these symptoms?

   1.3. What was your reaction to these symptoms?

      Probe: How bothersome were they?

   1.4. What did you think was wrong with you?

      Probe: Did it ever occur to you at this time that you might have AIDS?

   1.5. When did you first see a doctor about these symptoms?

   1.6. Did you talk to anyone about your symptoms before you saw your doctor?

   1.7. Would you share with me, in as much detail as you are able to remember, how you eventually found out that you had AIDS?

      Probe: What tests and procedures did you undergo?

      Who told you?

      What were you told?

      When did this happen?
1.8. At the time of your diagnosis, what did being told that you had AIDS mean to you?

Preamble: I would like to learn as much as I can about what this time, immediately following the diagnosis, was like for you?

1.9. How did being told that you have AIDS make you feel?

1.10. How did you deal with this information?

Probe: What did you do?

1.11. How did you handle your feelings at this time?

1.12. Was there anything you did at this time that was helpful to you?

1.13. How do you feel about your situation now, compared to how you felt at the time of your diagnosis?

1.14. Do you feel that you have accepted your illness?

2. Medical Information

2.1. At the time of your diagnosis, what were you told about the kinds of medical treatment that were available to you?

2.2. How did you view this information?

2.3. What advice were you given?

2.4. What did you decide to do?

2.5. What have you done to find out more about medical treatment?

2.6. Have you looked into other ways in which to deal with your illness?

Probe: What were they?

What have you done?
3. Medical Treatment

3.1. What medical treatments have you undergone since your diagnosis?

3.2. How is your illness now being managed medically?

(If no treatment has been undertaken, proceed to question 7.)

Preamble: I would like to learn as much as I can about what your medical treatments have been like for you.

3.3. Would you tell me about any problems you've had with your medical treatments?

Probe: What problems have you had with:

- making arrangements for your treatments?
- getting to and from the hospital?
- undergoing medical treatment?
- medical staff?
- side effects of treatment?

3.4. How have you dealt with each of these?

3.5. Was there anything that was helpful to you in dealing with these problems?

3.6. Have your medical treatments made you feel any better?

3.7. How have you found the attitudes of medical staff toward you?

3.8. What has it been like for you to be a patient?

3.9. Are there any professional people involved in your care who've been especially helpful to you?

Probe: How have they been helpful to you?

3.10. Are there ways in which you have been able to influence the course of your illness?

Probe: What have you done?
3.11. What other symptoms or illnesses have you had since you were first diagnosed?

3.12. What impact have these had on you?

3.13. How have you dealt with these?

3.14. What ongoing symptoms or physical problems do you have as a result of your illness?

3.15. How bothersome are these symptoms?

3.16. How do you deal with them?

3.17. Have you had to be hospitalized as a result of your illness?

(If no, go to question 3.23.)

3.18. What was it like for you to be in the hospital?

3.19. How did you view your situation at this time?

3.20. What problems, if any, did you have while you were in the hospital?

3.21. How did you deal with these problems?

3.22. How were others helpful to you at this time?

3.23. Since you were first diagnosed, have you had times when you've felt well?

3.24. Do you deal with things differently when you're feeling better?

4. Lifestyle

4.1. What changes have occurred in your lifestyle since you were first diagnosed?

4.2. What are the things you no longer do as a result of your illness?

4.3. What activities have you continued to do?

4.4. Have you started anything new?
4.5. In what areas of your daily life would you say that you've had the most difficulty?

4.6. How have you tried to manage these difficulties?

5. Relationships with Others

Preamble: I would like to learn as much as I can about how you see your illness as having affected your relationships with others.

5.1. Who have you told that you have AIDS?

5.2. What concerns did you have about telling them?

5.3. What kinds of reactions have you had from them?

5.4. How did you deal with their reactions?

5.5. Is there anyone you haven't told whom you feel you need or want to tell?

5.6. What concerns do you have about doing this?

5.7. How important is your family in your life?

5.8. In what ways are they important?

5.9. Would you share with me how you see your relationship with your family as having changed since your diagnosis?

5.10. What concerns, if any, do you have about your relationship with your family as a result of your illness?

5.11. How have you dealt with these concerns?

5.12. How important are friends in your life?

5.13. In what ways are they important?

5.14. Would you share with me how you see your relationships with your friends as having changed since your diagnosis?

5.15. What concerns, if any, do you have about your relationships with your friends as a result of your illness?
5.16. How have you dealt with these concerns?

5.17. Who are the people who have become important to you since your diagnosis?

5.18. In what ways are they important?

5.19. How have they been helpful to you?

5.20. Have you had any special experiences in talking to others about your illness?

5.21. What have you learned from these experiences?

6. Self

6.1. What would you say was important in your life prior to your diagnosis?

6.2. Has this changed since your diagnosis?

6.3. Is there anything from your past experience that has been helpful to you in dealing with your illness?

6.4. Do you have any spiritual or religious beliefs that have been helpful to you in dealing with your illness?

6.5. In what ways has your illness changed the way you think about yourself?

6.6. How do you see yourself as different from other people with AIDS?

6.7. What are the ways in which your illness preoccupies you?

Probe: What worries you most about your illness?

6.8. How do you deal with your feelings at these times?

6.9. Can you think of a time since your diagnosis when things just got to be too much for you?

Probe: What happened?

What were your feelings at this time?

What did you do?
6.10. Was there anything you did that you found helpful at this time?

6.11. What impact have changes in your body-image had upon you?

6.12. How have you dealt with these changes?

6.13. What are the things you do to forget about your illness?

    Probe: Is there anything you do to make yourself feel better?

6.14. What special meaning does your illness have for you?

6.15. In your heart or mind do you feel you may be able to overcome your illness?

6.16. What would you say has helped you the most in dealing with your illness?

6.17. If you were to recommend ways to help other people with AIDS deal with their illness, what would you recommend?

7. **Questions to Validate the Purpose of the Interview**

    7.1. Is there anything that you would like to add to this interview, something that my questions haven't covered?

    7.2. Are there any comments that you would like to make about the interview experience?
August 28, 1984

Mr. Dennis Haubrich
P.O. Box 14882
San Francisco, CA  94114

Dear Mr. Haubrich:

I am pleased to advise you of your appointment as Research Associate, without salary, in the Department of Dermatology, School of Medicine, for the period June 9, 1984 through September 1, 1985.

I speak for the faculty as well as myself in welcoming you to the University of California, and we look forward to what I hope will be a happy and mutually rewarding association.

Sincerely,

[Signature]

Senior Vice Chancellor, Academic Affairs

cc: Associate Dean Robert Crede
    Doctor William Epstein
REQUEST FOR VOLUNTARY PARTICIPANTS

Your participation is requested in a study of the psychosocial effects of AIDS and AIDS-related illnesses. The study is part of my doctoral dissertation in social work at the University of Toronto, and is specifically designed to contribute to our understanding of illness-related problems and needs among gay men with AIDS. The particular focus of the study is on the overall impact of the illness on the quality and meaning of your life as you perceive and experience it. Thus the study is entirely dependent on your contribution, and in return I would want to make your participation in the study as rewarding and meaningful as possible.

In the interest of obtaining as complete and as accurate an account of your experience as possible, your involvement in the study would consist of at least two or more tape-recorded interviews, to be held at a time and place of your convenience, each interview lasting about an hour and a half. There will be set questions; however the interviews will largely consist of talking about your experiences: the specific issues and difficulties that you have had to face, and how you have dealt with them; recurrent and enduring problems or disabilities; how others have been helpful or not helpful to you; the meaning of the illness in your life, and your view of your life situation.

Your participation in the study is entirely voluntary and you may decline to answer any question or questions or, indeed, may withdraw entirely from the study at any time. The information you provide is confidential; to be used for my dissertation research only, and to be published in a form in which your identity as an individual will never be known.

As the interviewer and researcher my interest in doing the study is to contribute to our understanding of the problems and needs of gay men with AIDS and AIDS-related illnesses. At any time during the study I will be open to any questions or suggestions that you might have, and am interested in making your participation in the study as convenient and as positive for you as I can.
If you would like to meet or talk to me about participating in the study, you may contact me at 621-1408 or 626-1921. Should you decide to participate, a written agreement of the conditions of the study will be required to insure your rights and privacy as an individual.

Yours sincerely,

Dennis J. Haubrich, M.S.W.
Research Associate
CONSENT TO BE A RESEARCH SUBJECT

Dennis J. Haubrich, a doctoral student in social work at the University of Toronto, is conducting a study of the psychosocial effects of AIDS and AIDS-related illnesses on gay men who have been diagnosed and treated for the disease. The purpose of the study is to learn more about the personal impact of the disease and how I am coping with it. Because of this I have been invited to be a participant in this study.

If I agree to participate, I will be interviewed two or more times as mutually agreed. Each interview will last about an hour and a half, and will be held at a place and time of my convenience. The interview questions will concern my personal background, my own experience in coping with the illness, and how others have been helpful or not been helpful to me. Given the personal nature of the study, there is a possibility that some of the questions may upset me or make me feel uncomfortable; however, I am free to decline to answer any question or questions at any time during the study.

If I agree, the interviews will be tape-recorded and transcribed verbatim. After transcription the tape-recordings will be erased. In order to protect my confidentiality as far as is possible under the law, the interviewer will delete all identifying personal information from the transcripts. I will be given a copy of the transcripts to keep.

There will be no direct benefit to me from participating in the study. The information gained from the study will be used to develop ways to help and support others in coping with the disease.

I have talked with Dennis J. Haubrich about this study and he has answered all my questions. If I have any further questions or concerns about my participation in the study I may call him at 621-1408 or 626-1921.

I have been given a copy of this consent form and the Experimental Subject's Bill of Rights to keep.
PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to refuse or to withdraw at any point in this study without jeopardy to my medical care. If I wish to participate I should sign this form.

_________________________   _________________________
Date                          Subject Signature

05/06/85  UCSF CHR APPROVAL NUMBER: 246210-01*
APPENDIX E

AIDS Clinical Research Center
University of California, San Francisco

Dennis J. Haubrich

BIOGRAPHICAL INFORMATION

Name: ____________________________

Address: ____________________________ Telephone: ____________________________

Date of birth: ____________________________ Place: ____________________________

Occupation: ____________________________ Education: ____________________________

Income: ____________________________ Source: ____________________________

Ethnic background: ______ Religion: ____________________________

Number of years living in San Francisco: ______

Family constellation: ____________________________

Parents’ residence: ____________________________
EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1. To be told what the study is trying to find out.
2. To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice.
3. To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes.
4. To be told if I can expect any benefit from participating, and, if so, what the benefit might be.
5. To be told the other choices I have and how they may be better or worse than being in the study.
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.
7. To be told what sort of medical treatment is available if any complications arise.
8. To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.
9. To receive a copy of the signed and dated consent form.
10. To be free of pressure when considering whether I wish to agree to be in the study.
If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 666-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94134.