

FREDERICK R. BLOOM

Division of STD Prevention
National Center for HIV, STD, and TB Prevention
Centers for Disease Control and Prevention

“New Beginnings”: A Case Study in Gay Men’s Changing Perceptions of Quality of Life during the Course of HIV Infection

This article reports results of an ethnographic study that sought to understand how a cohort of gay men living with HIV infection evaluated and worked to preserve or improve the quality of their lives. Themes of life story narratives are identified, each with an associated stylistic self-orientation to living with HIV infection. Changes in thematic content of a selected participant’s life story narratives are discussed, demonstrating how events of his daily life are integrated into the narratives. Resultant concurrent shifting of themes and stylistic orientations is linked to his perception of improved quality of life. [quality of life, life story, HIV/AIDS, illness experience, U.S. culture]

“I feel better about myself, and I just feel like new beginnings, you know, like everything’s open to me now.”

—Rob

A little over 45 percent of persons living with AIDS in 1998 and 33 percent of newly diagnosed adult HIV cases reported from July 1998 through June 1999 in the United States were among men who reported having sex with other men as their only risk behavior (Centers for Disease Control and Prevention [CDC] 1999).¹ Despite rising rates of transmission among intravenous drug users, women, and infants, gay men continue to constitute the largest single exposure category resulting in HIV transmission (CDC 1999). By gaining an understanding of how a cohort of gay men determine their quality of life over the course of this chronic and long-term illness, we may gain a greater understanding of the experience of living with HIV infection. We may also learn how best to identify the needs of such men through a better understanding of quality of life as a personally meaningful valuation of everyday experiences.

The following discussion addresses the efforts of a cohort of HIV-seropositive men, and one man in particular, to maintain or improve the quality of everyday

life as described in their life story narratives. I begin with a review of some of the theoretical and methodological underpinnings of life story narrative analyses. Narrative examples are presented in a discussion of select themes. Finally, I analyze one individual's narratives in the context of his life story and discuss implications of changes in the presentation of life story narratives over time.

For this study, I used a meaning-centered approach (Good and Good 1982), collecting life story narratives among a cohort of HIV-seropositive gay men to investigate the experience of living with HIV infection. Life stories have been shown to be an important component of such an approach in the study of chronic illness in general (Kleinman 1988) and HIV infection in particular (Clatts 1989; Levine 1992; Sobo 1995). The life story is a collection of narratives that serve as both substance (the stories) and context (the processual events of a life) for an understanding of the meanings of illness experience. The telling of life story narratives by the men described in this study explicates their efforts to maintain or improve their perceived quality of life through an integration of present experiences into the perceived course of their lives.

Study Description

The data reported here were obtained through an ethnographic community study of self-identified gay, HIV-seropositive men. Primary recruitment was based on attendance of an HIV outpatient clinic and the affiliated AIDS clinical trials unit of a large urban teaching hospital in northeast Ohio. Secondary recruitment was by referral of men already taking part in the study a little less than two years after completion of the initial study.

Twenty HIV-seropositive, self-identified gay men were recruited for participation in the initial study (Table 1). The mean age of the study participants was 36.8 years, with a range in age from 28 to 48 years. All participants had one or more years of college, and all were white (Anglo-American). These demographic characteristics were representative of the largest group of patients (> 60 percent) seen in the clinic ($n = 682$) and the clinical trials ($n = 250$). On average, the men had known their HIV diagnosis for 5.8 years, and there was considerable variation in morbidity from asymptomatic to end-stage HIV infection. Nine of the men had experienced AIDS-defining illnesses.

Audiotape-recorded life story interviews were conducted from early 1994 to early 1995 at each participant's home (except for one interview that took place at an HIV drop-in center where the participant worked). These interviews elicited a broad range of narratives relating distant and recent past experiences and events. Each of the men participated in five to seven interviews over a minimum of six months. Additional follow-up life story interviews were solicited from 13 of the 15 surviving participants in the fall of 1996.

Life Stories

The events and circumstances in the lives of persons with chronic illness are part of a personal narrative that places the illness experience in the context of the life story (Kleinman 1988). By placing an emphasis on life stories, we can understand each man's perception of his quality of life in terms of his subjective

TABLE 1
Illness and Sociodemographic Characteristics of Study Participants
 (N = 20)

Pseudonym	Age (years)	Education (years)	Reported Years HIV+
Eric	31	16	4
Jerry	37	15	11
Dan	31	14	6
Paul	37	14	5
Mike	41	16	6
Craig	40	16	5
Steve	42	15	5
Dave	40	16	6
Jon	36	16	4
Bill	40	13	6
Stan	33	13	2
Jimmy	37	15	1
Glen	32	16	5
Rick	38	15	13
Tim	28	16	4
Kenny	41	16	9
Rob	30	14	8
Evan	41	16	6
Frank	34	14	10
Alan	48	18	4
Mean	36.8	15.2	5.8
SD	(5.00)	(1.54)	(3.21)

interpretation of his present experience, as expressed in his life description through stories of his past, present, and anticipated future.

Themes of life story narratives are cognitive areas of meaning with symbolic force that explain, unify, and give substance to perceptions of self in relation to the sociocultural environment (Bertaux 1981; Kaufman 1986). For instance, the theme of the life course as survival, overcoming a series of obstacles, provides a description of the individual in terms of the relation between a perceived self and the environment. This theme emphasizes the individual's actions, the struggle to survive, as a defining feature of the relationship between the perceived self and the events of everyday life. In order to understand perceptions of quality of life, themes were identified from content analysis of life story narratives. As part of content analysis, an independent reader trained in qualitative methodology verified these themes as accurate. Review and critique were solicited from study participants after sharing initial analyses with them.²

Each theme was tied to a particular stylistic orientation of the self toward living in the HIV spectrum. *Stylistic orientations of the self* are equated with "impression management" (Goffman 1959), in which a particular image of oneself is

filtered and sustained through the narration (Kaufman 1986; Riessman 1990; Tarmann 1988). This image of the self is presented as the subject of one's life story narratives in a processual narrative (Hallowell 1955; Peacock and Holland 1993). Thus, themes are psychocultural expressions of the self.

The analysis in this discussion also explores the *types* of narratives (based on a typology used by Watt and Wong 1991). Four types of narrative are evident: (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; and (4) *descriptive* or *factual* accounts.³ Whereas themes and stylistic orientations describe the meanings and content of life story narratives, narrative type describes the intended purpose for presenting each narrative.⁴ Life story narratives generally illustrate the integration of past and present events by creating continuity of experiences and a coherence of the self (Kaufman 1981, 1986). To some extent, then, all life story narratives are integrative narratives. However, individuals may employ a number of narrative types simultaneously in presenting the life story. For example, descriptive narrative was used by all participants in this study for the purpose of providing pertinent biographical information and facts.

Similarly, participants employ more than one theme when narrating their life stories. At one time, life may be presented as survival vis-à-vis a series of obstacles, while another narrative may present the philosophy that life should be about people caring for one another. Stylistic orientation might be that of a survivor when talking about one's success in overcoming a particularly trying life event and that of a caring individual when talking about one's role in helping a sick friend.

Many themes were presented in the life stories. Some were specific to one or two individuals in the sample (e.g., taking responsibility for the future through actions today, or overcoming fear of disapproval through escape.) Others were more common, recurring among four or more of the men. The following discussion addresses four of the most common themes. They are (1) *survival* (overcoming obstacles and enduring hardships); (2) *reciprocity* (helping and caring for others in need); (3) *appreciation* (of one's daily life); and (4) *average life* (leading an uneventful, simple, or "boring" everyday life (Table 2).

The Survival Theme

The most common theme is the survival theme, that of overcoming obstacles and enduring hardships. The stylistic orientation associated with this theme is a presentation of the self as a survivor. Stories imbued with this theme focus on past events, difficult situations experienced, and the ability of the narrator to endure or overcome a particular struggle or hardship. These narratives are always instrumental, associating past experiences of survival to present difficulties. Fifteen of the 20 men making up the sample offered at least one narrative expressing this combination of psychocultural theme and stylistic orientation to living with HIV. Survival narratives were presented by men who were quite ill, men who were asymptomatic, and men at various stages of illness in between.

TABLE 2
Primary Themes
 (N = 20)

Pseudonym	Theme #1 Survival	Theme #2 Reciprocity	Theme #3 Grateful	Theme #4 Average Life
Eric	X		X	X
Jerry	X	X		
Dan	X	X	X	
Paul	X		X	
Mike		X		X
Craig	X	X		
Steve	X		X	
Dave		X		X
Jon	X			
Bill	X			
Stan	X	X	X	
Jimmy	X	X	X	
Glen		X	X	
Rick	X	X		
Tim	X			
Kenny	X			
Rob	X	X		
Evan				X
Frank	X			
Alan		X	X	
Total	15	11	8	4
(%)	(75%)	(55%)	(40%)	(20%)

One of the men, Jerry, gives an eloquent example of this theme, style, and narrative-type cluster. He talks about his success in keeping his business going despite numerous difficulties:

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.

Jerry was 37 years old at the time data were collected. He presented himself as having had a difficult life. He related stories of experiencing physical and verbal abuse as a teenager, survival by prostitution while homeless, and intravenous drug use. He learned he was HIV-positive 11 years prior to our meeting. At the time of the study, he still struggled financially, living in a run-down home, surviving only through the generosity of friends.

He had remained relatively healthy until about a year prior to the start of this project. At that time he developed joint pain, which was particularly severe in his

legs, and a decline in his energy level and stamina. During the course of the interviews, Jerry was forced to quit his job because of pain and fatigue.

Though he stated that most of his oldest friends had died from AIDS-related illnesses, he maintained several close long-term friendships. He stated that he had had an ongoing relationship with his lover over the past eight years, though their relationship was characterized by frequent arguments and separations. Jerry also mentioned several friends who stayed with him for months at a time.

He talked about his long-term survival with HIV infection:

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.

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.

Implicit in these statements was Jerry's ability to endure the suffering associated with his illness. The theme was that of overcoming obstacles and enduring suffering. His stylistic orientation placed him clearly as a survivor. However, it is the instrumental nature of his narratives that reveals their meaning. Jerry related that he survived, endured, and overcame obstacles in the past and gave this as reason to expect he would do the same in the future, that he could "handle anything."

The Reciprocity Theme

The second most common theme, the reciprocity theme, emphasizing mutual exchange in rendering help or care, was present in 11 of the narratives. In these stories, the narrator described how he helped or cared for another person. Nine of the men talked about caring for someone else in the HIV spectrum. The remaining two men presented this theme when they related stories about caring for family members (Table 2). Reciprocity narratives were presented by men who had experienced AIDS-defining illness and by those who were asymptomatic, by men who were ill much of the time and by those with little or no physical limitation related to HIV or any other illness.

Stan was 33 years old at the time of our conversations. He presented his family life as stable and supportive. He had been in a stable long-term relationship with his partner for 10 years and had only become aware of his HIV-seropositive status two years prior to this research. Since then, he had experienced a series of opportunistic infections, and he had been unable to work for the past year. Stan lived with his partner, David, and sought to retain a sense of reciprocity with David by assisting with the caretaking of David's grandmother, who had Alzheimer's disease. Since David worked during the daytime, Stan and some of David's other family members divided up the time needed to help care for her. Except when Stan was too ill, he spent three days a week with her, cooking, cleaning, and visiting. By getting involved in her care, he was able to be productive, to accomplish discrete tasks, to be caring, and to reciprocate support he received from David. Importantly, these actions were a source of his sense of his social worth. He said, "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." Referring

here to his disability check, Stan acknowledged that David's salary allowed them to live comfortably and without financial worries.

The style associated with this theme was one of being a good friend or a caring individual. Inherent in this style was the implication of reciprocity. Some of the men who cared for partners or friends who had died of HIV-related illnesses stated their anticipation that the same type of care would be extended to them. Integrative narratives were sometimes offered when presenting this theme and stylistic orientation to living with HIV. Stan gave an example of this in relating his efforts in caring for David's grandmother as one of several reasons he could accept David's assistance. Reciprocity was thus maintained through balancing present assistance to others with assistance received.

Jimmy was 37 years old when first interviewed. He had been in a stable relationship for about 10 years, during which time he and his partner traveled quite a bit. He ended that relationship about two years prior to this research and moved back to Ohio, where he shared an apartment with his brother, who supported him until he was eligible for subsidized housing. He was diagnosed with AIDS about one year later, when he developed Pneumocystis pneumonia. He then became very active in a community AIDS drop-in center and participated in support and social events there. Jimmy presented "caring for one another" as a dominant theme in his stories, but used transmissive narratives in relating stories infused with the philosophy that "people should just learn to care for one another." He intended to pass on what he had learned from his life, expressing his belief that the world would be a better place in which to live if others accepted his philosophy of caring:

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 overbounding. It could be just words, but in the end God will look in your heart. There'll be all kinds of stuff, but if you're generally a good person, that's what you strive for.

These life story narratives described how the narrator himself helped or cared for another person. When presenting narratives with this theme the men talked about themselves as being "a good friend" or "a caring individual." Inherent in this was the implication of reciprocity—that they maintained their sense of social worth and were deserving of care because they cared for others. Stories of helping and caring for others were integrated into the present or an anticipated future in which the narrator might need care, as turned out to be the case with Stan. As such, stories could be told as integrative narratives, or in Jimmy's case, transmissive narratives expressing his philosophy.

The Appreciation Theme

A third theme was evidenced repeatedly in narratives focused on appreciating life: the presence of other people, the beauty of nature and the arts, and material comforts. Eight people out of the sample of 20 presented this theme (Table 2). Like the previous themes, men presented narratives expressing this theme regardless of their health status.

Paul grew up in a small town near a large metropolitan area. His family was very religious. When Paul reached puberty, he felt intense shame for his growing attraction toward men. He described his family life growing up as very difficult.

His father, an alcoholic, physically abused Paul and his siblings. The family had financial difficulties relating to Paul's father's drinking behavior. After trying to stifle his sexuality through evangelical work, Paul eventually came to terms with his gay identity and left the church. During our initial interviews, Paul lived with his partner of two years in a home they had recently purchased. Both worked at well-paying jobs and lived quite comfortably. Paul narrated stories about his enjoyment of playing the piano, working in his garden, and relaxing. The style associated with this theme was that of being grateful or fortunate. Integrative narratives presented by study participants considered the impact of an HIV diagnosis on the way one lives one's life. Awareness of diagnosis was integrated into the stories as an impetus for appreciating what was important in life.

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.

When Paul told stories of past instances of appreciating life, he reflected on his foreshortened future as an incentive to regain that sense of appreciation, thus integrating the past with his present anticipation of a foreshortened future. The men who presented this theme described themselves as being grateful or fortunate despite or, in some cases, as the result of their infection.

Glen lived with his partner of four years in the outer suburbs of a large metropolitan area within a few miles of where he grew up and had been financially stable. Though he was asymptomatic for HIV infection, Glen felt that he tired more easily than he used to. He was rebellious throughout his childhood and into early adulthood but emphasized that he was always dedicated to his friends and has maintained the same friendships since grade school. Glen related that his mother was diagnosed with cancer when he was in high school and survived despite a grave prognosis. He talked about the support he received from friends and family throughout his life, drawing on his history for examples of caring, endurance, and achievement in presenting themes of survival and reciprocity.

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

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 HIV infection gave meaning to his continued existence. Through reframing the effects of HIV infection on his life, he was able to improve his perceived quality of life. Reflecting on how he had changed since becoming HIV seropositive, Glen said:

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.

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 perceived a change in himself since his diagnosis with HIV—"not overnight, but a long slow process." In describing himself as a child he used words like "free spirit," "defiant," and "spoiled brat." In his narratives of the present, by contrast, he spoke of having appreciation for life, caring about friends and family, and doing what he could "to help others in this situation." The change was not drastic but more of a shift in focus. His defiance growing up changed to defiance of the negative aspects of his limited future due to HIV infection. Through instrumental narrative he explained the importance of appreciating what life has to offer: "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."

The Average Life Theme

The last recurring theme was the average life theme, that of maintaining an everyday life that is uneventful, mundane, and "boring." The style associated with this theme was stability. Eric typified this theme and associated style. He owned his own home and lived alone, though he had been in a committed relationship for several years. He provided narrative stories of family picnics and summers in the country at a family-owned farmhouse. He remained close with his siblings and parents, but only one member of his family, a sister, was aware of his HIV-seropositive status (though he disclosed his seropositive status to some of his closest friends and his partner).

Eric presented his everyday life as uneventful, emphasizing stability. Importantly, he was asymptomatic and hoped to continue that way indefinitely. His stylistic orientation to living in the HIV spectrum was to equate his illness experience with his everyday life, which he described as routine and predictable. He said, "I feel sorry for you having to listen to these tapes. My life is pretty boring—uneventful. . . ."

Four men presented this type of theme in narratives of their life stories. All were asymptomatic (though not all men who were asymptomatic presented this theme) (Table 2). Typical of this group, Mike said, "The things that give me pleasure are being around people, having good friends. This is so mundane it's 'blech!' My life seems real simple—not real complex. I'm very content."

Implicitly, and at times, explicitly, the men expressed the hope that this average, uneventful life would continue indefinitely, precluding the onset of symptoms of HIV infection. Thus, such narratives were instrumental. To have a mundane, average, and uneventful life is the antithesis of what one would expect of someone with symptomatic HIV infection and the possible attendant opportunistic infections, doctor's appointments, experimental therapies, and hospitalizations.

Perceived Quality of Life

The individual's perception of his or her own quality of life is culturally mediated (Jonas 1983; Leininger 1994; Marshall 1990). Perceived quality of life, as used in this article, derives from individuals evaluating themselves in terms of their cultural ideals of self (Gerson 1976; Hallowell 1955; Watson and Watson-Franke 1985:199), their lives in terms of cultural ideals of what a life should be (Langness and Frank 1981) and the range of what is acceptable (Hagestad 1990), and their life story narratives in terms of coherence, propriety, and stability (Lindt 1993). Thus, perceived quality of life is closely related to perceptions of synchrony or asynchrony with cultural values, and expectations of the normative and acceptable range of life situations (Bloom 1997; Gerson 1976).⁵

Synchrony with expectations of attainment or maintenance of culturally meaningful values and norms is a key element in an individual's perceptions of quality of life during the course of HIV infection (Bloom 1997). This points to the way in which core cultural values mediate quality of life as core cultural symbols of ideal characteristics of self, behavior, and experience. Perceived quality of life can thus be understood as the individual's understanding and evaluation of the gap or asynchrony between culturally mediated expectations of the ideal and his or her personal evaluation of the experiences of everyday life. Life story narratives provide a means of eliciting perceived quality of life as a process of ongoing evaluations in a temporal as well as a cultural context. This view emphasizes how quality of life is perceived, how it is improved, and how it can be maintained despite threats from the effects of illness and other life events.

Core Cultural Values

The four recurrent themes discussed here reflect meaningful values previously identified in cultural studies of the United States. Such values include self-reliance, conformity, individualism, autonomy, rationality, egalitarianism, justice, and freedom (Beeman 1986; Bloom 1997; Hsu 1972; Johnson 1985; Kaufman 1986). Importantly, these values are not necessarily unique to U.S. or Western culture (Hsu 1972; Kaufman 1986), nor are they characteristic of any given individual (Spiro 1993). Yet, as detailed below, when values are considered within the context of a given culture, their explanatory power is evident.

As summarized by Geertz, values are "cultural products—products manufactured, indeed, out of tendencies, capacities, and dispositions with which we were born, but manufactured nevertheless" (1973:50). Values determine what is assessed as good and bad in everyday social life (Fry 1988:463) and are expressed in "two directions": positive and negative (Hsu 1972:258). Consider self-reliance, which, as previously indicated, has been identified as a core value of American culture. The positively valued aspect of self-reliance is exemplified by the quality of freedom as manifested in the self-reliance of an individual. The negatively valued aspect is illustrated as totalitarianism, in which case self-reliance is expressed by one individual or governing body infringing on the freedom of another less powerful. This occurs when those in power value their own self-reliance and freedom to act without consideration of the effect on others (Hsu 1972:258). Thus, to say that Americans value self-reliance is to vastly oversimplify this cultural concept. The

meaning of this value is dependent on the context, in this case a sociopolitical context contrasting the individual with the governing body or power relationships. When a value is expressed in a particular life story narrative, it is to be understood in terms of culturally meaningful concepts regarding the situational, personal, social, and historical contexts. The explanatory power of a cultural value is evident when the value is considered as a core cultural symbol that mediates the meanings of life story narratives (Bloom 1997; Kaufman 1986).

For instance, presenting the self in the stylistic orientation of a survivor—overcoming obstacles and enduring hardships—emphasizes core U.S. 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. Thus, being a survivor, as expressed through these attributes, places one's life and self-presentation in synchrony with these core cultural symbols and provides a basis for a perception of good quality of life.

Helping and caring for others emphasizes the positive side of interdependence. Fry suggests that interdependence is a "keystone of human society" (1988:462), with American emphasis on reciprocity and exchange as the positive side of interdependence, while dependence has a negative value (dependence representing the undesirable opposite to a core value of independence). This is what is evident in the presentation of helping and caring.

Stan voiced concern that he would become dependent, while he also described why he deserved to receive care based on his past actions, that is, helping David's grandmother. He needed to feel that he contributed enough through his actions to justify his need for financial assistance. Thus, he could view his receipt of financial support as reciprocity rather than as one-sided dependence. Stan presented this as cultural logic dictating that productivity in the past and caring for and helping others implied that one would be deserving of care and help from others. Therefore, being cared for and helped was not dependence but an aspect of reciprocation, and Stan's independence was thus preserved. In this way, Stan's perception of the quality of his life was, in part, maintained through an emphasis on his reciprocal relationship with his partner, rather than one characterized by dependence, which he acknowledged "would be awful."

For the men in this sample, the appreciation theme is tied to awareness of foreshortened future. Despite the fact that such awareness is a catalyst underlying appreciation for everyday life, use of this theme can be seen as a means of shifting focus away from awareness of death and resisting illness identification and death. Through appreciation for life, culturally described by the men in this study as inherently positive, illness experience with its negative connotations is minimized. As illness experience is minimized and a style of being grateful for or fortunate in having 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 this core cultural value and enhancing quality of life.

Maintaining an uneventful or boring life, as represented in the average life theme, through a style of stability and consistency also serves to limit the impact of illness on one's identity and reinforce 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 being boring is seen as highly desirable. Eric resists any illness identity and so maintains his autonomy and perceived quality of life.

New Beginnings: Rob's Story

The following discussion shows how one study participant worked to maintain his perception of good quality of life through the process of integrating his ongoing experiences into the narratives of his life story. In so doing, there was a resultant change in emphasis of salient themes. Life stories have been shown to vary significantly with each telling, depending upon a wide assortment of contextual factors (Angrosino 1989). Specific influencing factors may include the broad historical and cultural context (Kohli 1986; Riegel 1975); the age of the subject of the stories, as a point on the life course (Cohler 1982; Shafer 1978); the specific context in which the story has been elicited (Watson 1976); the particular audience or listener; and previous tellings (Bruner 1986; Crapanzano 1980). Rob's life story narratives, discussed below, validate changes in thematic content and stylistic orientation of the self relating to several of these factors, as will be noted.

Rob was in his early thirties. When I first met him, he was living in a subsidized apartment in an old urban neighborhood not far from the downtown area. He had recently stopped working due to HIV-related health problems, primarily fatigue. He had very little connection with his family. His father had left the family when Rob and his sister were very young. During his adolescence, Rob's mother sent him to live with his grandmother in the southwestern United States. He returned to his hometown in the Midwest in his early twenties and has remained there to the present.

At the time of our first interview, he had no contact with his father, little or no contact with his mother, and was trying to locate his sister. He maintained phone contact with his grandmother, with whom he had never discussed his being gay or HIV-seropositive. He related that his mother and sister were aware that he was gay but that he had not told them he was infected with HIV. His sister lived in the same city, though he had lost touch with her due to her own difficulties with drug use and frequent moves. Many of his friends had died because of HIV infection-related illness. Nevertheless, he had developed several close friendships through his active involvement in 12-step programs. He was very involved in a local AIDS drop-in center, volunteering at several social programs for persons living with HIV infection, as well as at 12-step meetings for persons with HIV infection, also held at the center.

Survival Theme at Baseline

During the initial life story interviews with Rob, he described 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 was his style to endure these experiences and to persevere. He presented himself as the kind of person who did not let life's problems get to him. Through instrumental narratives, Rob cited the serious difficulties he overcame in his past. These difficulties served as indicators that he had the strength to endure hardships in the present and move on.

During the initial set of interviews conducted during 1995, Rob spoke very little about the physical effects of HIV, though he was first diagnosed eight years earlier and had progressed to AIDS with the onset of his first opportunistic infection less than two years after that. He had been off all medications for the preceding couple of years because he was "just sick of taking it all." About four months into our visits, when his T-cells dropped below 200, he resumed taking one of the antiviral agents. "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 did not have much more to say about his infection during these initial interviews. He had experienced some periods of illness and complained of feeling lethargic. He talked about having 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.

Despite the effects of HIV on Rob's everyday life, he did not initially perceive his diagnosis as a major turning point. In fact, he minimized its effect, seeing the death of friends as having had 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 a 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 said that being a survivor and being able to laugh at obstacles in his life were his strengths. In addition, he talked about being a hard worker and about the value of work in his life. This was particularly evident when he discussed the job he had had as a designer, before he went on disability. He talked about how much he had enjoyed it and how hard he had worked 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."

While on disability, Rob began working at one of the local AIDS service organizations. He talked about how that activity had improved the quality of his life: "I feel useful and needed again and productive, even if it is a volunteer job."

Although Rob had experienced the loss of many in his network of close friends, he maintained a perception that he had "a good quality of life" and felt it was "improving." He felt that his remaining close relationships were the basis for this positive perception. He saw his quality of life as being tied to culturally meaningful values of hard work and productivity, values that are also emphasized in the

12-step philosophy and are embedded in American culture. Rob also reported deriving meaning from his work at the AIDS drop-in center. Interestingly, his work there reflected the 12-step philosophy of "giving back to the community." In summary, during my early interviews with Rob, the themes most evident in his stories were the reciprocity theme and the survival theme.

Changes in Thematic Content

During his most recent interview, Rob's narratives emphasized alternative thematic content to that expressed in earlier interviews. However, he continued to report a positive perception of the quality of his life.

I moved, and it's been a real positive move because I realized I had kind of shut myself off from my creativity, and I've gotten back into doing some art work. I'm learning how to do stained glass windows, and I really enjoy it. I've gotten back into the dating scene. I'm just really in a good space, I think—better space than I have been in. And I really enjoy living here. It's really a nice atmosphere—very calming and peaceful here. I feel better about myself and I just feel like new beginnings, you know, like everything's open to me now.

When he was initially interviewed, Rob had presented the reciprocity theme as important and had spoken of his work in support services at a drop-in center for people with HIV. This involvement contributed to what he perceived as his good quality of life and served as a measure of his social worth.

As time went on, this same involvement was perceived as having a negative impact on his quality of life. Rob attributed this negative impact to the limitation of his identity to that of "a person with AIDS." As a result, Rob had become less involved in HIV-centered activities and was trying to actively limit the extent to which his social life revolved around the drop-in center and groups whose membership was based on HIV seropositivity.

Social Course of Illness

In a chronic disease such as HIV infection, the social course of illness has been shown to have a substantial effect on some individuals' perceptions and experiences (Bloom 1997; Kleinman and Kleinman 1991; Ware 1992). The social course of illness refers to the emergent effects of illness on one's social interactions and relationships. Among this cohort of men, a limitation of the social course of HIV infection was seen as a means to maintain or improve their perceived quality of life (Bloom 1997).

Rob's experience with HIV infection had first led him to center his social activities on the general topic of HIV. He volunteered at an HIV drop-in center and attended social activities for HIV-seropositive men. Ultimately, he came to feel that his identity was tied to HIV infection. He therefore took steps to influence the social course of his illness through behaviors and narratives that reflected a reduction of his involvement with the HIV drop-in center and HIV-centered activities. In the narratives of the one-year follow-up project, he focused on an appreciation of what life had to offer. This appreciation extended to valuing himself, his talent, and his identity as being more than someone with AIDS:

I made some major changes. I was feeling like I was being defined as a person with AIDS, and I was getting tired of people asking about all that kind of stuff. Because I'm much more than this person with AIDS. So I decided to get out of volunteering for awhile. I gave up facilitating the support group. It was really difficult to let go of that. I think maybe because my identity was wrapped up in it. The same as when I stopped working.

This shift of thematic content in Rob's narratives reflected his integration of a wide array of events and situations into the fabric of his ongoing life story. In the year prior to our follow-up interview conversation, Rob moved to a new apartment; he relocated and resumed regular contact with his sister and has somewhat successfully introduced her to 12-step programs; he changed the focus of his daily activities from involvement in AIDS service volunteering to working on his art; he talked to his grandmother about being gay and HIV positive; he was hospitalized for the first time, though this was related to prescribed drug interactions; and he had responded clinically to experimental drug therapy. Because of all of these changes, he was more hopeful that he could maintain his physical health and his social worth as a productive member of society.

By integrating these diverse events into his life story narratives, Rob worked to maintain his perceived quality of life. For instance, he limited his illness identity by reducing his work with AIDS service volunteering and by emphasizing his identity as a creative and talented individual. In addition, he began dating again. His response to drug therapy had given him greater hope for his future survival. His T-cells had climbed from near 100 to well over 500. His viral load was now undetectable. He reported having more energy, no longer feeling "wanged out" after minimal exertion. He no longer lived in subsidized housing, but had moved to a standard apartment on the first floor of a duplex. In all, he presented the image of someone living an average, everyday life within the context of the community at large.

Rob's stories exemplified his ability not only to maintain, but also to improve his perceived quality of life. As a consequence of this, he demonstrated the success of his actions to alter the social course of his illness.

Conclusions

In narratives incorporating of all of these themes, there is an implicit striving toward attaining some core cultural value or values. This is true despite the marginalization or stigmatization experienced by these men as persons infected with HIV or as gay men. Though they acquiesce to larger cultural values, they resist identity tied to chronic illness through their attempts to limit the social course of illness. The same has been found in other chronic illness or disruptions of daily life (Becker 1997).

Other life story narratives show integration of past and present providing continuity and a more cohesive understanding of the self for the elderly (Butler 1963; Kaufman 1986), the disabled (Frank 1984; Riessman 1990), and persons with AIDS (Borden 1989). Narratives may also reflect the failure of integration and resultant loss of self (Bloom 1997; Corbin and Strauss 1988). Liminality or marginalization and their deleterious effects are expressed in the narratives of chronically ill persons (Monks and Frankenberg 1995; Murphy et al. 1988; Mwarira 1990;

Shield 1990), including those living with HIV infection (Bloom 1997; Sandstrom 1990).

I propose that participants in this study evaluated the quality of their lives in terms of the synchrony of everyday life events and experiences according to culturally mediated expectations, core cultural values, themes, stylistic orientations, and other facets of the life story (Bloom 1997). They worked to integrate HIV-related events and experience into their ongoing life story as a means of maintaining or improving their quality of life.

In this article, life stories have been shown to be works in progress with enormous potential for thematic and stylistic variation over time. Themes of the life story narratives emerge and change in tandem with perceptions of quality of life. Personally meaningful and culturally salient factors underlying everyday life experience are unveiled and emphasized through a meaning-centered approach to understanding life story narratives and the concept of values as core cultural symbols. Importantly, this approach allows us access to greater insight into perceptions of quality of life.

This suggests the value of investigating perceptions of quality of life as an essential component of the care of individuals over the course of HIV infection. By understanding the personal meanings attributed to quality of life, we are more able to understand the effects of illness on the individual's experience of everyday life and so better identify his needs. Through understanding the semiotic basis of themes presented in the life story, we can better determine what might support or improve an individual's perceptions of quality of life. Thus, we can understand how and why the individual may act to improve, maintain, or ameliorate the effects of illness on perceived quality of life.

NOTES

Acknowledgments. Funding for research and preparation of this article was provided in part by Center Grant P30-MH52776 from the National Institute of Mental Health. The author wishes to thank Brian E. Mendyka and Heather K. Cecil for advice and suggestions during the writing of this article.

An abridged version of the sections of this article detailing the four primary themes of the life stories was read in 1996 at the XI International Conference on AIDS in Vancouver, BC. An abridged version of the sections pertaining to changes in themes was read in 1996 at the 95th Annual Meeting of the American Anthropological Association in San Francisco, CA.

This manuscript received the 1997 AIDS and Anthropology Research Group (AARG) Paper Prize for a manuscript submitted by a professional anthropologist. AARG is an interest group of the Society for Medical Anthropology (SMA).

Correspondence may be addressed to the author at Centers for Disease Control and Prevention, NCHSTP/DSTDP/BIRB, Mailstop E-44, 1600 Clifton Rd. NE, Atlanta, GA 30333; telephone: (404)639-8278; fax: (404)639-8622; e-mail: fcb8@cdc.gov.

1. Point estimates of people living with AIDS were derived by subtracting the estimated cumulative number of deaths of persons with AIDS from the estimated cumulative number of persons with AIDS, adjusted for reporting delays and for redistribution of cases initially reported with no identifying risk, but not for incomplete reporting. Newly diagnosed HIV cases do not include individuals diagnosed with AIDS at the time of their initial HIV diagnosis.

2. Preliminary analysis and impressions were shared with participants on an ongoing basis, and their feedback was solicited and included. Participants were provided with copies of the dissertation and a draft of the first publication (Bloom 1997) reporting the initial study. Interviews were thus collected using a collaborative approach (Kennedy and Davis 1993; Ortiz 1985) and a philosophy of narrative production through negotiation among listener, teller, and intended audiences (Angrosino 1989; Bruner 1986; Crapanzano 1980; Tierney 1993).

3. Watt and Wong (1991) describe six narratives in their analysis of reminiscence. The two narratives not used here are "escapist," dwelling on the past as "the good old days to avoid or compensate for an unpleasant present," and "obsessive," preoccupation with particular past events. These two types were not employed at any time by any of the men in the sample.

4. The narrative typology employed in this article differentiates integrative from other types of narratives as a point of primary narrative function. Integrative narratives directly present this illustration as a focus. Other types of narratives are more indirect. That is, while descriptive, instrumental, and transmissive narratives may integrate past and present events, their respective foci are to provide information, to solve problems, and to teach.

5. For a more detailed account of the experience of asynchrony in relation to liminality, loss of self, and quality of life, see Bloom 1997.

REFERENCES CITED

Angrosino, Michael V.

1989 The Two Lives of Rebecca Levenstone: Symbolic Interaction in the Generation of the Life History. *Journal of Anthropological Research* 45:315-326.

Becker, Gay

1997 *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.

Beeman, William O.

1986 Freedom to Choose: Symbols and Values in American Advertising. In *Symbolizing America*. Hervé Varenne, ed. Pp. 52-65. Lincoln: University of Nebraska Press.

Bertaux, Daniel

1981 *Biography and Society*. Beverly Hills: Sage.

Bloom, Frederick R.

1997 Searching for Meaning in Everyday Life: Gay Men Negotiating Selves in the HIV Spectrum. *Ethos* 25:454-479.

Borden, W.

1989 Life Review as a Therapeutic Frame in the Treatment of Young Adults with AIDS. *Health and Social Work* 9:253-259.

Bruner, Edward M.

1986 Ethnography as Narrative. In *The Anthropology of Experience*. Victor Turner and Edward M. Bruner, eds. Pp. 139-158. Urbana: University of Illinois Press.

Butler, Robert N.

1963 The Life Review: An Interpretation of Reminiscence in the Aged. *Psychiatry* 26: 65-76.

Centers for Disease Control and Prevention

1999 *HIV/AIDS Surveillance Report*. Atlanta: Centers for Disease Control and Prevention.

Clatts, Michael C.

1989 Ethnography and AIDS Intervention in New York City: Life History as an Ethnographic Strategy. In *Community Based AIDS Prevention: Studies of Intravenous Drug*

- Users and Their Sexual Partners. Pp. 225–233. Rockville, MD: National Institute on Drug Abuse.
- Cohler, Bertram J.
 1982 Personal Narrative and Life Course. *In* *Life-Span Development and Behavior*, vol. 4. Paul B. Baltes and Orville G. Brim, Jr., eds. Pp. 205–241. New York: Academic Press.
- Corbin, Juliet M., and Anselm Strauss
 1988 *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Jossey-Bass.
- Crapanzano, Vincent
 1980 *Tuhami: Portrait of a Moroccan*. Chicago: University of Chicago Press.
- Frank, Gelya
 1984 Life History Model of Adaptation to Disability: The Case of a "Congenital Amputee." *Social Science and Medicine* 19:639–645.
- Fry, Christine L.
 1988 Theories of Age and Culture. *In* *Emergent Theories of Aging*. James E. Berren and Vern L. Bengtson, eds. Pp. 447–481. New York: Springer.
- Geertz, Clifford C.
 1973 The Impact of the Concept of Culture on the Concept of Man. *In* *The Interpretation of Cultures*. Clifford Geertz, ed. Pp. 33–55. New York: Basic Books.
- Gerson, Elihu M.
 1976 On Quality of Life. *American Sociological Review* 41:793–806.
- Goffman, Erving
 1959 *The Presentation of Self in Everyday Life*. New York: Anchor Books.
- Good, Byron J., and Mary-Jo DelVecchio Good
 1982 Toward a Meaning-Centered Analysis of Popular Illness Categories: "Fright Illness" and "Heart Distress" in Iran. *In* *Cultural Conceptions of Mental Health and Therapy*. Anthony J. Marsella and Geoffrey M. White, eds. Pp. 141–166. Boston: D. Reidel.
- Hagestad, Gunhild O.
 1990 *Social Perspectives on the Life Course: Handbook of Aging and Social Sciences*. 3rd edition. New York: Academic Press.
- Hallowell, A. Irving
 1955 *The Self and Its Behavioral Environment*. *In* *Culture and Experience*. A. Irving Hallowell, ed. Pp. 75–110. Philadelphia: University of Pennsylvania Press.
- Hsu, Francis L. K.
 1972 American Core Value and National Character. *In* *Psychological Anthropology*. Francis L. K. Hsu, ed. Pp. 241–262. Cambridge, MA: Schenkman.
- Johnson, Frank
 1985 *The Western Concept of Self*. *In* *Culture and Self: Asian and Western Perspectives*. Anthony J. Marsella, George De Vos, and Francis L. K. Hsu, eds. Pp. 91–138. London: Tavistock.
- Jonas, Paul J.
 1983 Quality of Life—A Possible Anthropological Approach. *South African Journal of Sociology* 14(3):96–99.
- Kaufman, Sharon R.
 1981 Cultural Componentens of Old Age: A Case Study. *Ethos* 9:51–87.
 1986 *The Ageless Self: Sources of Meaning in Late Life*. Madison: University of Wisconsin Press.
- Kennedy, Elisabeth L., and Madeline D. Davis
 1993 *Boots of Leather, Slippers of Gold: The History of a Lesbian Community*. New York: Routledge.

- Kleinman, Arthur
1988 *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.
- Kleinman, Arthur, and Joan Kleinman
1991 Suffering and Its Professional Transformation: Toward an Ethnography of Experience. *Culture, Medicine, and Psychiatry* 15:275-301.
- Kohli, Martin
1986 The World We Forgot: A Historical Review of the Life Course. *In Later Life: The Social Psychology of Aging*. Victor W. Marshall, ed. Pp. 271-303. Beverly Hills: Sage.
- Langness L. L., and Gelya Frank
1981 *Lives: An Anthropological Approach to Biography*. Novato, CA: Chandler and Sharp.
- Leininger, Madeleine
1994 Quality of Life from a Transcultural Nursing Perspective. *Nursing Science Quarterly* 7(1):22-28.
- Levine, Martin P.
1992 The Implications of Constructionist Theory for Social Research on the AIDS Epidemic among Gay Men. *In The Time of AIDS: Social Analysis, Theory and Method*. Gilbert Herdt and Shirley Lindenbaum, eds. Pp. 185-198. Newbury Park, CA: Sage.
- Lindt, Charlotte
1993 *Life Stories*. New York: Oxford University Press.
- Marshall, Patricia A.
1990 Cultural Influences on Perceived Quality of Life. *Seminars in Oncology Nursing* 6(4):278-284.
- Monks, Judith, and Ronald Frankenberg
1995 Being Ill and Being Me: Self, Body, and Time in Multiple Sclerosis Narratives. *In Disability and Culture*. Benedicte Ingstad and Susan Reynolds Whyte, eds. Pp. 107-134. Berkeley: University of California Press.
- Murphy, Robert F., Jessica Sheer, Yolanda Murphy, and Richard Mack
1988 Physical Disability and Social Liminality: A Study in the Rituals of Adversity. *Social Science and Medicine* 26:235-242.
- Mwaria, Cheryl B.
1990 The Concept of Self in the Context of Crisis: A Study of Families of the Severely Brain Injured. *Social Science and Medicine* 30:889-893.
- Ortiz, Karol R.
1985 Mental Health Consequences of Life History Method. *Ethos* 13:99-120.
- Peacock, James L., and Dorothy C. Holland
1993 The Narrated Self: Life Stories in Process. *Ethos* 21:367-383.
- Riegel, Klaus F.
1975 Adult Life Crises: A Dialectic Interpretation of Development. *In Life-Span Developmental Psychology: Normative Life Crises*. Nancy Datan and Leon H. Ginsberg, eds. Pp. 99-128. New York: Academic Press.
- Riessman, Catherine Kohler
1990 Strategic Uses of Narrative in the Presentation of Self and Illness: A Research Note. *Social Science and Medicine* 30:1195-1200.
- Sandstrom, Kent L.
1990 Confronting Deadly Disease: The Drama of Identity Construction among Gay Men with AIDS. *Journal of Contemporary Ethnography* 19(3):271-294.
- Shafer, Roy
1978 The Appreciative Analytic Attitude and the Construction of Multiple Histories. *Psychoanalysis and Contemporary Thought* 2:3-24

Shield, Renee Rose

1990 Liminality in an American Nursing Home: The Endless Transition. *In* The Cultural Context of Aging: Worldwide Perspectives. Jay Sokolovsky, ed. Pp. 331-352. New York: Bergen and Garvey.

Sobo, Elisa J.

1995 Choosing Unsafe Sex: AIDS-Risk Denial among Disadvantaged Women. Philadelphia: University of Pennsylvania Press.

Spiro, Milford E.

1993 Is the Western Concept of the Self "Peculiar" within the Context of the World Cultures? *Ethos* 21:107-153.

Tarman, Vera Ingrid

1988 Autobiography: The Negotiation of a Lifetime. *International Aging and Human Development* 27(3):171-191.

Tierney, William G.

1993 Self and Identity in a Post Modern World. *In* Naming Silenced Lives. Daniel McLaughlin and William G. Tierney, eds. Pp. 119-134. New York: Routledge.

Ware, Norma C.

1992 Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome. *Medical Anthropology Quarterly* 6:347-361.

Watson, Lawrence C.

1976 Understanding a Life History as a Subjective Document: Hermeneutical and Phenomenological Perspectives. *Ethos* 4:95-131.

Watson, Lawrence C., and Maria-Barbara Watson-Franke

1985 *Interpreting Life Histories: An Anthropological Inquiry*. New Brunswick, NJ: Rutgers University Press.

Watt, Lisa M., and Paul P. T. Wong

1991 A Taxonomy of Reminiscence and Therapeutic Implications. *Journal of Gerontological Social Work* 16(1-2):37-57.

Accepted for publication January 11, 2000.

A vertical bar on the left side of the page, consisting of a series of colored squares (red, orange, yellow, green, blue) stacked vertically, with a small red diamond at the top.

COPYRIGHT INFORMATION

TITLE: "New beginnings": a case study in gay men's changing perceptions of quality of life during the course of HIV infection

SOURCE: Medical Anthropology Quarterly 15 no1 Mr 2001
WN: 0106005370009

The magazine publisher is the copyright holder of this article and it is reproduced with permission. Further reproduction of this article in violation of the copyright is prohibited. To contact the publisher:
<http://www.aaanet.org/>.

Copyright 1982-2002 The H.W. Wilson Company. All rights reserved.