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LIVING IN THE HIV SPECTRUM: LIFE STORIES AND ILLNESS
NARRATIVES OF GAY MEN

by

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Submitted in partial fulfillment of the requirements
for the Degree of Doctor of Philosophy

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GRADUATE STUDIES

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*We also certify that written approval has been obtained for any proprietary material contained therein.
This dissertation investigates the illness experience of gay men living in the HIV spectrum (n=20). A reflexive approach serves as context for presentation of life story narratives. Emphasis is placed on psychocultural themes and stylistic orientations to living with HIV infection. Cultural values are identified in an exploration of the powerful influence of culture on the meaning of illness experience. Theoretical concepts of liminality (period of transition between states of being, e.g. neither sick nor well) and communitas (community of individuals without place attachment) are examined as a framework within which illness experience is better understood, particularly with regard to life events and social support respectively.

Two clusters of life events affected perceived quality of life, (defined as self-evaluation of everyday life experience): recurrent deaths of friends due to HIV-related illness (n=10), and recurrent exacerbations or complications of HIV infection (n=8). In one individual experiencing a cascade of both types of life events, there was a perception that a part of one’s personal history had lost its meaning resulting in a disturbance of the temporal orientation of the self.

Unexpectedly, Twelve-Step programs were a source of communitas for some participants in this study (n=5). Involvement in these groups influenced the content and structure of narratives which make up the life
story. This involvement, along with limiting talk about HIV in social interactions of everyday life (n=7) is presented as evidence of persons' attempts to regulate the social course of their illness.

Recurrent themes were identified among the participants of this sample, such as overcoming obstacles and enduring hardships. Associated with this was a stylistic orientation of being a survivor (n=15). This theme and stylistic orientation were extended to experience with HIV infection implying survival and endurance in this present situation. Core American (United States) cultural values of self-reliance and achievement are central to the meaning of this and other themes. These and other core American cultural values are shown to be implicit in the meaning attributed to illness experience and judgments of quality of life.
HIV is not living sometimes. I lost most of my friends out west real quick, New York, real quick. So very few friends left alive there, and then when it started hitting here... I have no sense of history anymore. I pretended for a long time, like an answering machine. You pretend they call you back; get back to you, leave a message. That just doesn't happen. They don't call back so you can't say 'Remember when we did this, went there?', 'Remember so and so, so and so', well there's no so and so to remember. So that's just erased, gone.

— Jerry

If something like this hadn't happened to me, I'm not so sure, I'd look at certain things the way I do nowadays. To be really honest with you, sometimes that kinda scares me. To have such a disregard for some of the simple things in life that I once had really does bother me. That's why I really appreciate my sense of well being, my ability to look beyond just the negative part of being HIV positive. You're thrown into it, and there's no turning back. I guess, because my time is limited, I'm thrown into more of an appreciation for something, because it may not be there tomorrow, or I may not be healthy enough tomorrow to be able to appreciate a walk through the park, or my dog, or whatever the case may be.

— Glen

You know, it's hard to make decisions. It's hard to make long term plans, So I end up living more moment to moment, more than anything. When you have this thing in here, it's like a time bomb in your body ticking, ticking, and you just never know when it's gonna go off.

— Jerry
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CHAPTER ONE
INTRODUCTION

This dissertation offers an intimate glimpse into the everyday lives of Euro-American gay men in the HIV spectrum, in the face of a disease which is considered a death sentence. Current illness experience is placed in the context of individuals' personal histories. Through an integration of ethnographic and life story methods, this psychocultural and meaning-centered approach is firmly grounded in the context of a life that has a past and future as well as a present.

Medical Anthropology and HIV/AIDS

An experience based understanding of illness (Engel, 1977; Kleinman, 1980) focusing on culturally relevant meanings (Kleinman, Eisenberg and Good, 1978; Young, 1982) is fundamental to this approach, where attention to the interpretive and meaning-centered aspects of illness are essential (Good, 1977; Good and Good, 1982). The importance of a meaning-centered approach is evident in the anthropological contributions to the study of chronic illnesses, whether primarily psychological in nature, e.g. schizophrenia (Jenkins, 1988a, 1988b; 1991, Corin, 1990) and depression (Kleinman, 1980; Good and Good, 1981; Kleinman and Kleinman, 1991), or physiological, e.g. end-stage renal failure (Alexander; 1981), hypertension (Blumhagen, 1982), cystic fibrosis (Rittenberg; 1985) cancer (Csordas, 1989; Gordon, 1990) and HIV/AIDS (Sandstrom, 1990; Lang, 1991a; Farmer, 1992).
Anthropologists have contributed to the cross-cultural study of HIV infection and AIDS across the globe. An abbreviated overview includes: in Uganda (McGrath et al, 1992, 1993; Rwabukwali et al, 1994), Zaire (Schoepf, 1992), Rwanda (Feldman, 1990), Nigeria (Orubuloye, 1994a, 1994b), Brazil (Parker, 1987, 1992), Mexico, (Carrier and Magaña, 1991), Haiti (Farmer, 1990, 1992), China (Gil, 1994) and Belgium (Vincke et al, 1993). Work in the U.S. has focused on particular minority groups, whether defined by ethnicity (Singer, 1992); e.g. Hispanic-American (Singer, 1990), Filipino-American (Manalansan, 1991) Navajo (Price, 1991); or by other defining characteristics, e.g. intravenous drug abuse (Clatts, 1990; Koester, 1994), women (Worth, 1990; Sobo, 1993), gay men (Bolton, 1992; Lang, 1990, 1991).

Much of this research has utilized an ethnographic approach with emphasis on culturally mediated behavior and has added to our knowledge of sexual behavior (Carrier and Magaña, 1991; McGrath et al, 1992), intravenous drug use (Kane and Mason, 1992; Koester, 1994; Clatts, 1990) and other issues related to HIV prevention and risk (Herdt and Boxer, 1991). Much of anthropological research relating to HIV infection and AIDS has focused on prevention and risk, however there is a growing literature relating to the experiences of AIDS in sufferers and families, and local communities.

McGrath et al (1993) investigated the impact of AIDS on sufferers and social networks in the context of the urban Ugandan family. Farmer (1990, 1991, 1992) has provided extensive material about the experience of AIDS in Haiti both on a community and individual level. Farmer and

While some progress towards identification of risk behaviors, and prevention has been made, HIV continues to spread and anthropologists and others continue to address this much needed area of research. Research contributing to a clearer understanding of the experience of illness of those already living in the HIV spectrum is equally important in identifying and addressing issues surrounding this often stigmatized population. Gay men continue to comprise a large proportion of those people living in the HIV spectrum in the United States\textsuperscript{1}. Survival of persons infected with the HIV virus can span a decade or more. By gaining an understanding of how the men in this study determine their quality of life over the course of this chronic and fatal illness, we may gain an understanding of what makes a “good life” good from their own perspective and how this good life may be threatened by the experience of illness during HIV infection, or maintained despite it. In so doing, we

\textsuperscript{1} As of 1993, 55% of persons with AIDS in the United States and 70% of persons with AIDS in Ohio, are classed as gay or bisexual in terms of transmission mode (Citizens' Committee on AIDS/HIV, 1994). In the clinic where this research was done, statistics from 1988, 1989 and the first two quarters of 1990, used in an annual report, show a relatively stable risk behavior profile of men being treated for HIV infection, with men who identify as having gay or bisexual relations as a risk behavior equalling 71.4%, 67.6% and 64% for each year respectively. Despite this apparent decline in percentage of men identifying as gay or bisexual, this risk behavior category remains descriptive of just under 2/3 of the total population seen at this clinic.
gain valuable insight regarding how to best address the needs of this group of people and also gain insight into the meaning of quality of life as a personally meaningful valuation of the experiences of everyday life. This dissertation will help to address this important topic of inquiry, adding to this presently limited body of literature, while also contributing to the literature pertaining to meaning-centered studies of chronic illness by addressing the applicability of the theoretical concepts of liminality and communitas (see pp. 10–14) to the experience of illness.

**Dissertation Overview**

In the following chapters, I will present a contextualized and ethnographic understanding of the lives and experiences of persons being treated for HIV infection. Subjective understandings and meanings of their experiences of HIV infection and treatment will be placed in a framework of narratives about everyday life. Variation in the sample will be discussed to present the broad range of impacts of HIV diagnosis on individuals who then live their lives in the face of a disease which is commonly considered a death sentence of uncertain duration. Investigation will focus on the meaning of experience in terms of a subjective understanding of the present in the context of an individual's description of his life course through life stories.

I will address the impact of HIV illness experience on the quality of everyday life in terms of individually and culturally relevant meanings of HIV/AIDS. This approach serves to emphasize the meaning of HIV/AIDS in the social, cultural and historical contexts (Treichler 1992).
(By 'historical', I refer primarily to the personal history of the individual, which may include subjectively relevant roles of the history of the community and the socio-political environment inhabited by the individual.) Specifically, this study will examine the narration of experience of HIV infection in terms of the life story. Perceived meaning of the individual's present life situation will be framed in the context of his personal history. In narrating the life story, people create themes which explain who they are individually and how they behave socially (Kaufman 1986:25). In this way the life story serves as both substance and context in understanding the experience of illness. Therefore, life stories serve as an important component of a meaning centered approach to chronic illness in general (Kleinman 1988b), and HIV infection in particular (Clatts, 1989, Levine, 1992).

The events and circumstances in the lives of persons with chronic illness are part of a personal narrative which places the illness experience in the context of the life story (Kleinman 1988b). Kleinman argues that for the elderly, life stories are a construction of an account of a life that symbolizes a bereavement for a life coming to an end. Like the elderly, persons with HIV infection are faced with death and also have reason to review their lives as something soon to be lost. For this reason, life stories are a valuable component of ethnographic research on the experience of HIV illness.

The goal of this dissertation is to gain and convey a contextualized and ethnographic understanding of the lives and experiences of persons being treated for HIV infection in terms of the subjective understanding
and meaning of the experiences of HIV infection and treatment for the men in this sample. I will focus on the meaning of their experience in terms of a subjective understanding of the present in the context of the individual’s description of his life through stories of his past.

I will discuss the experience of illness during treatment for HIV infection in terms of a theoretical framework of liminality and communitas (see pages 10–14).

Preliminary Studies

Four patients with HIV infection were selected from an HIV/AIDS clinic of a teaching hospital in a large U.S. metropolitan area for a pilot study exploring whether there are events during the course of HIV infection that serve as critical or crisis points that threaten perceptions of quality of life. The pilot study also examined how these critical events impact on health maintenance and social behaviors, including medication and treatment adherence. Finally, this pilot project sought to learn whether nurses and physicians at the HIV/AIDS clinic, or the clinic environment itself are an important source of social support during times when patients’ perceived quality of life was poor.

The study was conducted between November, 1991 and June, 1992. Patients were referred to this study by the clinic nurse based on perceived willingness to participate. The first four persons who were willing to participate were accepted into the study. These persons were interviewed in their homes during two visits lasting one to two hours each and
during which tape recorded life stories, which included perceptions of quality of life, and their experience with the clinic were obtained.

Two of the four persons died prior to follow-up interviews (and a third, shortly after our last interview). Two were interviewed again four to six months after initial contact, to obtain additional information about the life story and determine any changes in attitudes and recollections from those voiced in the first interview.

Interviews were transcribed by the interviewer. Transcriptions were analyzed for themes - conceptual expressions of meanings which are used to organize and explain the life story (Kaufman, 1986) and narrative retelling of events. Themes relate to such things as life being a struggle, which characterized much of the life story of one Puerto Rican woman in the sample.

Preliminary results of these analyses show that both liminality and communitas were expressed as themes when subjects talked about life after learning of their HIV infection, and over the course of illness. Liminality was expressed as feeling apart from previous social relationships and feelings of extended preparation for death.

Themes of self identity were tied to patients' perceptions of their own reactions to HIV infection. One man referred to his life as a constant struggle with HIV as just one more obstacle. The woman previously mentioned described herself as a survivor all her life and explained her decisions and longevity in terms of being a survivor.

All subjects were able to identify their own perceptions of quality of life as a basis upon which they lived their lives and made decisions. One
woman felt that experiences of communitas in locating and finally attending group meetings of women with HIV was instrumental in improving her perceptions of quality of life. She did not feel communitas at the clinic, rather she located a support group through word of mouth which served to provide her with communitas. A gay man attending the clinic explained much of his social support as coming from the clinic, in terms of the close personal friendships he developed with some of the staff members and other patients. He related these relationships as important to his determination of the quality of his life.

Due to the very small sample size, results from this pilot project cannot be generalized. However, the data suggests the following: 1) the clinic that the four subjects attended served as social support and possibly as a source of communitas, at least to some patients, 2) the presence of social support was linked to perceptions of quality of life, 3) concepts of self identified from the life story affected experience of illness, 4) feelings of liminality were present during treatment for HIV infection, and 5) women and gay men had differing experiences of illness with HIV infection and treatment.

Selected Variables

This preliminary research has shown that the perception of quality of life can act as a basis upon which everyday life decisions are made, and serves as a way in which people evaluate experience in terms of meaning as well as its positive or negative value. Preliminary research has also shown that social support and life events are important variables linked
to how quality of life is perceived. Liminality was shown to be an important effect of certain life events, negatively affecting the perception of quality of life. Communitas was shown to be one important source of social support having a positive effect on perception of quality of life. These selected variables of inquiry will be integrated into the presentation and discussion of the data, and conclusions in each of these chapters, as follows:

1) Life Events - experiences involving change in an activity, role, person or idea which would generally result in strong positive or negative emotions (Brown and Harris 1978:67). I was particularly interested in whether there are particular life events which trigger feelings of liminality in persons with HIV.

2) Social Support - perception of the availability of other persons to provide help and assistance during times of perceived need (Dressler 1991:19). I paid special attention to understanding where, when and how communitas might act as a specific form of social support to relieve negative effects of liminality and

3) Perceptions of Quality of Life - the subjective determination of what makes life a positively or negatively valued experience. My primary interest has been to understand how perceptions of quality of life are influenced by life events, social support and the
experiences of liminality and communitas for persons living with HIV infection.

**Liminality**

In the following work, I will discuss the applicability of a theoretical framework of liminality and communitas, as defined by Victor Turner (1969:94-130), as an aid to understanding the experience of illness during treatment for HIV infection. This framework will not be imposed on the data. Rather, I will identify when and if such a framework might apply in the present study. The following discussion will clarify the concepts of liminality and communitas.

Liminal persons are:

between the positions assigned and arranged by law, custom, convention and ceremonial. As such their ambiguous and indeterminate attributes are expressed by a variety of symbols in the many societies that ritualize social and cultural transitions” (Turner, 1969:95).

Persons in a marginal status deviate in that their positions, though ambiguous, are assigned and arranged by any or all of the factors Turner suggests. Liminal persons are temporarily without status. Turner attributes the concept of “the liminal phase” to Van Gennep’s (1960) definition of *rites de passage*, and emphasizes the contrast between “transition” and “state”. He reiterates Van Gennep’s description of rites of passage as “marked by three phases: separation, margin (or *limen*, signifying “threshold” in Latin), and aggregation.” (Turner, 1969:94) and clarifies this third phase in this and other work as “reaggregation” (1974:504-5).
The liminal period is the threshold between states. By "states", Turner is referring to status or social role which the individual occupies in the community. As example, he offers the Ndembu puberty rites which mark the liminal period, the threshold, between the status of child and adult. Liminality is contrasted to marginalization, which refers to those who are simultaneously part of two or more distinct social groups (e.g. "migrant foreigners... persons of mixed ethnic origin" as well as gay men in the US). What sets liminars (those in a liminal situation) apart from marginals is that liminars are assured of reaggregation. Marginals remain in between; part of the larger group, and part of the marginal group characteristically deviating from the greater cultural normative characteristics.

Several authors have used the concept of liminality to study chronic illness in differently abled, chronically ill and aging persons (Murphy et al, 1988, Mwaria, 1990, Shield, 1988), and in HIV (Sandstrom, 1990). In reading these texts, however, it becomes apparent that the definitions of liminality and marginalization are used interchangeably unlike the definitions proposed by Turner (1967, 1969, 1974).

Both liminality and marginalization are important aspects of the course of chronic illness, and HIV infection in particular (Kowalewski, 1988). Murphy et al (1988) discuss the rehabilitation of individuals with impaired arm or leg movement, e.g. paraplegia. They acknowledge the threefold aspects of the liminal period (separation, margin and reaggregation), yet only clearly define the separation aspect of their sample. This separation is the hospitalization in acute and rehabilitation
departments of the hospital. The hospitalization separates the social state before and after the precipitating event; e.g. traumatic accident. Before the event, someone may have been without physical handicap, but afterwards dependent on a wheelchair due to paralysis. The conclusion is that the status of being 'physically challenged' or 'differently abled' with regard to mobility is itself a liminal experience. If we are to understand Turner correctly, this is not liminality but marginalization. A liminal phase may be the margin between the initial status without handicap and the reaggregation as marginal. Such people are marginalized by virtue of being differently abled than what the larger community considers as ordinary. They are still expected to function in this larger community which does not accept them as fully functional members (Alexander, 1981). The liminal period, perhaps during hospitalization, separates a prior set of social roles from a resultant inclusion of a social role which results in marginalization of the individual after discharge from the facility.

Mwaria (1990) and Shield (1988) also consider the marginalization of comatose and elderly persons respectively. They too, mistake the ongoing ambiguous state of the marginalized individual as the liminal phase. Shields talks about the institutionalized elderly as being between life and death, but I believe this is a simplification. The elderly may be stigmatized, neglected and thereby marginal (Myerhoff, 1986) but they are not by these characteristics alone, at any given time, in a liminal situation. They are part of the community at large by their physical presence, as well as part of a group devalued by the same community.
Similarly, this is true for those comatose patients in a persistent vegetative state (PVS) which Mwaria presented. With their labeling as PVS, they leave any liminal attributes behind. They are in a persistent state by definition. The labeling as “PVS” marks the resolution of transition and the reaggregation as comatose.

Sandstrom (1990) discusses liminality and marginalization of men with HIV infection, though he uses the terms synonymously. He does give what may be an example of liminality in terms of the crisis of diagnosis with HIV, where an individual experiences a crisis which challenges his prior social identity, though this is not elaborated on.

Communitas and Social Support

Communitas is the comradeship of a community of persons without place attachment or the necessity of a shared living space. For liminal and marginal persons, communitas exists in a community of individuals who are cognizant of their common liminal or marginal situation and experiences, and emerges where the structure of daily life is not in force (Turner, 1969). This does not imply that liminality and communitas exist without structure, but rather that there is an alternative structure governing behavior (Ibid.).

With communitas, persons share an understanding of each other and of shared experience (Ibid.). As such, communitas is social support. Social support affects the course of illness, (Berkman, 1981, 1985, Pilisuk and Parks 1986, McKinlay, 1981, Dressler, 1991) and offers resistance to the
negative life events of illness (Dressler, 1991) thereby reducing the impact of illness on quality of life.

Communitas can be an enduring aspect of belonging to marginalized groups (Turner, 1969) which would include men who consider themselves part of a gay community in the U.S. Newton (1991) proposes that the experience of communitas was present in the gay community in the U.S. during the post Viet Nam and Watergate era offering a network of social support. During this time period gay men experienced a more positive social identity (Lang, 1990). Newton (1991) suggests that communitas of that time was based on promiscuous sexual freedom (see also E. Newton, 1993). The challenges to this sexual freedom occasioned by the intrusion of HIV-AIDS upon social awareness have greatly limited what Newton proposed as the source of communitas.

Several authors suggest that the gay community has at once embraced and supported HIV infected persons (Lang, 1990, 1991b, Feldman, 1990, Niehaus, 1990) and isolated or rejected them (Siegel and Krauss, 1991, Sandstrom, 1990). Communitas tempers the isolation of liminality experienced during HIV infection (Hearn, 1980) and most likely tempers marginalization experienced throughout infection, (and possibly experienced since self-awareness of a gay identity). In view of this, sources of communitas may be a focal point for sustained or periodic communitas as chronically ill persons face repeated life events or crisis points (Flaskerud, 1989) superimposed on a marginal status relating to ongoing illness identification and identification as gay.
Life Events

One aspect of quality of life that has received significant research attention has been life events. The varying nature of life events and the effects of life events on the social, psychological and physiological aspects of the individual have been well documented (Holmes and Rahe, 1967, Dohrenwend and Dohrenwend, 1974, Sarason et al, 1978, Brown and Harris, 1978, Kessler and McLeod, 1984, Kiecolt-Glaser and Glaser, 1987) including studies particularly addressing persons with HIV (Flaskerud, 1989, Rabkin et al, 1990, Blaney et al, 1991).

Holmes and Rahe (1967) measured the effects of life events with a weighted scale which yielded a calibrated score. They, as well as others (Dohrenwend and Dohrenwend, 1974, Sarason et al, 1978), found that higher scores (indicating greater frequency or intensity of events) were predictive of illness over a length of time showing an additive effect of life events. Life events may have either positive or negative value (Holmes and Rahe, 1967, Dohrenwend and Dohrenwend, 1974, Sarason et al, 1978). Life events are defined as changes in an activity, role, person or idea which would generally result in strong positive or negative emotions (Brown and Harris, 1978:67).

The meaning of a life event to an individual may be established through use of biographical information (Brown and Harris, 1978). Therefore, the life story is an ideal method to consider life events as they are presented in a biographical framework with close attention to personal meaning (Ryff, 1986).
Flaskerud (1989) calls attention to ‘crisis points’ during the course of HIV illness; diagnosis, treatment, treatment termination, new symptoms, recurrence or relapse and terminal stage of illness. Crisis points are life events associated with strong negative emotional responses to perceived deterioration of quality of life. Though Flaskerud acknowledges psychological and social sources of life events her focus is on life events directly attributed to HIV illness. Similarly, Bluebond-Langner (1991) observes a remarkably similar trajectory of critical points in the progression of cystic fibrosis.

Both of these studies focus on the recurring critical or ‘crisis’ points in the respective disease processes. In reading the following life stories, it will be interesting to note that in the progression of HIV infection, as Bluebond-Langner noted for cystic fibrosis, there is an overall pattern of increasing frequency and severity of crises over time, a pattern which is mirrored in other domains of the life course (Fitzpatrick, 1989). Two of these patterns of recurring crises are most evident in the following stories. The first is the progression of illness, sometimes gradual, but always punctuated by crises; e.g. hospitalizations, loss of physical abilities, onset of pain. The second is the death of friends, most often for those of us in this culture, a process that does not accelerate to such a great degree until later in life. For the first two men discussed in Chapter Three, death from advanced HIV has claimed all or most of their entire cohort of closest friends.

The effects of these two overlapping patterns of life events or crises will be examined in greater depth in the life stories in Chapter Three.
These three men expressed a great deal of illness related distress in terms of physical limitations and deterioration.

**Quality of Life**

When individuals evaluate the quality of their lives, they do not necessarily base determination of that quality solely on life events, the present life situation or even basic human needs, such as shelter, food, status or companionship. This dissertation will show that the valuation of what defines life’s positive and negative qualities is based on culturally mediated beliefs and personally relevant meanings. These beliefs and meanings define the perceived quality of life at any given time during the life course and determine valuation and appreciation of the experience of life. The same is true of illness experience. That is, culturally influenced beliefs and personal meanings affect the perception of the illness experience, and the impact on quality of life. This experience is embedded in the course of one’s life with chronological, physical, psychological and social dimensions. Perceptions of quality of life then, are seen as a critical evaluation by the individual of his everyday life experience, and illness experience.

By maintaining a focus on understanding the experience of illness, narrated as part of the life story, this study seeks to resist the objectification of experience criticized by Kleinman and Kleinman (1991) particularly as these authors relate this to biomedical delegitimation of suffering as disease.
Burgess and Catalan (1991) have stated the need for quantitative measures of health related quality of life for persons with HIV with regard to treatment evaluation. Questionnaires have been used to produce indices of subjective perceptions of quality of life in general (Heady, et al, 1985), despite acknowledgment of the inability to clearly define quality of life (Siegrist and Junge, 1989). Questionnaires have also been used in the same fashion for persons with HIV in particular (Kaplan, et al, 1991; Wu, 1991; Butters et al, 1992). Psychometric scales have been administered to attempt to measure emotional stress due to illness (Rabkin, 1991) only to conclude as Kessler et al (1988) that this is mediated by psychosocial factors. Chubon (1987) and Rickelman, Gallman and Parra (1994) acknowledge the subjective nature of quality of life, but impose their own categories as domains of investigation.

Burgess & Catalan (1991) review various quantitative measures of quality of life, acknowledging that personal interviews record patient's views more accurately and with more detail and greater validity than either uni- or multidimensional questionnaires. Fanning and Emmot (1993) seek to evaluate the effects of life events related to HIV infection on quality of life. They consider social, psychological and economic aspects of everyday life. Though they are able to evaluate the intensity of the impact of HIV on a given aspect, this gives no insight into the more personal meanings attributed to that impact or the value of the particular aspect affected. Closed-ended questionnaires are frequently ineffective in obtaining any but the most superficial data relating to illness experience (Kleinman, 1988a:66-67). This results in part, because perceptions of
quality of life are exceedingly complex due to the fact that all aspects of culture are relevant to quality of life (Jonas, 1983).

Additionally, this points out the questionable value of measures which reduce quality of life to domains such as health related quality of life suggested by Burgess and Catalan (1991). It is doubtful that the biomedical concept of health related quality of life is valid in terms of the individual's experience. That is, perceptions of quality of life entail virtually all aspects of experience drawing on a diversity of cultural values (Jonas, 1983). Health related quality of life cannot be taken out of the wider context of life experience.

Values

In analyzing the life stories presented in this dissertation, I will describe implicit cultural values of these Euro-American men in terms of their relevance for the men in this sample. My concern will be with the function of these culturally meaningful values in this group of individuals, rather than presenting the values identified as descriptive of American culture.

Values determine the positive and negative, good and bad, of everyday social life (Fry, 1988:463). Geertz (1973b:50) states that values are "cultural products—products manufactured, indeed, out of tendencies, capacities, and dispositions with which we were born, but manufactured nevertheless". Just as Chartres Cathedral embodies the "specific concepts

\[\text{Values}\

\begin{align*}
\text{In analyzing the life stories presented in this dissertation, I will describe implicit cultural values of these Euro-American men in terms of their relevance for the men in this sample. My concern will be with the function of these culturally meaningful values in this group of individuals, rather than presenting the values identified as descriptive of American culture.}
\end{align*}
of the relations of God, man and architecture" (Geertz, 1973b:51), so a value expressed in a given situation embodies a set of culturally meaningful concepts. When a value is expressed in a story telling of a particular situation, it is to be understood in terms of culturally meaningful concepts regarding the situational, personal, social, and historical contexts.

For instance, self-reliance is frequently expressed as a value in the life stories told by the men in this sample. Yet the self-reliance expressed by one man when talking about being a street hustler, trading sex for money or shelter, reflects a radically different set of culturally meaningful concepts than the man who expresses self-reliance through relating a story of building a business which became a source of support for him when he became debilitated from HIV related illness. Where the former finds meaning in concepts of sexual, moral and legal relationships between men, the latter is given meaning through an understanding of business relationships, illness and disability. Most importantly, the meanings of these concepts are culturally mediated. Though values may be culturally mediated concepts and thereby shared by members of a culture, the meaning of these concepts may be situationally determined, as in the above example.

Hsu (1972:258) states that values express themselves in "two directions": positive and negative. In the case of self-reliance, which he presents as an important value of American culture, these polarities are expressed in the qualities of freedom: self-reliance of an individual, as opposed to totalitarianism: self-reliance expressed by a governing body
(Ibid.). This points out the lack of explanatory power of values in terms of their use in description of a culture (Hsu, 1972; Kaufman, 1986). Thus, to say that Americans value self-reliance, is to vastly oversimplify this cultural concept.

Where values are inadequate in providing complete descriptions of a given culture, investigating the function of values, as core cultural symbols, is useful in increasing our understanding of the cultural meanings of behaviors and beliefs. So, for the street hustler, the behavior of trading sex for money or shelter reinforces a sense of self-reliance, even as it may carry a host of additional meanings. Through this psychocultural approach to understanding the meanings of behavior from a cultural perspective, we can gain a clearer understanding of the way in which culture functions in the behaviors and beliefs expressed in everyday life.

**Reflexivity as a Collaborative Approach to Research**

Marcus and Fischer (1986) voice their concerns relating to the "crisis of representation" in ethnography. That is, how does one interpret data of the ethnographic encounter without disengagement of the ethnographer and objectification of informant (Crapanzano, 1980)? I did not want to simply elicit a life story and description of daily life from an individual, which I would then interpret independently (Luborsky, 1990). How could I balance a commitment to responsibly reproduce these stories of lives and experiences without imposing my own agenda (Lincoln 1993)?
Crapanzano (1980:ix) explains this difficulty with interpretation as follows:

By eliminating himself from the ethnographic encounter, the anthropologist can deny the essential dynamics of the encounter and end up producing a static picture of the people he has studied and their ways. It is a picture, frozen within the ethnographic text, that becomes the "culture" of the people. The ethnographic encounter, like any encounter between individuals, or for that matter, with oneself in moments of self-reflection, is always a complex negotiation in which the parties to the encounter acquiesce to a certain reality.

I have facilitated this negotiation through sharing stories of my own everyday life with the men in my study over the course of interviewing. I also talked with them about some of my preliminary analyses and impressions, and invited comments, criticisms and their own perceptions. (I will discuss this in greater detail in the following chapter.) Ortiz (1985) emphasizes such a collaborative approach as inherent in life history research. Kennedy and Davis (1993:23-24) have also found this approach useful in studying the history of the lesbian community in Buffalo, New York.

**Development of Research Topics**

In order to clarify my own presence in the research process, it is necessary for the reader to have some understanding of my underlying reasons for choosing this particular study. There have been a number of factors in my own life which have contributed to my interest and involvement in this current research. In 1981, I was working as a registered nurse in a psychiatric nursing facility in Ft. Lauderdale, Florida.
A coworker had become ill, and was hospitalized with AIDS. I don’t recall when I heard of his death. I had left that facility and begun working in the critical care area at another hospital soon after he had become ill.

Working in critical care nursing was challenging and engaging work, being so closely involved with life on the threshold of death. Often there was a feeling of achievement in working with survivors who had reached that threshold only to return to life. From the onset however, I wondered how their lives had been transformed by the experience. Sometimes they were left with lingering illness and limitations. The issue of determining quality of life was frequently debated by the nurses and physicians I worked with. For the critically ill, there was a decision to be made by the health care professionals, and (sometimes) the patient, his family and friends. Should extraordinary measures be used to extend this person’s life? The answer always hinged on an assessment of the quality of life that would be experienced after recovery. I saw that assessment as hinging on knowing the answer to the question “What is it that makes an individual feel that life is worth living, and why?”. That question has followed me through my career in nursing and on into my studies in anthropology.

Over the next two years I remember two persons with AIDS with whom I worked. The first was a young man suffering from pneumonia. His room door was closed, with isolation equipment flanking both sides. The usual signs were posted which said that each staff person entering was to wear a protective paper gown, gloves, and a mask. His meal trays were served on disposable trays. As a member of the large gay
community in Ft. Lauderdale, I had heard quite a bit about what we were beginning to learn about AIDS. We were aware that the type of pneumonia which my patient had (Pneumocystis Carinii Pneumonia or PCP) was not contagious. (In fact, as a nursing student, I had worked with a woman with PCP related to cancer chemotherapy immuno-suppression. We required no special isolation for her.) I remember walking in to introduce myself to him and talking. My voice was muffled by my mask. As we talked I felt more and more uncomfortable. I knew that there was little if any risk to myself (or to him) from casual contact with this man; a handshake or touch without gloves, sitting in the same room and breathing without a mask. I had also begun hearing and reading about the profound isolation and distance experienced by people who had been hospitalized with AIDS. I don't remember what we talked about, but I remember being emotionally moved by what he was saying. As we talked, I removed my mask and gloves and put my hand on his arm as I sat at his bedside. I could not be party to the isolation, neither clinical nor emotional which I saw as an unreasonable response to fear.

By 1984, even as we began to understand more and more about the factors which contributed to developing AIDS, including the discovery of HIV, I saw sheer terror grip hospital staff when confronted with a person with AIDS or sometimes, with a person belonging to a group considered to be at risk. In the South Florida communities in which I worked, that included any gay man or Haitian. I had gone to a family wedding and reconnected with my cousin, Bobby, who I had been very close with growing up. He too was gay and we found we had much to catch up with
about each other. We regularly talked on the phone and occasionally corresponded. Within the following year he informed me that the last bout of hepatitis he had - which had left him feeling so tired last time we had seen each other, heralded the onset of AIDS Related Complex (ARC).

I continued to work as a nurse, though now I was working in home health. As part of my caseload, I was teaching persons with AIDS to administer intravenous medications at home. I visited four gay men over an extended period of time who influenced my decision to study quality of life in people in the HIV spectrum. I had returned to school to pursue my Masters and Ph.D. in Anthropology, and again began my inquiry into what I saw as the central question to quality of life: "What makes an individual's life worth living? and why?". Bobby, and the men I worked with in my home health job were my sounding board. I would talk to them about my interest in quality of life and they would tell me what they thought made their lives good. We also talked about our daily lives and I found that the more I knew about their everyday lives the more I understood why they felt their lives were (or were not) worth living.

Talk about everyday lives was frequently interspersed with glimpses of the past serving as illustrations of a way of thinking, or a point made. I became convinced that the answer to this question lay in the individual's personal history and began the pilot project described earlier in this chapter, "Preliminary Studies".
Chapter Organization

Chapter Two will present the research design and methods used to obtain the data, and introduce key theoretical concepts and variables.

In each of the three following chapters, life stories will be presented and analyzed. In Chapter Three, the first life story will be used to demonstrate the key components of life story analysis. The three life stories presented, analyzed and discussed in this chapter will focus on the impact of life events on the quality of life of these men living in the HIV spectrum. Liminality will be discussed in terms of its applicability in furthering our understanding of the effects of life events on everyday life and illness experience.

Chapter Four will present life stories of men who are associated with group support organizations, with specific attention to their involvement in 12-step programs. Communitas will be discussed in terms of its applicability in furthering our understanding of social support from this theoretical perspective.

Chapter Five will have as its focus, the social course of illness, particularly as this applies to ways in which study participants strive to manage the impact of the course of illness in the context of their everyday lives.

Chapter Six will review the nine life stories presented and place them in the context of the sample of twenty men. Conclusions and implications for further research will be discussed in this chapter.
CHAPTER TWO

METHODS AND DESIGN:
REFLEXIVITY AND THE RESEARCHER

Description of the Study Sample

The following work presents an analysis of the lives and stories of twenty self identified gay men living in the Cleveland - Akron metropolitan area of Northeastern Ohio and/or attending the Clinical Trials Unit of The University Hospitals of Cleveland. Data were collected as audio-tape recorded interviews from March, 1994 through March, 1995. All persons participating in this study were assigned pseudonyms which are used at all times in this dissertation. In addition, other identifying information has been altered when necessary to maintain confidentiality (e.g. career may be modified to a similar career or that information may be omitted entirely).

As shown in Table 1, six men were recruited through the Special Immunology Clinic (SIC) and eleven from the AIDS Clinical Trials Group (ACTG), both of University Hospitals of Cleveland. Three men were referred as part of a support group attended by another participant. All are Euro-American between 28 and 48 years of age. All participants are self identified gay men who believe that they contracted HIV through sexual contact with other men. In Table 1, “Reported Years HIV+” refers to the earliest date the men in the study thought that they had been infected. It does not necessarily correlate with medical measures, however I have included it to give the reader an idea of how long these men believe they have been infected. It is a subjectively meaningful
measure for many of the men. Jimmy, for instance, talks about his survival in terms of the number of years since his diagnosis with HIV, rather than the number of years he may have been HIV+ prior to diagnosis. He cites this as evidence that there really is no pattern to how long people with HIV live. "I see who’s been diagnosed for ten or twelve years. Their health drops dramatically. I’ve known people just got diagnosed; the same thing happens. You don’t worry about it. You just try to enjoy life now and go on."

All the men in this study have had some education beyond high school and 50% have college degrees. More than half of the participants live with partners in a spousal relationship. All but one of the men lived in the Cleveland/Akron area at the time of recruitment and through the period of the study. He commuted monthly from Toledo to the Clinical Trials Unit of University Hospitals of Cleveland.

Description of Recruitment Site

University Hospitals is a large (>1000 beds) teaching hospital. It is one of several hospitals in Cleveland affiliated with Case Western Reserve University as a teaching and research site. University Hospitals admitted their first AIDS patient in 1982. In 1983 several Fellows in the Infectious Disease Department set up a “Fellow’s Clinic” to see HIV/AIDS patients. By the end of 1986, 300 people were coming to the clinic for care of HIV infection. Federal funding for the AIDS Clinical Trial Group (ACTG) was awarded to University Hospitals in 1987. The SIC and ACTG were intentionally linked for parallel provision of research and medical
care. The physicians practice in both settings, integrating research and clinical practice. In this way patient care appears seamless to patients despite actual handing off of patients between the two units. Medical, nursing and ancillary staff of the two units has grown to accommodate the increasing numbers of HIV infected individuals.

As of 1992 there were 682 active patients attending the Special Immunology Unit, and 250 individuals enrolled in 17 protocols in the AIDS Clinical Trials Unit. As of 1991, Cleveland's metropolitan service area ranks fifty-second out of 101 areas with populations greater than 500,000 in the United States, with respect to the reported number of cases of HIV infection. The majority of HIV-related care in the Cleveland metropolitan area occurs at eight institutions, with University Hospitals providing care for 40% of individuals within the HIV spectrum receiving care in Metropolitan Cleveland.

**Methods and Design**

This study was an ethnographic, community study based on attendance of an outpatient clinic of a large urban teaching hospital which treats persons with HIV infection. Direct observation of the clinic was performed during my temporary employment as a nurse at the SIC during summer and fall of 1993. This allowed for a basic understanding of the clinic operations, the social space and social interactions between staff and patients. In addition and perhaps most importantly, this was an aid in familiarizing staff and patients with me and with my dissertation research plans thereby facilitating cooperation in selection of subjects.
Observation time at the clinic also served to provide the ethnographic context of the clinic setting while maintaining close contact with staff, as the source of referrals. Ethnographic observation was also conducted at participants' homes before, during and after interview conversations, and at social settings in the local community, e.g. restaurant/bars, an outdoor festival, a drop in center for people affected by HIV.

Recruitment

While working at the clinic during the fall of 1993 and the following winter, I was introduced to the data management coordinator for the clinic who helped me to formulate a preliminary list of possible participants from which to choose. I was thus able to assemble a list of 150 names of men fitting the following recruitment criteria: Euro-American, self-identified gay men presently seeking treatment for HIV infection at the SIC, between 25 and 40 years of age. Selection criteria would thus limit sampling to the modal group of persons undergoing treatment at the clinic with regard to age, ethnicity, and self identification as ‘gay’. Sampling was non-random with subjects selected on the basis of willingness to participate in autobiographic interviews over a minimum of six months.

Within the six months following the start of the interviewing process for the pilot study, the three subjects diagnosed with AIDS at time of recruitment had all died. For this reason, recruitment at this stage was limited to men whose HIV infection had not progressed to AIDS (end-stage HIV infection). By limiting selection to those persons without
diagnosis of AIDS, the likelihood of subjects being physically able to complete the study would be enhanced.

I reviewed the medical charts of the 150 men meeting the recruitment criteria to determine stage of illness, based on T-cells averaging >200, and the absence of hallmark opportunistic infections. I gathered the data from doctor’s, nurse’s and social worker’s notes, and laboratory data. I found 70 men who apparently fit my criteria and were approved by the clinic staff and director. Participants were recruited by myself or clinic staff at the time of a scheduled appointment. Of the 70, I was able to recruit only six men to participate in this study. This was due primarily to the fact that those people who were in the earlier stages of infection were significantly less accessible to me because they came to the clinic four times yearly or less. It is possible therefore, that recruitment of healthier subjects might have been higher if recruitment were not clinic based.

It is also interesting, however, to mention the refusals of men attending the SIC from the few men I was able to contact from this group of patients. Five potential study participants refused stating that they did not have one to three hours per month to spend talking. All five were patients of the SIC, working full time, and all five would have been in the younger half of my sample (<38 years old). Several factors may have contributed to their unwillingness to participate. Clinic patients are frequently approached to participate in various research projects by students of the university, as well as possible involvement in clinical trials. As I will discuss in Chapter Five, some persons in the HIV
spectrum make every effort to keep HIV-related activities from overtaking their lives. In addition, most of the men who did participate in this research reflect on their time as being limited by advancing illness and impending death. It is possible, therefore, that in prioritizing their activities, this study was just one too many HIV-related activity, and one that they might have perceived as not directly linked to their survival, health or enjoyment although additional study would be necessary to determine why "healthier" HIV affected persons refused. The end result is that few men with early HIV infection were recruited into the study, with a mean self-reported time since HIV diagnosis equal to 5.8 years (standard deviation = 3.21).

Additional referrals were sought from nurses working in the SIC and ACTG, based on a revised criteria to include those who were "healthy enough to tolerate one to two hour long interviews, monthly over six months to a year". Eleven additional participants were recruited from the ACTG. The final three men were recruited by one of the participants as men in his social network who were interested in participating in this project.

Initial verbal consent for participation in the study was obtained by the clinic nurse or the ACTG nurse. If this consent was obtained at a scheduled appointment and I was present, written consent was then obtained after describing the study to the participant. Otherwise, I contacted participants by phone to arrange for interviews. In this case, written consent was obtained at the first interview.
Participants were interviewed between five and seven times per person spaced over the course of six or more months. Interview visits lasted from one to three hours. All interviews were conducted at the participant's home (except one interview conducted at The Living Room, a drop in center for people in the HIV spectrum). This allowed for ethnographic observation of their home environment, and afforded me a glimpse into the everyday life of the participants, and I was also able to meet friends and partners as well. After the audio-tape recorded conversational interview, I would often visit with the men, obtaining additional ethnographic information. Phone contact was maintained monthly or more frequently, including rescheduling and casual conversation about what was happening in their lives. In this way, I was able to jog their memory during the next taped interview with regard to events of the past month. I also met with informants when possible at the Special Immunology Clinic, or socially whenever we would meet in our everyday lives. I visited three informants "just to talk" after the six month interview set of taped interviews was collected.

I found that with an initial two interviews to obtain a baseline life story, followed by monthly interviews (or a somewhat longer period, depending on scheduling difficulties), there was a period at about two or three months (the third or fourth visit) where conversations remained more superficial than I would have liked. However, these more superficial conversations did provide contextual data regarding everyday life and concerns at that point in time. It seemed we had talked about life story topics extensively and the month had gone by uneventfully. This
was particularly the case in those who were working to minimize the impact of HIV infection on their everyday life, discussed in greater depth in Chapter Five.

Interestingly, I can see little difference in depth and quality of data regardless of whether there were five, seven or more visits. If anything, some of my conversations with the less frequently visited participants were of greater duration, and on a deeper and more personal level than some of the more frequent visits. So, the depth and quality of data was not affected by visiting five, six or seven times, but the longer duration visits were of much richer quality and greater depth than those of short duration. My general impression is that the differences in the quality of the data reflect the ability of the individual participant to engage in the task of telling the life story and everyday experience, and my ability to develop a personal connection with him. If the engagement and or connection was not made during the first five visits, that trend continued into the six and/or seventh visit.

The Interview Visits

In addition to tape recordings, notes were taken during and immediately after each visit, describing ethnographic observation of the subject and the interview setting of the patient's home, and a rough sketch of topics discussed during the interview. The overall goal during each interview was to have subjects volunteer what is meaningful to them, and how they interpret the events, experiences, conditions and priorities of their lives.
Interviews were open-ended and in the form of a conversation based on the opening statement: "I'd like you to tell me about your life". Questions and probes listed in the Life Story Interview Guide (Appendix A) were used only if necessary to elicit information not discussed spontaneously during conversations. The Interview Guide was reviewed following each interview to determine what topics were discussed and what topics need to be addressed in following interviews.

The description of the present in terms of the life story continued throughout monthly follow up interviews. The goal was to determine what was meaningful to the study participant, and how he interpreted the meanings of events, conditions and priorities of his life. Additional excerpts from the life story were elicited as they applied to the life situation e.g. "Has this always been important to you?"; "Is this something you've thought about for a long time?"; "Has anything like this ever happened to you before?".

The Life Story Interview Guide

The Interview Guide has five sections. The first section, "Life Events" lists basic information of a life story. The information which relates to this section, at a minimum, offered information relating to any previous experiences of liminality relating to prior life events and perceptions of quality of life and social support over the life course.

In "The Present" section of the interview guide, topics were designed to obtain descriptions of additional information about social
interactions and the experience of everyday life as well as illness experience in everyday life and in interactions with the clinic.

The "Life Review" section identified topics related to perceptions of the meaning of life's past events and the relation of those events to what gives life its positive and negative qualities. Special attention was paid to those points at which subjects experienced feelings of liminality and communitas and how this affected their experience of daily life, its quality and meaning.

In the "Identity" section, more information was gathered about perceived quality of life in terms of self concept.

In the section, "Preparing for the Future", perceptions of self-concept, quality of life and feelings about death were emphasized.

Analysis of Initial Interviews

Notes, tapes and whenever possible transcriptions of each interview were reviewed prior to each following interview. Notes were correlated with the Interview Guide to determine what areas have been discussed and those which remain to be investigated.

Themes were identified from content analysis as they became evident. Tapes were reviewed and content summarized to determine themes. Themes of the life story are cognitive areas of meaning with symbolic force which explain, unify and give substance to perceptions of self in relation to the socio-cultural environment, e.g. life as being centered around the family, narration of the life course as 'a constant struggle' (Kaufman, 1986). The expression of these themes unify the
experiences of a lifetime and present a certain continuity to the life story (Ibid.). Sections of tape-recorded interviews which relate information relevant to themes as well as selected domains of investigation, (liminality and communitas, social support, perceived quality of life, life events and experience of illness) were transcribed verbatim.

As themes were identified, additional information was sought to verify and enrich existing data. For instance “It sounds as though your life has been a constant struggle” (to seek verification). If this was verified, then, “You’ve mentioned how your childhood was a struggle, what about college; after you were diagnosed with AIDS?” etc.

In addition, descriptions of quality of life, social support, life events and any implications of liminality or communitas were also expanded on in the same way, by verifying information given in the prior interview and asking for other examples or more in depth description.

Monthly Follow-up Interviews

Subjects were asked to review events of the past month and describe their current situation as in the “Present” section of the interview guide. Additional excerpts from the life story which were presented as they applied to the current life situation were reviewed with the subject. Additional probes were used as needed, e.g. “Last time we spoke, you told me about some things which relate to what you’re experiencing now. What are your thoughts on this? Is there anything else you’ve remembered that may be important for me to get a clearer
understanding of why this has happened or why this is important?" And so on, following up with increasingly specific probes.

In this way subjects could 'rewrite' their life story (Angrosino, 1989, Langness, 1986, Turner, 1986), as well as identify meaningful life events and changes in perceptions of liminality, communitas, social support, quality of life and experience of illness which might occur over the course of this study.

**Reflexive Description of Clinical Setting**

I began my fieldwork by procuring work in the Special Immunology Clinic at University Hospital. I had worked as a home health nurse with the hospital's staffing agency, and made my early contacts with the clinic by telephone. During that time, I became familiar with some of the clinical and secretarial staff over the phone.

During this clinical experience I noticed patients talking about the SIC in terms of a source of comfort as well as treatment. It appeared that there was a sense of identification with the clinic beyond a source of biomedical treatment. I noticed that when patients were experiencing crises in their lives they would increase their contact with the clinic staff through phone contacts and additional scheduling of visits. It seemed a number of the patients knew each other and the staff and could identify with each other in terms of understanding the experience of living with HIV. I wondered whether I was observing some sense of "communitas" as described by Turner.
In summer, 1993, I was asked to work in the SIC as a clinic nurse for the two weeks while one of the regular nurses was on vacation. I felt this would be a unique opportunity to delve into the workings of the clinic and to get a better understanding of the people who would be working as health care providers with the persons I would recruit. Additionally, I felt I would be able to strengthen my relationships with those I would be depending on to recruit my sample. I also wanted a more intimate glimpse at another aspect of the illness experience of persons in the HIV spectrum. I had worked with people with AIDS (the advanced stage of HIV infection) both in the hospital and in their homes, but until then - not in the clinic.

In fall, 1993, I again worked at the clinic in a nursing capacity. I took advantage of this time to continue observation of the clinical setting and also facilitate recruitment. The advantages of the added observation time, and my increased visibility with the staff which I felt I needed for my recruitment, far outweighed what I saw as the risk of overlapping my role as clinic nurse with anthropologist researcher. I did arrange with the other nurses not to care directly for any persons in my study once recruited. I would talk with them socially, if I saw them at the clinic but would not perform any nursing care. Other than taking the vital signs, and weight of one study subject prior to recruiting him to my study, I was able to limit my contact with study participants to minimal social contact during the time I worked at the clinic.

I limited my nursing contact with study participants particularly to avoid developing any relationship with them prior to the study. I saw
my role as a nurse who worked in the clinic where they were treated as less of a handicap than the risk that developing any relationship with a study participant would then eliminate that portion of their life from being disclosed to me as part of the life story. That is, I felt that a life story obtained by a previously unknown researcher might be more fresh and comprehensive than one obtained by a previously known caregiver, in that it would not be assumed that any given aspect of his life was known.

**Interviews or Conversations: Reflexivity as Collaboration**

This study was conducted as a collaborative project between myself and the recruited participants as follows: Participants were introduced to the study in terms of my interest in understanding their present situation and the impact of HIV infection on their lives. After giving potential candidates a brief overview of the proposed study as stated on the consent form, I asked if they could “help me out” with this endeavor. I hoped this would set the tone for a dialogue or conversational approach rather than an interview where I was the interviewer and they the interviewee. I told them that I believed that the only way I could get an understanding of what it was like for them to live in the HIV spectrum was to get to know them and what their life was like past and present. I explained that I was interested in quality of life and what that meant to them over the course of their lives. I did not volunteer a definition of quality of life as all participants were familiar with the phrase, and frequently responded with an immediate comment on their perception of their present quality of life.
The purpose of interviewing over the minimum six month period was presented as a way for me to get a better understanding of their everyday life. The men were told that I assumed that some of them would experience a life event during that time, and were given examples such as a death of someone close or moving to a new location, with emphasis that this may be a negative or positive occurrence. I informed them that this information would be used to increase the understanding of others in their situation, and to improve the understanding and identification of factors important to their quality of life, and also, these interviews would serve as a basis for my doctoral dissertation.

As interviewing progressed, I answered any questions asked about the study or about myself. In addition, whenever possible interviewing was conversational, and I shared information about myself when appropriate; e.g. reflecting on differences and similarities in our experience of any given topic, thereby encouraging further discussion. Any telling of a story depends on the audience (Shafer, 1978; Angrosino, 1989; Tierney, 1993b). I encouraged participants in this study to get to know me, as their immediate audience, and willingly shared with them any information about myself about which they asked. I occasionally volunteered additional information about my own experiences to encourage a more conversational interaction. This fostered an attitude of cooperation, and helped to engage many of the men in the task of telling about their lives as well as engaging myself as a more active listener.

Through the course of the project, I would also share my observations and preliminary conclusions about some of the topics.
addressed by the study. For instance, I thought that some of the men I was talking to were saying that they felt that their HIV diagnosis had pushed them ahead to a phase of life that would normally be experienced by the elderly; the death of friends, anticipating one's own death. I related this thought to several participants and asked for feedback.

The final interview of each participant included discussion of what I planned to write about in this dissertation at that time, often including how I thought some of their insights or stories may apply. I explained to them any theoretical framework which I thought might help me interpret what had been discussed, e.g. communitas and liminality. I welcomed any feedback at this and other times and sometimes received it.

This reflexive approach has been used to problematize and address the production of ethnographic knowledge (Rabinow, 1977; Dumont, 1978; and Dwyer, 1982). A reflexive approach has also demonstrated efficacy in uncovering cultural meanings in a number of situations: in addressing the ethical dilemmas of ethnography (Bowen, 1964); the emotional life of the Utuk of Northern Canada (Briggs, 1970), of the Tahitians (Levy, 1973), and of the Ifaluk of the Southwestern Pacific (Lutz, 1988); and addressing the life cycle, the self and emotion among the Ilongot of the Philippines (Rosaldo, 1980). Others have used a reflexive approach in examining the way in which history in the form of the life story is jointly produced by researcher and researched (Crapanzano, 1980; Shostak, 1981).

Lutz (1988:14) suggests that a “truly cultural description of the ethnographic encounter examines the interaction of both of the two
cultural meaning systems involved (those of ethnographer and host)".
By using reflexivity in this dissertation, I am addressing this concern as it applies to the variability of meaning systems intraculturally. As I offered my understanding of a situation or topic, I was, at times, corrected by the narrator for misunderstanding what he was trying to say. Had I not taken this reflexive approach in conducting the ethnography, I would most certainly have left the encounter, incorrectly believing that my understanding of what was said reflected the intended meaning of the narrator.

One problem with regard to conducting any type of research based on a collaborative approach is the risk that the research may be presented as a confessional of field experience (Marcus and Fischer, 1986:68). It is necessary for the researcher to balance an introspective stance in reviewing and analyzing data. If this introspective stance is overemphasized it is the researcher's experience which may become the subject of analysis overshadowing the research itself.

In presentation and analysis of the data, I have endeavored to limit reflexivity to the extent that it serves as context for the data. In the research itself, I have used reflexivity in responding openly and honestly to the study participants and offering information about myself. I limited this reflexivity to a few sentences, and always tried to maintain the focus of the conversations on the narrator of the life story, responding reflexively without shifting the conversation to talk about myself. Undoubtedly, this affected what was and wasn't said in conversation. There is the additional risk that by identifying the listener as another gay
man, or by any other characteristic, the narrator might assume knowledge or agreement, thus omitting explanation which may or may not agree with the listener's knowledge. Though this is possible, it was not evident in the conversations I had with participants of this study. There were two reasons why I believe this was not evident. Firstly, in listening to the tapes, my reflexive comments were generally made after the narrator presented his experience, thereby eliminating direct influence on the narrators initial presentation of the topical area. Secondly, my comments often stimulated additional conversation about the topic.

The possibility remains that information was omitted or filtered because of participants' awareness of my own history. However, additional data would certainly not have been presented, had I successfully withheld personal information. This was true particularly with regard to our shared gay identity. Five of the men made specific reference to the fact that they were not as open with 'straight' people whether socially or when talking to a 'straight' physician or social worker.

In addition, as I have acknowledged, there may be multiple life stories, dependent on a variety of factors including the audience or listener. In any of these life stories, information may be selectively presented or intentionally omitted. It should be kept in mind that the data I present may only be one version of a life story presented by a given individual. Even more important, the overall purpose of this research is to gain a better understanding of the experience of illness for these men in the HIV spectrum. I do not intend to present these life stories as factual biographies, but rather as thick description (Geertz, 1973a) where a
unique version of a life story presented is both data and context pertaining to narratives of everyday life and illness experience. As will be shown, this approach offers a rich and compelling account of the experience of illness of the men in this study, affording more than adequate data for analysis.

**Stigma and Disclosure: Developing a Reflexive Approach**

Issues of stigmatization and privacy limit disclosure of HIV status. I assumed it would be essential for me to be accepted as someone trusted and known to the persons in the HIV spectrum with whom I would be working. I thought the visibility of my clinic observation time would also give me the opportunity to become known to people in the HIV spectrum. Naively, I did not expect the border between my own everyday life and my research participants to become quite so blurred, though in the end, I think this enhanced my own understanding of the everyday lives of the people I was studying.

As a result of my clinic employment, I was well known to the SIC staff and was becoming familiar to the physicians, however I was only beginning to get to know the staff of the ACTG. I would smile and say hello to them when I saw them in the clinic. At one point early on, when I didn’t know everyone well, I passed by one of the men who worked at the ACTG. I was walking toward the main hospital building and he was walking away with two of the ACTG staff. We had probably passed in the halls half a dozen times or more. I generally said hello, and he returned my greeting. At this time however, when we made eye contact and
began to greet him, I was certain he averted his eyes to avoid the possibility of eye contact. The next time I worked, and passed him in the hall, he smiled and we said hi in passing. I really wasn’t sure what to make of this. Had I misinterpreted his avoidance? At that point I wasn’t sure. Was he unsure of whether I was patient or staff? If so, was this to avoid disclosure of my association with an HIV clinic? Or did he simply not recognize me out of context of the clinic?

Around the same time I met Todd. I was helping out in the front clinic area, doing peripheral blood draws. I walked with him to the laboratory where I was going to draw his blood. He requested that I use different equipment than I was used to, to draw his blood, because that was what the previous nurse had always done. Though I had no trouble getting the blood sample I needed, it took me a little longer working with the particular equipment he requested. He felt queasy and a little faint afterwards and told me that it was hard for him to get used to someone different than the nurse that used to work there. We talked for about ten minutes or so. I told him about how I get faint anytime my blood is drawn, and almost always have to lie down for fifteen minutes or more. He was polite, but I felt that he was unhappy with the situation: that he didn’t like the fact that his regular nurse had left and now there was another nurse. One of the clinic staff verified this had happened with other patients who resented having to change doctors when one of the clinic physicians went on maternity leave, or wanted their blood drawn with particular equipment that another nurse had used.
The next week I was out with two friends. We decided to stop for a drink at a bar near to where we had dinner. This particular bar is part of a restaurant in an old neighborhood between the downtown area of Cleveland and the Edgewater neighborhood that is in many ways the center of Cleveland’s gay community. We sat at the bar. There was only one other man sitting at the near end.

My two friends and I sat at the far end. Todd must have arrived after us. He knew the man at the end of the bar and sat with him. Another man had come in and they were talking and laughing. I looked over and saw Todd. He was having an animated conversation with the other two men. I was feeling unsure about whether to acknowledge him if he made eye contact. I felt uncomfortable. By being friendly, would he risk disclosing his HIV status, if he thought I was known as an “AIDS nurse”? I ignored the situation and concentrated on the conversation among the people I was with. I found it interesting that my field work was entering my own every day life, or that my every day life was becoming fieldwork - a little disorienting but pleasantly reassuring in terms of being able to understand the context of study participants lives. That is, I wasn’t sure how conducting an ethnographic study in the same city I had been living in for the past four years would influence my immersion into the field. Though there was no geographic change, I did feel that I had entered a different awareness of my surroundings, as a field site. I would see study participants daily, not only through planned visits and observation, but spontaneously while going about my daily activities.
We increasingly became visible as participants in each other’s lives, as acquaintances, coworkers and friends.

As we left the bar, I passed Todd, at first he made eye contact, but looked away as I got within about ten feet and avoided looking my way as I passed. His expression changed from smiling with friends to a blank expression and he seemed to purposely turn away from me and look toward the bar. The two men he was sitting with who were unfamiliar to me, smiled as they briefly made eye contact when we passed. At the time, I still wasn’t sure what to make of this. I suspected that he did not want to be associated with me because of my association with the HIV clinic. About a week later I saw him at the clinic. We exchanged greetings, he smiled and addressed me by name. Several conversations I would later have with the participants of this study and others, as in the following example, shed more light on this issue.

Several days later I learned more about the extent of fear of disclosure among persons in the HIV spectrum. One time about a month prior to this particular day, I was working in the treatment room, setting up aerosol treatments when I saw Jeanette, one of the nurse’s aides who worked with me when I had been working in home care. She was one of my favorite aides to work with. She was in the room when I got back to the treatment room desk. She had always been very friendly when we worked together. She appeared nervous when she saw me. I was busy with work related tasks. She left without talking. The second time, I set her up for her treatment. We talked some about our workplace. She was concerned about whether to let anyone at work know about her HIV
status. She really didn’t trust them, their reaction. I’m sure she was a little concerned whether I’d disclose her illness. I basically agreed with her assessment and said that if I were in her situation I wouldn’t tell the people at that particular work environment either, and indicated that I would never mention to anyone that I had seen her there.

At this point, I was beginning to feel a little overwhelmed by the appearance of HIV related issues in my daily life. There was Jeanette who through no choice of her own entrusted me with keeping her secret from the workplace; and Todd who avoided me at the restaurant. During the same time I was introduced to Carl, a nurse that I worked with when I wasn’t working at the Special Immunology Clinic. I had seen his name on the list of possible study participants. He had little or no knowledge of what I was working on for my dissertation nor could he suspect my awareness of his situation. We had only a superficial social encounter, however I left feeling like I was just beginning to see under the tip of the iceberg.

Another man that I would later recruit was introduced to me by several people as a resource person with regard to my interest in training horses. I waited to recruit him until I could meet him at one of his clinic appointments.

Reflexivity, Self Disclosure and Rapport

Another factor which I became aware of during this observation period at the clinic was the need for mutual disclosure of everyday life information. As I worked in the treatment room, I would sometimes sit
with patients for hours monitoring an infusion of medication or blood. During this time I would talk with the men and women for whom I was caring. I began to incorporate some of the topics that I would cover in my interviews in our conversations. Phil was at the end stage of HIV infection, very weak, but he liked to talk. He was in for a transfusion and so was in the treatment room for several hours. During that time, we talked about travel in the U.S., my upcoming trip to Washington, D.C., bed and breakfasts, Cleveland and its suburbs, religion, our parents and families and experience with relationships.

During this discussion, Phil assumed I was gay and structured his conversation by saying "are you out to your parents?" (That is, were they aware that I was gay?). I told him yes, and talked a little about myself and my family and we continued our conversation.

I met Andrew under similar circumstances. I introduced myself to him to which he responded, "Straight or gay?". When I answered yes to him, he smiled and said that it didn’t matter, he just wanted to know. I believe that this is simply a concrete example of the importance of the audience to the encounter. Andrew prefaced any interaction with me by identifying me relative to this category.

Tierney, (1993) addresses this issue in relating listening to the life story of a colleague, Robert. He notes that Robert acknowledged that he might not have brought up any discussion of "the gay stuff" had he not been able to relate to his listener as a gay man. He cautions, that this is not to suggest that "only a gay man can embark on the life history of a gay man, or that only a woman can study women...." (see also Herdt and
Boxer, 1991). What is necessary to establish credibility is that the researcher go “at least part of the way toward the world of the participant” in order to establish credibility (Ortiz, 1985:109, also Watson, 1989).

What is important as I have mentioned before is that a life story has both a teller and an audience and both impact the content of the ethnographic encounter. Interestingly, as Tierney found, the men I talked with related information in greater depth after they had determined that I was gay. They did not react to this information by giving more parsimonious narratives, assuming that the things they talked about didn’t need elaboration because we shared this in common.

I think that people in the HIV spectrum and those associated with it for any reason (health care workers, researchers, community volunteers) practice what Lugones (1987) calls “world-traveling” Lugones describes a “world” as follows using the example of her ethnicity:

A ‘world’ in my sense may be an actual society given it’s dominant culture’s description and construction of life, including a construction of the relationships of production, of gender, race, etc. But a “world” can also be such a society given a non-dominant construction, or it can be such a society or a society given an idiosyncratic construction... ...being stereotypically latin (sic) and simply being latin are different simultaneous constructions of persons that are of different ‘worlds’. (Lugones, 1987:10-11)

In the same way, there may be a dominant cultural construction of gay men in the HIV spectrum and a non-dominant and/or an idiosyncratic construction.

A “world” is a “description of experience” (Ibid.). To travel between worlds is to experience more than one construction of a given human characteristic of one’s self. Lugones talks about herself as playful
in the context of her Latina "world", but much less so in the Anglo "world". I began to see my task in understanding those I was studying, to be that of traveling to their world. I hoped to be able to enter their worlds. By sharing my understanding of the everyday life worlds of gay men, as well as my understanding of clinical issues related to HIV, I was allowed a broader glimpse of their everyday life.

Life Stories

My primary method of inquiry into the everyday lives of the participants in the study was that of eliciting their life stories. I sought information about the recent past as well as distant by following two lines of inquiry; asking participants to tell me about themselves and their lives "from birth until now", and asking about the everyday events since our last visit. In this way I hoped to contextualize stories of everyday life in terms of the life story and increase my understanding of their life stories by it's relevance to the events of everyday life.

Research about individuals' recollections of the experiences of their lives appears in a number of different disciplines by a variety of terms, which in turn refer to sometimes overlapping concepts, e.g., autobiography, biography, life history, life story, life review, reminiscence, narrative. Despite the integral part life histories\(^3\) have played in anthropology since the 1920's (Langness and Frank, 1965), issues

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\(^3\)Langness and Frank describe life histories as consisting of interviews with individuals about the events of their lives and any additional documents. Life stories are part of life histories so defined, and consist of those stories told by the subject of the life history, regardless of the reliability of these narratives.
surrounding the life story, its definition and use, are still being debated in the literature (Frank, 1995; Linde, 1993; Tierney, 1993a).

The collaborative approach which I have employed is one of a number of ways of studying life stories, and itself becomes definitional. The life stories I will present can be defined as conversations about distant and near past experiences of the study participants as co-constructed during interactions between each individual and myself. This follows the literature which discusses life stories as being retold in countless possible ways with shifting emphasis on certain events and omissions of others and vary significantly with each telling depending upon a wide assortment of contextual factors (Langness and Turner, 1986; Angrosino, 1988). Specific influencing factors may include such diverse factors as the broad historical and cultural context (Riegel, 1975; Kohli, 1986): the age of the subject of the stories, as a point on the life course (Shafer, 1978; Cohler, 1982), the context of the act of gathering the data (Watson, 1976), or the particular audience, or listener, and previous tellings (Bruner, 1986). I have emphasized the importance of understanding that the telling of a life story involves an interaction between the listener and teller (Crapanzano, 1980). This parallels Bruner's (1986:148) depiction of ethnography as a narrative that is "shared" or "co-authored" by ethnographer and subject.

One aspect which will be highlighted in some of the life stories is the process of integration of past experience with the present. Integration with regard to telling the life story is a process by which past experience is given meaning in the context of the present (Myerhoff, 1975, 1980;
Tarman, 1988) resulting in a more cohesive and comprehensive understanding of the self among the elderly (Butler, 1963; Boylin et al, 1976; Kaufman, 1986), the disabled (Riessman, 1990) and among persons with AIDS (Borden, 1989). Importantly, telling of a life story does not in and of itself guarantee this integration, but is one means of achieving it (Watt and Wong, 1991).

The twenty men who participated with me in this research endeavor reflected on a myriad of topics. At times I listened as one of the men brought up a topic that he was interested in talking about; at other times I responded or brought up a new topic of my own interest for conversation. Presentation of these conversations remains problematic. One of the benefits I saw to the life story method was that of maintaining the human quality of the people I would be writing about (Mandelbaum, 1973; Watson, 1976; Tierney, 1993b). I now have access to tape recordings of much of our conversations, notes which I’d written about the conversations, and my memory of the time spent with each. Yet, as Bruner, (1986:147-8) states: “Every ethnographer is painfully aware of the discrepancy between the richness of the lived field experience and the paucity of the language used to characterize it. There is a necessary reduction, condensation, and fragmentation of data.”

The data will be presented with the aforementioned concerns in mind, in my attempt to maintain the richness of the data. Narratives will not necessarily be presented in the order in which they were recorded, but will be arranged with emphasis on content in order that they make sense to the reader in terms of the discussion at hand. Narratives will also be
presented in first person voice (Tierney, 1993b:121). The reader will keep in mind that excerpts were taken from conversations between myself and study participants and as such, should be considered a negotiated product of the interaction (LeCompte, 1993). Pseudonyms will replace actual names and identifying characteristics will be altered to maintain confidentiality. Emphasis will be on the content of the narratives rather than linguistic accuracy, although the general style of the individual’s speech will be maintained. My intent is to facilitate the reader’s understanding of the challenges faced in everyday lives of these twenty men; the overall goal of this being to increase understanding of the range of experience and concerns for people in the HIV spectrum and also how this understanding may reflect issues in our own lives (Ibid.:121).

The following three chapters focus on the impact of HIV infection on everyday life. The personally relevant meanings of everyday experience are placed in the context of individuals’ stories of themselves as they seek to maintain continuity of a self with a past and future as well as a present. Of the twenty life stories recorded, I have chosen nine for intensive presentation in this dissertation, three in each of the next three chapters.

These life stories contain dominant themes which are representative of the four most common themes expressed by the sample of twenty. These themes, which will be discussed in greater depth throughout the text and particularly in Chapter Six, are as follows: overcoming obstacles and enduring hardships (n=15), helping or caring for others (n=11), appreciating life (n=8), and maintaining an everyday life
that is uneventful or boring (n=4). The nine life stories presented in the following chapters present the clearest and most complete presentation of one or more of these themes, though all of the life stories collected show some evidence of the presence of these same themes as well.

These life stories also were chosen because they related pertinent information to my selected variables; life events, social support and quality of life. Following the work of Kaufman (1986:33), life stories were chosen which represented some of the broad range of experience which was applicable to each variable, and which had the sufficient content and richness for analysis as discussed in the section, “Methods and Design”.

The life stories presented are representative of common themes, styles and values expressing core cultural symbols. However, it is important for the reader to remember that the twenty life stories collected were each unique, and outstanding, and as such, none of the life stories can be said to be representative of a “typical life”, but reflect the heterogeneity of human experience and associated perceived meanings, as well as commonalities.

The life stories cannot be said to be typical in that there cannot truly be a typical life, or a typical illness experience. In Chapter Six, the themes reflected in the selected life stories which are representative of the total sample will be discussed in greater detail, along with more general comments relating to the entire sample of twenty men.
CHAPTER THREE
LIFE EVENTS AND THE LIFE STORY

In this chapter I will present stories of several men whose stories illustrate the impact of life events on persons within the HIV spectrum. As a prelude to this I will discuss some of the literature pertaining to life events, followed by life story data, analyses, and discussion in terms of life events and other pertinent variables. In presenting the narrative data and analysis, I will focus on the timing, style, content and themes (Kaufman, 1986), as well as type of reminiscence (Watt and Wong, 1991). These domains of analysis will be defined in greater detail with the first case in order to provide examples of each in a more coherent and practical format.

Jerry

I met Jerry while I was doing my field work at the Special Immunology Clinic during February, 1994. He was one of the first persons I recruited. I first visited Jerry at his home, late the following month. I knew a little about him before I arrived; that he had been coming to the SIC since before 1989 (his was one of the oldest records I reviewed while recruiting men from the SIC). He had had no AIDS-defining illnesses, and from what I could tell from his medical chart, had some trouble with arthritic type joint pain or neuropathy, (pain in arms,

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4Jerry had recurrent episodes of bacterial pneumonia which could not be attributed strictly to his HIV infection, i.e. these infections were not uniquely present in immuno-suppressed individuals. He also had peripheral neuropathy. Recurrent bacterial pneumonia as well as peripheral neuropathy are indicative of the symptomatic conditions of Clinical Category B, similar to ARC.
hands, legs and feet probably due to nerve damage). He had been in several trials at the ACTG. He had used intravenous drugs and lived with his ‘lover’, Tom and up to three other friends. Over the course of our interviews people would stay at Jerry’s house for a few days to a few months, with only Jerry and Tom as permanent residents. Tom traveled quite a bit during the first two months of my visits, but quit his job and so was then a more permanent resident.

Jerry and Tom live in an old wood frame house on a large lot. It’s a little run down, but Tom, and some of Jerry’s other friends work on it periodically to fix assorted problems: leaky roof, painting, repairing the stairs. They are strapped financially. Jerry gets disability, and since Tom quit his job, there’s not much income. Their phone was turned off during the first two months of this study and they were unable to afford to have it turned on again. The furnishings are very old. During my visits, we sat at the Formica kitchen table. Jerry always had coffee for us to drink, and he’d usually smoke a cigarette or two while we talked. The kitchen table was usually cluttered with all sorts of things; newspapers, ashtrays, advertisements. It seemed like the center of activity. There was a big sack of cat food by the kitchen counter, and big bowls of water and cat food for the various cats who lived there. Sometimes one would jump up and sit in my lap while we talked. At times, Jerry’s roommates or friends would come and sit with us briefly. The kitchen was the brightest room in the house, and the table we sat at was beneath a double set of windows. The rest of the house always seemed dim by comparison.
Jerry lives in a small town near one of the metropolitan areas in Northeast Ohio where most of my fieldwork was done. During my fieldwork I came to look forward to the drive to and from Jerry's home, as well as our visits. Visiting Jerry for me, was reminiscent of some of my own memories of the "hippie" subculture of the early 1970's when I was an undergraduate at the University of Illinois. During that time I had become friends with a group of people working in a community drug-abuse rehabilitation facility. Visiting Jerry was familiar in the ever-changing array of people visiting or living at the house, the ramshackle look of the house and the second hand furniture, and the sometimes secretive talks about drugs, contrasted with Jerry's open conversations about his problems with drug addiction. The drive took me through some beautiful countryside; farms, woods, and small lakes, and I found the small town he lived in very appealing. Jerry was easy to talk to and had a lot to say. There was a college nearby and Jerry had attended for a few semesters working on a degree in psychology. He was insightful and very open and despite the disturbing composition of some of his narratives, he was a likable and humorous storyteller.

Humor

Before discussing Jerry's life story, I will introduce one aspect of the context of these interviews which is pertinent to the everyday life of many of the men who participated in this study. Much of the narration which I will present illustrates the sadness, and bleaker side of our conversations, as this is the data which relates most specifically to my
analysis. Yet when I read over the transcriptions of the conversations we had in conducting this research, I am struck by the frequent appearance of humor as counterpoint to the seriousness of what we were discussing. Jerry, who is the subject of the first life story I will discuss, expressed his sense of humor in the events and challenges of his everyday life and thought this was one of his best qualities. For instance, while talking about friends who are also in the HIV spectrum, Jerry says:

> People who aren’t HIV positive don’t understand. You can’t explain it. I laugh with a good friend of mine; we hardly see each other anymore. I called Frank on Sunday, but he’d already gone out for awhile and was exhausted so we missed each other again. For us, by the time we get out, dressed and down the steps, you don’t know if you want to do anything anymore anyway. It’s a sick joke but you don’t know day to day... Randy and me used to talk about that and joke - ‘Well I got dressed today.’ ‘I shaved today’ (laughs).

And talking about his philosophy of life:

> There are days I wake up and you think life is for the living and you’re part of the dying. I mean and you can’t shake that no matter what. Life is just one big disappointment after the next (sarcastic laugh) but I mean that’s all there is. I mean, you live with it. I joke about that, but... I don’t tell anyone anymore how to live life or not live life. When they’re ready to go they’re ready whether by choice or by disease, but I’m not ready. I laugh! You laugh at it! You can’t take it serious.

Both of these are examples of the serious and moving accounts of the difficulties and struggles which Jerry faces daily, yet to be there, talking with him, to see the mischievous smile and the engaging blue-eyed glance, to hear the sarcastic but hearty laugh, it’s hard to sort out the joy from the pain. For Jerry and others I talked with there were some days when there was no joy. Those were the rare but difficult interviews.
More typical was this point - counterpoint relationship between stories of a serious nature and humorous if sometimes caustic remarks. Reading over this and other transcriptions, I'm reminded of Laura Bohannon's novel "Return to Laughter" describing her fieldwork in Nigeria including a smallpox epidemic among the people she worked with.

Only in a very sheltered life of the sort made possible by civilization can one maintain a fine and serious sense of the tragedy of misfortune. In an environment in which tragedy is genuine and frequent, laughter is essential to sanity... Such laughter has little concern with what is funny. It is often bitter and sometimes a little mad, for it is the laugh under the mask of tragedy, and also the laughter that masks tears. They are the laughter of people who value love and friendship and plenty, who have lived with terror and death and hate. (Bowen, 1964:295-297)

I was frequently reminded of Bowen's assessment of the character of laughter and humor. Repeatedly, the men I talked with would reflect on "AIDS humor"5 or "sick jokes" and felt that this helped them through their darkest days. These men don't have the luxury of the "very sheltered life" Bowen talks of. Living as gay men with HIV infection has exposed these men to "terror and death and hate", as Bowen says, and though the laughter may be "a little mad", it is essential. Jerry says we have to laugh at the disappointments. Humor may serve essential functions; to allow us to talk about something not ordinarily talked about; to allow some release from pain and suffering; to help us feel more in control of a situation out of our control, and may serve as a "powerful [tool] for survival" (Jenkins, 1991:157).

5 Rob gives as example, when sitting with HIV+ friends at the walk-in HIV/AIDS center: A hearse drives by the storefront window, and someone yells out "hey, your taxi's here!" and everyone laughs.
But also, “it binds us together and promotes the closeness we need when we fear the unknown” (DeSpelder & Strickland, 1987:20). This is how Jerry’s humor, and others helped to define the “world” that Lugones talks about, when she refers to “world traveling”. I felt that Jerry’s laughter drew me into his world. The laughter was a shared experience. For me to laugh at his sarcastic remarks or the humorous irony of his stories was to share some of his perceptions of the experience.

Rick who I’ll talk about later in this chapter says:

At the clinic, we were talking about a guy trying to get out of going to jail ‘cause he’s overweight. I said I didn’t have to worry about that. I’m on the AIDS diet plan. The whole office went. Half the people went: ‘Oh God this guy’s twisted’, then the other half started laughing and everybody started talking to each other. And it doesn’t happen much in the waiting room.

Through the laughter, Rick describes the people in the waiting room; patients and nurses, apparently drawn closer through humor, opening up communication. Humor served an important function in many of the conversations I had during this research. It brought depth to our conversations, by closing the gap between our worlds, the worlds I was trying to bridge between researcher and informant. It also allowed conversations about what otherwise may have been too oppressive to talk about.

Timing: California Dreaming

In telling me his life story, Jerry’s sense of timing was primarily framed by changes in location. Timing serves to provide the organization for arranging and interpreting past experience (Kaufman, 1986:31). It
reflects the memory of the life course in terms of placing events in a
temporal framework. Timing focuses on the personal meanings of the
temporal context of the life course. It is not merely the structure of the
"sequencing" of events (Luborsky, 1990), but emphasizes meaning by
attributing valued characteristics to a particular time. In the following
example place and time are inextricably linked in the presentation of the
life course. In the stories Jerry told time was reflected by his location. He
outlined his life by first telling me the places he had lived in, in
chronological order. He mentioned moving between several locations in
Ohio, and Southern California. I asked about each place and time, i.e.
'Tell me about when you were in San Diego.' In talking about when he
lived in San Diego, Jerry related the following:

I was a [civilians] cook for the navy, occasional bartender which was
a scream because I bartended for officers wives; great paying; three
shifts and once you'd been there six months, short of killing the
president you couldn't get fired. It wasn't a great job - just a line
cook, but it paid good, and it was during gas rationing, and I didn't
have a car but I could always take friends on base and get gas, so we
didn't have to wait in lines.

Although Jerry found it difficult to remember dates, he occasionally
added information such as this historical marker of the gas rationing in
the 1970's.

Jerry further describes the time he was in California as divided into
the time in Los Angeles and the time in San Diego. He described time in
Ohio with respect to neighborhood or town in which he spent most of his
time. He was then able to describe each location in terms of sequential
events. Discussion of some topics would entail descriptions which
spanned time and location, e.g. HIV infection and treatment. Place, however, has great meaning for Jerry when he reflects on his life (Gesler, 1992). California was where Jerry spent the best times of his life:

...do odd jobs; whatever. For part of that I lived literally on the beach, but it was fun. You had your backpack; weren't tied down with a million things. It was pretty good; probably the best time of my life.

What was so good? The weather; the weather (sic); starting over; it was a whole new life... You were 2500 miles away from your life that you lived before. That was nice. That was the best part.

In contrast, for Jerry, his home town is where some of the worst times of his life have been, the life he was so glad to be "2500 miles away from". He gives the example of his home time during his high school experience:

I hated every minute of it. I was gay. I didn't belong. I had very few friends. Most of them were either older or younger. I got really bad grades; did a lot of drugs; never went. I did graduate. And I walked out with a four point, just to show I could do it, but, I had no interest in it. It was a very racist, homophobic society.

An understanding of Jerry's timing in telling his life story provides a hint of the framework in which Jerry will refer to his quality of life. Clearly, his quality of life was best in California and worst in Ohio. Why this is will become more apparent with further discussion of his life story.

The Pain of Living

The content of life story accounts is the actual narrative presented in conversation, and reflects the emphasis and value of events, relationships and ideas (Kaufman, 1986) or anything else of importance in
a particular story. It is important to remember that this content is filtered, firstly by the narrator's decision whether and how to present the story (Goffman, 1959), and secondly by my choice of whether and how to include the story as part of this text. For this reason, it should be remembered that it is the content of these stories that is being analyzed, and inferences cannot be made regarding the factual nature of events or representations. The relative importance of the content presented in the life story narratives is determined by the interaction between listener and narrator and as such reflects both individuals' attempts to address the task of this research (discussed in greater depth on pages 52–55).

The content of Jerry's narratives is primarily about the obstacles he has faced in his life. He focuses on the present pain and limitations of his illness and the impairment of his ability to work and achieve. He also talks about the difficulties of being gay in a homophobic world and of trying to overcome his drug addiction. About his physical pain and limitations, Jerry says:

And like pain's the biggest; pain and the fatigue right now.

They thought it was neuropathy and then they thought it was arthritis, and they don't know what it is, and I just don't care anymore what it is. I just want to be able to function. There's days I hurt too much, or days I'm just too tired; like yesterday I slept 24 hours. I just couldn't get out of bed. And I wake up stiff. I wake up sore.

If I felt good, Christ, I'd work everyday. I'd probably move. I don't know. I like working. I like the public. I like being busy. Even if I'm not working. I try to do something every day. Wish I felt better. It takes a lot of energy now to get stuff together to do anything. It hurts. I can't do it I can't.
I mean today if I could get rid of the pain and control the pain, then I could handle the life, y’know. It’s be a lot easier for me, y’know the fatigue, I could work with. But the pain, the other day, I was not suicidal, but you do want to kill yourself, where I thought of like laying down and cutting my legs off or something, cause they hurt so bad, you can’t describe it. And - and I have a high tolerance for pain. I’ve had pain, but I can’t live with this though.

Pain more than anything is the obstacle against which Jerry struggles. It is a struggle which he engages in actively and in conflict with his physicians. His regular clinic physician is leery of giving him pain medication because of his intravenous drug use, so Jerry uses his drug contacts to obtain illegal drugs to self medicate. The clinic staff see Jerry’s drug use as evidence that he is an “unreliable narrator” of bodily events, a voice which must be bypassed as quickly as possible to find ‘real’ evidence of pain. (Scarry, 1985:6).

Jerry’s perception is quite different:

And - and I have a high tolerance for pain. Y’know, I’ve cut my fingers off. I’ve went to a Dentist ‘til I was fifteen that never gives Novocain. I mean, stuff like that. I’ve had pain, but I can’t live with this though, and I’ll do anything; anything to stop it.

I get no pain meds. I can’t live like this. Is it because of my drug history? Doctor says: ‘Part of it is. And partly we don’t want to mask the pain. We want to figure it out. What causes it?’ Nice for them. And no tests in the past six months to help ‘figure it out’. I’ve gone through every one before.

Sometimes I’ve left the clinic thinking I’m crazy. The good thing of knowing so many other people with this is knowing they’re going through it too. So I’m not crazy or insane. The doctors look at you and say we can’t find anything so it’s psychological or can’t be happening.

During one of my visits to the clinic I mentioned how much I enjoyed talking with Jerry, and was impressed by his insight. At that, one
of the clinic staff looked at me with incredulity and said "But everything he says and does is so drug-seeking!". Jerry’s drug abuse made him ‘unreliable’, even in terms of having insights about his illness and life. The clinic staff doubted the reality of Jerry’s pain, and so did not feel they could justify treating it. This doubt, “the doubt of other persons... amplifies the suffering of those already in pain” (Scarry, 1985:7). Though Jerry says that knowing others in the same situation helps, he nevertheless is cognizant that he is one who is singled out to endure pain because, through his honesty in admitting his drug use, he is unreliable:

I have some friends who see one of the physicians at the clinic who writes them prescriptions for pain meds. It doesn’t do shit for me. They get [various narcotic analgesics] and other pills and they won’t even give me the time of day and I feel like I’ve been punished at that hospital for being honest.

People who are known to abuse drugs routinely receive less medication than non-users, despite the likelihood that they need heavier doses for pain relief related to their tolerance of lower doses (McCaffery and Vourakis, 1992). By describing Jerry’s complaints of pain as drug-seeking and unreliable, his clinical caregivers were able to minimize his situation as not real pain, thereby inflicting pain (Acker, 1993). They felt absolved from any responsibility to treat him, since there was no ‘real’ pain. Jerry suffered added emotional pain in feeling “crazy” and “punished”.

Pain for Jerry encompassed not only the physical pain which he described, but the pain of living. He says about people in the HIV spectrum: “The people I know have to face life everyday and it's a battle.
And so HIV is just one more brick around their necks that they’re tired of fighting (laughs).”

He is a survivor of a hostile world; one in which he tells of being beaten, raped, and ridiculed; one in which he has witnessed many friends’ death, and now one in which he is denied relief from physical pain. The content of Jerry’s stories reflects an intense focus on pain in his everyday life. Consider that pain has:

more to do with life - and specifically with the aspect of life which is dark and terrible and, therefore, denied - than with a disease process. Perhaps the healer and the family, like the historian of human misery, must allow themselves to hear - within the symptoms and behind the illness, especially for the complaints of those of us who are most ordinary - the wail. (Kleinman, 1988b:87)

Work for Jerry, is important to his perception of quality of life. Not only does work reflect culturally relevant values, but it is also a source of socialization: “I like working with the public”. Of course Jerry would be disappointed at not being able to work! However, Jerry also talks about laughing at life’s disappointments. Was the inability to work so important that his quality of life was overwhelmingly affected by it? Even though he mentions his high pain tolerance, was it the pain that was so bad he thought about cutting his legs off which caused his perception of this as one of the worst times of his life? Or was it the objectification of his pain as drug-seeking, or at best a symptom of disease which must be studied, which caused him more distress (Kleinman and Kleinman, 1991)?

All of these things must be taken together if we are to understand the impact of pain and fatigue on Jerry’s quality of life. Particularly
important is the meaning of pain. Jerry's pain is inability to work, which is inability to interact with the public. Pain impairs the simplest activities; walking, or even resting. Untreated pain is evidence of his devalued status as drug-addict. From the excerpts above, it should be clear that this delegitimation of his pain compounds existing suffering to a point where he refers to it as something he "can't live with". Jerry indicates that "the last five years" has been one of the worst times in his life: the poorest quality of life.

As Bluebond-Langner (1978:254-5) reflects, I too felt impotent to help Jerry who was doing so much for me, giving himself as data for a research project which would have such immediate benefit for me as work toward my Ph.D. I worried about whether my research would benefit Jerry or others in similar situations. I knew that in my present role there was little I could do to influence whether or not Jerry was given pain medication. I believe that I would be considered an unreliable witness as well by the clinic staff, by virtue of not using 'professional distance'. Professional distance is a pervasive, though debatable (Pettigrew, 1990) concept in medicine, nursing and other health professions in the U.S., referring to maintenance of objectivity in clinical practice. This distance which objectifies pain as something which may be observed and evaluated by another, protects a clinician from the "feeling of being overwhelmed by patients' demands; but it also may cut him off from the human experience of illness" (Kleinman, 1988b:225). Indeed, I was overwhelmed by Jerry's "demands" as I sought to understand his "human experience".
Jerry eventually convinced his physician to give him adequate pain medication, however it took more than six months. Had he finally been able to break down the barriers of distance and suspicion by his clinical caregivers? The answer is beyond the scope of this project, but I hope that he is being seen in a more human light, and that his demands are seen as comfort seeking, rather than "drug seeking". During my last visit with Jerry, nine months after we first began, he told me his physical pain was "better" because of the medication he had received, but he says it's never enough to eliminate it. Yet I couldn't help feeling that the emotional pain remained. Jerry no longer sought out illicit drugs to manage his pain. He still talked about relapses in his drug abuse, though these appeared to be less frequent occurrences. What was the source of this other, unspoken pain? Before I address what may be the answer to that question, I will discuss the style which Jerry often presents in the stories he narrates.

Style: Self-Reliance and Survival

Kaufman (1986:31-2) talks about style as it relates to thematic interpretation of life stories. She equates style to "impression management" (Goffman, 1959) where a particular image of oneself is filtered and sustained through the narration, an important function of narratives about the self (Tarman, 1988; Riessman, 1990). (Impression management involves the speaker presenting an image to an audience, and so relates back to my earlier discussion of the necessity of knowing the audience and context of the conversation as well as the speaker.)
Jerry’s talks about overcoming obstacles. Maintaining his sense of humor is part of his style in struggling to overcome these obstacles or in surviving the struggle. When Jerry says that life “is one big disappointment after another”, he is able to laugh at the disappointments. It is one of his strengths, to laugh defiantly at life’s disappointments. In the content of his narratives he relates his perseverance in enduring of a great deal of pain and suffering: “I think living is sometimes more... a lot more times than is dying... that’s where the struggle is. It’s been a real struggle.” The following series of statements which Jerry made presents himself in terms of how he struggles against and confronts the obstacles in his life:

My best qualities are my sense of humor and my loyalty to my friends, but I think I get that in return. They’re very loyal to me. I’m a survivor, no matter what, y’know? I can make ends meet. I can get through anything. I guess maybe I get that from the streets, y’know? No matter what happens, you gotta keep going. I can get through anything. I can handle anything. The flip of that is, I guess, my inability to say no; no to people, no to things I really don’t want to do. Y’know, no to coming back to Ohio. I really was gonna (laughing) consider faking my death cause I really dreaded coming back to this state, but I did it, for family - whatever reason - sense of loyalty or something.

Successes in my life? Surviving as long as I have. I only came back here for a year. It was fun, I guess, to make the business run. Certainly the odds were against me. I hated coming back to straight white America but it was kind of fun for a couple years; making it work, whatever it took. I guess beating the odds on that was good, and when it worked real well it was real good.

These are other aspects of Jerry’s style. He is loyal to those he cares about, but self-reliant and able to survive against the odds. To be the kind of “survivor” that Jerry presents himself as, is to be able to conquer
adversity and to achieve through his autonomous efforts. Though he mentions loyal friends, his achievements are described in the first person. It is his struggle and he faces it with an attitude of self-reliance.

Individuals evaluate themselves in terms of their cultural ideals of self (Hallowell, 1955; Watson and Watson Franke, 1985:199) and their lives in terms of cultural ideals of what a life should be (Langness and Frank, 1981). Jerry’s descriptions of survival exemplify American cultural values of achievement and self-reliance (Kaufman, 1986; Hsu, 1972). These are ways in which he sees his life as synchronous with his cultural values. Achievement and self-reliance are some of the ideals upon which Jerry evaluates his life.

Themes

Jerry presents his narratives in terms of his struggling to overcome the obstacles which threaten to prevent his achievement, succeeding through self-reliance and perseverance. This is a fundamental theme which is recurrent in his stories. By theme, I am referring to Kaufman’s (1986:25) definition: “(Themes are) cognitive areas of meaning with symbolic force — which explain, unify, and give substance to (persons’) perceptions of who they are and how they see themselves participating in social life.” Jerry’s theme of struggle gives meaning to and explains his style. He is self-reliant and perseveres in overcoming the obstacles which he struggles against, and this exemplifies culturally relevant values. This theme is also powerfully relevant to Jerry’s current struggles relating to HIV infection: the pain, his inability to work, and the
length of his survival. This theme and associated stylistic orientation were found to some extent in the narratives of fifteen of the twenty study participants, though not necessarily as a dominant theme (Table Two).

Jerry's theme of struggling against obstacles, and surviving, has served him well in terms of concrete accomplishments, e.g. making his family's business run. He contributed to keeping the business alive as an individual, again through self-reliance and determination:

We bought the business 'cause our old landlord was forcing us out. He thought he'd get it back in a year. I got real bitter. He sold it to three other people and always got it back and I refused, y'know? I sold drugs on the side. I turned tricks, I did anything to pay the bills so the fucker wouldn't get it back, and he was pissed.

His emphasis on doing anything also implies self sacrifice. Though he describes this part of his nature as a fault, (his inability to say, 'No'), it reinforces his sense of loyalty and commitment.

Another aspect of his style is his loyalty to his family and friends; evidence of his social worth. Jerry feels a deep commitment to friends. Several times he mentioned helping various friends who were sick. He said that his friend, Randy also was experiencing pain. Randy would get drunk when he ran out of medication, in order to numb the pain. I was at the clinic during one instance when Jerry called to say he and Randy would be a few minutes late because he was having trouble getting a cab to pick them up. Though Jerry doesn't drive, he asked a friend to take him to Randy's house where he could arrange transportation for both of them to the clinic. There were several phone calls back and forth between office staff and them. When they got to the clinic, Randy was quite drunk. I talked to Jerry in the lobby.
He knew that spending time helping Randy involved the possibility of his missing his own appointment, but he knew Randy’s situation; that he needed someone to get him to the clinic or he would just keep drinking and miss his appointment. If he missed his appointment he wouldn’t get his medication. If he didn’t get his medication, he’d drink to numb the pain. Jerry wanted to help Randy with this double bind which he understands so well as it is so like his drug use for pain.

Reminiscence

Jerry talks about being a survivor in terms of living for such a long time after infection with HIV, which he estimates at greater than twelve years. His stories of surviving difficulties and overcoming obstacles of the past are applied to present problems. Watt and Wong (1991) call this type of reminiscence “instrumental”, where past experiences in coping with difficult situations are drawn on, to deal with current difficulties. Jerry draws on his history of self-reliance, by self medicating, so that he may survive the pain, both physical and emotional, of the present.

Watt and Wong (1991) suggest six types of theme narration or ‘reminiscences’: 1) integrative, attempting to give coherence and meaning to one’s past, 2) instrumental, drawing on past experiences to solve a particular problem, 3) transmissive, attempting to impress upon the listener the importance of learning from the subject’s life experiences, 4) narrative, descriptive or factual accounts, 5) escapist, dwelling on the
past as 'the good old days' to avoid or compensate for an unpleasant present, and 6) obsessive, preoccupation with particular past events.

Individuals may employ a number of reminiscences in presenting life story narratives. In each of the life stories presented, I will focus on the type of reminiscence employed in presenting the particular theme being discussed but it should be understood that narrators invariably use more than one type of reminiscence. The fourth type of reminiscence for instance, narrative, descriptive or factual account, is used by all participants at some time for the purpose of providing pertinent biographical information, e.g. dates of events, names of persons.

Loss of History - Loss of Meaning

Randy is one of Jerry's closest friends. His friends are very important to him, but so few remain. He describes the loss and emotional pain he feels:

But I've probably outlived 85% of my friends, so that's weird. You meet new people. Some get sick. Some don't. You don't really want to meet new people. You went around straight people and they live forever. It's different. It's just not the same.

But sometimes you feel guilty. Why am I still alive, and some of these kids who just found out, I mean especially guys who just recently, that are just getting it and going in two years.

There's not much good going on at the moment. I have four real good friends that aren't going to make it through the summer if they make it through the spring. It looks like I'm going to, but I'm not too sure I want to some days. It's not that I'm depressed. It's just after, I even figured you've outlived y'know everybody, y'know?
HIV is not living sometimes. I lost most of my friends out west real quick, New York, real quick. So very few friends left alive there, and then when it started hitting here... I have no sense of history anymore. I pretended for a long time, like an answering machine. You pretend they call you back; get back to you, leave a message. That just doesn't happen. They don't call back so you can't say 'Remember when we did this, went there?', 'Remember so and so, so and so', well there's no so and so to remember. So that's just erased, gone.

Jerry's feeling that he has no sense of history implies the vulnerability of his memories of the past; an interruption in the continuity of the self through time. If Jerry loses his sense of history as this entire network of friends dies, the continuity of his life is interrupted. The personal narratives of the life story represent memories which are experienced in the present as a consistent or integrated understanding of past events (Cohler, 1982:212–213; Kaufman, 1986:150–151).

Perceptions of place and time are an integral part of how we organize self knowledge. Where and when events occur defines the self in relation to it's environment giving the self continuity through time. An interruption in self-continuity is a disturbance in the "spatiotemporal orientation" of the self resulting in distortions of memory. (Hallowell, 1955:92-100). But are Jerry's memories distorted?

What's interesting here is that Jerry's memory "loss" relating to the death of his friends is not distortion or amnesia. It is a paradox where he is able to state the content of the memory that is "erased". He is aware of the past, but it has lost its validity. Though he talks about this in terms of 'remembering' as being erased, he retains memory of the event. It is the
meaning that is lost. Jerry can share the story, but no one he can talk with shares the act of remembering this event.

The meaning of the story, as I've mentioned, is dependent on the context. There is a particular context in which a single event is remembered as an experience common to both teller and listener(s). The meaning is dependent on the context, which in this case is irretrievably lost, therefore this particular meaning of the memory is lost. It is a meaning which is important in terms of Jerry's social relations. It is the meaning of a shared history in a community of individuals.

"Stories about one's own experiences provide an important resource not only for establishing one's place in the community but also for identifying one's identity..." (Abrahams, 1986:54). There is no more community within which to share the remembering of these experiences. Because of Jerry's increasing physical limitations, it is more difficult to form a new community within which to establish a place and identity. Jerry describes this as losing a sense of his history. Shweder and Bourne (1984:191-2) talk about the inviolable "inviolable self" in Western culture. The horror for Jerry is that the continuity of his self has been violated. He has lost the meaning of part of his history and has lost self-continuity with it. The linkages to his past have been damaged.

With no one to share it, Jerry's history is vanishing. This is perceived as a disturbance in the structure of his everyday life. "There's no so and so to remember", no one to call on the phone, no one to talk with who can remember with him. This time is unlike any other because in it, this element of the past has lost its meaning. As members of the
community disappear, the meanings generated by shared remembering disappear.

People can "create new meaning as they reformulate and build viable selves. Thus, creating identity is a lifelong process." (Kaufman, 1986:163). The expression of loss of history reflects the damage Jerry sustained to the continuity of his past and the pain he still feels at the loss. The sheer number of how many of Jerry's friends died, coupled with his own increasing debilitation and pain has created what Kastenbaum (1969) termed bereavement overload. Jerry has seen the frequency and intensity of these two patterns (Fitzpatrick, 1989) of recurring life events increase dramatically, and has felt the effects in some part, as a loss of meaning of past memories of individuals.

This overload of losses is all the more intensely experienced in the context of Jerry's understanding of what is normal. He makes frequent reference to his frustration in seeing healthy, young (gay) kids, and "straight people", and at the same time, feels it would be too depressing to "sit around with a bunch of old queens, waiting to die." I propose that what makes these losses even more poignant is the lack of synchrony with the life course that Jerry, growing up in the U.S. has come to expect. By synchrony, I refer to the comparison of one's own experiences with the cultural ideal (Gerson, 1976) and the range of what is culturally acceptable (Hagestad, 1990).

Interestingly, in Hagestad's review of the literature on life course, she discusses the need to elicit emic views of what is normative. As far as his own foreshortened future, Jerry talks about his perception of what is
normative; not wanting to be around "straight people... they live forever", and wanting to live to be "a crotchety old man". Still, as Craig and other men I talked with said, "there are numbers of people in the world that have terminal illnesses of long or short duration. They're not that dissimilar." The implication is that though far from the ideal, having a terminal illness is not outside of what may be expected in the broader range of an expected life course.

I would propose that the loss of an entire network of friends to disease could not be an expected occurrence for the men in this sample (Moynihan, Christ and Silver, 1988). Prior to the advent of AIDS in the U.S., there was no precedent for experiencing this type of loss due to disease for those in the generation from which my sample was taken. Including myself in this generation, we grew up in a world where deadly epidemic diseases were eliminated from our immediate environment (there are few who even remember the polio epidemics ending in the 1950's.). Our newspapers touted the destruction of smallpox worldwide. In academic writing, we in the developed world were seen as emerging from the age of epidemic disease (Omran, 1971).

For Jerry, losing all of his friends was asynchronous with his own expectation of what this time of his life would be. This cascade of losses is overwhelming, and not even remotely within the bounds of what had been Jerry's understanding of the normative life course in the U.S. for the greater part of his life.

But at the same time, by including this story of the loss of meaning of these memories, Jerry is integrating the death events of his friends into
the continuity of his life story, creating new meaning. There is a point to be made by this story of loss and there is new meaning created. He tells this story as a means of expressing a present without history, "a moment in and out of time" (Turner, 1969).

Liminality & Marginalization

In our ordinary daily lives, we accept the uniqueness of the present and its relationship to a past and future, (what Sullivan (1953) calls syntaxis). Jerry lives in a world where the ordinary structure of life is disturbed. The past is fragmented; the future uncertain. Jerry suggests:

You know, it's hard to make decisions. It's hard to make long term plans, So I end up living more moment to moment, more than anything. When you have this thing in here, it's like a time bomb in your body ticking, ticking, and you just never know when it's gonna go off.

I don't feel like I'm alive. I don't feel like I'm dead. I feel like I'm in a limbo.

It is the experience of feeling in between, not alive, not dead, that alters Jerry's perceptions. He has always felt apart from others. "I've been beaten up on the streets and beaten by the judicial system. We're an oppressed minority. We grow up in their world and we know that everyday our lives are at risk because we're gay." But at the same time he always identified with others in his minority, and recognized that, though different from the cultural ideal, he also had to function in "their world". But this situation is different. This is not merely feeling marginal as a minority. This has the uncertainty and temporal ambiguity of liminality.
Self-Reliance and Compliance

Jerry’s experience of marginalization is clearly defined as far as being HIV positive as well as gay. He talks about “life being for the living” while he’s “part of the dying”. He frequently alludes to his inability to work and the importance of work in his life. He acknowledges his disability but resents it. His status regarding HIV infection is unpleasant but he sees it as stable:

I haven’t had any AIDS related illnesses; neuropathy, but that’s from the drugs; headaches, and that’s a result of the drugs; had pneumonia a half dozen times, but never PCP. I’ve had thrush and that’s the worst one I’ve had, coming back and coming back. My T-cells are 300 plus. I’ve kept them over 500 for years, or they’ve stayed there, but they’ve dropped. They fluctuate so much I don’t put much on T-cells anymore. Fatigue; I don’t know if that’s from the AZT or from having hepatitis in ’80, and that took me months to bounce back. Even during the ’80’s up til ’86 - that’s when I really began to slow down, it’s only in the last two, three, four years, I’ve really slowed down. I think I’ve stabilized. I don’t think I’m losing energy. I’m not gaining it back.

But sometimes it’s real depressing. You don’t see that ever coming back in your life. You can gain weight or slow down or do anything else in your life and think you can get back in shape, but I don’t have that illusion anymore. I used to think I’d get in shape next year; say “I’m gonna kick this!” But I just don’t see myself kicking this anymore. It’s hard; depressing. It’s frustrating to me. I don’t know what I have to look forward to. It’s hard to describe because I’m not suicidal, not nearly ready to check out. I just don’t know what. How do you define your life? What do you do? I feel like I should be retiring in Vegas or something. It’s weird. You feel like sometimes you’re 75 but you don’t have the options of a retiree.

You’re kind of forced into this weird space. You’re not retired and you’re not really disabled, but yet you are disabled and you are retired.

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Jerry's experience of pain and fatigue has precipitated a liminal period. He relates a prior status of self-identification with some of the content of his themes of overcoming obstacles having to do with work; making a living and keeping the business open as activities that demonstrate his self-reliance and lead to achievement that enhances his quality of life. In contrast, his present situation is one of being disabled, and relying on others; the clinic (or the streets) for relief of increasing severity of symptoms, particularly pain, and various governmental financial support programs. The pain and fatigue limit his ability to work. He has severe pain he feels for days after he works too much at the bar, or doing any sort of project at home. In order to obtain his pain medication, he must repeatedly return to the clinic, and talk about his pain to the physicians and nurses. This talk must reflect his compliance with, (obedience to) the prescribed plan of treatment. He had to be evaluated by a neurologist and psychologist as well as social worker, the clinic nurses and clinic physician. He had to present himself as obedient in not using illicit drugs for any reason as this delegitimated his pain in terms of the medical pain management. In this new status, it seems self-reliance is devalued.

Jerry's stories of self-reliance, 'doing whatever it takes', made his drug abuse all too evident. To use illegal or illegally obtained drugs for any reason was drug abuse. (For a physician to knowingly prescribe medication for the purpose of 'recreational use' is illegal and puts the physician at risk of professional and legal sanctions.) Jerry must only take drugs prescribed by his clinic physician (in conjunction with referred
specialists) for pain management. This is an issue of compliance. In chronic illness in the United States, "compliance is critical to control and amelioration of disease, and the patient's full participation in treatment has become definitional of the disease." (Alexander, 1982:365). If Jerry is non-compliant he is considered responsible for his pain because he prevents the physicians from treating him without professional and legal, as well as moral risk. Compliance has strong ramifications for someone who sees themselves as independent and self-reliant. These values are a disadvantage for someone who is expected to comply, to do as he is told, and to trust those who have refused to alleviate his pain in the recent past. Jerry's new status included this sick role (Alexander, 1982).

During the course of my interviews with Jerry, I believe he was negotiating with himself and others, a change in roles. He was becoming severely disabled by pain and fatigue secondary to his HIV infection and treatment. His pain was the most frequently mentioned symptom, but his other symptoms, e.g. anorexia, fatigue, sweating and confusion, were increasing in severity. To find relief for his pain, it was necessary for Jerry to trade his self-reliance for compliance with behaviors prescribed by his clinical caregivers; physicians and nurses. He was no longer working and so could not remain self-reliant in that way. Through understanding Jerry's life story, we begin to understand another factor influencing the deterioration of his quality of life. Not only have life events in the form of his physical deterioration, and the death of his friends challenged his quality of life. But he was unable to use his style of self-reliance as a resource.
The Feel Good Days are Over

All these changes, (falling T-cell counts, increasing symptoms, diminishing work activity, and restricted drug use), led up to this changed status. The medical treatment he receives now lessens the pain, but doesn’t help the fatigue, the sweats or the confusion. Jerry may have had the virus for more than ten years, but only now is he fully taking on a sick role, experiencing chronic illness and loss of ability to function publicly through working.

The borders of when Jerry was in a truly liminal phase are blurred. From our conversations, I believe there was a time period during which Jerry was negotiating with his physicians and with himself, regarding his increasing debilitation. It was during this time that he described himself as being in a limbo between life and death, being retired and disabled, but not retired and disabled, and of feeling that his history was being erased. Jerry was hospitalized at a community hospital for a week during this time and underwent extensive testing. This life event was a crisis period for him, entailing an emergency room visit resulting in admission to the hospital. This crisis, involving emergency hospital admission, and abnormal test results, was followed by an abrupt change in Jerry’s treatment when he returned to the Special Immunology Clinic.

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6 Jerry had a spinal tap which left him with an even more severe headache for which he had to go to the local emergency room for treatment. (He jokingly said that he thought the doctor was saying “this will teach you to complain! You want to see a headache? Blam!”.) He was then admitted to the hospital and underwent additional testing involving magnetic resonance imaging (MRI) which was used to create images of his brain for evaluation. The MRI showed a small cyst on his brain, but it was not determined whether or not this was the cause of his headaches.
My doctor had started me on Morphine Contin (sustained release narcotic analgesic) and then about two weeks after I got out of the hospital; upped the dose without my asking for it, then helped with the sinus thing, and also started the Marinol7 for my appetite. I'll go to the clinic at eight in the morning to see my regular doctor and the psychiatrist. I'm not doing cocaine which makes them happy so I guess I'll get the pain pills. I don't know what changed the doctor's mind; never said, but after seeing the psychiatrist and doing Zoloft and all the other stuff, they said try this.

During each of the six interviews prior to this, Jerry complained that the physicians at the Special Immunology Clinic were refusing to give him pain medication, that he was suffering because of his honesty about his drug abuse. He frequently talked about finding another clinic or physician. From the time of this interview, and over the next few months, Jerry no longer complained about his treatment, though he did complain about his continued physical deterioration.

The pain crisis which initiated Jerry's admission to the hospital was a life crisis which separated him from his everyday life. Before this his complaints of pain were suspect and he had to fight for any palliative medications. After discharge, his pain seemed to be legitimated, and his physician attended to Jerry's headache and generalized pain, as well as his anorexia without prompting. Whether this was a result of the 'physical evidence' of a cyst on his brain or whether something else about his hospitalization may have in some way validated the severity of his pain, he was no longer seen as inevitably abusing medication and was entrusted with prescriptions which would ease his suffering, both of which were controlled substances. The pain crisis was certainly the core

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7Marinol is a marijuana derivative used to stimulate appetite in cancer and AIDS patients.
of the liminal period, during which he made the transition from seeking drugs for recreation, to acceptable use of drugs for pain relief.

This also entailed a change in illness status. He accepted this new phase of his life, where he could no longer expect to fully recover from the "800" bouts of pneumonia, and the recurring thrush. Now he'd always have some pain and some fatigue:

Well I don't think I'm bitter or have a doomsday attitude, but I think somebody should write a book about the feel good days are over. There's not a pill or a dick or a drink or a place to move that's really gonna make you feel better about yourself. Life is just what it is. You can change it for short periods of time, maybe go to South Beach for a while, but eventually I'm going to have to go back to my horrid little life.

I could live like I feel now and keep going, but certainly not all of the enjoyment in life. There are a lot of people that feel lousy everyday for other reasons and you get used to it. You really do get used to it.

Jerry applies his general statement of "the feel good days" being over to himself. He implies that he will get used to this new phase of his life, but that he's lost some of the enjoyment. His quality of life is lessened.

Jerry's certainly not happy about his situation in life now. He doesn't return to the theme of doing whatever it takes to survive, but it's implied in his "getting used" to changes that define his enjoyment of life. Overcoming challenges is implicit in the stories Jerry related to me; making the business run against all odds, and surviving his "fast life; hustling and drugs". He even related, as a teenager, getting into trouble breaking into stores, and school. "We'd play basketball and get caught; just for the challenge of it." For instance, though Jerry talks about "the
feel good days being over”, it’s in the context of a continuity in his life; his strength lies in his ability to endure the struggle, and that keeps him going. “No matter what happens, you gotta keep going. I can get through anything. I can handle anything.”

In addition, Jerry sees himself to be within the range of what is acceptable, though not ideal. “A lot of people” feel lousy everyday, but they go on, implicitly there is a reason to go on. Some of the enjoyment of life remains. Jerry is trying to retain the quality of life he has, and possibly improve it, creating new meaning by integrating his present situation into his life story. He is physically limited but within the range of what is tolerated by many others. He has always been a survivor, and that is his primary task now. But his social system is still dominated by feelings of loss. He has for the most part lost his self-reliance, and it is likely that he will continue to experience an increasing frequency and severity of illness related life events. Because of this, it’s likely that his perceived quality of life is at risk of further deterioration.

**Rick**

Like Jerry, Rick has also lost many of his closest friends and also expresses the feeling that he is in a liminal or marginal state of being between life and death.

The way I feel it’s like: If I’m going to die, let’s get it over and done with now. I’m tired of being in this gray area of half alive and half dead. So I feel like I’m in limbo, or purgatory. Because you can’t do everything you used to but you’re still active enough to go on living. It makes it very purgatory-ish, you could say. In the long run, I wish it was all over and done with. Either find a cure or let
me die. There's no gray area left for me, but I am in that gray area. I usually feel that way when I am feeling sicker. If I'm feeling pretty good and can do my daily activities, I don't think about it, but like in the last month with my gland being swollen and this thrush problem, you know? And then also seeing Larry go through what he just went through. It's like let's get it over with. Do something now.

When Rick talks about experiencing life like he's in limbo or purgatory, he's referring to a recurring state of liminality. Each time he feels ill he is repeatedly thrust into the liminal experience with an awareness of death which leaves him questioning whether he even wants to continue living. When he feels better he no longer thinks about it. He only thinks about this being in between "when he's sicker". It is then, during this liminal experience that he gets depressed. When Rick gets sicker the possibility of further deterioration emerges, and death becomes a very real possibility. "When I can't drive anymore and have to use a walker and stuff like that - I'm gonna off myself somehow." Rick anticipates changes in his situation that will lead to this disabled phase of illness. In essence, each time he becomes ill, he reenters a liminal space hoping that his reaggregation will be as recovery and will not entail greater disability.

Rick is about the same age as Jerry, but grew up in one of the distant suburban neighborhoods relative to the metropolitan area. I recruited Rick from the ACTG though he was also a patient at the Special Immunology Clinic.

Rick lives in the first floor apartment of a double house. It's a large white, wood frame house. During my visits, we sat in the front room. He sat on the couch and I faced him in the chair with the tape recorder on
the coffee table between us, (except at Christmas when the house was rearranged and we both sat on the couch). Rick's house had an open feel to it. There was a minimum of furniture. The furniture was well used but in good condition, and everything always had the appearance of being recently cleaned. Rick also had several cats, who would occasionally wander by as we talked. Visits to Rick always felt fairly formal. It seemed like we always got down to business with the taped interviews, and then I left. I never felt that I was quite able to break out of the interview mode into casual conversation as I preferred. This limited the amount of data I was able to obtain from Rick, and points out the difficulty in eliciting information of this type. However, the data I did get is sufficiently rich enough to afford an understanding of this presentation of himself and his life. It should be understood that this is the case, to some extent, with all of the study participants.

I often felt that Rick was holding back on telling me much about his thoughts and feelings, and was reticent to talk about the things he cared most deeply about. For instance it wasn't until the last interview that he told me about the men in the social club he belonged to. These were his closest of friends; the friends that he talks about when he talks about his friends who have died from HIV infection. I later learned this was part of his style in life. He acknowledges not "being in touch with" his feelings and being reluctant to trust others. He notes these characteristics as weaknesses.
Rebuilding Social Networks

Rick lives in one of the neighborhoods in the Edgewater-Lakewood area of Cleveland with several gay bars, clubs and restaurants as well as gay owned businesses and a visible gay presence in general. He was one of five men I talked with who lived in the general area. When I first drove down his street, I saw a rainbow flag\(^8\) hanging by a doorway, but on checking the house number, realized I was still a few houses away. Many of the gay men in the area had rainbow flags, streamers or windsocks outside their houses and I sometimes used this to help me locate or identify houses of people I was visiting. On Rick's street I noticed three more houses on the street, also with rainbow flags. In this respect, Rick's neighborhood is the antithesis of Jerry's. Where Jerry saw himself surrounded by "homophobic white America", Rick lives in an area where he meets and interacts with other gay men throughout the activities of his everyday life.

Rick did some part time work for two of the businesses in the area, both owned by friends he knew from the local gay community. Rick's social network is composed in the large part, of gay, HIV positive friends. He says: "Quite a few are sick. I do what I can to help them. Two to three days a week, I'm either visiting someone in the hospital, or taking someone to the hospital or helping them out however I can." Rick, like Jerry, experienced the death of much of his network of friends. During my second visit, following the death of one close friend, he said:

\(^8\)The rainbow flag is a symbol of gay identity and pride, commonly used as a porch or front door ornament among the white gay male population from which my sample was obtained.
A lot of my friends have died; quite a few; twenty to thirty, and half of those in the last five years. How has it affected me? I don’t have as many friends as I used to. I’ve always been shy so it’s hard for me to make new friends. I don’t have the contact I used to have, so it’s kind of sheltered me. It’s made me wonder about a lot of things. People say to keep on going; keep on fighting. But it almost makes me want to give up. I’ve got no friends left. There’s really not much left to live for. It makes me kind of not want to fight anymore. When I’m feeling pretty good and things are happening a little better, I’m up and like maybe today is gonna be a good day and I should fight a little harder. But the days where I feel the opposite are more than the days that I feel like I want to fight.

The “contact” Rick is talking about, as I found out later, is in terms of the club he belonged to, which he felt helped him to overcome his shyness.

About four months after this interview, Rick and I talked about the idea that losing so many friends was like losing some of your history or memory. He thought that was a good analogy, but didn’t focus on it at the time. He said: “You just gotta keep on building and making new friends when other friends go away. It’s taken me a while to realize that.” When I asked him what made the difference, what event might have made him come to this realization, he told me:

I feel better. [laughs] I’m a little happier and don’t dwell on things much. I may not have much time left and I need to make the best of what time I’ve got left and If I’m feeling sorry for myself and shunning everybody then I’m gonna be miserable my last few years or whatever, and I didn’t want to be like that [laughs again].

Jerry lost the meaning of past events that could no longer be shared as a common history. In contrast, Rick says: “I still have my own memories and that’s what I keep thinking back on.” What is it about Rick that makes him more resilient to the impact of this loss of large parts of person’s social networks? Possibly, as he suggests it is because he feels
better. He is certainly more active, still able to work for short periods of
time to supplement his disability. Perhaps he simply has the energy to
make new friends where Jerry doesn’t.

When Rick presented his life story and narratives of his present
situation, his timing for organizing and interpreting stories of his past
and present was much richer and more detailed than Jerry’s. Rick
primarily places events in his life on a time scale which emphasizes the
comings and goings of important others in his life: “when I met Gary”,
“when my father died”, “when I moved to Avon with Brad”, and further
describes times numerically by year or his age at the time. He also
integrates broader historical data as explanation of cause for events. For
instance, he talks about leaving school to change careers as a response to
the difficulties of the historic period: “A lot of people were graduating
when I would have been, 1975, and there were not many openings during
that time in my field”, referring to the recession and high unemployment
rate of the time.

His timing by the coming and going of others will be seen to be
important in his daily life as will be seen in the following discussion.
During the course of my visits, one friend died, and at least one
hospitalized for HIV related illness. He also talks about actively making
new friends. People continue to come and go through the stories of his
life.

Rick talks about himself and his history:

My father died when I was nine. I guess I didn’t really have a
childhood. My older sisters were on their own and ignored
everybody else. I took care of my younger brother. My mom was
working all the time. Growing up was a little difficult, lonely. I
grew up overnight.

I was always shy and introverted. I was always getting picked on by
the bullies in the neighborhood. But I was smart, and looked out
for everybody else, but not myself. I was by myself even though I
had friends next door when I was growing up. It was difficult. I’m
still by myself a lot.

I’m like my mom. She’s quiet and doesn’t express her emotions
well either. She gets angry at bizarre intervals at dumb things. She
also was sick too; had a heart attack about two years ago.

I’ll do anything for a friend, if they need it. I’ll help them by giving
my friendship I guess. But I’m selfish too. It’s contradictory to
what I said, but I can be very selfish with personal, material things.

I don’t express my feelings well. That’s kind of a down side. I build
up little walls around me so nobody can get close and hurt me. I
have close friends but there’s very few of those I’d let get that close.
Larry’s the only one who’s that close. Otherwise, I’m building
those walls; just enough so I can see over and not let anybody get
close.

Part of Rick’s style is to help others, sometimes at the expense of his
own needs. He helped raise his younger brother and had to go to work
when his father died. He now helps friends who are sicker than he is. He
related quite a few incidents of helping friends; taking his friend Larry to a
doctor’s appointment and then for tests, house-sitting for friends,
working extra for friends who had business and needed help during a
particularly busy time, “and lending an ear” to his sister who was in the
process of divorce.

Like Jerry, Rick is self-reliant, and independent. Maintaining his
independence is very important. This is emphasized when he said he
would “off himself” when it came to a point that he couldn’t drive or had
to use a walker. He is willing to take care of and help people he cares for, but resists being dependent. With regard to his past actions he accepted "consequences" in the future as less important than being able to live for the moment. He sees his HIV as a consequence of past action, but acknowledges that no one had any knowledge of HIV at the time he believes he was infected which he estimates to be thirteen years ago.

Rick describes his style as having changed over the years as a result of maturity:

Since I was in my twenties, I’ve always had an attitude of living for today, and there’s consequences that I’m gonna have to pay for later down the road. So be it, but I’m not gonna beat myself up over it. So you just keep going on. That’s all you keep doing, and not worry about what you done in the past.

I’ve changed. I’m more cynical, less trusting, more practical about life; just with age. When you’re twenty, you don’t care about tomorrow; just living for today. You know there’s a tomorrow, so why worry. Now that I’m pushing 40, I feel differently. I’m not gonna get any better unless I do something to do it myself. So you gotta look ahead. And I’ve changed that way.

He accepts responsibility of present actions for future well being. Living for the moment has become secondary to future well being, instead of consequences being secondary to living for the moment. Both concepts elevate responsibility as the important attribute. He accepted responsibility for consequences when he lived for the moment as he did when he was in his twenties. He accepts responsibility in "doing something" today to insure a "better" future in his present situation. This is also part of his style. Rick is responsible and autonomous. He believes that he determines his future through his actions. His focus has merely shifted from 'living for today' to 'looking ahead'. The style
remains one of being able to influence the future through action and accepting responsibility for both action and effect. The dominant theme in his stories is one of taking responsibility for his future by his actions today. His future is, to a great extent, what he makes it to be.

He doesn't trust many friends to be close to him, and always keeps guard over his emotions to avoid being “hurt”. If he does trust someone else, he demands the same trust in return:

I’m not one to have relationships. I had a lover a few months ago. I was in a relationship in 1982. I’m not big on them. I’m a loner and don’t like being committed that much. Relationships usually ended up: “Where were you?”, “How come you’re spending this?”, “or doing that”, and it’s like: “Don’t tell me what to do! Don’t ask me who I’m seeing! You can’t trust me enough then I don’t need a relationship where you don’t trust me”. That happened both of the last relationships.

But Rick’s need for autonomy, and his caution in trusting people, are balanced by the endurance and quality of his friendships. “I build long term friendships more than long term love relationships. They’re easier to keep and maintain, and have less complications. And what I need emotionally out of relationships, I pretty much get from my friends so that works.” His style emphasizes culturally meaningful values of autonomy, responsibility and caution in trusting others.

Much of his narrative is in the form of “integrative reminiscence” the purpose of which is to “achieve a sense of meaning, coherence and reconciliation” with his past (Watt and Wong, 1991:43-5). He acknowledges his difficulties relating to people; shyness, reluctance to express emotion or let anyone close, yet much of what he says relates to the value he places on his friendships and the comfort they give. He talks
about the way he was in his twenties as living for the moment and accepting future consequences. He directly addresses the impact this had on his infection with HIV. "I can blame myself. I kinda suspected something was not right, so I could have changed it by not sleeping around as much, not having as many different sex partners. You can look at it that way."

In this too, he sees no reason to "beat himself up" over what he did in the past. "You just keep going on". He still has some control over his future, and if he acts responsibly, he can influence the consequences. "I'm not gonna get any better unless I do something to do it myself." This reinforces the dominant theme in Rick's narratives; how he is able to take control of his situation and influence his future.

Similarly, he responds to his feelings of depression from losing so many of his friends. At first he says that he felt like there was no point living without them. Then, he started making new friends. "All my friends were gone, and I kinda wished I was gone too. But during the last year, I've started getting close to other people I've known, and building a whole new group of friends." Again he can influence his future by preserving the friendships he has and building new ones.

Much of the content of his narratives centers around interactions with friends, past and present. He talked a lot about friends growing up and the friendships in the club he was in. He met one of his best friends at "the baths"9 after he left college: "He taught me to be proud that I was

9Gay bath-house can generally be described as a place with the following facilities: gym, steam room, whirlpool, etc. and private cubicles for rental; where gay men could go to meet other gay men, often for the purpose of having sexual relations.
gay; that there was nothing wrong with it and to be myself.” There was
the social club he was in: “The ten or fifteen of us were like this! (Rick
shows me by clasping his hands together so tight that his knuckles of his
fingers blanched.)” There’s his closest friend now, Larry, who can make
him feel better when he’s down: “When I’m down he can bring me out
of it. He calls me up and ‘Hey girl, what’s happening? I had a rough day
at work!’ We go out and have a couple cocktails and do dinner and go
on.” For Rick, the importance of friendships has always played an
important part in his life “moreso than biological family” or a spousal
relationship.

Rick uses integrative reminiscence to overcome depression of
losing friends, and guilt feelings of contracting HIV infection. Jerry uses
instrumental reminiscence to draw on past problems for help in solving
present ones. Jerry’s narratives about the future are minimal and focus
only on uncertainty. Jerry: “There’s always that question: What’s going
on? Should I plan to move in the fall or be cremated? (laughs). You
don’t know. You think about it daily.” Rick faces the future in more
certain terms of his actions to “keep going on” and “building
friendships” and “look ahead”.

Jerry saw a major success in his life as “surviving this long... (and)
making the business run” where Rick saw his success in “being a good
friend”. Both men were able to draw on past experience to apply to
present difficulties. Though Rick has had to give up working for the
most part, he still is able to work about twenty hours a week. He finds,
like Jerry, that: “If I work a normal eight hour day, I need two days to
recuperate”. Jerry’s response to this has been to quit working entirely, while Rick works shorter days. Jerry is crippled with pain as well as fatigue. Even after Jerry started receiving pain medication, he still had significant residual pain, and the medication side effects increased his fatigue. An additional contrast is that Jerry lives in a small town, doesn’t drive, and can’t walk much distance while Rick lives in a local community with an active gay social life and has a car that usually runs. Both men have presented narratives with reminiscence that are appropriate to their situations as well as their individual histories.

Jerry’s theme of survival helps him to integrate his increasing disability with his life course. Rick’s theme of controlling present actions to influence his future is the basis of his working to create a new social network by making new friends. Rick doesn’t address this time as the worst or best of times. But he talks about several things that contribute to maintaining a good quality of life. By making new friends he reinforces his belief that his actions can have positive consequences for his future. In working part time he is able to enhance his independence, and his ability to help others and be a good friend. Despite his illness, he can continue to be a contributing member of his community; someone of value to others, respected and cared about. And, though his situation is far from the ideal, the stories he tells about the recent past show synchrony with common cultural values: independence, self-reliance, community service, responsibility.
Stan

Stan is in his early 30's, and lives in an upstairs apartment in a double house which he and his partner David own. Like Rick, he lives in the Edgewater-Lakewood area which has the most visible gay presence in the metropolitan area. His house was exceptionally well kept up, there was new carpeting in the hallway, and the furnishings and house itself appeared to be in excellent condition. From his own statements, I gathered that Stan lived a more financially secure life than Rick or Jerry. He talked about feeling “wealthy” living on David's income, even though he wasn’t able to work. They had recently remodeled the attic, and made it a second floor to their apartment. We met in his den and usually sat on the couch with the tape recorder between us. I enjoyed our visits. His house had a warm and comfortable atmosphere, and Stan liked having company.

Stan grew up in a neighboring state about seven hours away by automobile. He remained close to his family, particularly his mother, visited them frequently, and called or wrote letters in between visits. He had lived in the Cleveland area for about ten years and considered this his home.

Keeping a Good Attitude

During our first interview Stan wasn't feeling all that well. He said he had been having breathing problems and fevers and was on antibiotics and antipyretics. He was sweating during that first interview, particularly around the temples and sides of face. After that, he frequently had to
cancel and reschedule interviews because of conflicts with doctor's appointments, and one hospitalization. After that first interview Stan had to be admitted to the hospital for treatment of pneumonia. He had a Broviac catheter\textsuperscript{10} inserted at that time, generally something which would be considered a significant life event (Flaskerud, 1989; Bluebond-Langner, 1991). A visiting nurse came several times to instruct Stan in the care of his catheter and self administration of antibiotics. At one point, Stan was administering nine different bags of medication per day. As he said, "I've been home everyday. I was going stir crazy. I was doing IV's twenty four hours a day." In addition he had to find time to get to the laboratory and doctor's appointments.

Stan's visiting nurse had not told him about his alternatives to changing IV bags all day. I took some time to talk to Stan about some of what was available to him which I was aware of from working for the same home health company that supplied his visiting nurse. I considered whether or not to offer information based on my nursing knowledge. I did not want Stan to see me strictly as a nurse and adapt his conversations with me to fit that role. At the same time, ethically I felt Stan had a right to be made aware of additional help available to him.

\textsuperscript{10}A Broviac catheter is a brand name for an intravenous device allowing access to the large, deep veins of the upper body for blood and intravenous medication administration and laboratory blood draws. It is a tube inserted through the chest wall. Access is made through a port at the end of the tube allowing the patient to avoid frequent needle sticks for IV insertion or labwork. The tube may stay in place for several months. Patients at home are taught to care for the catheter by cleansing the site and dressing it three times weekly, as well as flushing it with heparin solution to prevent it from becoming occluded by a blood clot. Care must be taken to keep the insertion site clean and dry, and the dressing may need to be changed more frequently if the patient showers or sweats. The exposed portion of the tube is frequently eight or more inches long and is coiled and secured against the chest with tape when not in use. A large area of the chest may have to be shaved. The tube and dressing cover approximately a six inch square area.
Since the participants of the study were all aware that I had been a nurse I decided in this and several other instances to freely share information I had. I believe this helped to build rapport. I told Stan about a variety of intravenous pumps, some of which were portable; that he could wear as a backpack to be more mobile. Unlike Jerry’s situation, I was able to share information directly with him, which he could then choose to pursue if he so desired. I was determined to talk with the nurses, physicians or others caring for patients as little as possible in order to try and maintain confidentiality as much as possible.

Over the course of this project, Stan’s physical condition gradually but relentlessly deteriorated. Despite it, he maintained a “positive” attitude and did not talk of marginal or liminal feelings. At the end of the last interview, I reviewed what I planned to write about including what some people had said about “feeling in between or in limbo; not alive and not dead”. Stan said he really hasn’t felt that way. Stan frequently talks about his everyday experience in terms of his attitude:

> My attitude is so good about it that I think that makes me healthier. I get my days when I get depressed and I lay around and think about it, you know. I don’t think I would ever commit suicide,

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11 I found with several of the men, that sharing information about treatments, side effects, sources of information, technology, etc. seemed to be an expected form of interaction with anyone affected by HIV, whether infected or working in any capacity, with those infected. If anything, sharing the information only served to improve rapport. Study participants did not in any case solicit advice from me with regard to nursing or medicine, though many were very interested in the progress of the study and what others were saying about their illness experience.

12 Undoubtedly, it’s likely that some of the more extensive discussions will be recognizable to clinicians who may read this report who have cared for any of the participants. This is unavoidable and study participants are aware that at least one of the physicians of the Special Immunology Clinic will be reading this dissertation. I do not believe the care they receive will be compromised in any way should their identity be determined by this reader.
unless it was really bad and nobody else could help me, you know? I'm on Prozac too, you know? I think I had bad days before I was HIV positive anyway. You get depressed. There's always something that you get upset about.

Some people—once they get the attitude they don't care anymore, that's when they start to go downhill. You've just got to keep your chin up and make the best of it.

I haven't always been like this. I usually would get upset and down. I think because of having the disease, and my friends and family are more aware of it and are being supportive about it. You try to cope to make it better for them, too. I keep a good attitude for the other people.

I think in smaller situations everyone has a right to get upset about something. It's just part of life. This is more drastic and you have to worry about not only yourself but others involved.

In the past months I've been really depressed about doing this. Giving the medicines really bums me out sometimes. I can't get up and go when I want and I have to worry about getting back to do my medicine. It can get real frustrating. I was very active. Now I have to plan around the medicine to go to a movie.

I've been pretty happy. David thinks it's amazing how I hold up. Everybody does. He can't believe my attitude sometimes. I think it's because I have such good support; my mom and my family. It makes a big difference in someone's life to have that support. I have a lot of friends too and that helps.

Stan told me that he first started getting very depressed about five months prior to our first interview. He had had to take a medical leave of absence for recurrent pneumonia. "For three or four days I couldn't stop crying. Whoever came in the door I was in tears." At that time his physician gave him Prozac, an antidepressant. From the above narrations, it's clear that it's very important for Stan to keep a good attitude for the sake of the "others involved"; his partner and his family.
His reminiscences, like Rick's, are most often integrative. He relates past events and situations to current ones, integrating the present situation into his life course. For instance when he talks about his relationship with his brother, Roy:

I've had a great support system. Like I said, my family; they have been wonderful, every one of them. Even my brother Roy; when we were younger, I can say we were close but we always had the brotherly fights. We were always competing against each other. But after a while, like in high school, he was always into sports and I was always the gay person. I was the rebellious one and Mom and Dad were always getting after me because I smoked, and I did this, and I was in trouble all the time. You know, as we grew older, we became less; we didn't talk to each other as much.

Now, a few weeks ago, we became close again and he sent me the nicest letter and like I said I couldn't believe some of the things that he said, you know; how he just can't believe that I have the disease and if there is anything he could do, he would do it, you know? He just made me cry. It was something that I never expected my brother to even write.

He says that he never expected Roy to write this letter, but integrates it into his life story as a natural progression of the relationship he has had with his brother. The closeness that was at first tempered by brotherly fights, and temporary distance has come to maturity in the present. All of Stan's stories of the past are descriptive of relationships with others. As will be seen, it is the quality of these relationships which is essential in Stan's perception of the quality of his life. As in the above example, he often presents these relationships in terms of receiving or giving support.

Like Rick, Stan's timing is complex and includes a variety of markers. His narratives are built primarily on a framework of his relationships with others; family, friendships and "relationships".
Equally important are the life events which punctuate his narratives and describe periods of his life in terms of that event. Location is mentioned frequently but as a secondary characteristic of the time, or as a life event itself. "I did meet another guy. His name was Gary and we were together for about three years. I didn’t want to leave my family, but I moved to Florida with him." His diagnosis was a major turning point in his life. Many other events he talks about also relate to major or minor crises related to HIV infection; his first illness and hospitalization, taking illness related leave of absence from work, first blood transfusion.

The Importance of Relationships

The content of Stan’s narrations is largely about his beliefs about the importance of the relationships he has in his life:

If you’re not in a relationship you definitely need your family and friends to support you. A lot of people aren’t as lucky as I am. They don’t have somebody who cares so much. I’ve read about people who’ve been alone. I’ve heard about people; their family disowns them and has nothing to do with them. I couldn’t imagine. I would probably blow my brains out if I was alone. I feel I’m living and want to live because of the other people, in my life.

As much as Stan depends on his relationships with David, friends and family, he is very concerned about becoming a burden to them, particularly emotionally. He has serious conflicts about whether to go to the hospital when he needs extensive care, or whether to stay at home.

I was afraid that if I really get sick, I would want to go in the hospital. I don’t want David and his family and my family all taking care of me and watching me suffer like that. But after being in the hospital and then coming home and having David taking care of me, I think I’d much rather have people that you know take
care of you than people that you don’t. Because, I’m the type of person, that if I don’t know somebody that well, like the nurses, I wouldn’t ask them for stuff that I really needed if I could get it myself.

The themes that Stan emphasizes center around this conflict. Most importantly, he stresses his independence and his concern at not becoming a burden to those he cares about. He also stresses a secondary, but also emphasized theme of reciprocity, a balance of his caring for others as they care for him. This theme of caring for or helping others was found to some extent in eleven of the participants’ life story narratives (Table Two).

In telling me about one of his early relationships, he indicated that the failure of this particular relationship was that his partner wanted to take care of him financially and didn’t want him to work, making him feel like a prisoner. He was in the intolerable situation of being unable to reciprocate the financial support he received, emphasizing the absence of his feelings of autonomy and independence. He is now in a situation where he is unable to work, but as will be shown, finds this tolerable because he is and has been able to reciprocate in other ways.

He mentions an episode where he was in the hospital and coughed up blood following a bronchoscopy. His main concern was to get the visitors out of his room. “I don’t want somebody sitting here watching

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13 A bronchoscopy is a procedure in which a tube is inserted into the lungs with a lens allowing the physician to visualize the bronchial tissue. A small piece of tissue is snipped for examination. There may be additional bleeding due to abrasion of the tissues of the throat and bronchi, particularly in Stan’s case where there was a chronic infection. Stan said that he was told they tore tissue on inserting the tube, causing more extensive bleeding than normal. Any bleeding will stimulate the individual to cough, and expectorate the bloody sputum. (See also footnote #27)
me.” When talking about his death, he mentions knowing the “awful” ways in which some people die. Stan had worked in a nursing home and mentions a particular patient who died of AIDS related illness. “At first he’d recognize you, and after a while, he’d just sit there, wouldn’t say anything; just skinny. You could see he was deteriorating rapidly.” Notably, this example is characterized not by pain and suffering, but by loss of autonomy and awareness and implied dependence. Several times during my visits, Stan returned to this fear of deterioration. His fear was not about pain and physical suffering. “I don’t want to suffer, nobody does.” But more importantly, he does not want the people he cares about to witness his deterioration. He does not want to be an emotional burden.

Reciprocity and Physical Decline

Autonomy and productivity or achievement are important cultural values for Stan and reflect his style. The support he gets from his family and from David has been reciprocated. Since his medical leave of absence from work, he has retained his feeling of reciprocity by assisting with the care-taking of David’s grandmother. She has Alzheimer’s disease, and lives with her frail older sister. Since David works during the days, Stan and some of David’s other family members divide up the time to help care for her at home as long as possible. Except for the time Stan was stuck at home self-administering his intravenous medications all day, he spent three days a week with her, cooking, cleaning and visiting with her. By getting involved in her care he is able to be
productive, to achieve discreet tasks, and to be caring and reciprocate support to David through his grandmother.

Stan has not resolved the conflict he feels in both needing the support and presence of the people he loves and wanting to spare them the pain of watching him deteriorate. By the content of his narratives, Stan presents his worthiness in receiving the support he gets, based on his relationships past and present. He helps with David’s grandmother. He encouraged David to seek counseling to help him deal with the pressure of Stan’s illness, David’s grandmother’s illness, and the everyday pressures at work. He also talks about having a long term disability policy to help with expenses and has recently arranged all his funeral plans so his family and David wouldn’t have to. In the past, he often helped out at his parents’ store, and he works hard at keeping a positive attitude for everyone’s sake. When his father died, he went to help his mother take care of arrangements. He talks about his volunteer work in several community AIDS organizations, speaking engagements he has had with groups of youth about HIV and prevention. He relates how when he was working, he would talk about risks and prevention of HIV to the younger people he worked with.

He shows himself to be the kind of person who cares about others, including his work in the community. And because of this, he is deserving of David’s help. “We’re like married in a way; like husband and wife. I feel that I earn my keep. I don’t feel bad about asking David for money. I don’t make near as much as he does.” Reciprocation is important because it helps to maintain Stan’s independence and
autonomy. Reciprocity and independence are important values in
American (United States) culture (Dowd, 1980, Fry, 1988), discussed in
greater detail in Chapter Six. When Stan does get sick he feels he can
depend on David and his own family. He provides numerous
descriptions of how much they all care about him. Still, he says he does
all that he can to keep his positive attitude for their sakes, as he works to
avoid becoming an emotional burden.

Stan describes his relationship with David as being “just like we
were husband and wife” referring to culturally traditional heterosexual
marriage. He offers a brief story of his mother caring for his father when
his father was ill. He points out his belief that in traditional heterosexual
marriage, if the husband or wife was sick, the other spouse would be
expected to care for them. In this way he places his relationship as
synchronous with heterosexual marriage and the expectation that one
will care for their spouse in illness. He also emphasizes his autonomy in
the history of his relationship with David. He has always worked and
contributed to their expenses, and he has been productive in helping
David care for his grandmother.

When I first described my research project to Stan, mentioning the
words “quality of life” he immediately responded: “I have a very good
quality of life”. He repeated that several times, regardless of his steadily
declining physical condition, and emphasized that the reason his quality
of life was so good was because of the love and support he perceived from
David and his family. This is an extremely interesting and important
example of the difficulty inherent in measuring quality of life, and the
complex and multiple factors which must be considered in such measurement. The life events associated with Stan's illness were largely overshadowed by the strength of his relationships with others, and had limited impact on his overall experience of quality of life.

**Liminality and Chronic Illness**

Stan didn't talk at all about feeling 'in between' or in limbo. During our last interview I talked to him about what I planned to be writing about. I mentioned how some people in the study had talked about feeling 'in between' or in limbo. He said that he never really has felt 'in between' or in limbo. Jerry talked about feeling between life and death in terms of his illness, which reflects on his self appraisal as a marginal individual, but the heightened sense of being in limbo came at the threshold of Jerry's acceptance of being completely disabled. He is past the stage that Rick is at where he can only work a few hours a day without recuperating for two days. He can't even get through the few hours.

Rick understands the feelings of being in between in terms of being marginal (see also discussion of liminality in Chapter One). He feels, as does Jerry, that HIV infection is like being between life and death, though he may experience liminality during periods of illness. Jerry and Rick do not see their deaths as imminent in any way. That is, they believe that their lives are foreshortened, but don't believe they are in the process of physically dying at the moment. Rick says “You can’t do everything you used to do, but you’re still active enough to go on living.” Jerry: “Sure I know it’s fatal, but do I have to think about it every week?”

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Jerry perceived himself to be in a liminal state when he was struggling with his becoming disabled. Jerry and Rick assume they will remain in a marginal state ‘between living and dying’, but when Jerry became disabled; when he actually could no longer plan on going to work with any hope of it actually happening, he moved from one state to another. This was the end of the liminal period. He entered the liminal state as someone who could perform some work tasks. His abilities were already severely limited, but he was able to persevere, overcoming the obstacles. In the end, he was reintegrated into a social role where the possibility of work was unrealistic:

I try walking. Somedays that’s not so bad. Other days my head throbs too much. A lot of days I shave and take a bath and go outside, cause if you sit down you’re ready to nap again. And I’ll spend the whole day that way; just napping.

Throughout, he remained marginal, particularly in his feelings about being between life and death. He reported that he already had feelings about being marginal in terms of being gay and having HIV infection.

Part of this changing status was what could be termed a social death. His friends were beginning to disengage from him. As Dowd (1983) noted with the elderly, Jerry did not choose to begin disengaging from the social world of the living, rather this was being imposed on him. “They’re just waiting for me to die. They just say ‘Jerry’s dying. He’s going.’ And I look at that and I go: God, I don’t want to hear that, cause I don’t feel I’m dying!” His friends may see the increasing debilitation as evidence that Jerry is dying. In this sense, his being in
between living and dying is a social death (Glaser & Strauss, 1965). He related how people will come by the house and not wake him up. He is frustrated by this because he desperately wants to maintain a social aspect to his life. He doesn't want to disengage.

I suspect that this is not the first or the last liminal phase that Jerry will pass through. The chronically ill move through periods of "separation, transition, and reincorporation, as exacerbation leads to remission and then circles back to worsening and so on." (Kleinman, 1988b:181). These exacerbations are experienced as a series of crises. "Within a crisis experience, there is both a threat to the integrity of the person and an opportunity for growth." (Fitzpatrick, 1989). For Jerry, the threat to his integrity was the threat to his perceived self value. Work was always a symbol of his self-reliance; his autonomy and ability to survive. Jerry does not see an opportunity for growth in this crisis, (though in the following two chapters I will discuss other men who see the challenges of HIV infection as opportunities for growth).

Rick didn't describe any liminal phases during the course of interviews, but he did describe feeling a heightened sense of being in a "purgatory-ish" state between life and death, whenever he wasn't feeling well. I suspect that in the life story, liminal experiences are described in terms of a crisis marking the threshold or transition, with emphasis being on the change from one state of being to another. Liminality is an experience out of the normal dimensions of structure, "a moment in and out of time" (Turner, 1969) and it may be difficult for people to define in terms of stories about the past.
When talking about the experience of liminality one may be talking about hours in a day. Rick doesn’t elaborate much about his crises. When I asked about his diagnosis with HIV, he said that even this didn’t affect him “like everybody else”. He says he had already suspected and worked out the “shock to your psyche about having a terminal illness”. He never says when or how he worked the ‘shock to his psyche’ out. Rick mentions recurrent crises related to HIV infection: the death of friends, recurrent illnesses, hospitalizations, and I wouldn’t rule out his experience of liminality at those times, though he does not talk very explicitly about this aspect.

Stan also has gone through crises. He talks about the last few months prior to the start of our interviews as a period of time where he cried all the time. He had just taken a medical leave of absence from work, and was very depressed about “being sick all the time and not being able to work”. Like Rick, he says his diagnosis wasn’t a shock because he already suspected he had HIV infection, but he didn’t recall how or when he had dealt with it prior to that. With Stan, as with Rick, I can’t say that he has not had liminal experience with exacerbations or crises. Where Rick can relate to the ‘in-between’ feeling of liminal experience in terms of feeling marginal in his “purgatory-ish” experiences, Stan can’t identify with this feeling at all. At the other extreme is Jerry, who repeatedly talks about it. For Jerry, diagnosis with HIV was “like waking up and aging twenty years over night. All of a sudden you’ve gotta live like you’ve lived for twenty years extra or something because you don’t have that time to make twenty years of mistakes.”
The stories people tell when relating their life stories are told in a process of accepting and integrating present events with their past and creating new meaning as they formulate their identity. For this reason, stories might emphasize what is most pertinent to the present experience. Jerry's liminal experience might have been more apparent because of the proximity in time between his liminal experience of hospitalization, and our conversations before and after. The stories that illustrated liminality were especially pertinent to his present experience.

Life Events and Quality of Life

The three men whose narratives I have reviewed in this chapter are all physically compromised by HIV infection and receive government disability. They are unable to work sufficient hours to maintain jobs, though Jerry has tried, and Rick still works a few hours here and there. Rick and Jerry have both lost many of their friends who have died of HIV infection. Stan too has had friends who have died, but does not talk about it as much.

Stan shows evidence of the most stable social network; his family and his "partner" of nine years. Rick and Jerry both have several long term friends. Rick actively is working to rebuild his social network by making efforts to make new friends. Jerry, has his "lover" of eight years, but it's a rocky relationship. At our last meeting, Tom was going to stay with his parents for a while since he and Jerry weren't getting along. Prior to that he had traveled extensively for his job and wasn't home much. Neither Jerry nor Rick talk about their families as being that
important, though they maintain contact and are fairly close to some family members. Stan’s family is vital to his well being. Jerry, Rick and Stan all place social relationships as paramount in their assessment of the quality of their lives.

For these men, the quality of their present day lives has been affected by their illness, primarily regarding social relationships. Jerry indicates the importance of autonomy and self-reliance but at the same time recognizes his need for close relationships in his life. He reflects on the friends who have died and the four friends who may not “make it through the summer” and how he has so “very few friends left alive”. His family, he says, “are nice people but my life is so different than theirs and always has been... It almost has to be if you’re gay”. And his relationship with Tom, though it spans eight years has always been characterized by being “tense” or “touchy”, and spending extended periods of time apart. Jerry says: “I know a lot of new faces”, but he doesn’t seem to be able to develop closeness with them. The reality of his physical limitations is undoubtedly to blame. He jokes about it, but, getting washed up and dressed and sitting up awake at the kitchen table can be “a good day”.

It’s this new situation of increased disability that prevents Jerry from investing his time in making new friendships, as Rick is doing. From my observations over the nine months of interviews and additional visits, Jerry’s activity level has markedly declined, though there were times that he actually felt good, and was able to get out and go for a walk in the park, or see a movie. But from his perspective “the feel
good days are over”. This new situation was marked by the events surrounding his increased pain and symptoms, hospitalization, awareness of the drop in his T-cells and increased medications. Together this cluster of life events compounded the damage to Jerry’s social system that previous events, particularly the death of friends, have precipitated.

These two clusters of life events, the death of friends in the past and the physical deterioration of Jerry’s present, are events which have led to Jerry’s present state of social isolation. And it is this isolation which is at the heart of his poor quality of life. Jerry talks about his life with negative emotions. Life is “one big disappointment after another”. He has little hope that there will be anymore “feel good days”. He has less enjoyment of life, and will just have to “get used to” feeling lousy, just like “a lot of people”. Both event clusters have shifted his life far from what he considers ideal. This is the nature of chronicity, to cycle between exacerbation and uncertain remission and to risk “being stuck in a place one has come to hate and fear” (Kleinman, 1988b:181).

Rick anticipates with trepidation, being stuck in this place and talks about wanting to “off” himself when it happens. He recently watched a friend die who had talked about having a similar plan, but waited too long and so was stuck. He recollects: “That night he decided he wanted to off himself, but couldn’t; that was horrible, most horrible night of my life He was just lying there. ‘Now, I want it now! Now! Now!’ Boy, Chuck, we can’t. It’s too late. It was.” This too was a life event for Rick, helplessly watching his friend stuck in the place of “hate and fear” but Rick sustains less damage than Jerry. He too cycles through remission.
and exacerbation. He is able to see a future and feel he has impact in reconstructing his social network and so maintaining his quality of life. He acknowledges the significant importance of his present friends, and also the loss of his past friends. He still has the ability to get out and work a few hours most days. Is it only his physical condition that allows him to still have the hope that “today will be a good day”? Or is it something in his beliefs and values that leads him to “look ahead”, that he can “do something” to make his life better, like his making new friends?

Stan’s physical condition is more like Jerry’s than Rick’s in that he is trapped at home, spending most of each waking day taking care of illness related tasks. The last time I saw him he had had a miserable month. He was sick most of the time; difficulty breathing from recurrent pneumonia, no desire for food, nausea, additional testing at the hospital which in itself was an ordeal. But through it all he is able to perceive himself as having a good life: “I have a pretty good outlook; like this past month. When you don’t feel good, you think is it almost time (to die), but I snap out of it. I have a pretty good life. But it really helps when you have someone to share your thoughts. People who are alone; I can’t imagine going through this alone. That would be really hard. If I didn’t have David, I’d have my family.”

He feels lucky to have the love and support he does. During his sickest times, he tries to keep a good attitude and a sense of humor in order to lessen the burden for the people he so values as his support. Stan has experienced the life events associated with his progressive
physical decline. He relates negative perceptions of the impacts of his hospitalization, his IV schedule and the Broviac catheter. With all these things, the things that really mattered to him, his relationships only seemed to get stronger, e.g. the letter from Roy, his relationship with David.

It's interesting that both Stan and Rick seem to narrate integrative reminiscences, where Jerry's is instrumental. Integrative reminiscence allows them to reconcile past conflicts, to achieve meaning and coherence in their life story. Instrumental reminiscence in contrast is used by Jerry to summon the resources he needs to handle his current difficulties by relying on his ability to survive and endure.

Where Stan shares with Jerry a comparable deterioration in physical aspects, Rick shares the death of his social network. Only Jerry has endured both. It is the composite and additive nature of life events, noted since Holmes and Rahe's (1967) work, and the overload of loss (Kastenbaum, 1969), which has taken its toll on Jerry's perceptions of the quality of his life.

**Chapter Summary**

In this chapter, I have analyzed three life stories, with a focus on two different types of life events; exacerbations and complications of HIV infection (mentioned in the narratives of eight of the study participants), and the multiple death of friends due to HIV related illnesses (mentioned in the narratives of ten of the study participants) (Table Two). The three life story narratives presented illustrate the simplest possible
combinations of these two types of events; Jerry experienced both, Rick primarily experienced the latter, and Stan only the former type. Not surprisingly, Jerry has had the most difficult time maintaining a perception of good quality of life. Most interestingly, Stan maintains a perception of a good quality of life, despite frequent illness related life events.

The concept of liminality may be significant in the experience of life events and the impact of events on quality of life, however further investigation is needed to gain a better understanding of how and why this may occur. I suspect that liminality’s transient nature would require a more intensive, prospective method of research, e.g. extensive daily contact over an extended period of time. Perhaps this would be feasible in one of the group homes which exist for persons in the HIV spectrum.

Additionally, the life story is shown to elucidate the basis for judgments of quality of life. For Jerry, his concept of himself, or style of self-reliance was challenged in the necessity of his taking on a dependent role in order to obtain pain relief, and because of his deteriorating condition. This was compounded by the loss of so many of his closest friends, a situation which is asynchronous with local, historical events of his lifetime (i.e. the place and time period he lived in prior to the emergence of HIV AIDS).

Rick has suffered a similar loss of friends, but without the more severe physical limitations which would challenge his style of independence. He has been able to translate an element of his style of being a good friend to recreate a network of friends.
Stan has experienced extreme frequency and severity of illness related activities, but has maintained the relationships which were most important to him, family and partner. His style emphasizes independence, autonomy and achievement, but he is able to transcend the challenges to maintaining this style, through the concept of reciprocation. His increasing dependence and inability to continue to be productive are balanced by his consistent past actions. His continued strength in maintaining a positive attitude for the sake of his family and partner is an achievement in itself. This fosters his autonomy by refocusing interactions away from talk about illness, thereby reducing emotional burden on others, and maintaining interaction based on shared history.

The three examples suggest several areas for further study: Stan and Rick both had stronger social support networks than Jerry, and seemed less affected by events of illness exacerbations and complications. Under what circumstances does a strong, intact network of relationships reduce the impact of illness related life events to perceived quality of life?

Stan’s stylistic orientation to living emphasizes attributes of caring for and about others, and appreciating the good in his life. He intentionally tries to maintain “a positive attitude” in dealing with the events of his life and his illness. How does an individual’s style determine risk to perceived quality of life relating to particular life events?

Both Jerry and Rick have lost most of their network of friends to death due to HIV-related causes. Loss of an entire network of friends to
disease had not been an expected possibility to people growing up for the demographic cohort from which these men were drawn. To what extent does synchrony of life events with the broad range of normative experience affect perceptions of quality of life? This chapter presents evidence that though the effects of life events on perceived quality of life may be additive (Holmes and Rahe, 1967; Kastenbaum, 1969) ultimately, a complex interaction of factors determine the impact those events may have on perception of quality of life. Furthermore, the life story can be viewed as a source of information defining and explaining those factors.
CHAPTER FOUR
COMMUNITAS AND SOCIAL SUPPORT

In this chapter, and continuing in the next, I will review data of some of the men with regard to social factors, particularly the concept of communitas. I will discuss participants involvement in organized social groups which function as a source of social support, including communitas as a particular type of social support found in some social groups.

Sources of Communitas

Five men in the sample describe overlapping participation in several social settings: “GAYLA,” “The Living Room”, and “AA, (Alcoholics Anonymous)”. I will begin with a brief description of these three settings, and the pattern of the five men’s participation. Three life stories will be presented and analyzed with a focus on the role of membership in these social groups as it influences illness experience and perceptions of quality of life, presented in life story narrations.

GAYLA is a week-long retreat for gay men on the Maine Coast, offering workshops, social events, and entertainment, as well as the beach and the natural beauty of the area. This yearly retreat has been held for 16 years in mid-summer. Three of the men participate in GAYLA. There is also an annual reunion on the east coast in January.

The Living Room is a storefront drop-in center “for the HIV-challenged”, significant others, friends and family. They offer a number of services, including an information telephone line, support groups,
workshops, massage, alternative healing, social events and more. The
Living Room is located near downtown Cleveland and is adjacent to the
Gay community center. Only four of the twenty men participating in this
research are active in Living Room activities and a fifth has been
involved with Living Room programs in the past.

AA, which claims to be a world wide\textsuperscript{14} self-help\textsuperscript{15} organization,
originally developed in the United States as treatment and support for
persons who are suffering from alcoholism. Over the past 40 years AA
has become the model for a number of other groups as well. The five
men participating in this study who attend Twelve-Step meetings also
mention affiliation with one or more of the following in addition to AA:
NA (Narcotics Anonymous), and SLAA, (Sex and Love Addicts
Anonymous), Al Anon (for families of alcoholics) CoDA
(Codependents\textsuperscript{16} Anonymous), ISA, (Incest Survivors Anonymous).
These groups share a system of beliefs, values and symbols based on core
statements derived from the texts of Alcoholics Anonymous (1955) and
The Twelve Steps and Twelve Traditions (Alcoholics Anonymous, 1957)
referred to by AA members as “The Program” (Rodin, 1985). Five of the
men in this sample are active in AA and/or other groups which share
similar ideologies based on the twelve steps.

According to Antze (1986), despite the interest of psychologists and
sociologists, there has been limited interest in Alcoholics Anonymous
\textsuperscript{14}Alcoholics Anonymous World Headquarters in New York City states they will supply
individuals with meeting sites for travellers to any part of the world.
\textsuperscript{15}Self-help groups are programs which facilitate mutual aid and/or support among
members.
\textsuperscript{16}Codependency refers to placing others before self with resultant harm to one’s self. It is
a concept widely used in AA.
and Twelve-Step programs by anthropologists. Rodin (1985) provides an exception to this in her examination of the cultural nature of AA taking a biocultural approach to the initiation or conversion of the alcoholic individual to AA's Twelve-Step ideology.

Interestingly, in his discussion of AA, Antze (1986) compares AA to the "cults of affliction" which Turner (1967) describes among the Ndembu. Both initiate victims into a "specialized community of former-sufferers-turned-healers" (Antze, 1986:151). Turner (1969:109) later describes this as communitas. As will be shown below, AA and the associated Twelve-Step programs may be considered as sources of communitas for some of the men in this study.

The following chart describes affiliation of the five men who participated in a variety of support and or self-help/self-growth\textsuperscript{17} groups. Though only three life stories will be presented, additional data from the other men will be offered to further describe their experiences with support and self-help/self-growth groups.

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\textsuperscript{17}Self-growth groups are self-help groups which have as their goal, self improvement in terms of some facet of mental or spiritual health.

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Tim

Tim is the youngest member in this study. At the time of our first meeting for this project, he was 28 years old. Tim was referred to me by Paul, along with Alan and Rob as some of the men Paul knew who would be interested in participating. When I began visiting Tim, he lived several blocks from Stan (see Chapter Three) where he shared a house with a good friend. It was a bright airy two-story house, with comfortable, modern style furnishings. When driving up, I noticed that the house was for sale. We sat at the kitchen table and talked. Tim’s roommate was making lunch for himself at the counter during part of the time we talked, and notably, Tim didn’t hesitate to talk openly about quite intimate subjects, despite his presence. I later learned that they had met in an HIV support group, and had become very close friends. Tim enjoyed talking to me about his life, and immediately came across as exceptionally personable, open and pleasant. He asked if I was still looking for participants and volunteered his roommate, Bob. I did talk with Bob several times, but he moved out of the area when he sold his house and I was unable to complete my series of visits with him.

After Bob moved out, Tim moved in with another friend in one of the more distant suburbs. This was a suburban style ranch house, with a much different ambiance. Where Tim’s old place was very modern, with sparse, plain furnishings, this house had numerous knick-knacks on display, a floral upholstered living room suite and country kitsch decorations in the kitchen and adjoining family room. We again sat at
the kitchen table for this and the remainder of my visits. Tim always made us coffee.

By the third visit, Tim's living situation again changed. His roommate began a romantic relationship with a man who then moved in to this new house. The interior of the house also reflected this new roommate as most of the country style items were replaced by Bob's things; antiquity replicas such as cherubs and urns. Tim didn't plan to stay in this location for more than a year, and possibly less time than that. He remarks that he's down to a minimum of furniture and possessions to make moving easier should he decide to move again. This chronic movement is an important aspect of Tim's style; his tendency to "escape" from unpleasant situations, home, relationships, work, counseling.

Tim had been diagnosed with HIV infection about four years prior to the study. He has no symptoms and is not undergoing any treatment other than monitoring his CD4 cell count every three to six months at one of the clinics in the area. He works full time, frequently more than 50 hours a week and is very active, socializing with friends, attending support group and twelve-step meetings, and working out regularly at a health club.

Explaining the Present through Stories of the Past

Tim's timing in telling his life story to me was presented in a loosely organized format where events of the past are uncovered in the context of the present. For instance, when talking about his reaction to HIV diagnosis in terms of disclosure to his family, he says:
When I found out I was HIV positive, I was so closeted and so scared. I thought I'd be gone in a year. And my family's never dealt with openness and honesty; like simple things, like I didn't know my sister was a half sister.

I'd get things like: 'Somebody's sick.' and the next day they'd die, like, I didn't know that they'd been suffering from leukemia for three years or cancer or heart attack or something like that. I remember once over a holiday, I wanted to talk to my grandmother, and my parents said, 'no', and afterwards I find out like she had a stroke three months ago. My history is like to keep secrets.

According to Watt and Wong's (1991) typology, this is an integrative reminiscence. Tim feels closeted regarding his lack of disclosure of his HIV status to his parents. He employs reminiscence to reconcile this behavior in terms of it's being the way he grew up. There is only vague reference to time in this reminiscence, though at other times he will place events in time by the date, his age or historical events. "I didn't realize until I was fourteen, but my mother had been married and divorced in the early fifties. I was never informed that my sister is really a half sister; didn't find out until later in life." He identifies a problem; that he is not open and honest with his parents. He identifies the cause; that he was taught to keep secrets by their example. He is in the process of reconciling an element of his style with events of the past. At one point, Tim says: "I would like to be more open and honest about my HIV status." Though at present he is unable to achieve this goal, he accepts the influence of his history integrating present behavior with past experience.

Tim's presentation of reminiscence follows a description of the present, and is most often integrative. Additionally, there is what
Luborsky (1990) calls a recursive sequencing of personal categories. This is a series of shorter life stories which describe a particular category of experience from early life to present day. In the example above, Tim describes the historical pattern of communication difficulties he has experienced with his family. His timing in telling his life story is characterized by an indirect presentation of his life before and after certain life events. As a listener, I superimpose his integrative style of reminiscence with the recursive sequencing of the life stories and construct a chronological version of his life story which I can understand in terms of themes, styles and the meaning of events. It should be kept in mind by the reader that the organization in all the life histories I present has been to some extent imposed by myself. I found Tim’s presentation of his life story to lack organization. The bulk of his life story data was told as explanation for conversations about everyday life. I enjoyed my conversations with Tim, and found him easy to talk with and understand. In reviewing the conversations for life story data, I found that this aspect of our talks was less organized. This may reflect Tim’s current assessment of his present situation:

I go to the gym on the road, in the hotel or here, at Scandinavian at home, if I can find the time. This year has been just incredibly busy. Like our appointments. This is our last session. It’s hard to believe it’s been six months. It’s just been insane; the timing constraints. It’s even crazy today. I have a social appointment this evening and a surprise birthday party tomorrow in Pittsburgh, then staying there for work ‘til Wednesday. I’m here a few days then gone. It’s usually hectic and chaotic.

Tim has been involved in introspective endeavors in his individual and group therapy, workshops, and 12 step groups (AA and
SLAA). He talks about his life in terms of his present, where the past is an explanation of the path he has taken. In reconciling the present in his life story, he has identified how his past has affected his present but has yet to determine what action, if any, to take.

I still want to work more closely with goal clarification, but it’s better than not knowing why I was unhappy. That’s why things are better now. I have a clear understanding of where I am and where I came from. Like there are areas I have difficulties with now. There’s a historical basis for it. I don’t have to consider myself hopeless; give up hope from what happened in the past. I can learn from it and move on.

Taken as a whole, the events in Tim’s life that he repeatedly refers to in talking about himself and his present life are as follows: his sexual behavior beginning in preadolescence involving sexual encounters with men in public bathrooms, his awareness of his mother’s alcoholism during the same time, his HIV+ diagnosis and entering “recovery”18.

The Great Escape

The content of Tim’s narratives frequently focuses on one or more of the topics related to these events. Tim frequently talks about his preoccupation with anonymous sexual encounters, and his attempts to control this “addiction”. He sees this as interfering with him forming close relationships. He also attributes his not moving further ahead in his career to the time he spends seeking sexual encounters.

18“Entering recovery” refers to beginning 12 step treatment which is considered to be an ongoing perpetual process that begins with using “The Program” (the Twelve-Step program) to cease their addictive behavior, followed by a continuing commitment to “work the program” on a lifelong basis.
I'm learning a lot about myself; wanting to get the hell out of a situation. OK, now I wanna go and sex out. What's going on here. I came to a lot of realizations; like with the employment situation, I'm bored silly.

I need to make the decision that its good and OK, that it will work out. It's that fear of losing something I know. I know how to act out sexually very well. There's the fear of that, but when will I have worse consequences. It could be police action if it's public or I could lose my career. I was afraid I hadn't actually hit bottom yet.

I'm afraid to give up this behavior. Where are my options. We've filtered through over four years, year after year, focusing in on it; that the behavior needs to change. I worked with a cognitive psychologist. When the abuse issue came up, I flew the coop. This time I'm not. But I have a commitment to group that you have to give notice. With the therapy, when we got to the underlying things, I left. The fear was overwhelming. I quit.

The above statements are representative of much of the content of our conversations. Though Tim is involved in both AA and SLAA, he never mentioned difficulties abstaining from drugs or alcohol. His focus is on "addictive sexual behavior". Tim strives to change his sexual behavior to avoid the serious consequences he sees ahead, as well as the consequences he has already suffered. To change behaviors he believes he must be introspective and seek to know himself more fully. Then he can determine what he truly wants. The theme Tim presents is that the problems in his life are self-generated by his behavior. To overcome his problems he must overcome his urge to escape, and change the damaging behavior.

19SLAA, (Sex and Love Addicts Anonymous), is an outgrowth of AA and involves the "re-pathologization of sexual behavior (Bolton, 1992). This is interesting in view of the history of gay liberation where the same behavior was glorified as "the normal way of living gay (Lang, 1990).
He talks frequently about escape, as above when he “flew the coop” with his psychiatrist. He later did the same with group therapy, in response to the groups confrontations regarding Tim not following up with treatment for his sex addiction. Tim began dating a man about three months into his conversations with me, and broke it off within two months. It is Tim’s style to escape from situations that he is uncomfortable with, and describes this with a certain amount of fear:

I’m running away from problems. I’m still running away from childhood sexual problems. It’s probably at the root of why I’m not dating someone; running in the other direction. But I’m still afraid to go and deal with that right this second. I wish I could be more open about being gay and HIV+. I’d like to be able to be more open and not fear people’s reactions at work; rejections. I’d like to date, dealing with past childhood sexual abuse, and openness about being gay and HIV+ in all areas of my life.

I can’t sustain a relationship for any length of time. I have to get into individual therapy for sexual abuse, ‘cause I am the most untrusting son of a bitch as far as relationships. All the walls go up. The thought of being in a relationship just scares the heck out of me. I started dating this guy and I thought this is the only guy I’m seeing. I felt trapped. What does this mean? It seems like it’s either anonymous or monogamous, I have to find some middle ground.

As far as his illness Tim has had no symptoms, but he is concerned: “I have a fear of the process of death; that period of time where I see folks lose grip. I have a fear of being dependent; not basically self sufficient. That’s resolved me to think about the Kevorkian thing.” Even in the hypothetical future his style is to escape the extended death process through suicide.

Tim has not resolved the conflict between his style of escape and his thematic value of facing your problems and persevering to change his
behaviors. This value has been instilled by his family: "persistence and diligence. I've been swamped with work and wondered how I'd get through it, but I have a sense that it'll be OK. Hard working ethics; that sort of thing. I definitely have that sort of influence." Though Tim probably was able to apply persistence and diligence to his work related challenge, he does not live up to these values on a personal level. He feels unable to control his sexual behavior on his own, and has not actively sought further individual counseling.

Twelve-Step Influences

Though Tim doesn't mention involvement in AA or SLAA at the last interview, it's interesting to note the syncretism of Twelve-Step concepts with his own individual belief system. In one of the previous quotes, Tim talks about his fears of not having "hit bottom" yet. Hitting bottom, as part of a conceptual model of the stages of AA recovery, is defined as the worst an addiction gets, "a time of despair, desperation and loneliness" (Rodin, 1985). Tim describes the consequences he fears may await him if he continues to engage in these escapist sexual behaviors. Awareness of hitting bottom is seen as a necessary part of recovery.

At another time he talks about his belief in a "higher power":

My spirituality is evolving and I'm getting a keener sense of not so much the business world or materialistic stuff but an inner peace and quality of serenity and believing in a higher power; a driving force that transcends any materialistic or physical being of oneness although I'm not quite sure of what that is exactly. I'm Unitarian so I can choose whether to believe in God or not.
Here, Tim points out that the Twelve-Step symbol of the higher power is compatible with his religious affiliation through his life course. He also has incorporated other aspects of Twelve-Step philosophy as explanation for his lack of action. He acknowledges that having a job which involves extensive traveling is ideal for a sex addict, but that he: "can't change everything at once. One day at a time."

Though Tim recognizes the conflicts he has with changing his behavior to live up to his values, his style of escape still dominates. In the previous example he escapes responsibility for taking action to change his job through using the Twelve-Step slogan "taking one day at a time"; that he doesn't need to change everything at once. Yet he describes his job as boring. He doesn't feel he's advanced to the degree he would have liked to and this job facilitates his sexual problems by providing him the anonymity and variation available through extensive traveling. So his conflict continues.

Though Tim hasn't been affected by symptoms of HIV, he feels he's changed because of his diagnosis, and recognizes the impact of the deaths of others with the disease:

I'll never forget my second therapy session after finding out I was positive. My therapist said: 'Boy, you sound just like my 35-40 year old men who aren't HIV+. It just hit you ten to fifteen years earlier.' I've found I can relate better to that age group, especially those who weren't in long term relationships who were in my cycle a lot longer before they crashed. That was the biggest life change I've had. Another thing, I wonder the role this plays: My closest friends; I listed fifteen people, at least ten gay. Bob is the only one who's positive. I'm surrounded by alot of gay men who are HIV-.
I've been sad. HIV has been hitting. The guy from MTV died from that show, "Real Life" where these people live together. One of my friend's roommates just died. There's a memorial service next week. Friends tell me about their friends dying. It's just lent more deaths. A friend who left group about one and a half years ago died a year ago, December 6, and I called his partner up on the phone to say hello and see how he's doing.

The HIV therapy group has been very significant, though not always the most supportive. I met Bob through the group. I found outlets for myself to reach out to other HIV+ people. Other than Bob, I have no other friends that I know are. I have my group. I compartmentalize that. They're from all over the city; different backgrounds. I can't always get together with them, but once a week I do, and go out for coffee after and its a safe space where we're all in the same boat.

Tim mentions that he wonders about his lack of involvement with other men who are HIV positive. Bob has moved out of state, though Tim talks to him almost daily. And Tim has quit his support group, which was the only group of HIV positive men he knew. He doesn't consider them close friends in terms of seeing them outside of group activities, because he doesn't have a "consistent active social life" with them. Talking about group, he mentions that when he's in group, "I'm held accountable. Like OK, now what kind of commitments can you make to get help, with what's going on with my life." The group confronts Tim about his sexual behavior, his preoccupation with seeking anonymous sex.

He talked about being depressed at seeing people in group deteriorate.

I'm seeing a lot more progression of HIV in people close to me for the first time ever. A couple people in group are definitional AIDS this year, and another one, last week, lost 20 pounds. But it's like
overwhelming sadness on that part. I’ve always been very removed from the grieving process and seeing someone go through the process of deteriorating and passing; I’m seeing it. They won’t die tomorrow - but 20% weight loss - it’s not low fat diet.

Tim uses the word escape to describe his urge to leave the group which he’d attended for four years. He feels that he is often chastised for behavior that other members of the group engage in but don’t discuss.

Tim says he can go to a different Twelve-Step meeting every time and “veg out”, never really addressing the dissatisfaction he feels with his sexual behavior. But in group, he’s confronted by group leader and members. As mentioned above, Tim feels that his sexual behavior is detrimental to his career, though the connection is weak; that the time he spent involved in “sexing” could have been time he spent working, and that there are possible future consequences. He also blames his promiscuous involvement in anonymous sex for his infection with HIV20. Yet, he acknowledges that he’s not totally willing to give this behavior up. Tim was faced with a conflict between not really wanting to change his sexual behavior, and feeling that the group was demanding that he act to change it. By eliminating his support group membership, he eliminated the need to reconcile the two and escaped from the immediate conflict, though some ambivalence no doubt remains.

Tim talks about his quality of life now primarily in terms of ambivalence. For example when talking about his dissatisfaction with his life in terms of relationships, he says:

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20At other times Tim states that he is aware that promiscuity alone is not a risk factor for HIV infection, unless it entails unsafe sex and believes that he became infected as a result of unsafe sex. Regardless, he sees his history of promiscuity as causative.
I'd like an exclusive relationship or a relationship period, encompassing all aspects including sexual.

I can't sustain a relationship for any length of time. The thought of being in a relationship just scares the heck out of me. I'm not so sure I want a monogamous relationship. I don't know how practical it is.

This ambivalence permeated much of what Tim talked about with me. During several interviews he talked with me about finding some type of counseling that would help change his behavior pattern with regard to sexual abuse in his childhood. He eventually acknowledged that he is unsure of pursuing this as it relates to changing his current sexual behavior.

Tim also talks about his quality of life with ambivalence. It's better than last year in that "he's getting out and doing some fun stuff", but at the same time, he mentions ambivalent, and frustrating feelings regarding his career, and living situation, as well as his inability to deal with his problems in counseling, and inability to form an "exclusive relationship".

Tim's life story is interesting in that the primary characterization of his style is in negative terms. His style is to escape from difficult situations. In the stories he tells, he says he is unable to persevere in finding and maintaining treatment for his sexual behavior, or to sustain a relationship. He is also "bored" with his job, "frustrated" with his living situation. At a conference he went to on goal-setting, he considered his future:

How will I be doing things today, tomorrow a week... Five years? It brought up the whole thing of HIV for me. I was like crying.
Where will I be? I had images like, 'Am I even gonna be alive?' and I thought "Jeez, probably not!'; hopefully not like calling some ambulance to bring me to the hospital or dead by that time. I keep going as though there's nothing wrong. I want to slow down enough to really absorb that I have a chronic, fatal disease.

In all Tim presents a perception of a poor quality of life. He is dissatisfied with his present and devastated by the future he anticipates. His material needs are well met, though he doesn't talk about that in his stories. He describes his relationship with his family with ambivalence as well, and though he talks about being a good friend, the only friendship he talks about in depth is with Bob, who no longer lives in the area, though he mentions other friends in the area and in the cities he travels to for work.

He still attends one or two Twelve-Step meetings each week, and as shown, has incorporated some Twelve-Step philosophy into his understanding of his life. But he does not talk about communitas with the people in the group. Rather, he emphasizes the superficiality of his participation, being able to "veg-out" at meetings and using meetings to meet men to date. Tim's involvement with Twelve-Step programs is notable in his lack of perceiving communitas in comparison to the other men involved with Twelve-Step programs.

Tim is the only participant of the twenty men I talked with who emphasized sexual relationships as important in his quality of life, and interestingly he felt that his sexual activity was detrimental to his quality of life. Other participants talked more about concerns of social relationships, when talking about everyday life experience and the quality of life. When they did talk about sexuality, it was in reference to general
comments regarding ‘safe sex’ and possible conflicts with preferred sexual behaviors.

Paul

Paul is also a member of this same support group which Tim recently discontinued. He lives with his partner, Jeff, in a mid-size suburban house, on a quiet residential street. He and Jeff just bought the house about six months prior to our first visit. Early in our meetings, Paul volunteered several men who he thought might be interested in this study. Periodically over the six months I had difficulties contacting Paul and following up on his visits. This was interesting for a number of reasons. Unlike times when I had difficulty following up with other participants, I was always able to contact them on the phone, or they would frequently call me to reschedule. Paul was unlike any of the other participants in that I was unable to contact him by phone periodically during the time we met. Interestingly, I anticipated just the opposite.

When I met Paul, he told me he had a very busy schedule but would participate in the study. He pulled out his appointment book and we arranged a time to meet. Paul was very insightful and open about his feelings and experience. Paul is a psychologist working primarily with persons suffering from PTSD (post-traumatic stress disorder). He relates this interview experience as the reverse of what he does in counseling sessions; that is usually he’s the listener, hearing others stories.

I had an unusually hard time maintaining contact with Paul during the first three months of his involvement with my research. Paul
had two answering machines at home, one for business and the other for personal messages. He also has a work number and an answering service number. Despite this he did not always receive my messages and at one time I was unable to contact him for six weeks, though I was able to talk with Jeff who said that Paul was very busy with work. Paul was aloof and distant at times during this period and I later discovered that he believed I was not making adequate attempts to contact him regarding our scheduled visits.

The last three months of our visits were dramatically different in that they were characterized by much more warmth. Paul would always ask about me in a friendly manner, for instance how my holidays had been, and our visits ended with a hug when saying good-bye. What created the change? It's possible that our difficulties communicating may have facilitated discussion of how much I appreciated Paul's input into this project, and that he needed to know that I cared about the effects of our interaction on him.

Perhaps this was partly a function of how busy Paul was during the first three months. In our first conversation of the second three months, Paul talked about reducing his workload, to make more time for himself. He had also recently participated in a weekend men's retreat (GAYLA) during which he was engaged in introspection. The issue of our visits adding to his busy schedule is interesting in the context of the men who I mentioned had refused my study. Paul talked about his perception that his time was limited. I suspect that he needed to make the personal connection with me to justify his allotment of time to these interviews.
(Or that I needed to provide the reason for his spending his limited time talking with me, by emphasizing how I valued his input and cared about what he was telling me).

Five Stages of Life and Four Life Events

Paul's life story is very clearly organized around five periods punctuated by four life events. The first period was his childhood which he spent growing up near a large metropolitan area. "It was a nice small town; had a movie theater, public library; it was real cozy. Everybody knew everybody. There were like two or three generations that knew each other, actually born and raised there." At the same time, growing up was far from idyllic. Paul's father was physically abusive. "There was a climate of fear in our home all the time. Even when he was in a good mood, he could lose his temper at any time. We could be anywhere."

At the age of twelve, Paul's life changed when he began masturbating. "Believe it or not, that changed a lot. I was having a lot of feelings and they were for men, not for women. I was different from other people and felt ashamed." This was a difficult period for his family too. His older brother became involved with drugs and ran away from home. His father was having financial difficulties exacerbated by his drinking.

At fifteen, Paul became one of Jehovah's Witnesses. "I stopped masturbating from the age of fifteen until twenty; completely; never looked at myself from the waist down; was afraid to look, prayed constantly. Today I would see myself as obsessive compulsive." He read
the Bible through several times, and gained respect from other Jehovah's Witnesses for his knowledge of the Bible. At twenty he decided to become a missionary. One day, he was preaching to his boss, who was a gay man, who asked him to go to one of the gay bars. He thought "well, Jesus went to where the sinners were so fine. And I went into a gay bar and to preach to everybody in the bar."

Jehovah's Witnesses publicly reproved him and took away his privileges in the congregation. Within the next year, he came out as a gay man, and was excommunicated by Jehovah's Witnesses. During this time, his father's alcoholism became worse, one of his younger brothers disclosed that he was also gay and an alcoholic, his older brother had gotten involved with drugs again and was moving back home, and his youngest brother ran away from home, only to end up hospitalized in a psychiatric facility. "It happened all at once, like we were all on the same biological clock". They began family counseling.

During the next ten years or so Paul worked as a salesman and made new friends. He had no contact with his old friends who were still Jehovah's Witnesses. Since he was excommunicated they would not interact with him. He became involved in his

"first few relationships. They tended to be pretty sick. I was very jealous and possessive, and tended to be with people who weren't very high functioning."

Toward the end of this period he began working as a counselor, and became involved in Twelve-Step programs: Al-anon and CoDA and eventually AA. At that time he found out he was HIV+.
Paul’s timing in relating his life story to me is based primarily on these four life events: masturbation and his first sexual awakening, becoming one of Jehovah’s Witnesses, coming out and his second sexual awakening as a gay man, and discovering his HIV+ status. These are the events that mark the divisions that Paul sees in his life based on changes in himself. He also points out that he has had three completely separate sets of friends.

When I became one of Jehovah’s Witnesses, they wanted you to cut off all contacts with anyone, so I disowned everyone in my life, and only associated with Jehovah’s Witnesses. And when I was 22, I came out and Jehovah’s Witnesses disowned me and they weren’t allowed to talk to me, so all the friends I had made, I lost. Also we had moved to Cleveland while I was Jehovah’s Witness. So, for the most part, it’s people I’ve met since I’ve come out, are the people in my life.

There have been other events in Paul’s life which also give structure to the timing in his life story such as meeting Jeff and buying the house together, but predominately his narrations are located within the framework provided by these five periods. He often specifies time with more precision by mentioning his age at the time of a given narration.

Balancing Hard Work with Leisure

Paul’s primary theme is that through the strength of his convictions or faith he can overcome fear and live a good life. A good life is foremost, an autonomous life, with a career which allows him to help others overcome their fears, a life with time for recreation and for
introspection. Part of Paul's style is that he is a hard worker, and he appreciates the value of hard work in terms of social worth:

I was a hard worker. That's something I did learn from my parents, and that I'm glad for it. But, I was just basically working too hard, keeping myself too busy and didn't think what that was doing to me.

At the same time, Paul has some reservations about working too hard, as this is in conflict with attaining a good life. His career in helping others provides him with productivity and social worth. He values these as the fruits of his hard work. But without making time for recreation and introspection he would be unable to truly appreciate life in terms of nature, the arts and literature, and friendships. He sees himself as working to achieve a balance between hard work, and a relaxed appreciation of life:

I've been busy. I think it's a natural tendency for me to be chaotic. I have to prune back my schedule and look at what I've done. Being consistent about that is one of my weak points. I can be a lousy manager; burning the candle at both ends. As soon as I stopped doing that and got more disciplined with myself, I felt better. I'm working less hours now, and more consistent. And I was on vacation last week.

Over the last couple years, I find myself not having time for any recreational things. I'll do things with people and go and have fun, but to sit home and play the piano for a couple hours; I can't do that. I have too much to do. I regret that I lost something that I gained through being HIV positive. It's one of the things I gained as I started thinking: 'What do I want to do on a daily basis?' and found that I rarely did what I wanted. Maybe an hour a month, I'd genuinely do something I wanted. The rest was scheduling a party, doing an event, doing work, but not necessarily something I wanted to do on a daily basis. And I've gotten away from that so that's disappointing. I think I'll get back to it. I get so involved in
the day to day business of living that I'm not living; just making a living.

I find myself trapped again into doing things because I have to, instead of want to. I'm angry at myself for letting that happen, for pulling out a charge card when I knew that I couldn't afford it, and racking up huge bills that now need attention and I don't like that. I want to have the freedom to relax and enjoy it. But I think I can regain that. I just got a new car a week and 1/2 ago. That expense is OK, but it reminded me that if I want to have and do things I want, I can't rack up bills that are nonsensical, and I forget that.

The value of hard work is consistently represented in the stories Paul tells about his work history. He was successful in sales in the past, and counseling in the present and has been rewarded with advancement and achievement in both careers. His faith and strong convictions have also been present in his life in the past as well as now. He was intensely involved with his religion growing up with the faith he would overcome his desire for sexual expression with other men: “I threw myself into it thinking, if I can get this right, I'll be OK. Y'know, I'll read the books and do what they say and I'll get a clean bill of health, and I'll be straight.” And he’s become intensely involved in recovery. He maintains his involvement with Twelve-Step groups, and attends a variety of retreats and workshops involved with self awareness and self growth: using his self awareness to understand and define his life goals and taking the necessary steps to achieve them.

The conflicts Paul faces with regard to achievement, productivity and social worth on the one hand, while maintaining his autonomy, particularly with regard to his time for appreciation of life on the other, arise in part from his experience with HIV infection. He alludes to this in
the following narrative with regard to losing something he had gained through being HIV positive.

The more good things that happen, that's what puts me in touch with being HIV positive; owning a home, having a lover, investing in mutual funds, actually - cause all those things are long term, and that's when I think: 'Wow! I wonder how long I'm gonna be here to enjoy those things?'

I've came across people that I haven't written, and I suddenly became extremely aware - went back four, five and six years ago, where all I did was work and had no ideas what I was working for. I didn't have a life to support my work. I lived my life to support the work.

HIV is there as an undercurrent I'm not even aware of. Just realizing I will probably live one more year, gives me one more year in my garden. Everything I plant will take years to develop. I got Wisteria cause it grows 25 feet a year, but it'll take five years to get the big trunk. It's this mild insanity that gets interwoven. I'm not aware of the influence, that part of my decision is from being mortal.

From what Paul is saying, he sees HIV as the catalyst which awakened his awareness of the important things in life. This theme of appreciating life was mentioned by eleven of the participants to some extent, as they narrated their life stories. Paul values his time more and regrets losing his balance between work and leisure. HIV has made him acutely aware of the value of that balance. Where work in his career gives him feelings of productivity and achievement, merely having leisure time gives him freedom from obligation and enhances his feelings of autonomy; that on any given day he can do what he wants to do, to have the "freedom to relax and enjoy" life. I believe that this may be at the source of my difficulties contacting Paul and for his negative reaction to scheduling time with me. During the first three months of
our visits, Paul was working more hours and had limited free time. During the second three months he had cut back his schedule and was much more relaxed. Additionally, he had attended the GAYLA retreat during the fourth month, before cutting back on his schedule. He told me a little about GAYLA at that time: “It’s a great week to just get away. There’s a lot of play. There’s workshops if I want to do something in depth and there’s the beach right there, so it was very relaxing.”

Overcoming Fear

Another aspect of Paul's style which he sees as conflicting with his best interests is his reported tendency to base his decisions on fear. He relates that this is directly related to the abuse he suffered growing up, which was amplified in his childhood experience:

I was picked on for not being traditionally masculine, not playing baseball or football. Not knowing how to stick up for myself, 'cause I had a father who would beat the crap out of me. Having somebody hit me, I didn’t feel like I had the right to do anything anyway. I was scared of my own shadow.

Paul first overcame his fear through his involvement as Jehovah's Witness. As mentioned, he found that his commitment to his religion and knowledge of the Bible brought him acceptance and respect from others, and with it less fear. Respect still is important to Paul in terms of being able to make decisions, and cope with changes:

I'm finally making decisions on what I want, and what's best for me, and not being so afraid. More than anything my life's no longer ruled by fear. In being assertive, I've started shaping my own environment instead of constantly trying to shape myself into whatever exists, hoping for the best. I get respected. In fact, I think I value respect, more than people liking me now.
Paul's style has evolved over his life course, from acting out of fear and avoidance, to recognizing his fears, and acting with faith that he can shape his own life into an environment which enhances his values. After he was diagnosed with HIV, he was considering changing jobs, but was concerned that if he quit the job he had, he would not find another. He viewed this as a "decisions to avoid something bad, which is how I was raised. Let's not let the bad happen." He quit his job and was offered the position he is now in, a job that he "thoroughly, thoroughly loves".

He relates a similar story about his fear of 'coming out' to others about his HIV status. When he did, "everyone was fine about it. I couldn't anticipate that. I just knew I had to be honest with myself, and the reason I wasn't telling them was again out of fear." These stories serve to illustrate his theme of faith. In relying on the strength of his convictions, his life was changed for the better, and his environment was shaped in ways that helped him achieve a good life. He left the old job, and a new better job was offered to him. He told others about his HIV status, and "when people found out that I was HIV positive and doing as well as I was doing, they thought I must have something to offer", and his respect grew and he was sought after as a counselor.

Paul's stories are largely integrative reminiscences (Watt and Wong, 1991). But his is a more positive integration than Tim's. He has altered two elements of his style: fear as motivation for decision making and hard work for its own sake. Not only has he integrated the events of his past with his actions and motivations, but has implemented changes in his style. Yet the strength of his faith and his commitment to hard
work have been consistent elements of his style throughout this presentation of his life story. The same faith which committed him to devout participation with Jehovah's Witnesses, also has been essential in his involvement with self-help and self-growth groups. His quality of being a hard worker, has also contributed to his commitment to and involvement with self-growth activities.

Paul emphasizes that his decisions, including changing jobs and disclosing his HIV status were not based on fear but on his convictions. In quitting his old job, he felt he was leaving a "dysfunctional and stressful" situation which had a negative effect on his daily life. He was choosing to improve the quality of his life. When disclosing his HIV status, he felt that people he worked with and counseled had the right to know about his situation. He was choosing to be honest and trustworthy. Both times, he had fears; of not finding another job, and of rejection respectively. Both decisions were not based on fear and lead to an improvement in his life situation. He had faith in his belief that by not acting out of fear, he was choosing a good life.

I think about how I live my life. Is this the way I’d live it if I had a choice? The one thing I say to a lot to people is: ‘Trust the process’. I find almost everything that’s happened in my life is not a direct result of me trying to make it happen. It just kind of did. I think I interfere with life. When I just slow down and look at what’s happening it’s usually just taking care of itself in a really OK fashion. When I stop trusting the process, and as soon as I tense up and think, ‘Oh I better do this or that’, that’s when all of a sudden I create this domino effect and create more problems.
"Trusting the Process"

In AA, "trusting the process" may be suggested in terms of being accepting of yourself as imperfect if you relapse in drinking. Relapse is seen as an expected part of the process of giving up alcohol consumption, and must not be taken as failure. The message is that one may still achieve success in giving up alcohol consumption, despite a number of relapses along the way. Paul applies this to all of his life as an element of faith. It's not that he is a passive observer, and whatever happens in life is as it should be. Rather, if he needs to make a decision to live as he would choose, he has the faith to believe that it is part of the process of life, and that whether the decision turns out to be good or bad, he may still eventually succeed with whatever he undertakes. Trusting the process is very much an aspect of the Twelve-Step programs, in which Paul has been very active for at least six years: Al-Anon, CoDA, Incest Survivor's Anonymous and finally AA.

Though Paul only goes to Twelve-Step meetings once a week on an average, and has friends outside of Twelve-Step programs, he is still committed to it's value.

The Twelve-Step programs provide a community for someone, a spiritual community. They help a person work on interpersonal skills. The 12 steps themselves are a good problem solving method, almost like therapy. But, the idea of Twelve-Step is you work it long enough, you can go anywhere and be with other people.

Paul has incorporated much of the Twelve-Step philosophy into his own beliefs. He talks about a "spiritual awakening" when he was first
diagnosed with HIV. He uses guided imagery\(^{21}\) as a self-help tool and uses inner child work\(^{22}\). Soon after finding out he was HIV positive, Paul went on a healing weekend\(^{23}\) for people with HIV. One of the talks really “burst (his) bubble”. He felt there was no hope for a cure, and became depressed, eventually deciding “to suicide”.

I decided to do an imagery where I go into this garden, and my inner child is there. I was gonna let him know that we’d done real well, but the reality is it’s only gonna get worse from here and let’s leave now. So I closed my eyes, and I couldn’t picture anything, just felt totally alone, and I put on music, and finally I pictured the garden, and there was no little kid. And instead, this old man, who was black, with short white hair came out, and I opened my eyes thinking, ‘What the hell?’, to make sure I was awake, and I close them again and he was still there. He said, ‘I’ve created you, and I created the virus too, and you’re gonna have to trust me on this one.’ And he gave me a kiss, and turned around and walked away.

And I was filled with warmth from head to toe, and realized it was gonna be OK. I didn’t like what was happening, or what the path was, but I stopped being overwhelmed by it. I know that whatever it was, whether it was my own mind or whatever, it did what it needed to do, and I got my life back together.

I don’t think it was God. I don’t know what it is, or he is. I know that I’ve never been able to picture it again, at least not with the same feel. I can like, picture it, but it’s like me picturing it, and when I was doing it was like it was coming from a part of my mind that I wasn’t aware of.

AA is culturally tied to American Protestant theology (Antze, 1987) and practice (Whitley, 1977). In Twelve-Step programs, this influence is

\(^{21}\)Guided imagery is a technique used for relaxation, or to create a specific mood, e.g. a safe space.
\(^{22}\)Inner child work refers to a type of self reflection or therapy popularized by Melody Beatty and also very well respected in AA ideology. It refers to working on that part of the self that remains anchored in child-like thinking incurred in childhood, in part, by visualizing one’s self as a child.
\(^{23}\)Healing weekends can be didactic, e.g. workshops or seminars, or experiential, reconstruction of past experiences/traumas, and can also be Twelve-Step oriented.
seen in the "spiritual awakening". "Spiritual awakening" is in many ways the goal of the program in making a conscious connection with a "higher power" and through that connection, seeing yourself in the wholeness of life and not taking yourself and situation too seriously. This is at the heart of what may be called a 'conversion' to Twelve-Step ideology which mimics conversion to a religion (Rodin, 1985; Antze, 1987; Galanter, 1990).

Paul felt he made the connection with his higher power, "my mind or whatever". The wholeness of life is evident in his awareness of himself and the virus as sharing the same creator. But at the heart of this narrative is in not taking yourself and situation too seriously; that Paul would have to trust his higher power, and trust the process. Through this image, Paul was able to generate a source of faith that "it was gonna be OK".

As far as his HIV infection, he reports that it has been uneventful. His only symptoms have been side effects of antiviral medications which disappeared with cessation of the particular medicine. HIV has affected his life, in the form of the "mild insanity" he mentioned when talking about his preoccupation with whether or not he would live long enough to enjoy what he was working toward; the house, the garden. But this again is his theme. If he has faith in the process of living, then regardless of what may occur, he can embrace his situation without fear of what lies ahead and so live a good life.

24 "Higher power" is a term originating in AA referring to a power outside of and greater than oneself.
Quality of Life

Paul perceives himself as living a good life. When I asked him when the best time of his life has been he responded that this time now is the best:

I’m finally making decisions on what I want, and what’s best for me, instead of acting out of fear. I’ve started shaping my own environment instead of constantly trying to shape myself into whatever exists.

I can’t control my death, but I can control how I live my life, and chose to do that. It’s a joy, and I love what I do. I’m in a career that I thoroughly, thoroughly love. My clients may even know I’m HIV positive. I tend not to hide it, only because, if my health changes, it’s going to affect my whole practice.

It is the change in style that makes this time the best time of Paul’s life. These statements emphasize his autonomy and independence in making decisions about his life, his responsibility to his clients, and because he loves his work, his commitment to hard work is both culturally valued and personally rewarding.

Paul is not as active in AA as he has been in the past, but still attends anywhere from one to four meetings a week. He recognizes AA as somewhere he can go whenever he needs “a group of people that are gonna be there for you and you can show up and interact with them”. If the communitas that AA offers is most sought during times of poor quality of life, it is possible that Paul’s involvement is less now, during a period he considers to be characterized by high quality of life. It would be interesting to know whether Paul increases his involvement with AA following a significant life event which might challenge his perceived quality of life.
Rob

Rob was about 30 years old at the time of his participation in this project. He lives in an old urban neighborhood not far from downtown Cleveland. His apartment is near a busy intersection on one of the city’s major arteries. There is a mix of businesses in the multi-storied brick buildings that line both sides of the avenue: a bank, a second-hand shop, restaurants, adult bookstore and a chain drugstore. There’s metered parking on both sides of the street, and I noticed a good amount of foot as well as motor traffic whenever I visited.

His apartment building is subsidized housing, with a storefront lobby. The entrance is through a glassed in alcove with a buzzer system to restrict entry. Usually as I walked through the lobby area to the elevator, there were three or four elderly men and/or women in the lobby. On the first visit I noticed a middle aged African-American woman sitting at a desk, who watched me quietly as I walked by. I wondered whether I was supposed to sign a guest register, but she never spoke, so I continued back. At every visit, I saw one or another of the elderly residents seated by the window watching the traffic. During one visit, we heard loud voices, sort of singing or talking in a sing-song voice, out in the hall. Rob mentioned that there were a lot of mentally ill people who lived here.

Rob’s apartment was a roomy two-room apartment with a large bedroom, living/dining area and a recently remodeled kitchenette. During my visits to his apartment we always sat at the dining table with the tape recorder between us. Despite the age of the building, the
apartments were very pleasant. There seemed like just a little too much furniture for the space, and by our last visit, Rob had been able to move to a somewhat larger apartment next door.

On my last visit with Rob, I met him at the Living Room. It was my first visit to the facility. It's located just over the bridge from downtown, right next door to the gay community center. Both are in storefront offices. I waited in the front of The Living Room, while Rob looked for a place for us to sit and talk undisturbed. There were two men in the front area having a lively conversation about some people they knew. Rob introduced us, but they pretty much went on with their conversation. I wandered over to the bulletin board. There were numerous announcements of HIV/AIDS related services, events, and meetings, and a number of leaflets about the living room, and other groups, as well as information about HIV infection. Though the workshop that was going on in the large 'living room' area was over by this time, Rob suggested we go to an equally large meeting room in the gay community center down the hall, so as not to interfere with other people's use of the facility.

Loss of Friends

During visits to his home, he usually had a pot of coffee brewing or made some while I set up the tape recorder. He was generally very open in talking about his life. On my third visit, while I was packing up, he mentioned that he forgot to tell me that two people he knew died this past month. As Paul said: “I guess those are big things, but with HIV,
there's so many big things: T-cells drop, opportunistic infections. Big things happen more often to HIV positive people who face a lot of things on a regular basis."

Like Jerry and Rick, in Chapter Three, many of Rob's friends have died or are in the HIV spectrum. He experiences this as frustration, and the loss of meaning of shared memories when there's no one who shares them, much like Jerry's experience:

Friends dying; that's a frustration. You want to turn around and have someone to share things with and things like that. They're dwindling down and that's really been on my mind lately. I found myself starting to close off to new people. Making new friends: for me it's hard to establish a friendship, and you have that history and you know them and they know you; know when you're not feeling great even if you don't say it. They just know you. It's hard to start up a new friendship and start that whole process again. I found I was closing myself off.

I get really frustrated cause I can't sit down and pick up the phone and call people cause they're not there anymore. Like half the people on my list here are dead. I just haven't changed the thing on the phone. Sometimes I sit and go through my phone list and 'who can I call?' and everybody's dead. That's when I really get upset.

I see that as my circle of support dies, I have to keep reaching out to other people. It's hard and kind of sad, because they really don't know your history and what you've been through and your experiences, which helps when you really need somebody there to talk to. You can't sit around, say you and I were friends for six to ten years, and say, 'Hey, remember when we went camping and something funny happened?' And you can't do that anymore.

Though Rob isn't consciously working to develop new friends as is Rick, he is making friends through being active in AA, The Living Room and other social settings, and he does cultivate new friendships. Rob says that all of his friends are "in the (Twelve-Step) program" except for some in
his HIV support group. Most of his friends in the program are gay men, though not in the HIV spectrum.

Rob presents one theme which is also similar to Jerry's involving his ability to survive the hardships of his life: "The biggest thing is that I'm a survivor. No matter what's happened in my life, I've managed to pick myself up, dust myself off and move on, and (laughing) I've had quite a few tragic experiences in my life." It is his style to endure these tragic experiences and persevere. He presents himself as the kind of person who doesn't let life's problems get to him. There have been serious difficulties to overcome in his past, and now in his present, but Rob's stories emphasize a subtle inner strength to endure hardships and move on. His response to the hardships in his life is similar to Jerry's also:

You gotta have laughter in your life. That's another of my strong points. After everything I've been through, I can still laugh. I can still have fun. You gotta have laughter in your life.

A lot of people not in the (HIV) spectrum don't get our humor either. Like when I'm around our positive friends - if we saw a hearse we always joke and say 'Hey your taxi's here!', stuff like that. If you say it to a (HIV) negative friend, they get all offended. How can you talk like that? We think it's funny.

Again, the type of humor that Jerry talks about in the latter narrative paragraph above, serves to define the world that he and other people in the spectrum inhabit. It's an "in-joke" definitive of who belongs to the group, and so understands the local idiom as humorous. It is also an indication of his ability to overcome the sadness of the situation he and
his friends who are HIV positive are in. He can laugh at approaching
death of him self or others as one more hardship which he will endure.

Changing Style

By including his ability to bring laughter to his life and others as
part of his style, Rob also addresses that he sees himself as overcoming
the negative influence of some of his personal history.

I was raised by my grandparents. They never talked about their
feeling. Whatever was going on in life I kept to myself. We
weren’t allowed to cry or express ourselves. No one said I love
you to anybody. I thought I was kind of worthless.

I used to be really shy and reserved; kept all my feelings to myself.
It’s been a very, very long process, but now more outgoing and
outspoken. I’m much more aware of my feelings and character
defects, more aware of who I’m about and that.

I’d love to be able to cry at the drop of a hat (laughs). My
grandfather, you know: You’re not a man if you cry. And I cried in
school one time and the teacher embarrassed me in front of the
class about it. After that I clammed up. It’s just embarrassing to do
in front of people. I’m vulnerable. It came up in therapy, too. I
noticed that my body language; like I’d put my hand around my
neck to hold it down. So now I try to like keep open, keep my
hands free, so I’m not trying to push anything down, but I still can’t
do it in front of other people, unless I can hide; if it’s dark or
something; which I hate. But I’m making progress.

These narrative paragraphs show Rob’s use of integrative reminiscence to
reconcile the changes in his style. Where once he was emotionally
stunted, unable to express himself or his feelings, he is making progress.

AA has been instrumental in his change in style. He came to understand
his shyness as a “character defect”, a term he learned in AA. He explains
a character defect as: “Like a pattern; when I was drinking I would
constantly move. I didn’t know it then, but it was a geographical cure, and running away from myself. But I brought myself with me. That’s a character defect.” Rob says he has “tons” of character defects. He works on one, then identifies the next and works on that one. “I’m always constantly working on my self-improvement”.

Rob is immersed in the Twelve-Step program. He goes to three to four meetings per week. All of his friends are in “the program” except the people in his HIV support group. His timing in relating his life story is primarily based on two events; leaving home in his early teens and getting sober.

When I left home, I didn’t know much about the world. I didn’t know how to take care of myself. I still wanted to be taken care of and trusted people too easily too. And I got into things I shouldn’t have; a lot of hardship and heartache, and that road I traveled was pretty rough. I learned a lot. I learned a lot, really fast; a lot of values and lessons.

Getting sober changed my life around. I’d sunk to the lowest level. I was miserable and everything, headed toward death or jail or institutions. I bettered myself getting sober; living life on a daily basis on life’s term’s. Before it was just alcohol, alcohol, alcohol and drugs. When I drank I felt like I was no longer defective. I always felt like I wasn’t a whole person. Drinking took away all the pain, and made me a different person. I could socialize. It changed me to the person I wanted to be or thought I did. The more I drank the more it took hold of me til I had to drink to survive.

At one time during our discussion, when Rob was telling me about the events of his past, and talking about events as above, he laughed and said that talking to me about these things felt like an “AA lead”. Being an AA lead is the act of telling your story in an AA meeting. The story typically follows a “standardized narrative outline: What it was like
when I was drinking; when I hit bottom; how I got on the program; what my life is like now in AA.” (Rodin, 1985). The narrative above outlines the first two components of a lead narrative. At other times, Rob elaborates on these and the latter two components. The two marker events he uses for timing; leaving home and getting sober, in fact mark the beginning of his involvement with alcohol and drugs, and his beginning the program, respectively.

Rob also focuses on relationships in his timing when relating life story narratives. Events are placed in terms of beginnings and endings of relationships. He grew up with his grandparents, and the death of his grandmother heralded his move to Ohio to live with his sister. As he moved out of his sister’s house he moved in with his first gay relationship. He moved back and forth between his grandfather’s home in Florida to Ohio twice in his life. But the important thing about these moves was the changes in relationships which occurred. Where Jerry talks about the difference of his experiences in California and Ohio, based on the differences in communities and lifestyles, Rob’s moves are secondary, in that they are merely one explanation of the endings and beginnings of relationships.

Quality of Life

During the period of my visits with Rob, he spoke very little about physical effects of HIV, though he was first diagnosed with HIV eight years ago and states that he progressed to AIDS with the onset of his first opportunistic infection more than six years ago. He had been off all
medications for the past couple years. He said he was just sick of taking it all. About four months into our visits he resumed taking one of the antiviral agents when his T-cells dropped below 200. "It's a little bother psychologically. You're at 200. So in your mind you've gone down to a certain level. But physically I don't feel different."

Rob didn't have much more to say about his own illness at present. He had experienced some periods of illness, and complained of feeling lethargic. He had to plan around his fatigue:

I still get really tired. If there's three engagements I have for one day, I can't do it all. I have to reschedule one or I get really wanged out. My mind turns to mush. I can't hold a conversation. My focus is on going somewhere and laying down. I've learned what I can and can't do. I sleep seven or eight hours a night, and usually take a nap for an hour or so.

HIV has affected Rob's life in many areas as he mentions, but interestingly, he did not initially see it as a major turning point in his life and minimizes its effect now. It is the death of friends which he sees as having the greater impact on his life.

I found out I was positive and thought about it for a couple days, but I didn't deal with it for year or so. I really didn't. I went to doctors and stuff, but it didn't affect my life really until my friends started dying and then it was at my back door. That's when it started affecting me. It wasn't a turning point. It's been a long slow process that's starting to speed up as more friends die. The only way it's affected me is the few times I've been ill, and lost my job; stopped working and got social security and here in subsidized housing.

Rob volunteers at the Living Room several days a week, and attends an HIV support group and Spectrum AA meeting. Other than that, his life is
tied more to the Twelve-Step community than it is to HIV-oriented social settings.

Rob's quality of life now is not the best he's had, but he indicates it's improving. He says that his style of being a survivor, and being able to laugh at obstacles in his life are his strengths. He also talks about being a hard-worker, and the value of work in his life. He enjoyed his job as a designer before he went on disability, and talked about working hard at it: "That's who I was. I put my identity in my job because I didn't have an identity other than that. Here I was getting into some career that had some value, some prestige; and that ended." Recently, he began working at one of the AIDS service organizations, and talks about his perception of how that has improved the quality of his life. "I feel useful and needed again and productive, even if it is a volunteer job."

Though Rob experienced life events in the death of two friends during the time of our interview, and he spoke about the impact in terms of the loss of meaning of memories which are no longer shared, he maintains his quality of life. In addition to the positively valued things happening in his life at this time, he is building new relationships. He attributes the Twelve-Step program as changing his life, and maintains attendance at meetings several times a week. It is the source of his support in that all of his friends are also involved as well. His membership in Twelve-Step programs overshadows his involvement in the Living Room in terms of offering social support.
Twelve-Stepping and Communitas

For all five of these men, affiliation with AA or other Twelve-Step program groups has had an impressive impact on their life stories and implicitly on their everyday lives. All utilized Twelve-Step slogans or concepts as the basis for their philosophy of life, or how to live a good life. Importantly the Twelve Steps embody the philosophy of the Twelve-Step program and represent the common goal in communitas. Tim’s connection to the Twelve-Step program philosophy is the weakest. Yet, when he talked about his philosophy of life, he talked about developing an inner peace and quality of serenity and believing in a “higher power”.

The connection to Twelve-Step programs lies both with his use of the term, “higher power”, and his acceptance of his sexual behavior as an addiction. Developing his faith in terms of belief in a “higher power” is a necessary step in “The Program”. He has sought treatment for “sex addiction”, through SLAA, through the use of hormonal medication prescribed by a psychiatrist, and is considering going to see a “behavioral psychologist”. Despite his not always dealing with his own problems in Twelve-Step meetings, he never mentions discontinuing participation, but rather the fear that he hasn’t hit bottom. “Hitting bottom” is seen as not only the point of the most severe addictive behavior, but also as the point of awareness that ceasing this behavior through involvement in the Twelve-Step program is the only way out of the situation. If you’re not ready to engage in the program, you haven’t hit bottom by definition.

Paul’s philosophy of trusting the process, as previously stated has ties to Twelve-Step philosophy. He has friends now who are not part of
the Twelve-Step community, primarily as a result of getting to know his partner’s friends. But Paul is committed to the program: “I like it. I think it works. I think it’s excellent. One of the ways it works is in providing a ‘spiritual community’”.

Rob believes in the program: “I agree with the whole thing. I do the basic twelve steps. They’re suggested steps so I do follow them in order, and it’s worked for all these thousands and thousands of people before me so why should I try to change it?” All of his friends are in the program, except the men in his HIV support group.

As for the other men involved in Twelve-Step programs, Alan, the oldest member of the group at 48, has been in the AA for fourteen years. It has had a major impact on his social life.

I have very few friends who are not in recovery. My peer group are recovering people. It’s always been my base of socializing, my family of choice25. If I got sick right now, my front line people would be from my recovery support group. I know that.

Alan thinks that one thing the program offers is “the built in peer group. You don’t have to be lonely unless you want to.” Alan talks about the impact of his involvement with AA on his philosophy of life:

I didn’t have a philosophy of life before I was in recovery. Now, it’s tied into the one day at a time idea, making the most out of the present moment in my life. A lot of that has evolved from my concept of spirituality that’s come from the 12 step program and I think my life is organized around that today.

25The family of choice is a non-biological (fictive) concept of family widely used in the recovery community.
Alan is asymptomatic, and has had a number of very close friends die. He talks about getting his support from his spiritual beliefs and close friends both of which he attributes to his involvement in AA.

Jimmy is 38 years old and has been involved in AA for three years. During our visit he was sharing an apartment with his brother who also is involved in the Twelve-Step program. He generally goes to one or two Twelve-Step meetings each week. Jimmy has been very involved in Living Room activities, and has friends both in and out of the Twelve-Step programs. His life story has been influenced by his involvement in the program. He uses ideological concepts and jargon in his stories. He talks about his “sobriety”, his dad quitting drinking on his own; a “dry drunk”, “don’t be too comfortable in your success; be there and aware”. However, as will be seen in the next chapter, the philosophy he relies on in presenting his life story is tied more to his religious, and personal beliefs, though he accepts some of the Twelve-Step ideology.

When I first began this project, I was very interested in the possibility that people were seeking out situations of communitas (Turner, 1969) in response to life crises which thrust them into liminal experiences.

In addition to my consideration that the Special Immunology Clinic was a source of communitas, I had considered that The Living Room might be another source, because of the idea that communitas is a group of people in a similar situation working toward a common goal. The common goal of The Living Room is to create a place for people with HIV to go for support and information. At some times, for some people,
the Living Room may very well be a source of communitas, and further observation would most definitely be warranted. Ultimately, I did not find either the clinic nor The Living Room described by study participants in terms which could be interpreted as communitas.

I was surprised by how AA was utilized as a source of social support and communitas for some of the men in this group (n=5). Twelve-Step program groups possess both alternative structure and group cohesiveness (Galanter, 1990) inherent in communitas. During times of difficulties, persons involved in Twelve-Step programs will frequently increase the number of meetings they go to, and/or their contacts with others in the community. For instance during the Thanksgiving and Christmas holidays, Alan and Rob both made specific plans to spend time with other people in the program. Rob was involved in a newly formed HIV Spectrum AA group and was surprised that the attendance over the holidays was low. He told me that generally, attendance was higher during those times because of people's "stress levels" related to the holidays.

Paul and Rob, and possibly even Tim, experienced what I interpret as communitas in their interactions, or comradeship with others in their Twelve-Step groups, and it is certainly a source of social support for Paul and Rob. Paul describes communitas in his involvement with the Twelve-Step program as a spiritual community, a community without place attachment, of members working toward a common goal, that goal being outlined in the Twelve Steps (AA, 1957).
It is possible that selection of Twelve-Step programs by this sample of men may reflect the high rate of substance abuse among gay men in the larger population. In talking with the study participants, I was impressed by what seemed to be a lack of evidence of substance abuse among those who were involved with Twelve-Step programs. This may reflect the efficacy of the Twelve-Step Program model in the treatment of substance abuse, but it is also possible that involvement in Twelve-Step programs is sought to address other needs, such as being a source of communitas and other types of social support for problems in living which may or may not be related to a problem with substance abuse. This is most clearly shown in the example of Jimmy in the following chapter, who seeks a source of social support that does not reinforce his illness identity.

Additionally, there may have been some selection bias toward involvement in Twelve-Step programs by recruiting from people active in clinical trials and regular treatment. This group may be more likely to be biased toward "self improvement". Even more significantly, four of the five men involved in Twelve-Step programs were involved in an HIV support group with each other. Paul referred Tim, Rob and Alan to this study. Since Twelve-Step programs act as social support, recruitment through Paul's social network clearly biased recruitment of the other three men toward membership in Twelve-Step programs. Paul mentions that other then friends he has met through his partner, almost all of his social contacts were also involved in a Twelve-Step program.

It is therefore beyond the scope of this research to determine whether or not there is a bias toward self-help groups associated with
participation in clinical trials and regular treatment, or whether the high rate of substance abuse among gay men is responsible for increased frequency of involvement in Twelve-Step groups. What remains most interesting, however, and clearly shown in this research is that Twelve-Step programs serve as a source of communitas, and so serve as much needed social support for certain gay men living in the HIV spectrum. All five of the men had been involved in a Twelve-Step program prior to their awareness of HIV seropositivity. This membership served as a factor of resilience when dealing with the negatively perceived effects of life events experienced during the course of HIV infection.

**Chapter Summary**

In this chapter I have argued that Twelve-Step program involvement serves as a powerful cultural influence on presentation of the life story, everyday life, and illness experience. Twelve-Step programs may also be significant sources of communitas (particularly during certain illness experiences), as discussed in the following chapter.

Though I'm very interested in defining more clearly the role of communitas in people's participation in the Twelve-Step programs, I believe it is beyond the scope of this research. What I find most interesting in terms of this project is the choice of Twelve-Step programs as a source of support for people with HIV. That is, only five people out of the twenty I visited participated in HIV oriented support activities. One additional participant was active in Living Room social activities.
All five men participating in group meetings for people with HIV are also involved in Twelve-Step programs as described.

Twelve-Step program ideology has been shown to affect the structure of the life story narratives presented by the men involved as well as the content as has been suggested by Rodin (1985). This chapter has emphasized the importance of membership in Twelve-Step programs as social support and the integration of Twelve-Step concepts in presenting the life story.

Regardless of length of time of involvement for these men, ideology and terminology were presented and integrated as content of themes, descriptions of style, and presentation of timing. This points to the incorporation of common goals present in the experience of communitas. Communitas is inherent in Twelve-Step group meetings and provides social support in its shared philosophy of living, the sense of belonging and egalitarian social structure (Rodin, 1985). This chapter has shown the importance of this shared philosophy in the life story as it reflects the integration of present with the past. Further investigation may afford a better understanding of the effect of Twelve-Step group membership on maintaining perceived quality of life in the face of significant life events during HIV infection.

In the following chapter, I will begin with one additional example of a participant who is involved in the Twelve-Step Program. His narratives will offer a more in depth understanding of some possible reasons why Twelve-Step Program involvement may be particularly attractive to these men living in the HIV spectrum, as a means of

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influencing the social course of illness by limiting illness identity. Additional stories will then be presented of two other participants' efforts to influence the social course of their illnesses in their everyday lives. This limitation of illness identity is one of the most interesting aspects of Twelve-Step programs as a source of communitas and/or other social support.
CHAPTER FIVE

THE LIFE STORY AND SOCIAL COURSE OF ILLNESS

In this chapter, I will review life stories which emphasize individual attempts to regulate the social course of illness. Just as there is a natural course of illness in terms of biological or physiological disease processes, there is also a social course of illness (not necessarily regulated by individuals) which mediates the illness experience, and also refers to the ongoing impact of the illness on the social experience of the individual (Kleinman, 1991; Ware and Kleinman, 1992).

Involvement in Twelve-Step programs as indicated in the preceding chapter serves as one means of securing social support, and possibly in providing communitas for persons experiencing liminality and marginalization. HIV/AIDS support groups and most Twelve-Step meetings differ in their problem focus, while overlapping in the function of creating a network of support. By choosing one or the other source of support, an individual may alter the social course of his illness, by either emphasizing or minimizing his HIV status as a defining feature of the support received and reciprocated. In the first life story discussed in this chapter, lack of association with HIV infection was seen as a desirable characteristic of Twelve-Step programs as a source of support. Interestingly, Franke (1984) found a similar situation in her study of a disabled woman who minimized those supports related to her disability and gave more positive evaluations to those supports which were unrelated.
Jimmy

Jimmy lives just a few blocks from Rick. During our visits, he shared an apartment with his brother in a duplex, above an elderly cousin. The house is old and in need of minor repairs. His apartment was bright and airy with large open rooms. We always sat and talked at the large dining room table. Jimmy always offered me something to drink, usually herbal tea. He always had a lot to say, and talked very passionately about the things he believed in. I looked forward to visiting Jimmy, and talking about whatever he was going to suggest. He always had an endless supply of topics to cover.

During the autumn of 1994, he was quite involved in HIV/AIDS social events at the Living Room. He consciously reduced his involvement there by the end of our six months of visits because he perceived his participation there as interfering with attainment of a desired social course of his illness. That is, he was trying to limit the influence of HIV/AIDS in his social interactions, in order to preserve and enhance his social life outside of illness experience. Though he didn’t feel ill all the time, he felt that all aspects of his everyday interactions with others had become focused on HIV infection, and was seeking to change this.

Jimmy’s timing in presenting his life story to me involves a recursive approach (as does Tim’s life story, Chapter Four). He begins by giving several short life histories with brief, descriptive reminiscences\(^26\).

\(^{26}\)Watt and Wong, (1991) refer to this as narrative reminiscence. As I use the term ‘narrative’ often in this discussion to refer to textual data, I use the term descriptive for those reminiscences which serve primarily to give biographic data, e.g. “I was born in Mount Vernon, Ohio.”, “I have an older brother who lives with me”...
His first historical narrative gives a framework of the timing of his life with changes in residence location, education and first relationship, HIV diagnosis and life after diagnosis. He then begins another history, timed by changes in location of the primary romantic relationship in his life. Over the course of our talks, he primarily uses life events as indication of timing in his life; particularly his HIV diagnosis, changes in location and changes in relationships. We talk mostly about the present; the time since his HIV positive diagnosis about one year ago.

"To Care for One Another"

Jimmy's style in the narratives he presents emphasizes both independence and interdependence. He tries to be a caring and loving person with regard to himself as well as others, and tries to keep a positive attitude.

I have a positive outlook on life. I hate negative people; especially when they keep complaining and don't do nothing about their lives. I'm very sensitive; caring. I get involved, especially now that I've been diagnosed. I don't let people step on my toes. Before diagnosis, I took my health and everything God has given me for granted. Now I do smell the roses when I walk by, and enjoy people's friendship and actually want to know their name. So this was like a positive change even though it's negative. Nobody wants to be inundated with HIV and all its complications. For me it has been a teacher.

The most important thing in life is so simple: It's just to care for one another. There's feeling in those words and it's over-bounding. Maybe I want a quick answer and because I have AIDS, I feel that time is a main factor. It could be just words, but in the end God will look in your heart. There'll be all kind (sic) of stuff, but if you're generally a good person, that's what you strive for. I love
the world. I thank God everyday I’m alive and it’s a day by day thing.

I think the fight also keeps me well. I don’t just sit in the chair and create cobwebs physically, mentally and emotionally. The world is good, but it’s hard to find the individuals that contribute to that. You have to look hard. And sometimes you don’t see them.

I think God has turned on the light with this HIV and my having AIDS. He’s turned the light on a lot of things. I’ve been more caring and genuine and concerned with people’s lives than I was earlier in my days. It’s given me a whole new light on life. The light is on.

Jimmy talks about the positive effects of HIV infection on his life and has been able to integrate his experiences with HIV into his life experience as finding something good in the bad things that happen. This is an important theme in his life stories and emphasizes a style of achievement and survival against the odds. To take a seemingly negative occurrence and transform it into a positive factor. Jimmy uses the impact of his diagnosis as a reason for self growth and appreciation of life. He is not only able to endure this difficulty and survive, but he can achieve a greater understanding of himself and others. Jimmy is very religious. He was brought up as Catholic, and retains a deep faith in “God and Jesus”. Undoubtedly, his narratives above reflect traditional Catholic beliefs of enduring suffering and being “ennobled” by it (Gaines, 1986).

During our talks he would occasionally apologize for being too philosophical, talking about what we both laughingly referred to as “the depths of stuff”, to which I would reply that I wanted to hear his philosophy. He sums up his philosophy of life in the second paragraph of the above quote: “just to care for one another”. As mentioned, this
theme is present to some extent in the life story narratives of eleven of the study participants. It is a particularly strong theme in Jimmy’s narratives, both present and past. He tells stories illustrating people who were and who weren’t caring of him, and of his efforts to embody his philosophy of caring towards others in his community.

He talks about caring in his upbringing. His mother died in an auto accident when he was an infant. His father was an alcoholic, and was very violent. Jimmy’s aunt raised him and his brother. “She would come in late and make sure we ate and the house was clean and leave before my father came home. She looked after us to make sure we were OK.” She was simply someone who cared for them, in the most literal sense. Jimmy describes her as the person “who raised me and did an excellent job”. He remained close to her until her death, several years ago. His father on the other hand “was too inundated with drinking and getting all of his vices and pleasures out of the way. He sort of threw us to the side.” He’s now remarried “involved in the type of family that doesn’t care. He has a fifteen year old son arrested for selling drugs at school, and it’s a mess, but they just don’t care.”

These two characterizations of his aunt and father exemplify the theme of caring through the contrast of their behavior. He tells a story in the present of a recent hospitalization. In this case he offers two physicians as contrast, the physician who managed his hospitalization and his primary physician from the Special Immunology Clinic. He was admitted to the hospital for a fever and infection. While he was there he developed additional problems, a skin rash from a fungal infection, and
diarrhea from a gastrointestinal infection. These were treated, and he mentioned having a headache. His physician wanted to perform a spinal tap to check for infection as a cause of the headache, but he refused.

The hospital itself can give you a headache. It lasted for two days and then it was fine. This is going in reverse. They prescribe something to you and create more symptoms, and it should be less; that’s why it’s called medicine. I’m normally very patient but I said I’m really sick of this whole thing and my stress level is so high, I can’t get rid of my symptoms. I’m thinking they’re mostly mental at this point. My fever was down. I told the doctor the best doctor for me is me. She didn’t seem to understand that. I said I was leaving tomorrow, so do what you have to do now.

Everyone should rely on themselves. I just let the doctor talk and do my own thing. I hate to pacify a physician, but this one was wasting my time.

They gave me a transfusion and a chest x-ray and then wanted to do half a dozen more tests, and I said, why didn’t you do that when I first came in. They don’t want me to think; just be sick and lay there. If you understand their business is pills and procedures; if you’re well, they’ll go broke. I don’t know how one gets around that. The doctor asked why I wasn’t taking antivirals. Why does she think I needed the transfusion? I said my body said no. She says you gotta give them time. I do have a brain though it may be unfortunate in the doctor’s eyes. It’s not that I’m a bad patient, but I know what my body needs.

Jimmy implies that this physician has an economic agenda in scheduling procedures and tests, and prescribing medications. Though not said specifically, this also shows Jimmy’s perception of this physician as one who doesn’t really care about him, or what he thinks. He contrasts this with his physician at the SIC. He says “My clinic doctor tries! My clinic doctor admits that medicine’s not precise, and that’s one thing I

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27 Jimmy refers here to the destruction of red blood cells, a side effect of AZT, which was the reason he stopped taking it.
like. My clinic doctor also admits that the AZT was a mistake; it never helped me, but OK.” And Jimmy expresses what he sees as mutual caring in this physician’s commitment to working with persons with HIV infection. He talks about his clinic doctor several times during our interview. In the above episode, the clinic doctor came to visit Jimmy while he was hospitalized even though Jimmy had a physician at the hospital. Jimmy was impressed that his doctor cared enough to come see him. “But my clinic doctor will take the time and do for you. I love this doctor and the feeling’s mutual. You don’t need a brain surgeon to see that; it’s just caring for humanity.”

Jimmy presents this theme of caring as a purpose in life that he feels should be shared by all of humanity. The stories he relates which exemplify this theme, whether of the distant or more recent past, are transmissive reminiscences (Watt and Wong, 1991). Watt and Wong define transmissive reminiscence in aging as stories which serve to instruct the younger generation regarding some “enduring values and wisdom which s/he has acquired”. The authors attribute this to the need for the elderly to “leave their mark” on following generations by instilling values and ideas they have learned from their own lives (Butler, 1963).

Watt and Wong’s (1991) explanation of transmissive reminiscence as being relating to aging may have more to do with the sample they used to research their taxonomy of reminiscence. That sample was “seniors aged 65–95”. Butler (1963) in fact suggests that the life review itself is more commonly observed in the aged “because of the actual nearness of
life's termination", and also because there is more time available for self reflection due to retirement. For the men in this sample, there is a perception of nearness to death, and half of them are disabled affording them ample time to reflect.

Along with Jimmy's theme of the value of caring, he presents his style of independence. Though he is grateful to his aunt for raising him, he says "I pretty much raised myself to my own beliefs of right and wrong." He attributes the aunt who "raised" him as telling him to "never depend on anybody except yourself", and describes himself as trying "to pull myself out of ruts and hang in there." In terms of the hospital, he demonstrates his independent style in telling of his plan to leave the hospital even though his doctor wanted him to stay, and in his statement that "the best doctor for me is me".

He demonstrates his style of caring in terms of the American cultural value of reciprocity inherent in the Twelve-Step ideal of "giving back to the community"; acknowledging responsibility to help others, offering emotional support, contributing to society through work or charitable acts and contributions, etc. He gives as example, his participation in a clinical trial involving bronchoscopy which as he says "is not a nice procedure". His reason he gave for undergoing the procedure was: "at the time I felt I needed to give something back, and that's what they tell you in a Twelve-Step program". He has also been

28A bronchoscopy is the passage of a tube through the mouth and into the bronchial tree in order to visualize the bronchi, and obtain tissue samples. The patient is sedated for this procedure, often using a drug that has amnesiac qualities (e.g. Versed) so that there is no memory of the time during the procedure. Some people do retain some awareness of the procedure, and there is difficulty swallowing for several hours after, and residual throat pain that may last a day or more. (see also footnote #12)
involved in organizing several social events for people with HIV, and sometimes participated in the Living Room’s social activities. He doesn’t always phrase his involvement from the Twelve-Step frame of reference, but also, it is his style: “I want people to care about others and stop caring about one’s self. It boils down to helping the community.”

A New Way of Living

Jimmy talks about his everyday life with HIV infection and AIDS. He wants HIV and AIDS to be less of a topic of conversation in the social settings he goes to. HIV has forced Jimmy to face the limits of his life span and frequently is forced into an awareness of death.

Sometimes when I pray at night, I don’t ask God for a cure. I ask for his courage for me to keep on going. If there is a cure, then that’s another big plus. I tell myself when I wake in the morning; I look at the sun and thank God I have another day going. That high energy from the sun is a healing and I look at it and I ask God to give me the strength to keep on going for however long many years he wants me to be here. And I never really thought about death until I was diagnosed. I felt my life was extremely limited now and time was at the essence and I had to do things right now for me because I may go.

But I’m always sticking around so that feeling of death has sort of subsided. But there are times when you see your friends get inundated with symptoms, and some just die, and you feel scared that it may happen to you. That’s the real bad thing that I fear. I gotta ‘do it now’ before I become; like if CMV creeps up into my eyes or something. HIV is not a happy thing. I’ve always known that, but now I’m actually finding things out. It’s a whole thing that you just don’t worry about it. You just try to enjoy life now and go on.

The awareness of death as described in the above first paragraph, is an intrusive awareness of death as inevitable. Becker (1973) suggests that it is
difficult if not impossible to function as a human being in everyday life with this awareness of death. He suggests a denial of death as an active stance; more an act of a refusal, and not denial in the common biomedical jargon, according to which denial is synonymous with disbelief.

Jimmy acknowledges fear of his own death, but he experiences it as a "whole new thing" and he doesn't worry about it. In trying to enjoy life and go on, Jimmy is resisting the inevitability of death. He expresses the difficulty of learning to live with his foreshortened future without being overwhelmed by trying to live an extended life before he "goes".

Importantly, he is not repressing his awareness of his death, but trying to learn how to live with all the limitations which HIV has brought to his life. He is "no more 'denying' in a repressive sense than (he) would be if (he was) learning how to drive on the left side of the road after having driven for a long time on the right" (Rosenblatt, Walsh and Jackson, 1976). The experience of HIV infection results in drastic changes from the culturally ideal course of events of everyday life, e.g. prior to the HIV epidemic, these men would never have considered that their entire cohort of friends may die, before they reached the age of forty, as is the case for Jerry, Rick, Rob and others. It is a matter of learning a new way to live, similar to the above metaphor of learning a new way to drive.

Jimmy describes his efforts to renegotiate his life after his diagnosis with HIV and AIDS, a little over a year ago:

I've seen so many people drop; die because of AIDS. It instills a fear in me, like 'Why should I make plans?'. I used to be very athletic. If I can get my laundry from the basement up here, I've accomplished a lot. I used to be involved in all sorts of physically oriented activities. Without the energy to do that, I feel limited.
And since I have zero T-cells, I can’t go to too many places or I’ll catch something. I think that’s psychological and I’m working on that. I know a lot of PWA’s go back to school and continue their life. But since it’s only been a year, I’m trying to get a grip on my health and I’ll go on from there. I’m realizing that going out and doing stuff you want is part of your wellness.

Jimmy is tired of being caught in between. Above, he talks about being unsure of how to function in his newly defined world. He is redefining his capabilities and limitations. He had become very involved with HIV/AIDS organizations and activities including the Living Room, but was beginning to pull away during our interviews, because he was tired of everything being “about AIDS”.

"More to Me than AIDS"

During the period of my visits, Jimmy’s prime concern was how to continue his life without surrendering totally to an “AIDS-centered” experience:

There’s more to you than just AIDS and HIV. HIV has attached itself to you. You are not it! I want to get away from people talking about meds and doctors. It’s like blanketing you with disease stuff and you should be talking about health and wellness and something to pull you out not bring you back in. I try to tell people that if you keep talking about HIV, you’ll feel bad. It’s hard to tell people to be in a good mood when they have KS lesions all over. I’m not that stupid. I take my Bactrim [Trimethoprim], Acyclovir and Ketoconazole. Those are tools for wellness, just like positive attitude is.

29Kaposi’s Sarcoma (KS), in this instance, is an opportunistic infection affecting people whose immune systems have been severely damaged by HIV infection. One result of this disease can be purplish raised areas on skin, as Jimmy mentions.

30These medications are all drugs which are used in prophylaxis of several different opportunistic infections in persons who’s immune systems have been damaged by HIV infection.
HIV is overwhelming, because I use it in my everyday life. I share it and communicate with it. The only way I can express myself is with getting into my philosophy of life. And you're not AIDS. Something has attached to you. It's up to you to shake it off and go on. It's like one of those remoras or a leech, and how do you get it off? There's a lot of ways but the good way is not even thinking it's there; like out of sight out of mind.

This was another of Jimmy's prominent themes. He believes that "life is good even though you see a lot of bad". To maintain a good life, the quality of his life, it is essential for him to maintain a "positive attitude". And the way to maintain this attitude in the face of HIV and AIDS is to not think about it. Jimmy is not suggesting that he pretends or does not believe that he has AIDS, but to change focus and transcend AIDS. He tries to think of his opportunistic infection prophylaxes as "tools for wellness" rather than treatment for AIDS. He acknowledges a conflict, for instance, in someone with KS. How do you transcend AIDS when it is so omnipresent as in visible lesions?

At one point he prefaces a comment with: "Before I got sick", then corrects himself, saying "see I did it again". He believes that to talk in this manner, and describe his life in terms of being "sick", will only serve to lessen the quality of his life as he lives the life of someone who's sick. He resents spending so much of his time concerned with his illness, the medications, the bureaucracy of disability, his appointments: "When is it time for me to enjoy life?! If I can pass through all the bullshit and start enjoying life then I think my T-cells would come up a little bit."

Jimmy recognizes an internal struggle to balance management of his illness and illness-related activities, with a life outside of his HIV-related experience. He is frustrated by others' influence on him bringing
his experience of illness to the foreground, as he is desperately trying to create an everyday life where AIDS, though present, is in the background. He talks about living with his brother:

Every morning, when I'd wake up my brother would get into my face and say 'How are you feeling?', like I'd explode any minute. There was some worry and fear there. I understand his love, care and concern comes from his heart and that's why I don't say much, cause I've experienced when there was nobody and no one cared. But when my brother keeps reminding me how I feel, it sets me back. I feel a loss of independence. My life is limited. I don't have the things that make me, me.

Once I get my own place, I think things will come together. I miss my life. I'm not living now. I'm existing now. That's not me. I need to live. A lot of caregivers I talk to think irrationally. Like what happens when you get sick and live alone? Well, I'll go to the hospital. It doesn't make sense. But you've gotta understand the person with the illness. First you're human! Then you have the illness. Please comprehend that!

At our last meeting, Jimmy had boxes packed and had secured subsidized housing a couple blocks away from where he was living. He was also frustrated by his experience in the gay community, where he felt that it was common knowledge that he had AIDS, particularly with regard to HIV/AIDS support groups.

Going to AIDS agencies and support groups and things like that, there's not much support. They talk about AIDS and then you leave. Sometimes people call me up and say 'How are you doing?'. I say I'm fine, then they look real worried and say 'How are you doing?'. Their voice drops and they look at you funny like you're a real sick individual because YOU HAVE AIDS!

I say I don't want to hear about AIDS. I really don't. They get mad, which is fine. I don't really need you then. I wanted to say that nicely, but you can't say that. I'm worried about my health and attitude and keeping my good disposition (maybe not every day). But when I go to the Living Room, I hear symptoms, medication

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foul-ups, doctor foul-ups, and health and diarrhea. I feel like not going there anymore, because it brings me down. I need just a plain group, so I'm checking out the community center - for a plain group, but it's real hard, cause I've been around in the gay community and they know me. Now I go to AA. Especially if I go to the straight community and interact. They don't know I have AIDS.

By the time of our last visit, Jimmy had cut back on his involvement with most of his HIV-related activities. When we first met, Jimmy's social experiences were enmeshed with his identification with the HIV spectrum. I observed him try to enlist others in the spectrum, to participate with him in social activities where HIV was not the primary topic of conversation. He was instrumental in implementing social activities for people with HIV, but found that this all too often led to more discussions about HIV.

It's interesting to compare Jimmy's experience with Jerry's. Jerry felt relaxed around his few living friends with HIV, as if things didn't have to be explained. HIV was just assumed, and they could go on with their socializing without intrusion of illness related talk. But Jerry's friends were long term friends, while Jimmy talks mostly about men he's met at HIV-related events and agencies. Jerry's friends with HIV were friends before HIV was an issue. Jimmy's contacts however, were social contacts because of their association with HIV. Jimmy's social resources were limited, because he had just moved back to Ohio after having been out of state for about ten years, and he was diagnosed with AIDS, less than a year after his return.
Quality of Life

Jimmy mentions AA as a source of support where he would not be forced to talk about HIV-related topics. Rob had even mentioned that AA meetings were not conducive to people talking about their HIV even in terms of HIV as a stress which might challenge their sobriety. Rob said: “It’s kind of taboo to talk about it. People don’t want to hear about AIDS and stuff. I hear comments about it. I think people are just tired of hearing about AIDS.”

Twelve-Step programs may well offer a supportive environment which at the same time allows an individual to step out of his identity as a person in the HIV spectrum. People involved in this type of group “experience a relief from emotional distress when they feel more closely affiliated with the group” (Galanter, 1988). This author maintains that as long as behavior is in accord with group expectations, e.g. sobriety, then well-being is enhanced. Rodin (1985) found that when AA members are compliant with Twelve-Step program philosophy, they are regularly rewarded with verbal approval from the group, reinforcing cohesion and feelings of support.

Jimmy may achieve a balance between involvement in HIV-related activity and social experiences where HIV is not the defining characteristic. He has moved out on his own, and for now has cut down dramatically on his participation in HIV-related socialization. He is achieving measured success in containing the social course of his illness. That is, there is more opportunity for him to have periods of time with no reference to HIV, due to his change in residence and activity. He is
acting to change the social environment of his life and thereby change the social course of his illness by limiting the frequency of illness-related socialization.

The change in his social course of illness results in an improvement in his quality of life. His style of independence is reinforced by his move on his own. His change in affiliation to sources of social support from those identified with the HIV spectrum to a Twelve-Step identity will limit HIV-related socialization, and emphasize his theme of caring for one another in the communitas of the Twelve-Step meeting.

The following two life stories are from men who have worked to maintain the social course of illness which Jimmy was seeking. That is, though they acknowledged their infection with HIV, they took measures as needed to limit the impact to the social aspects of their lives.

**Glen**

Glen lives in the outer suburbs of Cleveland in a modern apartment complex. At first he was somewhat hesitant about talking about himself, and wasn't sure of what he had to offer to my research, but after the first couple of visits was more comfortable about talking about some of the things that he initially felt strange about telling “to a total stranger”. His apartment was always immaculately clean, with new looking, modern, comfortable furnishings. Glen and I always sat in his living room, on the couch and lounge chair respectively, with the tape recorder on the floor between us. He always offered me a cold drink.
Then we’d take our places and I would ask him about his past month. In general, Glen would respond to my comments or questions fairly succinctly without rambling or getting off the topic. I was unable to break out of the interview format except during our last visit when Glen was able to reflect on my tentative analyses of how our conversations would fit into this dissertation.

Glen differs from Jimmy in that he has not suffered any tangible effects from HIV infection, and has as his primary social support system, his family, his partner and a group of heterosexual men and women he has been friends with since his childhood. He also has social ties to a number of other gay friends, some who are also HIV positive. Though all are aware of his HIV status, and have discussed some aspects of this with him “it’s not something we talk about all the time. It’s understood.” He is in his early thirties, and lives in a suburban apartment complex with his partner of several years.

Like Jimmy, Glen also tries to focus on the positive aspects of life and is concerned with acting to help others in his situation by participating in clinical trials and this study. Jimmy sees his positive attitude as a “tool for wellness“. Glen doesn’t specifically label his positive attitude as such, but emphasizes that it has opened his eyes to appreciating what it is that gives his life meaning and value.

A lot of people really look for the negative aspects of being HIV positive. I try to look for the positive aspects. As goofy as this may sound, becoming HIV positive has had a lot of positive influences on my life. I’ve gained a better appreciation for my family, my friends. I don’t take for granted the things that at one time never crossed my mind. I stop and look at a flower in bloom. I have
more appreciation of nature, people, people's remarks, what I may say. I've become more tolerant of people. I try to take more time out, for my family for one, I try to make the best of a negative situation. Throughout growing up I never tried to find the positive aspects of a bad situation. Now it's one of the first things I'll do.

I think it's the positive outlook that you project that makes you feel better inside. So the better you feel, the better you look, the better overall you're gonna do. If you really dwell on all the negatives, then you're gonna feel like crap, look like crap and chances are, in my opinion your time's gonna go a lot quicker. If I have the ability to help somebody along the way, that's what counts to me and makes me feel good so I always try to look for that. Where does the positive emotion come from? The only thing I can attribute it to is being involved with a very loving and understanding family, and loving and understanding friends. I've never been shunned or asked to leave or brushed off.

This is very ironic I guess, but I have become a better person because of the fact that I've become HIV positive. I'm sure I would probably be singing a different tune if in fact I was ill, but I think I look at things much differently and appreciate life much more. And I don't think I'm willing to give that part of it up. Am I crazy for saying something like that? I would have preferred to learn these things in another way, but I can't change that so I have to try to find the most positive outlook that I can in the situation that I'm faced with.

If something like this hadn't happened to me, I'm not so sure, I'd look at certain things the way I do nowadays. To be really honest with you, sometimes that kinda scares me. To have such a disregard for some of the simple things in life that I once had really does bother me. That's why I really appreciate my sense of well being, my ability to look beyond just the negative part of being HIV positive. You're thrown into it, and there's no turning back. I guess, because my time is limited, I'm thrown into more of an appreciation for something, because it may not be there tomorrow, or I may not be healthy enough tomorrow to be able to appreciate a walk through the park, or my dog, or whatever the case may be.
Glen's narratives emphasize the change in his style since his diagnosis with HIV, "not overnight, but a long slow process". When he was a child he described himself using words like "free spirit", "defiant", and "spoiled brat". In his narratives of the present, he contrasts this to having appreciation for life and caring about friends, family and doing what he can "to help others in this situation". The change is not drastic, but more of a shift in focus. His defiance growing up has changed to defiance of the negative qualities of his limited future due to HIV infection. Like Jimmy, Glen transforms the negative consequences of HIV infection positive influences on his life, and so moves beyond merely surviving while living within the HIV spectrum, but uses his experiences to achieve good in his life, and for others.

Positive Thinking Revisited

Though Glen uses a number of events in timing his life; changes in location, illness and death of friends and family, his narratives often contrast life before and after HIV diagnosis. This is the event to which he attributes his change in style. It is this style of striving for a positive outlook which has allowed him to develop one of the primary themes of his stories: the value of learning from experience. By learning from his experiences he is able to grow and mature and become a better person. This theme is illustrated in the above narratives as the essence of his change in style precipitated by his diagnosis with HIV. With the diagnosis of his HIV infection, he has grown to be a more caring and
appreciative person, through awareness of his mortality and foreshortened future.

In addition, Glen’s mother was diagnosed with cancer when he was in high school.

For me the only thing I could do is look back to the way she responded to what was told to her as a death sentence. She never gave up. She continued to raise her children while going through the worst time of her life. If she can do it so can I.

Like his mother, Glen is a survivor who not only endures and perseveres, but continues to achieve. Achievement for his mother was in the form of raising her children. For Glen it is in his work. Glen says: “I’m a workaholic. I really love my work”. During the second month of our visits he talked about being a little disappointed at his advancement in the company he worked for, and within the next two months, was promoted. As he mother achieved through raising her children during her illness with cancer, so Glen achieves in his work.

And though he was defiant to his parents, he states that he was always dedicated to his friends and has maintained those same friendships since grade school. He talks about the support he has received from friends and family. In this way he was able to draw on his history for examples of endurance and achievement as well as the sort of caring and concern which he can now integrate into his style.

During the first several months of my visits with Glen, I had difficulty with his insistence on HIV as being a positive influence in his life. It was hard to reconcile my own observations of the death and
suffering which result from HIV infection. Eventually we talked about this. Glen responded:

God forbid! I would never wish this on anybody, or myself if I had that opportunity again. I don’t thank God for being HIV positive. I thank God for giving me the strength and ability to look at things in the manner in which I’ve chosen to do at this point in my life.

I came to understand that for Glen, finding the positive effects of his infection with HIV gave meaning to his continued existence.

Jimmy also talks about the importance of knowing that “life is good even though you see a lot of bad”, and keeping a good attitude. He says that it’s the way to improve his “wellness”, and like Stan and Glen, believes in the overall benefit of positive attitude to how you feel. Glen uses his positive attitude as an internal modifier to shift his focus from dwelling on his illness, to concentrating on the good things in life; his relationships, and appreciation of nature. I believe that one of Glen’s strengths is his ability to bring this attitude into his social interactions and so avoid a focus on HIV.

Glen did not have any difficulty in maintaining social relationships independent of illness, as was the case for Jimmy. However, Glen’s friends and family had known him long before knowledge of his infection. Glen also is still working full time, and though he mentions being close to another HIV positive friend at work, his social environment is overwhelmingly not related in any way to illness. In this way Glen has been able to keep a positive focus in the foreground of his social interactions.
"The idea of “positive attitude” also offers insight into perceptions of quality of life. For Jimmy, the overwhelming intrusion of an illness focus into his social life was diminishing his perceptions of quality of life. As his social experiences became inundated with experiences colored by talk or inference of HIV infection, he could not keep a positive attitude and his quality of life was impaired. Only by limiting the impact of illness on his social interactions, would he able to again maintain his positive attitude.

In Chapter Three, Stan talks about maintaining a good attitude despite the fact that he may be involved in illness related activities during a majority of his waking (and sometimes sleeping) hours. Keeping a positive attitude is a means of expressing perception of a good quality of life and Stan does this by considering his relationships with his partner and family. His reciprocal love for them gives him reason for perceiving a good quality of life, a good attitude.

An interesting contrast is seen in the basis for perceived quality of life for Glen, Stan and Jimmy. Glen and Stan see the source of their positive attitude, their perceptions of a good quality of life, in the reciprocal love and caring in their relationships with family, and/or friends. Stan acknowledges that he “gets down” when he’s feeling physically ill, e.g. when he was up all night, sick to his stomach. Otherwise, he is able to keep his good attitude, because of his awareness of the strength and love in his relationships. Glen frequently uses the word “fortunate” in describing his relationships with his family and friends, and the support and care they give him. The source for his positive
attitude is "a loving and caring family and loving and caring friends". This is the theme of appreciating life expressed by eight of the men in the study (Table Two).

Jimmy's situation is different. He's searching for supportive and caring relationships in the hopes that this will help him to shift his focus away from relationships and everyday life dominated by illness to one in which illness is secondary to his relationships. Interestingly, though Jimmy needs social support, HIV support groups only serve to make him feel worse about the domination of his life by HIV.

Eric

Eric lived not far from Paul in an attractive Tudor house. It was a very comfortable home, conducive to our doing interviews. His living room and dining room were furnished with formal, but warm and comfortable furnishings. The entire house had an immaculate aura to it, as if it had just been cleaned. We sat at the dining room table where I set the tape recorder up. My talks with Eric were more formal than with other participants though at the same time his affect was for the most part warm and pleasant. He has lived alone in this house for the past seven years though he has an ongoing relationship with a man who lives in the "gay neighborhood" described previously.

Eric was the first study participant that I interviewed and my initial reaction to our talks was a combination of alarm and disappointment. It was exceedingly difficult to get him to talk in depth about anything regarding his thoughts, feelings or experiences, yet at the same time I felt
that he wasn’t consciously holding back information. At first, I was concerned that my interview approach would not yield adequate quality or quantity of data, and was quite relieved when I interviewed the next several participants and found that they had much more to say. I wondered whether Eric might just not be a “good informant”; that he wasn’t able to engage in the task of telling his life story. Ultimately, this was not the case.

“My Life is Boring”

Eric presented his life to me as “boring”; that nothing much ever happens. I took this at face value for a time until I interviewed others who also presented themselves as leading lives that were uneventful or “boring”. I began to see that Eric and others were presenting their lives as boring with a resulting incorporation of stability and routine. Four participants expressed this theme of life as boring or uneventful (Table Two). Eric took this presentation to the greatest extreme, and referred to his life in such a way at least once during each visit.

Eric’s timing in initially presenting his life story is based on changes in location. This initial description is very brief and relates minimal information about his family, education and occupation, and moving. I found I had to elicit all additional information. Eric was able to give much greater detail when asked, but didn’t offer his own structure for telling his story until more recent events. I had asked him to talk about any important relationships, and for the first time, Eric offered a historical account of his life. He talks about two men in particular and
from that led into telling me how he found out he was HIV positive, using location, historical events and date to place these events with reference to timing. Primarily when relating historical information, Eric uses his age or the date to place the event in time. He does on occasion refer to his HIV diagnosis as a time marker; “when I found out I was HIV positive”, but primarily talks in terms of age and or date.

This facilitates his use of descriptive reminiscences which offer historical data. The majority of Eric’s narratives are of this type: “I remember my father teaching us to swim. There was a pool at the end of our street. Actually it belonged to a motel. We lived on a cul-de-sac. It wasn’t built up and there were a lot of woods.”

In Eric’s narratives, he presents his style of trusting other people. For instance, in talking about his involvement with Keith he tells the following stories:

My second relationship was with Keith, and it’s not something I’m proud of. It was basically just a one night stand. But he gave me his number, and then I did call him back and we had a couple of dates. One night I called him, and he said oh, he forgot to tell me that he had a lover. Two days later, he calls me back, and said he was breaking up with his lover for me, and I said well if you’re doing it for me, don’t do it. Just do what you have to do, but it’s your decision. So then he called back a couple of times, so it was just basically kind of like a year of dating. I guess, we got off to that bad start, when he forgot to tell me he had a lover. OK, we can go out, have some laughs together, but I’m not, y’know, it can’t be much more.

When I found out I was HIV+, Keith and I were still like kinda friends. It was at that time though that he told me that he was carrying the disease, and I thought OK, thanks for telling me now; everything after the fact, but I guess that if I was going to get it, it was fortunate that I was seeing Keith, because he introduced me to
my doctor, 'cause to be quite honest, at that time, I was devising different ways to take my own life.

Interestingly, Eric describes himself as being a little too “willful and unyielding” though he is “hard working and basically [has] a good heart”. In his stories, however, Eric consistently gives examples of his flexibility as in the example above in his willingness to continue any relationship with Keith despite the two incidents mentioned. He does present himself as hard-working and valuing his career: “I look forward to going to work. I like the people I work with, enjoy their company.” He works as a statistical advisor to a large corporation, and regularly works overtime. He mentioned that there’s always a lot to do when he’s been on vacation, because work piles up for him to do. “I guess it’s job security. It’s kind of complicated paperwork. I know I’m missed, and I am compensated for it, so I’ll be prepared for the bills from vacation.”

Though Eric acknowledges his infection with HIV, he remains hopeful for his own survival. He looks to his family history as an indication of an inherited physical resistance to illness. He mentions that he does not plan to take any antivirals should his T-cells fall because if they worked “it would only be temporary”, and the virus would develop resistance to the drug and continue to grow. He says he’d rather know that he fought off the illness himself, and so reinforce his self-reliance.

There’s always hope or I’d be gone now. There’s always hope that it’ll be put off a long time before I get sick. In the back of my mind I have hope about the possibility of my having some sort of natural immunity. I read somewhere that people who were chronically sick before infection tended to succumb and healthy people have been warding it off. I’ve always been healthy, never missed a day in high school, always healthy, and we have no heart disease,
cancer or diabetes in our family. Three of my grandparents lived into their 80's and 90's.

I've been reading about people who carry it and don't have any problems and now they're wondering if there are going to be people who never develop full blown AIDS; just carry the antigen. Part of my hope too is that I'll fight it off on my own. It's that Christian Science background of my grandma. It worked for her. They never thought she'd live past sixteen; she made it to 83. She had diphtheria. Her grandmother recommended two glasses of sherry every day if you weren't feeling well. I remember hearing that, and I've always kept that decanter of sherry for when things get really stressful. Of course that could be a sign of alcoholism. [laughs]

Self-reliance is important to Eric in many avenues of his life. He talks about living alone, and renovating his house independently. He has an ongoing relationship with a man named Jack, but generally sees him only on weekends, enjoying his time alone, to read or work on the house. At his job, he is proud of the fact that no one can do his work while he's gone and calls it job security. Through his self-reliance and hard work he achieves at work and at home.

Infection with HIV challenges this self-reliance. He wants to survive, but not by relying on medication, rather on his physical self-reliance which he attributes to his family history. Eric resists the intrusion of HIV on the social dimension of his life to an extreme. He is asymptomatic, and sees the physician once every three months. Nevertheless, he sees this visit as intrusive and takes steps to avoid it's having much effect on his life. He refuses a social engagement, because by attending it he would allow himself to ruminate about this appointment, representative of his HIV infection.
Next Sunday we’re having a big cookout, so I thought about taking Monday off. But then I thought, I have my clinic appointment Monday afternoon. I decided not to take the whole day off, because I’ll keep thinking I have to go there and it will just ruin my whole day.

Jack thinks I should be in counseling or something like that. He thought I might be very upset; that if I talked about it more, I’d feel better. He asks if I’d like to talk about it, but I prefer not to. Partly too, it’s self-reliance in not going through counseling. In fact, I never saw the counselor at my first visit to the clinic. I was supposed to set up a meeting with the counselor or social worker. I said I did it already.

Keith had a friend in a support group, but he dropped out. It was so depressing because people were dying. That’s too depressing for me.

Repeatedly in audio tape-recorded and casual conversation, Eric emphasizes how quiet and uneventful his life has been. During one interview, after telling me about how little had happened the last month, I asked if he had anything exciting coming up. He said that “all the exciting stuff happened the last three weeks [laughs],” referring with sarcasm, to visiting his parents at home, going out to dinner once, working on the garden and reading. Later in this interview, I found he omitted some of the more interesting events of his life; a gay wedding he had been to of two HIV+ friends, and plans for a vacation to Hawaii. At every visit he would make some comment about how boring his life was. His affect was always bright and he frequently laughed when making these comments. “I feel sorry for you having to go home and transcribe these conversations. It must be so boring!”

I suspect that this approach serves to control the social course of illness as it relates to our visits. By presenting his life story as
"uneventful", "nothing unusual", "typical" and "boring", Eric implies a continuity which is desirable in the face of his HIV infection. A life that is boring precludes significant HIV related life events.

Eric perceives the quality of his life as good. He maintains his independence to the extreme, and enjoys it. He has a great deal of autonomy, in his everyday life at work and at home. His closer friends are aware of his HIV infection, but his social interactions are not influenced by it, unless it is characteristic of others he knows, as with the wedding he attended of two HIV positive men.

Navigating the Social Course of Illness

The men discussed in this chapter have responded in very different ways to living in the HIV spectrum. All are concerned with the social course of their illness and make attempts to lessen the impact of HIV infection on the social interactions of their everyday lives. Glen and Eric differ from Jimmy in that they both report that they are feeling well, and have had no symptoms of HIV. Jimmy on the other hand reports a number of physical symptoms, and was hospitalized for several opportunistic infections over the course of his involvement with this research project. In addition, Jimmy has just recently moved to Ohio, after an absence of ten years.

Jimmy also differs from Eric and Glen in that he has been involved in support groups for gay men in the HIV spectrum and was previously very active in The Living Room’s activities for gay men in the HIV spectrum. Eric and Glen on the other hand, specifically reported that they
had no interest in attending HIV support groups. Interestingly, Jimmy was in the process of extricating himself from his involvement with groups which based their membership on HIV infection. Jimmy chose to seek out Twelve-Step meetings as one source of social support.

All three men have said that they have told their closest friends, and some or all of their family members. All three also talk about ways in which they have limited conversation about HIV among their closer social contacts. For instance, Jimmy talks about moving to another location, in part because he says that he can’t tolerate his brother’s constant doting on him, reminding him that he has AIDS. Glen has told his friends, family and partner about his diagnosis, but states that they don’t really talk about it. He presents himself as keeping a positive attitude and looking for the positives, even what others might see as negative experiences, but never specifically says what he does to discourage talk about HIV infection, or if his friends, partner or family ever try to talk about it. Eric reports that his partner, Jack, thinks he should talk more about his feelings of being HIV positive, but Eric told him that this is unnecessary. Eric also relates an incidence where he even avoided talking to a clinical social worker when he was first diagnosed because he didn’t want to be involved in any type of counseling or group where he would have to talk about being HIV infected. Interestingly, he relates this to the cultural value of self-reliance.

All three men talk about their efforts to limit the impact of the social course of their illnesses, through regulating talk about HIV infection and AIDS. This points to their resistance to accepting an illness
identity as so directly stated by Jimmy "you're not AIDS". Something has attached itself to you. In the following chapter, I will elaborate on the idea of resistance to illness identity in reviewing recurrent psychocultural themes and stylistic orientations to living in the HIV spectrum.

Chapter Summary

The life stories of these three men have shown their attempts to influence the social course of their HIV infection, and thus its impact on their everyday lives, through emphasizing attributes of their style and selecting social situations which are generally free of reference to HIV infection. This is important to their perceptions of their quality of life, and is quite interesting when considering the treatment of HIV positive individuals, where both lay and professional caregivers often suggest participation in an HIV support group. Glen and Eric mention their lack of interest in attending support groups for men in the HIV spectrum, and Jimmy is actively disengaging from HIV oriented support. These men are all presented as resisting illness identity through actively limiting talk about HIV in their social interactions of everyday life. In the following chapter, this discussion will be continued and shown to be an important factor in maintaining quality of life in terms of culturally meaningful values.
CHAPTER SIX
CONCLUSION

In this chapter, I will begin by discussing the findings of this research and implications for future inquiry, regarding the selected variables of life events and social support with attention to implied culturally meaningful values. Following this discussion, I will review the principle psychocultural themes and participants' stylistic orientations to living in the HIV spectrum. Finally, I will discuss contributions of this research and dissertation to anthropology, medical anthropology and the anthropological study of people living in the HIV spectrum.

Review of the Life Stories: Cultural Values

Chapter Three: Jerry, Rick and Stan

In Chapter Three, I discussed two categories of life events affecting the lives of the participants of this study. The first category is that of exacerbations and complications of HIV infection; the second, death of friends due to HIV related illness. I chose to focus on these two categories of events, simply because they were the most evident in conversations with participants. That is, the eight of the men in the study spontaneously talked about their physical changes due to HIV infection, and ten of the men talked of their loss of friends to HIV infection. These two types of events were also presented as having a significant impact on the present everyday life of the participant.
Three life story narratives were reviewed with the following findings: Jerry and Rick narrated the effect of both categories of life events on their everyday lives, though they differed in perception of severity of illness events. Stan related severe illness events, recurrent infection and hospitalization, but denied the loss of friends to HIV related illness.

Jerry talked about this time being the worst time of his life. He had lost all of his closest friends, suffered from chronic pain, fatigue and an increasing number of hospitalizations and visits to physicians and health care facilities. He had financial problems and struggles to control his drug addiction. I argued that beyond this cascade of events, there were several less obvious factors which had a perceived negative impact on Jerry; asynchrony of events with the culturally normative life course, liminality, and a threat to his concept of self in terms of culturally meaningful values of productivity and self-reliance. In addition, I presented the impact of the death of friends in terms of the vulnerability of his memory, and resultant discontinuity of the temporal orientation of the self (Hallowell, 1955).

Rick has had a comparable series of life events with respect to the loss of his social network. Although he also suffered from chronic fatigue and other HIV related illnesses, he considered himself to be stable, that his illness was not progressing at the time. Unlike Jerry, he continued to work part time, and was working at reconstructing his network of friends. This reinforced his concept of self in terms of the influence of culturally meaningful values of productivity and independence with regard to work.
and self-determination in overcoming the loss of friends through his independent actions of making new friends.

Stan experienced a relentless series of illness-related life events, with several hospitalizations for a number of complications and exacerbations of HIV infection. He had, however, not experienced the loss of his social network as has Rick and Jerry. He presented reciprocity as a culturally meaningful value which helped to maintain a positive concept of himself. He emphasized reciprocity in his ability to lessen the burden on his social network by maintaining a positive attitude no matter what occurred, thereby emphasizing self control, also a cultural value.

In this chapter, I critically evaluated life events and their impact on perceptions of quality of life by focusing on the complexity of additional factors: concurrent life events, asynchrony, liminality, social support and social networks, and self perception in terms of culturally relevant values. Implicit in this presentation is the prospect that quality of life does not necessarily deteriorate with advancing illness and physical deterioration due to disease.

Chapter Four: Tim, Paul and Rob

In Chapter Four, I explored the concept of communitas as a type of social support, and discussed Twelve-Step groups as a source of communitas. Tim had limited involvement with Twelve-Step programs, though he incorporated Twelve-Step ideology into his life story. He understood his life at the time, in terms of his struggle to
overcome "sex-addiction". He talked about his faith in a "higher power" in achieving inner peace and serenity which was an implied improvement in his quality of life. He also recited the Twelve-Step slogan, "one day at a time" as something he tried to do, and the Twelve-Step concept of "hitting bottom" as the turning point that he hoped he had already passed in his struggle to overcome his addiction. Despite his talking about his involvement in Twelve-Step and his incorporation of that ideology in presenting his life story, Tim did not relate any sense of communitas as a result of this. He presented a perception of a poor quality of life, particularly in his lack of ability to live up to the culturally meaningful value of self-control. He balanced this to some extent with his perceived self worth in other cultural values of perseverance, hard work and independence.

Paul's life story was heavily colored by twelve step ideology. He talked about "trusting the process", "spiritual awakening" and "trusting his higher power". He related an understanding of Twelve-Step programs as providing a "spiritual community" and much of his social network at the time, consisted of people who were also involved in Twelve-Step programs. He saw the present time of his life as being the best quality of life he has experienced. Through following the Twelve-Step ideology, he believed that he had overcome his fears. Hard work, autonomy and independence are the cultural values that typify his descriptions of what he had striven for in himself and believed he has to some extent achieved.
Twelve-Step ideology also influenced Rob's life story. At times he presented his story in the same format as a "Twelve-Step lead". Rob immersed himself in the Twelve-Step program. Virtually all of his close social contacts and support was from other people in the Twelve-Step programs. Though Rob experienced the loss of his entire network of friends, he maintained a perception of a good quality of life, and felt it was improving. He felt that his close relationships were the basis for this positive perception, and the Twelve-Step program meetings and activities were ultimately the source of most of these relationships. He saw his quality of life as being tied to culturally meaningful values of hard work and productivity, values which are also emphasized in Twelve-Step philosophy as a reflection of American culture. Rob's work in an AIDS service organization interestingly corresponds to this philosophy in terms of "giving back to the community".

In this chapter, I argued that Twelve-Step program involvement served as a source of communitas for several men participating in this study. This was the only ongoing source of communitas expressed in conversations conducted as part of this study. This is particularly interesting in that this source of communitas was seen as a source of social support for these men living in the HIV spectrum, despite the availability of support groups specifically targeting people infected with HIV. Further research is needed to: address the role of communitas in the social support provided by Twelve-Step programs for gay men with HIV, and to increase our understanding of the impact of involvement in
Chapter Five: Jimmy, Glen and Eric

In Chapter Five, I explored individual efforts to regulate the social course of illness. Jimmy, like the men in the preceding chapter, involved himself in Twelve-Step programs as a source of support. Jimmy's narratives clearly showed the importance of this source of support in its lack of association with issues surrounding the HIV spectrum. Though Jimmy had been involved in Twelve-Step programs for three years, he had become increasingly involved in HIV related activities. He began pulling away from these activities during the same time he was involved in this research, and moved from the apartment he shared with his brother, to a place of his own, shortly after our formal conversations ended. He explained that these actions served to maintain his identity apart from his illness, that he was “more than just AIDS”. By doing so, he saw himself as improving his quality of life, regaining his independence and autonomy apart from illness identification. He saw Twelve-Step meetings as a source of support that did not identify himself with HIV infection.

Like Stan, Glen perceived his quality of life as very good in terms of his close and enduring relationships, with family and childhood friends. Also like Stan he saw the value in keeping a positive attitude to maintain these relationships. He accomplished this by defining the meaning of his HIV infection in terms of the positive effects his knowledge of infection
had on his everyday life, in that he appreciated his life more because of his experience with HIV infection. He avoided identification of himself with his illness through maintaining a positive attitude in his interactions with others. Culturally meaningful values of autonomy and independence were shown to be enhanced by resisting identification of the self with illness.

Eric felt he had a good quality of life, and in part maintained this through presentation of his life as boring. Like Glen, he maintained a positive attitude with friends who were aware of his status, but he minimized the impact of his infection by presenting his life as uneventful. In this way he implied a continuity of the boring and uneventful qualities of everyday life, precluding HIV related life events, such as exacerbations and complications, which, it is assumed, would be anything but boring. His positive attitude in everyday life, combined with his perception of a stable, uneventful life serve to limit the possibility of an illness related identity, thus maintaining culturally meaningful values of autonomy, independence and implicitly, self-control. Self-control was also presented as meaningful to Eric in descriptions of everyday life, where he reported several instances in which he said that he would avoid an argument with Jack by remaining even-tempered and aloof, and wait for the disagreement “to blow over”, or be forgotten.

In this chapter I discussed some of the means by which illness identity may be limited. Where Jimmy sought to limit an illness identity which already colored much of the social course of his everyday life, Glen
and Eric sought to prevent further intrusion of illness identification. I argue that this active resistance to accepting or continuing an illness identity is critical to their maintenance of quality of life. Further implications of this important theme are presented below. In terms of perceived quality of life, further research is indicated to determine both benefit and risk of resisting illness identity during and after illness related life events. Such events would present a contradiction to a self-identity which resists the significance of illness.

Principle Themes and Stylistic Orientations

In these selected life story narratives presented in this dissertation as well as the entire sample of twenty men, there were several recurring psychocultural themes. Each of these themes was tied to a particular stylistic orientation to living in the HIV spectrum and reflected common cultural values expressed by this sample as a whole. Though the themes I will now discuss were presented in many of the narratives, they were not necessarily the dominant theme expressed in any given life story. In addition, many of the participants expressed more than one of these themes. The significance of these themes and styles is in their commonality across the sample, reflecting the importance of culture through the meanings given to cultural values implicit in each theme. I will discuss each of four recurring types of themes, with associated style and reminiscence below, follow by implications for understanding their significance in terms of cultural values. The four recurring psychocultural themes are: overcoming obstacles and enduring
hardships; helping and caring for others in need; appreciating one’s daily life; leading an uneventful, simple or “boring” everyday life.

The most common theme was that of ‘overcoming obstacles and enduring hardships’. The stylistic orientation associated with this theme was a presentation of the self as a ‘survivor’. Stories of the past were narrated, telling about difficult situations experienced and the ability of the narrator to endure or overcome the difficulty. Implicit in this is the ability of the individual to endure the suffering associated with their illness, or for some, the hope of overcoming illness (through immunity as suggested by Eric, or biomedical advances in treatment, “the cure”, suggested by Stan). These reminiscences are always instrumental, associating past experiences of survival to present difficulties. Jerry offered a good example of this type of theme, style and reminiscence cluster. Fifteen of the entire sample of twenty men offered at least one narrative which expressed this combination of psychocultural theme and stylistic orientation to living with HIV.

The second most common theme is that of ‘helping or caring for others’, present in eleven of the narratives. Stories are narrated which describe how the narrator helped or cared for another person. Eight of these men talked about caring for someone else in the HIV spectrum, e.g. Jerry taking care of his friend Randy, Rob working for an agency providing services to people with HIV. The remaining two men presenting this theme related stories about caring for family members. Stan gives an example of this type of help and care in his helping care for David’s grandmother. The associated style to this theme is one of being ‘a
good friend’ or ‘a caring individual’. Inherent in this type of style is the implication of reciprocity. This was sometimes stated clearly by some men who cared for partners or friends who died of HIV related illnesses, and anticipated the same would be done for them. This was sometimes seen as a direct relationship, e.g. Alan had taken care of a friend, Mark, over the course of Mark’s illness and death, and Mark’s family has volunteered to help Alan should that become necessary. Others presented this as an indirect relationship. Jerry and Rick regularly helped their friends who were ill whenever they were able, and both felt that other friends would in turn, help them when the time came. This stylistic orientation to living in the HIV spectrum primarily presents integrative reminiscences where past stories of the narrator helping and caring for others are integrated with the present or expected future situation of being in need of care. Stan gives an example of this when he talks about his efforts in caring for David’s grandmother, as one of several reasons he can accept David’s assistance now that he is sick, and in the future. Past actions of helping aid in equalizing receiving assistance in the present. Jimmy presents ‘caring for one another’ as a dominant theme in his stories, and uses transmissive reminiscence in relating stories about caring to a philosophy that “people should just learn to care for one another”. He is passing on what he has learned from his life with hope that the world will be a better place to live if others accept his philosophy.

The third type of theme common to this sample is ‘appreciating life’ and includes appreciating the presence of other people, appreciating
the beauty of nature and the arts, and appreciating material comforts of life. Eight people out of the sample of twenty told at least one story which was an example of this. Paul narrates stories about enjoyment of playing the piano, working in his garden and relaxing. Scott talks about appreciating the other people in his life, his family and friends. The style associated with this theme is that of being 'grateful' or 'fortunate'. Integrative reminiscence is in evidence with this theme. When Paul tells stories of appreciating life he does so in the context of reflecting on his foreshortened future, and perceives this as an even greater incentive to appreciate his life, thus integrating past with present anticipation of foreshortened future. The type of reminiscence is not clear-cut in that this is also transmissive, i.e. appreciating life is presented as important because none of us knows when our lives may end.

The last type of recurring theme is that of 'maintaining an everyday life that is uneventful and boring'. The associated style to this theme is that of being stable. Eric presented this as a dominant theme through instrumental reminiscence. Eric presents his everyday life as being boring, without much occurring, implying a constancy to that concept. He is asymptomatic and hopes to continue that way indefinitely. His stylistic orientation to living in the HIV spectrum is to equate his illness experience with his everyday life which he describes as routine, predictable and "boring". There were four men out of the sample of twenty that presented this type of theme in narratives of their life stories.
Values as Reflecting Culture

As was the case with the dominant themes discussed in Chapters Three, Four and Five, these recurrent themes reflect culturally meaningful values. For instance, presenting the self in the stylistic orientation of being a survivor through the theme of overcoming obstacles and enduring hardships emphasizes core American (United States) cultural values of self-reliance, independence and achievement. By incorporating this theme into the life story, overcoming or enduring the hardships and suffering associated with HIV infection can be in and of itself, evidence of self-reliance, independence, and achievement.

Helping and caring for others emphasizes the positive side of interdependence. Fry (1988:462) suggests that interdependence is a "keystone of human society" with American emphasis on reciprocity and exchange as the positive side of interdependence, and dependence having a negative value. This is what is evident in the presentation of helping and caring in this sample. Stan voices concern that he will be dependent despite also describing why he deserves to receive care based on his past actions, helping David's grandmother, volunteering for services to others in the HIV spectrum. He also bases this on his personal characteristics of maintaining a positive attitude and the spousal relationship he has with David. It seems he needs to feel he has contributed enough to justify his needs as reciprocity rather than as one-sided dependence. Stan presents this as culture logic which dictates that productivity in the past and caring and helping others implies that one is deserving of care and help from
others. Therefore being cared for and helped is not dependence but reciprocation, and independence is thus preserved.

For the men in this sample, the theme of ‘appreciating life’ is tied to awareness of foreshortened future. Despite the importance of a foreshortened future related to HIV illness as a catalyst for the theme of appreciating everyday life, this theme can be seen as a means of a shifting focus away from awareness of death, toward resistance against illness identification and death. By appreciating life, with what is culturally described by the men in this study as having inherent positive attributes, illness experience with its negative connotations is minimized. As illness experience is minimized and a style of being grateful or fortunate in having appreciation for the good things of life is assimilated, illness identity is minimized. The more one is a fortunate appreciator of life, the less one identifies with a stigmatized, life-threatening illness. By denying illness identification, autonomy of the self is reinforced, thus reifying cultural values.

“Maintaining an uneventful or boring life” through a style of stability and consistency also serves to limit the impact of illness on one’s identity and reinforces autonomy. It is unlikely that a life reported to be uneventful and boring could include reporting events associated with exacerbations and complications of a life-threatening illness. In fact, Eric suggests that even routine office visits are an intrusion into the continuity of his “boring” life, where the quality of being boring is seen as highly desirable. Eric resists any illness identity and so maintains his autonomy.
Independent of any theme, another recurring statement spontaneously made by ten of the twenty participants when talking about their mortality with respect to HIV infection, was that they could be hit by a car (or other motor vehicle) at any time. In addition, two other men spoke of the uncertainty of death in even more general terms, that anyone could die of any number of things at any time. Like the themes of appreciating life and maintaining an uneventful life, statements about the universal uncertainty of death serve to minimize effects of HIV infection and shift the narrator away from identification with illness, by identifying with anyone else who could be hit by a car at any time. Autonomy as a culturally meaningful value, is preserved by minimizing illness identity.

Concluding Remarks

It is also important to note here that narratives and themes presented in these life stories showed a lack of content expressing depression or anger at the situation of living with life threatening illness, death of friends, loss of job, increasing debilitation and other losses, as might be expected. These both might be expected findings of reactions to losses and grieving (Kubler-Ross, 1969; Kavanaugh, 1972; Weizman and Kamm, 1985; Raphael, 1983).

The average length of time since being aware of HIV seropositivity reported by the men in this sample is 5.8 years (standard deviation = 3.21). Possibly, anger and or depression as a response to grieving may be expressed more often during the earlier periods of illness following initial
discovery of HIV+ status. It is therefore possible that this perceived chronicity, (the relatively long term awareness of seropositivity), precludes the expression of anger or depression as being associated with dominant themes.

I suspect that the relative lack of anger and/or depression expressed in the majority of the narratives, may in part reflect the use of the life story as the primary method of research. Jerry clearly expressed anger in talking about his difficulty obtaining pain medication and depression in response to his deteriorating physical condition. Stan talks about his need to take medication to treat his severe episodes of depression. Jimmy speaks with anger about his perception that there is a lack of progress in AIDS treatment research. It is important to realize that this research focused on understanding the present experience in terms of the life story, rather than focusing strictly on the response to particular life events outside of this temporal context.

Are anger and depression (as responses in grieving for losses that these men experience during the course of this chronic illness) overshadowed by the emphasis on everyday life experience in the life story? This is part of a very important topic of inquiry regarding whether or not people with chronic illnesses see their lives as dominated by illness (Jenkins, 1994). If illness experience is perceived as only a relatively small part of the sum of everyday life experience, then anger and depression in grieving for losses experienced during chronic illness may also be seen in a smaller part of the myriad experiences of everyday life, particularly in
the context of a life story, which tends to place emphasis on the broader contexts of life experience, rather than on one or two particular events.

In the course of this study, there were conversations with Jerry, for instance, during which he focused on grieving for losses of the past and present, expressing both anger and depression. During other conversations, he was upbeat and optimistic, and the stories he told of past and present at those times reflected this attitude. Paul reflected on this same idea, and correlated his periods of depression with his feeling ill. When he felt relatively good, he was upbeat. This was also reflected in my conversations with Paul.

By spacing conversations over a period of six months, there was a greater chance that I would see people during a variety of different situations and emotional states. Importantly, during the course of scheduling interviews, participants would frequently reschedule appointments to meet with me, if they were feeling ill. As with Paul, this may have further limited my access to the participants when they might be more likely to be experiencing emotions such as anger or depression.

In all, further research is indicated to determine whether this negative finding of the lack of depressed or angry content in these narratives is indicative of persons’ perceptions of their lives as not being dominated by illness.

My central question in pursuing this research is as follows: What is everyday life like for persons diagnosed with a chronic and fatal illness? To understand what this everyday experience is like I have presented the concept of perceived quality of life. Fundamental to this concept is
synchrony or asynchrony with ideal and acceptable expectations in comparison to the real experience. To understand and further develop the meanings of the difference or concurrence between the real and the ideal, I have framed everyday life experience in the temporal context of the life story, and focused on American cultural values as core cultural symbols. As demonstrated in Chapters Three, Four and Five, this approach has been quite effective in presenting a meaning-centered perspective of illness experience in the cultural context.

I have argued that liminality is a negatively valued experience that may be tied to the occurrence of certain life events in the course of chronic illness. The concept of liminality can aid in our understanding of the impact of these life events on the perception of quality of life. As a negatively valued experience, liminal experience is perceived as negatively affecting quality of life. Five of the twenty men participating in this study told stories which reflected experiences which may be described as liminal. All five had experienced job-loss and physical symptoms which limited their social functioning due to pain and/or fatigue. Jerry and Rick had also narrated stories telling about many or most of their friends who have died due to HIV-related illnesses. For this group of men, the experience of liminality was tied to stories of the onset of, or change in, physical symptoms and the loss of social function through disability or the death of friends.

Liminality was most notable in the example of Jerry, who experienced the death of many friends and the loss of social functioning due to his deteriorating physical state. He was no longer able to work and
had difficulty participating in daily social interactions. Jerry was the only participant in this research study who experienced this cascade of high frequency, high intensity life events with loss of social functioning due to both illness and the deaths of others in his social network.

I have argued that liminality (and also communitas) are concepts which may be applied beyond "tribal" cultures to heterogeneous society, as Turner (1969) suggests. I have shown that liminality, as a theoretical construct is useful in describing a particular type of experience which negatively affects the perceptions of quality of life. In this group of men, liminal experiences are further shown to be tied to high frequency and severity of life events which result in losses of social functioning. Further investigation is indicated to determine whether other life events trigger experiences which may be described as liminal, and to what extent frequency and severity of these events, in turn, influence liminal experience.

Jerry's stories were the most vivid descriptions of experience which indicated liminality. I suspect this is because Jerry was the only one (of the five men who described experiences which suggested liminality) who was experiencing liminality in response to events of the present. As suggested in Chapter Three, liminal experiences may best be investigated as they occur, rather than retrospectively narrated.

Future research may generate more information on this topic by focusing on persons who are experiencing loss of social function at the time of research and following those persons for an extended period of
time. In this way, some of the questions I have raised in the preceding paragraphs may be further elucidated.

Nevertheless, an important contribution of this dissertation to the study of the experience of illness, is the relationship between life events and liminality as a theoretical construct which describes and clarifies a particular experience. I have shown that certain life events may trigger feelings which can be described as liminal, which in turn negatively affect perceived quality of life.

I have argued that communitas, too, is a related theoretical construct which describes an important type of social support for the men in this study. Communitas, as a form of social support, and in contrast to liminality, has a positive effect on the perception of quality of life. Additional research as suggested above, might address whether communitas serves to alleviate the negative effects of liminality on the perception of quality of life. I therefore conclude that use of these two theoretical constructs (liminality and communitas) is useful to an understanding of how people perceive quality of life and the relationship of liminality to life events, and communitas to social support.

This dissertation has also contributed to the field of Anthropology through increasing our understanding of the importance of culture as mediator of the meanings of behaviors and beliefs expressed in stories of everyday life. By analyzing themes presented in life story narratives with attention to underlying culturally meaningful values, this psychocultural approach has elucidated the illness experience of the participants of this study in terms of salient cultural meanings. Cultural values are shown to
be an important area of inquiry in a meaning-centered approach to the study of culture.

This dissertation contributes to Medical Anthropology by reinforcing the importance of a meaning-centered approach in gaining insight into the experience of illness. The life story is shown to be a powerful tool in uncovering some of the culturally-mediated qualities of illness experience, in the behaviors and beliefs expressed in stories of everyday life. In addition, liminality and communitas are demonstrated to have merit as theoretical perspectives which can improve our understanding of life events and social support during chronic illness.

Finally, I have argued that synchrony with expectations of attainment or maintenance of culturally meaningful values is a key element in individual's perceptions of quality of life during this chronic illness. This points to the way in which values mediate quality of life as core cultural symbols of ideal characteristics of self, behavior and experience. Quality of life is the evaluation of the degree of asynchrony of real characteristics of self, behavior and experience with values as core cultural symbols of ideal characteristics.

More specifically, relating to the study of HIV infection and AIDS by anthropologists, this dissertation offers an intimate presentation of the experience of illness in self-identified gay, Euro-American men living in the HIV spectrum. Though beyond the scope of this discussion, the experience of illness of this particular group may serve as contrasting data to HIV illness experience in other areas of the world, and vice versa in cross-cultural or other comparative studies. Conant (1988) suggests this
method for increasing understanding of the social consequences of HIV infection. For instance, consider the preponderance of the theme of being a survivor in overcoming obstacles, as a stylistic orientation to living with HIV infection. Is this preponderance influenced by the individual's prior experience as a self-identified gay men, a marginalized and stigmatized member of American culture, who had already developed this style and theme in response to the difficulties of growing up gay in straight America (as with Jerry who describes his survival in part in terms of being beaten and harassed because of being gay)? Or, could this theme simply tied to the hope of overcoming chronic illness where the wish to be a survivor is the impetus for recalling any life events which may serve as evidence of the abilities of the narrator to overcome obstacles (as with Eric who cites his overall health and resistance to disease as possible indication that he will remain asymptomatic)?

The nature of this project, by eliciting stories of the past and present, skews it toward the more temporal aspects of the self. A temporal orientation "is directly related to future conduct, to contemplated action, to the destiny of the self. This implies the notion of self-continuity as one of the ubiquitous aspects of self awareness." (Hallowell, 1955:99-100). These chronically and terminally ill men may have to spend many hours each day dealing with their illness and treatment, but in terms of self-awareness, the continuity of the self is what guides their responses, actions and interpretations of their conception of the present and future. In this way they continue to create new meaning as they integrate the ongoing events of the course of their
lives to continue to form and build their identities. As core cultural symbols, values such as self-reliance and productivity are consistently represented in the life story. New meanings are created in the interpretation of experience which may exemplify an unchanging cultural value. By understanding chronic and terminal illness in terms of personal experience, we can better understand the meanings of cultural values and the way in which meaning may be created through narrations of the stories of everyday life.

For instance Paul talks about the cultural values of productivity and hard work. He immersed himself in his religion growing up, working as hard as he could to alter his sexual preference, and being productive in his evangelism. He talks about himself as a hard worker in his current profession, putting in long hours counseling his clients, and feels productive being able to help others through difficulties in their lives. He also talks about his involvement in the Twelve-Step Program, providing evidence of the hard work he has put in, in receiving counseling, and attending meetings, retreats and workshops. His productivity is in his feeling that he has undergone significant self-growth. Interestingly, one of the results of his self-growth since becoming HIV positive is his keener awareness of balancing work with leisure. Through his hard work on self-growth, he is able to gain greater appreciation of leisure time, when he is not working.

The stories Paul tells about each of these topics all have to do with hard work and productivity, yet the meaning of these cultural values, as personally experienced by Paul, change with the topic of narrative. Hard
work as a Jehovah’s witness has meaning for Paul now as repression. I suspect that at the time of his involvement the meaning was different, with more positive attributes. His hard work at counseling others has meaning in terms of social worth. And his hard work in self-growth, has meaning in his learning to appreciate the time he has, and to balance his need for hard work, with leisure.

Additionally, this dissertation offers the broader perspective of illness experience as a window on culture. By focusing on illness experience as integrated with the experience of everyday life as narrated in the temporal context of the life story, the powerful influence of culture in mediating the meaning, quality and evaluation of a given experience is elucidated. It is interesting to note that regardless of the acknowledged or implicit fact of stigmatization and marginalization of this group of men (whether related to being gay or HIV positive), the stories they narrate rest on templates of cultural values which serve as potent underlying core cultural symbols.

Though these cultural values serve as core cultural symbols they are expressed in themes which may or may not be generalizable to the greater culture, as discussed in terms of the “survivor” theme. The experience of illness of this group of men may be compared to other chronic illnesses to increase our understanding of what might be more specific to HIV infection in this example and what may be found in other chronic and terminal illnesses.

In this dissertation I have addressed the experiences of those living in the HIV spectrum, the importance of the function of cultural values in
the meanings they give to the experiences of everyday life, the synchrony with culturally mediated expectations of maintenance or attainment of those values, the experience of liminality associated with certain life events, and the role of communitas in ameliorating this experience. This has served to enhance our insight into the powerful effect of HIV infection on the everyday business of living and perceptions of quality of life.

The complexity and richness of the narrative data presented reflect the multiple facets of this daily life. These narratives may be analyzed from any number of perspectives (cultural values, liminality and communitas, illness experience and quality of life) but at all times remain grounded in the stories of living. They are testimonies of living in the face of chronic illness and death and provide a critical glimpse into the experience of this devastating illness.
TABLE 1
ILLNESS AND SOCIO-DEMOGRAPHIC CHARACTERISTICS
OF STUDY PARTICIPANTS
(N=20)

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<th>Pseudonym</th>
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| Mean Age | 36.8         | Standard Deviation | 5.8         |
| Mean Education | 15.2 | 1.54 | 3.21 |

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<th>Life Event: Recurrent Illness</th>
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<th>Theme #2: Caring</th>
<th>Theme #3: Grateful</th>
<th>Theme #4: Uneventful</th>
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APPENDIX A

Interview Guide

(Topics adapted from Kaufman, 1986)

Life Events:

1. Birthdate and location.
2. Earliest memories.
3. Parents, siblings, other important family and friends during childhood.
4. Family life during earliest memories.
5. Additional childhood memories.
6. Description of self during that time. Description of quality of life. How other's may have described subject.
7. Adolescence.
8. Memories of that time. Concerns. What that was like. Family relations. Friends.
9. Description of post-adolescence.
10. Description of what stands out about that time.
11. Description of self during that time. Description of quality of life. Family. Friends. How other's may have described subject.
12. Young adulthood (if applicable - that is if subjects feel that they are past that stage of their lives).
13 - 16. (As per 8-11)
17. Religious background/training.
18. Marriage and/or relationships, first job, leaving home. Concerns. What life was like for subject then.
19. Children (if applicable).
20. Career, occupation past and present. Self concept and quality of life at each time of life.
22. Feelings about no longer working (where applicable).

The present:
1. Description of typical day.
2. Closest persons to subject. Frequency of contact. Number of close persons and description of persons, relations and circumstances.
3. Mutual aid and reciprocity - financial aid, housekeeping, transportation, emotional support, medical advice.
4. Individuals involved in subject's medical care - role.
5. With each person identified in 4: time spent with them. Feelings toward them, their feelings toward subject. Description of these relationships, examples.
6. Overall plan for medical treatment. Parties involved in formulation of plan. Feelings about this
7. Adherence with medical recommendations - doctors, nurses - friends - other caregivers.
8. Description of Special Immunology Clinic. Facilities. Who do you usually see there when you go? Made any friends there? Who are they? What are they like? What kinds of things do you do together - at the clinic - away from the clinic?
9. Ideal situation @ present.
Life Review:
1. Important successes - frustrations.
2. Major events and turning points, past and present. Description, examples, self-description for that time.
3. Influential experiences.
4. Periods remembered most vividly - examples - descriptions.
   Concerns.
5. Times in life when subject threw out a lot of stuff - examples.
6. Things that frighten subject now and in past.
7. Things that give subject pleasure now and in past.
8. Coming out.
9. HIV+ diagnosis
10. Description of gay community.
11. Description of HIV+ ‘community’.

Preparing for the Future:
1. Preparations for the future, aging, illness, death.
2. Expectations of aging past and present. Parent’s expectations.
   Friends and others expectations
3. Feelings about the future and growing older
4. Long and short term plans - feelings about plans and planning.
   Concerns.
5. Description of living with HIV infection - symptoms? treatment?
   Others reactions?
6. Thoughts about death.
Identity:

1. Subjects perception of similarity between self and parents.
   Description of self. Description of appearance.
2. Comparison of feelings about self past and present.
3. Best and worst qualities.
4. Philosophy of life.
5. Things that changed through life, things that have remained the same.
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