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NARRATIVE VOICE AND COUNTERING SILENCE: WOMEN TALK ABOUT LIFE WITH AIDS

by

ANN ELIZABETH CAMERON

A dissertation submitted to the Graduate Faculty in Psychology
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy, The City University of New York

2001

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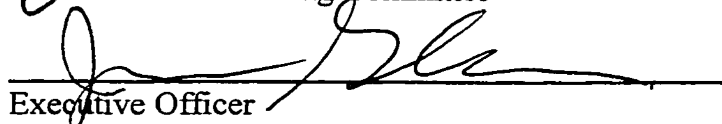
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Abstract

NARRATIVE VOICE AND COUNTERING SILENCE: WOMEN TALK ABOUT LIFE WITH AIDS

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ANN ELIZABETH CAMERON

Advisor: Professor Suzanne C. Ouellette

Although women with HIV/AIDS have been identified since the beginning of the epidemic and their numbers have climbed steadily in the past two decades, until recently women were largely absent from AIDS discourse and research. When women were included, often they were categorized and studied as problems -- "prostitutes," "AIDS mothers," "drug addicts" -- who transmit HIV to others. Rarely were women seen as individuals who were themselves vulnerable to AIDS or as individuals with a life-threatening illness.

"Master narratives" are the cultural stories we rely on to understand ourselves and others. Social science and medicine have their own master narratives of illness and of women who have HIV/AIDS, and these are the perspectives most often represented in discourse and research. Working from a perspective of offering alternative stories, this dissertation addresses how the meanings and experiences of AIDS might "look different" if seen from the perspective of women living with this illness. Through the life stories of 12 diverse women, I explore questions such as, How are women's lives and selves affected by AIDS? What stories do women tell about their lives and about HIV/AIDS? How do women perceive, make sense of, and respond to AIDS? What are the personal,

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social, cultural and historical contexts that shape their experiences, meanings and stories of HIV/AIDS? What can life stories teach us, and how are they useful?

I examine women's stories concerning primary transition periods along the "AIDS trajectory." The first chapter focuses on women's diagnosis stories; the second chapter examines how women create lives that incorporate HIV/AIDS, focusing on the "healthy" period. The third chapter examines the transition to illness, as well as the meanings of health, illness and AIDS in the context of changing treatment options. In each chapter, I use Mandelbaum's (1973) life history framework to examine the turning points, adaptations and contexts most central to the women's stories, and I explore how women make use of illness narrative forms outlined by Frank (1995) in their stories. The final chapter discusses the utility of these interpretive frameworks, as well as the methodological and ethical issues raised by this project.

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First, I would like to thank the women who participated in this project and trusted me with their stories so that others might benefit from them. They have taught me so much.

Thanks to my entire family (including dogs) for love and support in this sometimes lonely endeavor. Thanks especially to my mother, Mary, who has supported me in whatever I've tried and never asked me when I was going to finish. She also read this dissertation, gave comments and asked questions that assured the text would be accessible to non-academic readers.

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TABLE OF CONTENTS

List of Tables ix

Introduction 1
Statistically Speaking: Women with HIV/AIDS in the U.S. 4
Master Narratives of Women Living with HIV/AIDS 7
Use of Research and Theoretical Literature 10

Methods 14
Selection of Participants 17
Co-Constructing the Life Stories 19
Interpretation of the Life Stories 22
Turning Points in Women's Life Stories 23
Thinking with Stories Through Narrative Forms 26
A Note on Terminology 29
Organization of the Dissertation 32

The Women 33

The Journey Begins: Diagnosis and The Different Facets of Chaos 40
Losing Hope 41
Emily: "It wasn't testing positive...that made me try to kill myself." . . . 42
Susan: "And then, my life fell apart..." 46
Suffering in Silence 50
"I was so afraid somebody would find out." 53
"I thought I'd have three months to live." 54
Keeping Chaos at Bay: The Utility of "Denial" 56
Talking Around Chaos 63
Looking Across Diagnosis Stories: Dimensions and Adaptations 69

Creating Lives with HIV/AIDS 75
The Transition from Silence and Isolation 76
"I think the worst part about this disease is the secrecy." 77
The Importance of Communities 81
Shifting Meanings of HIV, Self and the Future 87
"I feel like I have so much to give at this point in my life..." 92
Finding Meaning in AIDS: Quest Narratives 102
"AIDS isn't the best thing that happened to me. The way that I chose to have it is the miracle." 103
"It's not like AIDS ruined my life. ...It kind of gave me a life..." 107
Enacted Quest Stories 112

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Adaptation and Quest Narratives 116
Changing Adaptations 120

Getting Sick: Illness and Restitution in Women's Stories 124
"That's it, I've just fallen off that cliff.": The Progression to Illness as a Turning Point 126
"Damn, this is taking control of my whole life": Adapting to the Losses of Illness 135
Restitution in HIV/AIDS Narratives 139
Confronting Death and Dying 155
Health and Illness in the Era of Protease Inhibitors 165

Method, Interpretation and Representation: Ethics and Politics 173
Mandelbaum's Life History Framework 173
Frank's Narrative Forms in Women's Life Stories 182
Texts as Partial Representations 185
Assessing the "Goodness" of the Research and Text 188
Ethical Reflections and Considerations 190
Representation of the Women and Their Stories 191
Relationships and Responsibility 195
Summary and Conclusions 202

References 211

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LIST OF TABLES

Table 1: Demographic Information at Time of Interview 210

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INTRODUCTION

In the summer of 1981, the Centers for Disease Control and Prevention (CDC) reported the first cases of rare infections and cancers in gay men in California and New York City (CDC, 1981a; CDC, 1981b). First termed gay-related immune disorder (GRID), the syndrome soon became evident among heterosexuals, injection drug users, Haitians residing in the United States, hemophiliacs, and people who had received blood transfusions, and was renamed Acquired Immune Deficiency Syndrome (AIDS). In 1983, researchers discovered the first strain of Human Immunodeficiency Virus (HIV), which they believed to cause AIDS.

According to the CDC, AIDS is defined as "a specific group of diseases or conditions which are indicative of severe immunosuppression related to infection with the human immunodeficiency virus" (CDC, 1999, p. 1). It differs from other diseases because there is a long asymptomatic period between infection and the development of illness. It takes an average of 10-12 years for someone infected with HIV to develop AIDS (Stine, 1998). There is no set disease course, and there are no constant or specific symptoms. Once an HIV-positive person reaches the point of immune deficiency, there is a broad range of symptoms and diseases (opportunistic infections) that he or she could experience (Stine, 1998).

Although AIDS is an infectious disease with the potential to debilitate and kill similar to other diseases, it also represents what Paula Treichler (1999) calls an "epidemic of signification," imbued with social meanings and metaphors (Sontag, 1989). Since

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AIDS was first recognized in the early 1980s, it has been a symbol for immoral behavior and socially constructed as a disease of "Others" -- gay and bisexual men, injection drug users, prostitutes, minorities, hemophiliacs (Silin, 1995). The designation of AIDS "risk groups" for purposes of public health in effect defined who those Others were (Schiller, Crystal, & Lewellen, 1994), as well as who were the "innocent victims" (i.e., children, hemophiliacs and blood recipients) in the epidemic and who were personally responsible for their illness because of a lack of self-control or self-discipline (Sacks, 1996). The social construction of risk groups thus set the stage for "stigmatizing, silencing, and abusing individuals with AIDS" (Singer, 1994, p. 941). As Jonathan Silin (1995) writes, "It is easier to blame victims of an epidemic when they are conceived of as different, the space between self and other increased through stereotyping, misinformation, and innuendo. Public opinion becomes structured ignorance" (p. 13). The stigma of HIV/AIDS stemmed in part from its association with immoral and deviant behavior, and from beliefs of personal responsibility for illness. AIDS also evoked stigma because it was perceived as a fatal disease that was contagious and threatening to the general public (Alonzo & Reynolds, 1995; Herek, 1999). Merrill Singer (1994) suggests that "AIDS involves two epidemics in one, a health epidemic and an epidemic of accusation and condemnation against the afflicted" (p. 945).

Although women with HIV and AIDS have been identified since the beginning of the epidemic, and the number of women with HIV/AIDS has climbed steadily in the past two decades, until recently women were largely absent from AIDS discourse and research. When women were included, often they were categorized and studied as

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problems -- "prostitutes," "AIDS mothers," and "drug addicts" who transmit HIV to men or to their children. Rarely were women seen as individuals who were themselves vulnerable to AIDS or as individuals with a life-threatening illness (Patton, 1994; Sacks, 1996; Treichler, 1999). This "cultural silencing of women" (Treichler, 1999, p. 271) throughout the history of the AIDS epidemic, stemming from "entrenched biological and social narratives about gender, scientists' stereotypes about particular kinds of women, and the established surveillance system..." (Treichler, 1999, p. 274), had very real consequences for women in terms of prevention, diagnosis and care, treatment, social resources and support, and information about sexuality and reproduction, particularly in the first decade of AIDS. The signification assigned to AIDS early in the epidemic, though, still has consequences for women. As Treichler (1999) writes,

> ...for women, even in the late 1990s, AIDS's long-standing identity as a "gay disease" and a "man's disease" still places a burden on them to prove their own significance -- as spokespersons, persons at risk, objects worthy of scientific and medical attention, and as agents of social justice and political change. But...this has proved very difficult to do. The current state of affairs in the United States with respect to women and AIDS is that we lack knowledge, social policy, and cultural consensus -- in part because we lack conceptual coherence about the role of gender in HIV transmission and about the impact of the AIDS epidemic on women, on families, and on society at large. (p. 263)

Next, I present some of the recent statistics concerning women living with HIV

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and AIDS in the United States. Although this is a standard in most research and writings on AIDS, these statistics underscore the fact that AIDS is not entirely an "equal opportunity" killer. Structural factors of gender, race/ethnicity, social class and economic status are very much associated with who gets AIDS in our country (Zierler & Kreiger, 1997). As Singer (1994) describes, "In the U.S. especially, AIDS is disproportionately a disease of the dispossessed, a disease of the socially condemned and denigrated, a disease of social outcasts and a disease of the poor" (p. 944). Poverty in particular has been at the core of women's risk of contracting HIV and affects their lives with HIV/AIDS, although this has been largely overlooked in research and discussions on AIDS (see Farmer, Connors & Simmons, 1996, for an in-depth exploration of this issue).

Statistically Speaking: Women with HIV/AIDS in the U.S.

By June 2000, 124,911 cases of AIDS among women had been reported to the CDC, representing 16.8% of the AIDS cases in this country to date (CDC, 2000). Although the number of women with AIDS has been small relative to the number of men, in the 1990s the proportion of women with AIDS increased steadily; women represented only 7% of the AIDS cases reported in 1985, and over 23% of the AIDS cases reported in 1999 (CDC, 1995, 1999). The CDC estimates that an additional 33,775 women are currently infected with HIV (but do not have AIDS), although this number is an underestimate because it includes only cases from states that currently report cases of HIV infection (CDC, 2000). Women represented 32% of the new HIV cases reported in 1999 (CDC, 1999).

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Up to this time, the "portrait" of women with AIDS in the U.S. has looked different from that of men, and this has implications for women's lives with HIV/AIDS. Among men, over one-half (56%) have contracted HIV through sex with another man, and white men represent 48% of AIDS cases, although new cases are declining among gay/bisexual men and rapidly increasing among black and Hispanic men (CDC, 1999, 2000). Among women, 41% of AIDS cases are attributed to injection drug use, and 40% to heterosexual sex (in 40% of these cases, women reported sex with an injection drug user). Over one-half (57%) of women with AIDS have been black, 22% have been white, and 20% have been Hispanic (CDC, 2000). Most women living with HIV/AIDS are mothers and they are usually the sole caretakers of their children (Schable et al., 1995).

Federal and state surveillance statistics on HIV/AIDS do not report the socioeconomic status of individuals with HIV/AIDS, which obscures the extent to which social class and economic resources are connected to HIV/AIDS (Farmer et al., 1996). As Singer (1994) suggests, AIDS is a health crisis rooted in social conditions as well as social relations. This is particularly true for most women with HIV/AIDS, as they are more likely than men with HIV/AIDS to live in poverty (Farmer et al., 1996). For example, a multi-state study of socioeconomic status (SES) differences among people with AIDS found that women's overall SES (i.e., educational attainment, household income in previous year, and current employment) was considerably lower than men's SES (Diaz, Chu, Buehler, et al., 1994). Among men with AIDS, 22% had less than 12 years of education, 77% were unemployed and 54% had household incomes of less than $10,000; among women with AIDS, 50% had less than 12 years of education, 90% were

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unemployed and 77% had incomes of less than $10,000. Further, educational attainment and income were significantly lower for black women with AIDS compared to white women. When compared to women from U.S. Census data, however, both black women and white women with AIDS had a much lower SES as measured in this study.

Although research on women and HIV/AIDS has increased in the past decade, there is still little focus on women's lives and experiences with AIDS. When women living with HIV/AIDS have been included in or are the focus of research, often it is their psychological functioning that has been examined. A primary research question seems to be: Are women with HIV/AIDS worse off psychologically than their HIV-negative counterparts? Thus, research attention (in the U.S. and abroad) has often been focused on the negative psychological impact of HIV (e.g., depression, anxiety) and how individuals cope with their HIV infection (e.g., Brown & Rundell, 1990; Catalan et al., 1996; Fleishman & Fogel, 1994; Kaplan, Marks, & Mertens, 1997; Moore et al., 1999; Pergami et al., 1993; Siegel, Gluhoski, & Karus, 1997; Simoni & Cooperman, 2000; Simoni & Ng, 2000). Studies vary widely in terms of samples and time since diagnosis, which likely has affected the findings on psychological adaptation. Although some studies report high levels of depressive symptoms among women with HIV/AIDS (e.g, Simoni & Ng (2000) reported depressive symptomatology in 66% of women in their study), in general findings are mixed in terms of whether women with HIV/AIDS are "worse off" psychologically compared to women who do not have HIV. For example, a recent prospective, multi-site study found no differences in depressive symptoms between women who were HIV-positive and a similar sample of women who were HIV-negative (Moore et al., 1999).

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Further, depressive symptoms were related to factors such as adverse life events, drug use, and HIV-related physical symptoms, but not HIV status per se.

Women living with HIV/AIDS face a variety of psychological and social challenges, both HIV-related and not. As activist Rebecca Denison (1995) has noted, "For some women, HIV is the first major disaster in their lives. For many more, AIDS is just one more problem on top of many others" (p. 205). Recent U.S. studies suggest that a large percentage of women who have HIV/AIDS have experienced physical and sexual violence in their lives. Cohen et al. (2000), for example, found that 66% of their sample of women with HIV/AIDS had experienced domestic violence in their lifetime (21% in the past year) and 31% had experienced childhood sexual abuse. Similar numbers were reported by Gielen, McDonnell, Wu, O'Campo and Faden (2001); 63% of the HIV-positive women in their study reported physical or sexual assault as an adult and 41% reported a history of childhood sexual abuse. Among a third sample of women living with HIV/AIDS in New York City, 59% had been sexually abused and 69% had been physically abused at some point in their lives (Simoni & Cooperman, 2000).

Master Narratives of Women Living with HIV/AIDS

These statistics on women living with AIDS in this country paint a particular portrait of who these women are and what their lives are like. From them, we might conclude the following: women with AIDS are poor, they are minorities, they have limited education, they are drug users or spouses/partners of drug users, they are struggling, single mothers, they are battered, and they may (or may not) be

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depressed/anxious/suicidal. These images are not altogether wrong, but they are incomplete.

"Master narratives" are the cultural stories that we rely on to understand ourselves and others. As Romero and Stewart (1999) describe, "These stories operate as 'master narratives' when they subsume many differences and contradictions and restrict and contain people, by supporting a power structure in which gender, class, race/ethnicity, sexuality, and ability all define who matters and how" (p. xiii). Social science and medicine have their own master narratives of illness and of women who have HIV/AIDS, and these are the perspectives most often represented in discourse and research (and they dictate how the topic is conceptualized and studied). But the stories told *about* women with AIDS are usually not the same as the stories told *by* them. Certainly, the stories told by women with AIDS are more complex and they usually offer other sides to master narratives that are rarely revealed (or even considered) in research or popular images of women with AIDS. For example, Hassin's (1994) life story of Roberta, an injection drug user, showed how Roberta used her HIV-positive diagnosis to redefine her social identity from one that mirrored the dominant societal image of an injection drug user as an "irresponsible junkie" to a more positive one in which she perceived herself as a responsible person and mother. Similarly, in Alicea and Friedman's (1999) analysis of Millie's (an HIV-positive, former heroin user) life story, we see a woman's personal testimony that complicates and challenges the master narratives and stereotypes of drug users and women with HIV/AIDS as deviant, unfit mothers. Millie presents herself as a caring, good person and mother who did the best she could given the complex

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circumstances of her life. Further, Millie's narrative suggests that "she is aware that her 'diseases' are integrally connected to larger social ills such as sexism, racism, classism and heterosexism and cannot simply and only be attributed to her own individual pathologies" (p. 165).

Romero and Stewart (1999) suggest that "Perhaps the best way to counter master narratives is to offer new, compelling and even more interesting stories -- stories that sustain us, inspire others, and aim to subvert" (p. xvi). That is, we need to provide counternarratives that "contrast self–image and experiences with dominant cultural models" (p. 11, Personal Narratives Group, 1989). Silin (1995) writes:

> What HIV/AIDS signifies cannot be determined by the narratives of experts -- scientific, religious, or political. A democratically structured discourse must be initiated that will encourage all those who have been directly affected by HIV to enter the dialogue and tell their stories. Hopefully this will serve to counter many of the mythical stories that have been generated by those who have attempted to control and explain the meaning of AIDS. (p. 23)

Working from this perspective of offering alternative stories, this dissertation addresses the question, How might the meanings and experiences of AIDS "look different" if seen from the perspective of women who are living with this illness? I use the life stories of 12 women to explore many sub-questions, such as, How do women create lives with AIDS? How are women's lives and selves affected by AIDS? What stories do women tell about their lives and about HIV/AIDS? What experiences and

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themes do they emphasize in their stories, and what do they leave out? What are the various ways that women perceive, make sense of, and respond to having AIDS? (Massey, Cameron, Ouellette, & Fine, 1998). What are the personal, social, cultural and historical contexts that shape the experiences, meanings and stories of living with HIV/AIDS? What can women's stories teach us, and how are they useful?

Women living with HIV/AIDS are by no means a homogeneous group, and their narratives reveal the ways in which each woman's life experience is unique and diverse, as well as the common themes or experiences within and across women's stories (Franz & Stewart, 1994). Life stories provide a means for understanding how these women construct and make sense of their lives and how the larger sociocultural context has shaped their lives and framed their experiences and stories of HIV/AIDS (Franz & Stewart, 1994; Personal Narratives Group, 1989; Romero & Stewart, 1999). Hopefully, as you read you will come to understand that each of us has something to learn from these stories, although exactly what that "something" is will be influenced by each of our personal and professional experiences.

Use of Research and Theoretical Literature

Although I presented a brief overview of the research on women living with HIV/AIDS, I felt that an extensive literature review in the introduction to this study did not make sense given the diversity of the literature (theoretical, topical and methodological) that has informed this study. Instead, I weave the relevant theoretical and research literatures throughout each of the chapters as they relate to the overall study and

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to my interpretations of the women's stories. For example, in the chapter on methodology and in the discussion, I discuss the theoretical frameworks and methodological and ethical perspectives that shaped the study and my interpretations of the stories. In the "data" chapters that focus on the women's stories, I use existing theory and research as a conversation with the findings (Ely, Vinz, Downing, & Anzul, 1997) and as interpretive tools as I move through the stories.

In AIDS discourse and research, the perspective of individuals living with the illness has more often than not been overlooked. When I began this project, I found only one study that examined in-depth the personal experiences of people with HIV/AIDS. In this study conducted from 1986-1989, sociologist Rose Weitz (1991) explored how the lives of individuals with HIV/AIDS in Arizona changed as a result of their illness and how individuals responded to these changes. This research was unique because it focused on the issues that the participants deemed important, including testing and diagnosis, managing stigma, and how illness affected their lives, self-concepts and social relationships. Since then more researchers have solicited the experiences of people living with HIV/AIDS in their work, although the methodologies, content and outcomes of these projects vary widely. Some projects are narrative-focused, using individual life stories as the basis for interpretation (e.g., Hassin, 1994; Zappulla, 1997). Others studies are more "theme" based, where the focus is less on individual experience than on the development of relevant themes. In these studies, there may be short excerpts from individuals' interviews to illustrate a particular theme, but the themes generally are not interpreted or presented in the context of individual lives (e.g., Adam & Sears, 1996). Often, the themes

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are delivered to us piecemeal -- one article on theme X, one article on theme Y -- so there is little sense of individuals' own understandings of their experiences or how themes are woven together and made meaningful in the context of a life story.

Since I began this research project there has been much more attention paid to the issues concerning women and AIDS. What is absent from both research and commentary, however, is the perspective of the women themselves. We have many generalities and statistics about women with HIV/AIDS but not a lot of knowledge about how these women construct and talk about their lives with HIV/AIDS. Recent research by Patti Lather and Chris Smithies (1997) is one of the first to present such a perspective from women living with HIV/AIDS in a Midwestern state. Their research "explores the cultural meanings and social ramifications of the experiences and understandings of a particular grouping of women who live with the disease" (p. xiii). The book has a unique textual style, presenting several "uninterpreted" group interviews with women discussing a variety of topics (e.g., relationships, support groups, diagnosis, finding meaning from illness, death and dying),

The present study is one attempt to represent the lives and stories of women living with HIV/AIDS. To this end, I rely on a methodology that allows women to speak about their lives and their realities, and as such this study has much to contribute to our understanding of how women live with HIV/AIDS. Most importantly, it presents information that will be useful to other women and people who are living with HIV and AIDS. As Rebecca Denison (1995) reminds us, "Every time a woman with HIV speaks out, another one learns she is not alone" (p. 202). Finally, this study allowed me as a

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researcher the opportunity to care, and to be involved with my participants in the construction of their life stories (Tierney, 1994). In the next chapter, I discuss in more detail the methodology used in this study and the co-construction and interpretation of the life stories.

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METHODS

Life Stories and Illness Stories

This dissertation is based on what Norman Denzin (1989a) terms "subjective knowing," which is to draw on "the personal experience of others in a effort to form an understanding and interpretation of a particular phenomenon" (p. 27). In this study, I use a life story methodology to examine the experiences of women living with HIV and AIDS. Following Titon (1980), I use the term *life story* to mean "a person's story of his or her life, or of what he or she thinks is a significant part of that life" (p. 276). Life stories, as well as other narrative forms, are co-constructed through dialogue (Reissman, 1993; Titon, 1980). The construction of individuals' stories is as important as the events they are narrating, as life stories are shaped by personal, social, and cultural histories, contexts and ideologies (Denzin, 1989a). Stories and storytelling are also viewed by some as important expressions of personality and identity (Charmaz, 1999; Frank, 1995; Reissman, 1990, 1993; Rosenwald & Ochberg, 1992). Titon (1980), for example, notes that "The most interesting life stories expose the inner lives, tell us about motives. Rather than mere chronicling, the life story affirms the identity of the storyteller in the act of the telling. The life story tells who one thinks one is and how one came to be that way" (p. 290).

Because this study concerns women who are living with HIV/AIDS, much of the their life stories can be considered *illness narratives*, which "give voice to the life disruption that illness engenders. In situating illness within the context of a particular life,

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illness narratives focus on the meaning that illness has for the individual in the midst of everyday life" (Toombs, Barnard, & Carson, 1995, p. x). Such stories are important for what they reveal about what it is like to live with an illness, and the act of telling stories seems to be meaningful and even therapeutic for individuals who live with serious illness (Frank, 1995; Kleinman, 1988; Toombs et al., 1995).

Arthur Frank (1995) suggests that illness is a "call for stories" on different levels. First, people who are ill are required to tell their stories over and over -- to doctors, bureaucrats, friends, family, coworkers -- whether they want to or not. Second, telling stories is a way to re-navigate a life and self that is disrupted and changed by illness, and an opportunity to find meaning through the experience (Charmaz, 1999; Frank, 1995). Illness is not only an occasion for storytelling, in postmodern times individuals have a responsibility to tell their stories, "not just to work out their own changing identities, but also to guide others who will follow them" (Frank, 1995, p. 17). Frank further makes this point in his differentiation between "survivors" and "witnesses" among those living with illness.

> Survival does not include any particular responsibility other than continuing to survive. Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into moral responsibility. (p. 137)

Thus, stories are for others as much as for the ill person. Many of the women who told

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their stories for this study did so because they believed their stories could be useful to other women. At the time most of the women were diagnosed HIV-positive, few women's stories were available to help guide them in their experience. Although many ill individuals are reluctant to tell illness stories initially, over time their stories develop and are told in resistance to the silence that suffering inflicts on them. "Finally, their resistance finds a voice; they make suffering useful. In the wounds of their resistances, they gain a power: to tell, and even to heal" (Frank, 1995, p. 182).

Responsibility for illness stories does not end with their telling. We, as individuals who are engaged in work with the ill, have a responsibility to listen to these stories; to witness and to share them (Kleinman, 1988). Frank (1995) notes:

> One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy. These voices bespeak conditions of embodiment that most of use would rather forget our own vulnerability to. Listening is hard, but it is a fundamental moral act; to realize the best potential in postmodern times requires an ethic of listening. (p. 25)

An important part of our responsibility as researchers is to share these stories, to make sure they are available and are heard in all their various forms. In part, this means not fragmenting stories based on their content. Reissman (1993) suggests, "Precisely because they are essential meaning-making structures, narratives must be preserved, not fractured,

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by investigators, who must respect respondents' ways of constructing meaning and analyze how it is accomplished" (p. 4).

The stories that individuals tell about their lives are not meant to represent some "objective" truth. They are, rather, a person's account of their life experiences at a particular moment in time, as they are currently trying to make sense of it. They are representations of experience (Denzin, 1989a; Personal Narratives Group, 1989; Plummer, 1983; Reissman, 1993; Titon, 1980; Watson & Watson-Franke, 1985). Tierney (1993b) makes this point in describing his life story of Robert Sunchild, a gay man with AIDS:

> Robert reflected on his life when he had AIDS; his version of his life came at a particular moment in time. We must interpret his words not as if a concrete reality existed irrespective of the individual, but cognizant that his reality was socially constructed and constantly undergoing reinterpretation. (p. 129)

Thus, life story and other narrative research is not so much concerned with narrators' potential distortions or reinterpretations of past events. As time, experiences, and even audiences change, so do individuals' stories (Charmaz, 1999; Frank, 1995; Gubrium & Holstein, 1998; Reissman, 1993).

Selection of Participants

Recruitment for the study began after I received IRB approval from my academic institution and from the ethics committee at the AIDS organization where I posted fliers

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for the study. Women were informed about the study through the fliers and through an advertisement placed in a magazine for people living with HIV/AIDS. My only requirements for the women's participation were a willingness to talk about their lives and experiences living with HIV/AIDS, and the ability to converse in English. Women who were interested in the study contacted me by phone, at which time I explained that I was a graduate student doing a study for my dissertation. I also told my participants that I was employed as a researcher at a major AIDS organization. I explained the purpose of the study in greater depth, and what their involvement would entail using the informed consent agreement as a general guide. If women wanted to participate, I arranged an interview time and place that was convenient for each woman.

After much back and forth, I decided not to pay the women for their participation. Although there were financial reasons for this decision, ultimately I didn't feel comfortable paying women for their stories. I felt strongly that there is a different relationship between a researcher and participant when one is paying for a story, and a different story told. I wanted this to be two people constructing a narrative because each person believed that the project was important, so I chose to talk to women who wanted to tell their story for reasons that were other than financial. Most women did not want or expect to be paid for the interviews, and the few who did chose not to participate. Participants were reimbursed for any expenses for travel to and from the interview.

About 36 women in total responded to the advertisement or flier, and I conducted interviews with 12 of these women. I could not re-contact four women, three were interested in participating only if they were paid, and another changed her mind about

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participating before our interview. Although the remaining women said they were interested in participating in the project, I encountered several obstacles to completing interviews with them: many of the women were extremely busy and could not find a time to meet with me, some became ill or were dealing with family illness and had to back out of our scheduled interviews, and others weren't there when I showed up at their homes.

Studies that attempt to understand in depth the experiences of individuals typically sample a small number (6-12) of people (Morse, 1994; Ray, 1994). My goal had been to interview 10-15 women about their experiences living with HIV/AIDS, and I stopped once I had completed 12 interviews. At that point I had a sample of women who were diverse in many aspects (e.g., race/ethnicity; education and social class background; age; drug use history; sexual orientation) and thus reflective of the diversity of the epidemic among women. Also, the same issues and themes were being discussed by each of the women. I stopped interviews once I believed that I had heard the major themes, and I was hearing variations on experiences and themes rather than new ones. Finally, the type of interpretation and analytic depth that I planned for each of the stories required that I focus on a smaller number women.

Co-Constructing the Life Stories

Interviews were conducted from July 1996 through July, 1997. Each interview was conducted by me, in a location that was most convenient for each woman. Three of the interviews were conducted in a private room at the AIDS organization where the fliers were posted, and the remaining nine interviews were conducted in the women's homes.

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Two of the women were interviewed on two separate occasions, and the other ten women were interviewed only once. The taped interviews lasted between one and three hours; most interviews averaged two hours. Often an additional half-hour or so was spent talking before and/or after the actual taped interview. Before the interview, this conversation consisted of typical conversation that one might have with another whom they've never met (e.g., children, home, weather). On two or three occasions, women brought up an additional issue or experience after the "formal" interview had ended and I had put away the tape recorder. In these instances I recorded these conversations in my field notes.

Before the interview began, I read and discussed the informed consent agreement with each woman. The agreement explained the purpose of the study, the time requirement, how confidentiality would be maintained, that their participation was voluntary and that they could withdraw from the study at any time. Interviews did not begin until the women said that they understood the agreement and we both signed the consent form. Each woman was given a signed copy of the consent form to keep.

A "good" life story interview is one where the narrator is able to talk freely and in a sense control the interview situation (Bertaux, 1981). This lets the researcher know what issues are important to the narrator, and conveys to the narrator that his or her experiences and agendas will guide the interview (Anderson & Jack, 1991; Langness & Frank, 1981). For the most part, my interviews were not directed by a list of questions or topics, but focused instead on the issues brought up by the women or those that developed through our conversation (Minister, 1991). I documented the topics that were discussed in each interview so that as the study progressed, I could ask other women about particular

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issues if they did not bring them up. In most cases, I asked about specific issues only after each woman had finished telling her story.

To start the discussion and allow women the chance to tell their own story, the first interview question was very general (Anderson & Jack, 1991). I asked each woman to tell me a little about herself, and typically this led to a discussion of the circumstances surrounding her infection with HIV and how she found out that she was HIV-positive. Many of the women already had an "available" story, and they were able to talk about their lives and AIDS experiences with little prompting (Adam & Sears, 1996). All talked about their lives since testing HIV-positive, but they also talked about other aspects of their lives that were inextricably linked to how they lived with HIV/AIDS, such as drug addiction and it's consequences, physical and sexual violence in their lives, and the stress of trying to raise children without partner support or adequate financial resources. I encouraged women to talk about these other aspects of their lives as much as about AIDS because AIDS happens within a life-in-progress, and to focus only on HIV/AIDS would provide an incomplete picture of their lives. Further, half of the women had not yet been seriously ill as a result of their HIV infection, so HIV/AIDS did not dominate the narrative as much as I had anticipated. In these narratives, *fear* of illness was present but their narratives focused to a great extent on other life issues. Their narratives are a testament to the fact that lives go on in the context of illness, and in many cases and at various times the "non-illness" life dominates a narrative.

After each interview was completed, I transcribed the tapes verbatim so that the interpretation of the stories could begin while I continued to interview other women.

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Participants were given the option of having a copy of the interview transcript to read or edit; most did not want a copy, and those who received a copy did not make further comments.

Interpretation of the Life Stories

Although my history of working in the field of HIV/AIDS reassured some of my participants of my knowledge and commitment to AIDS work, as an HIV negative person, I consider myself an "outsider" in this research process. I am also a white, educated woman from a middle-class background, and although I may have race or gender in common with some of my participants, for most of the women I've interviewed, our lives are separated by a chasm of background and experience. I was well aware that at times during this research project, I could not relate to what these women were telling me about their lives, and that I had to be particularly attentive to their interpretations as well as my own.

Although this study focuses on the life stories of 12 women living with AIDS, my thoughts, beliefs, hunches, and interpretations were inevitably informed by my broader experiences with people who live with AIDS in my work and in my personal life. In the years before and during this study, I worked as a researcher in an AIDS organization and was involved with many different projects. For one project, I worked as an intake clinician, which involved talking to new clients (both men and women) in-depth about their lives, and working with them to identify their needs and to determine what services would be most useful. During the time I was interviewing women for my own study, I

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also worked as an interviewer for another organization on a study of women who had AIDS and were on welfare. For this study, I traveled to homes in different parts of the city to interview the women, their children, and the caregivers of children who had lost a parent to AIDS. I also have friends and acquaintances who are living with AIDS, and we talk about that experience when discussions are not being recorded and notes are not being taken. But I consider these discussions, as well as my other involvements, to be part of my "fieldwork," as each has contributed to my understanding of what it means to live with AIDS in our culture.

The process of interpreting the stories was a reflexive activity (Coffey & Atkinson, 1996). In some sense the analytic process began even before any interviews were conducted in that my prior experiences and research stance (i.e., my philosophical and theoretical perspectives and approach to the research) influenced what I would be asking about and looking for in the stories. My examinations of initial interview transcripts also informed subsequent interviews and interpretation, as did my continuous reading of various literatures related to my study and to what I was hearing in the women's stories.

Turning Points in Women's Life Stories

The stories that individuals tell us about their lives and experiences require interpretation (Denzin, 1994; Kidder & Fine, 1997; Personal Narratives Group, 1989). As Kidder and Fine (1997) write,

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> ...in our writings, research psychologists need to advance a theoretical framework around the "voices" of informants, to help analyze these voices in their historical and current circumstances. That is, we cannot merely reproduce narratives or present them as if the interpretations were self-evident. Whether we agree with the words of informants or not, whether we even like them or not, we have an obligation to surround their words with analyses for which we are authors. (p. 49)

My analytic goal was not to develop formal models or theories, but rather to interpret women's life stories using different frameworks. Following Coffey and Atkinson's (1996) advice to explore qualitative data from a variety of perspectives, I drew on two frameworks to interpret the texts, as each revealed different facets and complexities of the stories. Borrowing from anthropologist David Mandelbaum (1973), I explored the key moments, people, and events that were central to each woman's life story (Coffey & Atkinson, 1996). Mandelbaum proposed a framework for examining life histories in terms of the dimensions of a person's life, the major turnings or transitions in a life, and a person's characteristic ways of adaptation. *Dimensions* are essentially the various contexts "for understanding the main forces that affect a life" (p. 180), including the psychological aspects of a person, and the personal, social and cultural contexts of an individual's life. These life dimensions also shape how individuals tell their life stories. *Turnings* are described as transitions in which a person "takes on a new set of roles, enters into fresh relations with a new set of people, and acquires a new self-conception" (p. 181). Turnings may take place through a particular event or experience (a turning

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point), or may occur more gradually. They may be socially ascribed, self chosen, or unexpected. *Adaptations* are adjustments or changes that individuals make in their thoughts and behaviors in order to maintain continuity. When turnings and life dimensions are taken into account, one has a fuller understanding of how individuals adapt to their changing life conditions:

> We can then look to the main opportunities and limitations that the person faced at each juncture and ask how and why the person adapted his behavior (or failed to do so) at this point, what he tried to change and what he tried to maintain. (p. 182)

Mandelbaum applied this framework to interpreting the life history of Gandhi, relying on historical, biographical, and autobiographical information. Geyla Frank (1984) used this life history framework to examine a woman's adaptation to disability, but asked the woman herself to chart the significant events and turnings in her life. The life history primarily serves to document the markers or events that occur in individuals' lives, and therefore in both of these applications of the framework the authors emphasized the objective turning point experiences in the individuals' lives. Others have applied turning point frameworks to individuals' life stories, examining how such experiences are subjectively significant and meaningful in individuals' stories (Coffey & Atkinson, 1996; Denzin, 1987; 1989b). Denzin's (1989b) interpretive biographical method, for example, focuses on the turning point moments, or what he terms "epiphanies," in individuals' personal life documents (stories, accounts, narratives). He defines epiphanies as:

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> Interactional moments that leave marks on people's lives. They have the potential for creating transformational experiences for the person. In them, personal character is manifested, made apparent. They are often interpreted by the individual and by others, as turning point experiences. Having had this experience, the person is never again quite the same. (p. 15)

A serious illness is almost always such a turning point experience, and the concept of turnings or turning points seems to be an important component of illness stories, including stories of living with HIV/AIDS (Frank, 1993; Nye, 1997). In my analysis of turning point experiences, I examined some of the "common" events or experiences evident in women's life stories, and the similar and unique themes that were addressed within these turning point stories; the personal, social and cultural contexts that shaped turning point experiences and stories; and the adaptations related to each turning. I also explored the meaning of experiences; why events were pivotal and how they were made sense of by each person.

Thinking with Stories Through Narrative Forms

Sociologist Arthur Frank (1995) distinguishes between thinking *about* stories and thinking *with* stories. Thinking about stories is to reduce and fragment stories according to their thematic content, and to analyze that content. Thinking with stories requires an exploration of narrative forms as well as content, and examines the story as a whole. Much of this study thinks about stories and their content, primarily because we lack

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knowledge about how women's lives and selves are affected by HIV/AIDS. I believe there is also value, however, in thinking with women's stories, to take them in their entirety for what they represent. Therefore, I also examine the form of women's turning point stories and overall life stories in terms of Frank's (1995) typology of narrative forms found in illness stories.

To facilitate our listening to illness stories, Frank has proposed three basic narrative types, or general storylines that characterize how illness narratives are structured and told. He notes, "People tell their own unique stories, but they compose these stories by adapting and combining narrative types that cultures make available" (Frank, 1995, p. 75). Most illness stories contain all three of the following narrative types, as each may be prominent at a different point in the illness experience.

The dominant narrative type, *restitution narratives*, have the general plot, "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995, p. 77). This "culturally preferred" narrative of restoration to health is most often told by the recently ill, and rarely by the chronically or terminally ill. The content of such narratives typically are about the methods used to restore health -- medical care, treatment regimens. These narratives are shaped by a natural desire to return to health, but also by the assumption of society and institutional medicine that every problem can be remedied, and the expectation that individuals will do whatever possible to return to health.

Chaos narratives are described as the opposite of restitution narratives. Such stories have no real plot or sequence; instead, they "are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or

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discernable causality" (Frank, 1995, p. 97). They are difficult stories to hear in their lack of narrative order, and Frank characterizes them as "anti-narratives." He notes that those who are truly living chaotic lives cannot relate that experience through story:

> To turn the chaos into a verbal story is to have some relative grasp of it. The chaos that can be told in a story is already taking place at a distance and is being reflected on retrospectively. For a person to gain such a reflective grasp of her own life, distance is a prerequisite. ...Lived chaos makes reflection, and consequently storytelling, impossible. (p. 98)

Chaos can be identified in stories, even if the chaos story cannot be told. Presented in these narratives are often overwhelming problems or suffering. Because true chaos cannot be told in story, those who are able to describe chaotic experiences have already moved past them to some extent (Frank, 1995). In the present study, most of the women recollected chaotic moments or experiences in their lives from beyond the chaos, and they were now able to articulate those experiences and reflect on their meanings.

The third narrative type is the *quest narrative*, which is a true narrative of the self. These narratives describe how an individual's life and self are influenced by the illness experience. In quest narratives, "Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience" (Frank, 1995, p. 115). There are at least three different styles of quest narratives: memoir, manifesto, and automythology. Memoir is the telling of illness events in the context of other events in the

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teller's life; illness is incorporated into a life story. In manifestos, "the truth that has been learned is prophetic, often carrying demands for social action" (Frank, 1995, p. 120). What is learned from suffering has social as well as personal value, and must be voiced. The third manifestation of the quest narrative, automythology, depicts the transformation of the individual through their suffering. Compared to the manifesto, the language of the automythology concerns personal transformation more than a call for political or social change.

I draw on the broad narrative forms of chaos, restitution, and quest as one way to think with the women's stories in this study. For the most part, I focus on each narrative type in terms of plot, and do not go into the same depth that Frank does with his narrative analyses of mostly published illness stories. As I explore the women's life stories, I will discuss these narrative forms in further detail as they relate to different aspects of the stories.

A Note on Terminology

Throughout this study, I use the terms *story* and *narrative* in a broad sense, and do not adhere to a strict linguistic definition of narratives "as discrete units, with clear beginnings and endings, as detachable from the surrounding discourse..." (Reissman, 1993, p. 17). In the interpretation of the life stories, I examined the entire interview transcript, including what narrative theorists would refer to as narrative and non-narrative segments of talk (Reissman, 1993). I do this because the women were very diverse in the ways they formed and told their life stories. All of the women did not, for whatever

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reason, articulate their experiences with narrative coherence, sequence and structure. This is similar to how Squire (1999) described her interviews with people affected by and living with HIV/AIDS: "Multiple narratives occurred in each interview, and few of the stories proceeded uninterrupted from an opening scene-setting to narrative closure. Narrative lines were usually discontinuous, repetitive, and incomplete" (p. 119).

Reissman (1993) writes, "Individuals facing the biographic disruption of chronic illness reconstruct a coherent self in narratives" (p. 3), and for the most part women did construct coherent stories of their experiences when they were removed enough from the chaos. Reissman also notes that some experiences are simply too difficult to speak about (and to listen to), and thus these stories are not coherent because they have never been spoken. Women speaking about their life experiences for the first time (as some in this study were) may not have developed their narratives yet, much less have developed coherent selves or stories. Lincoln (1993) argues that eliciting narratives from those who have been marginalized or "silenced" in some way requires active and patient listening:

> As women discovered in the consciousness-raising groups of the 1970s, it sometimes takes an extended amount of time for the silenced to seek and find their voices, and to frame their stories. Many of the stories which the silent could tell remain at the tacit level: they have never been spoken aloud. (p. 34)

Thus, some women are just starting to voice their experiences. This rather tentative, newly emerging narrative has been described as a "prenarrative: it does not develop or progress over time, and it does not reveal the storyteller's feelings or interpretation of

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events" (Herman, 1992, p. 175, cited in Reissman, 1993). Although these so called incoherent or "anti-narratives" may be more difficult to "hear," as Frank suggests in his discussion of chaotic narratives, they may be as important, meaningful and revealing as those narratives that are structured. Further, in Denzin's (1989a) discussion of "self stories," or stories in which a narrator tells about his or herself in relation to an experience, he notes that these stories are often about critical or turning point life experiences, and that "they need not be coherent, linear accounts" (p. 44). Stories are told in diverse circumstances, and as such there is no privileged or genuine form that a narrative should have (Gubrium & Holstein, 1998; Morris, 1998).

Along these lines, I transcribed the narratives verbatim and for the most part I have not "cleaned up" women's language to make it more readable, except to eliminate false starts or repetitions within sentences (Reissman, 1993). The reader, then, is able to examine women's language and perhaps come to find meanings or interpretations other than my own. I have also included long segments of the interviews in some parts of the dissertation, especially when women were related turning points experiences in a more structured story form. I did this because I did not want simply to fragment these stories according to their thematic content, as is commonly done with qualitative analysis (Coffey & Atkinson, 1996; Reissman, 1993). Instead, I wanted to preserve the form of the narratives, as well as the contexts in which certain themes were being addressed.

Finally, although each of the women's stories informed my interpretations and analyses, I selected narrative examples that best illustrated the relevant discussion. Thus, there is variation in the extent to which I present each of the women's stories.

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Organization of the Dissertation

Next, I present a brief introduction to each of the 12 women. In the three chapters that follow, I examine women's life stories concerning primary transition periods common along the "AIDS trajectory." The first chapter focuses on women's diagnosis stories; the second chapter examines the ways in which women create "new" lives that incorporate HIV/AIDS, focusing on the "healthy" period of living with HIV. Finally, the third chapter examines the transition to illness in women's stories, as well as the meanings of health, illness and AIDS in the context of changing treatment options. In each of the three chapters, I focus on the turning points, adaptations and contexts most central to the women's stories of these transition periods, and I explore how women make use of the illness narrative forms outlined by Frank (1995) in their stories. At the end of each chapter, I summarize the major themes or issues raised in the stories. The final chapter discusses the utility of these frameworks for interpreting the women's stories, as well as the methodological and ethical issues raised by the research.

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The Women

Twelve diverse women were interviewed for this study. Three of the women are black/African American, five are white, and four are Puerto Rican or Puerto Rican-American. Their ages at the time of interview ranged from 28-49. All but two of the women had children, and two women had grandchildren. Of the nine women who had dependent children, eight were single mothers. Most of the women in this study had been living with HIV and AIDS for several years. With the exception of Barbara, who had been diagnosed 19 months prior to her interview, on average the women had known of their HIV status for over eight years, with a range of four and a half to eleven years. Seven of the women had tested positive between 1985-1989, and the other five had tested positive between 1990-1994. Demographic information about the women is summarized in Table 1. Below are brief introductions to each of the women, and all names are pseudonyms to protect confidentiality.

Barbara : is a 36 year-old African American woman who tested HIV-positive 19 months prior to her interview. She has had only minor symptoms, but has an AIDS diagnosis because of a low T-cell (i.e., <200) count. She describes herself, “I'm...a single parent of a sixteen-year-old daughter. It took me a while to get to where I am today. I'm not working, but I plan to go back to work. I try to enjoy life as best I can. I first found out my status in December, 1994. I'm in recovery, I'm three years clean. Before that, I was doing drugs, and not payin' attention about myself or my daughter. If it wasn't for my daughter tellin' me that she can't live like this, I don't know where I'd be or what I'd be

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out there doin." Barbara had been working since she was 17, but went on disability five months ago to reduce the stress in her life and focus on her health.

Joanie: is a 41 year-old white woman who has four children (ages 19, 14, 11, 8) and one grandchild. She found out that she was HIV-positive in 1989, seven and a half years before her interview. She has had only minor symptoms, but a low T-cell count gives her an AIDS diagnosis. Her husband passed away from AIDS in 1994, and since then she has been struggling to raise her children, although her boyfriend helps out financially. She describes herself, "I'm a mother of four children. Two of my children know I have the virus, and two don't. It's very hard for me to tell them, you know 'cause they're kids. I got the virus from my husband, who was an IV user. I found out because I went and I donated blood. And for many years I was scared to tell anybody. I was just scared. ...But now I really don't care. All I care about right now is how it's going to affect my children. ...I don't want for them to suffer for what I have, and that's my only concern."

Kay: is a 36 year-old African American woman who lives alone with her seven-year-old daughter. She was diagnosed HIV-positive in early 1992, and had minor symptoms until early 1995 when she developed AIDS. Since then she has been hospitalized three times. She says, "This is just where my life ended up." Kay had experienced a number of changes in her life in the past couple of years. She left an abusive relationship and lived in a shelter for a year, then she moved into her own apartment and her daughter came to live with her for the first time in several years. Six

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months ago, Kay had to leave her job and go on disability because of her illness, and she is trying to adjust to this difficult new life situation. She says, "I don't look that old, but I've been through a lot. Thirty-six is not old, it's just that with the disease, and the virus, and the stigma. ...I do feel it's a stigma ...and bein' a mother and a black, American woman is a stigma."

Nancy: "I'm a white, 44 year-old woman...diagnosed with HIV in 1985. My husband also had the disease, passed away in 1992, and I have an 11 year-old daughter. ...You always try to figure, 'When did I get it? How did I get it?' I could have gotten it either through sexual intercourse, you know with my husband, 'cause he had it, or from just sharing needles." AIDS, she says, "is just part of what I've become, 'cause it is a part of me." Nancy was healthy until 1995, when she developed her first and only AIDS opportunistic infection. More recently, she became physically disabled from the side effects of her medication, and was forced to leave her full-time job and go on disability. She says, "I just want to make sure that I don't waste my time, and I do good things with it. Things that I enjoy, things that I want to do. Instead of sayin', 'I can't do this. I can't do that.' So, I just treat myself a little better."

Delores: is a 34 year-old woman of Puerto Rican background who grew up in the "barrio." She has two teen-aged children (ages 19, 16) and a five-year-old son, and she lives in a small apartment with her youngest son and her ex-husband, who she is supporting as he tries to stop his injection drug addiction. She tested HIV-positive in 1986, and has experienced only minor symptoms and/or illnesses. She says, "I'm living

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with the virus. ...And it's been tough. It's been rough living." She struggles with little money and few sources of support. "I do wish life could be a little bit more fun. You know, I'm just practically existing and surviving."

Maria: is 31, was born in the U.S. to Puerto Rican parents, and she lives in a large apartment with her husband and her two children (ages 14, 5). Six months before she found out that she was HIV-positive, she had ended an extended period of drug use. She describes herself, "My name is Maria, I have two children. ...And I was diagnosed with the virus in 1990, when I was pregnant. ...the first three years, my life was hell -- crying and crying and crying. But then I said, 'Nah, this gotta stop.' ...And it's been going on three years I've been getting out of the house, goin' to [an AIDS organization]. I see a therapist, I go to group. ...And it's been pretty good. I cry less -- way less." Maria has been fairly healthy since she tested HIV-positive, and is the only woman in the study who does not have an AIDS diagnosis. Four months before our interview, Maria's father had passed away from AIDS.

Susan: is a 34 year-old white woman who is a single mother to her 11 year-old son. She describes herself, "I've been HIV-positive for nine and a half years. ...I was diagnosed with AIDS two and a half years ago. ...I have my son. My son's been living with me about three years. I caught the virus from his father, I believe. His father was an IV drug user at some point." Her health has been declining, and she is no longer able to work. She lacks support from family and has few friends, and works hard to find other sources of support for herself and her son. Living with AIDS, she says, "has been such a

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process of letting go of so many things." Susan had to stop working when her son came to live with her because motherhood, illness, and work became impossible to manage physically. She said, "I don't know how much HIV is affecting [me] right now, or is it just being a parent, and poor, and having problems. I mean, how much is the HIV? I know stress makes me ill. But I know it's more like I'm not ready to give up. And I know if I didn't work so hard I'd be sick."

Emily: is a 28 year-old white woman who is an "out" lesbian and AIDS activist. She found out that she was HIV-positive in 1988 at the age of 20, and was diagnosed with AIDS in 1993. She lived in the Midwest at the time, where she had a difficult time finding medical care and support for people with HIV/AIDS. After several years of being a national and international AIDS activist, Emily moved to New York to take a new job. Although her health has been up and down, she said, "I really believe I would be dead if I didn't [move], because I wasn't getting the health care I needed. I couldn't get the medications. ...And I'm alive, and doing quite well I think." She lives with her partner, and is employed full-time.

Roberta: is an African American woman who is single and lives alone. She says, "I'm 49 years old and I found out I was HIV-positive in...1991. I've been diagnosed AIDS, since then." For most of her adult life, Roberta had been an heroin user and a prostitute, and found out that she was positive shortly after she finished drug treatment. Since then, she has started "a different lifestyle" and focuses a lot attention on staying healthy physically and emotionally. She has worked as an HIV/AIDS peer educator, and

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looks forward to going to college and working in the health field. "AIDS," she says, "is a very, very lonely disease. And it keeps you real humble."

Angela: is a 33 year-old single mother of two children, ages 13 and 14. She moved to New York from Puerto Rico when she was 19; she was pregnant and needed public assistance to take care of herself and her child. She found out that she was HIV-positive in 1990, and got an AIDS diagnosis in 1991 because of her T-cell count. She has been hospitalized several times with a lung problem, and is limited physically. She was attending college at the time of her diagnosis, but she found the combination of school and single motherhood too stressful. She said, "I decided just to take the time that I have to just dedicate it to me, to find ways to heal, you know. To live stress-free. So that's what I've been doing." She would like to move back to Puerto Rico and her family, but knows she will not have the same financial help or social services available to her there.

Judy: is a 45 year-old white woman with a grown daughter. She lives with her husband of three years, who is also living with AIDS. She contracted HIV in the early 1980's from a blood transfusion, and tested HIV-positive in 1987. She spent the first several years completely isolated and terrified, and felt that she could not tell anyone about her diagnosis. Since then she has become more open about her HIV-status. Although she has not had any major illnesses, she retired from her teaching job a couple of years ago because she became too fatigued physically to get through a day. She no longer views her life as she once did, "I think I look at life very differently. You know, life was always, '...work and work and work and save, and you'll enjoy it later.' And now

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it's, 'Let's do something now...let's enjoy it now because you don't know.'"

Gloria: "My name is Gloria. I'm 49 years old. I have three children. I have four grandchildren. I'm Catholic and my nationality is Puerto Rican." Gloria tested HIV-positive in 1987 and has not experienced any health problems thus far. She has an AIDS diagnosis because of a low T-cell count. AIDS, she says, has been "a big part of my life. Very big part of my life." Several of her family members and friends have had HIV/AIDS, and she has cared for some of those people through their deaths. She deals with having AIDS by living her life as before and not giving HIV any control of her life. She said, "I've had my share of pains in my life. But you know, it's made me...stronger." Gloria lives with her youngest son (age 16), and is in the process of completing her bachelor's degree.

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THE JOURNEY BEGINS: DIAGNOSIS AND THE DIFFERENT FACETS OF CHAOS

As mentioned, most of the women in this study had been living with HIV and AIDS for several years; seven of the women had tested positive between 1985-1989, and the other five tested positive in the early 1990s. The women in this study had a variety of risk histories and were tested for different reasons. Over half of the women had experienced HIV-related symptoms prior to being tested, although those symptoms did not necessarily prompt testing. Some of these women were tested at the urging of a physician. Three of the women became aware of past sexual partners who were HIV-positive, although they had not yet experienced symptoms themselves. Of the remaining women, three were tested on their own or at the urging of others because they had risk histories, although none was experiencing symptoms. Finally, one woman found out she was HIV-positive when she donated blood, and thus had not sought out testing at all.

Diagnosis with HIV/AIDS is an experience that has the potential to shatter a person's life, or at the very least to change it irrevocably. Culturally, our expectations for a life plan do not include illness and death at a relatively young age. Diagnosis with a life-threatening illness almost invariably disrupts an expected life course and thus is a major turning point for most individuals. An HIV-positive diagnosis is particularly devastating because there is no cure and the course of illness is unpredictable, which adds to the fear and uncertainty already present when one is seriously ill. Denzin (1989a) notes that some turning point experiences "are totally emergent and unstructured, and the person enters them with few if any prior understandings of what is going to happen" (p. 71). This

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characterizes how a person often begins his or her life with HIV/AIDS.

I have heard many people describe their experiences living with HIV/AIDS as a "journey." On some level, this journey is the same for all HIV-positive people -- the same fight to create a life that incorporates this virus, the same daily battles with fear and uncertainty, and the same struggle to come to terms with failing health and a failing body. Living with illness, however, takes place within the contexts of particular lives, and this experience and its attendant meanings are influenced by all of the personal and social conditions that shape human action and experience. These dimensions also shape life stories. As Frank (1995) notes, "Disease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed" (p. 54). As such, women's stories of finding out that they were HIV-positive were as diverse as the women themselves, demonstrated in *how* they told their stories as well as in what themes they emphasized (Reissman, 1993).

Losing Hope

Illness stories often begin in wreckage, portraying lives that are disrupted by illness (Bury, 1982; Frank, 1995). Thus, it is not unexpected that women's turning point stories of diagnosis with HIV/AIDS revealed lives thrown into chaos and crisis. All of the women referred to their experience of finding out as devastating, although there were differences in how women represented the chaos of diagnosis in their stories, in the themes that they highlighted, and in how they tried to adapt to their diagnosis initially. The stories of two women, Emily and Susan, related extremely chaotic life circumstances

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after diagnosis. By chaotic, I mean that their stories portrayed a sequence of negative events that culminated for each woman in a sort of "breakdown" and a desire to die. Hopelessness, vulnerability, and a lack of control were prominent at this point in their life stories. They are not true chaos narratives in the sense that they were told in a coherent, "hearable" manner, but in them we can identify the "voice of chaos" (Frank, 1995, p. 98).

Emily: "It wasn't testing positive...that made me try to kill myself."

Emily tested HIV-positive in 1988, days after her 20th birthday. At the time, she was in college, and was having a very difficult time coming to terms with her lesbian sexuality. She had also been experiencing intermittent health problems for over a year -- chronic fatigue, diarrhea, vomiting, nausea, weight loss, chronic yeast infections. Doctors could not figure out what was wrong with her; it was the Midwest in the 1980s, so none recognized her symptoms as HIV, which delayed her diagnosis. In fact, she sought HIV testing on her own after someone gave her a pamphlet about HIV/AIDS and she realized that her symptoms were similar to those described in the pamphlet. She got tested in order to rule out HIV infection and fully expected a negative result. She had never used drugs or been sexually active with men. At fourteen, Emily had been raped by her mother's boyfriend, but she said that neither she nor the HIV counselor connected sexual assault with the possibility of HIV infection.

When she tested HIV-positive, Emily could not believe the diagnosis and subsequently got tested eight more times. She kept her diagnosis to herself for weeks, until she felt she had to tell someone. Soon, the word had spread and no one would go

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near her. Emily said that at first she could not process the change in her life because she didn't believe the diagnosis. She could not understand why people who were her friends one day would not come near her the next. She described looking at her hands and wondering, "Why is this week different than last? ...I just *did not* understand." In her mind she was the same person, and processing that change was difficult. In the passage that follows, she described the post–diagnosis events that culminated in such a profound sense of helplessness and rejection that she attempted suicide.

> It wasn't testing positive and finding out about HIV that made me try to kill myself. It was the fact that I couldn't get a doctor, that I had lost all my friends -- I innocently told a couple of people and the word got around. And the statistics that I read, of the short-lived lifespan of a person with AIDS. And going to a doctor, and [getting] this AIDS physical and him telling me...I more than likely would be dead in a year. Those were the things that sent me, you know, off in this feeling of helplessness and lack of empowerment. It wasn't the virus that fucked me up. It was the way people treated me that fucked me up. ...I had spent literally two months feeling so alone. No one would touch me, doctors wouldn't see me, you know, couldn't afford AZT, finally got the money to try AZT, had to stop takin' AZT 'cause it made me sick. So, I tried to kill myself.

In Emily's distinction between the effects of the diagnosis itself and others' reactions to her diagnosis, she demonstrates the power that social and institutional perceptions have on individuals' experiences with this illness. The social rejection and

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the "death sentence" confirmation from her doctor shaped her initial understanding of what life with AIDS would mean. What Emily did not reveal at this point in her narrative, but did discuss later, was how her childhood and adolescence also played a part in this reaction. When Emily spoke about her childhood and how she dealt with it, I saw a parallel in how she talked about living with AIDS. Emily described her childhood as "awful." Her father died before her birth, and she and her half-sister were raised by her mother amidst poverty, and physical, emotional and sexual abuse. "I was white trash," she said.

> I was born in North Carolina, and raised everywhere because my mother was a chronic mover, as well as a chronic drinker, as well as a chronic drug addict, as well as a chronic sex-aholic, as well as a chronic rage-aholic. I mean she tried every vehicle she could to not deal with her life. And I got caught in the crossfire, big time. ...I felt like I had to take care of her, so I was constantly around, constantly rescuing her. So, I always felt like I deserved everything that I got. I felt like a bad child or a bad seed. I felt stupid, ugly. ...Which is odd because everybody liked me at school. Everybody loved me. ...There wasn't anything I couldn't do. I was an overachiever. I could play basketball, I ran track, I did art, I was smart in school, I did construction. ...I decided that because I was so awful, I would be good at everything. Which is handy now. 'Cause I never feel like there is anything I can't do, which is a nice feeling. I was a survivor. I survived childhood, and it never occurred to me not to survive AIDS, you know? It was

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> part of it. So on some level I felt like that I had deserved to get AIDS. I had done something, somewhere. Which is I think the way a lot of people feel.
>
> ...I don't talk about my family much, because what's to talk about? You know, it's painful but I just have to go forward. I mean it's nothing that I could change. I just have to deal with it when it comes up. And be grateful for what I do have. Instead of whining about what I don't have or what I didn't have, I look to the things that I do have and I'm grateful. But I am from a pretty sick family. Lots of abuse, lots of violence.

When Emily was raped at age 14, she ran away that night to a friend's house and never returned. She met a woman who supported her, took care of her, and later became her lover. She attended school on and off, but eventually left so that she could support herself by selling drugs. She had been suicidal and depressed at various times in her life before HIV. When she was 17, she went to a treatment center for three months because, she said, "I was so suicidal...and I couldn't deal with being queer, I couldn't deal with my childhood." When the HIV testing counselors asked her what she would do if she tested positive, she said that she would probably kill herself, because that had always been her first inclination in difficult circumstances.

In the above narrative and throughout Emily's life story, there is a contradiction between her descriptions of herself as survivor and as someone who is vulnerable and never wanted to live. Her narrative suggests that her abusive childhood shaped a negative self-concept early on and left her angry, but at the same time set in place a desire to

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achieve, to see the good in awful situations, and to survive; strengths that later became important to her adaptation with HIV. Both of these aspects of her self-concept have played a role in how she has dealt with AIDS. The low self-image and sense of vulnerability left from her childhood, and her "self-hate and self-loathing" surrounding her sexuality are dimensions that played a role in her suicide attempt and are aspects of herself that she admittedly still struggles with. Even with Emily's history, the social rejection she experienced and the bleak outlook provided by the physician contributed greatly to what she saw as a hopeless situation. I wonder if her initial experiences with friends and physicians had been different, Emily might have responded differently to her diagnosis.

Susan: "And then, my life fell apart..."

Susan's narrative of her post-diagnosis period also described tremendous chaos in her life. Before her diagnosis, she and her husband had broken up and gotten back together several times and their relationship was abusive. He had also been an injection drug user at various points in their relationship. She was tested for HIV when she was pregnant with her second child at the recommendation of her gynecologist. When the test came back positive, the physician delivered the news in a manner that Susan described as "just horrible," and that in some ways set the tone for her feelings of hopelessness.

> My gynecologist first of all told me, "I have bad news for you. ...Come in after hours, tonight after the office closes." There I am all alone, I go down there and

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she gives me this news, and then she shook my hand [with as little contact as possible], and said, "I really don't wanna further your care. I suggest you go elsewhere. There's a hospital...that could do an abortion for you if you want. Good bye and good luck." And that was it, and I just walked out of there and like wandered the streets. I didn't know what to do, you know. It just wasn't real, you know. ...So...it was the beginning of '87, and you know, there wasn't any information or nothin', so I terminated the pregnancy because they were sayin' you know, "You might die. You won't be alive for your son. What's more important?" My son had just turned one...so it was like, it was a really hard decision.

Shortly after Susan's diagnosis, her husband got tested and he also was positive. Her life seemed to unravel completely at this point, and she had few opportunities for support.

Susan: And, so right after that it's like I started to use drugs, drinking really heavily. I mean I had used in the past, but never [like this]. I had still been working a job, like 8 or 9 years. ...And by that time, then I just was like, "I'm gonna die." I thought, "That's it. There's no hope." You know, I went and had this abortion. [At the hospital] they were like, "There's really no support groups at all. We have a woman's name who shoots IV drugs, do you want her phone number?" And I was like, "No thanks." That was it, and there was no, you know, literature or anything like that. ...And then,

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my life fell apart, like almost immediately. My husband got out of this rehab, and he was just angry, and he stayed sober, and I just started using, and he left like immediately. And I...had felt like, you know, doomed. Totally doomed. And so he left, and I was there with my son. I lost my job within like a couple of months. There had been a lot of abuse, and I had broken noses, and so I had had a lot of time off, comin' in with bumps and lumps and bruises and stitches...so I had a bad track record anyway there. I've always been a very emotional person, and stressed and anxious, and never dealt with life or people well, you know, I never had a clue. Totally clueless. So I went in there and I had told them I had to take a day off, and I told them the truth. ...You know, I said I had to terminate the pregnancy, I have this illness, and then they like said, "If you take a day off, we're gonna fire you." And I said, "Well, I have no choice. I have to take the day off." And they did, they fired me. 'Cause they said I had already taken too many days off. And at that time I didn't think of it, but it's like, I had also disclosed that I was just diagnosed with HIV, you know, and that's why I had to terminate this pregnancy. So I don't know [the actual reason], but anyway I was let go. And I mean, I would let me go too, if I was the supervisor. You know, so...I just continued to like really fall apart. And my son was still with me. Then his father like took him for a weekend visit, and like didn't bring him back, which was like, really good...and then I just really started using, and ended up like in a hospital, a psych hospital --

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paranoid, and anxious, and depressed, you know.

Ann: Do you think that was because of the HIV or just everything that was going on in your life?

Susan: I think, no, no. Because I had ended up there like right after I got married too, from the abuse and everything. That was right after the first time we broke up, so it was like, "Oh my God, my life is over. My husband just left." So that went on for years and I just tried like to kill myself. ...You know, I went in this hospital for like a month, and then lost my apartment and everything, and then I got back out, and I was living with my mother, and it's like, I don't really get any family support. And, I just continued to use drugs until like 1990, and I was like almost dead. Everyone hated my guts. I was like just sobering up enough to see my son on the weekends. He was living with his father, but all this time I had weekend visits, sometimes. And, it was like really, really bad. I just wanted to die. ...I was a mess. Total emotional, physical, mental mess. Like gone. I never thought I'd get any of it back, you know.

Frank (1995) remarked that what is told in chaos narratives "only begins to suggest all that is wrong" (p. 99). Within a relatively brief portion of her life story, Susan provided a long list of difficulties, if only partial. She described an abusive marriage, a difficult emotional past, an HIV diagnosis, an abortion, a separation, an unsupportive

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family, the loss of her job, the loss of her child, the loss of her home, a descent into drug and alcohol addiction, social rejection, a lack of support, a lack of HIV information, a breakdown and hospitalization, a desire to die. Within the major turning point story of finding out about HIV, she incorporates multiple turning point experiences that do not get elaborated, but that provide context and contribute to our understanding of the larger story of how and why her life took the turn it did after her diagnosis (Denzin, 1989a). For both Emily and Susan, the circumstances of their lives at that time, including the responses they got from others, contributed to a sense of hopelessness and overwhelmed their abilities to adjust. Like Emily, Susan did not come to the point of wanting to die just because she was HIV-positive, which is important to realize because these are complexities that are likely to be glossed over in studies that examine the impact of diagnosis on individuals.

Suffering in Silence

Other women told stories in which their diagnosis with HIV was devastating, but chaos in these stories was less overt (the suffering more internal), and in contrast to the narratives above, was very much about HIV/AIDS. Common elements of these stories included self-isolation, hiding HIV status, and attempts to manage HIV alone for the most part. Judy's was one such story that reflected this "quiet chaos." She found out that she was HIV-positive 10 years ago, and her experience was unique in this study because she was the only woman who was infected through the transfusion of blood products. Her diagnosis came as a complete shock to her, and she described being totally unprepared to

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deal with it. Her narrative portrayed a life that was turned upside down by this unexpected event. In her words, that positive test result "completely changed my life."

Judy: I never thought I was HIV-positive, I had no symptoms. I took the test because my sister, who also has the same [clotting] problem, had also gone for blood transfusions at the same time. She took the test, and she convinced me to take it 'cause she came back negative, and she said, "This way you never have to worry." I said, "I'm not worried." She says, "But this way, you never have to worry." So I went and took the test, and found out that I was, which completely changed my life. It was totally devastating. ...I mean, I don't even think they have a word in the dictionary for it.

[I felt] absolute, terrible, horrible fear. Totally consuming fear. Um, "This can't be happening to me. The tests are wrong. [This is] unfair." I'd wake up in the middle of the night, and the first thing in front of my eyes was HIV. I mean, it was like there in big red letters. At that point, back in '87, I thought I'd have three months to live. You know, it was just the most terrifying thing. They were burning houses in Florida, for kids that had HIV. I mean, and I was so afraid somebody would find out. It was this total disclosure fear that I mean for years I lived with this, so many years. I didn't tell anyone. And I had an added problem because I had just gotten married for the second time six months before. So, this

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totally destroyed my second marriage. Totally destroyed it.

Ann: What about it affected your relationship?

Judy: I would not talk about it. I wouldn't talk about it to myself, I wouldn't talk about it with my husband. And I certainly couldn't talk about it with anybody else, 'cause nobody else knew. And it was the secrecy that put such incredible strain on my marriage. He knew that if he had the TV on, and it had anything about AIDS or HIV on it, it better be off when I walked in that room, you know. Um, it was like, "It's not happening to me, and if I don't think about it, it will go away." And it put a tremendous strain on him. I wouldn't let him tell anybody. And I put a very, very, very bad strain on my marriage, which he ended up taking out on my daughter. So, he became very mentally abusive to her, because he couldn't be overtly abusive to me. And the interesting thing about that was that as much as we were sure that I had gotten it from the blood transfusions, you're never 100% sure, and he always had this feeling that maybe he was positive and gave it to me. But he would not get checked out. *Refused* to get checked. He didn't wanna know. ...You know I mean, it was just a tremendous strain.

...You see the reason I didn't divorce him, and I stayed with him for like five years, was because I really thought I was gonna die any day. And I had my 10 year old, 11 year old, and I didn't want to end up -- and

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> this was my vision -- in some little studio apartment with her, where the lights were turned off 'cause I couldn't afford to pay the electricity. Wasting away dying where she had to take care of me. So, I've always tried balancing which was worse -- staying with this guy who was treating [my daughter] like shit, you know, or [my daughter] having to take care of a mother who was dying...with no money and whatever.

Judy's narrative encompassed several important themes that worked in concert to create a situation that she believed left her no options, and greatly affected how she lived with HIV/AIDS in the first several years after her diagnosis.

"I was so afraid somebody would find out."

Although many of Judy's fears and concerns were the same as other women's, some of her reactions seemed more extreme. In particular, she had an overwhelming fear of disclosure, and she felt stigmatized and ashamed to an extent not described by others. Race and social class were important dimensions in her fears, secrecy and isolation. She felt that AIDS was not an acceptable disease for a white, middle-class woman, and initially she saw herself as different from those who contracted HIV from sex or drug use. She was also fiercely protective of her daughter and she believed she could not tell anyone because of the repercussions for her family. Because of her intense fears, she would not talk about her diagnosis with anyone, which destroyed her marriage and left her completely alone with her HIV for several years. Although HIV pervaded every

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aspect of her life, Judy was forced to keep up the facade of "life as usual," because to fall apart would be to reveal what she was desperately trying to hide.

Judy was certainly not alone in her fears of discrimination or her hiding. Joanie, for example, kept her HIV status silent for five years. When she was diagnosed, the counselor told her not to tell anyone because of the potential for discrimination. As a result, she shut herself and her family off from outside relationships almost completely.

> I was scared. I was scared of people finding out. I was scared of how people would react. I was embarrassed. You know I didn't wanna explain to nobody why [my husband looked like that]. ...I didn't want friends. ...I didn't want my kids with nobody. And I didn't want to explain to nobody, 'cause people ask like, "What's wrong with your husband? I heard he's dyin'." Or, "Why did he die?" And I didn't want to tell people, you know. ...I really secluded people 'cause I didn't wanna answer nobody's questions. I didn't wanna talk about it to nobody. I'm not a person to lie, so I didn't wanna lie. I didn't wanna have to make up stories, so for that I just avoid.

"I thought I'd have three months to live."

Chaos stories lack any sense of a future, and in this respect many narratives of finding out about HIV status might qualify as chaotic (Frank, 1995). Like most women in the study, Judy equated her diagnosis with a death sentence, which is a reaction described by many individuals who test HIV-positive (Adam & Sears, 1996; Davies, 1997; Lather

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& Smithies, 1997; Weitz, 1991; Zappulla, 1997). As a result, her thoughts of a future disappeared completely, and she was no longer able to think long-term. From that moment, she said, “Everything was an occasion that I marked being alive by.” Initially, she and many women were simply at a loss as to how to proceed given their uncertainty about the future. Nancy, diagnosed in 1985, used the metaphor of “suspended animation” to describe her uncertainty during this period.

> It’s funny when you realize what you know now as opposed to what I knew then. I figured, “That’s it -- 18 months -- that’s all I have.” And I was talking to people at [an AIDS organization] on the phone...I said, “Well, what am I supposed to do?” ...And they said, “Well, one of our clients, he just went to...his parents’ [house] and he’s playing with his dog on the beach.” And that’s all I could ever think of was that. “That’s it?” You know, you just give yourself the time, figure out what I can do in 18 months, do it, and time to die? ...I felt very angry. Very scared, very angry, and just, you know, at a loss. Like you really don’t know what to think. You’re kind of in a like suspended animation kind of thing. And just grabbing onto straws, and listening to people. ...’Cause at that point, you wanna hold on to, gravitate to, anything that’s gonna take you out of that 18-month countdown.

For Judy and other women, how they dealt with their diagnosis initially stemmed in large part from this belief that they had no future. For example, when Angela was diagnosed, she had just finished her associate’s degree and was in college pursuing her bachelor’s degree. But she was also a single mother caring for two children, and she

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didn't think she could manage the stress of motherhood and school as well as the uncertainty of HIV and her future. So she gave up her desires for an education and a career and chose to focus on herself and her health, and her children's well-being. She said, "I decided to take the time that I have to just dedicate it to me, you find ways to heal, you know. To live stress-free." In many ways, though, diagnosis meant the end of her dreams, and she experienced a great loss in terms of the images she held for herself and her future.

> [My life], it changed. It changed big deal. I mean, like not being able to do the things that I wanted to do. You know like...I have so many goals. I always think I wasn't born to be a housewife, or a woman that be in the house. I was like born to be a businesswoman, or a woman in the workforce, and be making lots of money, and having big success, you know. So that kind of like trenched those goals that I have. ...Sometimes, I feel...like I lost so many things.

On the other hand, this decision to focus on herself and "healing" her life was very important for Angela in terms of getting through the post-diagnosis period.

Keeping Chaos at Bay: The Utility of "Denial"

Other women dealt with their diagnosis by continuing their lives much as they had before. One theme that ran through all of these women's stories was that in order to adapt to this difficult turning point experience, some level of "denial" was necessary. Judy's narrative above reflected the difficult balance that HIV-positive women must try to

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find between obsessing about HIV ("I'd wake up in the middle of the night, and the first thing in front of my eyes was HIV"), and trying to deny its existence ("It's not happening to me, and if I don't think about it, it will go away."). Denial is a tricky word, because it often has negative psychological connotations, but it was cited by several women as being the "strategy" that got them through that initial devastation and allowed them to continue on with their lives. Denial in women's stories took various forms. For example, when Joanie was diagnosed, she thought she would die, and was terrified of the discrimination she and her family would experience if anyone found out. She blamed herself for not being informed enough about HIV to protect herself, and felt anger and blame toward her husband for infecting her, and robbing their children of a mother. For her, trying to forget about HIV was one of the only ways that she could manage all of these feelings initially and still care for her husband (who was also HIV-positive) and her four children.

> I tried to forget that I have it. I just wanted to make it go away and just wait 'til the day that it would get me sick. At then I didn't wanna know nothing about it. I didn't wanna talk about it, I didn't want therapy, I didn't want support groups, I didn't want to dwell on it. ...And at then I used to say, "I'm strong and it's weak. It's not gonna get me. I'm the stronger one." 'Cause the virus is very weak. ...But I just didn't wanna know nothing about it.

Delores decided to get tested at the same time she had decided to stop using drugs. She was also the mother of two teenaged children, and was caring for her dying mother and supporting her husband, an active injection drug user. She used the term "denial" to

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describe the first couple of years after her diagnosis, but her life circumstances were such that others' needs took priority. She also articulated the other ways that she has dealt with her diagnosis since then, hinting at the ineffectiveness of presumed social supports such as social workers or therapists for managing her complex issues (Fine, 1989).

Delores: Then, I was kicking I decided to take this test, and it was like the biggest bag somebody can throw on me. So, you know, [finding out] almost like started a trigger on me 'cause I was like, "Uh oh, I'm dealing with, you know, trying to get off these drugs, trying to straighten out, and now this." You know like, "Oh great. What am I gonna do now?"

Ann: And you had two kids?

Delores: At the time, teenagers, yeah. And I was going through hell because it's like I was living with my mother, I was with this guy that was active, I mean [my mother] was dying of cancer, I mean, I was going through so much crap all at once and I'm surprised I still got half a brain. You know, and I try to search to see what's keeping me on my feet.

Ann: Mm hm. And what do you think?

Delores: And, I think the only reason is the faith that I have in my God. Because it's really no social worker or no psychiatrist. I mean, yeah, I've seem them but when I walk out that door who gives me support then? You know, I

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still have to search for that support. So, it's that little bit of faith that keeps me going. I don't know, it's just been hell...but I've been dealing with it. Sometimes I have people talk to me and I've been to groups, and I've been to agencies, and it's like they give me a lot of credit for even coming as far as I have. But they still look at me with that question, the look in their face like, "How is it she can deal with it?" Because once I got clean, then I was dealing with my son's father that was like, all messed up, and then dealing with my issue. And I kinda like neglected myself for those first couple of years, because all this stuff that was going around. It's like, I was actually using that so that I can forget about what I had gotten in that office -- that result.

Ann: So for the first couple of years you just...

Delores: I went in denial.

Although some might interpret Joanie and Delores' words and actions as negative forms of adaptation, the utility of "denial" is apparent. In Gloria's story of diagnosis, she described the devastation she felt right after her diagnosis, and how her faith in God and her own strength got her through that time:

> It was crazy. It's like your life -- I don't know about anybody else -- I was able to see my life go right by me. And...you know, if it wasn't because of my religion, and what I believe, I would have said that I would have killed myself, too.

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...Religion plays a very important part. I'm Catholic...as Puerto Rican, you know, and because my mother brought me up not only with the Catholic religion, but with...this other religion. I don't know if you ever heard of it, called Santería, you know that deals with saints and things like that. If it wasn't because of all that, you know, I think I would have been one of those statistics. But since I'm a strong person...I said to myself, "I'm gonna go through this, no matter what it takes." So, I dealt with it. You know, there was times that I was crying, you know and thinking, "Why me?" ...But it was um, it was devastating. I wouldn't wish that on anybody, to go...through that. Because I'll tell you...that year, it was, you know it was hard for me.

Although Gloria's story began with the potential for chaos, she decided not to give HIV that kind of control over her life. As such, her life coherence did not seem to be disrupted for long, because she made a conscious decision about how she would live with HIV/AIDS.

Gloria: Well, I tell you. It took me a year for me to deal with that, because I um, right then and there I made it my point that this was not gonna take my life totally over. That I had a lot of things in my life that I had to do, you know, and I wasn't gonna be one of those people that they find out that they have this and that's all they think about, you know. That wasn't gonna be me. That was it. I mean, I made it my point to put this [in] the back of my head, and leave it there. And that's it. Okay, I'll read about

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AIDS, and I'll read about the HIV, and I'll read about this, and I'll read about that, but the way I deal with it is like if I didn't have it. ...Which, I know I have it, but...it's not an issue with me. It's not something that I'm constantly thinkin' about.

Ann: So you...made that decision early on?

Gloria: That's right. That's right. I mean, I have a son. My baby is sixteen years old. I have to be there for him. I was not gonna let this thing take over my life. And that's how it's been. I have not let this stuff take over my life. 'Cause I have things to do, you know. I'm a mother, I'm a homemaker, I'm a student. ...And that's how I look at it. If anything, I'm gonna be in charge of my life. This is not gonna be in charge of my life. I'm in charge of my life. And I do and say what *I* feel about this, you know.

If Gloria did have the perception that her life (or aspects of it) had been taken away because of illness, she didn't reveal it in her story. She presented herself as a strong woman -- just like her own mother -- whose roles of student, mother, and homemaker took precedence over HIV. Perhaps as a testament to this resolve not to let HIV take over her life, Gloria said that she did not remember the year she was diagnosed, a date quite memorable for most.

Roberta also went through a period of what she termed denial. When she tested HIV-positive, she had recently ended a 35-year drug addiction. Although she was not

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shocked by her diagnosis, she felt angry about the unfairness of it. "My reaction was like, I was really, really very upset. Oh God, it was like, 'How could this happen to me? I've just gotten clean,' and, 'Oh, this is truly not fair, God,' and, 'Why would you do this to me?' And oh, God, it went on and on and on and on and on." Instead of isolating herself and trying to forget about AIDS, her denial took the form of immersion in the AIDS world and in helping other HIV-positive people. She went to "almost every agency there was," and was involved in a 12-step program at the time of her diagnosis that helped her to not to turn back to drugs.

Roberta: At first, I kind of like went along with the program, right. You know, people were, "Okay, we're HIV-positive, we're grateful that we're alive," and you know this big support group type thing, and I was just like, "Okay." I went along with the program until I finally was able to get my own feelings about this...it lasted for maybe a couple years. ...And when I found out, because I was in a 12-step program...I says, "No, Whatever it is, I can't use."

...But I didn't wanna see it, you know. I just did not want to believe that this had happened to me. I just didn't wanna see it. I just stayed in denial for a while, you know. ...I was so busy. I took the 8-week [peer educator] course, I volunteered. ...Oh my goodness, I mean I was all over the place. I did [peer education], I went to NA meetings, I went to [AIDS organizations]. I didn't have a moment to think about it.

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Ann: You just filled up your life?

Roberta: I filled up my life. And when I got home, I would be too tired to think about me bein' HIV-positive. It was laying down, it was getting up in the morning, "You gotta be at your meeting, you gotta be at [peer education], you gotta help these people."

Every person's story is shaped by the dimensions of their lives. Roberta's initial HIV-story ("...we're positive, we're grateful that we're alive") and her feelings about being HIV-positive were shaped by the philosophies of 12-step organizations; it was a discourse available to her when she didn't know on her own how she truly felt about being HIV-positive. This "story," if only temporary, helped her through the first couple of years until she could "get her own feelings" about being HIV-positive. Also, her attention to helping others with HIV and recovery issues, and her involvement in groups and organizations kept her so busy that she didn't have time to think about being HIV-positive herself. Rather than being maladaptive, her initial reliance on this 12-step "story" and her involvement in groups and organizations helped her to avoid the chaos experienced by some of the other women, kept her from going back to drugs, and allowed her opportunities for support, even if these sources were useful only for a time.

Talking Around Chaos

In three of the women's stories, it was more difficult to understand the meaning of their diagnosis and the impact it had on their lives. Although the event was likely to have

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been a significant turning point experience, it was not represented as such in their stories. In contrast to the other women's stories, Barbara and Angela's diagnosis narratives were brief, lacked detail and were told in a rather flat, detached manner that didn't convey the emotional impact of the experience. Barbara, for example, described her diagnosis as "rough," and provided only the following as an explanation of what this meant:

> I mean, I wasn't suicidal, 'cause that's the first question people ask, "Well, [are] you suicidal or not suicidal?" But a part of you don't want to live no more. I won't say kill yourself, [but] stop working, stop socializing; that part of not living. And a part of me didn't want to live no more. But I had my daughter to put up a front for. And that was a hard front. And I have friends. Look, I've never had the time to grieve. Because I've got people -- my phone constantly ring, and peoples talkin' to you, and they need you. I have more friends need me, than I could say I need my friends. So, I never had time to get into myself.

Although Barbara begins to tell me how her life was affected by her diagnosis, she quickly invokes her child and the needs of her friends as obstacles to grieving her diagnosis, and the story ends there. Her lack of a story is perhaps reflective of her statement that she had not yet had time to "get into herself" and to process her feelings about being HIV-positive.

Similarly, Angela's narrative included very little of the emotional impact of her diagnosis:

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> I was like, devastated. I mean, I was more scared not for me, because I'm not scared of dying. I mean for me dying is something natural, something that I know has to happen. And you know it's like, I mean I have lived...a good life, so I can't complain. But I was more afraid about the kids, you know their future, what was going to happen to them. So that was my main, main concern at that time. ...Also I was thinking, "Who's gonna want to be with me, you know, knowing that I'm positive?" And at that time I was in love with this person that I was with so I had the feeling like he was gonna leave.

In contrast to the "diagnostic chaos" revealed in other women's narratives, Angela minimized the impact of the diagnosis on her own well-being and reassured me that her children were her biggest concern at that time.

In his discussion of chaos narratives, Frank (1995) describes the stories of Holocaust witnesses as having a "hole in the narrative that cannot be filled in...The story traces the edges of a wound that can only be told around. Words suggest its rawness, but that wound is so much of the body, its insults, agonies, and losses, that words necessarily fail" (p. 98). Frank suggests that individuals who are living in chaos lack the distance necessary for reflection and the development of a verbal story with sequence or narrative order. Thus, the lack of a coherent story reflects lived chaos. If indeed unstructured, "anti-narratives" (Frank, 1995) are reflective of chaos, Kay is someone whose narrative would suggest a chaotic life. In telling her story, Kay jumped from topic to topic, never quite revealing the significance of the events she was describing. In terms of her diagnosis with

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HIV, she did not relate this as a major turning in her life, but her narrative differed from both Barbara's and Angela's. In fact, she told two different versions of how her diagnosis affected her. Initially, she said that because she was asymptomatic for the first several years, her life stayed much the same. "Everything was fine -- socially, physically, financially, familywise," she said. Later in the interview, she told me a bit more about her diagnosis and suggested that her life was not really "fine" after she tested positive.

Kay: I said, "Now I feel like I'm in a box, I'm confined, I'm under restriction. Am I gonna tell my boyfriend, my family?" So then I just kind of like felt like a overall shock thing, you know, so I think I was in a deep depression and I never went for counseling.

Ann: What were the first few months like after you tested positive?

Kay: Very long, very long. I stayed depressed, then I went into like a denial thing. My friends, my family, my work, my boyfriend...I just felt like it was my fault. About what though? It was just my fault, everything, even at work. Then my social and my family life, and my work-related life, and my boyfriend life changed. You know as far as me personally, I didn't think the same about each issue. I just started not calling them. It was my fault. Though that's a big question mark...I don't know what was my fault, everything was my fault. ...But in the meantime, I'm healthy, I'm fine. We still go out to parties, me and my boyfriend. We go everywhere, you know.

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> I still do my physical hygiene. I always kept myself up. You know, but it got harder and harder, like cloudier to do these things.

Kay's life circumstances perhaps made this post-diagnosis period more difficult. She was living with an abusive man when she found out that she was HIV-positive, and she hid her diagnosis from him and everyone else that she knew. Until recently, she dealt with her HIV completely on her own and in secrecy. About her boyfriend, she said, "He didn't really advocate for me to get my health, I had to do that on the side, like in the back door. I had to go make a dental appointment on my own, and without him knowing. ...I was like livin' a double life, livin' a lie." According to Kay, though, she's always been intensely private and the hiding was not difficult "because I been doing it all my life." She also resisted the idea that her diagnosis was the only source of her depressive emotional state. She said, "I always seemed like confused and depressed, and worrying, and wondering. So you could say I always had a low self-esteem. And as far as my mental health, it was kind of low." Further, she believed that much of her depression and "confusion" stemmed from her life circumstances, including her boyfriend's abuse and control over her. She said, "And...you know where my depression stems from? I'll be like, 'Why is the world like this? Why do I have to live here? Why am I in this situation with this guy?' So I believe I would always be trying to 'why, why, why' all the time. It just pulls you down."

The second time I met with Kay, she told me that when she was diagnosed she didn't know what it meant to be "HIV-positive" or to have "full-blown AIDS," and she

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returns to her original story of diagnosis as something that didn't change her life in any significant way. She said, "I didn't correlate the two. I'm like, 'I'm HIV-positive. What is that?'" Although she may have understood the differences between HIV and AIDS on an intellectual level, Kay said that when she was diagnosed, "I was well, so it didn't really affect me like that." She suggested that she might have reacted differently to her diagnosis had she truly understood the implications of being HIV-positive. This didn't happen until several years later when she developed a serious illness that gave her an AIDS diagnosis.

> Imagine if I would have knew, 'cause I found out toward the end of our relationship that I was ill. Imagine if I would have knew in the beginning or somewhere in the middle when we was goin' through all of [our problems]. I probably would have been very stressed out, and just over the edge with, "Oh, I got HIV, I'm gonna kill myself."

Barbara, Angela and Kay each provided reasons in their narratives for why their diagnosis was not presented as major turning point in their stories -- Kay didn't understand what it meant to be HIV-positive, Barbara hadn't yet had time to grieve and process her feelings, and Angela worried more for her children than for herself. Barbara and Angela were also somewhat unique from other women in that each sought HIV-related support and information almost immediately after their diagnosis, which perhaps lessened the chaos surrounding this experience. It is also possible that these women have not developed detailed (Barbara and Angela) or "coherent" (Kay) stories around their diagnosis because they have so rarely spoken about it to others (Lincoln, 1993). For each

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of these women, speaking about AIDS "publicly" was a new experience and none seemed completely comfortable talking about this aspect of their lives. But I also think that to some extent talking *around* the chaos and devastation of diagnosis reflects David Morris' (1998) suggestion that suffering is to some extent inexpressible and exists outside the realm of language or description. Diagnosis may be one of the most devastating or painful aspects of their AIDS experience, and thus they are not able to integrate their feelings about it into their narrative. Indeed, "One function of narrative is to bring this deeper silence to awareness, to make such silences 'speak' by extending our recognition of an irreducible, nonverbal dimension of suffering" (Morris, 1998, p. 196).

Looking Across Diagnosis Stories: Dimensions and Adaptations

As evident in the above narratives, there was variation in the extent to which diagnosis was presented as a turning point experience. Although turnings are very individual experiences, it is possible to identify common themes and adaptive strategies across the women's stories. In terms of Frank's (1995) typology of illness stories, most women's stories of diagnosis and the initial months and years after were recollected as a chaotic time in their lives. For most, the chaos of a life disrupted by the threat of illness came on top of a litany of other problems. Their responses, then, were influenced by what other issues they were facing at the time. For some, these issues in combination overwhelmed their abilities to cope. Others had to put HIV out of their minds in order to deal with daily life.

If chaos narratives do not imagine life getting better, then stories of diagnosis

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with HIV/AIDS are where chaos was most evident. The shock, the intense fears, and the uncertainty that existed in the beginning often overwhelmed any sense that life might get better in the future. Restitution was not an option; there was no sense of "I can beat this," or even, "I can live with this." Further, if purpose and meaning were to be gained from the experience of living with HIV/AIDS, this was not present in women's diagnosis stories. Instead, diagnosis stories were characterized by a general lack of direction -- "What do I do? Where do I go? Who can I tell? What, if anything, will get me through this?" For some women, this "diagnostic chaos" lasted for several years, whereas for others it was relatively short-lived. Kalichman (1995) wrote, "initial reactions to testing HIV-positive precede long periods of psychological adaptation, eventually progressing toward acceptance" (p. 158). The term "initial reactions" may be misleading, because many women described initial reactions, fears, and isolation that went on for a period of many months or even years. Judy, Maria, and Joanie, for example, each described several years spent in isolation in order to keep their diagnosis hidden.

Looking across women's stories of diagnosis, what are the important *dimensions* or *contexts* that influenced how women adapted to this turning point experience? The women's responses to diagnosis made sense given the historical time period. Between 1981, when AIDS was first identified, and 1987, the only approved drug to treat HIV/AIDS was the highly-toxic AZT. Although other antiretroviral drugs were produced and/or approved subsequently, it wasn't until late 1995 and early 1996 that the first promising treatments for AIDS became available in the form of a class of drugs called protease inhibitors. Thus, most of these women were diagnosed during a time when

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AIDS was still understood as a deadly and untreatable disease. Treichler (1990) writes of this time,

> For much of the 1980s, the notion of AIDS as an irreversible, communicable, largely untreatable, and usually fatal viral disease...represented a widely accepted view among scientists, physicians, and other opinion leaders, not to mention people with AIDS themselves. Disseminated through public health institutions, the biomedical and the general media, and the arts, this view of AIDS constituted the media's boilerplate on the epidemic -- that is, the authoritative, consensus view that could be taken for granted as a starting point for commentary -- and dominated research, prevention, and treatment efforts long after counterevidence had begun to emerge. (p. 317)

In addition, because of women's lack of visibility in the epidemic, resources and information for HIV-positive women were scarce. Susan, for example, noted that part of her initial struggle had to do with being a woman diagnosed with HIV in the mid-eighties, with nowhere to turn for support.

> When I was diagnosed, it was such a different time. There wasn't support. I just called my sister on the telephone and said, "I have HIV. I'm gonna die in a year. Do you want to raise my son?" You know? It's like, I didn't know. I didn't have a clue. And...it was hard to go from being' already like five years diagnosed to thinking, 'Oh, it doesn't have to be that way.' But it's been that way -- doomed --

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for five years. You know, it's so hard to change my thinking...and regroup.

The intense stigma that has enveloped HIV/AIDS since its discovery is one of the most important dimensions or contexts for understanding how women reacted to their diagnosis, and is a theme that was most prominent in women's stories of diagnosis and initial experiences living with HIV/AIDS. Toombs et al. (1995) note, "...just as the illness experience itself influences an individual's capacity to engage the social world, so the social world (societal attitudes, social practices, public policy) influences the subjective experience of illness and its attendant meanings" (p. x). The stigma of HIV/AIDS is a powerful entity. As the narratives suggested, the terror of learning that one is HIV-positive comes not only from the fear of a life-threatening illness, but also from the stigma that has come to be associated with this virus (Alonzo & Reynolds, 1995).

Women's stories were replete with the effects of the stigma of HIV/AIDS. It led them to feel shame and embarrassment, to hide or otherwise conceal their HIV status, to stop seeing friends and family, to seek medical care far from home or not at all, and to limit their social interactions to other HIV-positive people. Several of the women even distanced themselves from existing relationships with friends, acquaintances, and family because of the need to protect their children from the stigma of AIDS. Whereas most initially isolated themselves to avoid rejection and discrimination, a few women were unable to avoid it. Emily and Susan's experiences with physicians provide a glimpse into the real consequences of AIDS, but the fears of such rejection had almost as damaging an effect on women's adaptation as actual discrimination.

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Many of the narratives are notable for their lack of supportive others. Many initially tried to deal with HIV on their own, or believed that was their only option. According to Frank (1995), "The chaotic body is disabled with respect to entering relationships of care...it cannot tell enough of its own story to formulate its needs and ask for help; often it cannot accept help when it is offered" (p. 109-110). In these diagnosis stories, women rarely spoke of having supportive relationships or resources available to help them through this period. In terms of HIV/AIDS and women, there are other, more complex sides to Frank's assertions about individuals in chaos being unable to formulate needs, and to ask for and accept help. As many women noted in their stories, there were few if any opportunities for support and information at the time of their diagnosis. Further, the stigma of being HIV-positive kept many from seeking help and support if it entailed revealing their HIV status. It was simply too dangerous in terms of what could happen to their families, and many women placed the well-being of their children ahead of their own needs for help and support. Even for women who disclosed their HIV status to those very close to them, there were no guarantees of support. Some experienced a sense of separation from healthy others that inhibited support, and in the case of Judy, destroyed her relationship with the only person who could potentially offer her support.

In terms of adaption, most women began their illness stories in chaos, with little sense of direction or hope -- here we do not see the resilient spirit. Most women adapted to their diagnosis and initial illness experience in ways that did not necessarily help to repair the diagnostic wreckage (e.g., silence, isolation), but that did allow them to continue with their lives (e.g., "denial" and distractions). I don't want to suggest that

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these strategies were maladaptive, because they served a particular purpose and for many women, were the only options they believed they had at that time. Further, many of the strategies that women relied on at this early point in their illness experience ultimately were abandoned in favor of other ways of adapting to life with HIV/AIDS. If illness stories begin in wreckage, then repairing the wreckage is also a significant part of the illness story. The next chapter examines the important turning point experiences, adaptive strategies, and dimensions that enable women to move beyond the chaos of diagnosis to create meaningful lives with HIV/AIDS (Franz & Stewart, 1994).

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Creating Lives with HIV/AIDS

Because the course of HIV disease is unpredictable, individuals may live with HIV and AIDS for many years. If HIV infection is detected early, the first years are often lived under the threat of illness, or with minor symptoms, and later years with the more serious illnesses associated with a depleted immune system. Thus, a place has to be made for HIV/AIDS in an individual's life and self-concept. The processes through which illness is incorporated into one's life are very individual, and the degree of incorporation fluctuates over the course of the illness experience (Corbin & Strauss, 1987). As Kleinman (1988) notes, "...illness becomes embodied in a particular life trajectory, environed in a concrete life world. Acting like a sponge, illness soaks up personal and social significance from the world of the sick person" (p. 31).

Kathy Charmaz (1987) characterizes the chronically ill people in her study as "innovators:"

> Illness forces people to experiment, adapt and reorganize in order to maintain control over themselves and their lives. In this sense, chronically ill people are innovators. They create new ways of living that foster their identity pursuits. ...[My sample] participated actively in creating their lives and, moreover, themselves. (p. 318)

In my study, I saw similar evidence of active participation in creating lives that include illness. Each of the women's narratives told of the ways in which they came to

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terms with HIV and moved forward with their lives. Often this was framed in terms of life "getting better" at some point after diagnosis, although women reached this point at different times, in different ways, and through different circumstances. In some of the women's narratives, there was a discernable shift in how they lived with and thought about HIV. Their stories took the form of, "In the beginning it was like this, and now it is different," and contained one or more turning point experiences that contributed to this shift. In other narratives, women described the strategies and resources that were instrumental in rebuilding their lives after diagnosis, but they did not make the same then/now distinction in their stories. Taken together, these narratives provide valuable insight into how women make the transition from diagnostic shock to meaningful lives with HIV/AIDS.

The Transition from Silence and Isolation

For many women, the stigma of HIV/AIDS shaped their initial experiences, leaving them fearful, isolated, and silenced. Although secrecy and hiding were how many women managed their HIV status initially, these strategies often created their own difficulties, and most reached a point at which disclosing their HIV status became necessary, or where hiding was no longer the most important issue for them. Each of the women's stories contained at least one disclosure story, as it was an issue that affected all of them. It was evident that being able to talk about this experience was a crucial piece of the adaptive "puzzle," creating opportunities for needed support, new or different relationships, and community involvement, all of which were influential in how women

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lived with HIV. Further, for some women, talking about HIV was a way of protecting their self-concepts, and a form of resistance to the stigma that was once powerful enough to keep them silent, alone, or feeling shameful about being HIV-positive. Disclosure of HIV status is a difficult and complex process for almost every person with HIV/AIDS, because in each situation he or she must weigh the benefits of telling with the potential for a negative reaction. "Coming out" about HIV status (Squire, 1999) was often cast as a turning point experience, particularly for those women who had hidden it for a long period of time.

"I think the worst part about this disease is the secrecy."

In Judy's life story, for example, she related several disclosure experiences, each of which was told as a long and detailed turning point story that influenced her HIV experience, whether positively or negatively. She elaborated themes of secrecy and disclosure repeatedly because it had been a primary issue for most of the years since she had tested positive. "I think the worst part about this disease is the secrecy," she said.

> Telling people was this huge hurdle to get over. I mean, the words would could not come out of my mouth. I don't think the words came out of my mouth easily until maybe three years ago. I couldn't say "HIV", I couldn't say "AIDS." They got stuck, they wouldn't come out.

In Judy's case, she had kept her HIV status silent for six years, and had stayed in a bad marriage for the sake of her daughter's future. Disclosing her HIV status for the first time

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was a critical turning point in her HIV experience, and she marked it as the event that started to change how she thought about living with HIV.

> It took me a number of years to tell anybody. And the second person I told -- and I really didn't wanna tell -- it was my brother and my sister-in-law. And what happened was that everybody kept saying to me, "Why don't you divorce him?" 'Cause they could see the way he was. You know they kept saying, "Why?" and I kept saying, "You just don't understand. I can't tell you. You don't understand." And they kept saying, "Why don't you divorce him?...Nothing can be that bad." And so I would come out with, "Well, I have a health problem, and I can't leave him because of this health problem." And one day I was sitting in my brother's home...and I was literally crying over something [my husband] had done to [my daughter]. I was like just devastated. And I was crying, and my brother said, "I don't understand. Why don't you leave him?" And I said, "You just don't understand." I was like so upset. And he said, "What? What could you have? What are you gonna tell me you have AIDS? " And I just went "Huuhhh," and the whole house got real quiet, and he realized, you know. And the two of them were so supportive, they were just so incredible, that it just changed everything. You know and they said, "If that's what you're afraid of, you will always have a place here. Always. You will never die alone in an apartment. ...We'll always be here for you, if that's what's keeping you." ...And it was like a thousand pounds were lifted from my shoulder. You know it was like, "Oh my God, I have an out." I

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> mean, I really thought I had no out. I was like at this dead end. And then I had called the doctor to get a T cell count, and it had stayed about the same level, and I said, "I'm taking this as a sign from God to get out while you're feeling good," you know. And I went home, and that was it. Two weeks later I was out. I lost 20 pounds in two weeks. I couldn't eat. I mean, it was such hell at home. I found an apartment, we moved out. The minute we got into the new apartment, my appetite came right back. ...I think that was the hardest part of having this, was having to stay in a situation that I knew I didn't want to be in because I was so afraid of what was gonna happen, you know so soon. So, that changed.

This story represented two significant changes in Judy's life. First, the burden of silence was lifted when she finally revealed her HIV status. Because she felt so stigmatized by her HIV infection, she believed that she would never talk about it to anyone, let alone receive support and compassion. For the first six years, she had envisioned only suffering and dying alone, which made this experience so remarkable for her. The story also revealed a change in the role she allowed HIV to have in her life. Before, the stigma of HIV and her expected death guided her thoughts, decisions, and behaviors. This experience of disclosing and getting support was the beginning of her seeing other options for her life. She said, "Knowing that I have this disease and still saying I was going to support myself and my daughter," was a significant change that came out of this experience.

Ending secrecy and isolation was also a turning point in Joanie's life with HIV.

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When Joanie found out that she was HIV-positive, she tried to forget about her HIV, and didn't want help from therapists or support groups. Because of her fears of discrimination, she isolated herself and her family from others, and she did not know anyone else who was HIV-positive except her husband. During the first five years that Joanie and her husband knew they were HIV-positive, they told only their oldest child, and her husband's family. After her husband's death, Joanie's daughter started "going crazy," and she said, "I knew that I had to get help." She also realized that she herself needed support to help her cope with her HIV and her anger toward her husband.

> ... my [oldest] daughter, she started going on me, throwing things, attackin' me...she started acting out. And she was going crazy, like getting very violent, so I didn't know what to do. I went to family court...they referred me to [an AIDS organization]. And I went there, and I started gettin' therapy, and I started getting involved in support groups. Then I had a friend in there that was a women's peer educator, and then I became a women's peer educator and then I started to open up because I was so scared I wouldn't tell nobody. And then I started makin' speeches, you know and I started telling people.
>
> ...I figured that I needed help because I didn't know how to deal with [my daughter], and you know, I just needed help. I needed friends, you know to support me. I had one good friend, and I told her and you know she was very good but I just felt like it wasn't enough because I was havin' this problem with my daughter. ...I knew that I had to get involved in these places. And then in the

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> support group I met some friends that were like me. And I have one friend that is still she won't tell nobody, and she's very hush hush. But there was another girl that I was working with, and through her attitude, you know it rubbed off on me. And then [as] I exposed myself to the public more, it because easier for me to tell people, you know.

As Joanie began to open up and to get support for her HIV, she also began to see the potential for some happiness in her life. She said, "After eight months that the kids' father was dead, I said 'enough is enough. I'm gonna find somebody, I'm gonna live.'" At the time of her interview, Joanie had been in a relationship with an HIV-positive man for over a year. "I have a normal life now with him," she said, which is something she didn't have with her abusive husband.

The Importance of Communities

A sense of isolation can stem not only from the stigma of HIV/AIDS, but also from a sense of separateness or alienation from healthy individuals, and from the seemingly "normal" world. For many, socializing in usual circles was no longer comfortable or even meaningful. As Susan noted,

> It's hard for me to pretend I don't have HIV. It is a very much a part of who I am, and I don't know if it has to be as much as it has been, but I don't know how to change that. Now...when I go up to [my son's] school and I look in these parents' faces, I feel so different. I feel like I want to say to them, "You know, I don't

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> know how to talk to you because I have AIDS." ...I don't say anything to them, I just try to like grin and bear it, but it's so uncomfortable. ...it's hard, you know. It's hard to feel different.

For most women, part of adapting to life with HIV/AIDS involved finding HIV-related communities and resources, and in particular building relationships with others who shared the experience. Many women's stories showed how a sense of belonging to an HIV-positive community was crucial to their adaptation. Maria's story exemplified how finding such a community transformed her experience of living with HIV/AIDS. She spent the first three years after her diagnosis completely isolated, not telling anyone about her HIV except for her husband. She described these years as the worst part of her HIV experience, but said that her life "got better" after she ran into an old friend who "woke her up."

> I was at a my clinic appointment, and an old friend walks in. Well, he saw me, right away. Whoever you see, at that spot...infectious disease clinic -- you know what's going on. So that's how he caught me. And when he caught me, first thing I did was cry when he sat next to me. And he said, "I know, I know. I know why you're here." And I cried, and I cried, and he saw me like that. He's like, "You are devastated. You can't do this to yourself. What are you doin' with your life?" I tell him, "Nothin'. After here I go back home. And watch TV. All day long, cook, clean, and be with my kids. I don't do nothin' for this." He said, "No, you're goin' about it all wrong. There are millions of other people just like you livin' with it

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> every day. And that goes for me. You know I'm here, you know I have it too. I go to [different AIDS organizations], I got a therapist. And also my wife is positive, and you know we go to positive parties together, positive group meetings." And when I hear him talkin' like this, I got happy.

The next day Maria went to one of the AIDS organizations that her friend had recommended, and she said, "That's how it started." Her life and outlook began to change for the better. For the first time in three years she was getting out of the house, getting support from a therapist and support groups, and most important for her, talking, laughing, and socializing with other HIV-positive people.

> Those days I was crying, the years, I'd say, "Oh my God, I wish I had an HIV-positive friend." Boom...the first day I went to eat lunch, I met a girl. ...She was my first friend. From there on, I got a whole bunch of them. ...Everybody's my friend. Everybody knows me in there. And when I go in there I go with a smile, and I come out with a smile. ...And I be happy the whole day once I go in there. I'm finally getting to enjoy myself. Before, I had a drug history, and once that history was finished...I was locked up in here, and I wasn't happy about that.

Becoming part of this organization was particularly important for her because she did not get any support from her husband when it came to HIV. She began to consider her own needs as well as those of her children and husband, despite pressure from her husband to keep things as they were.

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Maria: I tried to speak with my husband [about going with me], and he's not into that. He's in denial. ...He don't wanna talk about it. He don't wanna join no group. He don't wanna go [to the AIDS organization] and have dinner with me. He don't want nothin' to do with HIV. So I'm out by myself, doing things. ...He don't go to these places, but I do it all myself, and it makes me happy. Even though he don't wanna come with me. I wish he would come with me, but he just don't want to, so I leave it alone. I'm not gonna push him no more.

Anna: Is it hard not to have his support?

Maria: At first it was. Oh, I used to cry over that. ...At the end I just made up my mind. I'm gonna leave him alone. When he's ready, he's ready. I ain't gonna push him. But he knows me, I told him, "You're not gonna stop me." He was used to me being locked in here. But once I started [getting out], he thought he was losing me. ...And I never had time for him. And he started, you know, to get mad with me. "What's this? You never got time for me. I mean, you cook late." And I told him, "I'm sorry. I suffered for three years, crying and crying and crying. And I think what I'm doin' is helping me with my health. Also, my T cells have boomed up, and I ain't gonna do nothin' that's gonna bring it right back down. I'm sorry, you got to understand. I gotta do what I gotta do. And this is what I do now."

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In the three years since Maria has been going to this AIDS organization, her life has gradually gotten better. She is no longer depressed, cries "way less than before," and her T cell count has improved, climbing from 640 to 1,140. She credited the change to the chance encounter with her friend. She said, "I mean, I snapped out of it. It was probably because of that friend, it was God's will to wake me up. But, I couldn't see myself keeping on like this." Maria's life and identity has become focused around HIV, and for her, being an active participant in a community of people living with HIV/AIDS supports the positive aspects of that identity.

Similarly, after three years of living with HIV, Angela joined two AIDS organizations that became integral to her daily life, and helped her to focus on herself, to heal, and to live with as little stress as possible. She said, "[These organizations] are places that...are very important in my life. It's like, I depend on them a lot." She spent most days at the one or both of these organizations, and relied on them for a wide range of services -- meals, a monthly a food pantry, children's services, nutritionist, individual therapy, art therapy, support groups, exercise classes, acupuncture, massage, and herbs, and social interaction. Through her involvement, she was able to get different types of support whenever she needed it.

> I'm sometimes depressed, but I try to work out that, you know by talking it. That's why I like to go there to the [AIDS organizations], 'cause I could like...if I got something really bothering me a lot...I just talk with anybody -- my case manager, or the psychiatrist, or my acupuncturist. You know, there always is

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somebody...willing to listen to you and for me, that's important to get rid of the stress you know. To talk about it.

For Roberta, immersion in AIDS (and recovery) organizations and communities was critical to her adaptation after her diagnosis. In contrast to stories above, a turning point in her HIV experience and adaptation came when Roberta had to *stop* her HIV peer education work because the stipend put her government benefits in jeopardy. She said that she didn't get "her own feelings about this" until she no longer had the distraction of caring for others.

Roberta: So I had to leave. And I think when I left, you know is when...I started dealing with it more. I mean it was like, "I hate this. I really hate this." But all the time I was [doing peer education] I was tryin' to help people see this in such a positive way, and "We're gonna beat this," and "Don't worry, I'm gonna save you."

Ann: But you didn't believe that?

Roberta: I don't know what I believed back then. ...I was tryin' to not deal. And I was givin' out this positive message, and oh, I was the greatest person there, and you name it. But my therapist had told me, "You're not taking care of your own self, but you're trying to take care of all these other people." ...But I couldn't see it until I left there, that you know, I was doin' all this stuff with these other people, and I didn't even know what to do

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with myself, with my own HIV.

Although AIDS-related communities and resources were an integral part of adaptation for each woman, there was a range to how much or how little a role they had in their lives. Some found that their existing support systems and personal strengths were most helpful in adapting to life with AIDS, whereas others relied on these outside resources for a great amount of their support. The important point is that each woman in the study eventually had some type of HIV-related support in their lives, whether it came from AIDS organizations, support groups, therapists, physicians, or personal relationships. For those women who lived without that support early in their HIV experience, this was a significant change in their lives.

Frank (1995, 2000) proposes that stories have a recuperative role in illness: "entering the relations of storytelling recuperates persons, relationships, and communities" (Frank, 2000, p. 355). At a fundamental level, being able to talk about the AIDS experience -- to tell one's story -- was transformative. Not simply to disclose HIV status to another person, although for some women this was a critical turning point experience, but to enter into relationships with other people with AIDS and with others who could support them in that experience. In many cases, forming relationships with others who shared "the same story" was the first turning point from the isolation, fear and hopelessness of diagnosis, and the burden of silence.

Shifting Meanings of HIV, Self and the Future

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For many women, the chaos of diagnosis stemmed from beliefs that they had no future, and fears that they would die very soon. Part of rebuilding their lives with HIV/AIDS was the realization that death was not necessarily imminent, and that a future -- however uncertain -- was possible. As such, they had to reconceptualize their thoughts about the future, and to consider what they wanted for the remainder of their lives. A changing sense of the future was reflected in various forms -- pursuing new goals of school or work; starting new relationships; getting substance abuse treatment; even continuing on with life as before, not letting HIV change plans. For most of the women, the consideration of a future was a shift from their initial HIV experience, and was an important part of making a life with HIV/AIDS because it represented "the recovery of hope and courage" (Barnard, 1995, p. 52).

For instance, the terror and devastation of Judy's diagnosis went on for several years. She said that a big turning point in her HIV experience came "when I started realizing I have a future." When her fears of immediate death did not materialize, she began to think beyond the present. As she talked about previously, disclosing her HIV status and getting out of her bad marriage was a first step in seeing options for her future besides death. She began to date again (and eventually remarried), and decided to further her career, which was a significant event for her because it reflected her renewed sense of a having future.

> There was a job at school that I wanted to go for. ...And it meant going back to school. It meant a lot of extra work. And it was to get this license. And before

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that, the last few years before that it was like, "What am I gonna do that for?" You know, "I'm not gonna be around to see the end of it." And I think that was the first time when I really took a deep breath and I said, "I'm gonna do it," you know, "And I'm gonna be around to do it." So that was like really important to me.

After 10 years of living with HIV/AIDS, Judy said, "I'm doin' okay. Now, it's like I'm expecting to live a long time." A number of dimensions have affected her sense of having a future, perhaps the most important being her continued health and the development of more treatment options. But this change in her sense of the future has contributed to a notable change in her adaptation.

Judy: [My new husband and I] took a lot of trips the first couple of years. We took a lot of cruises and stuff because we figured we wouldn't be able to again. And we, you know, charged up a lot of bills! But, I don't have that terrible [sense of], "I gotta do it right now because I don't know if I can do it next month." And I've lived with that for so long.

Ann: What do you think changed that?

Judy: I think just seeing that I've been around for a long time. And seeing that I'm okay. And knowing that there are so many more drugs coming out, you know, that will give me my options. And I calmed down a bit. I have. And I think it's also easier being able to be with other people who are

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> HIV-positive, like I'm finding other people and I'm being able to talk about it more. It makes it a little less frightening, although every time a friend dies, it like hits home because the media seems to think, you know, [AIDS is] not out there anymore.

After expecting death, looking forward to the future was not always an easy transition. Susan noted the difficulty in trying to change her thinking from, "I have HIV, I'm gonna die in a year," to, "Oh, it doesn't have to be that way." For the first five years after her diagnosis, she felt only "doomed and hopeless," which was a common feeling among those diagnosed early in the epidemic, when information was scarce, treatments not yet developed, and futures uncertain. She described the image she held of herself and her life at that time.

> ...I just kept sayin', "I have this illness, I must be a really miserable person. And...my husband left me and took my child, I must be miserable. Let me show them how miserable I am." Went on for a long time, which was really, you know, self-defeating. You know, just really destructive.

Susan reached a point, however, when her attitude became, "Oh well, I'm not dead yet. I better get my act together, and get on with my life," which marked a turning point in her life. She went through a drug rehabilitation program because, she said, "I knew I needed a total change of life." This change came not only through stopping drugs and alcohol, but also through a change in her self-concept.

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> And I just kind of decided one day, "You know what? I can't just keep walkin' around sayin', 'poor me I'm a victim.'" You know, "I didn't deserve this." Or you know, "Poor me, I have AIDS, help me," and had to just like kind of take my power back. And do it for me, and not for anybody else in the world. And what I did was I got on a bus, and I went up to Boston to a rehab, like a 21-day rehab or something. But I did it just for me. And when I was up there, I was so shaken, and so scared, that I was like sayin', "Oh, I really would love to take a tranquilizer just to calm down." And it's like, that's where the problem comes in. That's always gonna...numb me enough so that I'm never gonna grow. And I just shook, you know. And I just really went from like bein' a victim of this all, to like...take back your power, own your own power. And that was like incredibly helpful, you know.

Susan recalled this rehab experience as the point at which she stopped thinking of herself as a "victim" and reclaimed her "power" over her life. Perhaps this change in her story reflected the point at which she adopted a 12-step program/therapeutic discourse, but from there her life took a different turn. Her son became a more central part of her life, and a turning point came when she regained custody of him and they started a life together.

> I went to court, and I never thought I'd get him back. [My ex-husband] always said, "You'll never have your son again. Ever. ...You don't deserve him." And I felt like, "He's right. I'll never get him back. He's fine where he is." I thought,

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> "I'm too sick. [My ex-husband's] better than me." So, I never had a plan. That's why I moved here. I never thought I'd have my child again. You know it wasn't in the plan, at all. ...As neurotic and nervous as I am, it was just went so smooth. It was just the right thing to do.

From there, she focused on "healing" her own life and her son's life, and she made sure that each of them had supportive resources and environments in which to deal with AIDS. These turning point experiences marked a shift in her sense of agency, and she began to take control of situations that previously she had considered out of her control.

"I feel like I have so much to give at this point in my life..."

Some women had never planned for their futures, even before being aware of their HIV status. For these women, life before HIV was taken up with other issues -- raising children, taking care of partners, drug use, or simply day-to-day survival. Maria, Roberta, and Delores, for example, had each ended drug addictions shortly before they found out their HIV status. Illness didn't necessarily alter their sense of the future or their goals, as each noted that they had never had the opportunity or desire to develop goals prior to their illness. For them, seeing possibilities for the future and starting to achieve new goals emerged both from new drug-free lives and from HIV. Maria referred to her life without drugs as her "new life," and said, "Me, I started a new life. The bad thing about it was I started it being HIV." Her diagnosis, though, kept her from wanting to go back to the drug life, which has allowed her the space in which to contemplate new possibilities for

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herself and her life. To get her GED and attend college classes, to get a job, to move beyond what she was in the past. "I want my son to be proud of me, you know and one day say, 'At least my mother did something...she didn't just wait for checks.'" These goals, she said, are what "keep her going with this HIV thing."

Roberta was already in her 40's when she ended the decades of prostitution and heroin addiction that had consumed her life. When she found out that she was HIV-positive, she had just gone through drug treatment and was making the transition to life in the "normal" world of friends, family, work, and relationships. Like many long-term injection drug users, Roberta was so estranged from the mainstream world that in many ways this alone was an enormous and scary turning point for her (Singer, 1994). She spent the first five years after her diagnosis making this transition and concentrating on herself and her health for the first time in her life. She didn't think about her future because she kept expecting to get sick. When she remained healthy, Roberta began to consider her future and her potential, and she realized that what she wanted most was to go to college and to work. This was a challenge for Roberta not only because of her age or the potential for illness, but because she had never conceptualized these possibilities for herself or her future.

Roberta: I really want to go to work. ...I've been doing this recovery work in the field of HIV and AIDS. And you know I was like, God, I've got so much more to give than to go out and do presentations. I mean, I could be writing presentations, or doing curriculums, or training. ...I'm like, "You

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got so much to give," you know. But I'm so afraid. You know, I'm afraid to let go of my benefits.

Ann: Because you don't know if you'll get 'em back, or something else?

Roberta: Or I'm scared I'm gonna get sick, or it may have a lot to do with self-esteem. It may have a lot to do with getting success. You know, a whole bunch of stuff is wrapped up in that. But...that's gonna be my next goal, because it's like, I do real real good in school, very very good. I do real, real good [as a peer educator], so what would make me think I wouldn't do real, real good at work. So the other day I was thinkin,' "Well, what if you went and got a job, and you got off your benefits, and you got fired?" And, "Well, what do you do? You go get you another job," you know. "There's a solution for this, Roberta!"

Ann: But, it's scary.

Roberta: Yeah, it's scary because really and truly I haven't been in that space and it's a different thing because I'm clean, you know. I'm not, you know, I'm not hiding from my feelings, and...my insecurities and all of this. And it's like, "Oh no...I'm not big enough yet. ...I'm not old enough!" I was so scared, God. And I really didn't know how petrified I was too. And it doesn't have the whole entirety to do with HIV and AIDS. It does not, it just does not. ...At first it was. You know, I was like, "Oh, everybody's

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> gettin' sick, so I'll be next, then pretty soon I'll be dead so why go to work?"
>
> ...But I seriously want to [work], so I just have to get up the courage. I have the courage, really and truly. I have to take that step, and for me right now...that is like trying to step across the Atlantic Ocean. That's how I look at it, you know. ...I just don't know how I'm gonna do it. But if I got clean, I can do anything. If I got clean, I can do anything.

With the encouragement of a "mentor" at one of the AIDS organizations, Roberta had made some long-term goals for herself in terms of education and a career. When I interviewed her, she had already completed a cosmetology program and was taking alcohol counseling classes at a local college, and she was planning to pursue a college degree.

> I plan to get a degree. I said, "Okay, I'm gonna do this."...I wanna try to get into a Bachelor's program okay. For social work or whatever, you know. And then I even truly want to get my Master's. I really do. And for some reason, I don't know, for some reason I feel that. It's crazy, but I do. I'm workin' on tryin' to find some money, a scholarship, somebody, somewhere, anywhere, you know. ...That's my plan, you know. And you know somethin'? All my plans have materialized. ...But yeah, I make long-term goals. I don't know, I just feel that I have this time, and not only that, I feel like I have so much to give at this point in my life, right now. So, if I have this much to give with five years clean, can you imagine what

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I'll have at ten years clean? Because I always tell my therapist -- now this is just my theory, or my feelings -- but I said, "You know somethin', I feel if I hadn't used drugs, I may be able to be the President," you know. She smiles at me, she likes that, I think. I like it anyway, to think that...I have that.

Similarly, Delores had dreams of achieving something for herself, because her life had been focused on taking care of others and their problems. She wanted to work to improve her financial situation and she believed she had something to offer. She felt that her own experiences provided her with a lot of knowledge about the issues that affect HIV-positive women. But at the same time, she was afraid she would never have the practical support she needs to succeed.

Delores: There's times that I think about, you know, wanting to work, 'cause I feel like being on this SSI stuff is nearly as crippling as it sounds. ...Sometimes, I become isolated in the house because the thought up here (points to her head) of going places is there, but being financially that money's not there to get me there, it's like I just have to sit in the house and do what I can -- put on the TV, look at videos, listen to my music, or just take a walk. 'Cause...I could go but so far.

Ann: Have you worked before?

Delores: I don't have a very long history of work. I mean the longest I stood maybe was one year in one job, and then one year I did an internship at an agency

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that was dealing with people with the virus. And I loved it. And I have like this thing in the back of my head that I would like to work in the field of, you know, dealing with HIV. ...'Cause I would love to, if there was a chance that I could just get off all this social system money and probably work somewhere that I can feel comfortable and the people would understand that if there's a day that I cannot come in, it's because I'm dealing with what I'm dealing with. I would definitely go for it. But you know, I have like this little -- I don't know if you can call it like a little complex -- that I want like a college education, I wanna like, strengthen my education. But I have like this fear that I might not do so well. 'Cause I do have my GED but it's like, I wanna go to college to take up human services but it's like, the desire is there, but you know goin' back to school, and then dealing with home and then dealing with everything I'm dealing with, I think that it's gonna like overload me and I'm afraid that I might not do so well. So that's what's really like holding me back. 'Cause I know that sometimes the way I speak to people and...present myself at groups...I might come out a little harsh at times, but you know I'm for real. I tell them the truth. You know, I tell them how I feel. And I feel that sometimes I get through to these people, and I feel that I could be a good help if I have the proper education to back me up so that I can better myself. Not feel like a failure, you know. I want to do that, but...it's just I'm scared and I feel that I'm not ready for it. The desire is there, but I

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> don't know if the timing is right.

These issues were compounded by the fact that she had no one to help her care for her young child, and she wondered how she would be able to manage him and school by herself.

> That's how come, you know, when I think about the college stuff, I wonder if I'll ever have the freakin' energy to do it. You know because it's a beautiful thought, and I know that I would be real good at it, but it's like I'm stuck. ...So it's like, one day at a time. I'll do it. I just have to be patient.

Delores was aware of her potential and had the desire to create change in her life, but there were very real obstacles besides her illness. Like Roberta, her motivations, hopes, dreams, and goals were juxtaposed with the realities of her life, including the personal (e.g., potential illness; lack of self-esteem) and social and structural obstacles (e.g., lack of practical support for achieving goals; loss of established benefits if one takes a job, with no guarantees of getting them back in case of illness) to achieving them. Still, that these women had goals and saw potential for their futures implied that they did not let AIDS diminish what they hoped for in their lives. In some ways, AIDS shaped their desires.

Of course, physical health status is an important dimension of a person's sense of the future, and of the goals or plans that one can pursue. Most of the women who were pursuing goals of work and school, or planning to do so, were women who were

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relatively healthy. The women who had experienced illness were more cautious about envisioning and planning for a future. Nancy's narrative, for example, showed the struggle of the seriously ill to balance their hopes for the future with the realities of illness. Nancy spent many years not making long-term plans and avoiding thoughts about the future, but the more she believed (and experienced) that she had some control over the course of her illness, the more she began to allow herself those thoughts.

> Well...I guess I'm just like...used to not making, or trying not to think about things. But lately I've been, things have been comin' into my head and I laugh. Like thinking of [my daughter] goin' to college...of being here when she gets...the money that we put away for her. And, you know thinking in terms of me being here for certain things, that I wouldn't have, I would've been too afraid to think of before. ...You know like I wanna be here for the change of the century. That's something I've wanted since I was a little kid. ...I would really wanna like, be somewhere and like, believe that I was here when everything changed. That's like my main thing, to be here for the year 2000. Sounds nuts, but. You know like I think about that and I get all excited, and then I say, "Hmm." You know...you can't help it, like you feel that thing pulling you back and saying, "But remember? Remember you may not be here for this." And I say, "I better listen." And I try not to listen to that voice, you know. And I say, "Ah, screw you. I'm gonna do this," you know. And if I don't, I don't have power. Like, I don't wanna say I don't have power over it, 'cause I believe I do have a lot of power where my life is

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concerned, and the length of my life, and the way my illness goes. So I just keep sayin', "Just think about that, and keep goin'. And if somethin' else happens we'll deal with it." ...And you know, I have like short-term goals, long-term goals. You know like I wanna drive again, I wanna get like another job. I wanna, you know, volunteer -- doing things to help people like I was helped. You know, stuff like that.

Not all of the women planned for futures or even allowed themselves to consider a future, however. Joanie, although she was relatively healthy, felt that AIDS had dashed any possibility of a future or a better life for herself.

Joanie: I really don't have no thoughts about the future. I don't see a bright future. I have hope that they come up with something, that they can maintain it like diabetes, but I don't see a future. If I'd seen a future I'd go to college, do something with my life. Like one of my therapists used to tell me, "You should go, 'cause what if they find a cure tomorrow? Then you'll have your education." I don't see a future.

Ann: Has that changed? Before you knew that you had HIV, did you look forward to the future, did you make plans? Did you think, "I'll go to college?"

Joanie: Yeah, I always thought about goin' back to school, and doin' somethin'. At that point, I wasn't thinkin' about doin' anything, 'cause my life, I was

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> tired from takin' care of those kids. It's a real hard job. And I really didn't have the time, but in my mind I always thought of going back to school, you know and getting a good job, you know, not just stay on welfare all the time. But um, I did think of that, but now I don't think of that because in my mind, I know that I don't have a future. I may have five years if I'm lucky, 'cause my T cell [count] is low. But I don't see a bright future at all.
>
> ...I have no plans, at all. No plans. I just live to live for my kids, you know. To stay strong, and just hope that they get old enough that if I die they could take care of themselves, you know. That's all I wish, that I could live long enough for them to get bigger. ...That's all I really hope, 'cause you know nobody's gonna take care of them the way that I do.

Joanie's narrative could be interpreted as "nonacceptance" of her illness, or she as someone who has not come to terms with it. According to Corbin and Strauss (1987),

> Nonacceptance essentially means there is a radical biographical discontinuity with the past, and that the future and present will always be the same, or even worse. ...There is no future imagery of progress or of better times ahead to pull one through the rough periods. (p. 271-272)

In Joanie's case, I would suggest that her lack of envisioning a future is not the result of a discontinuity with her life in the past. According to Joanie, her life before HIV was "miserable," and consisted of taking care of her four children with few financial

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resources, and dealing with an abusive husband who was a drug addict for the entire 22 years they were married. She said, "My life never was happy with him. I was with him because I had nowhere to go. And I stood with him because of the kids. And it's not easy. He used to hit me." Before she knew that she was HIV-positive, though, she could retain the hope that life for her and her children would get better in the future. With HIV, that hope disappeared. Further, Joanie was not simply being pessimistic about her future; she had witnessed her husband's death from AIDS, and she felt that she was being realistic.

> This is my future now. ...[My boyfriend] talks about when we get old, and to me it's not a reality. You know, he says that we take care of ourselves, that we're not on methadone, like my kids' father, that we're not gonna die like he did, but I don't believe that. I don't believe that because he was on methadone, he died. I believe that the virus finally took over.

Individuals' understandings of "future" can be very different, especially because serious illness involves ever-shifting conceptions of time. A future orientation, though, reflects what Barnard (1995) refers to as "hope." He writes, "The ability to formulate and pursue wishes is also part of the hopeful person's creative responses to his or her situation" (p. 52). For some, looking toward the future and striving toward something makes the uncertainty of illness more manageable.

Finding Meaning in AIDS: Quest Narratives

Illness is not always represented as an interruption to a life. In many illness

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narratives, individuals make reference to a "new" self or life that emerges from the illness experience (Frank, 1993). In quest narratives, illness is often represented as an opportunity or impetus for personal and life changes. Individuals who tell quest stories often find meaning and purpose in their struggles with illness; some are transformed through the experience (Frank, 1995).

"AIDS isn't the best thing that happened to me. The way that I chose to have it is the miracle."

Emily's life story is probably the most dramatic example of a quest narrative. Although finding out that she was HIV-positive and the ensuing chaos left her suicidal, soon after she found very different meaning in being HIV-positive. Her story shifted from the social world shaping her response to being HIV-positive, to her seeing HIV as an opportunity for doing something positive with her life. This shift in the meaning of HIV began through the turning point experience of having lived through her suicide attempt, and meeting someone who accepted her unconditionally and encouraged her to find meaning in this circumstance. She noted this experience as the start of her "journey" with HIV; in essence, her quest.

Emily: When I woke up [in the hospital] there was this old nun, holding my hand, and she was praying. And I woke up, and I saw all these lights -- I thought I had died and gone to heaven. ...But she was so loving, she was so great. And she told me that no matter what, God loved me. No matter what. And

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I was like, confessing all this stuff, "I'm a lesbian, and blah blah blah." She's like, "It doesn't matter." So I befriended her, and I would go to like counseling sessions with her. Not really like counseling sessions, but visiting. But she loved me. She held me, she hugged me. And so, she kind of planted the seed that maybe there was a reason that this thing had happened to me. And that big things were in store. That I was gonna do amazing work. And for whatever damn reason I believed it. And then I got mad. I got mad. And when I got mad I started makin' things happen. I became an activist. I started screaming, I started confronting people. Literally. And my journey began, and next thing I know...I'm doing international AIDS work, and doing a lot of advocacy work for people with AIDS in [the town where I was living]. I just started reaching out.

...I was like the local AIDS girl, you know -- AIDS poster girl, or whatever. And I was good at it too because I had a passion. I didn't want anybody to go through what I had gone through. And I wanted people to realize that it wasn't about *me*. People were like making it this individual thing, that it's about "Emily with AIDS." It's like, "No, this is about a health issue. It's about something that's killing young people, you know, and people need to respond." And so I never made it about me, and I think that that's why people responded.

Ann: And did that help you deal with it?

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Emily: Well, I didn't realize that my initial reason for doing it was to help people. ...You know, "this is my purpose." I didn't realize that in the midst of all of this, that the very thing that I thought I was doin' for everyone else saved me. That the more I talked about it, the more, you know, empowered I got, and the more hope I had. And the more feeling of a purpose I had.

Emily's initial involvement in activism was a response to her anger about being positive and about the way she was treated by people, but it became an integral part of her adaptation for the first several years of being HIV-positive. She went from not being able to "process" HIV in her life to embracing it as her purpose; it became the most central aspect of her identity.

From this point, Emily's life story traced the changes that she has experienced through numerous turning point moments. Corbin and Strauss (1987) described the incorporation of illness into self and life as a fluctuating, recurring process, and Emily's story reflected this process. Through each new experience, her character, her sense of self, and the meaning of AIDS in her life evolved and shifted. For example, AIDS and activism was her quest in the first several years of living with HIV, and it was adaptive for her at a particular time. More recently, she had come to new realizations about the role of AIDS in her life and her identity.

> ...And now it's not just about AIDS, it's about me. I'm realizing all of those times I said, "It's not about me, it's about AIDS," that was a way for me to detach my feelings from...myself or my individuality. And that all my adult life I've lived

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> with HIV, and that I didn't want to embrace who I was as a person because of the grief and the anger that I feel about being infected would engulf me. And I wouldn't get anything done that way. You know, AIDS was my cause and my mission. [But] I wasn't living my life, my life was living me. The circumstances of my life are living me, instead of me living the circumstances of my life. And now that's kind of where I'm at. Tryin' to live my life as a person. ...you know, AIDS living with me instead of me living with AIDS.

In her story, Emily noted the difficulties in her life, but did not dwell on them. Instead, she chose to emphasize the achievements or gains acquired through each experience. Adversity is represented as opportunity for learning and growth, and as impetus for doing better. She talked about her quest -- finding meaning and purpose in her AIDS experience -- using language of agency and choice. For Emily, framing her illness as a quest was a choice that contributed to her personal, emotional, and spiritual growth.

> You know, AIDS isn't the best thing that happened to me. The way that I chose to have it is the miracle. That's the best thing. The best thing that's happened to me is that I have made a decision to be proactive in a positive way. In a way that feeds me emotionally, and spiritually. That's what's happened. I've just had the courage to be willing. Willing to let things touch me emotionally. It's hard. Willing to let people care about me. That's really hard. You know, willing to be honest and to let people know where I'm at, most of the time. I'm not as good as I'd like to be,

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> but I've got something to aspire to. ...I think that there is no doubt that suffering makes you grow. I mean, there just isn't. ...When a traumatic thing happens in your life, and you allow yourself to move through it and to try to see the good. There's gonna be good and bad. I can choose to look at the good or the bad. ...It's all about attitude and outlook. It really is about choice, and that's the hardest thing for me. I always want it to be something external, like, "I'm the victim and this happened to me, and it's not my fault." Um, it isn't about that. No, I am a human being, this is where I'm at. ...It makes me *so* angry. It *is* not fair. But what am I gonna do? I don't wanna be depressed about it. I don't wanna be angry my whole life. You know, I wanna build upon that. And that's as good as anyone can do. And you know, everybody has to do it their way. Nobody does it better or worse than me. Everybody does it their individual way.

Emily's life story mixed quest styles of manifesto and automythology. As an AIDS activist, parts of her story contained implicit demands for social action, but she also traced her self-conscious growth and transformation through how she lived with AIDS -- how she *chose* to live with AIDS.

"It's not like AIDS ruined my life. ...It kind of gave me a life..."

A common theme in quest narratives is that one credits their struggles for positive changes in life or self. Susan, for example, believed that HIV had been instrumental in helping her to change her life and her self-destructive behavior, and to experience

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personal growth. She stated what is often heard in quest narratives:

> I guess the HIV in a way helped me to hit a bottom. Otherwise I might not ever hit a bottom. ...So I'm glad in a way, 'cause I never would've got it. Never. I just would've continued in this really dysfunctional world. ...But, it's been such a process. Now it's like a whole different life.

Susan's quest has been to "heal" her life as much as possible, and her illness experience became an opportunity for her to do this. Her decision to stop using drugs was in many ways a starting point to achieving this quest. Another important aspect of her quest has been her decision to treat her illness with alternative medicine (e.g., herbs, vitamins, acupuncture). She felt that this approach had helped her to heal on "all levels," emotionally, physically, and spiritually. These decisions, along with self-work in therapy and support groups, have culminated in a sense of agency and growth that she did not have previously.

> ...I mean I kind of was doin' [work on myself] all along, but I was so sick, that I needed to go through all those phases. ...I mean, I guess I'm not there anymore, at least. You know, it's very different. It's more very conscious, and very much a choice, of what I do each day, you know. I didn't think I had any choices in the past. And to stand up to people, or go against what the doctor said is really terrifying, you know -- I'm disobeying an authority. So it's kind of like as you grow, you're able to just really take care of yourself. And just, set boundaries.

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And...I never had any of those kind of things. And they were all really necessary to get through a situation, especially a difficult situation like this, that's just an ongoing illness, that affects us in a lot of ways. ...You know, it's a very personal disease, too, AIDS is. [I had to respect] myself enough to know my decisions were okay even if everyone else didn't agree with them. I didn't have to please my family. My friends even. Even my friends I respected. It's like, I needed to respect myself and my decisions. And it's been hard, because I've gone against the norm a lot. And done well with that. And people had their doubts, like my therapist at points, but then they always see that I was on the right path in the end, so far. But it's hard to stay there, and to know that my choices are important, and they're right for me.

Although Susan's life had changed considerably since she was first diagnosed, and she believed that her HIV experience had made her and her son more emotionally healthy, her life had not necessarily become easier. There were still aspects of chaos in her story, moments where her life circumstances were beyond her control, and where despair crept back into her story.

Susan: [Drugs and alcohol are] not a main concern of mine. It's more living than anything, you know. And even dying seems easy to me. It's living that's difficult. I never learned how. I never had a clue. It's not like AIDS ruined my life. I didn't have a life. It kind of gave me a life almost, in a way. But I feel so limited, you know. I have no energy at all."

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Ann: You feel limited by your physical condition?

Susan: Yeah. Because I never have enough energy. And I guess just bein' a single parent is hard enough. And to be poor, and then to have a health problem. So, the combination of the three, you know, it's really hard.

Ann: What do you do for support? How do you get through every day?

Susan: Lately, it's been really hard. As you can see, this apartment has no sunshine, and I get depressed every winter. And that's hard. I'm fighting it now. I've been crying every morning. There's a church by my son's school...and I go in the church every morning and I sit there and I cry. I feel like I just would rather...sometimes, you know, not even be a human being. It's just, it's too hard to live my life. If I could just 'be' and didn't have to function, I'd be wonderful. But, it's really hard and I can't feel that way. You know, I can't give that message to my son, 'cause I'm all he has. We don't have family support at all. None. We don't have financial support. ...You know, I've learned to try to get support elsewhere, which has been hard. ...You know and it's not an option for me to be sick. I have AIDS, but it's not an option for me to be in my bed.

Ann: You have to take your kid to school everyday.

Susan: Yeah. And back. And feed him, and be there for him. And be there

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mentally for him, which is really hard sometimes. ...If I didn't have a child, I think I would have given up years ago. I think he's what keeps me goin', absolutely. It's like, I'm tired of this planet. I've had enough. I mean, I lived like a million lives in those insane drug years. It's like, I was gone, you know? And it's like, I am so tired sometimes. I'm just so tired. It's hard. And it's like, I don't see a break, you know?

...Sometimes I don't know how I could go through another day. It's so hard. And a lot of it is depression, because there's such real things going on. And it's always been real-life things that have been hard, and you know when I'm in crisis I seem to do much better. When I'm not in crisis, it's when it gets more difficult. Everyday stuff, you know.

Ann: What do you mean, you do better in crisis?

Susan: I always seem to just pull through and be really strong. You know like when I was going through all of those changes with my son and getting custody, and years before that I was always in a crisis, and it always was easier than day-to-day living. Yeah, I well enough, but it's like how do I go on like this? I'm totally poor, it's totally hard to get through a month. I don't know how to make that better. You know, it's like a lot of sacrifices ...And you know even now that I've worked through for so many years the drug issues, the abuse, I mean...it seems like so many years ago. You'd think the reward would be that my life would be settled and okay now.

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> That I could just deal with the HIV issue. But it's like it doesn't ever happen, you know?

Frank (1995) recognizes that one of the risks of quest stories, in particular the "heroic" stories of self-transformation through trauma or illness (automythology), is that "they can present the...process as too clean and the transformation as too complete, and they can implicitly deprecate those who fail to rise out of their own ashes" (p. 135). Susan's narrative reminds us that adaptation is never complete, and that the presence of quest does not negate the presence of chaos or struggle; we must listen for and hear both in any story. To understand how women create lives with HIV/AIDS, we must also remain aware of *all* of the dimensions of their lives. For Susan, like many other women living with AIDS, her day-to-day problems extend far beyond her illness; to focus her attention solely on her illness would be a luxury. As a poor, single mother, she struggles continually to provide her son with stable and supportive environments, and to protect his well-being. At the same, he is a central part of what "keeps her going."

Enacted Quest Stories

For both Susan and Emily, their illness is cast as a personal and spiritual journey; it is transformative. Most people do not find the same meaning in their illness, but many are able to find some purpose in their illness or make less dramatic changes in their lives (Siegel & Scrimshaw, 2000). In the women's lives and stories are several instances of what Frank (1995) refers to as "enacted" quest stories, or lived examples of personal

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changes that come out of illness. Gloria's story is one example of an enacted quest story. Although she described being "devastated" by her diagnosis, soon after she made the decision that "HIV was not gonna take my life totally over." In a sense, Gloria's quest was to maintain her self-concept and to achieve her goals even though she was HIV-positive, but at the same time she derived meaning from the experience. She saw how being HIV-positive could be used as an asset for herself and for others. She described AIDS as "a very big part of my life," as she and many in her circle of family and friends were also living with HIV/AIDS. But her self-concept was very much focused on other aspects of her life, such as her roles as mother, caretaker, student, and worker.

She made sense of having AIDS by believing that it was her purpose on this earth. She said, "I know [God] has put me here for a purpose, you know. ...That's why...I have this disease. Before I was thinking, 'What is my purpose here on this earth?' And now I think that's what it is." She said that all of her life struggles, including AIDS, had made her stronger, and that having AIDS had allowed her "to really know what these people are goin' through with this disease." She planned to use this understanding and her experience as a women to create an AIDS organization for women that would address their most essential needs.

> Well, you know, my thing is I would like to start an organization for women. ...You know there's still a lot of women out there that have this disease and they don't have no medical coverage, you know. And a lot of them are dying out right there in the streets. You know. We need to pay a little bit more attention to that,

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> especially women's needs. You know, everybody talks about "women this" and "women that," but nobody's really paying attention to what they really need out there. Because we're considered second-class citizens compared to men, you know. And it shouldn't be like that.

At age 49, Gloria was completing her goal of a bachelor's degree and making plans to pursue graduate school in social work so that her organization might become a reality.

Enacted quests can take the form of social actions, or personal life changes. As AIDS activists and peer educators, Emily, Joanie, and Roberta were involved in activities that brought their individual suffering into a social forum for the purpose of countering the silence and social isolation of HIV-positive women as a group, and to educate people about HIV. At the same time, these actions held some sort of personal meaning for the women or helped them to live with AIDS. Roberta remembered how peer educators had helped her when she was considering getting tested, and she became a peer educator in the hopes that someone else would benefit from her story. Her involvement also helped her get through the initial years after her diagnosis, and provided incentive to further her education.

After many years of isolation and silence about her HIV status, Joanie started giving public speeches because she wanted to prevent other women from being ignorant about HIV risks and safe sex.

Joanie: I became a woman's peer educator, and then I started to open up. Because I was so scared I wouldn't tell nobody, and then I started makin' speeches,

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you know and I started telling people. Because at first I used to do outreach -- I used to go out, you know get- distribute condoms, and people used to tell me, "I don't need that, I'm married." And it used to make me furious, 'cause here I was 22 years with this man, and I had it. I wasn't sleepin' around, people on my block that was sleepin' around didn't have it. And me -- innocent me -- I had it. So that's when I said, "I have to do somethin'. I have to let these people know just 'cause you're married, you're not safe." So I started going to schools and makin' speeches.

Ann: And...what did it mean to be helping other [people]?

Joanie: To me, it meant that maybe I could save one life, you know. Even if I saved one life, out of all my speeches, you know to make people understand, that just 'cause you're married don't mean nothing, 'cause your husband ain't gonna come home and tell you [he slept with someone else], you know. And that's what it mattered to me, because I feel maybe this wouldn't have happened to me if I was educated, if I knew how to protect myself, you know. If I wasn't so naive, so stupid, so ignorant -- you know, this wouldn't have happened. And if I could help someone else realize, you know. At least I feel me having this, at least maybe I could help one person.

In the process of this work, Joanie found it easier to tell people about HIV, to care less

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about hiding it, and to reach out to other HIV-positive people for support. Despite these positive changes that came out of this "enacted quest," Joanie did not necessarily define it as personally meaningful. She said that she didn't find meaning or derive purpose from her HIV experience, and that she hadn't been changed in any fundamental way because of it. She told her story in hopes of protecting others from her fate. As such, she did not tell a quest narrative, but she enacted quest in her sense of responsibility to pass on to others what she had taken from the experience (Frank, 1995).

Adaptation and Quest Narratives

What does it mean to tell a quest narrative, or to find purpose in the illness experience? Often people construct some sort of meaning from tragic events or serious illness because it allows them to maintain a sense of control over their lives (Kleinman, 1988; Schwartzberg, 1993,1994; Taylor, 1983). Indeed, the struggle for meaning is one of the characteristics of a "survivor," or "one who has encountered death, literally or figuratively -- one who has witnessed and been touched by it, while remaining alive" (Lifton, 1993, p. 82).

Does framing the experience or the story in terms of a meaningful quest make illness easier to live with? For some individuals, it does. As Emily said, she *chose* to frame her illness in this way, and although it has been difficult to do that, it has been adaptive and has allowed her to grow on many levels. But she makes an important point about how people live with AIDS: "Everybody has to do it their way. Nobody does it better or worse than me." How we live our lives, the meanings we give to experiences,

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and the stories we tell are shaped by numerous contexts. Emily and Susan's quest stories are representative of one type of cultural story that Crossley (1999) describes as "conversion/growth," which are stories influenced by self-help, therapeutic and 12-step philosophies. These women's stories and their language (e.g., understanding of life as a journey; use of a "healing" discourse that incorporates themes of survival, empowerment, choice, and growth; focus on self-understanding and self-evolution) are undoubtedly influenced by therapeutic environments and philosophies. Their reliance on such culturally conventional rhetoric of self-change (Frank, 1993), however, was accompanied by real personal and life changes. Also, most of the women in this study were in therapy or members of support groups (AIDS and/or 12-step), but they did not tell this same type of story.

Although some of the women's narratives contained elements of quest, most lay somewhere between chaos and quest. These women have managed to make lives with HIV/AIDS, they see something of a future and are not waiting around to die, but neither do they believe that anything useful or meaningful will emerge from their suffering. They carry on with their lives and try to live with AIDS the best they can. Judy is someone who felt this way about her illness.

> I don't [make sense of HIV]. I don't. It's one of those unfair things that I can't explain. I used to say, "Why me? What did I do wrong?" And then it used to be where I'd have to explain, "I didn't get it from sex or drugs," you know. "It's not my fault, I don't deserve this," you know. And then it was like, "It doesn't

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> matter." ...But it's like it doesn't matter how you get it, it's there. It's unfair. It's like people with cancer except people with cancer can go around and tell everybody. Um, it's something you live with. You don't make sense of it. And I'm a person who really needs to make sense out of everything. Everything has to be very logical for me. ...I don't do it the religious or spiritual way. It's there, and I have to deal with it, you know. Hopefully, things will get better. They have gotten better. You know, which makes it a lot easier.

Kleinman (1988) writes, "Meaning is inescapable: that is to say, illness always has meaning" (p. 144). Although most women did not derive the same meaning from their HIV experience as Emily, Susan, or Gloria, several women spoke about HIV as an opportunity to make life changes at a more concrete level, in particular changes in their lifestyles (Siegel & Scrimshaw, 2000). Such changes were considered turning points, and were adaptive in that they gave women a sense of control over their lives and the course of their illness. For Maria, HIV (and her intense fear of progressing to AIDS) meant that she would stay off of drugs and try to live a healthier lifestyle, and she was grateful that God gave her the chance to make these changes while she was still healthy.

> That's why I'm scared to go back out in the street, no matter how mad I get about things. [HIV] has changed my life. ...Like I used to every time I would argue with my husband, but what kept me back was the HIV. ...I say to myself, "If I keep doing what I'm doing -- I stay home, take care of my kids, cook, do what I gotta do to deal with the HIV -- I think I'll be better and I'll live a little longer if I do

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these things. But if I go and do the wrong thing, I feel like God ain't gonna give me that chance. He gave me a chance now, and I gotta stick with this." I feel lucky. That's how I feel. I could've come out of this with AIDS, but I didn't. And I feel like I was lucky. I stopped right on time. ...The way I live my lifestyle, I felt like she should've been telling me I have AIDS -- full blown AIDS. I mean right there, I paused that life, definitely. I have to, you know. I'm doing very good, and I feel like this is a chance maybe God gave me, because I'm Catholic and I believe in God. I may not go to church, but I pray a lot, and I believe this is just luck. I got HIV, but I don't have AIDS. ...God told me, "When you go back out there, then you mess it up. Don't go back out there. ...You were lucky. You got this, and you know, it ain't that bad. If you go back out there, it's gonna get worse." That's the way I put it in my mind.

Roberta characterized HIV as a "whole turning point for me" in terms of her lifestyle and attention to her health.

Not only to get clean, now I'm tested HIV-positive. So since I wasn't gonna take the AZT, I took this holistic approach, you know. Not to treat the disease, but treat the whole person. So I stopped smoking cigarettes, I stopped eating red meat...I just decided I'm gonna do this holistic thing. ...I felt like it really helped me a whole lot. ...All this happened after I tested. Not immediately, but...that's the approach I felt like was best for me. So, I've kept this attitude, and I've did the best that I could with it, you know.

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Although Roberta appreciated the changes she had made in her life because of HIV, at the same time she struggled to accept it in her life.

> It's hard to accept. Just hard to like say, "Oh I accept the virus, and that's it. I got it, and I'm gonna [accept it]. No. You know, and...sometimes I get so mad when I go to support groups and people say, "Oh, the virus keeps me clean." I was like, "Well gee whiz, what if they made a cure for it? That means you'll go out and get high?" you know. "The virus keeps me clean, and I am so grateful to have it." You know and I sit there, and I say, "Oh my God, they're sick." But that's how they feel. And of course, I wanna say, "Well, you're crazy," you know. But no, I am truly -- I'm not grateful that I have the virus, but I'm grateful for the changes that I've made in my life. But if anybody wanted it, and I had a way to give it to 'em, I would gladly give it away.

Changing Adaptations

Consistent with other research, the personal meanings that women constructed from HIV/AIDS varied widely -- from the search for and inability to find meaning, to the recognition of AIDS as one's purpose in life (Adam & Sears, 1996; Lather & Smithies, 1997; Zappulla, 1997). What is particularly interesting is how meanings discussed in this chapter represented a shift from those in the diagnosis stories. In diagnosis stories, HIV meant immediate death, lack of a future, fear, stigma and isolation; essentially, those meanings reflected the social meanings of AIDS. For most women, these were replaced

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by more personal meanings as they came to terms with HIV/AIDS as part of their selves and their lives. As Patti Lather (Lather & Smithies, 1997) writes in her research on women living with AIDS,

> People make sense of their lives via story lines or narratives that are available at particular cultural moments. No life fits neatly into any one "plot" line and narratives are multiple, contradictory, changing, and differently available, depending on the social forces that shape our lives. Some cultural stories are easily available to us, some not. Some help us tell our lives well; some break down in the face of the complications of our lives and times. (p. 125)

In the diagnosis stories, it seemed that women's responses were shaped by what they felt was happening *to* them. There was little language about options for how to respond, or how to live with this information. But this changed throughout the stories, as women came to terms with HIV/AIDS and found ways to make it part of their lives. Although creating a life with illness is indeed an individual experience, there were common themes across women's stories in terms of the adaptations and dimensions most central to this process: disclosing HIV status and finding supportive people and environments; regaining hope and looking toward the future; and finding new meaning in self or life through illness. Each of these central aspects of adaptation was more or less important to each women depending on her personal circumstances, and there were other adaptations and circumstances important to individual women that I did not discuss in the interest of space. The themes discussed in this chapter seemed to be the most important in

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that each of the women's stories touched on them in one way or another. Further, although I've examined the different adaptations and dimensions involved in creating lives under separate headings, they are very much intertwined. In Judy's story, for instance, it wasn't until she disclosed her illness and felt support from her family that she began to see and make plans for her future.

As the stories in this chapter suggest, women incorporate HIV/AIDS in their lives in different ways, and it is a dynamic, fluctuating process (Corbin & Strauss, 1987). At certain times, HIV can be very much a part of one's life, and at other times less so (Squire, 1999). For example, both Emily and Susan described going through a period where their lives and self-concepts revolved around AIDS. As Susan said, "...I don't know how to be normal again. It's like I almost was HIV for a long time, and then after that I had to go through a thing where you know, 'I am not my illness.'" Emily noted a similar process of needing to embrace that identity in the beginning, but at some point acknowledging that she was "more than her illness." Most women "accepted" AIDS as part of themselves and their lives, but tried not to let it be the defining feature. Women created lives not just around HIV, but around other dimensions as well. As such, adaptations were constantly changing as new issues arose both in lives and in illness. Roberta's narrative emphasized that her adaptation to life with HIV and life without drugs is an ongoing process that requires constant work and support. She said, "I've been going for five years, and I should have this under control, but feelin's never go away. You just learn how to deal with 'em better."

Finally, the narratives discussed in this chapter focused on the time after diagnosis

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when most women were still relatively healthy. The latent period that many experience between HIV infection and the experience of physical illness is an important dimension of the stories and the adaptations discussed in this chapter, and is somewhat unique in terms of adapting to illness. Because individuals can remain symptom-free for many years, the incorporation of HIV into one's life and self-concept is a psychological more than physical process when a person is still healthy. The physical disruption of illness is not yet tangible. In the next chapter, I move to how women's lives and stories change further when they experience the physical manifestations of AIDS.

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Getting Sick: Illness and Restitution in Women's Stories

During the "asymptomatic" years or during periods of relative health, the centrality of HIV in individuals' lives and self-concepts is variable. When HIV progresses to physical illness and decline, however, HIV/AIDS assumes a more prominent presence in individuals' lives and stories. By chance, half of the women in the study had experienced rather serious, AIDS-related health problems (Kay, Nancy, Susan, Emily, Angela, Judy), and the other half had remained asymptomatic or had experienced relatively minor health conditions (Barbara, Joanie, Delores, Maria, Roberta, Gloria). As such, how they talked about illness was very different. For those women who had not yet experienced illness, the fear of becoming ill was a prominent theme in their stories. Illness was an anticipated or expected turning point in their lives, and the uncertainty of when this turning point would come was a source of great anxiety. Most of these women were vigilant for any signs that their health was worsening, and any change in physical status instilled a fear that this could be "the beginning of the end." In living with such uncertainty, there is always the underlying potential for chaos, and it requires constant management. Women controlled their fears of becoming ill in different ways, including being active in their medical care, living healthy lifestyles, trying to continue with a "normal" life, and some level of distancing from AIDS.

At times, the unknown was more difficult to deal with than actual illness, and many voiced the struggle of trying to find some balance in what amounts to an emotional roller coaster. Roberta said,

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> If the diseases don't kill you, seem like just emotionally you can't handle it, you know. And thank God I haven't really been sick, but emotionally I've had it, you know. ...You really have to sometimes stay right in the minute, not go anywhere past that. You just can't, or else you'll really drain yourself out, you know, wondering, and hoping. And then sometimes you say, "Well, if it's happened to everyone else," you know, "it just may happen to me." And, oh mercy, just one thing after another sometimes. And then sometimes I go through it and [say], "I'm all right now. Keep going, keep going, keep going." ...Then sometimes I go all the way to the other extreme. " I'm gonna be the person...that has HIV but doesn't develop AIDS...that doesn't really get sick," so okay here I go. Then I'll go all the way to that extreme. All the way over here, all the way over there. It's sometimes, once in awhile, I'll find a balance, you know.

At one point, Emily told me that she was tired of this "anticipatory grief," and sometimes she "wished that I'd get whatever it is that's going to kill me and get it over with." Eventually, there comes a time in the HIV/AIDS experience where physical illness does become a reality. Although most women went to great lengths to protect their health, several had experienced physical decline as a result of their failing immune systems or from their AIDS-related medications. The progression from asymptomatic HIV infection to illness was a significant turning point in their lives, and that transition brought about new challenges and required new adaptations. Below, I present Nancy's illness story in some depth because it illustrates many of the issues that individuals with AIDS face as

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they begin to lose control of their health.

"That's it, I've just fallen off that cliff.": The Progression to Illness as a Turning Point

The first major turning points in Nancy's story were her experiences of illness. Her diagnosis with HIV was certainly a turning point in her life, but she remained healthy for many years and was able to continue with her life much as before her diagnosis. She also felt very supported and self-sufficient up to the time that she developed her first opportunistic infection, pneumocystis carinii pneumonia (PCP), one of the most common AIDS-related opportunistic infections. Although PCP is a leading cause of death in people with AIDS, Nancy considered it minor episode because it caused little disruption to her life. Further, she attributed the illness to a lapse in taking her preventive medication. She said, "I blame myself for that. 'Cause I say, 'Dammit, if I had taken that treatment, it would have kept me from [getting sick].'" In framing the illness in this way, she has constructed it as something within her control.

> And even now I'm tryin' to like rationalize [the pneumonia] away -- it was because I didn't do my pentamidine treatments, I wasn't really compliant, and I think I missed three months in a row. And all of a sudden then I had pneumonia. But I only got it at the top, the apices. So they said, "Oh, it's not bad." It was really very mild.

At the time, the illness was significant turning point for her because she thought this was the beginning of her decline. But now she minimizes it by comparing her PCP experience

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to others' and considering herself fortunate.

> So, I remember we used to ask the doctor...all sorts of questions, and he said, "It's hard to tell, sometimes people will just go along and then all of a sudden it's like they just fall off the edge of a cliff." ...And all those things always like stuck out, like I kept them like in the forefront of my mind. And when I got the pneumonia, I said, "That's it, I've just fallen off that cliff." But I say, "Well, it wasn't that bad, the pneumonia." And I didn't even have a lot of the symptoms that people have. So I said...okay, I'll say I had an opportunistic infection, but it wasn't nearly as bad as I've seen in other people so I was very fortunate.

More recently, Nancy had become seriously disabled from the side effects of one of her AIDS medications and she was still recovering when we met. In this illness story, she described the common experience of questioning whether her symptoms were "normal" or HIV-related, the progression of her physical decline, and her slow movement toward recovery.

> There was like three years when I was taking [no medications], and I said, "I'm getting a little nervous, you know I'm scared. I'm doin' okay, is there anything else I could take," you know? So he gave me this d4T, and I was on it for a year, and then this happened. I just started to feel...like my legs would bother me, but I was at my job, up and down, running around, and my personal schedule with my daughter and everything, I was like going from like 6 in the morning until 10, 11

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at night, being you know two parents for her, and my mother had been sick -- and there's always something. So it's just like my legs would ache, and I said, "Oh, I'm doin' too much, I have to rest. I'm really pushing myself." And then my legs started to ache, I mean at night, and I felt that every night. I came home, I would just be finding myself coming in here and lying down. And I started thinking, I saw the pattern, I said, "Oh God, what's happening now?" ...And then it just got like, every day it got a little bit worse, and then I finally I said to them at work, "I'm gonna have to go on disability. I went to the doctor, they did all the tests, yes it's neuropathy." But I was still able to ambulate. And then finally, after the tests were done to verify the neuropathy, he said, "Well, you're gonna have to go in the hospital for like a week. We're gonna...try and reverse it. ...So I said, "All right." I figured this is gonna be great. It was October, so I'll take off like six weeks, maybe two months, do the holiday thing without being crazy. I was looking forward to it. Went into the hospital...stayed for a week, came home, and within three weeks I could not walk. I couldn't get up without someone picking me up, practically. I lost 35 pounds in about three weeks. And I could not walk. And then about ten days later...the same thing happened [in my arms and hands]. ...It was just like, like a spasm, like a continual spasm. And my legs really hurt, like everything was really sensitive. I had a commode in here, that if I had to go to the bathroom, I had to call one of the aides, they'd come in. ...I couldn't even get there, they had to put me on it. Put me back into bed. And..I had physical therapy three times a week. ...I mean I had to do exercises, I used to walk around the bed

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> sideways, and I had the walker, and I'd walk. And just for me to get around the bed like three times, that was it, I was dead for the day. ...And by the end of March, I was walking around with a walker by myself. And then all of a sudden, things just started coming back, a little bit at a time. So now, I can walk around -- and this has only been like in the last two months. I can walk around, I can go up and down stairs. I've been doing much much better. Because now we're into the protease inhibitors. And they really help. I mean, I've made a marked improvement.

There are several components to Nancy's adaptation to this turning point of disability. First, Nancy believed that her daughter and the support of family and friends had a significant influence on her positive attitude and her recovery.

> When I got really sick, you know, [my daughter] used to just look and she'd say, "Are you ever gonna get better?" And I said, "Yeah. I am." I said, "I believe I am." I said, "But you know, even though it seems that I will...sometimes things don't happen like that." I said, "But, I think it's gonna be okay." And I think a lot of it has to do with her. Having that drive, you know for someone else. It's easier to do something for someone else than for yourself. And when I used to be with the walker, and somebody with me, I'd be walking over there and...she said, "Can you let go of the walker?" Now this is how bad it was, I said, "No, I can't." I was afraid to take one hand off, and then just because she was asking me, I took my hands off. I was walking, like just trying things, and if I fell, I fell. So, her starting

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> to ask me to do things, started I think a process of some kind, you know, a different attitude for me. And I've been [walking] ever since then. So it's a lot of different things that make that kind of stuff happen. There's a lot of different parts and pieces to it. But I think I've been very lucky that my attitude has been okay, you know, and the support of family and friends I think is most important.

When Nancy was most disabled and no longer able to work, it was still very important for her to keep a routine because it gave her a sense of control over her life. She equated lying in bed with giving up. Any setback was upsetting to her because it threw off her schedule and made her feel more vulnerable.

> Every morning as long as I've been home here, I get up at 6 o'clock, wake my daughter up, go take a shower, get dressed, put my makeup on, make the bed, and by the time she goes to school, I'm like ready to go. Not that I ever went anywhere, or did anything, but I just felt that that was very important, for me, that I keep some kind of a schedule, and I don't just lay in bed. ...And then it means like giving in, you know like you don't get up, or you get up and you don't get dressed. I could never do that. That would've been me no matter what. But I think that was a very important part. ...I was having like reactions to one of the protease inhibitors that I cannot take -- I was so sick that I had to lay in bed for a day, and that really upset me. Not as far as like I was thinking I was getting sicker, but it threw me off my schedule. And it kind of makes me more vulnerable. I know I couldn't have done anything else, and the back of my head was, "You're staying

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> in bed all day. You're sleeping all day. You should be up."

Although at times she contemplates resuming her "normal life" of work, her illness has forced her to question the realities of managing work, single parenthood, and illness.

> Like sometimes I'll be thinking of all these things -- working and doing that -- and all of a sudden, like I'll feel sick. And I say, "Oh wait a minute, wait a minute. I forgot about that." You know like I actually forget, and then I'll start feeling really sick and I'll say, "What am I, crazy? What are you doing? Why are you rushing back?" And I guess it's because I wanna rush back to be where I was before, so that I don't have to think about where I am. So...I'll just...see how it goes. That's all I can do. And that's very hard for me -- waiting to see -- 'cause I'm like just sittin' here. And like a lot of days, like this week, I really realize I couldn't have been anywhere else.

For Nancy, the loss of her physical health has been the greatest adjustment she's had to make in her HIV experience.

> Now, the difference between the beginning times and now is like actually knowing what it's like to really feel sick. You know, and to be physically unable to do things, like drive my car, go to the store, go to a movie, just go anywhere. Just go outside and walk around the block, or do anything. It's very upsetting when you know like you're in your forties and your lifestyle is that of your parents, you know, in their seventies. And a lot of times I get, you know, "It's not

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> fair...Why me? Why'd this happen?" Who knows, but whatever it was before [I became sick], it's the same now only much more intensified, that's all. You know, when I think about it, it's like, God, I'm so tired of thinkin' about it. Talkin' about it.

Nancy's story illustrated many of the issues that individuals face when they become physically vulnerable to AIDS, and the losses and life interruptions of illness become real. For the first 10 years of being HIV-positive, Nancy led a mostly conventional life where physical illness and disability were not factors in her daily life. When people become seriously ill, they are forced to reorganize their daily lives and reconstruct their self-concepts (Charmaz, 1987, 1995). Her narrative suggested that as she was recovering from this disabling episode, she was still coming to terms with the real physical limitations of picking up her life where she left off, and working to construct a self-concept that included illness and disability.

Illness not only poses physical and social limitations and losses, it raises new issues of stigma as the symbols of AIDS become apparent to others (Alonzo & Reynolds, 1995; Goffman, 1963). For Kay, becoming seriously ill was a turning point because it forced her to come to terms with her feelings of stigma and face disclosure among her family and friends. She had experienced two serious illnesses that required hospitalization. With the first illness in 1994, she developed PCP and stayed in the hospital for almost a month. At the time she had been living with an abusive boyfriend, and she had tried to hide her HIV status from him. She thought this secrecy may have

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contributed to this illness. She said, "So, all of this holdin' back I guess contributed...to me getting worse and worse and worse. Not telling, not saying anything." It's this first hospitalization, which constituted an AIDS diagnosis, that she considered to be the beginning of her illness. That, she said, is when "everything started caving in." One of the most important changes that came out of Kay's illness was that she could no longer hide her HIV status, something she had been doing since her diagnosis. Kay was the only woman in the study who was never able to disclose her HIV status (except when absolutely necessary), or to overcome the sense of stigma she felt. As such, issues of stigma and disclosure were recurring themes in her story and in our conversations. She had imagined that when she got really sick, she would simply go to the hospital and die alone so that she would not have to tell anyone. Kay was so afraid of anyone finding out that during her most recent hospitalization, she stayed there alone for three days before she told anyone. On the fourth day, Kay finally called her brother.

> I said, "I'm in the hospital." Like, that was a shock. I should have just said, "I'm ill. I'm sick." So I'm kind of glad that I did say it like that, because I was kind of scared. I just felt awful. I thought I was gonna die.

Her brother then notified family and friends, who called and came to visit. This hospitalization was a turning point in terms of disclosure because she realized that her family and friends were aware of her HIV status, despite her never having told them. One of her friends brought up the subject when she was in the hospital.

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> "Yeah, your brother told me that you have full-blown AIDS." ...So, I was wonderin' at that moment, for one second, "Who told my brother?" I didn't. Did the nurse, or the doctor, or the social worker? So I was a little angry, but I wasn't really angry because it's obvious. I'm sitting there in the hospital room, you know. My brother had been to that same hospital to see me, two years back. I believe he put two and two together, you know.

Having her HIV status out in the open was both upsetting and a relief to Kay. Although she didn't explicitly tell people, she felt, "[It] was a load off of me. It was a load off of me that I felt like I had to keep holding it in." She believed that perhaps her illness had happened for this reason.

> Yeah, maybe that episode was meant. Maybe it was meant to come up. Maybe it was meant for me to get the pneumonia, and maybe I was cryin' out -- not literally, but when I did get in, I was treated. It's out in the open, per se. ...They kind of know that I'm ill. And it's kind of out. I don't mind that someone might have said it. If they did it, it wasn't maliciously.

As a result of her fears of disclosure, Kay had a difficult time accepting support from anyone. When she was hospitalized, she was happy to see that so many people cared about her, but at the same time she found it difficult to accept support. She said, "I was proud when my brother came. I had a whole hospital, but I felt...the walls started comin' back up. I couldn't accept it. Like I wanted to do it all on my own."

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"Damn, this is taking control of my whole life": Adapting to the Losses of Illness

The progression to illness brings up new issues of loss, and turning point stories of illness often weave together numerous themes of loss, including loss of control and predictability, loss of health and physical appearance, loss of social roles, and loss of a sense of the future. Kay, for instance, was leading a relatively normal life the first years after testing HIV-positive, but with illness began the collapse of her everyday existence. Illness was a turning point in terms of her family becoming aware her illness, but another turning point came when she took a leave of absence from her job, and eventually had to resign. Her failing health, single motherhood, and the possibility of co-workers finding out about her HIV status led her to stop working. Kay said that testing positive didn't change her life as much as stopping work, because that was the point at which she realized her life would be forever different. With the HIV diagnosis, she could still maintain most of her normal life activities, but stopping work meant the loss of many things, primarily social interaction and a sense of control over her life. The isolation she spoke about in the following passage was not due to stigma or self-isolation, but the loneliness and isolation that come from the loss of one's health and the daily activities that provide interactions with others.

Kay: I went through one drastic change, like maybe six months ago...when I left my employer. Not a depression or low self-esteem, just adjusting. Just, so that was tellin' me that my life was gonna be different from now on. ...You know, not even when I first hear about the test, that wasn't nothing.

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Ann: It was stopping working?

Kay: Yeah, and then I felt like I lost like, my friends, and my continuity in my life course, some of my activities. So now it's startin' to affect me, the changes are. I feel more so isolated and lonely, in all aspects -- all aspects.

Whereas HIV may not have been a great part of her life initially, once she became ill and left her job she realized, "Damn, this is taking control of my whole life, on all aspects," and that was her primary concern when I first met her. Although she had dealt with her HIV secretly and alone up to that time, she eventually conceded to seeing a psychologist at her clinic when she felt she was losing control of her life.

> So, now I just go see him because of my...disease condition, and because now I'm depressed about...I wish I could be livin' in Queens, where I used to live -- I don't like livin' here, but...we manage. And dealin' with [public assistance], and me longin' for my job back, and...I have Social Security now, so I feel kind of low...like I'm just gonna stay here and die.

The loss of work was one of the most significant turning point experiences in women's illness stories, because work is so connected to a person's self-concept and sense of control over his or her life. Work provides structure, a sense of purpose, a connection to the outside world, money, and self-esteem, and adapting to the loss of that role requires a tremendous amount of adjustment. Nancy had stopped working about nine months before I interviewed her. This was a significant event not only in terms of the

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financial consequences, but also because of what work represented for her -- health, power, strength, and control. Stopping work also raised the issue of having to disclose her HIV status to her young daughter.

Nancy: ...the idea for me to stop working...to me that equals being sick, and not being able to take care of myself, and not being able to take care of [my daughter]. And if I can't work and I get sick, then I have to tell [her].

Ann: Aside from the income part of not working...how did it affect the way you thought about yourself?

Nancy: You know, to me, not being able to work takes a lot of my power away, a lot of my strength. And a problem that I've had is dealing with the loss of control. And I never realized what a big issue it is with me until I started losing control.

For Emily and Susan, work represented an important part of what "kept them going." Emily had recently experienced working again after being on disability, and she believed that work has contributed to her survival.

> [Work's] very important. I think that it contributes to the reason I'm alive. ...You know, somebody said..."You give someone a reason to get up out of bed every day, and then they will." And that's one reason why I moved here too. I was so depressed on disability. I hadn't worked in over a year. ...And I laid around and I

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> watched TV eight hours a day -- literally. I felt like I was like a nobody. I wasn't contributing to society. I mean our whole society tells us our identity is about what we do, and our work. And when you're not doing it, you're like a loser, you know. So, it was hard. It was really hard, not working. And I feel really good going to work. It's so great. I just feel like I'm doing something. ...So, work is important for me, it's vital. I will work up to the moment of my death. If it's not doing like "work" work, I'll work, like I'll write or I'll do art, or I'll do something that is productive. I will be productive in some fashion. I don't care if it's, you know, gardening, you know whatever, growing food or flowers or cleaning house or being a wife. I'll still work.

Each of the women who had been seriously ill had stopped working at some point because of their illness. Although they experienced this transition as a loss, they actively worked to accept the limitations of their bodies, and to restructure their self-concepts and their lives to adapt to this loss. Like Emily, if women were unable to resume the same work, they resolved to be productive in some other way or to focus their attention on other activities. That is, most women talked about how they refocused the goals and expectations they had for themselves in order to maintain a sense of control over their lives (Charmaz, 1987).

Individuals reconcile the loss of control over their bodies through different strategies. Frank (1995) writes that, "people interpret their bodies and make choices: the person can either seek perfected levels of predictability, at whatever cost, or can accept

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varying degrees of contingency." (p. 32). Nancy, instead of becoming depressed about the fact that she had lost the ability to walk, tried to maintain a positive attitude and refocused her attention to physical therapy and each small movement toward recovery. In a portion of Emily's narrative, she suggested that because her health, and therefore her body, is unpredictable, she chooses to focus on her emotional well-being and healing, because she does have control there.

> When I can't get out of bed, I'm stuck with this shell. And what is on the inside dictates how my day is gonna be. And if I don't love myself, and I don't enjoy my company, I can't take this body out into the world so I can divert myself. I've gotta work on it. You know, that I am more than a shell. And for me to really embrace my dying, I have to really learn to live and love myself. And for me to live a quality life, these things are necessary.

To adapt to a failing body, she has had to distance her sense of who she is -- her identity -- from her body (Charmaz, 1995). She said, "AIDS will take me physically but it will not take me emotionally and spiritually. I have the choice there. I don't have to let it rob me of these things."

Restitution in HIV/AIDS Narratives

As mentioned, different narrative types are prominent at different points in the illness experience. Restitution narratives often are told early on in an illness, when there is still hope for recovery, and are rarely told by the chronically or terminally ill. As a

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reminder, restitution narratives have the general plot, "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995, p. 77), and content of these narratives involves methods used to restore health, such as medical care and treatment regimens. These "culturally preferred" narratives are shaped by a natural desire to return to health, but also by the assumption of society and institutional medicine that every problem can be remedied, and the expectation that individuals will do whatever possible to return to health (Frank, 1995).

I did not see true restitution narratives in the women's life stories, as they are rarely told by the terminally ill. Because an individual can be infected with HIV for several years before any decline in health status, I did see what could be thought of as a modification of restitution narratives as told by women who will never return fully to health, but who were not yet seriously ill. That is, women talked about the various ways in which they tried to control the progression of their illness (e.g, lifestyle changes, alternative or holistic treatments, active participation in medical care and decisions, positive attitudes), and to stay as healthy as possible for as long as possible, but for many the goal of staying healthy stopped short of taking medications.

Frank (1995) suggests that tellers of restitution narratives want to regain predictability and control of their bodies, particularly to keep mortality at a distance. He uses the example of how brochures and commercials for medications and medical services serve as models for restitution narratives, for how illness narratives *should* be told. Restitution is brought about by the institution of medicine -- medication or a service -- and thus is a commodity:

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> Commodification is a crucial aspect of the deconstruction of mortality: as long as I can buy this to fix that, I sustain an illusion of permanence. So long as there is more to buy, whatever needs fixing will be fixed, and I will continue to be. (p. 86)

In the past few years, more and more medications have been developed to slow the activity of HIV. The newest class of drugs, protease inhibitors, seems to be the most promising so far in suppressing viral replication and prolonging life. When protease inhibitors became available in late 1995 to early 1996, the media was replete with stories of dramatic recoveries from debilitating illness, and scores of individuals taking them found that the HIV replication in their blood slowed to levels considered "undetectable" by sophisticated "viral load" tests (CDC, 1998). In the *New York Times Magazine*, Andrew Sullivan (1996) wrote,

> The power of the newest drugs, called protease inhibitors, and the even greater power of those now in the pipeline, is such that a diagnosis of HIV infection is not just different in degree today than, say, five years ago. It is different in kind. It no longer signifies death. It merely signifies illness. (p. 54)

Epidemiological trends after the availability of protease inhibitors reflected the benefits of these new drugs. In From 1995 to 1996, the United States saw its first decrease in new AIDS cases since the beginning of the epidemic, deaths from AIDS declined by 23%, and the prevalence of people *living* with AIDS increased by 11% (CDC, 1997). Protease inhibitors became available to people with HIV/AIDS in the months

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before I began interviewing the women for this study. Thus, there was a rather dramatic historical change occurring both in the conceptualization or meaning of AIDS, and in the potential for life ("restitution"). There was, for the first time, a potential "fix" to buy.

Recently, I saw a television commercial for protease inhibitors that was targeted toward women with HIV, and consisted of several women relating a similar message -- "If it weren't for these medications, I wouldn't be alive." The message is not that the medication is a cure, but that at least it can allow one to live like before; thus, it reflects the only restitution narrative available to those living with HIV/AIDS. Women get this message not only from pharmaceutical company commercials, brochures and posters. Many felt bombarded by pressure to take these medications, primarily by physicians, but also by other people living with HIV/AIDS. Given institutional medicine's emphasis on restitution, it is not surprising that women's physicians were pushing them to take medications. What I found interesting is that very few of the women in the study employed restitution in this way in their narratives; in fact, most resisted it. Despite the great amount of media attention paid to this breakthrough class of drugs, only five of the women were taking protease inhibitors (three were taking antiretroviral drugs but not protease inhibitors, and four women were not taking any "traditional" medications). Delores, Joanie, and Gloria each told stories of their physicians' anger in their refusals to accept medications. Gloria said,

> Oh forget it. My doctor, she got very um, very annoyed with me. She even screamed at me. You know, I says, "You know what? I'm older than you are.

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> Screaming at me? No, I don't think so!" "But Gloria, you know how I feel about you, how are you gonna not [take medications]?" I says, "Because I told you doctor, I didn't want the medications." I didn't want 'em."

Why is it that many women didn't adopt "restitution" in their lives and stories? I should note that access to medications, including protease inhibitors, was not an issue for the women in this study. Each of the women had coverage for medications through either public or private health insurance, and almost all of the women had been offered the opportunity to take medications by their physicians. The exception was Maria, who said that she was "not eligible" for medications because of her high T-cell count. For the women in this study, then, how they approached their health and treatment decisions was more complex than simply access or economy.

Taking these medications is a complex issue for many people living with HIV/AIDS for a variety of reasons (Brashers et al., 1999). On a very fundamental level, the newness of the medications makes people skeptical that they will be beneficial in the long run and fearful of the damage they might do to their bodies. Roberta, for example, was very wary of taking any medications because she felt these drugs were so new and had yet to be researched thoroughly. "They have no idea what's going to happen. All they know is what's going on day by day, you know. And I don't like that," she said. Although many of her friends and acquaintances were taking protease inhibitors and touting them as miracle drugs, Roberta remained skeptical.

> People are goin' to their doctor that are taking these protease inhibitors, and

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> because their viral load is going down and it's being undetectable...people really do believe that this is the miracle. ...I was thinkin' maybe I was bein' pessimistic. But these drugs have not even been in research. The people who are takin' these drugs are the people who are the researchers, really. ...And you know what it reminded me of, is like when...AZT was the hot thing on the market, you know, and a lot of people got very sick from it. ...They're not tellin' these people that the protease inhibitors cannot heal the damage that the virus has already done. So, you still get opportunistic infections, even though you're takin' them. I've known people that got them. So it's like, that part is real scary, I mean because...it's all in the news, and all in the newspapers, and I really feel...that they're kind of doing this for money purposes. ...Yeah, it's real scary because...human beings are the experiment. I mean, what's so scary about it is nobody knows the long-term effect of this medicine. They know that it worked for a year, or however many months it's been into effect, they know that it's worked that long, but what about next year?

She believed that the pharmaceutical companies and the media were selling hope to people with AIDS, and "playing a long shot that it's going to work," and she tried not to buy into that.

> I never had a lot of hope. I never had a lot of faith in doctors, with HIV. I just didn't. They always...told me that they were learning from us. So here I am, I don't know nothin', so what do you know? I've always felt like that.

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Even if protease inhibitors could prolong her life, Barbara was reluctant to take them because she felt that she was already taking enough pills, but also because taking medication conflicted with her self-concept as a "healthy" person.

Barbara: [My doctor] wanted to put me on that new Crixivan, and I don't wanna go on no more medication. I'm like, "Look, I'm not tryin' to take no new medicine."

Ann: Why don't you want to take the protease inhibitors?

Barbara: It's more medication. I'm not a sick person; I was never a sick person. Whamo. This! The only time I stay home from work [was] when I had the flu, and then wham! This. I'm not into medicine. ...Its just that now all of sudden, okay, I'm takin' the two Zerit, two Epivir -- that's four -- plus the INH because I was exposed to TB...so that's six plus my vitamin -- seven -- a day. I ain't tryin' to take six extra pills! Three in the morning and three in the evening...that would be thirteen pills, a day! It's too much! Then you gotta remember what they all look like, so you won't take double of this. It's too much.

For most women, decisions about whether or not to take medications was an issue of their quality of life, which is something that many people with AIDS are concerned about (Brashers, 1999). Delores, for example, decided not to take medications other than preventive medications for pneumonia and sinusitis because she was uncertain how they

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might affect her, and because thus far she had been okay physically without them. She feels that her physician and other medical professionals have not been very supportive of her decision. She described one encounter that she had with a "clinical researcher":

> The first thing she asks is, "Okay, what medications are you on?" I'm like, "None." She looks at me like, "What?" Like, "How dare you not drink medications" look, you know? So I'm looking at her like, "So what? I'm not drinkin' medications, what's wrong with that? I've been positive all these years, what the hell? You know? And, she goes, "But you know that they got these new protease inhibitors, and you know that they're making miracles," and I mean she started saying things to me as to makin' those protease inhibitors sound like something that God threw from heaven. You know, I understand that for some people they do work, but I also have read about those people that have been takin' it, and the difficulties they've been having with it, and I think I would rather spare myself all that trouble. Because I've been doing fine now, I haven't been with all those chemicals in my system, why mess my system up with all these chemicals? ...I mean, I like natural stuff, like herbs and teas, and my vitamins, and you know, just plain relaxing.

In general, the women were not naive about AIDS treatment research and information, and their decisions about treatment reflected both knowledge and personal experience. Further, their beliefs about medications were reflective of very real debates and divisions within AIDS activist and medical communities about what constitutes safe

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and effective treatment (Treichler, 1999). Like Delores, many people with AIDS rely to some degree on alternative treatments (e.g., acupuncture, herbs, nutrition) in the management of their illness. For the most part, Susan has treated her AIDS-related symptoms and illness with alternative medicine, which she believes has prolonged her life considerably. About her physician (who treats her with alternative medicine), she said, "I think I'd be dead years ago if it wasn't for her. It's like you have a certain amount of energy in your body, and once that's gone, that's it. And it's like, I feel myself fading. I mean, I've had to let go. It's been such a process of letting go of so many things." Although Susan recognized the hope in these new medications, she also considered what taking them would mean in her life (both emotionally and practically), and whether she even desired "restitution."

Susan: And it's really scary, but I work so hard on it. To heal, just to heal. You know, and I don't even know what form healing's supposed to take. It's like, I don't know if I could pump all these toxic medicines in me, and feel like I'm healing. I don't know if that's me. But I'm not in a position to explore that right now. ...I think it might just make me sicker. I mean I've seen the drugs make a lot of people sicker. And I also right now am starting to, for the first time, see some hope in the drugs. You know, for the first time, because I've seen them damage a lot of people. I mean, it's such a personal choice. I respect everyone's decisions. Just, I like people to respect mine, but you know sometimes I don't get that and people freak

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out.

Ann: You should be on medications...?

Susan: Yeah, yeah, always. You know, "the pill is gonna cure you." ...But it's like I don't necessarily want that, except for my son. If it didn't have my son, it's like, I would not want to be cured. I just want to heal my life. I don't want to be physically -- my body -- cured by this...

Ann: Magic pill.

Susan: Yeah. It's not gonna cure what's illing me. So, I think it's a lot, not just the HIV. I think what the HIV does do is like really saps the life out of me. And I see it do that to people. It steals, it just really saps the life out of me. ...I think on top of the AIDS it gets mixed so much for me with the stress, and I can't sort it out. You know, and I guess it doesn't need to be sorted out, but it's all like one illness for me almost, you know. It's all just trying to heal from that. ...It's more, just you know, like I said if I didn't have a son, I wouldn't be so concerned about having AIDS, you know. That I'd need to go cure it 'cause everyone else is finding this cure. Let me go. So that's been a real struggle right now, and I don't even know where I'm at with it, you know. ...I see people like literally getting stronger, telling me they have more energy and stuff. And it's like I don't know, for me to take a pill it would be like, I feel like I'd have to be all alone in a very calm

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> place, with no pressures, no responsibilities -- or not as many as I have anyway -- and settled financially and comfortable. And then maybe, maybe I could even like have a discussion about seriously deciding to take one of these pills. So it's like, I just feel like there's too much going on. It's like I'm in no position to be off my feet even for a day, for any reason if I could help it. And by doing what I'm doing, I've been every day on my feet.

Echoing many people who are managing the physical manifestations of AIDS, Susan remarked that staying healthy "is like a full-time job. I actively do things." Although her pursuit of health might be viewed initially as a desire for restitution, according to her it is actually a desire to remain healthy enough to be a mother to her son. She personally does not feel the "need to go cure [AIDS] because everyone else is finding this cure." This theme of staying healthy for others appeared in several women's narratives, as many were trying to stay healthy for their children, spouses and families as much as for themselves. Frank (1995) suggests that the issue of responsibility differs among the narrative types: responsibility in the restitution narrative consists of following a medical regimen and getting well. To the extent that women's narratives contained elements of restitution, their motivations in staying well were often connected to a sense of responsibility to others, in particular children and families. And sometimes, that sense of responsibility to others is what kept them going. Emily said,

> I have to take care, I have to go to therapy, I have to pray and meditate ...I have to take my meds -- not *have* to, I *choose* to. I work out, you know, I have to all of

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these things. I'm committed. And on days when I don't want to do it, because I'm sick of it, I think about [my partner]. And I do it because I'm committed to this relationship and it's not fair. I'm committed to do everything within my power to be present in this relationship, and that means physically, emotionally, and spiritually. And when I think that I don't wanna go down and get my meds...then I have to think about, you know my commitment. To myself. And if my commitment to myself isn't enough, then I give myself permission to be there -- I'm human -- and then it's about [my partner]. I'll do it for her, you know? And that's okay. And...I don't have to label it anything. When I think about the times in the past when I hated myself so much and my therapist says, "If you cannot do this for you, do it for me. And then you'll do it. You need this body here, and eventually you'll see the wonderful person that I see, and you'll be able to do it for yourself."

Women also don't tell the restitution narrative of the pharmaceutical commercial because the realities of the treatment are such that often health is not restored, and life does not "go back to normal." Restitution narratives as formed by the medical world typically gloss over the realities of restitution (Frank, 1995). The theme of, "I would be dead without these pills" was heard infrequently; when medications were part of the illness story, the positives were always qualified by the difficulties associated with "restitution." After describing her drug-taking protocol and a litany of side effects experienced from her drug "cocktail," Judy remarked, "You know, it raised my T-cells,

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and got my viral load down, but it was like, I hated living."

Similarly, Emily detailed the process she went through in deciding to take the new medications, and then once she did, the psychological difficulties of giving into the hope they offered. Until recently, she had not taken medications. Her feeling was, " I've adjusted this long, you know...I guess I kind of just accepted the fact that I wouldn't have any treatments before my death from AIDS. And that I had acquired a kind of a regimen [without them]." She changed her mind when a viral load test revealed a very high count. Since that time, Emily has tried various combinations of medications on and off, including protease inhibitors, but found that she cannot take most of the medications available because of side effects or because she is resistant to them. Her doctor told her she was "running into walls" in terms of the medications. Although the last combination of drugs she tried increased her T-cell count and reduced her viral load to undetectable, she felt "horrible" the entire time she was on the medications, and she questioned whether taking them was worth the quality of life they gave her. Like Nancy, Emily developed neuropathy from one of her drugs, and despite the pain she was afraid to go off the of the medication because she knew she didn't have many more options.

> ...the neuropathy would wake me up in the middle of the night. And I was afraid to go off the d4T. ...I was terrified, I'm still terrified. It's the last of those of class of drugs that I can take. Or, I thought I could take. So I just woke up one morning and said, "Enough. The quality of my life is awful." I wanted to die...and it was messin' with me emotionally. I would have weird thoughts. I was always

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isolating too. I wasn't seeing or talking to anyone. I would be walking down the hallway to go to the toilet at work and I just was like, "I wanna die. I wanna die." ...So, I woke up one morning and stopped all drugs. And so the next day, and it was so great. To go a whole day without taking drugs. Oh my God. But I felt guilty. And I felt nervous about it. Like, you know, what do they say, if you don't take drugs for a day, you make like a billion viral particles a day. And takin' these drugs, antivirals, combats that. It's unbelievable, this virus is just incredible.

These new medications bring up issues of hope, but also new uncertainties about the future (Brashers et al., 1999). For many people with HIV/AIDS, health improvements have created some confusion -- How should I live? Where do I go from here? Am I getting my hopes up too high? People who have struggled to come to terms with their failing health and death have been suddenly confronted with the possibility of life. All of the "biographical work" (Corbin & Strauss, 1987) done to adapt to life with a terminal illness has been thrown into question. Angela, for example, was someone for whom an HIV-positive diagnosis ended the pursuit of her goals of a college education and a career. At that time, she chose to live her life to the fullest, but in the present. Despite the difficulties she's had with side effects, the medications have represented a source of hope for managing AIDS as a chronic illness, and taking them has been a turning point in Angela's life. She has experienced an improvement in her health and physical functioning, and she has begun to consider, albeit cautiously, what the future means for her now. She's exploring the possibility of working and has applied to an organization

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that helps people with HIV/AIDS to get training and employment in the wake of protease inhibitors. And, after making arrangements to have her children cared for after her death, she has put negotiations with her children's adoptive family on hold.

> I feel like before, I was afraid. I mean, everybody said like if you got [HIV], you will have only years to live, you know -- or less. And now they say it's getting to be a manageable disease, you know that people can live for a long, long time. So it's for that reason I feel like there's hope. And I feel like more things will come. I mean, I'm feeling very hopeful that I could be able to be around my children when they grow bigger. So, in that sense, it has changed.

Emily's experience with medications has left her confused and scared about what the future holds for her. Like many others for whom these new drugs are not working, she felt let down because they gave her false hope.

Emily: I've never been more scared. I am, I'm scared. I think these protease inhibitors are mean. It's like, they teased me. They teased me to somehow, you know, believe that I was gonna live. Before, I didn't even think about living a long time. I just thought about kind of staying in the moment, thinking about that year. Life was in the context of a year. And I began to explore my future. It gave me the permission to think about a future. And, when you think about a future and you have a disease that's still killing so many people, it's scary. It's scary. It's almost like it teased me. It's like,

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"Nah nah nah nah nah nah. You can think about the future. Huh, no you can't." You know, it's like on a roller coaster. Before, it's like I knew that I was gonna die much sooner than I wanted to. And that was life. And I made the best of it. And I think on a lot of levels I made a better best than I am now. Because I think about the future. I like myself more and I have more to lose. I like my support system, my life. I love my life with my partner. There are a lot of things that have changed emotionally within me.

Ann: Like...what's changed? You mean since you started on these drugs?

Emily: I think that I would, in a way I would probably be here emotionally because I mean, emotional health is a process like getting to love yourself or like yourself is a process. So I think that it was just a convergence of a lot of things. I've been in therapy, and I'm in a functional relationship that isn't abusive. That helps, because when I'm not in an abusive relationship, I have more energy to focus on me. ...You know, I'm in a relationship with someone who has self-esteem, takes care of herself, and does what she needs to do. And as much as it frustrates me sometimes, and scares me most of the time, I have more energy to focus on who I am as a person. And what it is that I want to contribute to this planet. What is it that I wanna do? Who do I wanna be around? Who do I not wanna be around? So, I think that it's just kind of coming full circle. Which is scary, because I always believed that...if things came full circle it was time for me to die.

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> That I'd done what I needed to do on like some spiritual level. I'm scared too because I'm older. The longer you live with it the scarier it is. 'Cause you know, you outlive people. ...And you know, having the virus in my body for 15 years. I've had the virus in my body more years on this planet than not. ...That's hard to digest. And I just keep wondering, "I've had this damn thing so long, when is it gonna happen?" You know, I do. And it scares me. It scares me a lot. I don't wanna die. I think I was so emotionally miserable before, on some deep level I didn't care.

Each of the women's narratives illustrates how personal life circumstances shape ideas about and desires for restitution. Emily and Susan, for example, both distinguished their emotional "healing" process from physical healing and assessed the meaning of each in their lives. For Emily, who allowed herself the hope of physical healing, the ineffectiveness of the drugs was particularly devastating because she had finally reached a point in her life where she was emotionally and spiritually healthy, and as she said, "I like myself more and I have more to lose."

Confronting Death and Dying

Whereas planning for a future might have been adaptive early in women's HIV experience, letting go of the future and preparing for death became important as health declined. Qualitative work requires one to examine not just what *is* talked about in narratives, but also what is left out. Maracek, Fine, and Kidder (1997) suggest that

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qualitative work requires attention to language, including such absences of language.

> ...a qualitative stance means listening to and theorizing about the layers of contradiction and uncertainty that emerge when people try to make sense of their lived experience. ...It means listening to and interpreting silences -- refusals to speak, gaps in a narrative, or the absence of a language for speaking about certain things. Are they retreats into safety? Reassertions of agency? Signposts pointing to the speaker's blind spots? (p. 636)

For a study that dealt with women living with terminal illness, I was struck by the lack of talk about death and dying. For women who had not yet been ill, death was rarely part of their story. I didn't get a sense that women were in denial about death. For instance, each woman with dependent children had confronted that reality to the extent that she had endured the very difficult process of making arrangements for her children's care after her death. For the most part, when death was mentioned, it was only briefly (e.g., "I'm not afraid of dying." End of story.), and with an urgency to move on to the next topic. For example, both Joanie and Nancy's husbands had died from AIDS, yet their stories omitted or glossed over this event, even when I asked about it. Perhaps they felt it was too private to discuss, or too frightening in terms of what they had to look forward to in their own illness. Nancy admitted that coming to terms with dying is the greatest process she's had to go through with AIDS, and it has become more necessary now that illness has become a reality. She has confronted her fears about death in various ways -- by thinking about it, but not dwelling on it, by trying to focus on the positive aspects of

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her life, and by trying to keep busy and active.

Ann: What have been changes or processes that you've gone through...

Nancy: Well, I guess the biggest thing is like coming to terms with dying. I don't do that well at all. Since I'm a little kid, I went to Catholic school, and I was there at the time of the Bay of Pigs, and they used to have us get under the desks, and [cover our heads], like they have air raid drills. And I remember goin' home and layin' in bed and thinking, "Oh my God, what is it like when you die?" Like, "Where do you go?" And I used to start thinking about the end of the world. I was seven years old, and I was thinking about these things, and I was worrying. So I've always worried about [death], or have had this kind of like thought in the back of my head, "What happens when you die?" So then when this whole thing happened, I was like, "Oh no please, I can't, I just can't. Not that! Not that! Anything but that!" And I had no choice, that was it. You know so, it's funny 'cause [for] somebody who hates this subject, and has a very hard time dealing with it, I have to deal with it every day. And I try not to, you know like sometimes I say, "I'm just not gonna think about it," but it's just, it's always inside your head. And I guess like dealing with death...is not something I can do very well, or that I wanna do, but I'm kind of forced to do it.

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Ann: And how do you do it?

Nancy: I don't know. Honestly I just like, I think about it a little bit, and then I say, "Okay that's enough." You know and it's like, putting your finger next to like a fire and [pulling back quickly].

Ann: How close can you get?

Nancy: Mm hm. And, you know, it depends. Like sometimes, it's good because I see like how lucky I am in a lot of ways, and that's how I'll deal. I'll say, "Well, I'll think about this," and like, "This is so good, and that's good." 'Cause...I think if anybody starts thinking about dying, and all that, I believe that that's where you're gonna go. You know, like if you're just like morose and depressed. And I don't. I don't do that. And I can't. You know it's very hard for me to do that 'cause [my daughter] doesn't give me a chance to. My family, my friends. I'm always, you know, active in some way. Try to keep busy. Like, my mother used to say to me, "You're running, you're running. You gotta stop running. Running away from everything." Like, "If I run over here, it won't catch me." But, you know, you can't run away from it. And it's like I say, "Forget about the AIDS. Everybody's gonna die...they all gotta think about it too." 'Cause I used to get angry and I'd say, "You don't know what it's like to sit [and think about your death]." And I still think they don't know what it's like. Their

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thoughts of death are much different than mine. 'Cause you can sit and think about death -- usually, you think about it in terms of other people. When you think about it for yourself, it's such a totally different thing.

Emily and Susan were the only other woman who spoke in-depth about dying, but from different perspectives. Elsewhere, Susan has talked about death as something "easy," a relief from the difficulties of her life. For Emily, as for many people, coming to terms with her death has been a back-and-forth process. Several years ago, Emily had a serious illness that was potentially life-threatening, and she thought she was going to die. This was a turning point experience for her in terms of how she thought about her illness, her life, and her death.

Emily: And I wouldn't go in the hospital, because I was having such a hard time paying the bill. And the message I [got from doctors] was that it's part of [HIV], and they can't do anything anyway. I should have been in the fuckin' hospital. But I wouldn't go because of the money. I didn't have insurance. And you know, I was trying to negotiate paying off this humongous hospital bill from [my last illness], so I didn't wanna go. You know, not having the money stressed me out. So, I didn't go in the hospital, and I almost died. I thought I would die. I really did. Um, my partner at the time said, "What can I do?" And I had her call in a couple people, and I said "bye" to 'em. And I remember layin' there, fading off. And I didn't think I would wake up the next morning. And I thought about

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all the women [I had worked with]... and all these wonderful women. And I felt grateful. I was ready. I was okay. I felt like I had done so much. And that was my purpose on this planet. And I woke up. The next day my fever was gone. Talk about drama. ...[But] everyone thought I was gonna die.

Ann: Did that change how you thought about-

Emily: It changed how I thought about a lot of things, 'cause I thought I was gonna die. I was willing to deal with less bullshit. I was in a terrible relationship, and eventually I got out of that. And, just tryin' to better myself. And I didn't have a hard time dealing with death. I mean I had dealt with it. So, I was very much into processing my mortality, and really exploring, you know, the potential of having AIDS is that you'll die. And that's what everyone's so afraid of. And I had learned that not only were people afraid of you know, getting the virus and the whole issues around HIV/AIDS, [and] sexuality issues, STDs, sex, queers, drug users, prostitutes -- all these stigmas. But I had decided, and still believe, that the one thing that is bigger than all of that, is that AIDS kills you. And our society does not talk about it. And that, I have certain rights. When I had decided not to go into the hospital to get treatment when I was sick, that was my right. And little did I know, it empowered me to take responsibility for my life. And while I was laying in that bed I thought of this friend of mine...and he said that if he got to a certain point, that he

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> would not do certain treatments and that it's his life and it's not just about AIDS and activism, it's about his spirit. And it's about him healing on a lot of different levels. And I had decided that that's what it was about for me. And I didn't make that decision consciously. It happened through the process of while I was dying -- embracing it and accepting it and being okay with it. Instead of going, "I'm gonna get better. I'm gonna get better." I just was like, in the moment. I'm here right now, and whatever happens tomorrow, I'll deal with it then. So that gave me lots of support as well.

In this turning point story, Emily resisted the expected behavior of one who is sick -- going to the hospital and getting treatment. In some ways, her refusal to go to the hospital could be viewed as a consequence of her economic situation. It can also be construed as a manifesto of what she's learned from her suffering, and a demand to be allowed to die on her own terms. Emily viewed this decision as an expression of agency; a choice that allowed her to feel empowered and in control of her life and her death. Kathy Charmaz (1999) found similar instances of "defiance" or risk-taking in men's illness narratives to be ways that they asserted "moral claims to rights due moral beings" (p. 371). She writes,

> Their stories echo with their claims to moral rights and struggles to preserve their moral status. An implicit view of rights, a quest for control, and an insistence on autonomy define how these men know themselves and wish to be identified by

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others. (p. 371)

Further, when restitution narratives are not available, as when one is terminally ill, "the reality and responsibility of mortality, and its mystery, have to be faced" (Frank, 1995, p.84). Emily's narrative displays a resistance to restitution and an embracing of death and dying that is disallowed in restitution narratives, and discouraged by the institution of medicine and society in general. Frank (1995) notes that, "The ultimate limitation of restitution is mortality: the confrontation with mortality cannot be part of the story" (p. 95). In her story, Emily demanded that she be able to talk about what is prohibited for many who are dying.

Emily's narrative made me wonder if women's lack of talk about death stemmed at least in part from our cultural understanding of death as something that doesn't get discussed. I question the extent to which people with terminal illnesses are really "allowed" to tell their stories, to talk about their illnesses and their deaths and what it means for them (Kleinman, 1988). Even among medical professionals, family and friends there is an encouragement of silence. Maria, for example, was essentially disallowed from discussing HIV around her husband -- despite her need to do so -- because he could not handle the idea of her illness or her death. Similarly, whenever Delores tried to speak to her ex-husband about the care of their son after her death, his response was, "Shit, you're not going nowhere so don't even speak about it." In other circumstances, the disallowance is more subtle, as in the turning of a discussion to more "pleasant" topics. Nancy said that friends and family, thinking they were being supportive, told her, "Nah,

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that's not what's gonna kill you. It's gonna be something else." Thus, in numerous ways and circumstances all of us process the message that death, in our societal insistence on restitution, does not have a place -- even in terminal illness. As Farmer and Kleinman (1989) noted over a decade ago, "...AIDS testifies vividly that our secular public culture is simply unable to come to terms with mortality" (p. 366).

But death is inescapable, and illness narratives represent an important opportunity to explore the meanings of life, illness and death that have often been evaded in the interest of restitution. Kleinman (1988) writes, "If there is a single dimension of illness that can teach us something valuable about our own lives, then it must be how to confront and respond to the fact that we will all die, each of us..." (p. 157). And people now seem hungry to learn what illness has to teach about life and death, suggested by the immense popularity of books such as *Tuesdays with Morrie* (Albom, 1997), about the lessons learned by one man from another's process of dying, and the recent PBS documentary series about end-of-life issues, *On Our Own Terms: Moyers on Dying* (Moyers, Moyers, Mannes, & Pellett, 2000).

Coming to terms with death is a complex, back and forth process. In the above narrative of Emily's, her death represented a social statement at a time when AIDS activism was the primary aspect of her life and her identity. But later in her story, she shifted her perceptions about dying as she shifted her perceptions about living.

> Having AIDS is not hard. But the hard part for me is dealing with the issues that make me want to have AIDS. Make me want to die. That voice deep down inside

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of me that sighs with relief that I'm positive, and that I'm not gonna have to live. You know and dealing with the guilt that I feel that, I never wanted to live. You know, it's really hard. And it's much easier when you wanna die. It's easier living with AIDS when you wanna die. You know, but when you want to live and you love your life, there's like this whole level of grief that's completely intense, and then the feeling of helplessness and powerlessness is so hard to balance out. It's a constant, it's tricky. It's a puzzle.

Emily's narrative demonstrated how one's acceptance of death can change when life circumstances change. She had accepted her death at the time she was very ill and believed that she was going to die. When the circumstance of her life changed, however, and she felt differently about herself, her life and the role that AIDS played in it, her acceptance of death changed. The more she loved her life and self, the more fearful and conflicted she felt about dying. The ups and downs of her physical health have also affected her acceptance of death. As her health has declined, she has become more afraid. On a day when she was not feeling well, she said to me that "the little voice inside of her" that had always pushed her to live life to the fullest was now saying, "I'm tired. I just want to lay down," and how immensely terrifying that was for her. As the other women experience declining health and facing their mortality becomes more urgent, death will likely have a more prominent place in their lives and stories (whether they are spoken or not). Many do not begin the psychological work of coming to terms with dying until they actually become terminally ill.

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Health and Illness in the Era of Protease Inhibitors

In this chapter, women's stories portrayed the many losses associated with illness, and revealed the various ways that the women have tried to maintain control over their lives and self-concepts in the face of such loss. No matter where women were in the trajectory of physical illness, a significant theme in their stories was the struggle to maintain control. Before serious illness, they described the ways in which they tried to preserve their health. During illness, attempts to maintain control took various forms, such as Nancy's story of keeping a routine despite physical disability, and in Kay's struggle to manage the stigma she felt about her illness. Even Emily's story of dying was constructed in a way that emphasized her control, autonomy, and self-respect.

Attention to health was extremely important, but women made their own decisions about health care and treatment based on what they felt was appropriate for their lives. Women did not readily buy into the medical "process," storied in refusals to go to the hospital, to accept what they considered inferior medical care, and to take "traditional" medications. Given the hype that surrounded the new treatments when these interviews were conducted, initially I was surprised about the extent of women's resistance to taking them. Since these medications became available, much of the behavioral research has focused on individuals' adherence to the complex regimens. Although understanding adherence is important, most research has side-stepped the important decision-making processes, and personal and social circumstances that go into decisions even to take medications. For example, the issues that women raised here

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regarding protease inhibitors were similar to those raised about AZT in a qualitative study of women's treatment attitudes and decision-making (Siegel & Gorey, 1997). This study revealed overwhelmingly negative attitudes toward taking AZT among a sample of ethnically diverse women, including concerns about the health risks and debilitating side effects, skepticism regarding physician's knowledge of AZT, suspicion of the "medical establishment's" promotion of AZT, and concerns that the drug had not been tested among women or people of color. (Interestingly, Siegel and Gorey interpret these findings within the master narrative of medicine -- that women *should* be taking AZT -- and conclude from their findings that interventions should focus on increasing women's acceptance of and adherence to AZT). What becomes evident from the stories here are the complex personal, social, and psychological issues surrounding treatment and concepts such as hope, healing and future.

The themes raised in the stories around issues of health and illness are not necessarily unique, but the uncertainty about what health and illness now mean is perhaps greater than ever. In many ways, these are confusing times in which to live with HIV and AIDS. As new treatments become available and people are living longer with this disease, the meanings of AIDS are undergoing constant revision. At the time these interviews were conducted, AIDS was beginning to be considered a "manageable" chronic illness instead of a death sentence, although as Paula Treichler (1999) notes:

> This transition from a concept of AIDS as a classic epidemic of acute infectious disease to that of AIDS as a chronic, potentially manageable disease represents

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> one of the pervasive, influential, yet still contested shifts in meaning in the course of the 1980s and 1990s, one debated through personal observation and testimony, epidemiology, laboratory studies, clinical trials, and actuarial statistics. (p. 325)

This change in the conceptualization of AIDS in turn has affected how people live with AIDS, and consequently their stories. As such, these women's stories "ride the fence" of experience, representing both the beginning of the epidemic, and what it has/might become. In them, we sense the fear that stems from an understanding of AIDS as a stigmatizing and terminal illness, and from the women's very real experience with a disease that has claimed the lives of so many people. We also see glimmers of hope that life with AIDS might be changing. Even with the hope of new medications, there was still great uncertainty, which has been perhaps the most defining characteristic of AIDS since its discovery. Similar to other people taking protease inhibitors (e.g., Brashers et al., 1999), the women were still uncertain about how their illnesses would progress, and what these new treatments could mean for their futures. For women like Angela, Nancy, and Judy, the protease inhibitors they were taking offered a reprieve from declining health, and relief from the sense of, "I gotta do it right now because I don't know if I can do it next month," as Judy referred to it. For others, the new medications were something to be feared or avoided because of their uncertain effects. For Emily, they simply didn't work.

Five years into the protease inhibitor era, it is reasonable to wonder, "How would these women's stories have continued?" and even, "If these women were diagnosed now, would their stories offer a different version of life with AIDS?" We might suspect that

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individuals diagnosed now, 20 years into the epidemic, have a different experience -- that they need different "survival skills" (and perhaps, they don't possess the survival skills of those who were first diagnosed -- the same urgency, the same fight to live fueled by grief and loss) now that AIDS is more often conceptualized as a manageable, chronic illness with the "correct" medications. The social contexts in which people experience AIDS are also different, but how this might affect experiences and stories is not clear. It is possible that the narratives of people diagnosed now are different -- where AIDS and illness are less the focus of a life story, where issues of time and the future are less urgent and less uncertain, and where fear and stigma have a less prominent place in the story. That is a question for another study. But it seems that the stigma of HIV/AIDS is alive and well in the United States (Herek, 1999), and an exploration of web sites and publications (e.g., POZ Magazine) by and for people living with HIV/AIDS provides a wealth of insight into the often harsh realities and disappointments of new these treatments, the diminishing hopes of prolonged life (much less cure), and the myths of AIDS as a "manageable" chronic illness. It is in these spaces that we find counternarratives to media and scientific representations of AIDS in the post-protease inhibitor era.

But five years into this era, the scientific literature now becoming available seems to concur with individual and collective experiences that these new treatments are not living up to the promise they once held. Although initially protease inhibitors and other highly active antiretroviral therapies (HAART) resulted in dramatic decreases in HIV-related disease progression and mortality, five years into the protease era the success of these medications is being compromised by factors such as medically complex regimens

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(affecting adherence), virus mutations and multi-drug resistance, and serious side effects (Fauci, 1999). Studies among non-clinical trials samples have found that over 50% of participants do not achieve "virologic success" over the long term. Valdez et al. (1999), for example, reported that protease inhibitor therapies were successful in only about half (47%) of the people taking them, and that the success of these treatments was even less likely in women. Among an inner-city HIV clinic sample, protease inhibitor therapy was successful in only 37% of the sample after 7-14 months (Lucas, Chaisson, & Moore, 1999).

Some of the women in my study (e.g., Nancy, Emily, Judy) described the debilitating side effects of their medications and how these affected their quality of life, and in fact toxicities caused by antiretroviral therapies are becoming so pronounced and serious (e.g., diabetes, hypertension, atherosclerosis, fat maldistribution) that clinicians and federal health officials are now rethinking previous recommendations of early, aggressive treatment for all individuals with HIV (CDC, 1998; Henry, 2000). In February, 2001, the federal HIV treatment guidelines outlined in 1998 (CDC, 1998) were revised to reflect a more conservative approach of delaying treatment for as long as possible in asymptomatic individuals. Further, clinicians are urged to work with patients in considering the risks and benefits of initiating treatment (including patients' quality of life), and to balance treatment recommendations with an individual's "willingness and readiness" to begin therapy and his or her ability to take medications correctly (CDC, 1998/2001).

Time and the familiarity of AIDS have also changed how AIDS is thought about

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in our society. With the advent of protease inhibitors came the collective sense that "AIDS is over." Associated with this is the belief that AIDS no longer deserves "special attention" because it is now just one of many of the chronic illnesses affecting people today. People with AIDS are left to balance the hope of a manageable (yet still stigmatizing) illness with the hopelessness of being forgotten. As "AIDS beats" in the nation's major newspapers have disappeared and AIDS organizations have lost funding or closed their doors, there is a general sense that people have lost interest in AIDS. As Paula Treicher (1999) has written, "AIDS is a war whose participants have been in the trenches for years, surrounded daily by death and dying, yet only gradually has the rest of the population come to know that there is a war at all" (pp. 2-3). So, although new treatments offer hope for prolonged life, they also threaten to send us as a society back into a state of cultural apathy regarding AIDS, and people with AIDS are not unaware of the implications this has for their lives. Judy expressed frustration that the world seems to think AIDS is over, because she still struggles with the practical issues of AIDS on a daily basis (e.g., "How are we gonna get another lease somewhere, 'cause we're not employed. And then, how do you explain why you're not employed?"). She remarked:

> ...the drugs are bring this [sense of a future], and people are thinking, "It's over." You know, it's *not* over. And I'll tell you, living on these drugs is as difficult as having a full-time job. ...There are a lot of really unanswered issues out there, and I really wish the public the public wouldn't think that it was over, 'cause it's not. ...There's no end of AIDS right now. There's an extension, and I'm happy for that.

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Similarly, Emily noted the dangers inherent in the conceptualizion of AIDS as an epidemic now over, but at the same time this once-ardent activist admits that she's tired of AIDS in some respects. Living with and fighting against AIDS has burned a lot of people out, and in a climate of cultural apathy it becomes more and more difficult to fight for the next generation of people who will live with AIDS.

Emily: It seems surreal...Like this really did happen, this AIDS plague. It really happened. It's happening. And it's interesting because I think that I'm buying into that whole thing that AIDS, the AIDS crisis, is over. In a way the crisis is over, for a while. I'm not saying it's not gonna start up again, 'cause I think it will.

Ann: Right. People's attitudes are changing.

Emily: Oh, totally.

Ann: How does that make you feel?

Emily: Um, sometimes it makes me angry, and sometimes I feel relieved because I wanna believe it too. So, it sets the tone. And it's nice to be, you know, part of a system that's in so much denial. It helps validate my own denial, 'cause I have denial spurts. I have had for ten years. So it's interesting for the first time in ten years I'm actually surrounded by people who validate those denial spurts. And they're being *real.* So, that's interesting. It's nice,

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but I think it's dangerous. But I feel ambivalent a lot lately.

Ann: About what?

Emily: Um, like I used to be on this clinical trials bandwagon. "Why aren't women part of clinical trials?" And lately, I don't know if it's because I'm just tired, but lately I don't care. Like when people say it, there's a voice inside that says, "Oh, I don't care." Maybe I'm burnt out, I don't know.

With all of these current understandings of AIDS, it seems unlikely that the narratives of those individuals diagnosed now would differ dramatically from those told here. As attention to AIDS and resources diminish, people living with AIDS are feeling less hopeful and less secure about their futures, and the isolation of AIDS will continue.

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METHOD, INTERPRETATION AND REPRESENTATION: ETHICS AND POLITICS

In the three previous chapters, I highlighted some of the common themes in women's stories and brought in the relevant literature as it related to those themes. But this project has utility and importance beyond the specific content of the individual stories, which is what I focus on in this chapter. First, I review what each of the interpretive frameworks contributes to our understanding of the women's life stories, and then I turn to issues of interpretation, representation and ethics involved in the research.

Mandelbaum's Life History Framework

The three "data" chapters represent the common turnings or transition periods in a person's experience living with AIDS: the diagnosis and initial months or years; the incorporation of AIDS into a life; and the progression to physical illness. Although women talked about these transition periods in one form or another, they were experienced and storied differently by each. Further, within each of these periods, most women described one or more different turning points that affected her life and/or her experience living with AIDS.

Turning points can be objective or universal, or subjective and unique to an individual. As such, some turning points reflected those common among people with HIV/AIDS. For example, both an outsider (e.g., a researcher) and the person telling a life story would likely view diagnosis with HIV/AIDS as a critical life turning, whether or not it is storied as such. Other important turnings/turning points could be identified as

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experiences meaningful to a particular individual. Angela's life story contained an example of a more subjective turning point experience that became evident only through her telling of the experience. Angela attended a workshop series at an AIDS organization that greatly affected her senses of hope, responsibility and control in her life and illness. It was also an experience that she felt changed her relationship with her boyfriend for the better. Whereas this workshop may have had little influence in another's life, for Angela "it was the most wonderful thing I ever did," and something she marked as a life-altering experience.

Each turning point experience was significant because it in some way required or enabled new adaptations. Adaptations in Mandelbaum's (1973) framework refers to adjustments or changes that an individual makes to maintain continuity in their lives and self-concepts. Charmaz (1995) offers another useful conception of adaptation that refers specifically to physical illness and impairment: "Adapting means altering life and self to accommodate bodily losses and limits and resolving the lost unity between body and self. It means struggling with rather than against illness" (p. 657). Similarly, Corbin and Strauss (1987) use the term *accommodation* to mean the daily struggles of illness management, but also the "action aimed at achieving a sense of control and balance over that life, as well as giving it continuity and meaning despite the illness and the changes it brings. Accommodation...must therefore take place not only in terms of illness management, but also of biography" (p. 251). Adaptation or coming to terms with illness as part of one's life does not necessarily mean acceptance. Making illness part of one's biography "does not imply full acceptance of the illness, [but] rather making it a

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sufficient part of identity so that one does what is necessary to ensure both physical and biographical survival" (Corbin & Strauss, 1987, p. 267).

Consistent with other research that relies on the perspectives of people who are ill, there were differences among the women in the extent to which AIDS or illness was part of their lives, self-concepts, and stories (Corbin & Strauss, 1987; Squire, 1999). Emily, for instance, knew only life with illness, and therefore illness/suffering and life were inextricably linked in her story (Charmaz, 1999; Frank, 1993). In her case, part of the struggle to accommodate AIDS came from trying to find a life and an identity beyond AIDS. For most of the other women, illness was a less defining feature of their lives and stories, although this fluctuated throughout the illness experience. What life stories do is provide a context for understanding the processes through which women accommodate HIV/AIDS within their existing personalities, histories, and life circumstances.

In their research with women who have HIV/AIDS, Lather and Smithies (1997) raise the question, "How can we not make the mistake of taking AIDS as an isolated event in someone's life, to place it at the level of primary identity?" (p. xvi). This is an important issue because much of the behavioral and social science research does precisely this, reflected in the continued interest in and (over) abundance of research focused on the search for "negative" psychological outcomes and psychopathology among people who have HIV/AIDS. In some ways, diagnosis with a life-threatening illness does "change everything" (Frank, 1993), but the changes evoked by illness are not the same for everyone and they are not always perceived as devastating or unwelcome. In time, some individuals are able to portray their illness as an opportunity for powerful changes and

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transformations in life or self, evident in the stories of Emily and Susan. Others tell "tales of continuity" (Frank, 1993) and struggle to hang on to a "normal" life; they resist the idea that illness has changed who they are in any fundamental way. Joanie, for example, thought that she *should* change after her diagnosis ("I have to be a better person. ...I have to be closer to my kids. I gotta do more."), but later she came to the realization that, "...slowly but surely, I just turned out to be the same old me. And I'm still the same old me."

For some of the women, HIV was not their greatest concern, and it had not disrupted their lives in the ways that I thought it would. When I talked to Joanie about the issues she was facing in her life, I *expected* her to talk about AIDS. Instead, she talked to me at length about how being the sole parent to four children was the most stressful experience in her life, and she emphasized that she had the same problems as anyone else. For example:

Ann: So, what's going on in your life now as you deal with HIV, what issues do you have, if any?

Joanie: Really, nothing. The only thing I really have is financial, like any normal person, HIV or not -- financial issues, car problems, the kids drive me crazy. You know, just normal things that even regular people will go through.

Among individuals with chronic illnesses, illness is typically only part of a life

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story; "illness remains part of the texture of a biography -- certainly something to be managed and taken into consideration but certainly not the only aspect of life" (Corbin & Strauss, 1987, p. 251). If there was one message that I could take from all of the women's stories, it was that "I am more than my illness." Other important dimensions that shaped women's daily lives and self-concepts included racial, ethnic and social class backgrounds, and personal biographies. Most of the women were mothers who had raised or were raising their children alone, with limited social and financial resources. Thus, children and their motherhood role were significant themes in women's stories; AIDS affects not only the women, it affects their children, their families, and their ability to parent. The women were also caretakers, workers, students, activists, or strived to accomplish those roles. Many women enacted in their lives or spoke of their desires to help others in their struggles with AIDS. In the women's stories, their AIDS experience was never solely about themselves, and I suspect that is very much connected to gender (Franz & Stewart, 1994; Personal Narratives Group, 1989).

I want to make one final point about adaptation as it exists in women's stories and in literatures on illness and other traumatic life circumstances. Adaptation is a *process*; it occurs over and over as new losses or issues arise (Charmaz, 1995; Corbin & Strauss, 1987). When individuals are faced with trauma or challenge, they can either stop living or they can continue to live the best they can. Robert Jay Lifton (1993) writes that a survivor has two psychological possibilities, "to shut down or to open up" (p. 82). Usually, he suggests, a person does both, and this dissertation is essentially about how women both "shut down" and "open up" in their survival with AIDS. The shutting down was most

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obvious in the diagnosis stories, whereas the opening up -- the proteanism of survival -- became evident as the stories progressed. Both perhaps are necessary elements of survival -- loss and grief juxtaposed with meaning, hope and new potential. There are many, including some of the women in this study, who believe that out of loss comes meaning, wisdom, and even growth. That it is only when things fall apart that they can be put back together again. Humans are by nature survivors. To use Lifton's term, we are "protean," quite capable of changing our selves in order to adapt to our life circumstances. Our nature is not to give up in the face of difficulties, but rather to look for the proverbial light in the dark, to keep going, to hope. From my perspective, what is so bewildering is not *that* we continue, but *how* we continue. What is intriguing is to learn from where individuals gain their power, strength, and support, and I think these stories allow us insight into how individuals live through difficult circumstances.

Michelle Fine and colleagues (Fine & Weiss, 1996; Fine, Weiss, Weseen, & Wong, 2000) have noted the tension between representing individuals, particularly historically oppressed groups, as either victimized/damaged or resilient/strong, and they question these categories as our only choices for representation.

> We share the worries, but worry more about the fixed "choices" that are being offered. Simple stories of discrimination and victimization, with no evidence of resistance, resilience, or agency, are seriously flawed and deceptively partial; they deny the rich subjectivities of persons surviving amid devastating social circumstances. Equally dreary, however, are the increasingly popular stories of

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> individual heroes who thrive despite their difficulties, denying the burdens of surviving amid such circumstances. (Fine et al., 2000, p. 125)

As the women's stories suggest, the reality of living with any difficult circumstance is that individuals have moments of "success" *and* moments of struggle (Massey et al., 1998). The women were not always accepting of their illness, and they were not always dealing well with the demands of their lives. Most recognized and articulated the limits of what they could and could not manage or make sense of in their lives. But braided through their narratives of struggle were many instances of personal strength and growth, of taking control of life and health when circumstances did not make it easy, and of trying to attain new goals in the face of an uncertain future. By characterizing our participants as either "resilient" *or* "damaged," (Fine & Weiss, 1996) we lose sight of the fact that adaptation is a back and forth process that occurs within particular personal, social and structural contexts. In reference to adapting to chronic illness, Arthur Kleinman (1988) writes,

> Successful coping...is not something that can be achieved outright, once and for all. Patients and families...struggle to cope on a daily basis. ...It is even uncertain what successful coping means in any generic sense apart from an individual's particular experience in a particular local context. What is clear is that chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order, and individual mastery. Like the rest of life...it must be taken in total without valuing one part and rejecting others: we are

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> both courageous and weak. Few of us are heroes in the grand sense; but in a small, quiet way and in a moral rather than a military sense, there are real heroes among the chronically ill. (p. 144-45)

We can recognize heroism, then, in an individual's perseverance through the ups and downs of daily life with serious illness (Frank, 1995; Kleinman, 1988). We can also recognize it in the telling of these stories; in an individual's willingness to be a witness to the struggle of living with HIV/AIDS in our society, and to show others the possibilities that exist in seemingly impossible situations (Frank, 1995). Barnard (1995) suggests that for the chronically ill,

> ...hope involves telling ourselves a new story. Through the play of the imagination we detach ourselves from the story of our lives up to the present and fashion alternatives. The dynamics of hoping in the context of chronic illness and disability thus amounts to what we might call the "renarratization" of illness. (p. 53)

This renarratization, he suggests, can take place on two levels. On a personal level, it involves the "reformulation of our image of the self and its possibilities;" on a social level, renarratization "can take the form of a critique of the very categories by which society defines deviance and disability" (Barnard, 1995, p. 53). In the women's stories we see changing images of self and possibility, but if we look closely we can also see social critiques -- in refusals to remain silent about their lives and shut themselves off from

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society; in refusals to accept the stereotypes, stigma and discrimination of AIDS; and in refusals to strive for restitution at all costs.

Whereas Frank's (1995) framework of illness narratives has been criticized as a-contextual (Atkinson, 1997), Mandelbaum's framework points to the importance of dimensions or contexts for understanding the turning points and adaptations in people's lives and life stories. An analysis of stories requires a focus on *both* the personal experiences and social circumstances and structures that shape them (Personal Narratives Group, 1989; Romero & Stewart, 1999), particularly now when individualistic concepts such as coping, meaning-making, posttraumatic growth, resilience and thriving are becoming more prominent in psychological research. The women's stories revealed how social (e.g., stigma) and historical (e.g., availability of new treatments) dimensions affect how one lives with and talks about AIDS. Other life story research supports the importance of context in interpretation. Catherine Zappulla (1997), for instance, traced the life stories of three teachers with AIDS as they struggled -- from diagnosis through illness -- with the ignorance and stigma within the "moral community" of the school. Through these stories, Zappulla explored the impact of AIDS on both the personal and professional lives of these individuals, and the responses of school communities once the "secret" of AIDS was revealed. The stories showed how the perception of teachers as role models and "ideal citizens" was a social context that only intensified the personal struggles of these individuals, in particular the struggle between secrecy and truth, the burdens of living a lie, and the fears and realities of judgment and rejection (Zappulla, 1997).

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Frank's Narrative Forms in Women's Life Stories

In the previous three chapters, I explored in-depth how women made use of Frank's narrative forms in their stories, so I will limit my discussion of this framework to a couple of points. First, this framework required me to be attentive to aspects of the stories that went beyond content. For instance, the idea of chaos narratives led me to look closely at narratives that I might otherwise have overlooked or dismissed as "bad storytelling," and to see that perhaps there was meaning in such narratives. This was particularly true for Kay's life story. She would tell me the same "stories" over and over, so I know that she was trying to convey experiences and issues that were important to her, but I was not always sure what she was trying to tell me. Her narrative was scattered and difficult to hear, and I did not always understand the meaning of what she was telling me. I'm not sure if this was related to her chaotic life circumstances, as Frank would suggest, or if it was reflective of her history of secrecy and keeping her life private. She did not have practice telling her story because she had never wanted anyone to know it, and coherence of stories comes through their practice (Gubrium & Holstein, 1998). This study seems to have been one of Kay's first attempts to develop her story on her terms.

Further, attention to the narrative construction or "frame" of a life story provided context and meaning to the events that women retold (Charmaz, 1999). For instance, most of the women's stories were filled with extreme hardships (both HIV-related and not), but I don't think the women told me of these difficulties just to reveal how hard their lives had been. Several women framed their difficulties as challenges that contributed to

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their sense of strength and survival. The detailed retelling of these adversities served as a narrative strategy for making sense of experience, created a sense of drama in overcoming adversities, and provided a frame for understanding each woman's survival with AIDS. Susan's life story, for example, might easily be interpreted as a "crisis" or chaos narrative. But if I listen to the many crisis situations revealed in her story along side her statement, "When I'm in crisis I seem to do much better. When I'm not in crisis, it's when it gets more difficult," I see the possibility that constructing her story in this way actually reveals her successes and her resilience. She tells a crisis narrative, but she always gets through the crisis, and according to Susan, this is what keeps her going. The different interpretations derived from examining thematic fragments versus narrative themes throughout a life story become apparent here. That is, if I had looked across the stories for themes of "adversity" and "overcoming adversity," this narrative strategy most likely would not be apparent. But an examination of narrative threads and thematic linkages within individual stories suggests that there is strategy and meaning in their construction (Gubrium & Holstein, 1998).

In terms of content, Frank's framework was important for "hearing" and interpreting thematic variations in the stories. For example, the concept of restitution narratives provided an explanation for the disparity between the medical and popular discourse on protease inhibitors (i.e., master narrative) and how women storied their beliefs and decisions surrounding treatment (i.e., counternarrative). A consideration of restitution in women's stories was also important for hearing the distinctions between "curing" and "healing," and for providing one interpretation for the lack of talk about

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death. Another recent study (Ezzy, 2000) used Frank's narrative forms as a foundation for analysis of narratives of living with HIV/AIDS, although the narrative forms were modified and used in such a way that make comparisons with my study difficult. In this study, Douglas Ezzy assigned one narrative form to each interview (contrary to Frank's idea that in any illness all three narrative types are told), and then identified differences among individuals in each "narrative group" according to their orientations toward the future (especially as connected to new treatments), religiosity, and connection to HIV communities. Although Frank's framework was used somewhat differently, it remains an important "listening device" that encourages careful attention to the stories and provides a common framework within which to hear the different narrative threads woven through individual stories (Frank, 1995).

Narrative privileges the particular (Skultans, 2000), but there are shared understandings and social experiences that both shape narratives and are depicted within in them. The frameworks of Mandelbaum and Frank provided a common way for me to structure and interpret the life stories, while retaining the individual understandings, meanings and contexts of experiences. This attention to individual meaning is important, even if it means that we end up with multiple stories, identities and meanings that complicate our interpretations and our writing. As Denzin (1989a) points out,

> When sociologists and other listeners seek to find a common ground of consensual meaning within a story or to establish common meanings that extend across stories, all they end up with are glossed, indexically meaningful, yet de-

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personalized versions of the life experiences they wish to understand. There is no warrant in such practices. (p. 73)

Doing life story work means having to manage multiplicities and partialities (Tierney, 1993b). The goal of this study was not to develop theory or to generalize beyond these stories, but to represent and interpret the women's stories of their experiences with as much detail and diversity as possible. To expose the complexities of lived experience -- the multiple voices, identities, histories, contexts, and perspectives that exist in women's lives and are reflected in their stories (Franz & Stewart, 1994; Romero & Stewart, 1999; Tierney 1993b).

Texts as Partial Representations

Stories do not speak for themselves. Although we as researchers are obliged to provide an interpretation of our participants' stories, our interpretation is not the only legitimate one. Meanings and interpretations are always incomplete and partial, and all interpretive texts are open to challenge (Denzin, 1994). Indeed, interpretations will differ among individuals because each of us views and understands human experience through a different "lens." Denzin (1989a) remarks that, "Each teller speaks from a biographical position that is unique and, in a sense, unshareable. Each hearer of a story hears from a similarly unshareable position" (p. 72). The authoritative text -- a singular version of the "truth" -- is an impossibility.

I cannot be sure that I have adequately interpreted and presented what the women

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were trying to communicate through their stories, a concern that stems in part from my belief that the written text of the story is not the real communication; it can't be given that the transcription, and from that the presented text, is only a partial representation of what happened in the interview (Mishler, 1986). Kvale (1996) reminds researchers of the danger in thinking of interviews in terms of the transcript and written text:

> Although produced as an oral discourse, the interview appears in the form of a written text. The transcript is a bastard, a hybrid between and oral discourse unfolding over time, face to face, in a lived situation -- where what is said is addressed to a specific listener present -- and a written text created for a general, distant, public. (p. 5)

The true communication comes with the act of listening to and participating in the creation of the story -- the storytelling relationship -- which can only be portrayed partially in the text as an "artificial construct" of a lived oral conversation (Frank, 2000; Kvale, 1996). At some point after writing the first draft of this dissertation, I realized that I had overlooked those lived interactions and taken for granted that the transcripts were the interviews -- they represented the "data" to analyze. I had coded each section of the transcripts according to content, and when I fragmented the stories and put the draft together using the prominent themes, I found that much of the meaning of their stories was lost (Reissman, 1993). What I had thought, learned, and felt during and from those interviews was also absent. This became dramatically evident to me as I started to reread the research journal I had kept throughout this project. As I revisited those lives and

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experiences, the thoughts and feelings that I had at the time came flooding back. It was disturbing to realize that I had forgotten all of those feelings. Somehow, I had managed to place them in the background as I went on with the academic task of "writing up the research." These people's lives, our interactions, became their "stories," and I forgot that I had once cared, worried and even cried about them. I suppose it is inevitable that we all move on with our lives, and new concerns and projects take precedence. But a conscious effort to keep those interactions and feelings in the foreground was a necessary part of interpreting the stories.

I essentially started over to write and interpret the women's stories -- or rather, my story of the women's stories. As my writing and interpretation evolved, I came to rely on my record and memory of our interactions and conversations, the taped recordings of the interviews, and the re-reading of my research journal to understand the themes in their stories, the thematic interrelationships, and how these were manifested in the women's lives and stories. Within the frameworks that I chose for interpreting the women's stories and structuring the larger story of the dissertation itself, I looked at and listened to each of the stories as a whole, within my understanding of each woman's life circumstances, and with my understanding of *how* various experiences were talked about by each person -- their tone of voice, body language, emotions, tears, hopes, excitement, disappointment, and fears. I also reconsidered how my own understandings, feelings and experiences during the research process were important to the development and interpretation of the women's stories. All of this was grist for the interpretation that did not (could not) come from a transcript, but that was critical to my interpretation.

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Assessing the "Goodness" of the Research and Text

Because interpretive understandings are necessarily subjective, partial, incomplete, contextually located and kaleidoscopic (Kidder & Fine, 1997), criteria for judging the legitimacy or "goodness" of interpretive texts is a ongoing challenge and often-debated issue in qualitative inquiry (Angen, 2000; Denzin, 1994; Lincoln, 1995; Tierney, 1999). Some researchers have argued for specific criteria to judge the credibility or validity of qualitative work, such as member-checking, reflexivity, data triangulation, and peer review, but each of these "solutions" to assessing validity raises its own problems (Angen, 2000). For example, member-checking and other forms of collaboration presume that respondents are willing to, capable of, and interested in being involved in the interpretations of their stories. Other than a willingness to be interviewed and a desire "to be of use," I found that the women were not necessarily interested in following up on their interviews by viewing/commenting on them, or in the outcome of the project. Other researchers have noted similar disinterest among their participants in terms of what is written about them (Tierney, 1995), and a range in participants' interest and ability to participate as collaborators (Estroff, 1995). In this study, only Kay read her transcript and asked that certain information about her life be removed. In addition, for women who were not "out" about their HIV status, even keeping a copy of the consent form meant risking exposure.

In my research I did share my interview tapes, transcripts and interpretive ideas with various faculty members and peers involved in AIDS and/or research communities.

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Although in certain respects the sharing of the data was helpful (e.g., the identification of some important themes), it was less useful than I had hoped because we were not working from the same standpoint in the research. I was coming from a place of much deeper and longer involvement in the research topic, with the women, and with their stories. The meaning and interpretations that I ultimately derived from the women's stories came from this involvement, from my various interactions and experiences of working in the field of HIV/AIDS, and from the different theoretical and research literatures and disciplines that informed my interpretations.

From poststructural interpretive perspectives, quite different interpretive criteria have been proposed (Denzin, 1994; Lather, 1995; Lincoln, 1995; Mishler, 1990). Some suggest that validation of qualitative work should be more focused on the practical and moral/ethical values of the research, and researcher responsibility, than on specific methodological criteria that can be applied to every interpretive study (Angen, 2000; Bochner, 2000). Lincoln (1993), for instance, suggests that texts should be faithful to our participants lives, and must be persuasive to those whose lives are represented as well as to social science and policy communities. Further, such texts must be explicit about the analytic process -- how the text was developed -- and must be clear about the ethical and political considerations involved in the research. Bochner (2000) writes that he judges ethnographic and qualitative texts on a variety of factors, including: the abundance of concrete life details and emotions/feelings of narrators; the structural complexity of narratives; the emotional credibility, vulnerability, and honesty of the author; the ethical self-consciousness of the author; and the ability of the story to move and compel.

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Richardson (2000) relies on similar criteria of substantive contribution, aesthetic merit, reflexivity of the author, emotional and intellectual impact of the stories/text, and whether the text embodies a sense of lived experience.

In terms of this study, I draw on these alternative criteria to determine what I feel are the most important questions raised by the research: Do the women's stories deepen our understanding of women's lives and experiences of HIV/AIDS, particularly as they are anchored in biographical, social, cultural, and historical contexts? Does the research have practical value and meaning? Does it raise new questions and possibilities? Does it have the capacity to affect thoughts and actions? Throughout the dissertation, I have attempted to address these questions, and to provide the reader with adequate detail to understand how I came to write this particular text. Next, I turn to the ethical considerations and the practical and theoretical values of the research.

Ethical Reflections and Considerations

Life story research raises a number of methodological and ethical issues, and these become amplified when we are working with people who are chronically ill or otherwise "marginalized" (Estroff, 1995). These issues cannot be swept under the rug or relegated to a couple of sentences about informed consent and assurances of confidentiality (although this is common practice). This research is fraught with the same issues that accompany most qualitative and ethnographic research, including issues of interpretive authority, voice, and representation, and the responsibilities we have to those who participate in our research.

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Representation of the Women and Their Stories

Most of us who tell the stories of Others struggle with issues of representation -- how we represent our participants' voices/stories/lives in our texts; how we represent ourselves; the frameworks and categories we use to interpret "data", and even the language we use in writing others' lives (Fine & Weiss, 1996; Lather, in press; Tierney, 1995, 1998). Much of the qualitative work on AIDS has relied on more "traditional" approaches to analysis, which typically involve fragmenting an interview transcript according to its thematic content (Coffey & Atkinson, 1996; Reissman, 1993). Sometimes, relevant themes are counted in terms of how often they are mentioned by participants (e.g., Hackl, Somlai, Kelly, & Kalichman, 1997). In other studies, a few lines from an interview might be presented in the context of researchers' discussions or theorization about particular themes (e.g., Adam & Sears, 1996). In such work, perhaps because the themes become decontextualized from individual life stories, issues of interpretation, representation and voice are rarely problemetized.

Patti Lather and Chris Smithies' (1997) study of women living with AIDS is an exception. As researchers, they situate themselves "not so much as experts 'saying what things mean' in terms of 'data', but rather as witnesses giving testimony to what is happening to these women" (p. 127). In their experimental ethnography they specifically address issues of representation and voice through textual strategies (Lather, in press). The book has a split-text format; at the top of the page are individual stories and what appear to be "transcripts" of group discussions with the researchers. At the bottom of the

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page and in a smaller font, is a running commentary of the researchers experiences and interpretations of the research. Between the thematic chapters based on the women's interviews are "inter-texts" about angels, which "function as 'breathers' between the themes and emotions of the women's stories, shifting the book from women's testimony to short engagements with popular culture, history, poetry, and sociology, returning again to the women's stories" (Lather, 1995, p. 3-4). Also included throughout the book are "factoid" boxes that provide various types of HIV/AIDS information and resources. This intentional "messy text" serves to challenge and "trouble" readers on various levels. The book's format also reflected an effort to complicate ethnographic representation. Lather (in press) writes that she and her co-researcher Chris Smithies wanted

> to construct a book on women living with HIV/AIDS where the reader comes to know through discontinuous bits and multiples of the women's stories. Such textual dispersal works against easy categories of us and them, where 'us' is the concerned and voyeuristic and 'them' are the objects of our pity, fear, and fascination. Refusing to deliver the women to the reader in a linear, tidy narrative, our intention in the book is to block and displace easy identifications and sentimentalizing empathy. Thus the text works toward constructing a respectful distance between the reader and the subject of the research...

The book is meant as a popular text, a so-called "K-mart" book for women living with HIV/AIDS, but it is also an academic text that "reflects back at its readers the problems of inquiry at the same time an inquiry is conducted" (Lather, in press). Lather

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(in press) notes that some academic audiences have commented on the format/content as "distanced and disembodied" and "caught up in academese." Some of the women themselves commented on the angel inter-texts as being "above" them. I don't know if the book works as both a popular and academic work -- the authors purposely do not write the book for a particular audience or reader. In that approach, though, they run the danger of trying to accomplish too much, with the result being a text that may not be understandable to any audience (Tierney, 1995, 1998). Although it is open to debate whether or not the format of the book works for different audiences, I respect the efforts of these researchers to engage their participants in the production of the text, and to trouble us about what it means to tell stories that are not our own.

Throughout this research, I have struggled with the question, "Should I even be telling these stories?" (Estroff, 1995). I worry about voyeurism and exploitation, and I admit that on many levels it makes me uncomfortable to talk about others' lives. But this isn't "comfortable" research -- it challenges methodologies, ethics and politics. It challenges me personally. As Patti Lather (Lather & Smithies, 1997) writes about her research on women with HIV/AIDS, maybe it's good that we don't know how to talk about the women in our research, and that we *should* be uncomfortable telling the stories of other people (p. 9). It makes us more careful about easy generalizations and presumptions of understanding their lives.

The typical representations of women who have HIV/AIDS as minority, impoverished, drug-addicted, isolated, depressed, voiceless, etc. are both based in fact, and they are fictions. In this study, I do provide an interpretation of the women's stories

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because I think the frameworks are useful in many ways that I've already described. They have allowed me to present the thematic elements of the women's stories within the individual contexts and particularities of their lives and stories, so a reader gains a sense of the individual meaning of experiences. I have tried to place the experience of AIDS within the larger social and cultural contexts of women's lives, and to represent the women as human beings who struggle but who also have strengths. As I wrote in the introduction, the stories told *about* women with AIDS are usually not the same as the stories told *by* them. I hope this project shows that the stories told by women with AIDS are more certainly more complex, and present alternatives to the master narratives that are rarely revealed (or even considered) in research or popular images of women with AIDS.

"Women with AIDS" as a social issue was and still is in need of visibility and attention. The idea of the women as silenced, and this project as a mode of providing them a "voice," is a partial truth (Clifford, 1986). Several of the women were out there resisting silence and voicing their stories long before I came along, in forums that researchers and academics do not often encounter. One of the practical values of this study is that I can introduce the women's stories (or rather, my interpretations of their stories) into areas -- such as social science communities -- that are still very much in need of hearing them. This project can be a source of information that *should* inform the work of researchers involved in AIDS issues, can promote awareness of the multiplicities and complexities of human lives, and encourage all of us to work these complexities into our theories, frameworks and texts. Following Frank (2000), in this respect my standpoint in this project is self-consciously ethical:

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> Social scientists may not be formulators of emergent ethics, but they can facilitate this emergence by circulating stories, finding commonalities in those stories, and confronting people with the 'inconvenient facts' (to adopt Weber's [1972] phrase) of stories that have been unheard. Creating a space for absent subjects...and filling that space with those subjects' presence and spoken experience is a form of ethical work. (p. 363)

This study, then, is about addressing a gap in the research literature, and about making visible the stories that do not often get told, and less often get heard. But it is also about critique and the hope for change in how we think about and conduct our research.

Relationships and Responsibility

There is no one purpose that life stories (or illness stories) serve (Tierney, 1999). At first, the primary reason that I wanted to research the life stories of women with HIV/AIDS was to address what I saw as a glaring omission in the AIDS and social science literature, and in the larger AIDS epidemic -- depictions and explorations of women's experiences were conspicuously absent. As the research progressed, my involvement with these women and with other people with AIDS became the most significant and meaningful purpose of the work I was doing.

How researchers are involved with their participants is an ethical as well as methodological issue raised by qualitative work. I had initially conceptualized and proposed the project as a series of interviews with a smaller number of participants (four

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to six). There were some concerns about this design, and after consultation with my dissertation committee and other colleagues, the project ended up being one interview (with the possibility of a second) with a larger number of women. The concerns, including my own, were primarily practical, such as managing the breadth of such interview material and the realities of ongoing, collaborative work with women who are living under demanding circumstances. But one of the concerns raised by an ethics review committee was that repeated interactions with my participants might result in an "undesired attachment between the subject and the researcher." Although this was a legitimate concern, it raised a dilemma for the research. I had envisioned a participatory project -- how was I supposed to be involved with the women on an ongoing basis and not form a relationship? That was the whole point. Further, I found that issue did not diminish just because I limited my interactions with the women to one interview.

For the most part, my involvement with the women was limited to one interview, but I had ongoing relationships with two of my participants. One, Emily, became a friend independent of the research project. Another, Kay, rather unexpectedly involved me in her life. The first time I met Kay, she spent most of the interview talking *around* the issue of illness and how AIDS had affected her life. She later admitted, "I was tryin' to avoid the subject, and get into my life, about what I've been through as a woman, black, single, 36, out-of-wedlock children." It was important to her that I understand her as a person -- the circumstances of her life, her character. That I didn't look at her as a "statistic" or categorize her in a way that she felt the Welfare system had done, "Puttin' you all in this little category, until it's just like a peephole." The stigma she felt from being black,

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having AIDS, and having to rely on public assistance was not as bad as the injustice of not being seen as a person.

Shortly after our first interview, I came home very late to find a long, distressing message from Kay on my answering machine. I remember the panic I felt about being the one person she called when she was scared, when her illness became severe and she didn't know what to do. "I had only met her once," I thought, "Why was she calling me?" I never anticipated that someone who was so secretive with friends, family and even her psychologist would seek me out as a source of support, especially in a time of uncertainty and panic about being ill. It was too late to call her back at that night, and so I waited until the next day. I worried when I couldn't reach her for a week, and I felt guilty for not calling her back right away. She finally called me to let me know that she was okay. She explained that she had been experiencing "strong physiological changes," and that she had been a bit panicked when she called me. She then assured me that next time she had a stressful situation, she would be able to handle it.

For some reason, Kay trusted me, and eventually we got around to talking about her illness in another interview. As she became more ill over the period of our acquaintance, illness became a more prominent part of our conversations. I got to know Kay better after our interviews because she would call me or stop by my desk at work to let me know how she was doing. Although our relationship beyond the interviews consisted of talking once in a while on the phone or at my office, I still felt uncomfortable about forming a relationship that I knew could end. Right before I moved out of the state, Kay left me a message that she was in the hospital again. I called her there several times

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to see if I could visit, but she didn't have a phone and there was no way to reach her. I left messages on her home phone, but I never heard from her again. After I moved, I continued to leave messages, but with the generic voicemail message I couldn't even be sure this was still her number. But I did, and still do, feel some guilt about having left without being able contact her, and uncertain about my responsibility to Kay given the relationship that we did have. I'm not sure what I offered her, but I know she felt uncomfortable talking about AIDS with most of the other people in her life.

At the beginning of the project, before I had even begun the interviews, I was aware of my "outsider" status. Probably, I even thought about the women I would interview in terms of a distant Other. My awareness of this was one of the reasons that I didn't want just to have a single interaction with each person. My relationship with Emily was perhaps most important in terms of diminishing my sense of distance from the women in my study. We were near the same age, we shared friends and interests, and eventually we became friends who spent a lot of time together. During the time we spent hanging out in our apartments, AIDS was often in the background. Sometimes we talked about it, usually if she was having a medical crisis or just a bad day, but mostly we didn't. It wasn't the basis of our relationship. But in our often daily interactions, I saw what life with AIDS could be for a person -- the roller coaster of health and emotions that does not ever stop. I understood better when story and life reflected one another, and when they diverged.

I'm not sure we can determine at the outset how we should or should not be involved with our participants. I discovered that the nature of the interactions between a

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researcher and the participants has to be negotiated by them in the course of the research (LeCompte, 1993). I could not have anticipated that Kay, a shy, reticent woman who at first seemed so reluctant to talk about her experiences, would want to involve me in her life beyond our interviews. I relate these experiences not as a narcissistic endeavor, but because they are a significant part of my interpretations. As Tierney (1998) remarks, "...who we are and how we relate to those with whom we work circumscribes our daily research interactions" (p. 52). As I've suggested, I believe that if I had been involved with people living with AIDS in my work, and if I had not had the personal encounters that I did, I would not have come to the same understandings or even thought about or conducted the research in the same ways (Clandinin & Connelly, 1994).

Tierney (1994) has argued that we must include in our research the capacity for empathy and caring, and his life story work with Robert, a gay man with AIDS, reflects this possibility.

> My initial goal in this text was not to produce a written work but to enable Robert the time and space to reflect on his life during a most difficult period. That is, I did not initially see my role in a traditional manner as an "expert" who conducted research to advance knowledge or to solve an empirical question. ...Indeed, at the outset I cared very little about the "outcome" of the "research;" my concern was for the individual with whom I was engaged in the research encounter. (p. 104)

Tierney (1993a) writes that our task as researchers is not just to record the lives of those who have been forgotten or overlooked, but that "critical research needs to

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challenge the oppressive structures that create conditions for silencing" (p. 4). Our interactions with our participants and our involvement in the development of their life stories, he suggests, is one act of resistance.

This brings me back to positions such as Arthur Frank's (1995) "ethic of listening," and Arthur Kleinman's (1988) "empathic witnessing," and David Barnard's (1995) discussion of the social dimensions of hoping. Central to these ideas is the importance of the storytelling relationship, and the responsibility and commitment we have to facilitate and listen to stories of illness because people who are ill have a *need* to tell their stories -- to relate something of importance, to gain distance from what threatens them, or to work through the "narrative wreckage" of illness (Frank, 1995, 2000). Paul Atkinson (Atkinson, 1997; Atkinson & Silverman, 1997) has criticized the narrative work of Kleinman (1988), Frank (1995) and others because of its emphasis on advocacy, or what he describes as the "empowerment and the promotion of respondents' insight into their own problems, experiences, and interest..." (Atkinson, 1997, p. 334). Atkinson seems to believe that narrative as a methodological issue should not be confused with narrative as an ethical concern or a "surrogate form of liberal humanism and a romantic celebration of the individual subject" (p. 335). In his response to this criticism (Frank, 2000), Frank rejects the idea that advocacy has no place in "principled investigations," and says, "What makes an investigation principled is its advocacy. What counts, given my standpoint, is not to describe the experiences of the ill but to provide resources for the ill to experience their situations differently" (p. 357).

Although I am concerned about the exploitation of others' stories, I also believe

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that the women in this study told their stories not just for my benefit. As I have mentioned, there were no financial or material incentives for the women to talk to me; the reasons then were social and personal. Some women participated because they wanted to help other women by getting information about women's issues, experiences and lives "out there." Others participated to help me out, and some just needed someone to listen to their story. Telling a life story can also represent agency, resistance, or a form of taking control (Frank, 1995). I agree with the following point made recently by Arthur Bochner (2000):

> Too often, personal narratives are demeaned as some sort of victim art or confessional. What we miss when we react too quickly that way is how narrative is used as a source of empowerment and a form of resistance to counter the domination of canonical discourses. Often, the expressed purpose is to devictimize the stigmatized identity, to confirm and humanize tragic experiences by bearing witness to what it means to live with shame, abuse, addiction, or bodily dysfunction and to gain agency through testimony. (p. 271)

Frank (2000) suggests that ill individuals are responsible for telling their own stories about the meanings of illness in their lives. Our responsibility as health professionals and researchers is to enter into relationships of storytelling -- to listen, to represent the stories faithfully, and to make those stories "hearable" to others, particularly to those whose perspectives are most often privileged.

What I hope for my own future work is to develop projects that allow me to work

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more collaboratively with those participants who have an interest. Of course, this goal does not work for all topics or with all people, but I think it is a worthwhile effort. For example, I would like to work with fewer individuals to develop life stories over a longer period of time, and to explore how stories develop and change with time and through different circumstances. I also want to work in ways where texts and other forms of (re)presentation are accessible to wider audiences (Tierney, 1995). People want to hear others' stories -- not necessarily our analysis of them. As Frank (2000) writes, "Storytellers do not call for their narratives to be analyzed; they call for other stories in which experiences are shared, commonalities discovered, and relationships built" (p. 355). Thus, our work requires that we represent stories for lay audiences as well as for academic audiences.

Summary and Conclusions

There is no singular purpose to this dissertation. One purpose was to present the stories of women living with AIDS as a response to the "cultural silencing" (Treichler, 1999) of women in the epidemic. These stories contribute to what is still a limited literature on women's experiences with AIDS and they provide a foundation for further exploration. In the introduction, I wrote that this dissertation sought to understand how the meanings and experiences of AIDS might "look different" if seen from the perspective of women who are living with this illness instead of from the perspective of Others (e.g., social scientists, physicians, public health officials, the public). Thus, the women's stories offer alternative perspectives to the master cultural narratives that are

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available to us regarding the meanings of AIDS, and the lives and experiences of individuals who live with it on a daily basis. This work represents and encourages a social scientific perspective of AIDS that more closely resembles individuals' lived experiences (Frank, 2000), and it seeks to understand those experiences within specific contexts -- not just person-specific contexts, but what it means to have *this* particular illness at *these* moments in the epidemic's history.

To this end, I interpreted the women's life stories using two different frameworks that revealed different facets of the stories. Mandelbaum's framework allowed me to trace the significant experiences and contexts that influence how women create lives with AIDS, and Frank's narrative forms allowed me to explore the ways in which women make use of certain cultural narratives of illness. Although I do not presume to understand completely the women's lives or their experiences, their stories do provide us with some sense of *their own* understandings of their lives, the important turnings in their lives and illness experiences, the relevant and changing adaptations, and the diverse personal, social and cultural/historical contexts that have shaped their lives and stories. We see how stories were told about particular events or points in the illness experience, but also how the larger story was told, the themes that were elaborated (or not), and how narrative themes came together to create meaning in an individual's story. Finally, we see how different narrative forms are meaningful at different points in the illness story, and how they are meaningful to the larger life story.

I should note that this dissertation *does not* represent a systematic or in-depth thematic analysis of the life stories. The themes that I do discuss are those that came from

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or were revealed through the two analytical frameworks. We do, however, gain some important insight into the issues that women struggle with throughout their HIV/AIDS experience (both HIV-related and not), and how they manage these issues; the meanings of health, illness and treatments; the contours of uncertainty, loss, and hope; and the ways in which AIDS becomes integrated into the fabric of life and identity.

I also do not suggest that these women's stories or my interpretations of them are "generalizable" to all other people with HIV/AIDS or even to other women with HIV/AIDS. The stories presented here probably are not the same stories told by all women living with AIDS in this country. Emily's contrasting experiences of living with AIDS in a Midwestern state with few HIV-related resources and living in New York City suggest that much. These women were also all connected with AIDS-related groups and organizations in some capacity, so the stigma, isolation and loneliness of this illness may be more central to stories of individuals who are not similarly connected. That these stories were even told to me makes these women different from the many who still keep their HIV status a secret, and their stories to themselves.

I take seriously Arthur Frank's (1995) suggestion that part of our ethical responsibility as researchers is to listen to individuals' stories of illness and to make them available so that they might guide others through the illness experience. Thus, a primary goal of this project was to represent women's stories in order to "be of use" (Lather, 1997) to those who live with AIDS or are otherwise affected by it. This dissertation complements and extends the research and writings of Adam and Sears (1996), Lather and Smithies (1997), and Weitz (1991), all of whom have solicited the perspectives of

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individuals living with HIV/AIDS in order to "build knowledge of direct interest and use for seropositive people themselves" (Adam & Sears, 1996, p. xi). Although these works discuss several of the same thematic aspects of life with AIDS (e.g, diagnosis, coping strategies, relationships, death and dying) each does so in a different manner and among different "groups" of people living with HIV and AIDS. This dissertation study differs from these and other qualitative studies in various ways. First, it focused on a small number of women living with AIDS in a major city that has been hit hardest by the epidemic, but that also offers perhaps the greatest amount of resources and support available for people living with HIV/AIDS. Second, most other research represents a thematic analysis of interview data; this study used two different analytic frameworks to interpret fuller life stories. These frameworks offered unique perspectives on women's experiences living with AIDS, and allowed me to look a these experiences within particular contexts -- individual, social, cultural and historical -- that are crucial for understanding how people live with AIDS (or any illness), but that are rarely considered in theory or research (including qualitative). This is also one of the first projects to explore how the availability of new treatments has influenced the meanings, experiences, and stories of people with AIDS, and it presents narratives that complicate and counter subsequent cultural ideas that these treatments have transformed AIDS into a "manageable chronic illness," or that "AIDS is over."

So where can we go from here? For researchers who are interested in exploring particular aspects of illness or AIDS, the themes that were revealed through Mandelbaum's and Frank's frameworks provide a starting point for a more in-depth

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exploration of these issues. The stories in this dissertation do not represent all of the themes that were part of women's fuller life stories; thus, there are further opportunities within these stories to explore in greater depth particular topics or issues relevant to different research areas (e.g, illness, AIDS, women's lives), or to examine the stories with other frameworks. In terms of more narrative-based research, this study raised some interesting questions for me, such as: How are these stories similar (or not) to the stories of women being diagnosed HIV-positive in this decade (post-protease inhibitors), and to the stories of women who live outside of urban areas hardest hit by the epidemic or who are not connected to "AIDS communities" and resources? Like others who study serious illness or other life traumas, (e.g., Charmaz, 1995; Corbin & Strauss, 1987; Kleinman, 1988; Lifton, 1993), I have suggested that adaptation is an ongoing process. This idea is generally glossed over in quantitative studies of adaptation to illness, and acknowledged but not often explored in qualitative studies. The women's stories provide us with some insight into that process, but a story that recounts the past differs from a story told about the present, as events unfold (Charmaz, 1999). I think the process of adaptation could be examined more effectively through the collection narratives over the course of an illness experience, exploring how individuals' stories take shape and change as they struggle to make sense of illness and to incorporate it into their lives.

Although in theory this dissertation represents a psychological study of how women live with AIDS, I view it as more broad than that. To understand a "personal" experience such as this, I have argued that we must think beyond the individual and his or her psychological functioning in response to illness. That is, we must consider the other

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(i.e., non-illness) dimensions of individuals' lives, as well as dimensions such as social and cultural understandings and representations of AIDS. In my effort to understand and present this larger story of how women live with AIDS, I've relied on information from an array of disciplines and sources: psychology, sociology, women's studies, cultural studies, life history and narrative, medical humanities, biomedicine, public health, popular media, and literature produced by AIDS communities, activists, and people living with AIDS. Each has provided me with a different, although invaluable perspective on the women's stories, and I would encourage other researchers to broaden their frameworks and to venture outside of their own disciplines in order to gain a more holistic understanding of a particular phenomenon.

As I pointed out in this chapter, this project is also about an ethical perspective of research (Frank, 2000), and thus its value extends beyond the particular content of the women's stories. From my perspective, the most important implications for future research concern why, how and for whom we conduct research. I would like to see more self-conscious reflection on what and whose perspectives are guiding research, and serious consideration of how those perspectives influence what we "find out." In much of the literature that I've reviewed for this study, across disciplines and methodologies, researchers tend to suppress difference in order to come to some general consensus about the data. If there is one thing that becomes clear through these stories, it's that life with AIDS is not straightforward or uncomplicated. Thus, I've tried to reveal and respect contradictions and differences as well as consensus and similarities among the women and their stories, and to consider what those differences might mean. Confronting us with

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the "inconvenient facts" (Frank, 2000) and complexities of lived experience, stories such as these encourage us not to keep repeating the same studies, and challenge all of us to think beyond what we already think, and to know beyond what we already know. What I have learned and gained from thinking with these stories is on some level indescribable and immeasurable. But I believe the endeavor has made me a better researcher, thinker, and person. I think each of us has something important to gain from these stories.

That said, although I have theorized about and "interpreted" the women's stories, in the end I find myself resistant to drawing broad conclusions about what, exactly, these "findings" mean in terms of how women live with AIDS. As Patti Lather (Lather, 1997) writes, "... my struggle against making sense of participants' efforts to make sense of their experiences of HIV/AIDS troubles the ethics of reducing the fear, pain, joy, and urgency of people's lives to analytic categories" (p. 252). I also understand Arthur Frank's wariness of and stance against offering advice about the meanings of stories to professionals (e.g., clinicians, researchers, academics); in postmodern times, just as the ill are responsible for articulating what illness means for them, professionals themselves are responsible for determining the value and lessons in those stories (Frank, 2000).

In any research encounter, we are unlikely to come to a complete understanding of anyone or anything (Tierney, 1998). Like Lather and Smithies (1997), this text represents a mosaic of women's feelings, stories, and lives that reveals complexity as well as pattern. My intent here has been to present the stories of women living with AIDS so that we expand our gaze beyond AIDS when we talk with/about/for them. That instead of viewing people with AIDS as a problem of the Other, to be solved by social science or

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medicine, we use life stories to listen to how individuals understand and make sense of their own realities, and how they work within and against the circumstances of their lives to come to terms with AIDS.

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Table 1

Demographic Information at Time of Interview

Name	Age	Race/ Ethnicity	Year of Diagnosis	Time Since Diagnosis	Children	Education Completed
Barbara	36	Black	1994	1 yr., 7 mos.	1	1 yr. college
Joanie	41	White	1989	7 yrs., 6 mos.	4	10th grade
Kay	35	Black	1992	4 yrs., 7 mos.	1	2 yrs. college
Nancy	44	White	1985	11 yrs., 0 mos.	1	High school
Delores	34	Puerto Rican	1986	10 yrs., 3 mos.	3	High school
Maria	31	Puerto Rican	1990	6 yrs., 5 mos.	2	9th grade
Susan	34	White	1987	9 yrs., 6 mos.	1	High school
Emily	28	White	1988	8 yrs., 6 mos.	0	B.A.
Roberta	49	Black	1991	5 yrs., 6 mos.	0	High school
Angela	33	Puerto Rican	1990	6 yrs., 6 mos.	2	Assoc. degree
Judy	45	White	1987	10 yrs., 0 mos.	1	Masters work
Gloria	49	Puerto Rican	1987	10 yrs., 0 mos.	3	In college

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