

Pain, Courage, and Wisdom:
Stories of Women Living with HIV

by
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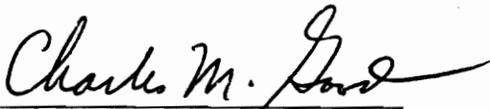
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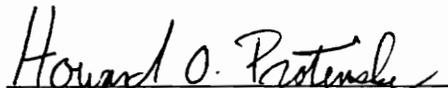
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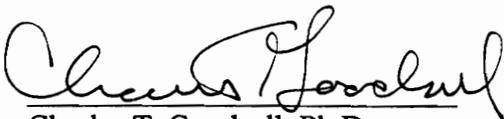
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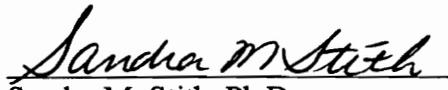
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In memory of
James Barton Gosling
May 17, 1959-November 12, 1993
your spirit and music lives on
and
for Jessica and Hannah
may you always have places to tell your stories
and plenty of good stories to tell

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TABLE OF CONTENTS

Acknowledgments	iii
I. Overview and Purpose of the Study	1
Background of HIV/AIDS in the United States	1
Rationale for the Study	4
Researcher's Stance	7
Research Questions	9
II. Review of the Literature	10
Theoretical Frameworks	10
Research on Women and HIV/AIDS	15
HIV/AIDS Risk Assessment for Women	16
HIV/AIDS Education and Prevention Programs	19
Studies of Women with HIV/AIDS	20
Summary	21
III. Methodology	22
Design	22
Networking	23
The Pilot	24
Participants	25
Conversations and Analysis	30
Ethical Considerations	35
IV. Introducing the Storytellers	37
V. Becoming HIV Infected and Finding Out	44
Beginning at the Beginning	44

Becoming HIV Infected	46
Diagnosis	53
VI. Telling Others	61
The First Ones to Know	62
The Circle Widens	65
Reflections on Telling Others	79
VII. Secrets and Leaks	84
Not Telling	84
The News Spreads Like a Virus	90
VIII. Going on with Life	98
What Hinders	98
What Encourages	107
Images to Live By	112
IX. Effects of the Research on the Researchers	114
Effects on the Author	114
Effects on the Participants	115
X. Suggestions and Recommendations	121
What Might be Helpful to Others?	121
Policy Recommendations for Practitioners	124
Recommendations for Further Research	134
Some Last Thoughts	137
References	138
Appendices	144
Appendix A: Letter of Agreement	144
Appendix B: Notice of Study in Newsletter	148

Appendix C: Interview Guide	150
Appendix D: Demographic Information	152
Appendix E: Research Assistant's Confidentiality Statement	154
Appendix F: Interview Questions	156
Vita	159
Abstract	

Chapter I

Overview and Purpose of the Study

This study was designed to recount an insider's perspective of the learnings, strengths and challenges women face as persons living with the Human Immune Deficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS). The study created a context in which five HIV positive women told their stories in informal, unstructured audio taped conversations. As experts on their own lives these women were considered co-researchers. Their status as co-researchers was integral to the feminist perspective of the study and was ensured through open-ended conversations which followed their narrative account rather than the researcher's agenda. In addition the co-researchers were supplied with transcripts (and audio tapes if desired) of the conversations which they could review, reflect on and edit. My analysis of these conversations and the co-researcher's recommendations provide implications for practitioners, public policy, and further research.

Background of HIV/AIDS in the United States

The rationale of this study is closely linked with the history and current status of HIV/AIDS in the United States. Currently AIDS is the leading cause of death in the United States for persons between the ages of 25-44 (Center for Disease Control, 1995). In June of 1981 the Center for Disease Control (CDC) reported five cases of pneumocystis carinii pneumonia (PCP) in Los Angeles. By August of the next year these and other new cases were linked to a new disease termed AIDS which was initially reported primarily in homosexual men (Malinowsky & Perry, 1991).

AIDS, a fatal disease, is caused by the HIV virus. The HIV virus attacks the immune system, killing T-helper white blood cells. With a decrease of T-helper (T-4)

cells the immune system is vulnerable to attack from opportunistic diseases (such as forms of cancer and pneumonia) that would normally be warded off. These opportunistic diseases account for AIDS deaths. The HIV virus is present in the body without visible signs for years. One of the insidious aspects of the disease is that it is possible to spread the virus via body fluids (such as blood, semen and vaginal secretions) without knowing you are infected and are infecting others (Richardson, 1988).

Early association of AIDS with homosexual men stigmatized it as a gay male disease (Corea, 1992). As the medical community documented AIDS in other segments of the population AIDS became associated with additional high risk groups: intravenous drug users and hemophiliacs. This initial association of AIDS and later HIV with two highly stigmatized high risk groups allowed many people to keep a distance from the disease through its identification with otherness (Corea, 1992). This otherness was heightened for persons living in rural areas, because of the lower numbers of persons in the high risk groups. For example the geographical area represented by this study has much lower numbers of persons with HIV/AIDS than urban areas of Virginia (Virginia Department of Health, 1995).

Women were not originally identified as a group affected by the disease, although the first woman with HIV was reported in 1982 (Pearlberg, 1991). The lack of public awareness of women living with HIV/AIDS is related to the long-standing under-representation of women in the official data reported by the CDC (Anastos & Marte, 1989). Official figures failed to account for women partly because the CDC diagnosis of AIDS is dependent on the presence of opportunistic diseases. These indicator diseases such as PCP and Kaposi's sarcoma were originally identified in the male population and did not include the gynecological diseases common in women with AIDS. Opportunistic diseases affecting women such as pelvic inflammatory disease, cervical cancer, and yeast

infections were not among the official indicator diseases required for an AIDS diagnosis and yet were common among women (Corea, 1992; Anastos & Marte, 1989; McKenzie, 1989). The medical treatment of women is still based primarily on the documented progression of the disease in men (Melnick, et al, 1994).

The original definition of the disease was based on the first cases of reported AIDS who were primarily male. Even women with the same clinical symptoms as men were diagnosed and treated differently (Anastos & Marte, 1989). For example, PCP the most common opportunistic disease and a major cause of AIDS deaths was often treated in women as a minor respiratory disease, and not identified as an indicator of AIDS. As a result of this non-aggressive treatment and the lack of awareness of the underlying condition of AIDS, there were higher rates of death in women. The definition of AIDS as a male disease continued to leave women out.

Melnick et al. (1994) in a study of survival and disease progression according to gender have noted that women have a poorer survival rate than men. Although they have not been able to identify why, they surmise it might be a result of different access to or utilization of the health care system. Other reasons might include lower socioeconomic status, homelessness, physical abuse, alcohol or drug problems, and the absence of social support.

The absence of women in the official figures was partially responsible for the under-funding of research on women living with HIV/AIDS, and the exclusion of women from drug trials (Corea, 1992; Anastos & Marte, 1989). Without adequate research on women the myth of HIV/AIDS as a male disease was perpetuated. This lack of awareness contributed to the spread of HIV/AIDS among women. Under-representation of women in official documentation of the growing AIDS epidemic resulted in inadequate prevention education for women at risk and inappropriate treatment for infected women

(Anastos & Marte, 1989). These inaccurate statistics resulted in the deaths of countless women who died undiagnosed.

Rationale for the Study

The absence of women in the AIDS picture has caused some to ask "Where are the women?" (Weiner, 1991, p. 375), to identify women as "the missing persons in the AIDS epidemic" (Anastos & Marte, 1989, p.6; Anastos & Marte, 1990, p.11), and to characterize the story of women and AIDS as the "invisible epidemic" (Corea, 1992). Unfortunately when women have been found in the social science and medical literature it is primarily in relation to their role as transmitters of the virus, not as sufferers with the disease (Anastos & Marte, 1989; Corea, 1991).

The missing voice of women living with HIV/AIDS needs to be heard not just because they have been neglected in the literature, but because these women, who are increasing in number dramatically, have unique concerns and needs defined by their biology and gender. In the following discussion the increased numbers of women living with HIV/AIDS will be documented first, followed by an exploration of the impact of child bearing and role expectations for women in the United States living with HIV/AIDS.

The numbers of women infected with HIV/AIDS are rising dramatically in the United States. Between 1981 and 1990 the women infected with AIDS increased 20 times (Quinn, et al, 1992). Virginia, the site of this study, is representative of these skyrocketing rates. In Virginia the current number of reported cases of women with AIDS is 722 while 1,567 women are officially documented as HIV positive (Commonwealth of Virginia, 1994). Women comprise 12.1% of the total number of persons with AIDS in Virginia, however women have jumped to 23.8% of the total HIV population (Commonwealth of Virginia, 1994). These figures reflect projected numbers

of women with AIDS doubling as these women move from HIV status to an AIDS diagnosis. As these women are diagnosed with AIDS, the proportion of women to men with AIDS will rise from a ratio of approximately one woman for every ten men to one woman for every four men. Black and Latina women are disproportionately represented in these figures for Black and Latina/os comprise only one fifth of the U.S. population, but Latina and Black women constitute 72% of all the women with AIDS (Pearlberg, 1991).

This shift in the gender composition of HIV/AIDS brings with it different medical needs, and psychosocial concerns. These concerns stem from the roles of women in this culture as both child bearers and caregivers. The great majority of the infected women are young and of childbearing age. In Virginia 92% of the women with HIV are between the ages of 20-49 at the time of diagnosis (Commonwealth of Virginia, 1994). Most young women who are HIV positive must grapple with different sexuality issues than men which include contraception, pregnancy and abortion (Campbell, 1990). These sexuality issues are particularly complex for women because HIV can be transmitted in utero, at birth, or through breast milk to their child.

The expectation of women as the caregivers in our culture compounds the already complex nature of these procreative issues (Richardson, 1988). For instance, one primary concern for many infected mothers is securing care for their children during possible extended illnesses or after their death. Michaels and Levine (1992) identify the issue of AIDS orphans as a social issue of enormous proportion and a neglected area of study. The care and possible orphaning of children is just one of the areas of women's care giving in this social/medical crisis. As McKenzie (1989) notes in the AIDS epidemic women's roles as friends, sisters, wives, mothers, grandmothers, partners, and paid

caregivers at work and in the home have gone unacknowledged. Many women fulfill these multiple roles and are HIV positive themselves.

HIV/AIDS affects not only procreation and care giving but all aspects of these women's lives: economic, social, physical and spiritual (Richardson, 1988; Matocha, 1992). The impact of HIV/AIDS reaches far beyond the infected individual to the family, extended support systems, and the community systems (Landau-Stanton & Clements, 1993). Despite a call for the immediate coordination of legal and counseling services for women with HIV and AIDS and their families as early as 1988 (Zuckerman & Gordon, 1988), scanty research has appeared in the social science literature to address this pressing need.

It is the voices of the women themselves that are missing from the research on women with HIV/AIDS. This study was designed to give voice to the narrative accounts of women living with HIV/AIDS because of their rising numbers and unique needs. The longer women are silent and silenced about their infection with HIV, the more women will suffer (Taylor-Brown, 1992). During the interview process I attempted to create a context in which the women's stories could be told in their own voice by beginning with the invitation to "tell anything and everything" about their experience of living with HIV.

In this study women with HIV/AIDS are placed in the center as persons with a life-threatening disease in a specific cultural context. Rather than dismissing these women as failed caregivers, child abandoners and spreaders of a contagious deadly disease, their welfare as well as that of their loved ones is valued. In this light the strengths and resources of these women can be highlighted through the telling of their stories.

Ultimately this process of story telling is one of co-construction. A story is never told exactly the same way twice. The variation in telling is influenced not only by the choices the teller makes but by the presence, stance, questions, response, and attention of

the listener(s). In this way the story is not just the creation of one person, but a shared event between two or more. The co-construction of these women's stories evolved as we developed our relationship through the negotiation of our conversations and the process of listening and speaking to one another.

In addition, the course of our dialogue was influenced by the design of the study: the research questions, methods, and assumptions. Gale (1991) asserts that research questions, methods and assumptions are not randomly chosen but deeply rooted in personal experience. Complex contextual elements such as gender, race, class, age, sexual orientation and family status compose our personal experiences (Allen & Baber, 1992). Therefore these contextual elements are germane for both the participants and myself.

The participants are introduced in Chapter IV. Prior to hearing their stories it is useful to know where I am situated in this culture and some of the experiences which frame my perspective. I bring myself into the picture in the next section, the researcher's stance, in order to acknowledge some of the ways my story may have influenced the co-construction of these stories.

Researcher's Stance

As a white, middle class woman and mother, I have been sheltered in a small town in rural Virginia from the ravages of AIDS. My life has not been touched directly either personally or professionally by someone with AIDS. Rather, my interest in women living with HIV/AIDS grew out of my commitment to women's and justice issues from a global perspective. After I chose this topic my husband and I each discovered poignantly we had a cousin dying of AIDS. Though we have not been in contact with these parts of our families for years, these two young men, now both dead, are with me in my thoughts and feelings as I write. I think about their courage and suffering, our family's ways of dealing

with their gay orientation, the different ways our families dealt with the news of their deaths and their funerals. I have cried with my cousin's mother and sister, and renewed acquaintance with that branch of the family. This research is now in part for them. They are not my only personal link to the topic.

My mother died of cancer almost 30 years ago, when I was 15. It is striking that in the mid 1960's cancer was a stigmatizing and secretive disease, in some ways like AIDS today. My experience with the loss of my mother to cancer, such a similar disease, in part motivates me to pursue this work. I know something of family secrets and societally imposed shame about disease; I know something about a child's untimely loss of a parent to a slow, debilitating death. One particular place I hope to make a contribution by hearing the stories of HIV/AIDS women is to find ways that are supportive of women and their children in the process of separation and death.

My commitment to hearing the stories of women living with HIV/AIDS is also partially born out of my experience of sitting at our dining table at dinner one night when I was about ten. I told my parents how painful their drinking was for me, and was silenced with their denial. I was given the choice to stop crying or go to my room. I know now the better choice was to go to my room. Instead I stopped crying. The silencing of my voice closed me off to my feelings and perceptions for many years. It was only as I told my story to confidants and therapists years later that I began to have access again to the vibrancy of my emotional life and to trust my own experience. My silencing as a child and teenager was born out of maintaining a family secret.

The AIDS experience too contains many secrets (Walker, 1991; Black, 1993). I feel that my experiences of living with a secret and my acquaintance with death can help me cross the boundaries of race and class to hear the truth of these women's stories as they tell them. Being silenced in this culture not only as a child of alcoholics but also as

a woman has acquainted me with some of the treacherousness and necessity of speaking up. The liberation I have known in being heard gave me strength to listen as openly as I could to these women. It is my hope that in turn, the telling of their stories was liberating for them and for others.

I share these personal reflections because of my social constructionist perspective that objectivity does not exist, and my knowledge as a feminist that it is not possible or preferable to separate ourselves from the personal. My stance as a researcher reveals some of my limitations, and strengths as a researcher, and discloses a part of my agenda for this work. My research questions follow from this personal sense of self, as well as the frameworks of social constructionism and feminism.

Research Questions

1. What are the stories of these HIV positive women?
2. What encourages or hinders these women to gain access their strengths, learnings, supports, and resources?
3. What do these women have to tell others from their vantage point?
4. In what ways are we affected by working together as co-researchers?

Chapter II

Review of the Literature

A rise in the documented cases of women with HIV presents a social problem of increasing importance as the epidemic of HIV/AIDS continues to spread. The epidemic affects all portions of the population, disproportionately striking the economically disadvantaged and persons of color (Zuckerman & Gordon, 1988). This in-depth exploration of the narratives of women with HIV/AIDS is grounded in the theories of feminism and social constructionism. This chapter first delineates relevant elements of these two theories. Attention is given to the assumptions which underlie the choice of the topic, methodology and the research process. Then pertinent social science literature addressing women with HIV/AIDS is reviewed.

Theoretical Frameworks

Social Constructionism.

The theory of social constructionism challenges common assumptions about objectivity and our everyday notions of the world. For social constructionists a "sense of self and relations with others are constructed and reconstructed through social interaction" (Allen & Baber, 1992, p.12). Gergen (1985) notes that social constructionism begins with a fundamental questioning of the "taken-for-granted world" (p.267) of our beliefs.

These beliefs are formed by categories derived through observations. For example, the beliefs about the differences between the genders do not reflect unitary truth about the nature of human experience. Under a historical and cultural analysis the fixed categories of man and woman lose their sharp boundaries. This disintegration of hard facts about

the differences between men and women provides room for alternative meanings of the distinctions which define gender in this culture. Ultimately such explorations may even encourage the abandonment of the distinctions between genders completely (Gergen, 1985).

In social constructionism understanding is not considered implicit in nature nor bestowed truth status. Rather, understanding is considered a co-construction of persons in relation. Even one's sense of self is directly related to social circumstance (Gergen, 1977). Certain understandings may persist over time. This endurance of long-held beliefs is not attributable to their validity but to the power of this social process. For example, an attitude toward a person can remain the same, even though their actions may change (Gergen, 1985).

These negotiated understandings are central to social life far beyond the level of discourse. World views are both socially constructed and constructive. Descriptions and explanations form not only conceptualizations of the world they also encourage certain actions and deter others (Gergen, 1985). To understand this process Gergen (1985) offers the example of original sin which encourages certain actions and not others. The influence of original sin on behavior is secured by the community belief systems. There is a close relationship between our thoughts and our social environment. For example, social, community and family perspectives can be extremely influential in the self-perceptions and actions of the person with HIV/AIDS (McKenzie, 1989).

There are many constructions about women with HIV/AIDS which may influence their attitudes about themselves. From a social constructionist perspective these attitudes invite particular ways of being in the world. When women with HIV/AIDS are defined by the medical community primarily as vectors of the infection, medical care and social service programs are designed to halt the spread of the disease not treat them as persons

with an illness. This instrumental approach to women with HIV/AIDS invites negative self-definitions and exerts influence on their actions as well.

A central question in this study is what encourages or hinders these women to gain access their strengths, supports, learnings and resources? In order to begin to answer this question, the women in this study will be invited to tell their own stories, and to trace this construction of self, and its influence on their activity. Feminism is the perspective I employ to question the "taken-for-granted world" (Gergen, 1985) and reveal the hidden lives of women living with HIV.

A feminist perspective.

The many forms of feminism are unified in their common desire to change society in ways that allow for full economic, political and social participation for all persons (Luepnitz, 1988). This focus on social change is understood to have three elements. First, feminists draw attention to the exploitation and subordinate position of women in this society. Secondly, a feminist perspective values women's experiences, priorities and activities. And lastly, feminism includes an active commitment to empower women and change the social conditions under which women live (Acker, Barry, & Esseveld, 1979). In the following discussion each of these three aspects of feminism will be explored, expanded and linked to the issues of women and HIV/AIDS.

The subordinate economic and political position of women is clearly documented, and is evident in U.S. society from the most intimate household arrangements to the structures of our political system. The connection between these two far reaching points is evoked in the feminist slogan the personal is political. The political nature of women's personal lives is exhibited in the most common arrangements of family life. The equal sharing of family responsibility is "the great revolution that has not happened" (Okin, 1989).

Significant economic and political inequalities for women in our society are reflected in many ways. Unequal pay rates are one example. Full-time working women on the average make only 71 cents for every dollar a full-time working man earns (Okin, 1989). At present in American culture the patterns of gender structured community and family life are not just (Thompson, 1991; Glenn, 1987). The under-estimation of the numbers of women with AIDS and the underfunding of research on women with HIV/AIDS is a tragic example of this injustice which has cost many women their lives (Corea, 1992; Anastos & Marte, 1989).

The second aspect of feminism, the valuing of women's experiences, priorities and activities, begins with the articulation and understanding of the realities of women's everyday lives (Smith, 1987). These everyday realities constitute stories which until recently have been unavailable to the wider community (Laird, 1989). Instead, women's experiences have often been "hidden, inaccessible, suppressed, distorted, misunderstood, ignored" (Dubois, 1983, p. 109). For example, the sexual abuse of women and girls has been suppressed and ignored until recently. It is in the recovery of women's stories that the lived experiences of women are known. As Glenn (1987) notes, "the touchstone of feminist analysis must, in any case, be women's own experiences, however complex and contradictory" (p. 358). In the telling of one's own story the self and meaning of life are constructed (Laird, 1989).

Stories are not just personal constructions. The ideologies that are promoted by educational, publishing, advertising and media institutions (Smith, 1987) become the dominant stories of a culture (White & Epton, 1990). These dominant stories exert a powerful institutional influence. Sometimes a tension exists between one's own story and the dominant stories in the culture, or perhaps one's own story is lost. The shame and stigmatization of persons living with HIV/AIDS encourages the silencing of HIV positive

women's stories and invites them to live double lives to protect themselves from rejection and discrimination.

One dominant story is that women with HIV/AIDS are vectors of transmission of the virus and not a persons who are suffering with a disease themselves. The central purpose of this study is to hear in depth a few women's stories, as a way to understand their lived experiences as person's with HIV/AIDS, not as they have been defined by our culture and media.

The analysis of women as subordinates, with hidden stories, is fruitless without the third aspect of feminism: empowerment. It is crucial for feminists to move beyond the detailing of oppressive conditions to the creation of "imaginative alternatives that suggest how women themselves have changed and how they have resisted or neutralized the forces that control their lives and constrain their options" (Baber & Allen, 1992, p.18).

The methodology of this study is structured to enable the telling of these stories in a way that is consistent with this feminist agenda (Klein, 1983). Through an analysis of their stories it will be possible to identify ways in which these women with HIV/AIDS have resisted self-definitions as vectors and victims. In this resistance are the seeds for empowerment and the creation of alternatives. These alternatives may have implications within the social service and public policy realms. In this way the challenge is to move beyond a study about women to a study for women (Klein, 1983).

As the face of HIV/AIDS changes in public awareness it is increasingly more common to see the countenance of a Black or Hispanic woman. These women are often heads of their households with care giving responsibilities for dependent children (Zuckerman & Gordon, 1988; Pearlberg, 1991). For this reason Collins' (1990) expansion of the feminist critique beyond gender to include the interlocking systems of race and class oppression is a critical part of the picture. From this vantage point of

oppression Collins (1990) eloquently defines Black feminist thought as "a process of self-conscious struggle that empowers women and men to actualize a humanist vision of community" (p. 39). It is this vision that inspires this study.

Research on Women and HIV/AIDS

Adequate medical and social science research on women with HIV/AIDS is lacking (Rosser, 1991; Levine, 1990). In addition assessments of women's health care needs and models for effective prevention programs are deficient (Bezemer, 1992; Krieger & Margo, 1991). Many in the health care field urge increased research into health care for women with HIV/AIDS (Bezemer, 1992; Taylor-Brown, 1992; Michaels & Levine, 1992; Corea, 1992; Anastos & Marte, 1989). This mandate is due in part to the rising numbers of women infected with the HIV virus and the scarcity of current research on HIV/AIDS in women. In addition, our current gender arrangements and the physiological differences between men and women raise specific issues and needs for women.

These differences between men and women are manifested in the AIDS epidemic in a variety of ways. For instance, sex roles, social conditions and economic factors are gender specific, and influence the viral exposure and disease process (Ickovics, 1992). Rape, incest, inequity in negotiating sexual relations, and economic vulnerability or dependence are some of the factors for women in contracting the HIV virus. In addition, many sexuality issues that women face do not have to be directly addressed by men, i.e. conception, pregnancy and abortion (Campbell, 1990). One unique sexuality issue for women is perinatal transmission. These social, economic, and physiological factors are only accounted for and addressed by gender specific research on and for women.

What research has been done on women with HIV/AIDS identifies them in their role as vectors of the virus rather than persons dealing with a disease themselves (Corea, 1992). Research and prevention programs have focused on prostitutes or prenatal women

(Carovano, 1991). King (1990) concludes by a content analysis of newspaper articles that the media's portrayal of prostitutes as transmitters of AIDS to men played a role in the social construction of prostitutes as an AIDS target group, despite the low number of prostitutes infected. In this way women are treated more out of a public health concern for their partners or children than for themselves (McKenzie, 1989).

The current concern about children orphaned by the AIDS epidemic (Adams, 1992; Marcus, 1991; Martin, 1991; Rich, 1992; Toll of American, 1992; Lee, 1993) threatens to continue to take the focus off women. It is important to note that the definition of "orphan" in the epidemiological studies is "motherless children" (Michaels & Levine, 1992). This definition does not account for the presence of the father or the family structure for the child prior to the mother's death. This definition of orphan perpetuates the pattern of blaming women, for it assumes that when the mother dies she is responsible for orphaning her child. Although the needs of the children in the AIDS epidemic are critical, so are the needs of women while they are living with the disease.

Despite the specific economic, social and medical concerns of HIV/AIDS women detailed above, the empirical social science research on women and HIV/AIDS focuses primarily on two areas of investigation: risk assessment and education/prevention. Though both are important, neither substantive area deals directly with HIV positive women's needs and care. In the following literature review, I first cover current research on risk assessment and education/prevention will be reviewed, followed by research on HIV positive women. The chapter concludes with a discussion on the importance of this proposed study in light of the current status of women in the HIV/AIDS epidemic.

HIV/AIDS Risk Assessment for Women

The social science literature on the assessment of risk for women for HIV/AIDS is a prerequisite for the development of HIV/AIDS education and prevention. The

following review on risk assessment includes both qualitative and quantitative studies. The samples studied consist of Intravenous Drug Users (IDUs), recovering IDUs, sexual partners of IDUs, at risk women, and prostitutes. However, unfortunately few of the studies include identified HIV positive women speaking from their experiences.

Some studies indicate that education is not put into practice. For instance, Weissman (1991) found that both IDUs and non-IDU women engaged in risky sex despite knowledge about the transmission of HIV. In a comparison of female rural and urban crack-cocaine users, Forney, Inciardi, and Lockwood (1992) found that despite knowledge of HIV/AIDS, both groups engaged in activities that put them at risk for HIV. These researchers found little difference between the rural and urban women in terms of their crack use and sexual activity. When 91 African-American and Latina female participants in a methadone program in New York City were queried, Schilling, El-Bassel, Gilbert, and Schinke (1991) found that less than half changed their sexual activity to make them less susceptible to HIV. These are disturbing results.

Attempts to identify causes for continued high risk behavior point to a variety of factors. Although sexual politics may be a contributing factor, it does not appear to be responsible in all cases. Kline, Kline & Oken (1992) found in a study of 134 minority women in a drug treatment program and a community agency that lack of control over decision making in sexual practice was not the most important factor in condom use. Rather these women reported they did not use condoms because of difficulty in assessing the level of risk with specific partners. This was the only study which utilized HIV positive women as a resource for risk assessment. This indicates an important gap in the literature

In two separate studies the researchers found that women at risk even with knowledge of risk factors did not consider that they were at risk themselves (Harrison,

Wambach, Byers, & Imershein, 1991; Ehrhardt, Yingling, Zawadzki, & Martinez-Ramirez, 1992). In the first study, Harrison et al. (1991) noted that over half of the 620 women surveyed, regardless of racial or ethnic affiliation, engaged in unprotected sex with their primary partner although the reasons for this were not clear. In the second study (Ehrhardt et al., 1992) an important contributing factor to unprotected sex for the 78 African-American and Latina women was the desire to get pregnant. From these studies it is clear there is a need for the development of more aggressive and effective outreach to these populations of women. Specifically it is important to factor the context of these women's lives and their difficulty in practicing safe sex into the development of HIV/AIDS education programs (Weissman, 1991).

In the development of a HIV/AIDS education program for women it is important to determine the knowledge base of the women and to consider social elements which may inhibit women from acting in their own best interest. In some instances lack of knowledge is an important component for women in the risk factor for HIV. Flaskerud and Calvillo (1991) identified many inaccurate beliefs about HIV in a sample of 59 Latina women. Cultural factors such as some Latino health practices also increase HIV transmission risk.

The inclusion of cultural context in some research has resulted in lowering risky behavior. A creative use of context was employed by Dorfman, Derish, and Cohen (1992), who recruited former prostitutes as field workers in their study of 182 Bay Area prostitutes. The study reported that the active prostitutes, though knowledgeable about HIV, considered themselves safer with their partners than their clients and used condoms accordingly. The field workers then served as role models for positive behavior change.

An important direction for further research is the investigation of the life experiences of HIV positive women. Such work might possibly add a dimension to the

scientific understanding of risk assessment for women and potentially contribute to HIV/AIDS education. The perspectives of these women are missing.

HIV/AIDS Education and Prevention Programs for Women

Risk assessment research has practical applications for the development of HIV/AIDS education and prevention programs for women. Yet the two studies of educational programs I found in the social science literature (Falskerud & Nyamathi, 1990; Mason, Preisinger, Sparling & Walther, 1991) identify the same gap between HIV/AIDS information and reduced risk behavior. Increased knowledge of HIV transmission does not necessarily reduce high risk behavior in women. Flaskerud & Nyamathi (1990), in a nonequivalent control group design of Black and Latina women, report the experimental group made significant gains in knowledge about HIV transmission (N=205 Black, 201 Latina women; control N=105 Black and 101 Latina women). However as previously documented in other studies, this information was not translated into behavioral changes. At 2-3 months post-intervention the attitudinal changes were not retained. To-date there do not seem to be other more effective methods of education for women.

Similar conclusions about the difficulty in effecting behavioral change were found by Mason, Preisinger, Sparling, & Walther (1991) in a prenatal clinic at Mt. Sinai Medical Center in New York. The clinic integrated a HIV education and counseling program as a regular part of prenatal care for all mothers regardless of their risk behavior. The goal of the program was to increase prenatal HIV antibody testing in order to decrease the number of HIV positive babies. Pre- and post-tests indicate that increasing the women's HIV knowledge did not increase their desire for voluntary HIV-antibody testing. This is not surprising given that the intervention did not address the context of the mother: in particular the high value of child bearing within their culture. In addition

these disenfranchised women encounter numerous high risk situations in their everyday life which outweigh the 30 percent probability of an infected mother bearing an HIV infected child (Anastos & Marte, 1989).

Studies of Women with HIV/AIDS

The current social science research literature on women living with HIV/AIDS is extremely limited. The studies I found reflect the constructs previously discussed above, sexual activity and reproductive issues. In addition issues of stigmatization and denial of the person with HIV are addressed. These studies for the most part are alarmingly devoid of concrete applications to the present needs of HIV positive women. Pivnick, et al.(1991), in a study of reproductive decision making, noted that HIV positive drug using women were most likely to terminate their pregnancy if they were residing with a child already. This study has policy implications for HIV positive women, but in an area which is riveted with ethical implications. This research could be used to impose values on HIV positive women in an attempt to control their reproductive choices. It is important to ask questions about whether the applications of this research will be for women.

Another study of HIV positive women utilized a questionnaire to 48 HIV positive persons to determine the level of stigmatism they felt (Crandall, 1991). It concluded that the perception of stigmatization was highest for those who were the least stigmatized by perceivers because their means of transmission was heterosexual. It is of questionable value to determine whether the amount of stigma someone feels is consistent with real stigma. In a research area with dramatic need for applied work it might be of more value to HIV positive persons to develop ways to deal with feelings of stigmatization, whether felt or real, or to address the societal process of stigmatization.

The final study I located on HIV positive persons found three styles of denial in a sample of 53 men and 5 women. Persons with the same knowledge of HIV transmission evaluate risk behavior in different ways (Earl, Martindale & Cohn, 1991). Although the spread of HIV/AIDS is an important subject none of these studies address the need of the persons living with HIV/AIDS.

Summary

This review of the social science literature on women and HIV/AIDS indicates there is a research emphasis on risk assessment and prevention programs. In many of the studies women are often selected because of their potential to infect men and children. This is evident in the number of studies on prostitutes and perinatal transmission. There is scanty research for women and about their process of living with HIV/AIDS.

This review identifies the need for research designed for and about women living with HIV/AIDS. In this study women are placed in the center as experts of their own experience. The methods in the following section detail this design.

Chapter III

Methodology

Design

This study from social constructionist and feminist perspectives involves the collection and analysis of the stories of five women living with HIV. There were three individual in-depth conversations with each woman about her experiences living with HIV. The first two conversations were unstructured to allow the women's perspectives and concerns to surface. I structured the third conversation to provide clarification and to cover topics not addressed in the first two meetings. All of the conversations were audio taped and then transcribed.

The participants and I reviewed the transcripts and reflected on our conversations. In this way the participants became as co-researchers as well. The movement back and forth between text and reflection encouraged private as well as public accounts of the women's experiences living with HIV (Cornwell, 1984). The public accounts form the top layer of the story; the private accounts are the more intimate understandings and meanings. Both levels are important to the story.

The development of this proposal to study HIV women's stories began with networking because I had no prior experience of talking with someone I knew had HIV or AIDS. My network includes researchers, educators and persons living with HIV/AIDS. I read the social science literature and viewed educational videos about HIV/AIDS while I was networking. The combination of didactic and anecdotal investigation provided a valuable basis from which to develop a methodology for this study.

Networking

During the summer and fall of 1993 I networked locally and at a distance with persons who work in AIDS research, prevention, education and treatment. This process eventually led to talking with persons living with HIV. At a distance I contacted: The Orphan Project, in New York; The Johns Hopkins University School of Public Health, in Baltimore; The Center for Disease Control, in Atlanta. Locally I contacted: AIDS Council of Western Virginia, Roanoke AIDS Project, Southwest Regional HIV/AIDS Resource and Consultation Center, The New River Valley AIDS Coalition, The Veterans Administration Hospital and local Health Departments.

Beginning conversations.

The contacts that I made through local Health Departments formed the basis of my network. There an AIDS specialist shared stories with me about women with whom she had worked and maintained their anonymity. She introduced me to my first glimpse of local women's struggles and resiliencies in living with HIV/AIDS, from a public health perspective.

The AIDS specialist also served as a key informant for me of others working with HIV/AIDS. One of the contacts I made through her was the leader of the women's support group in the area who acquainted me with the women's issues and struggles from her perspective as a social worker. I audio taped and transcribed my interviews with both of these women and later they both became sources for participants in the study.

HIV antibody testing.

By mid summer 1993 I identified a local Health Department as my primary local resource and referral source for this study. Therefore I chose this Health Department as a site for my final project in a Program Evaluation course. The Health Department requested an evaluation plan for their Anonymous HIV Antibody Counseling and Testing

Program. As a part of the program evaluation I was tested for HIV at the Health Department. The testing process introduced me to common fears and anxieties of being tested in a public program. The evaluation plan was presented to the Health Department as a way to thank them and the participants in the study for their participation as financial reimbursement was not possible.

Interaction in the Community.

Later in the fall of 1993 I was invited to a make-over and pizza party planned by the Health Department for HIV positive women. This informal gathering introduced me for the first time to some of the women in the community living with HIV/AIDS. The party served not only as a source of participants for the study, but as a way to begin to get to know some of the women and their families in the community living with HIV/AIDS. This process of networking was an invaluable aspect of my research and set the context for the pilot and the subsequent selection of the participants for the study.

The Pilot

During the spring and summer of 1994 I searched for participants in the pilot study. I sought women who were living with HIV/AIDS within a two hour drive but was unable to find any who were willing to participate in a pilot study. In the end I interviewed a local man who was living with HIV. His generous contribution of his time and interest enabled me to refine my methods. Although the content of our conversation varied from those I had with the women later, I was able to evaluate the proposed research methods.

Narrative analysis.

I met the participant at his house and taped our conversation about his experiences living with HIV. I transcribed the tape and during the second conversation we discussed the transcript and his experience of listening to the tape. During the second conversation he selected a theme to look at in greater detail and I transcribed those sections of the text

into a stanza format (Gee, 1991). I chose to analyze the text using the narrative analysis model of Riessman (1993). This new text was returned to him and he was asked to read and reflect on it. It was very difficult to structure the conversation on the text and I concluded that the narrative analysis was not the most accessible way for the participants to review their own stories. Therefore I altered the methods to include a text of the conversation for review by the participants and opted for a less formal method to elicit their comments.

In order involve the participants as co-researchers as much as possible in the project they were encouraged to change their texts in any way they chose. I am generous in my inclusion of direct quotations of their accounts in the following sections in order reflect their individual voices. In addition their introductions in the section Introducing the Storytellers set the stage for the analysis which follows and provides a presentation of themselves from own perspective.

Participants

Criteria for participation.

Participation in the study was limited to women at least 18 years of age who had known about their HIV diagnosis for at least six weeks. The six week prerequisite of HIV status is derived from previous research (Matocka, 1992). Matocka (1992) defined the initial adjustment period for an HIV positive diagnosis to range from two to six weeks after diagnosis. Her criteria was based on two years of work with persons with HIV/AIDS and is a minimum initial adjustment period.

Selection of the participants.

Participants/co-researchers were sought through a variety of methods. Contacts at a Health Department, an AIDS Project Women's Support Group, The New River AIDS Coalition and a private physician agreed to inform women who were HIV positive about

the study and give them my telephone number for more information if they were interested. In addition, I made presentations about the study at four Health Department HIV/AIDS gatherings. At each event I established contacts for the study, and met additional persons working with women living with HIV/AIDS. I also placed an announcement in the local HIV/AIDS newsletter asking for participants (Appendix B). And finally, the participants/co-researchers were asked if they knew other women who might be interested in participating in the study.

I screened each potential participant by telephone to determine if she met the criteria for the study. If she qualified I described the study to her and when she agreed to participate we set up an initial meeting at a mutually convenient time and place. At the initial meeting we talked about the purpose and format of the study and I stressed the importance of her active participation. There were no promises that the study would benefit others.

Our first meeting provided time for the woman with HIV/AIDS to make an assessment of her interest in and ability to participate in the study. Speaking about HIV/AIDS can be difficult due to the risk of stigmatization and discrimination (Walker, 1992). A meeting was necessary for the potential participant to determine her degree of comfort with me and ability to have further conversations. So this initial session was not only informational but a time to establish rapport. We began to get to know each other as well as talk about the study. I encouraged questions about the study and me. This initial meeting was not audio taped however I recorded my reflections in my journal afterwards.

The potential participant/co-researcher was asked to meet for a minimum of three two hour sessions. When the woman agreed to participate I asked what would be necessary for her to take part in the study. Often issues of child care and/or scheduling

were discussed. Then we signed a copy of the letter of agreement (see Appendix A) and set up a meeting time and place for the first tape recorded account of her story.

Anonymity and confidentiality.

Anonymity of the participants/co-researchers was assured through the use of pseudonyms which they chose at the initial meeting or during the first session. Most of the women mentioned something about the particular name they chose. India, Tora and Patricia stated that they had always liked those names. Felicia said that she was flamboyant as a young woman and dressed expressively. She named herself after a soap opera star who reminded her of that part of herself. She took Elizabeth Taylor's last name. Charlene gave herself the name she gave her daughter seven years ago when she placed her for adoption

For me the pseudonyms became their names. It was those names I used as I went over their texts and looked up their telephone numbers. Because they named themselves a name they had always liked or had special meaning for them, the names became associated for me with their self definition.

Pseudonyms were used for any person or place the participant desired. Some women only chose a name for themselves while others altered all names of persons and places. A code sheet of names, pseudonyms, and telephone numbers was secured at my house. This sheet recorded whether a telephone message could be left and the best times to call. The pseudonyms were the only names on other written materials. The audio tapes of our conversations were locked in my house.

Two research assistants helped with the transcription of the tapes. The confidential nature of the study was explained before they began and they signed an agreement of confidentiality (see Appendix E). In addition to keeping the information on the tapes

confidential, the assistants agreed to cease transcription immediately if they knew the person whose tape they were transcribing. This was not necessary.

Profile of the participants.

The participants/co-researchers in this study were five women living with HIV. All eight of the women I screened fit the criteria and were willing to participate in the study. Five were able to complete the interviews. One woman was too ill to participate, one died before the interviewing began, and one had time constraints which prevented her from meeting. The study was open to women with HIV or AIDS but only persons with HIV participated in the study. The location of the study was southwestern Virginia. All of the participants came from a small city in that region although participants were sought within a radius of 100 miles. Only one woman from a rural area was interested in participating but she was too ill to do it.

The participants ranged in age from 25 to 42 years old with a median age of 33.5 and an average age of 32.2 years. This age span is reflective of the statistics in Virginia where 92 percent of the females infected with HIV are between the ages of 20-49 (Commonwealth of Virginia, 1994). Tora is 25; Patricia is 26; Charlene is 30; India is 38; Felicia is 42. Patricia, Charlene, India, and Felicia are Caucasian. Tora's father was Native American and African-American; her mother is Caucasian.

Three of the women dropped out of school before completing high school. Patricia and Tora completed the requirements for their graduate equivalency degree (GED). Charlene began work toward a GED but found the combination of work and childcare inhibited her from finishing. India completed high school, and Felicia has an associate's degree.

In terms of marital status four of the women are married. Tora has never been married. Three of the women (Felicia, Charlene and Patricia) have been separated from

their husbands for years. Both Charlene and Patricia stated that they felt more married to their boyfriends with AIDS (who both died last year) than to their husbands. India has been married for 16 years and is living with her husband.

Children are an important part of all the women's lives. Four of the women are biological mothers and have given birth to a total of 12 children. India has miscarried many times. She explained one of her heart breaks in living with HIV was giving up the hope of having children of her own. She currently has custody of her sister's two girls ages 9 and 4. Tora is living with her two young sons, ages 2 and 6 years. Her two year old has AIDS. Her 9-year-old daughter lives with her grandmother. Patricia lives with her three sons, ages 2, 3 and 6. Her oldest child, a daughter aged 7, was taken out of the country by her father and Patricia has lost contact with her. Charlene is living with her two sons, ages 4 and 14. Her daughter was placed for adoption at birth in 1988. Felicia daughters are teenagers and she lives with her youngest daughter. Her older daughter lives away from home at college. The ages of the 14 children range from 2-19 years.

Four of the women discussed their employment backgrounds. Patricia has worked at a convenience store associated with a gas station; Charlene has worked as a janitor; India has been employed as a nursing assistant and as a medical transcriptionist; Felicia is an administrator in a social service organization. During the study two of the women worked outside their homes: Felicia was employed full time and India one day a week. Recently India quit her job at the recommendation of her physician.

All of the women have more than one source of income. Tora receives Disability for her younger son who is living with AIDS, and child support for her older son. Patricia receives SSI, Disability and ADC. India's income is from Disability, and she cares for an elderly woman in her home. Charlene receives SSI, Social Security, Disability and child support for her oldest son. Felicia is employed and receives child

support. All of the women except for Felicia are living with male partners although Tora was the only one who named her partner as a source of income. India, Patricia, and Charlotte have at least one other adult in addition to their partners living in their home. India identified her roommate as contributing to the household income.

The women have known about their infection from two and a half to six years. India was diagnosed in February of 1989, Patricia in August of 1990, Felicia in April of 1992, Charlene in May of 1992, and Tora in July of 1992.

Conversations and Analysis

The major texts used in this study were three audio taped conversations for each of the five women living with HIV. These 15 tapes total 460 pages of transcription. The participants also shared other forms of information. Charlene shared her journal, Patricia contributed a letter she had written, and Felicia gave me a newspaper article about her story. I also reviewed my journal.

Meeting places.

Each conversation lasted from one to two hours and was audio taped and transcribed. Four of the women chose to meet in their homes and one came to my office to talk. I met with each participant individually, though when we met in their homes our conversations were often interspersed with interchanges with other persons in the house. The meetings were scheduled at their convenience.

The conversations in the homes often included the pattern of everyday life: visitors at the door, telephone calls, children to tend and requests from others in the home. This activity interrupted our conversations but we became adept at picking up where we left off and replayed the tape if we needed a cue. Although the interruptions sometimes seemed to interfere with our ability to follow a train of thought, the home provided a familiar place for these women to discuss personal parts of their lives.

Being in the midst of everyday occurrences provided me with a richer and fuller picture of their lives. The one participant who chose to meet in my office was able to talk without interruption. Our unbroken conversations invited depth but I did not meet any other members of her family or have the opportunity to see her in context.

Conversations with a Purpose.

Kahn and Cannell called qualitative interviews "a conversation with a purpose" (as cited in Marshall & Rossman, 1989). Although the participants and I often began our conversations informally, I asked near the beginning of the first conversation, "Can you tell me a little about your experience of living with HIV?" The participants were invited to tell all and everything with the option of editing out material later (Cherian, 1991). Transcripts of the conversations were given to each participant. Although none of them chose to delete material from their texts, the transcriptions provided an opportunity for them to clarify parts of their story, and were a catalyst for further conversation.

The open-ended nature of the conversations was intended to allow the participants to compose their experience in a way that was meaningful for them (Mishler, 1986). I kept my questions to a minimum rather than suggesting alternatives or directing questions along specific predetermined topics during the first two conversations. My probes were for clarification (Jack, 1991) rather than to direct the conversation. Sometimes there were silences which gave time for the storyteller to organize her thoughts and tap her feelings. Demographic information was gathered from the conversation and entered on the Demographic Information Sheet (see Appendix D) after the meeting from the transcription. I reviewed the demographic sheet before our final taped conversation and asked specific questions if there were gaps in the information.

The use of the word story in this study is synonymous with personal narrative. A personal narrative is "talk organized around consequential events" (Reissman, 1993, p. 3).

In this study the focus of the talk between the participants and myself was their experiences living with HIV. As these women recalled their stories they were not only recounting events and feelings but as Reissman (1993) quotes:

what they emphasize and omit, their stance as protagonists or victims, the relationship the story establishes between the teller and audience--all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone (or oneself) about one's life: they are means by which identities may be fashioned (Rosenwald & Ochber, 1992, p. 1).

I honored this fashioning of identity in the process of the study. As these narratives are co-constructions in which teller and listener each play a part, I strove to maintain a respectful attitude toward each participant. A part of this included making every effort to meet their needs in terms of place, time, physical comfort, emotional security, and the pacing of the conversations. We met where they chose at times convenient in their weekly schedule and daily pattern. Often this was during the day when their children were at school. We usually settled into a pattern of a convenient time. The one participant with whom I met in my office came at different times which accommodated the work schedule of her two jobs. She was free to come in the evenings and weekends because she did not have young children.

The women often forgot our arrangements. When this happened they either asked me to return later or made time for me then. Sometimes no one was home when I arrived at the appointed time. The women also canceled many sessions. I changed my initial assumptions that an appointment made at the previous meeting would be kept. A few of the women suggested I call before I came. Some wanted to schedule our appointments at the previous interview; some wanted to wait until right before the next interview to set a date. I adapted to a more fluid arrangement of expecting and making room for changes

often hours before the appointment. I accommodated their shifting schedules, but also told them I would like to know ahead of time if they wanted to change an appointment. This process of negotiation taught me about my assumptions and preferences as well as theirs.

Riessman (1993) posits a less structured interview format gives more control to the participant. I adopted a format of less structure and more participant involvement because it is consistent with my feminist perspective. In our work together I strove to balance the power between the interviewer and the participant by enabling the participants to take the lead, direct the course of the conversation, and interpret their own narratives. In this way I attempted to use my privileged position in this culture to create a context in which these women were the recognized experts of their experience.

In order to answer my research questions and for purposes of analysis, I delineated topic areas in advance based on my review of the literature and networking (Marhsall & Rossman, 1989). To ensure the inclusion of some common areas of discussion I designed an interview guide (see Appendix C). I used one guide for each participant and noted the topics of our conversation after each interview. Additional topics the participants introduced during our conversations were added as the study progressed. The final session was structured to introduce topics on the interview guide which had not been addressed during the unstructured conversations. I used the interview questions in Appendix F.

Co-constructing a story.

The conversations were transcribed from the audio tapes (omitting my portion of the dialogue) into a verbatim text. This transcription was given to each participant when possible before the next meeting. The text was double-spaced to provide a place for each of us to write notes, questions, record feelings and/or note the importance of particular

aspects of the narrative. If the participant wanted to delete any material she was encouraged to do so on this text.

I invited the participants to look over the transcript between sessions and make notes as described above. A copy of the tape was also offered for review. Sensitivity to and accommodations for variations of reading and writing proficiency were primary in the negotiations about the review of the transcripts. In addition the participants/co-researchers were queried about how the research process affected them and what they felt might be helpful to others about their experience. I then shared what our conversations had been like for me and expressed my gratitude for their participation. A typed copy of each woman's response about the effects of the research was sent to her for review. She was encouraged to change or add anything she wished, and then return it to me.

Finally each participant was asked to write a brief introduction of herself. One woman requested to complete her introduction verbally. Our conversation was transcribed and edited, and sent to her for revisions. Another woman worked from a letter she had written for the Health Department. These introductions are included in the next chapter.

Analysis.

I analyzed the original transcripts for themes through the process of open coding (Straus & Corbin, 1990). I read the transcripts through without any notation first, and then went back and made notations in the margins. This careful reading without notation was done to slow the process of coding down to allow for unseen concepts to emerge. My notations reflected broad themes in the descriptions the women provided of their experience (Marshall & Rossman, 1989).

After a concept was tagged, a code was placed next to it to identify the speaker, the number of the conversation, the page, and the half of the page. For example, a concept on

India's second interview, page 34, on the bottom half of the page was notated: I.2.34.2. Each woman's transcript was color-coded by a line of magic marker down the left margin. Then the transcripts were Xeroxed and the original was cut into sections according to the concept.

I used a series of manila folders to begin to sort the material before the interviews were finished. Originally the concepts were tentative and the name was penciled in on the tab of the folder. As the categories changed in relation to the development of my thought, some of the folders were condensed into another or the text was resorted. After the interviews were complete, the transcripts were all coded, filed and then grouped in categories. Some of the sections of text referred to more than one concept and so I developed a running list of cross references. This list was utilized during the writing process.

I completed another level of analysis during the writing process. I developed matrices to organize the concepts and to indicate where each of the participants was located on a particular issue. The process of developing a matrix pushed the analysis a step further and uncovered new areas of data (Marshall & Rossman, 1989; Bernard, 1988).

Ethical Considerations

This study was reviewed by the human subjects committee of the research division of Virginia Tech. The participants were given a clear description of the study and invited to ask questions about the research process or researcher. Each participant and I signed a letter of agreement (Appendix A) prior to beginning our study. In addition two research assistants were involved in the study and signed a statement of confidentiality (Appendix E).

Every effort was made to create for the participants a positive context for the conversations, including location, scheduling time and conversation pacing. The participants were given a referral sheet of local counselors to contact if they wished to discuss further any issues that came up in our conversations.

Chapter IV

Introducing the Storytellers

I feel honored to be the witness for these five women's stories. I am impressed with their courage to recall and share many deep aspects of their lives, despite the constraints which limit their time and energy. Before their stories are told the women need to be introduced and it is appropriate that they introduce themselves in their own voice. I only wish you could be in their presence as I have had the privilege to be. Their introductions are a way to bring you into their presence while preserving their anonymity.

Each woman was invited to introduce herself and include what she felt was important for the readers of this study to know. Charlene chose to talk with me and I taped our conversation. I sent her a transcribed portion of her part of the conversation for changes or revisions. She wanted to keep it as it was. The rest of the women wrote their introductions. I made minor editorial changes.

India

I am India. To introduce you to myself was quite a difficult task to try, but hopefully you may know me a little better by the time I'm done.

I have lived in S.W.Va. all of my life. I am 38 years old and have been married to a wonderful husband with no children for over 16 years. I am a caregiver to sick people with diseases from AIDS to Alzheimer's and other geriatric diseases. I have been doing this seriously eight years and did this several years before that.

The family I came from is a very large one. I have a very strong loyalty to my family. As a family we are of strong character. They are my lifeline and my true support system. I am one of the few lucky humans to have a family such as mine. Strong, loving,

non-judgmental and Christ loving. I truly found this out when my baby brother died of AIDS two and a half years ago.

Six years ago I was informed that I was HIV POSITIVE. I always took for granted everything in my life until that wretched day. I had my world literally rocked. Since that time I've had to re-evaluate who I am, what I am, and where I came from. I believe in being straight with people. Being HIV positive can really throw you for a loop because it's truly a hard thing to be honest about.

I have always been Miss Social Butterfly, getting into all kinds of messes and have tried every rebellious act it seems in my life from going to jail, prostituting and shooting drugs. Now that I'm older my standards, morals and religious beliefs have changed to a much more responsible style of life. Who would have thought 20 years ago that this would have happened to me? I own my own mistakes and can't be angry with anyone for something that I created for myself.

I am a long-time survivor and am determined to not give in to this hideous virus.

I believe in taking care of the innocent and doing my part to try and make this world a better place for myself and the people I love.

I love music, art and dance. They are my true passions, but I also love to get involved with and play lots of sports. I always encourage all young people to do the same. Play sports, enjoy music and the arts, and most of all get a good education. Since I was diagnosed, all of these things in my life have taken on new meanings for me.

When my brother died of AIDS (I had already known of my diagnosis for two and a half years) my whole attitude and my priorities changed. He helped me in his death to learn about myself and about this disease. I became less afraid after a time and started living my life and letting go of so many secrets.

Participating in this project made me face issues I'd never dealt with and has made me grow so much. It has made me more determined than ever to fight for my life.

Recently I have acquired two beautiful children (ages 4 1/2 and 9 years) to raise and care for, and I feel I owe it to myself and my new children to fight, teach, grow and love. NOT DIE!

There is truly something to be said about facing yourself and running from yourself. If you face your battles head on, you're going to win some of them. Maybe not all, but, I think the important ones.

Educate, fight, and don't give up!

India

Charlene

To begin with my name is Charlene. I just found out my T- Cells came up a whole lot and that made me really happy, because I have been real sick through the whole summer and winter with a bad cold and bronchitis, and I am feeling much better and I feel happy with myself and my children of course. I have two boys, one is 4, one is 14 years old, and they are in good health. I was raised in Maryland, and I kind of miss it but I have gotten used to being here and I like it a lot better.

If I could do it all over again, I would change a lot of things by being safe about having sex. I wasn't really sure about that and I just didn't care at the time when I was growing up. I didn't use protection, and if I could start all over again I would. When I first got pregnant with my first child I didn't know you could get pregnant if you didn't use something. My mother didn't set down with me and explain the facts of life and it has been real difficult for me all these years. If I could just do it all over again, I would and I would make things better. I would get married first and then have children. I was

married for five years and now that me and my husband are no longer married we are good friends, and I think that is better than being married, it really is.

I wanted to have a child and I can't because I know if I have a child I could risk its life as well as mine. I was really upset about getting HIV at first because I have always wanted to have another baby, and now I see how hard it is. It is really hard to raise a child in these years you know. I really was just sad at the time because this guy I was involved with I wanted to marry him and have his child. Things just seemed like the end of the world when we started finding out all of these things--about him getting HIV and then I am getting it.

I am just glad there is a place out here like the Health Department to learn about it, and if it wasn't what would this world be like it would be just crazy, tremendously. It would just be like a nightmare, you can't wake up.

I used to love to work and there are certain things I could do all the time, and like I am real tired all of a sudden. If I go and do the dishes, it is like when I am done, I am just exhausted like I did an all day's work. Just certain things I do I get exhausted real easy. I sweep the floor and it is like an all day's work, and I get real tired usually and use to never get like that.

I guess because I worry so much, I ended up getting an ulcer. I have an ulcer from worrying so much about myself, about my health. Every pain I have it is like "Is that the HIV or is that me?" I can't always be like that and I have been, and I can't always be like that. Now I have to stop focusing on my health and focus on how to take care of my children the best way I know how, and quit worrying about myself because there are doctors out there if there is something majorly wrong.

Painting has helped me deal with my feelings. I paint, and sometimes I write. I have a journal that I have been writing, I just kind of just stopped. It helps me to get out

of the house and visit other people and make sure my children are happy too. I always wanted to learn to make a quilt, that is something I have always wanted to do and I want to do that soon, as soon as I get the patterns together and other things together. I like to make things and make other people happy.

From my experience now I know that people need to be more careful and not just be with anybody. They need to be very very careful and they need to always protect themselves by using protection because if they don't they are just going to be tremendously hurt. I mean if you get into a relationship with somebody and you know sex is going to be talked about sometime soon, they should always use protection. If they don't something tremendous can happen. AIDS is one of them and then there is HIV and there are other infections you can get that can be painful, especially if you fall in love with somebody and they give it to you sometimes purposely. That is the most painful thing I have ever heard happen. This has happened to a couple of my friends.

When I found out I had HIV I thought you know "Did he really do this to me purposely or did this happen accidentally?" I found it was accidentally because he didn't even know himself. He was really sick but he didn't think he was sick from AIDS or HIV. He just thought he was sick because he had gotten a cold or whatever, but it got tremendously worse, but I dealt with it the best way I knew. He was really out of it, he didn't want to take his medicine, he didn't want to do anything. I encouraged him.

In terms of my health and dying, I could just not care. At first I did not care: I drank, I did drugs, I said, "Why should I live? I am going to die anyway why should I even try?" I thought to myself, "Now you get yourself back in there and you take care of yourself and take care of yours sons. Who is going to be their mom? They are not going to have a mom." And I just spun back and I thought I don't need that stuff and I just quit.

I have been on my feet ever since then, trying to struggle and take care of myself and do the best I know.

Patricia

Hi my name is Patricia. I live in the Roanoke Valley and have been here all my life. I am 27 years old and have three children Tom, Dick and Harry.

I have HIV and I have been dealing with this issue for about four years. Tony the man who gave this to me was my boyfriend. He had AIDS. I seen him go from a healthy energetic man to a baby. I took care of him. We had been together for about four years. We had a great relationship. He showed me how to make different kinds of food.

I am glad God put him in my life! Nobody could have did what I did for Tony.

Now I have a different life, a new boyfriend who cares about me and my children.

You never know until you actually experience it what you can accomplish. God gives you the strength to get through the good and the bad, as long as you have faith.

I don't dwell on things I cannot change. I look forward and be positive about all things.

Felicia

I have no idea where to start introducing myself, I've always joked about not ever being me--I started out being referred to as my parent's daughter; then I became my husband's wife and finally my children's mother. When do I become just me? Then I realized I'm just me now--once I was told that I was HIV positive I've never been more alone (or just me). Nobody else can really share what I feel--sure my loved ones and friends feel the hurt and fear but there is nothing anyone can really do.

To start in the beginning I was born a small town country girl. I've never felt like I quite fit into the life I was born to. Somehow I just always felt out of place. I guess I was a normal child and teenager but seemed to always do or say things to get myself into

some type of trouble. I was never very good at making choices in matters of the heart. I seem to always be attracted to or to attract men that were not good for me.

To move on to the present I am a middle-aged woman separated from her husband trying to raise children alone. I was told about three years ago that I was HIV positive and have gone through number of phases since that time. I try not to take people or life for granted anymore. So, I guess if I had to introduce myself I would say "I'm a woman scared of being alone and wanting to live." I was married fifteen plus years; have two wonderful and intelligent children. I don't understand why a cure cannot be found--How can this country ignore the hundreds of thousands of people that have already died and the countless number of people that will certainly die if something is not done? We can send men to the moon but we can't give much hope for anyone with this disease. As a nation we cannot continue to ignore the numbers or spread of this illness, for if we do I and many others will die. So, who am I? I'm just an average middle-aged working woman with a disease that statistics say I shouldn't have. I feel cheated by life and now cheated by my country that refuses to realize the magnitude of a disease that has the potential to destroy mankind.

Chapter V

Becoming HIV Infected and Finding Out

Beginning at the Beginning

Let me begin with reflections about my process of listening to these stories and some suggestions about how to enter into these women's lives. The stories are detailed here in loose chronological order but this is not the way all the stories unfolded. At our first conversation Felicia began, "Starting in the beginning, I think that I will probably as long as I live remember the day that I found out." In contrast India, Patricia, and Tora discussed their care of their loved ones with AIDS during a good portion of our first and second taped conversations. I was at first a bit resistant to listening fully to that part of their stories. I found myself leaning toward the parts of their accounts that were their own responses to their own infection. I was listening for them to discuss what living with HIV was like for them. They taught me about very important parts of their experience as I slowly allowed myself to listen. This is where I would like to begin their stories.

In reflecting on why they included so much of their loved ones' illnesses in their stories the women had some interesting observations. One concerns the initial lack of symptoms. Patricia and Tora mentioned that they have not had any symptoms yet, at least not in comparison to the reeling symptoms of the opportunistic diseases of AIDS. The more visible signs come later in the disease progression and so, as Patricia tells, "I basically go on what I have done with Tony....[and] through Tony...I dealt with Tony the whole time I was HIV positive." The absence of symptoms in the beginning can make it very hard to believe that HIV is present. Many of the women echoed this perplexing aspect of the virus. As Tora relates, "I guess even to this day it is hard for me to believe

that I have this sickness that is going to really really get me sick one day, because I have never really been sick from it."

A second point concerns rising awareness. India states she focused on her brother with AIDS in her first years because "I lived out a lot of fear a whole lot of fear, but I also was helped to get more educated about it....It helped me to be more aware of things like trying to take care of myself." Much of her knowledge about HIV/AIDS came through the information and experiences she received in dealing with her brother's illness. Living with her brother's AIDS was really the beginning of living with HIV for her.

The last point is that caring for a loved one with AIDS is a profound, painful, demanding experience. As Patricia shares about her boyfriend Tony:

He was my heart! When I watched him suffering, like he did, it was literally tearing me apart. Could you imagine your husband or wife in pain and no matter what you did it wouldn't help?...He was more important than I was, I didn't think about my HIV I thought about his AIDS....It was more what I was doing to him than what he was doing to me....what I could do for him to make his life better for the next years he had left....He was my life the whole four years of my life I was with him.

Her experience speaks to the immediacy and extreme needs of someone living with AIDS. Those needs easily overshadow the needs of someone who is asymptomatic with HIV. But also embedded in this discourse is the self-giving, self-effacing position that many women feel in relation to their men and other loved ones.

This focus on others initially presented a struggle for me in my listening and probably for the women in feeling heard. I came to understand their focus on others is an important part of their stories. It points to the systemic nature of life, which is punctuated by the elaborate webs that HIV makes as it spreads often between intimates and loved

ones. It also points to the roles of women as caretakers. I acknowledge the importance of the systemic and connecting elements of these women's lives and yet I chose to focus on the women themselves in recounting their stories. I do this for two reasons: 1) because women have been neglected in the social science literature except in reference to others, and 2) because it is also easy for women to neglect themselves. Keep in mind this wider web as backdrop to the close-up perspective of these women's stories about living with HIV.

These stories of women living with HIV provide an inside perspective on their lives and it is from this unique vantage point that this study offers suggestions for practitioners. As we begin to listen to the stories of these women let us position ourselves in their perspectives as much as possible so that we can hear their words and begin to understand about their lives. Within these stories are needs and concerns which call for action. In addition they tell of what encourages and hinders them which may be applicable for other women living with HIV. I was sometimes a resistant listener but it is my hope that we can listen with openness to their stories.

Becoming HIV Infected

The intimate nature of HIV transmission raises the question "Who gave me the virus?" For some participants in the study the answer is clear, but the invisible nature of transmission means that for most of the women in the study the question cannot be answered definitively.

The route of infection.

All the participants in the study wondered who gave them HIV and were able to answer the question with varying degrees of certainty. India identified that she contracted HIV when she used drugs for the first time in a long time and she shared a needle with her best friend Ruth. India recalls, "The guy that Ruth was going with told her, she got

tested and then she told me." This is the only case of transmission through drug use for these women. The rest of the women are quite certain they contracted it through sexual contact with their male partners.

Patricia thinks that she contracted HIV from her long time boyfriend, as does Charlene. As Patricia tells:

Everybody was so concerned that I was switching boyfriends so much and they thought that I was promiscuous. Well everybody told me to get tested. And I didn't think nothing about it and I didn't go get tested. Now when I was pregnant with Tom I got tested twice maybe three times the whole pregnancy because I was worried about that. I just had that feeling the whole time I was pregnant. And I think a month or two after he was born I went to donate and it didn't take long for that test to come back I'm going to tell you. I think I donated once after he was born and I actually got paid for it, and the other times I didn't, I couldn't go back because of the HIV.

It turned out the father of her new son had AIDS.

Charlene also thinks her boyfriend infected her but like Patricia she had a number of sexual partners:

You can't really sit and say who it was because all these people I had sex with I didn't have protection with them, so you can't say who gave it to who. All you know is that I had my son in 1990. He doesn't have it so it had to have been Lee because him being the last person I had sex with. I was the only person he was having sex with too. And he got sick and he was having thrush. And thrush is one of the things...with HIV...He was drug addicted too, he was using dirty needles and that was the only way that I got it through having sex with him because I didn't do no drugs.

Unlike Charlene and Patricia, the partner that Tora was with when she was diagnosed with HIV tested negative for the virus. Tora had been tested once two years before her positive test:

With everybody talking about HIV blood I had heard that somebody I had been sleeping with had it and just went and got tested that was 1990...I was never really promiscuous, but I had at least two sex partners a year and I wasn't steady dating anybody....even back then I would say to myself you should always use a condom. And a couple of times I did, but a couple of times I didn't. So I don't know if I was really trusting that person or I don't know what I was thinking. I always had you know STD on my mind, but I didn't really think that much about AIDS back then. I always thought that AIDS was something that happened to somebody else, but I should have been protecting myself against the deadliest thing as AIDS. But you didn't hear as much about it then as you do now...

There is two particular people that I know has been tested positive for HIV. One of them has full blown AIDS so I am not really not sure which one I got it from, it was probably one or the other. But it was like I said if I was sleeping with a couple of people a year it could have been...a lot of people could have it and not even know.

Felicia feels quite certain that her husband gave her HIV which he may have contracted through secret affairs during their marriage. However there are two other possible routes of transmission:

I had not run around, I had not been out on him, or I had not been with anyone else and at the very end, when we had separated there was a man that I had started seeing and had been intimate with and now, in hindsight, looking back that was a mistake. It is a possibility that it could have been him. I don't know....I really did

not know anything about this man. I mean I had worked with him, I knew him but I didn't really know anything about him. It was kind of like taking things at face value. He seemed OK, he didn't look like anybody that had anything. Well, guess what that taught me. I doubt that I look like that either....AndI did have some surgery in '85...It is a possibility that I was given blood in '85 so that is a matter of having hospital records pulled and we could find out on that.

The knowledge of the transmitter.

Considering the routes of infection can raise another question: Did the persons who were HIV positive know they were positive when they engaged in high risk behavior with these women? Of the four women, only Patricia indicated that her boyfriend knew he was HIV positive. Patricia states, "Tony knew that he was positive, I didn't know that he knew." India and Charlene are clear that the persons who transmitted the virus to them did not know they were positive at the time. India is clear, "Ruth did not know that she was positive when she infected me." Charlene explains that Lee "thought he had cancer. They didn't tell him he was HIV until the 30th which was a couple of weeks before I found out. I found out the same month he did."

Both Felicia and Tora are not sure who infected them. Felicia was separated from her husband when she found out she was infected with the virus and she states, "I think he had no idea. I know just from the look on his face the day...I told him I was positive. I thought he was going to pass out." She has not talked with the man with whom she had an affair. Tora also makes no mention of talking with the two men that she identified as potential transmitters.

Questions of certainty.

India and Patricia were the only woman who expressed no doubts about who transmitted HIV to them. India draws a clear line to her best friend with whom she

shared needles. India recently celebrated her sixteenth wedding anniversary, her husband is HIV negative, and she identified no other risk factors. Patricia indicates her boyfriend Tony transmitted the virus to her. Often there are multiple possible routes of transmission. Because viruses are invisible it can be difficult to know how it was transmitted.

The importance of knowing.

Just as the women vary in their certainty about who infected them, they also differ in how important that is. Felicia is unclear about how she was infected. Her uncertainty is uncomfortable but useful for her. She states, in reference to the man she was seeing after her separation from her husband:

It is a possibility that it could have been him. I don't know. I think that is one of the things that bothers me a lot about this, is that there is so much that you just can't know. You don't know and you can't know...But then sometimes I think on the reverse side of it, I'm kind of glad there is that doubt, because after I got past the point of wanting to die and wanting to kill my husband and all this stuff. And I told my mother and my children that (now my children do not know that I was with that other man, I have not quite... I don't know whether it's brave enough or whatever to tell them that) I did have some surgery...And I just told them I don't want to know. But I don't just want them to think Daddy did this to Mommy.

Felicia is able to protect her children with her uncertainty.

In our conversations Tora did not focus on who gave it to her, but she does admit: Sometimes I wonder who I got it from, but I shouldn't dwell on that because I should have been protecting myself so I try not to dwell on that. I don't blame myself either cause all of us are victims of the disease but it is natural to wonder why it came and where it came from.

Tora does not blame the men, or herself, but shifts the blame to the political level and ponders the origins of the disease:

I have lost my trust against the medical and the government. I guess I shouldn't blame them either. I just feel like if the president would have come on TV back then and said you should be using a condom and making us more aware of it, but then again, I don't know. But I kind of blame the government because they are still giving people blood and which that is not the way I got it but it could have made it more wide spread, I don't know. I don't hold grudges I guess I just think about it and why I got and why all of sudden it came here. Where did it come from and how it came about. I am always thinking about that.

Tora changes the question from who gave the virus to her to how did the virus come to be. Patricia, Charlene and India did not focus on the issue of certainty.

Looking back.

Patricia's boyfriend Tony warned her, "Well, I might have HIV, I don't know how true it is, but I don't think I do." Patricia looked me in the eye: "Now what is that telling you? I just didn't pay attention to him." She reflects later:

I had that feeling. I thought he might be, and I don't know, it really didn't bother me, it really didn't. I was in that period of my life...It is like I had had sex with him for more than a thousand times by that time, you know he had confronted me.

What is the use of using protection? You've got it. I knew there were ways, but he insisted on not using them.

Patricia identifies that she thought her partner might be HIV, but she does not really look back much.

Tora raised the issue of HIV being a disease for others. She thought her gender and identity protected her from HIV. No one she was close to was infected. "It sounded like

a gay disease, so I thought 'I'm not gay, so I am not going to get it. I am not using IV drugs so I am not going to get it'." The defined otherness of HIV positive persons led her to conclude:

We are in this circle and we are protected. It is going to happen to other people; it is going to happen to drug addicts; it is going to happen, you know, to gay people; it is going to happen to people who are bad or seem to be bad anyway.

Tora was careful about protection during intercourse most of the time but sometimes she admitted that she was so "caught up in the moment and I just wanted to be with that person so much that I didn't think AIDS would invade my territory, or my home, or this person that I knew so well." But there is no protected circle from HIV.

Felicia attended one of the first AIDS conferences in Richmond in December of 1985. She identified the disease with homosexuals, prostitutes and drug users. She links some of her thinking about taking precautions also to her age: "during the time that I grew up protection was to keep from getting pregnant...it never occurred to me to protect myself from anything else." She was monogamous while she was living with her husband though she suspected he might be cheating on her: "I never knew for a cold hard fact that my husband was having an affair until we did split up, and in my head I knew it, and in my heart I didn't want to believe it."

Felicia's monogamy in her marriage and the otherness of the disease deluded her into feeling she was in the protected circle also. She did not think her husband would be sleeping with IV drug users or prostitutes. In addition when she allowed herself to consider her safety she thought that most of the women would be younger and would be using protection because they did not want to get pregnant. Unfortunately protection from pregnancy is not necessarily protection from HIV.

Felicia realizes in retrospect that she did not really know anything about the man with whom she had an affair. She was lulled into false security because she had worked with him. She knew he was married, divorced and had two children but "it was a mistake to sleep with him because I didn't know anything about his past, and I still don't. I didn't know that he wasn't a drug user." It is this hidden aspect of HIV which is so insidious.

Diagnosis

The decision to be tested, the testing site, who gave the diagnosis to the woman and under what conditions all combined to form a different story for each of the participants. For all of the women the information was a shock at first but the way in which they were told made it more or less traumatic, and laid the ground for follow up medical and emotional care.

Initiating the test.

Tora, Patricia, and India suspected they might be HIV positive because they knew they had been exposed to the virus. They each arranged for a HIV antibody test. Tora had already gone for a test in 1990 and then arranged to have another test when she was pregnant in 1992. India first tried to get tested in jail. She said, "I begged them, 'I need to be tested, I need to be tested, there's something wrong with me.'" But she states they refused to test her, so after she was released from jail she went for her test.

Patricia had initiated tests but her HIV positive status was identified another way. She was tested three times during her pregnancy with her third child at her own request, and all her tests came back negative. "I just had this intuition to keep getting tested through this pregnancy, and it was free, they did it, so why not?" Instead her diagnosis came when she attempted to give blood a few weeks after the birth of her son.

Charlene and Felicia did not initiate the tests themselves. They were both receiving medical care for gynecological problems and an HIV test was suggested by the attending medical personnel.

The test sites.

Two of the women (India and Felicia) were tested at the Health Department. Two weeks after India completed her jail term she went to the Health Department and was tested through the HIV Antibody Testing and Counseling Program. Felicia also went to the Health Department, but not initially for a HIV test. She went for medication for a yeast infection. Felicia notes she could have easily failed to find out her diagnosis so soon. First, she self-diagnosed her yeast infection and almost bought over-the-counter medication for the infection rather than seeking medical care. Then she chose to go to the Health Department rather than her private physician because she was out of work and short on money. At the Health Department they interviewed her about her risk factors and then asked her if she had ever had an HIV test. She was at risk for HIV but had not put the pieces together. When they offered a free HIV test she thought, "Well I'll just do it. It's one of those inconvenient things that you have done but you know what the results will be but you just do it anyway." If she had sought medical care in another context it may have taken much longer to put the pieces together, as it did for Charlene.

Charlene went to her doctor "for the longest time" because of "female problems." After repeated trips and different courses of medication the physician finally asked her how many sex partners she had. When she said one, he asked how her partner was doing. Charlene told him that Lee had thrush and pneumonia (two of the indicator diseases for AIDS) and then he asked what she would think about taking an HIV test. She said, "I don't care, because I know I don't got it. I ain't done anything to get it." Charlene, like

Felicia, thought there was no chance she would test positive for HIV. The other two women had their suspicions.

Tora chose her obstetrician to do the testing because she was seeing him on a regular basis during her pregnancy for her third child. As reported earlier, Patricia's HIV status was identified in routine blood screening when she gave blood to get money to buy diapers for her newborn baby.

Finding out.

In recounting the details of the day they found out their HIV positive diagnosis, three of the women (Felicia, Tora, and Patricia) reported waits from one to three hours to learn their results in either private physicians offices or public settings. Charlene and India reported no waits for their results. Each woman has an distinct story to tell of how she was informed of her diagnosis which ranges from informative and supportive to confusing and infuriating.

India returned to the Health Department when her test results were back. Even though this is standard procedure for all HIV antibody test results to ensure post-test counseling India thought: "Well, hell, if you're not positive it seems they would tell you everything's OK." So she was already on edge when her time came to be taken back into a private room for her results. She describes the situation before was told she was positive:

I knew because why would two people set me down?...I sat there for just a minute, and then I boo-hooed. And then it's like, "I'm sorry, I'm sorry", and Rachel (the AIDS specialist at the Health Department) said, "Well if you didn't cry I'd think you weren't normal".

The Health Department follows a protocol for informing persons of positive HIV status. Though the news upset India, the process was handled so well that she plans to take her niece there for testing.

India overwhelmed at first was then able to turn her attitude around:

As far as my own care-taking it is like at first why bother? And then I thought, wait a minute I can work with this disease and I can live a better life. And if I do the things I need to do to actually physically take care of myself and emotionally take care of myself I will live healthy and longer.

Felicia was also tested at the Health Department, but when she returned for her results she was surprised at the crowded waiting room and the long two and a half hour wait: "I'm sitting there with a bunch of college girls, a gay couple, and a lot of people who were clearly destitute and I'm thinking, I don't need to be here." She was on her way to the hospital to visit her father, who had just had a heart attack, and she almost left a number of times during her long wait. Her youngest daughter was with her but had gone out to the car to listen to the radio and do her homework when Felicia's number was called to get her results. Rachel also informed Felicia and she describes her response:

It was...I can't even tell you...it was like, at first I thought I was going to be sick. It was like heat hit me. And I told her, "Shouldn't I be crying? I can't cry." I mean I was just in shock. And then she began to tell me that the first thing they would like to do is re-test me, to make sure. And that they would like to do that that day. And she was talking, and she was telling me all these things, and it was like I wasn't even there. I mean I heard her talking and everything, and I don't even remember what all she did say, and I don't remember at what point I finally started crying, and then it was like I couldn't stop.

Felicia was clearly in shock when she found out, but she was responded to in a sensitive manner. Charlene's experience was not as informative or supportive as Felicia's and India's.

Charlene was more concerned about her thyroid than the possibility of HIV when she was tested. The nurse in the physician's office called to tell her that the doctor wanted to meet her in the emergency room to give her thyroid medication. When she met him there he admitted:

"I have some bad news to tell you." I said, "I know your nurse told me." He said, "She kind of lied." I said, "Kind of lied? What do you mean lied?" "I had her call you to get you over here because I had to tell you your results of your tests."

"Yeah", I said, "About the thyroid--that I have it." He said, "No, you have HIV." I said, "No, I ain't got no HIV. I ain't gone and ain't did nothing to get no HIV. I'm not that kind of a person to get that." He said, "Well I hate to tell you this but you got it." And I started crying and he was like, he didn't even want to get near me.

He didn't want to touch me or nothing, and he kind of handed me the paper towel like wanted to not touch me. That kind of irked me.

The physician gave her resource numbers and directed her to the Health Department for retesting. Charlene cried all the way home on her seven-to-ten block walk from the hospital. She was "just thinking and crying and saying 'Why me? How can this happen to me? I didn't do anything to deserve this.'" She discovered her diagnosis in the impersonal atmosphere of the emergency room, and was handed a towel like she had the plague. At least she was given resource and referral numbers. Charlene followed through with the calls she was retested and counseled at the Health Department. Patricia was not so fortunate.

Patricia was at the Plasma Center to donate blood. She had donated blood before, but this time she waited for two hours to donate--all the while trying to figure out what was wrong. She suspected either HIV or VD. When the doctor finally called her back he used a medical terminology on me and I thought--what in the hell are you talking about?...He didn't use HIV, he used another word, he said Hemma, something, something, something...then I figured it out. I turned red when he told me. I didn't want this to happen.

He told her she couldn't donate anymore and she says she was "ticked" and left. Because she left precipitously health officials spent three months looking for her to follow up. They called at work, but she did not return the calls. "I didn't know who she was at that time so I said forget it."

Patricia was angry when she found out, but her anger was short-lived in her account. She states, "It took me about two hours to get home. After I got home I blew off the steam, and I was fine. And that's as long as it lasted....It really hasn't affected me." She was angry at herself. "How I could let myself get that knowing I had a son to raise? Knowing I was pregnant basically. I wasn't pissed off at him, I was pissed off at myself."

Tora had the longest wait of all--three hours in her physician's office. The doctor's office wrote that her tests results had revealed abnormal blood and she knew immediately that something was wrong. She made an appointment to find out the results and took her sister-in-law and girlfriend for support. During the three hour wait to see the doctor they all concluded that nothing was wrong or they would have called her back right away. When the nurse took her to the examining room she told her to take her clothes off, but Tora stayed dressed because she knew she was there for test results, not an examination. When the doctor came in he seemed confused that she was dressed and asked her why she was there. When she said test results he said:

"I have some good news and some bad news." The way I was told was bad. He just left me in the room by myself. I think he may have said, "I am going to go and get a nurse for you." It might have taken about five minutes before he got somebody, but one minute felt like forever sitting in there by myself knowing that. I just wanted to get out of there and get home.

She expected to be told that she needed to be retested but instead she says she was told she was definitely positive. "I just remember going and laying on my mom's bed crying and my mom crying. I remember my boyfriend crying. It was a terrible day."

All the experiences of diagnosis outside the Health Department were inexcusable. Clearly all women need emotional support and accurate referral information. Some of the women received that information and some did not.

Suicidal and homicidal thoughts.

All of the women were very upset when they found out they tested positive for the HIV virus. Three of the women Charlene, Tora, and Felicia mentioned considering suicide. As Charlene recounts:

That one whole year after I found out, it was tremendously painful to go through. I am glad I had Lee [her boyfriend]. If I had not had Lee and my kids, I probably would have committed suicide to be honest with you.

Tora was also suicidal:

When you first find out you are going to go through weeks, months, and maybe a year of not believing it and feeling sorry for yourself and wondering why and that is the main thing you are going to ask yourself is why me? why me?...When I first found out I was depressed all the time and I wasn't spending time with them [my kids] like I should, you know quality time...I...was tore up about [it], I didn't know what to do. I didn't know whether to live or die. I was suicidal.

Felicia was most direct in her anger toward the person she thought infected her--her husband from whom she had been separated for over a year. Her suicidal thoughts became homicidal:

In the beginning I hated him too. And my thought that night, I began to think of suicide. I began to think, I can't put my family through this. I can't put my kids through this. You know everybody will just think that the separation just got to me. I'll commit suicide and it will all be over. And then it turned from that to that I wanted to kill him, and I started thinking of ways to kill him. I really did.

Chapter VI

Telling Others

The invisibility of HIV makes it possible to hide the disease even as it is often hidden for many months or even years from the person who is infected. Disclosure about the disease is a delicate and difficult issue because of the stigmatization associated with HIV, yet the infectious and deadly nature of the virus often situates disclosure in the ethical realm.

Disclosure is an immediate issue and frequently the person who has just been diagnosed with HIV is oblivious to the possible ramifications of telling. India was diagnosed at the Health Department where there is a long history of witnessing the complex issues of disclosure for their clients and the community. India recounts a conversation at the Health Department on the day she was diagnosed:

When I was first told I had the virus, the first thing I was told was you don't tell people. You have to be very particular who you tell because it does create a lot of pain...I even had to decide whether I could tell my siblings and my mom.

Initial disclosure often happened within minutes and sometimes was intentional, sometimes not. After first finding out two of the participants went home to confront the persons they suspected had infected them, one tried to put on a good face and hide it from her daughter, and the other two went directly to family for support. In whatever way the disclosure began it was and continues to be an important theme for all the women. Regardless of how others found out, or how they responded, disclosure has affected these women's lives in dramatic ways.

The First Ones to Know

Four of the women (India, Charlene, Tora, and Patricia) were involved in intimate relationships with men when they were diagnosed, and they all told them that same day. In addition, two of the women (Tora and Felicia) were accompanied to the test report encounter by people close to them who found out immediately. I will begin with their stories.

Tora, after her long wait in the doctor's office, really had no choice but to tell her friend and her sister-in-law who were waiting with her. She cannot remember exactly how the day unfolded, but she also told her mother and boyfriend the same day:

The way I told Jack was, "I told you something bad was wrong," and I was really really crying. And he said, "Oh, my God!" It was the first thing he said--he already knew, I didn't even have to say it. He knew I was going for my HIV test results. He was like, "I wish I had gone with you." He thought everything was going to be all right, but I knew when I got that letter that something was wrong.

In that first day Tora told four persons, more than some of the women disclosed to in months.

As Felicia recounts the day she was told she was HIV positive at the Health Department, she is in a quandary:

They did the test again. And then I kept saying, "I have to get myself together before I go to the car. I don't want my daughter to know. I don't want to tell my daughters. I'm not going to tell them." And then I stayed with Rachel what seemed like forever in there, and I think for my daughter it did too. And when I walked outside and I got in the car she looked at me and she said, "What's wrong?" ...I mean I just completely lost it...I told my daughter right there when I got in the car because I started crying and then she immediately is like, "No", because she knew I

had gone back to get the results. And she kept on saying "No", and then she started saying that she hated her dad, and all this.

Charlene, India, and Patricia were alone when they were tested and so they had a bit more time to think and opportunity for intentionality about their disclosure. They all told their partners first. Charlene's and Patricia's initial disclosures were colored by the fact that the persons they first told had infected them.

Charlene went home from the emergency room after she was told she was HIV positive to tell her boyfriend:

I flipped out, I was like, "I can't believe that this is happening to me." And he goes, "What do you mean?" I go, "They told me I have HIV." He says, "What?" "They told me I have HIV." He says, "Well, I got something to tell you." I says, "What's that?" He says, "I have it too." I was like, you know, "Well that's how I got it through him."

She does not go on to discuss her immediate reaction but reflects on how hard it is really to know who gave it to who. The news of her boyfriend's HIV status caught her as much by surprise as her own diagnosis, but Patricia had her suspicions.

As Patricia indicated earlier, her boyfriend Tony had told her that he "thought" he was HIV positive and then he took it back. When Patricia finally deduced that she had HIV at the Plasma Center she was so mad that she left. Her anger was short lived as she recalls her

pissed off feeling...I borrowed this woman's car which did not have no gas in it at all...It lasted from the blood bank all the way down on Eastern Avenue. I was doing 50 down Campbell Avenue until I ran out of gas. It took me about two hours to get home. After I got home I blew off the steam and I was fine. And that's as long as it lasted.

I told him--I showed him the paper, I didn't really tell him. He said, "What does this mean?" I said, "I got HIV." And he looked at me funny and I said, "And they're going to be looking for you too I just imagine, because I'm going to go through that process--well who did I have sex with in the last four years?" It really didn't bother me that I had it, I was expecting it I guess, in a sense. I'm one of them type people, I just have an intuition before it happens that it is going to happen.

Her anger was short lived for the partner who, probably knowingly, infected her. Even among her cohorts her acceptance was hard to understand:

People can't conceive why I'm not angry with James but I'm not. I guess because...we had a good relationship before I found out. We were together a year. I didn't hold it against him. I did that first hour, I'd say, I found out, but I didn't see no sense in separating or doing any of that stupid shit that most people would do or cuss him out.

I fussed at him. I said, "You could have at least let me know." But what he did, he said that there was a possibility that he might have HIV, but he didn't think that it was true. I figured he was just bullshitting me. Was I wrong. I don't hold nothing against him, only that he died too soon.

Patricia told Tony by showing him the paper with the diagnosis on it because as she said, "I don't talk good to a serious degree with men...I couldn't talk my feelings out to him." Her quick lived response of anger is characteristic of the way she describes she handles many things: "The only way that I dealt with any of my past problems is to push it down and deal with it later. And nobody taught me any other way." By the time of her diagnosis she had been with him a year, carried and given birth to their child, and it was the best relationship she had experienced, so she confronted him and then pushed it down.

The Circle Widens

With the first disclosure there is a kind of compulsion to tell, either for support or confrontation. Following the disclosure to the primary person(s) in their lives, the process of telling became more carefully measured. Questions of whom to tell and when arise. The answers to these questions for each woman are individual.

Parents and siblings.

All the participants mentioned their mothers in their stories of disclosure. Tora and Felicia told their mothers on the first day. Tora went to her mother's house, Felicia tried to hide it from her but couldn't. Tora admits: "It was so grim. I just remember going and laying on my mom's bed crying and my mom crying." She chose to tell her and went to her for support immediately. They cried together.

Felicia on the other hand went to the hospital directly after finding out to visit her father, and she had put on the "face to face everyone." Felicia had taken a tranquilizer and put on make-up but her mother

knew what I had gone for, because I was so sure nothing was wrong that I never hesitated to tell her...She just kept looking at me, and I couldn't look at her. We were at the hospital, and when we left, I went downstairs, and I went outside the hospital and I started screaming to the top of my lungs. It was just like I had put on the act. I had done my job, but then the emotions hit. The security guy came running out and of course, I was sitting there and I was just stressed. I just lost it for about five minutes, I just was completely...I was just screaming.

She does not mention choosing to tell her, rather she acknowledges "we are so close, she can read me." India is the opposite. If Felicia didn't want her mother to know, but couldn't keep it from her, India wanted her mother to know, but felt that she had to withhold it from her.

India had told her husband first and then her mother. She waited "probably about six months" to tell her mother:

I waited a long time to tell my mom. I couldn't imagine what emotions she would go through after losing her baby and her last one, getting ready to lose one (because I told her before my brother died), then lose her first born also. And I wanted to tell her that day. That is a long time for me to hold something from my mom, because we are so close--my mom and I are buddies.

Her mother responded, "'Oh India, no,' and then she started asking me questions. 'You had better start slowing down.'" Her mother was sympathetic and she began "mother-henning" her immediately.

Charlene told her mother after she told her boyfriend and states that she has been "real supportive for me. At first she didn't want to be--she couldn't handle it." Patricia's mother still does not know and that is fine with Patricia, at least on some level:

My mom don't know that I've been married, my real mom, she don't know that I have children, she don't know I have HIV, she don't know I went through, what I went through with Tony--she don't know nothing about me. I'm like a whole different person if she were to meet me now. I haven't seen her since I was about 14 or 16, one of them two, because I was in a group home when I finally got the guts to go see her. But that was a lot of bad stuff happening in our childhood. I don't know where she lives...but life goes on.

Patricia's other mother is Tony's mother:

Me and her were real close. There weren't too many people she said that she loved, "I love you and I adopted you into my family." She's Black, I'm White, that's rare to be the least expected. But she met me; she liked me. She told me..."You just call me Mom." And we got along ever since until he died.

Patricia does not mention disclosing to her but she does know and she also encourages her to take better care of herself.

For the most part the participant's fathers were quietly absent in their stories. Tora's and Charlene's fathers are dead. Tora imagines her father's response if he were alive:

My father has passed away, but I know if he was living it wouldn't bother him. He died of cancer, he would understand completely. Sometimes I think it would be a lot easier if my grandmother and father had been living. Had my father been living he would have probably went off and wondered who I had gotten it from and stuff.

I really don't know what his reaction would have been since he had cancer himself. She seems to see him as a possible protector but also indicates that he would have been sympathetic because of his own experience with illness.

Both India and Felicia have not told their father and do not intend to. India reports: My father does not know. I don't want him to know, don't need to know. I could care less. Well, maybe I do care, that's probably I do care or it wouldn't matter, I don't know.

India is clearly estranged from her father but as Patricia has an other mother, India has an other father. He is the uncle she lived with as an adolescent and she tells about disclosure issues in relation to him:

My uncle really devastated me when he died, he was like my dad, he gave me away at my wedding, he was my daddy to me. I have a biological father, but my uncle was my daddy. When he knew I was going out there and I would be taking care of my brother, and that I would be cleaning up his bodily secretions and everything else you know, he was really concerned. "You be really careful, you wear gloves, you do this, you do that, be careful you don't want to get it." I could not have told

that man. I don't know how he found out, I think my aunt may have told him, you know, but, that's okay, he never changed how he felt about me.

While India's distance from her father kept her from telling him it was Felicia's closeness to her father that keeps him in the dark. Felicia simply states, "my dad has got heart problems and I don't think he could take it."

Patricia does not mention her father or an other father. Her important family members are her siblings. She first mentions her sister and "it kind of shocked the hell out of her." Patricia did not really tell her that she was positive:

I didn't tell her that I was positive (that I had it) but I said that I thought that I had it...and...then that they were going to be testing me again. They test you like three times in a row, or something like that, to make sure it is accurate.

Charlene's most detailed disclosure story was also to a sibling, her brother:

I shared it with my mother first and then later on I told my brother, and my brother couldn't handle it, he couldn't accept. It tore him up. He cried and it was hard it was painful and he was just so much tore up. He was drinking when I told him but the way he handled it, he was tremendously hurt. It was like he lost a piece of me or something.

Her choice to tell him while he was drinking affected his response and ability to cope with the news. In her retelling of the story she indicates in a tender way that he seemed to feel he lost a piece of her.

Children.

All of the women in the study are mothering dependent children. How and when to tell these children is something that all the women have wrestled with. None of the children under age seven knew their mother's diagnosis, at least consciously. As Tora puts it, "I would never want my kids to not know, because I think not knowing is scarier

than knowing. Like I can sense that my six-year-old knows that something is wrong, but he doesn't understand."

At first Felicia thought she wanted to protect her teenage daughters from her diagnosis. When she first found out her diagnosis and was still in the Health Department she "kept saying, 'I have to get myself together before I go to the car. I don't want my daughter to know. I don't want to tell my daughter. I'm not going to tell them.'" But as soon as she went out to the car and saw her she broke down crying:

And I knew right then there was no way there was no way I could not tell my children. I lived with them and I knew that I could not explain the emotions that were going on in me for that period of time. So I talked to my children and told them. I told my daughter right there.

Tora also told her young daughter. She remembers:

I was thinking about getting counseling and then telling her but I just went ahead and told her about it. And I asked her if they talked about it in school and she said they did and she understood a little bit about it. And she said, when I told her, "If you have it, I want it too", the same kind of reaction that Jack had at first...I want you to know that hurt me...because I would never wish that on anybody, especially a child...

I explained to her that I wasn't going to die tomorrow. I wasn't going to die next week. I was going to try and live as long as I could, and it was a lot like cancer, that God could make a miracle for us. I tried to explain things as best I could. She cried, and I cried with her. And she said well, would I still be able to do things with her like we have normally been. I said, "Yeah", but when I get sick there would be some things I wouldn't be able to do.

I told her it would probably be a while before I would get sick, but I told her that this virus works different on different people so I explained to her there is a possibility that I could get sick next month or next year, but usually you get over it with the medicine. And then I said, "Usually after you have it for while you get sicker and it is harder to get over it, and each year it is harder to get over it." I tried to explain it to her, the way I would want somebody to explain it to me.

Tora's 6-year-old son Bobby does not know yet but she has thought about telling him also. Her reflections about him are sparked by his questions about death but she still feels that he is too young to understand:

I don't think he would understand what this sickness is. He certainly does not understand about dying because...he asked me this question a couple of times, "Well if you die and I die, who will take care of David?" He would always ask me questions like that, and if we die before him who would be down here to take care of him?...He doesn't realize that most of the time your parents die before you, and he will say, "What will happen to me if you die?" You know, that is the same question I ask myself, because I really don't know who I would want to raise them.

Bobby is a young child asking large questions, and his questions reflect a lot of understanding. As Tora has stated earlier he may sense something is wrong. His baby brother David has been hospitalized many times for AIDS, and his mother is living with HIV.

Charlene does not discuss telling her children she is HIV positive but in her journal she notes that one of the local psychiatrists is concerned that her teenage son who knows she is positive is having difficulty handling her "dying." She resists this description of herself, preferring to see herself living with HIV. However her son may have concerns about her constant illness. He is intimately acquainted with AIDS through the death of

Charlene's boyfriend Lee, who lived with the family. Charlene states that Lee "loved my children a lot and he helped me with my boys a lot in a lot of ways."

India has two children in her care to consider. The youngest is a preschooler who does not know, but the older girl confronted India:

She said, "Well I heard you have a disease and that you are going to die." And I said, "Well, I do have a disease, I am HIV positive and that is the virus that causes AIDS." She freaked at first, "Can I get it?" "No dear, you cannot get it from me, blood has to touch blood." And then she really flipped out over it, "Are you going to die?" And I said, "Well, what do you think? Don't I look pretty healthy to you? Kind of stout and healthy, do I look like I am going to keel over any time soon?" She goes, "Well, no...." She said, "Are you going to be around a couple of years?" And I said, "Well, I plan on being around a lot longer than that, I'd like to see you graduate from college and get married before I clock out, you know." And she's like, "OK." When she knew I wasn't DYING she was OK with it. And every now and then she wants to talk about it, we do. I'm going to be totally honest with the children, because they have been lied to. You know, I am going to be as honest as I can without it being detrimental to them.

Naturally the news is upsetting to the girl, as it was to Tora's daughter. India finds similar ways to comfort her, by assuring her that she was not going to die right away.

Tora indicated that she wanted to tell her like she would like to be told. India states that honesty is primary to her in disclosing to the children.

Former partners.

One last important disclosure in the more immediate circle of partners and family is Felicia's disclosure to her husband. Her disclosure to him is unique because she is the only one who mentioned disclosing to a former partner. Disclosure to former partners is

critical in controlling the spread of the disease but this does not have to be done by the infected partner. The Health Department provides anonymous partner notification. Felicia, Patricia and Charlene spoke about giving names of previous partners to the Health Department for notification.

Felicia had been separated from her husband for over a year when she informed him. Her disclosure to him came only after he repeatedly and relentlessly accused of her affairs. One day he stopped by and

he kept on telling me he didn't know why I didn't go on and bring my man out, why I was hiding my man. And I said that I'm not even going to deal with that, I'm tired of arguing with you, and I'm tired of telling you, you don't even listen. You are just trying to justify what you did. And he said, "I know that you are hiding something. Even members of my family have said that they can tell that there is going on in your life that you are hiding." And I thought I am so tired of him thinking that he knows everything, and he is so sure.

And I said, "Do you want to know what I am hiding." And he said, "Yeah, but" (and this is his exact words) "I don't think you have the balls to tell me." And I said, "Well let me see if you have the balls to hear it then." And so I told him and when I told him he started crying. He said, "No." And then it's like, "I have to go." And I said, "No you brought this up and you got me upset" (because I just lost it when I told him) "and now we are going to talk about it." And he is like, "NO, I have to go." And he started out of the door, he turned around and looked at me and he said, "Do the kids know?" And I said, "Yes." And he left.

His response was extreme and included threatened suicide. He still has not revealed whether he is positive or not but his behavior indicates that he probably is.

New sexual partners.

Because HIV/AIDS is a sexually transmitted disease, disclosure to new sexual partners is critical to controlling the spread of the disease. Although precautions such as using condoms can be taken, no protection is completely dependable. Therefore disclosure with a new sex partner is an ethical issue. Charlene, Felicia, and Patricia all have begun new sexual relationships since their diagnosis. They each resolved this issue for themselves in different ways.

Felicia thought when she was diagnosed that she would never have a sexual relationship again. She and her husband were separated at the time and she thought "even though I knew I could, I didn't think I would ever feel...comfortable enough with anybody to tell them and then I thought I knew I could not have sex with someone without telling him." She was able to have frank discussions with Rachel the AIDS specialist at the Health Department and "I kept telling her I'm not a nymphomaniac but the thought of never having sex again does bother me, you know, I would like to have a nice long intimate relationship."

She feels strongly that a partner has the right to know and so when she found herself headed toward a sexual relationship with a co-worker and old friend she felt disclosure was necessary. One of her best friends thought it was a mistake. "If you wanted to have sex with him you should have had sex with him and just made sure that he used protection unless you fell in love with him and then tell him." Felicia equates sexuality with intimacy, communication, and trust so she counters her friends objections by putting herself in her partner's position:

I can't imagine. I mean if I had fallen in love with somebody and was having an intimate relationship with them and six months down the road they go "Oh, by the way I just didn't tell you..." That's not a "by-the-way" that you just don't tell.

And so she felt that she must tell her new beau:

When I told him I was just like terrified. I thought I was going to throw up I was so scared, because I thought if he walks out the door I will never tell another person as long as I live. I was just so scared because I just thought...I can't imagine how I would react if a man would tell me that. I really can't. I think it would be real scary.

He sat for a long time and didn't say anything. Then he said, "It's scary." He said, "You know what hurts me or bothers me, I don't know whether it's hurt, bother, or what, but is that I could lose you when I just found you." And I mean my heart just died, because I was like I can't believe it....And so after I told him and after we kind of got through the part that you could cut with a knife (when the air eased up a little bit) I said, "Do you still want to go to bed with me?" And he said, "Yeah."

After they discussed how fearful Felicia was of giving it to someone and what would make having sex safer:

He said, "Why did you decide to tell me?" And I said, "Because I would like to have some type of a relationship with you and I said I don't know whether it would be sexual....But I would not just go to bed with you and not tell you. I would not say well you just have to use protection and not say well you know why or anything. I think you need to know that up front and if it happens between us then you need to know. I'm not saying that so you can come back and say "You gave me this" if something would happen and I'm not saying it so I could say "Well I told you so" because...we have to be smart. If this happens we have to be smart, we hope. But we both know what possibilities are too."

Sometimes I think now I can't believe I did it because I thought, you know, you feel like you know somebody, but here I thought I knew my husband and I thought I knew this other guy. And I thought I could have told him this and he could have just gone out and told anybody. But I just felt like we were real close friends, I felt like he was somebody that I could confide in, somebody I could trust in...He is still interested in sex. I'm still scared to death.

Clearly Felicia and her friend are frightened. She is frightened about telling him and being rejected, and frightened about infecting him. But by giving him the knowledge of the virus she clearly expects the responsibility to be shared.

Patricia also mentions one new sexual partner since she was diagnosed. She handled the situation of a new boyfriend differently than Felicia:

I just made sure he had protection because he didn't know at first. Then I wrote him this long letter and he knew. He knew before I told him...After having sex three or four times, he already knew, because somebody else had told him. But I used protection and that is the main thing...

Just like when I told Darrell and I actually didn't come out of my mouth and say it I had to write it down because I knew that if I would have told him I would have been as confused as hell....And I thought I'm going to tell him and he's going to leave me. Well he didn't leave me and I'm glad of that.

Patricia states that the important thing for her is that he had protection. When she confronted her fears about telling him he already knew. She was keeping a secret from him, and he was keeping a secret from her. She does not indicate that her disclosure or her delay in disclosing has had any negative effect on their relationship.

The first men Charlene had intercourse with she disclosed to and used protection.

She tells:

Lee couldn't accept it at first because I guess he was afraid I would get it, but it was too late. We didn't have sex for a month and a half, and I couldn't handle it anymore so I ended up cheating on him, I cheated on him maybe twice, he didn't know anything about it...I told them both. The other guy didn't believe me. I didn't know him that well anyway, but I did tell him. It was important for me to tell him. He didn't want to see me anymore after that. I guess it is scary, it really is to a lot of people to know you are dying and you can't do anything about it.

But unlike Felicia and Patricia, Charlene has not always had protected sex in new relationships or disclosed her HIV status. As recently as New Year's Eve 1994 "things got out of hand and I ended up having sex with three different people without protection."

Charlene expresses concern during our first conversation that

it just bothers me a lot to see people out here that is having unprotected sex. It bothers me a lot, but there is nothing I can do about it you know. I think it would help to talk more about it in schools to children.

She did not discuss the circumstances around her sexual activity or how she felt about it.

The workplace.

Three of the women in the study have been employed during some of the time since they were diagnosed: India, Felicia and Patricia. Only India disclosed her HIV status at work yet all of the employers found out with varying effects on the women's work life and employment. Felicia's and Patricia's stories are covered in the section on unintentional disclosure. India however disclosed her HIV status in her workplace in a rather dramatic way.

When India was ready to disclose her status at work she recounts:

I stood up in front of a group of people and came out with it at work. And talk about some shock treatment..... and then there was thousands and thousands of questions. You take 10 questions multiplied by 30 people, and they are all really honest...That was really tough. I cried. Everybody was floored, of course they felt like I had a tremendous amount of courage to do what I did....And all of sudden everybody wants to ask you all these questions, and you have to repeatedly go through the answers and repeatedly go through the emotions. That was real tough, because those emotions keep coming back and coming back every time.

But on the other side of the coin it was a good way for me to process it after knowing for four years and not processing it properly. So...it was bad, but it was good because of the people I was around...counselors, and medical people and everything thing else, you know. There were a lot of questions at that meeting, that I did not want to answer, like when did you find out? I didn't think it was necessary to tell, you know. Why did you keep it so long? Well, I was afraid, I was afraid of losing my job, questions like that. When they ask me how long? I said, "It doesn't really matter. I don't think that is an important issue...I have know it for a good while." "Why didn't you tell us sooner?" Because they are all my friends and they all love me. "Why did you carry this around with you alone?" A lot of tears over that. "Why didn't you share it because we love you and we would have accepted you anyway. You didn't have to carry it around with you." Which I have for almost four years, other than my few friends and few family members, but since that time, all my friends know.

It showed me that they really did love me and was really concerned about my feelings and my emotions....Every person that was in that meeting, well 90% of these people or maybe 100% have been through treatment themselves. So they are

saying to themselves this could have been me. And they are telling me, "Yes, it is a blow to us because it hits close to home it could have been me, because I was abusing alcohol and sleeping around and shooting up drugs and doing everything else and it could have been just as easily be me."

India was in a unique work setting to be able to reveal that she was living with HIV. The 30 staff members reacted in a caring and concerned way for a number of reasons: India had long standing personal, supportive relationships with the staff, they were more educated than many people about the disease, they were part of an organization which valued processing emotional material, and they may have realized it could have been them so they did not cast her into the "other" category.

India indicates it took courage and was emotionally exhausting for everyone involved. For her it was a relief to process it after keeping it a secret for four years. She was able to maintain her privacy about specific information and in the end she felt embraced by their unconditional love.

India acknowledges that others might not have as positive an experience as she did disclosing in the workplace. She explains:

See, I was in a very unconditional situation to be able to do that. One in how many people would be in that situation to be able to come out with it like that? No many, and I guarantee...Maybe I am the only one that has come out with it like that [here], you know what I mean. It is like, I know if it was, say my best friend, if she were to do that, it would destroy her whole life...[She and my other friends]...don't have jobs with...counselors, and that type of situation. They have work with stuffy business people, now and work in the public.

India concludes that what worked for her may not applicable in other situations.

Reflections on Telling Others

These women had many opportunities to disclose their HIV status. Their varied situations and experiences made them experts in the art of disclosure. In our conversations they shared some of what they learned about telling and the factors which influenced their disclosures.

Assessing the situation.

Prior to revealing HIV status some of the women in the study mentioned ways to evaluate whether they would tell. When Felicia told her new sexual partner she put herself in his position. She considered what it would be like to be told and not told, and admitted she didn't know how she would respond. Tora also took the position of her daughter, both in the way she told her "I tried to explain it to her, the way I would want somebody to explain it to me" as well as in her need to know. Tora recalls a dream she had as a child:

I remember when I was a little girl, I would dream a lot and I had this dream because my mother had to have a hysterectomy. They had found cancer and after she had the surgery, I had a bad dream that it came back on her and she was dying and she didn't want me to know that she was dying and she tried to put a wig on and tried to dress herself up as someone different...I will never forget that dream. I would never want my kids to not to know, because I think not knowing is scarier than knowing.

One step of disclosure for some of the women was to place themselves in the other person's position.

Imagining the response.

Another element in the process of disclosure was to imagine the response. Felicia tried unsuccessfully to imagine the response of her new sexual partner but then realized

how unpredictable a response can be when she remembered telling her husband after they were separated:

I guess preconceived notions are so terrible, but in my mind for a year and a half that I knew before I told him I was, like going through all the things, "Now this is what he will do." And I thought there were several possibilities:...he's going to go berserk and kill me and his self and that's going to be it; he's going to tell me how much he loves me and how sorry he is and he wants to be with me until the end, and take care of me and be back with the kids because we need him now, we all need to be together. That's what I really thought he was going to do. And then he did totally what I didn't expect at all.

Often the imagined response was given as a reason not to disclose. Felicia ponders:

Sometimes I think about how would some of my people that I work with and my family, how would they react if I told them? There are members of my family...(of course, I shouldn't say I think this is what they would do because I have all of these expectations, and I thought I knew how Judas [her husband] was going to react and it was totally different) I feel like with my brother, it would be either he would want to kill Judas, or he would blame Judas and want to kill him right away, or he would just have nothing else to do with me, and he could want to kill Judas and still not have anything to do with me.

Acceptance.

India noticed that "my disclosure is connected to how much acceptance I feel." It is easier for her to disclose her HIV status if she feels that the person will not be judgmental. Her sense of possible acceptance is directly related to how educated the person is about the virus and the disease.

Education.

Three of the women indicated that education was an important part of the disclosure process. India found it easier to disclose to her family because they all were "pre-educated" by her brother with AIDS. Her family had both information about and experience with a person living with AIDS. Tora, Felicia, and India evaluated how knowledgeable the person they were going to disclose to was about HIV/AIDS, and educated them as part of the disclosure process if necessary.

Tora began her disclosure discussion with her daughter by asking her if she had learned anything about HIV in school. She built on her daughter's knowledge and filled in the gaps during her disclosure process. India has developed a method of revelation which consciously includes education:

If they can't understand a lot I sort of make it a point to begin the teaching process, because they all know that I have done a lot of volunteer work and they know that I have dealt with it with my brother, and lots of friends. And then I just sort of wait...I have done this: I have educated and then told them. It works well especially if you get someone who is interested but knows nothing about it. I think fear out of ignorance is one of the worst things. And if you know something about it then you don't have to be afraid of it. You can take precautions in a household.

India had to be educated herself before she could disclose in this way.

Felicia and her new sexual partner both expressed fear about becoming more intimate. After Felicia told him that she was HIV positive she notes:

And now we're kind of going through the education phase, of asking me what can you do? And what can't you do? How do you know how you are doing? And are you taking medicine? And what are you taking? When do you take it? And when do you have to go to the doctor again? And all those things like that.

The size of the circle.

The circle of people who know about the HIV infection expands after the first disclosure. The pattern of this expansion can vary terms of the number of people in the circle, how quickly they find out and also who communicates the news. Felicia has controlled the number of people who know she is living with HIV very carefully and effectively. India and Patricia have a wide circle of persons who know about their HIV status. Often the spread of the news was not in their control. Patricia likened the spread of the news to a virus.

Currently, Felicia's circle is quite small. She mentioned her mother, both daughters, husband, boyfriend and two best friends. The reason that so few people know is in part because Felicia is abiding by her mother's wishes. The other persons that Felicia told apparently have been respectful of her wishes to keep quiet about the news. For more details see the following section Not Telling.

Patricia and India both spoke about a wide circle of people who know about their HIV status. Some of the people found out through unintentional disclosure which will be addressed in the next section. India was diagnosed in February of 1989 so she has been living with HIV for six years now and has had the longest time to deal with disclosure.

Second thoughts.

When India reflected about her family she stated "I wish I had told them sooner. I didn't want to cause them anymore pain." She held back in part because her brother was living with AIDS, and she thought it would be too painful for her family to deal with two losses at once. On the other hand she states at another time, "I would have disclosed differently. I wouldn't have told anybody at work, I would have kept it from my family just as long as I possibly could. A lot of my friends I would have never told."

India expresses an ambivalence about disclosure. When asked directly what she would have preferred she states, "Actually, I would have preferred that nobody would have ever had to know at all. Actually, I would have preferred that it never happened." It seems then that her ambivalence is not so much about telling but that she had to tell. Felicia echoes India's ambivalence.

Felicia is also concerned about the pain for her family and though she immediately told her mother she reflects on the cost. "Sometimes I regret telling her because I think it put a lot on her--a lot for her to handle--she is in her late 60's." But she concludes she had to tell her because "We are so close, she can read me." In a way her conclusion is the same as India's. She regrets having to tell because she regrets that she is infected, but she needs the support which is only available from persons who know what she is experiencing.

Chapter VII

Secrets and Leaks

Not Telling

All five of the participants negotiated the intricacies of disclosure, and part of that negotiation is deciding whom to tell and whom not to tell. India and Felicia reflected on keeping the information a secret more than the other women. This section will address issues of not telling. First secret keeping will be discussed, followed by lies, living a double life, and finally freedom from the secret.

Secret keeping.

As stated previously Felicia's secretiveness is at her mother's request. Her mother has three stated reasons why she feels it is important not to disclose the information. The first is family judgment:

She is afraid that a lot of my family is very straight and narrow, black and white no gray area, they are going to believe that I used drugs or I am gay, or I have been with a lot of men, and she said that she could not stand to think about some of them thinking he [my husband] was right all along, that I was the one running around all along. And I think she is thinking they will blame me, and I was telling her the blame doesn't matter it doesn't matter who had it first...She doesn't want me hurt anymore.

The second is that certain family members could not handle the information. Felicia thinks her sister would faint, her father could not take it because he has heart problems, and her brother would either kill her husband or not have anything to do with her. The third reason for not disclosing is that she may be healed. Felicia said her mother "still is in a lot of denial. Still believes that if we pray hard enough that it is going to go away."

India felt compelled to keep her diagnosis from her family because her brother had AIDS and she felt it would cause them too much pain. (See previous section about disclosure to family.) The difference between the two women now is that India has disclosed to her family and Felicia has not.

Lies.

One difficult aspect about withholding such important information from people who are close is that the information is not merely withheld but the secret often requires lies. With people who are not as close, maintaining the secret is a matter of privacy. Lying in these circumstances does not carry the same weight as it does with intimates. For example, after her separation Felicia received a phone call from one of her husband's lovers:

She called me, fishing. Just called to say hi like we were best friends and then she went on to say , "Have you been sick? Judas was saying something about that you hadn't been feeling good." I said, "No I am fine, why?"

In this situation she did not express any discomfort in hiding the truth, but when she is secretive with intimates Felicia feels she has lived a lie. She recounts what it was like to be hiding her HIV status from a co-worker who she saw nearly every day:

I felt like I lived a lie with him. He had picked up on some little things because when I would go get blood test most of the time I would wear longer sleeves for a couple of days to make sure that nobody notices the bruise on my arm. I will just leave work a little early. I don't say I have a doctor's appointment, I just say I have to leave early. But he had a couple of times noticed that I had blood work done, and one time he said something about are you getting married? I said "Yes." I backed out and then I would go and get the blood work again, and then I would back again.

Even most of Felicia's family does not know she is living with HIV:

Not telling anybody--that is my mother's wishes...she ask me not to. I have mixed feelings about it, about telling them, or not telling them. It is just that I have lived half my life a lie.

She honors her mother's wishes and yet her secrecy leaves her with conflicting feelings. In some ways it is a burden to lie to people she is close to in order to maintain the secret.

India found herself caught in lies also. She recounts one powerful story where her best friend Nancy confronts her:

She had come to my house a couple times trying to track me down because she wanted to confront me herself...and I really hurt her because then she finally showed up before nine o'clock on a Sunday morning. She said, "I knew you'd be here." She came knocking on the door. Well, my husband [Jerome] was awake and he didn't forewarn me that he had told her that I had the virus. And I sat there and I lied my ass off to her.

And I just kept seeing the expression changing her, and then finally she went, "India, don't you know?"...And I said, "Know what?" She said, "Jerome told me."...And I hurt her so bad I lied....And then I tried to justify my lying, and that was when I decided I was not going to lie about it any more, because I hurt my friend and I had never lied to her in the 20 years that we had known each other.

In the end both women describe the experience similarly. India was "living a big secret" and Felicia was "living half my life a lie." Living secrets and lies reflect a double life.

A double life.

Both of the women discuss the experience of keeping the secret as a double existence. In this section India recounts what it felt like to keep the secret at work:

I was starting to get sicker and sicker and the stress of hiding it and that stress dragging me down, and you know constantly having that mask on, and all these other things going on at one time and trying to cover everything up...I would hold two different personalities. This one person that was always me, that is what my personality had always been. But then there is another side of me that went through the depression and the crying and the worrying and knowing that I had to go to the doctor, couldn't really tell anybody. "Well I am going to the doctor." "Why? Have you been sick?" "No, no it's just a check up." "Well, I thought you just had one a few months ago." "Well,..."

This sense of double personality was mirrored by Felicia's description of living a double life:

Sometimes feeling like I live a double life with certain people that I can be honest with who say, "Well how are you doing?" "Well I'm doing OK. My blood check has been good." And then other people even immediate family, "Well how are you doing?" "Oh I'm fine."

Both India and Felicia mentioned this sense of a double life around their medical status and the bind they feel they are in when they are asked questions they do not feel they can honestly answer.

There are many facets of the pain of not disclosing. Felicia mentions here her sense of alienation and loneliness, her need for comfort, and fears of being found out:

It is hard, because sometimes I am depressed and I just want to cry. Or when the family is making plans for next Christmas and I am just saying God please let me be here next Christmas. And sometimes I would just want to cry, I just want to call somebody and cry. And my sister and I have probably gotten closer in the last five years of our life than we have ever been....she lives away, she doesn't live here

and that makes it harder to be closer but we have gotten closer. And there are times I would really just like to cry. Sometimes when she comes or we go and visit, we stay up until 3:00 in the morning talking and telling each other everything. And it is like sisters that tell each everything and it is like I have to stop short of everything, and sometimes I think if she does find out will she be angry with me, will she be mad at me for not telling her.

Felicia mentions three times that she would like to cry and yet she can't cry with her sister, with whom she has a new and precious closer relationship. Even in subtle ways she is disguising her life and the catalyst for her peaceful state. "My sister made the comment that turning 40 had really changed me. And I thought she has no idea, she thinks it is because I turned 40." There is a pain in this kind of secret keeping for Felicia as she struggles with finding a way to be in relation to others with her infection.

India found that when she lived in this double world that she lost touch with herself through wearing a mask. "You know I couldn't be who India really was and...after that much time it was affecting my personality and it was dragging me down because I am not one to hide stuff." Eventually India reached the point where she felt that she had to be more honest about what was going on for her. "It got really tough sometimes because you really couldn't talk about it because there was really no one who you could really talk with about it. And finally I just couldn't stand it any more." So she opened up her secret to the wider community.

Freedom from the secret.

After India dealt with her friend Nancy she made the decision not to lie anymore. She resolved to approach the issue differently:

If somebody asks me I'm going to tell them the truth. And if it makes a difference in whether that person is a part of my life, well...it will hurt, but that's OK.

Patricia came to a similar conclusion after a period of lying about what was going on for her.

Somebody would say such and such told me you had this, is that true? I said, "No, why would you conceive it would be true, don't I look fine?" I would play like that mind game with them.

She turned it into a game but now "if honestly somebody wants to know, I'll tell them but you know what is up with that. If you ain't going to be my friend then you don't need to be my friend."

Stepping out from under the cloak of the secret not only with friend but at work gave India a sense of freedom:

As far as my freedom from the secret of my HIV, when I get sick, I need more than one day off, I don't have to hide that I am sick. I don't have to hide that I'm just really depressed. I don't have to hide that when I go to the doctor and I come back and my count is down 150 from the last couple months ago. I don't have to put on another person or another face to go to work. You know I did that for a couple years.

These freedoms most people take for granted.

India has come to a greater sense of peace about her situation within herself and so she can be more honest with others. When she tells friends now it is with the attitude "Well, you have to know if you are going to be a part of my life because this is my life."

There is a kind of liberation in her attitude toward other's acceptance of her now:

I'm at the point in my life that I really don't care who know except that I don't want to mess me up with my elderly [who she cares for in her home]. If it wasn't for that I wouldn't give a shit who knew. Because I'm at the point that I've accepted it and if other people around me can't then they don't need to be around me.

She links her acceptance of herself with her ability to be free of the fear of rejection.

The News Spreads Like a Virus

Sometimes the news about HIV can be kept a secret, as painful or powerful as that may be. Sometimes the news leaks out into personal relationships, the workplace, housing, medical facilities, or the media. Just as all of the women told stories of containing their HIV diagnosis, they also all relayed experiences of others spreading the news. This unintentional disclosure was often to persons or places they would have rather kept private. These are the situations which will be detailed here.

Personal relationships.

Patricia presents a lively image of the spread of the news:

It was like a virus itself actually. I mean it was just like it, if you think of it. You catch the virus and then it spreads through your body. You tell one person and it spreads all over town. Cause there was one person I really could smack my brother for telling because I really didn't want her to know. She would be the type person that would try to get welfare and them involved. Because me and her never hit it off. We were never friends even though she acted like she was my friend. But she would try anything to get my kids taken, she did before.

Patricia's brother told the last person she would want to know because she could be so destructive to her. India's husband told her best friend Nancy and it was so hurtful to her and India (see story in secrets: lies).

The workplace.

Disclosure in the workplace can not only be painful but costly. Unintentional disclosure in the workplace can leave one vulnerable at many levels. Patricia and Felicia both had others tell their bosses that they were sick. It may have cost Patricia her job, but for Felicia it may have been a hidden blessing-at least so far.

Patricia told her sister about her HIV status. They worked at the same convenience store. Patricia recounts:

I told my sister which she told the manager because I don't know why. Something about the fact that I deal with some food, cause it is like a mini mart that had a deli. If somebody wanted something I would just go in there and grab something and take it out of there. I didn't see nothing wrong with my hands...After she found out that I had HIV ...she treated me like a whole different person actually. She stopped kidding with me. I would work third (actually 11-7). I would stay there an extra hour just sitting there joking with everybody, you know, until they got the shift change over and everything. I could have left at 7:15, but I stayed there. It was impossible after she found out. "Why don't you take her home, get her out of here?" Like, "You bitch."

Eventually Patricia lost her job because she had to be home with her children while her partner was in the hospital with AIDS. She feels

the manager could have been a little bit more compassionate and said why don't you take a leave of absence until he [Tony] gets better? I'd stayed there for a good year. I was like a week from my year when he got put in hospital. I said, "You all really suck. You know that." And they really did do me wrong. I lost it because I was taking care of somebody who had AIDS. Basically she wasn't, she wasn't sensitive whatsoever to that...there was just a lot of bad things but I loved the job.

Patricia acknowledges that she lost her job because she decided that she could not afford child care while Tony was in the hospital, but the manager's response to her HIV certainly may have come into play.

Felicia's situation is slightly different. She had been laid off from work and had just entered into a business partnership with a co-worker to do contract work for her

previous employer. She told her future partner that she had a life-threatening disease which was stable now but she felt she should tell her because she was entering into a partnership with her. She swore her not to tell anyone but

she went to the Assistant Executive Director who is over top of my immediate supervisor...What she told her was, "You are aware that Felicia is dying." Of course, they thought she was just making it up to try to get...it [the business contract] all herself. They called me and ask me to come in and talk to them and I went in having no idea...This was like three days after I had told her this is the strictest of confidence--do not ever divulge this to anyone.

And I walked into the office and my immediate supervisor was sitting there and her boss. And she shut the door, and she said, "I have to ask you something", she said, "You are not going to believe what she...said", and I said, "What?" And she turned around and looked at me and she said, "Are you sick?" And I mean, I immediately knew what she told them. I just started crying, I lost it and just started crying. At first I thought, what am I going to say? The second, was the betrayal, I felt so betrayed.

And once they saw I was crying they were like, "Oh my God, you are. What is wrong?" I said, "I can't talk about it, I can't handle it yet, I just can't talk about it." They said, "But it is true?" I said, "Yes." I mean they both (I worked with them for nearly seven years now)...were crying and we were all three crying together you know. And they were just like, "Let us know if there is anything we can do, you know just tell us."

The consequences of this unintentional disclosure were mediated by Felicia's quick thinking. Now she says:

They have been wonderfully understanding at work, especially not to know anymore than they know. They know I am ill, that something is wrong, and sometimes I will tell them I have been for blood work. And sometimes they will ask me if I have been to the doctor lately and I will say everything is still fine.

And the Assistant Executive Director knew I had gone to the doctor one day and when I came back she said, "Are you still in remission?" Of course, that is a cancer term and I just said "Yes," because my T-Cell count was going up so I was just like "Yes." So they have just...by answers I have given, I have never said it is cancer, and they have never come right out and asked, and I pray that they don't...

I don't have to totally lie to them. It feels real good with those two because they know something is wrong, so if I am all emotional one day and crying you know. I have had days like that and I just really can't deal with today, I need to just go home, and they will say, "Get out of here." I think, in a way she did me a favor by telling them, even though I have never been able to have much of any type of relationship with her other than to speak to her when I see her now.

So for Felicia a betrayal turned out for the best, probably only because they think she has cancer, and her HIV is still a secret.

Housing.

Being infected with HIV can jeopardize not only relationships and job but housing. India recounts a time when her landlady found out she was HIV positive:

The girl who I rented from was a friend of mine for so many years and someone had told her that I was [HIV positive] and we had a big row, because she asked me why I didn't tell her. We had known each other for so many years and I looked at her and said "Because I couldn't trust you" and it went from there and it escalated, and "You're going to have to move out."

The move was traumatic for her, and she remembers it as a very stressful time.

Medical settings.

Unintentional disclosure can take place in a hospital or doctor's office. Felicia was alert to the problem:

When I saw this doctor that I don't normally see (usually they will just mark office visit) there is a little box down here that says diagnosis and result in big letters he wrote HIV. I have to take this to billing. It goes all the way through the billing department. Here is my name, my address, my phone number, my social security number. And I said, "What is the purpose of this?...Why can't you write the code? I know it is the same thing that any personnel here sees it. They are going to know what it is. How about when I hand it to the lady in the accounting department? Or when I am leaving and she stamps it and marks it and lays it on top of her file and it lays there until the next person comes? And then the next person sitting here paying her? I have done it, looking at the person's things laying there and if you see HIV in big letters you are going to look to see whose name it is."...He just looked at me as if he couldn't believe I was saying anything about it, that it even bothered me...He didn't change it.

After consulting with Rachel, Felicia called the office manager:

I said, "I have been very pleased with coming there. You all have given me wonderful treatment and everything like that and everybody has been great to me there," I said, "But I have to think long and hard. I have children that go to school here and play sports. There are people that work in the office..." She said, "Anybody that works in this office is sworn to secrecy." I said, "Look Watergate was sworn to secrecy too, but now look at it." I said, "That is ridiculous."

I said, "You know as well as I do that this illness is something that people talk about and if there are people that work there that know me and know my children," I said, "It would only take one person to say something."...To me why do you have to put the diagnosis? Why not just mark office visit? It was not a diagnosis, it was a check up. Ever since then if they put anything down they put the code in.

Felicia pressed long and hard with two persons before the policy was changed to protect her situation. India found out the hard way about confidentiality in medical settings when she cut her leg:

Well, I got down to the doctor's office, and he was in there. He had put his gloves on more for my safety than anything else. And he said, "India, didn't you tell me you were HIV positive?" And I said, "Yes sir." And he said, "OK, I think I want you to take a little bit of an antibiotic just for safety precautions."

Well, the nurse that was working went out in the waiting room. Remember the person I lied to and it hurt her so badly? She had left the funeral and taken me to the doctor. And Nancy was sitting out in the waiting room, and the nurse came out there where the window is, and said, "That girl back there is HIV positive." Right at the window and there is about a dozen people sitting right there, and everybody just looked up.

It was six months before India found out what happened because Nancy was worried that she would be upset. When she was told about the incident India tried to speak with the doctor, but it was her sister who finally told him:

I just couldn't believe it, I was so mad I just couldn't see straight....My sister went to the doctor's office and she said, "Have you talked with India or Mom?"

And he said, "No, why?" And he goes, "Man we got a problem here" because she told him what had happened.

The man went berserk. He took her chart and just flung it across the examination room. See we have known him since we were children and worked under him, my sister has worked under him for years, Mom has too, and we know each other as people, not just as doctor and patient. She just went, "Oh man." You never hear this man raise his voice, very seldom, he'll fuss every now and then. He just went nuts...and he yanked the door open to the examination room and said "Everybody to the back." Everybody to the back. And my sister said, "I shut my door."

He just went nuts on them....he was so mad, even after he had calmed down and had called me. He was so angry, he said "There are not enough apologies for you India." He said, "I cannot believe that one of my nurses did that." ...I haven't seen that person in all the times that I have been back in there. I don't know if she just works different days or if she got fired which I am sure she may have cause he was pretty angry.

India's confidentiality was broken but she did not even know about it for six months. She and her family had a hard time getting in contact with the physician but when they did he was at least as outraged as she was. The confidentiality that Felicia's physician's office professed clearly cannot be assumed. A disclosure like this in a medical setting can have widespread implications. Media exposure can be even more damaging.

The media.

The media can exploit situations of HIV for their own ends. India describes a situation in which her friend Rita testified in court:

The past couple of days has been dreadful with my friend, I've been so distressed over that. I talked to her the night that it was all on TV. And she said that she was glad that it was over but she knows that it's not over, because now the reporters are calling and it was on CNN, it's just...Oh God, my heart is just going nuts for that girl. It devastated me and it hurt me because she said once she got in the court room she wasn't as afraid as she thought she would be, and she just went on with it...

The Commonwealth's attorney and the detective had told her that there would be no cameras, they promised her no cameras. Keith Humphries refused not to show them. But he said, "No, it's news, I'm showing it." He didn't have a right to put that question on there. He could have edited that one question out of that news broadcast, and it wouldn't have been such a big deal, but he had to leave that question "Are you HIV positive?" on, and then it went to national news yesterday, and it was on TV. That's dirty, I called the TV station and raised hell.

Although this is an unusual situation, exposure does occur through the news media and India had to consider carefully being interviewed in the context a tribute to her brother. She felt it was a situation in which her confidentiality could be jeopardized.

Chapter VIII

Going On with Life

The women all had emotional responses to their diagnoses. It was clear from their stories that their responses are ongoing, as they continue to make meaning and put into place the events of their lives. This section includes what hindered and facilitated their adjustment and ability to go on with life.

What Hinders

In our conversations the women mentioned elements that seemed to inhibit them from drawing on available and necessary resources for a positive adjustment living with HIV. These inhibiting factors included substance abuse, family conflict, mother-henning, child care and concern, changes in sexuality, the loss of loved ones, family resistance to new relationships, abuse, and stigmatization. These issues will be discussed in the following section.

Substance abuse.

When Charlene learned she was infected with HIV her initial response was to try to find a way to escape:

When I first found out, I didn't care about nothing or anybody as long as I could forget about this nightmare and make it go away....At first I started drinking and doing some drugs, and said "I don't care."...Drinking shows the kids you don't care, if you drink you don't cook, you don't clean you don't do nothing.

In turning to drugs and alcohol Charlene undermined the strengths she needed not only to adjust to living with HIV but also to take care of her children and the pattern of daily life.

India and Charlene were the only women who admitted problems themselves with substance abuse. Both of them stated that their problems were in the past. However

substance abuse problems are systemic. Substance abuse is threaded through these women's lives: India and Charlene indicated that both of their parents had problems with alcohol; Tora's father was an alcoholic; India noted that all of her siblings have abused substances; and Patricia and Charlene indicated their brothers have problems with alcohol.

Family conflict.

The legacy of substance abuse lives on in families and can inhibit finding positive resources. India spoke about family conflict over her custody of her nieces as a part of a dysfunctional family pattern that left her feeling attacked:

I don't know, it has been pretty stressful. I have been real overwhelmed in the past week or two weeks, especially this past week. And it is like this idea crops in my head, they are doing this, they are stressing me, they know what stress can do to a person with HIV--you feel like you are being attacked. "Lets make her sick and she won't be able to keep the kids, this type of thing."...Really that is how vindictive they are, and dysfunctional. I am dysfunctional, but I am not out to hurt people intentionally, and they are.

Mother-henning.

The opposite situation interfered with some of the women's adjustment. India found that she was the focus the concern of others in a way that bothered her at first. She termed this hovering attention mother-henning. India reports:

I think even at work I had all of a sudden 30 mother hens on me when I told them. That is how it has been with everybody. I was always called mother hen. My brothers and sisters would make me so angry. They said, "You are always watching out and telling us what to do and not to do this and to take care of this." And all of a sudden now it is everybody else telling me, "You go to do this and

you got to do that, and you got to watch what you are doing, and you can't get out in that weather you will get a cold, and that will make you sick, and you had better slow down." I am not going into hibernating because I found out I was HIV positive. If I did that I would not have any kind of life at all. I have always been like social butterfly you know, always outgoing and into everything all the time.

It brought back memories of childhood when I was mother hen to everybody else--no wonder it bothers them because it bothers me. It is like, I am an adult, I know what can be harmful to me, you guys have to lighten up. But, I also realize they are doing it because they love me and they cared about me and they still do. They are still mother henning me, after a year. But I have learned to accept that.

Tora also describes her experience with being mother-henned:

My mom would call me 50 times a day and everybody would call me--I felt overwhelmed. I felt like I was going to have a nervous break down or something, because everybody...it seem like ever since my diagnosis people call me more and spend more time with me. I wish they would just treat me like they did before....instead of always "Are you OK? Do you need anything?" Just treat me normal until I get sick and then pamper me.

Tora reports the stress of adjusting to her diagnosis at the same time she is flooded by the concern of others. Their anxiety and even good will creates more anxiety for her.

Child care and concern.

All of the women had child care responsibilities and concerns about their children. In addition to everyday child care responsibilities they also have or will have to arrange for care for their children during their illness or hospitalization. Tora has the additional demands of caring for a child with AIDS. First Patricia recounts her hospitalization which is followed by Tora's reflections on caring for her son. Patricia states:

But I had to go to the hospital and I was just laying here, could not take care of the kids. And I got left here by myself which really pissed me off, because I got roommates. And I told them, "No matter what, if I look like that again put my ass in the hospital." They knew something was wrong with me, they just didn't want to take the time to have to take care of my children. I know that is the whole thing in a nutshell....And that's when Allison popped up and said, "Well, we'll watch them if you get put in the hospital."

And for four days I was in the hospital worrying. That was right before school started, I was so glad it was not during the school, because they weren't getting fed right. I know that, they wasn't getting bathed, they wasn't getting cleaned, I mean I could tell when I walked in. I'm like, "Oh my God." I didn't like what I seen, I'll put it that way. Rob and Allison took care of them, they took turns. One took care of them during the day and then the other took care of them during the night. But they didn't take the sheets off the beds when they peed on them and it hurt me when I came in and seen that. Diapers on the floor. I know I'm not a perfect housekeeper but my kids are number one.

One of the positive things for Patricia in being in the hospital was that she was able to have some time to think:

I mean positive things came out of it. I got out of the hospital, I felt better, because I had time to think. I did not have kids around me 24-7, even though I was concerned about them.

During the time she was in the hospital she realized how depressed she was over Tony's death and she managed to shake her depression bug. The relentless tasks of child care (which go on, as she says, 24 hours a day, 7 days a week) did not give her time to take care of herself.

Tora agrees "When you have a child you don't have time to think about yourself...I am so stressed out because the baby is sick...I feel if your child is that sick and that disabled that disables you." Occasionally Tora does get a break but very infrequently:

Every once in a while we will go over to Jack's grandmother's house and usually when I get there her daughter, which is Jack's foster sister since he was adopted, she will take over my son and I can relax and it is very seldom we go over there. But you know she will play with them and stuff and that is a break for us and we can visit. That is a big break when somebody else can take him and say you just have a good time and we will take him.

Respite just for a few moments is a big break for her but it does not happen very often.

Finding a sitter for her son was even more difficult:

One time I was going to go to work and I was going to get a baby-sitter through Social Services. And the person that was going to be taking care of him, I had to tell her you know everything that was wrong with him , which would be natural. And she said she was taking care of three other children so she said she would like to tell the parents of the other children that she would be taking care of a HIV child. And she said she thought it would truly cause her not to be able to watch the other children. And this has been when he was a couple of months old--that was a couple of years ago...You know things might be different now, but I just was like the hell with it you know, if they don't want to watch my baby.

Tora's difficulty with child care led her to wonder:

I wonder if he ever gets well, will I ever be able to live a normal life? Or if he dies will I ever be able to live a normal life again? Or if I die will my kids ever feel normal?

Her world has been turned upside down and it will never be the same again. Just trying to get a bit of time to herself, or finding someone who will watch her son points that out to her.

Changes in sexuality.

Sexuality can also be affected by HIV. As Tora recounts:

When I first found out, I didn't want to be touched. When I first found out I thought I was dirty. I didn't want him to have sex with me. And we went and talked to some lady from the health department....we were like how are we ever going to make love again?...I guess before I use to look forward to cooking dinner and relaxing, putting the kids to sleep. And we never had sex every night anyway, maybe a couple times a week or something, and maybe now it has turned into maybe once every two weeks or you know, there are other ways of making love besides having sex.

I wish we could find time to spend with each other, but it is not the same as it use to be. Before I felt more sexier or something. Now I don't feel dirty anymore because I know it is not my fault. I mean before when we would make love, he would kiss me everywhere, he doesn't do that now. It is not as...he kisses me you know and still French kisses me but not as often. Maybe now he kisses me when we have sex, whereas he used to come home from work and give me a kiss. You know a woman every now and then when her man comes home from work she wants something to grab on and give her a kiss and say I love you. He is not as loving as he use to be and it is probably to because we are so stressed out after going through this. He keeps a lot of his feelings inside.

Sometimes I feel like when we are having sex the condom might break, and I don't feel comfortable and I just wish it was over. Other times it is like on my

birthday he had me some flowers and he had me some candy and he bought me a nightgown and he bought a movie home and we sat and watched TV. And I felt sexy when we had sex and when we were doing it, I didn't even think about it and then when it was over, I said, "Are you sure that condom didn't burst?" I am always asking that. He said he could feel it if it burst, but I am afraid I will give it to one more person. And he said you shouldn't feel that way you didn't give it to our son.

Tora notices her partner is less physical with her and links their distance to being so stressed. In addition, sexuality which invites a basic sense of affirmation, relaxation, and closeness to another is shadowed by her fear of infecting the one she loves.

Loss of loved ones.

India, Charlene, and Patricia all have experienced deep losses since they have been living with HIV. All of them have had a close loved one die of AIDS which is typical of the pattern of this illness. In addition India and Charlene have had numerous family members and friends die over the last two years as well. The depression that can follow a loss can be debilitating and is compounded if there are multiple losses, as there often are with AIDS. Patricia recalls the time after Tony died:

I couldn't sleep, I wouldn't eat: couldn't eat, couldn't sleep, couldn't talk to nobody about anything because nobody understood except for my sister. And then at a point I wasn't understanding she was understanding I was so depressed.

Patricia describes that during the most intense period of mourning she was so depressed she was out of touch with even her sister who is a vital resource for her.

Family resistance to new relationships.

Patricia and Charlene mentioned that problems with their deceased partner's family made getting on with life difficult for them. Within a few months after the death of their

partners they were involved with new men. Neither of their former partner's families approved. Patricia recounts:

My boyfriend's mother thinks that I am not ready for another relationship. Or it is too soon for her to deal with another relationship with me. There has just been a bunch of bull happening because of me and my new relationship. It's like she wanted me to sit here and die because he died...or to suffer. I have suffered enough. And that has really added stress on me...

Where I am book smart he [Tony] is street smart. "Don't dwell on things too long because you might end up the same position I was in." That's when I pushed down him being dead and brought back up all the good memories. But now that Mom is doing what she is doing it is bringing back bad ones. I am kind of pulling myself in a positive mode but then there is this negative pulling back in this "You know James died." No shit.

As Patricia is trying to pull herself out of her depression she feels his mother is pulling her back.

Abuse.

All the participants are survivors of abuse: either physical, emotional, or sexual. The pervasiveness of the abuse that these women suffered was staggering to me. Abuse was not included in the interview questions, so I did not ask direct question about it, however all of the women reported instances of abuse in the course of our conversations. Many of them had been assaulted in more than one way, sometimes both as children and adults.

India was emotionally abused as a child. Patricia was physically, sexually and emotionally abused and neglected as a child, as well as physically abused as an adult. During their childhoods both India and Patricia were placed in foster homes. As

adolescents India lived with her aunt and uncle, and Patricia lived in a group home. Tora was sexually and physically abused as a child, and physically abused as an adult. In adulthood Charlene was sexually assaulted, and Felicia was emotionally and physically abused. This wide spread abuse was self reported in the process of conversation and therefore may not cover the extent of the abuse.

Patricia was the first to tell me about the connections for her between her history and her adjustment to living with HIV. She reflects:

I have noticed that most people [with HIV] had an abnormal childhood. I didn't have a good life before I had HIV, you know. My whole life, there wasn't any good part. Basically it was more like my Mom didn't know how to take care of us. She abused us physically, she kept us up locked in until we were a certain age. We went to school and home and back in the house kind of thing. I was molested by my brother, and there are a lot of things that go on aside of HIV that might be important in the factor of why I feel about how I feel about HIV.

India also suggested that "if my life would have been different or less dysfunctional maybe I wouldn't have been out drinking and having sex with everybody and doing drugs, and going through that." Tora and Patricia said that their abuse still haunts them and they wish they could let it go. Patricia has been in therapy, but she stated she was just given medication and it did not help.

Stigmatization.

The final factor the women reported hindering them was the stigmatization of HIV. The stigma associated with HIV made it very difficult to be open about the disease. This puts stress on the women in a number of ways. They were concerned about their jobs and their housing, but also their support systems. Fear made disclosure difficult, and keeping the secret added stress and isolated them from potential outside support. This issue is

covered in the section on secrets in detail but here India speaks to the stress of keeping secrets:

Now I think that my mental health is even more important than my body health. If my mental health is in check--my body is better: I'm not as sick. I'm not as sick as the whole time that I was lying about this thing. And then last fall when I got sick, there were reasons I got sick, I got pneumonia. I was really depressed, just the constant stress, stress, stress on me all the time was wearing me down, wearing me down, wearing me down.

Despite these factors these women were able to marshal their strengths. The following sections address factors that were helpful in moving on.

What Encourages

All of the women were able to move through their despair in part by constructing a way to work with the disease though it took time. Charlene admitted that the first year was very hard. Tora and Felicia indicated it took a year to a year and a half before things began to turn around.

There were a number of elements that contributed to the women's finding ground again. The factors which the women identified as helping them find a more positive outlook were HIV/AIDS education, talking with someone living with HIV/AIDS, an improved living environment, support from family and friends, children, self-acceptance, assistance with material needs, and faith. The following section addresses these factors.

HIV/AIDS education .

The first important step for most of them was education. Often this began with talking with someone who was knowledgeable about HIV/AIDS. This was usually an HIV/AIDS educator, a medical professional, a counselor or social worker. For some of the women joining a support group broke through their isolation and despair.

Talking with someone living with HIV/AIDS.

Often information about HIV/AIDS is not enough. Tora found it particularly valuable to talk with someone with AIDS:

I think the best thing to do is go to groups, HIV groups that they have...just meeting someone that is going through the same thing I am going through has helped me a lot, because when I first found out I didn't think there was anybody else that I was going to know that had it....And if you are depressed then get some kind of counseling and just talk about it with somebody. I know you sometimes don't want to talk to your family and your friends and that is okay, and later on you might want to tell them, but at the time you don't want to tell anybody the best thing to do is to talk with somebody that is HIV positive or that has AIDS or whatever. And they are going to keep it in confidence because they have it also. So talking with somebody that is going through the same thing you are going through is a big help.

Tora suggests formal and informal supports, but especially underscores the value of talking with someone who is infected.

Improved living environment.

Tora, Patricia, and Charlene all moved since I have known them. The moves to safer, more comfortable homes were important for them. For Charlene the move to her new home created a more positive attitude that enabled her to be open to talking about HIV. As Charlene states:

We moved away. We moved out of the place where we were, and our life changed. We tried to look at a better life instead of a sad life, and change a little bit....then I got more information about it, talked about it to other people.

Support from family and friends.

When the women became more educated about HIV/AIDS their conversations often expanded to friends and family. All the women counted the support of loved ones as important in their movement away from initial despair. Patricia's support from her sister came as she was nursing Tony:

Me and my sister, we are close now, she helped me through the major part of Tony being sick, and him forgetting me. I'd call her up and she would help me out through it. She said, "You know, the Lord is looking after him, and He is looking after you."

Children.

Children also encouraged the women to live. Charlene credits her children with helping her adjust to a more positive attitude about the disease:

I got my kids to think about if I want to die I might as well do all the wrong things, you know, but they are not going to have the same mother to take care of them if I don't take care of me. I figured if I want to live long I had better take care of Charlene or else. No one can do that but Charlene. And then you know I started processing by taking care of myself and taking medicine and trying to eat right.

If it had not been for her children and her partner, Charlene said she would have committed suicide.

Felicia considered homicide as well as suicide. Her children called her back to what she really wanted from life:

Then came the reality that killing him is not going to change things for me at all, and killing myself is doing exactly what I don't want to do, that is dying....I kept thinking about my kids. I don't want anybody else to raise my children. I want to see my children grow up. I want to see them graduate from high school and go to

college, and graduate from college, and I want to see grandchildren. And you know I hope and pray that I will be able to but I don't know that I will.

Tora's children were also a turning point for her:

I have two other children, I can't just stop living like I thought I was going to be able to. I just thought I was going to give Chassy [her daughter] to her grandmother and give my children away, and go in a home somewhere and go crazy. But you can't do that you have got to keep on living.

The children inspired purpose and an incentive to live. This incentive was not only inspired by biological children. India found more care for herself as she cared for an elderly person in her home. Then with the custody of her nieces she realized "Hey, I can't get sick, I've got two children now that I adore, that I would die for those children."

Self-acceptance.

Self-acceptance helped India access her strengths and fight stigmatization:

One big way that I have grown is accepting HIV myself, learning to deal with it myself. That this is a disease, that this is my thing, and it is up to me and how I handle it. I can either make it very dreadful for myself and moan and lament and get myself very sick or I can buck up and fight the damn thing. You know I think that attitude as time went on got better and better and I grew in that way. I also grew in meeting myself and coming to terms with who India really is, and are you going to be embarrassed or why are you embarrassed?

Assistance with material needs.

Assistance with material needs can be really helpful. As Charlene states:

I didn't have hardly any money to get the kids stuff for school and this other lady....came over and "I have some things to drop off at your house." I said, "Okay." She came over to my house and she had four or five bags of stuff--brand

new clothes for Calvin and O'Dell [her sons] plus stuff for school. And I just about wanted to cry right then and there and I said, "You mean to tell me that you have people to help you like that? I have never had nobody help me except my mom." And then a year later went by and they helped me with my food and it was just so it was like a dream. There are really people out there that will help people with this stuff. I was so happy.

Faith.

The renewed will to live is reflected for all the women in framing their experience in a spiritual context. Their theologies vary but each woman mentioned the importance of their relationship with God. Felicia searched for an answers but came to realize that no one could give it to her. As she reflects:

I finally realized the only place I could get any help and get any solitude was to have a peace of mind for myself was to get that peace from God...I didn't get that peace of mind until I got what I thought my life was straightened out in God's eyes and in my eyes.

Tora found that she had to surrender also. She stated, "Now I feel like there is a time when you just have to let go and let God take [over]." Patricia noted, "It is not really bad you know because God never promised you tomorrow anyway."

Charlene mentions her family's faith, particularly her grandmother who read the Bible. This faith is something that she wants more for herself as she articulates:

I am going to get into that and try to be faithful. God is always there to help and I think sometimes His strength helps a lot of things. If there wasn't one I don't know how I would make it.

Images to Live By

In our conversations each of the women articulated an attitude toward HIV and its influence on their lives. I think these various images hold within them kernels of how to move on from the initial despair. Felicia spoke of resisting the control of the virus and gaining control over it and her life:

If I live my whole life saying I can't do this because I am sick, to me the illness would be controlling my entire lie....the last year has been the most stable as far as my mind being where it should be feeling like I was a whole person, like I was in control of me and in control of my life and not my life controlling me.

The question of who or what is in control is a stabilizing image for Felicia, something that can help her manage all that is unknown. As she admits, "I guess as much as anything I hate about this is the parts I don't know, that I can't know."

Patricia and India both have active images of moving on with life. Patricia states: Look, I like living. Life is what you make it. It can be sucky if you want it to be, it can be suckier than you want it to be--it depends on how you conceive yourself in the next 10 years....This is what I got--deal with it! And I have.

India is practical and active also: "I can work with this disease and I can live a better life and if I do the things I need to do." She expresses a cooperative spirit in working with the disease, but in her introduction she also gives a call to fight.

Charlene chooses to try "to look at a better life instead of a sad life." She takes on a new view as a way to cope the virus and its influence. Tora's image of her life as a hand of cards reflects the limitations she experiences. From this image she has constructed a way to be positive within her limits, in part by acknowledging that everyone has limits.

She states that

nobody's time is forever...I feel like you were born in this world to die and it's just what you make of your life until then. I could have found out that I had Sickle Cell Anemia, you just never know. But with the days I have left, I am going to make exactly the most of...we are dealt these cards and we have to play them.

She is using the image of a game of cards to strengthen her sense of control to make the best plays she can. Tora asserts, "I could live 20 or 30 years but if I don't, the five years I am going to be here, you are going to be able to say, 'That girl really had a good life'."

Chapter IX

Effects of the Research on the Researchers

The unstructured qualitative interviews in this study provided a place for these women's voices to be heard. The stories of these women were co-constructed by speaking to and listening to each other. One of the research questions was "In what ways are we affected by working together as co-researchers?" In this section we address this question. My reflections are followed by the women's experiences.

Effects on the Author

When I began this research I knew little about HIV/AIDS. My knowledge of the disease and its implications for women increased as I read the literature and interviewed practitioners and researchers. I am impressed by the committed people I talked with who are working on local, regional, and national levels with persons living with HIV/AIDS. My fears of HIV/AIDS and persons living with the virus decreased as my knowledge broadened. I feel freer having confronted some of my fear out of ignorance as India would put it.

My most powerful learnings came through the co-researchers on this project as they let me into their worlds to hear their struggles and triumphs. I have been touched by their courage, wisdom, humor, and pain. I am struck by the multiplicity of issues with which they contend and the large network of people affected at various levels by this virus: children, family, friends, co-workers. I have been moved by the many poignant aspects of this disease such as being infected by someone you love, being an active caretakers of a loved one with AIDS while living with HIV, infecting someone you love or fearing you will, and having to face not seeing your children grow up.

It was not always easy to hear these stories. I often felt my own powerlessness as I created a place for these stories to take shape. I found that I had to take care to contain the material for myself. I did this by taking time to write in my journal directly after our conversations and then to put the stories aside in my mind until the next scheduled time to work on the project. I processed not only the content of the work but my emotional responses with my colleagues in my dissertation group as well as my advisor. I structured my work on the project so that it and my emotional responses did not seep into my other commitments.

I grew fond of the women with whom I was working and it was sad for me to complete the series of interviews with each one of them. I consider myself richer for having known them. They have sensitized me to the preciousness and fragility of life, and the importance of community. My sense of reality has altered this year and some of that shift I am sure is because of my relationships with these five women. Change seems more capricious to me now, situations unjust in spite of our best efforts, and I am much less certain of the order of things.

As I listened to these women's stories I dropped below the story line of my own life to feel there is something else going on here which is the real plot. Something which is trustworthy and evokes in me endurance, and persistence at a deep level of faith. I join with Anne Lamott (1994) in clapping along with the absurdity of life. Sometimes I even dance. My conversations with these women have been a part of this shifting sense of life for me. Their pain has rocked me. Their courage and ingenuity affirm for me our ability to move forward creatively as human beings whatever our situations and challenges.

Effects on the Participants

The women living with HIV all reported a positive or neutral experience in being a part of the research. Their responses may have been skewed in a positive direction

because they were reporting to me. I did specifically suggest it might not have always been easy and asked for their suggestions to improve the study. Patricia suggested that there could have been more time allowed for each conversation. India and Felicia expressed an interest for the research to continue. Patricia suggested a follow-up in a year.

Patricia was the only one who stated that the research did not affect her much. She explained: "I can block a feeling if I don't want to feel them." She indicated that she was doing the research to help others. The rest of the participants mentioned the conversations were emotional for them, and they talked about the effects of the research on their lives.

Tora noted that it was sometimes depressing or sad to talk about her experiences living with HIV but it also helps her to confront reality:

I guess sometimes it is depressing because when you talk about it you are talking about reality. You get caught up in daily stuff and you just forget. When you talk about it you have to bring up that you have this disease...like... the last time I brought up stuff that I wanted to forget.... It makes me sad, especially the first time I found out. That usually hits the spot with me. And sometimes when I talk about other people not protecting themselves it really makes me want to cry because I think about all the innocent little children that it will probably affected by them not protecting themselves.

When Felicia reflected on what ways the research affected her she mentioned that she realized how guilty she felt about her affair: "I really had a lot of guilt feelings about it before and I guess just the guilt feelings were always there and I never really rationally thought it." India stated that the project "helped me process a lot of my feelings, good and bad" and Charlene was enthusiastic about how the research affected her:

I have really loved it. Yeah, it is real exciting to know that somebody wants to know about me. It would really make you feel good to have someone come to you and say, "Anne, I want to know about your life and how are you?" It makes you feel good.

She admitted that some things we talked about bothered her, that is brought up strong feelings.

Felicia, Charlene, Tora and India indicated that bringing their feelings to the surface helped them confront issues in their lives. Charlene stated:

If I don't realize and get on with my life this is going to hold me back. And it is going to hurt me more if I keep holding it in...Talking about it helps a whole lot, it really does...To talk about it and open up and talk about it, it is tremendously great...just talking about it and getting it off your chest and thinking about it.

For Felicia our first conversation brought up a lot of memories which she reflected on when she was at home by herself the next day: "I thought more about things, just a lot of memories that I thought about when I was talking to you that had been shoved aside." She was thinking about the man with whom she had an affair who may have infected her.

Felicia and India likened the process of research to therapy. India states:

It is good sometimes to just be able to talk to somebody, somebody that you really don't think is judging you....it is almost like a therapy thing to just to be able to talk with somebody who is not involved, and who will listen and just let you talk. It is good.

India has been in therapy and worked in a therapeutic environment where her co-workers challenged her about her behavior and denial. She went a step farther than Felicia by identifying the research as "good therapy" for her:

I have gotten a lot out of it. I have gotten a lot of positive stuff because I guess I have had to make myself look at things that I just sort of shoved back and stuck on the shelf. And then after we bring it out and we process it, and there have been tears...and then it makes me think about it later. It helps me to decide how I really do feel about it.

India dealt with loss and ultimately the loss of self. Here she recites a litany of events she processed in our conversations:

I guess bringing up people like my aunt, helped me process her death, and accept it. It helped me accept my brother's death. Just thinking about the things we talk about and where my feelings are, it helped me to be more open about my feelings, and the disease, and how I felt about things. Through the processing I think it has helped me be in less denial. I guess, because until this year, there is still denial, even now there is still denial. I think it has helped me come to grips with it because I had to think about it more. And after us talking about it each day, I may think a lot about what we have talked about all day long. Even a couple of hours or a couple of days later something might trip or trigger something we talked about sitting here and make me think about it....And in turn when you do that it helps you with other aspects, even little things like how you react to a situation when you are having to think about something.

She uses psychological language (i.e. breaking through denial) to talk about her experience. Reflecting later on what she said helped her in her life.

These four participants each gleaned something different for themselves through the research process: Felicia, self-forgiveness; Charlene, relief from the burden of her problems; Tora, a sense of the goodness of life; India, self-acceptance.

Felicia noted:

I think the biggest thing I got out of this is, like I told you, I felt like I had crucified myself so much for this [affair] when my marriage first broke up and I don't know if it just took somebody that wasn't a close friend or a relative to say this to me or whether it was just the time had come that I could look at myself in a different way...it is not right but I did it and I feel like I have been forgiven for that. And I think that is probably one of the biggest things I have gotten from it is that I stopped beating myself up over it.

Charlene observed:

If you just have it in your head you don't say anything and then one day like today you talk about it and it is out of your head. Now it is somebody else's problem. It is gone, it is not there anymore--you don't have that problem. You just try and get on with your life. If I dread on having HIV all the time I wouldn't be healthy, I wouldn't care. I just try and get on with my life, like a normal person you know.

She indicated that talking about her problems released her from her dread of HIV.

Tora stated:

Sometimes when you talk about stuff that happens, like when I talked about the last time it was blown up stuff that I wanted to forget. But I guess sometimes it is good to bring it up because it makes you remember how sad things use to be, and how good they are now, and how they should be. I guess that is the good part of it.

It is hard to talk about things you would like to forget. Tora turned the difficulty of talking about painful situations into a positive.

India says:

It has made me think a lot about the disease itself and about me as a person and it has helped me accept a lot about myself because I have had to voice (my emphasis) it instead of thinking my feelings....You can think something but when you say it

out loud to yourself, like you can think "I am an alcoholic, I am an alcoholic", but you got to say it and accept it...I have been saying it out loud for years (that I was HIV positive), but this had made an impact. I really am. Not so much more that it has been unpleasant, but more to make me think about what I need to do about me. I tried to provide a context for each of their voices to be heard and at least for India it was important to hear her own voice as well.

Chapter X

Suggestions and Recommendations

During our conversations the participants told me their stories of living with HIV and new meanings were made. In this section the participants and I detail our reflections and conclusions about what might be helpful for others. The participants' thoughts about what might be helpful for others are first, followed by policy recommendations for practitioners and directions for further research.

What Might be Helpful to Others?

During the final taped conversation I asked each woman to speak from her own experience and offer what she thought might be helpful to others. In the following section they each have their say.

India Educate, just educate: more compassion and less fear.

Educate, just educate, that is so important. I think with the education there comes more understanding. With understanding comes more compassion and less fear. And fear out of ignorance is so detrimental to people. I think that is so important.

The one thing that reached me was my brother being so sick. I took every risk taking factor there was down the road and until it hit home with my brother, it didn't sink in. Maybe if we started younger, you know, I don't know. I feel like where I have helped other people to get educated about it, and see the personal side of it through me (like friends for instance) it has helped them to understand a whole lot about the disease and it makes them more interested. It is a really a hard thing to say, sometimes it has to hit close home before you become interested. I wish there was another way to make people aware to be interested and not be afraid.

You can't put chastity belts and keep everybody off the streets and locked in a cell to keep them from getting out there taking those risks. But I guess if my life would have been different or less dysfunctional maybe I wouldn't have been out drinking and having sex with everybody and doing drugs, and going through that. I wouldn't have to be educated , because I wouldn't be doing it--but the truth is anybody can catch this. This is true, so everybody needs education.

Maybe they need to start in schools at a very young age--I don't know you try to teach children to share but you don't want them to share everything. But I don't think you should teach them out of total fear. I don't think they should be scared but I think they should understand, and understand the impact, and how important it is as far as taking care of their bodies and not using their bodies. Because that is the bottom line--unless it is an accident or hospital situation or a blood transfusion that can't hardly be helped.

Charlene Always protect yourself: you don't know even if you think you know them.

To be more safe with sex--that is the most important thing to do. You never know who that person has been with: he could have been with a thousand people. And you don't know even if you think you know them--you really don't until you live with them. It is getting worse and worse--this world is not getting any better. There are a lot of people out there are just fooling and they don't care. There are people that need to wake up and be more cautious with their bodies and don't have sex unprotected. Always use a condom or something so you won't catch this or something they might have.

In the years I have grown up, I wish to God I could turn the clocks back--I really do. I would make my life a lot better than it has been. One, I would be more

safe about sex and another, I would want to start a family being married first and being in God's eyes: doing right and not have sex without being married first. My mother never told me that, and I learned the hard way. God knows I have had a rough life and I wish to God I could change it all but I can't.

Felicia It can happen to us: don't live in denial.

I just want to make people feel aware it can happen to anybody. I would not be afraid to bet you that there wouldn't be one person, out of all the people that know me personally or in business or whatever, that would have thought I would have it. I think they think they are gay, even if they are married, they have had a gay relationship somewhere, or they think they are on drugs. My nephew comes to mind he tends to think that women that are positive and are not lesbians had to have been prostitute or promiscuous.

I feel like so many heterosexual woman probably know their husbands are having affairs, or at least was like I was--pretty sure, but in denial. I want to say "Don't be afraid to tell you husband, 'Look I am sorry, you are going to have to use a condom or we are not going to have sex'." I want to make women realize this can happen to us. I am not perfect by any means, but I never did drugs, I never used needles, I was never a prostitute, all the things that people associate so much with HIV.

Patricia Care for loved ones with AIDS: show them that you care.

Nobody would have did what I done for Tony. I thank God for letting me be there. If anybody could do what I did for Tony to do it. There will come a time you need a break. Take the time regardless whether the family wants to help you or not. It all comes to a point, you know, when it will all be over with, and you learn from your experiences, regardless how good or bad they are. There will come a

time in all of the uncertainty of not knowing that you will know that it will be over. I prayed that the Lord would take him so he would be a peace. And he did. The lord gives us the strength to handle and deal with all things. Just hold on to your faith in the Lord and He will never leave you.

Tora It is not only yourself: it is the children.

What people will have to understand is when you have unprotected sex you could have HIV and not even know it because you can still be healthy when you have HIV. Like I said: I would have never known had I not been pregnant that I even had it. I believe that every pregnant woman should be tested for one thing. I knew I was going to get tested when I got pregnant with AIDS being out and all the other things that are out there.

I think about all the innocent children, because when you have HIV and you don't know and you go and sleep with other people, and those other people get it from you, and they go on to have babies, (and more than likely they don't think they have AIDS) and they don't get tested, and their babies end up having it. It is not only yourself and other people, it is the children who go through it. I think sometimes if they could see the faces that go along with AIDS that would help.

I look forward to some days. I try not to look too far in the future. I try to live that day to the fullest. Which is something I would give advice to anybody whether they have a disease or not, not take anything for granted to live life to the fullest and be as happy as you can.

Policy Recommendations for Practitioners

The conversations of the five women included in this study illuminate policy issues for practitioners in the many contexts these women live and work. Their experiences point to thoughts and concerns about the following issues: the perception of HIV as a

disease for others, problems with testing and diagnosis, the necessity of confidentiality, what encourages the access of resources, the complexity of disclosure, the value of discussing living with HIV, and the need for respite and child care. I address these issues in the following recommendations and conclude with suggestions for family therapists working with women living HIV. The recommendations include the participant's suggestions as well as my reflections on the five women's stories.

The practitioners addressed in this section include professionals affecting the emotional and physical well-being of women including mental health professionals, social service providers, public health officials, and medical personnel. Further studies are indicated to understand women's experiences from diverse backgrounds including different localities (such as suburban and urban areas), varied SES, and other cultural groups (to include variations in race, age, sexual orientation, class, and ethnic backgrounds).

A disease for others.

The common cultural misconception of HIV/AIDS as a disease for others (Corea, 1992) was apparent throughout these stories. Tora named it the protected circle. The perpetuation of this misconception in these stories has an effect on issues of prevention, referral for testing, and the treatment of women with HIV. These three areas will be addressed in this section.

In terms of prevention the women all considered that they were immune to HIV in part because they saw the disease as affecting others and not persons like themselves. This illusion is based on the original identification of HIV/AIDS with high risk groups who are labeled bad. This moralistic attitude associated with HIV infection makes monogamy or even heterosexual relationships seem safe (Walker, 1991). In addition marriage, friendship, class, race, sexual orientation, or blood screening do not protect

anyone from the virus. The women felt protected by one or more of these factors. These women's experiences bear witness to the indiscriminate reality of HIV: emotional closeness or a long-term relationship are not a shield from the virus. This is a virus, not a judgment or a plague affecting certain outcasts in the population. There is no protected circle. These women's stories illustrate the continued necessity to consciously and consistently deconstruct HIV/AIDS as a disease for others through education and practice. Increased education is called for at all levels in school systems, health professions, and community for improved HIV prevention for women. It is critical for all practitioners to be knowledgeable about HIV and its transmission and to be more conscious and direct with their clients about the risks involved with sharing needles, transfusions, and sexual activity in order to raise critical issues of self-care when clients are exposed to risks to their health.

Another consequence of continued lack of education and the misconception of HIV as a disease for others is inadequate referral for testing. In these stories this issue surfaced in the medical domain with the oversight of reoccurring gynecological problems. However consistent referral is needed in all arenas of social service and health care. Increased awareness of indicator diseases and risk factors is critical in improving the referral rate for earlier detection.

The treatment of some of the women as if they were untouchable is a sad extension of the otherness persons living with HIV/AIDS into the physical realm. This kind of treatment is inexcusable. It is imperative that persons living with HIV/AIDS are treated respectfully and in ways consistent with our medical knowledge. The fact that the persons who behaved inappropriately in these stories were a doctor and a nurse underscores the widespread need for more education and direct experience with persons living with HIV/AIDS.

Testing and diagnosis.

There were many issues raised in these stories related to testing and diagnosis. One of the women with reoccurring yeast infections mentioned that she almost bought over-the-counter medication. As yeast infections are one of the opportunistic diseases of HIV it is recommended that the labels of over-the-counter medications for opportunistic diseases provide clear information of the possible serious implications of repeated infections. Information recommending testing and the value of early diagnosis also could be included.

Testing was not available in jail. Tests should be provided in the jails and other residential institutions as a standard practice. No one should be denied a test and delayed treatment.

The women recounted many examples of inexcusable treatment when they were diagnosed. The diagnosis of HIV is a life threatening disease and receiving the news of a HIV diagnosis is traumatic. Therefore the communication of the diagnosis must be done in a sensitive and informed manner. There are a number of issues that the women identified or are implied by their experience as important factors in the delivery of the diagnosis: the waiting time, the gender of the informant, clear direct language, adequate information, follow-up testing, supportive context, and connections with support systems. These will be addressed in the following section.

The women reported waits of one to three hours in the waiting room to hear the results of their tests. A long wait like this is inconsiderate and unnecessarily stressful. The results of positive HIV antibody tests should be scheduled to be given in a more timely manner.

One of the participants recommended that a women report the test results to women because she felt it would be easier to talk with a woman about the issues involved.

Although this may not always be possible women who work with HIV positive women could be included on a referral list.

It was reported in the study that one of the physicians used complex medical terminology to give the diagnosis. This is only confusing to the patient. It is vital that the wording of the diagnosis is clear and simple to understand.

It is critical to include information about the disease and disease process even if the woman is in shock and will not retain all of it later. Printed resources could be helpful for the person to consult later. It is also important to alert the women of the possibility of error in the test results. Re-tests are routinely done to verify results because the first test may be a false positive. A re-test could be done at that time.

A supportive context is important for the women when they receive their results. This was not available for some of the women. The way the diagnosis is delivered is vital not only for the comfort of the person who is HIV positive but in order to ensure they will remain long enough to receive critical information about the nature of the virus, the need for additional testing, possible implications of disclosure, the names of persons for anonymous notification and resources for support.

Adequate counseling with supportive, educated staff should be allowed for HIV antibody testing. This may require training if qualified staff is not available. Pre-test and post-test counseling are recommended. Pre-test counseling provides information which can situate the diagnosis in the appropriate context later. Post-test counseling includes additional assessment and education, and as well as the report of the test results. There is excellent counseling training available and it should be required for all persons who give HIV antibody test results. A sensitive protocol for the process of testing should be developed and adhered to at any site involved in testing.

All the women suffered severe depression after hearing their diagnosis. Their responses included substance abuse and thoughts of suicide and homicide. This indicates the traumatic nature of the news and emphasizes the importance of both educational and support resources at the time of diagnosis. Educational programs and emotional support need to be available in our communities to empower women to overcome despair. A variety of options are possible including support groups, buddies, and counseling resources. Both verbal and written information should be given about the resources at the time of diagnosis. The inclusion of printed material is useful as they may not be able to remember much of the conversation later.

Confidentiality.

The breach of one of the women's confidentiality in her physician's office underscores the need for all agencies and institutions which have records of HIV status to review and reassess confidentiality issues. Disclosure of HIV status can have serious discriminatory effects and confidentiality must be ensured.

What encourages the access of resources.

For the women who experienced despair about their diagnosis there were four common elements to their ability to move forward with life. They identified the importance of learning about HIV/AIDS, talking with someone else who was infected, focusing on their children or other positive aspects in their lives, and drawing on spiritual strength. They also conceptualized their lives in ways that helped them to move on. For practitioners working with women who are living with HIV this points to: 1). the need for education from the beginning for persons who are infected, and their loved ones, 2). the value of resources which can link newly diagnosed persons with persons who have been living with HIV for a while and are willing to talk about it, 3). the importance of focusing on the positive, and 4). the opportunity in deepening or reestablishing spirituality.

Images can be a resource for practitioners working with women living with HIV. The guiding images that the women used included taking control rather than letting the disease control you and playing your cards in the best way possible. The first image of control fits well with narrative therapy approaches of externalizing the problem (White & Epston, 1990). Externalizing HIV may work well to encourage women to resist being defined and dominated by the disease. The second image of a deck of cards is one of a myriad of images which might be drawn on by practitioners or listened for in the language of the women themselves. These images then could be used to provide encouragement to cope with the challenges of living with HIV.

Disclosures.

The women raised many aspects of disclosure in our conversations. They evaluated who to tell, when, and in what way. They assessed the possible reactions and implications of disclosure. The prevalence of this topic indicates that opportunities need to be made available for the women with social service providers, therapists, or in support groups to discuss their thoughts about disclosure. The themes which surfaced in our conversations give a framework for issues to consider in discussing disclosure. 1). For most of the women it was very hard not to tell close relatives or friends. 2). It was often considered a betrayal of a close relationship to withhold the information. 3). Putting off the disclosure left the women vulnerable to the possibility the person would find out from someone else. 4). Disclosure in retaliation or to someone who is drinking can lead to unforeseen and heightened emotional reactions. 5). Unintentional disclosure can spread like the virus. 6). It is imperative to tell sexual partners because of the impossibility of eliminating all risk. 7). Partial disclosure of a life threatening illness may be possible in the workplace to explain doctor's appointments and absences.

Disclosure necessitates two additional resources: one for the loved ones who are told and one for disclosure to children. First, the person who is told often needs support. This reflects the importance of support networks and educational resources for the loved ones of persons living with HIV. Secondly, the emotional descriptions of the women's disclosures to their children underline the delicate and vital nature of informing children of their mother's infection. It would be a valuable resource to have a short set of guidelines to assist parents or guardians in their thoughts about the developmental capacities and emotional needs of children at different ages. These guidelines could include information about the needs of children living with family members who are ill or dying as well as the necessity of advanced preparation for alternate care while their guardians are ill and after their death.

Talk about living with HIV/AIDS.

Most of the women responded positively to talking about their lives to someone who was not personally involved with them. At one level this need could be addressed with a buddy system. However there are many issues the women discussed which are more appropriate for therapy, such as incest, rape, physical and emotional abuse, substance abuse, family and parenting issues, losses, and eventually death and dying. Counseling services at affordable rates are needed for women living with HIV/AIDS. In addition, the unique grief issues caused by the young ages of the persons dying, the prevalence of multiple losses, and the complications arising from the infectious nature of the disease call for new resources. These resources include the development of innovative methods of grief work suited to these unique grief issues and the establishment of support systems to address the loss of loved ones to AIDS.

Respite and child care.

The women expressed difficulty in meeting their needs in relation to the demands of caring for persons with AIDS and parenting. Respite care for persons caring for adults or children with AIDS is needed. In addition we need to develop resources for competent, non-discriminatory child care for children who are living with HIV/AIDS. Resources are needed for children whose parent(s) or guardian(s) are ill with HIV/AIDS or who are orphaned by AIDS. These resources need to be available and appropriate for children who may be infected themselves.

Notes to family therapists working with women living with HIV.

I am a family therapist by vocation and though my role with these women was researcher, our conversations have implications for family therapists. I will conclude this section of recommendations with a few notes to family therapists. As I have stated my conversations with these women were challenging for me to listen to because of the deep emotional content. In working with women living with HIV it may be valuable to develop strategies to nurture oneself as therapist in whatever ways are effective, perhaps by creating contexts to process the emotions, or working with ways to contain the material. In addition, I found that some of the women's deeper appreciation of life inspired me to keep a good balance in my life. This balance enabled me to be present to their more painful experiences.

In our conversations these women indicated family support from many persons. In working with women with HIV it is important to keep in mind the most inclusive notion of family rather than limiting family to relatives by blood or marriage.

The issues of secrets and disclosure were threaded through these women's stories. It is vital not to assume all secrets are negative but to create a context where the women can discuss their disclosure decisions while maintaining respect for cultural and familial

patterns. Family of origin issues and work with genograms may be helpful to clarify underlying family rules and enable the women to be more free to make their own choices. In some situations secrets are unethical or destructive, and these situations may necessitate further education and clear interventions. Two excellent resources on secrets and HIV/AIDS are Walker (1992) and Black (1993).

Finally, the previous sections on what encourages and hinders these women may be useful in empowering women to be less under the influence of the personal and cultural challenges of living with HIV. Family therapists have an effective resource in the narrative approach of White and Epston (1990). Externalizing HIV and noting its present and possible future negative influence could facilitate women moving toward living creatively with the infection.

Summary of policy recommendations.

The following policy recommendations for practitioners are derived from an in-depth look at these women's stories:

- Continued education to deconstruct the otherness of HIV/AIDS in prevention, testing, and treatment programs
- Improved labeling for over-the-counter medications for the treatment of opportunistic diseases
- Universal availability of testing in jails and other residential institutions
- Improved communication of diagnosis of HIV to include pre-and post-test counseling
- Reassessment and implementation of protocols for confidentiality of a HIV diagnosis
- Utilization of factors which encourage women living with HIV to find access their own resources
- Provision of contexts to discuss disclosure issues
- Increased availability of competent and affordable counseling

- Increased respite and child care service

Recommendations for Further Research

This study has provided an insider's perspective of women living with HIV. Further descriptive research is needed to understand the challenges and strengths of women living with HIV. The positive outcomes of the research process for the co-researchers indicates this study functioned as an intervention. Additional qualitative research of women living with HIV could incorporate focus groups, produce manuscripts of their stories for publication, and include follow-up interviews or longitudinal analysis. The results of this study also highlight a number of areas which are appropriate for prevention and treatment intervention research. The following section addresses research on abuse issues and HIV infection, disclosure, testing for women, secrets, the needs of children, and grief work.

Relationship of abuse issues and HIV infection.

The women in the study have all been abused. The effects of abuse range from poor self-esteem, feelings of helplessness, tendencies to care for others and neglect self, and difficulties in asserting oneself and setting clear boundaries. These effects of abuse may predispose women to be more likely to become infected to HIV. The women expressed intuitions about the risks they were taking and yet they neglected to act on their inner knowing. This neglect is related to a lack of self-care and self-esteem. Therefore the relationship between abuse and its effects on HIV infection warrants study. Measures for self-esteem, assertiveness, and the Silencing the Self Scale (Jack, 1991) could be used to explore these questions. Qualitative work could be developed to determine the process which encourages women to listen to their own voice (Belenky, Clinchy, Goldberger & Tarule, 1986). An additional area to investigate might be the invasion of body boundaries through abuse and its relationship with the difficulty of women to establish psychological and physical boundaries to protect their bodies from further invasion. This

area of study could be done as a prevention intervention in which therapy or education is provided for survivors of abuse. This group would be compared with a control group in relation to rates of HIV infection.

Factors which encourage persons to self disclose about HIV infection.

These women's stories emphasize the fact that education and good intentions are not enough to eliminate exposing others to potential HIV infection. Research is needed to determine what encourages persons to self-disclose about their HIV infection in situations involving high-risk behaviors. One hypothesis developed from the women's stories is that the ability to role-take may positively affect one's ability self-disclose.

Factors which contribute to resistance in early referral for HIV antibody testing.

Women are dying sooner than men even though the progression of the disease does not vary by gender. One possible cause for more rapid death rates may be later HIV detection. Delayed referral for testing was one of the findings of this research. Studies are needed to investigate the resistance of professionals to refer women for HIV testing and to determine more effective ways to educate practitioners for effective health care for women.

The role of secrets in managing HIV infection.

The women in this study all maintained secrets about their HIV status. Research is needed to determine the role of secrets in managing HIV infection. In addition it would be valuable to investigate the problem areas of secret-keeping and to develop effective interventions for the unethical keeping of secrets. One hypothesis derived from these women's stories is that the history of secret keeping in the family of origin may correlate with the secret keeping about HIV.

The needs of children in families living with HIV/AIDS.

Children were a large part of all the women's lives, and their care and futures were a concern for the participants. Further research is needed to determine the needs of children with HIV. Some of the factors related to the needs of children which surfaced in the study were issues involving disclosure to children, children living with an infected or dying parent(s) or guardian(s), and the care of children who are orphaned by AIDS.

The development of new models for grief work.

Most of the women in the study were grieving loved ones who had died from AIDS. AIDS deaths often involve a combination of uncommon factors including multiple deaths of young persons and infection which may have spread between loved ones. This complex combination of factors indicates that traditional methods of grief work may not meet the needs of those left behind. It is important to explore in what ways traditional grief work applies to these circumstances and if necessary develop new models to work through these particular of grief issues. This could be done through an intervention study where different models of grief work were compared and then evaluated.

Summary of research recommendations.

The stories of these women living with HIV provide directions for further research for HIV prevention for women, and the evaluation of treatment and services offered to women living with HIV and their families. The following areas are recommended for further research:

- Relationship of abuse issues and HIV infection for women
- Factors which encourage persons to self disclose about HIV infection
- Factors which contribute to resistance in early referral for the HIV antibody testing of women

- The role of secrets in managing HIV infection
- The needs of children in families living with HIV/AIDS
- The need for and development of new models for grief work

Some Last Thoughts

The value of hearing these stories of women living with HIV is many faceted. Lamott (1994) in her book Bird by Bird answers the question of the purpose of writing, but her words speak to the importance of telling our own stories as well:

So why does our writing matter again? Because of the spirit, I say. Because of the heart. Writing and reading decrease our sense of isolation. They deepen and widen and expand our sense of life: they feed the soul...We are given a shot at dancing with, or at least clapping along with, the absurdity of life, instead of being squashed by it over and over again. It's like singing on a boat during a terrible storm at sea. You can't stop the raging storm, but singing can change the hearts and spirits of the people who are together on that ship.

Through this research these women and I have deepened and widened and expanded our lives in the process of constructing their stories. We join together in the hope that our work can move hearts and spirits about HIV for indeed we all are on this ship together.

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Appendix A

Virginia Polytechnic Institute and State University

Informed Consent for Participants of Investigative Projects

Project Title: Pain, Courage, and Wisdom: Stories of Women Living with HIV

Principal Investigator: Anne Gosling

I. THE PURPOSE OF THIS RESEARCH PROJECT

You are invited to participate in a study about women living with HIV/AIDS. This study involves in-depth interviews for the purpose of learning more about what women's experiences are like in living with HIV/AIDS. It is intended that the information gathered from this study will provide recommendations for social services, public policy and further research.

It is planned there will be six to eight participants in the study.

II. PROCEDURES

The procedures to be used in this research are in-depth interviews. You will be asked to participate in a minimum of three interviews with the principal investigator. Each interview will last from one to two hours long.

It may be possible that discussing your experiences of living with HIV/AIDS will bring up strong emotions. If you want to discuss these feelings and experiences in greater depth than we are able to in the interview you will be referred to a professional counselor.

Every effort will be made to meet your needs in terms of time, and place of our meetings. In addition, we can pause, or slow down during an interview according to your needs. A meeting can be canceled and rescheduled if need be.

III. BENEFITS OF THIS PROJECT

Your participation in the project will provide information about what it is like for women to live with HIV/AIDS. There is very little research in this area and your participation can possibly be useful for others living with HIV/AIDS or those working with them.

No guarantee of benefits has been made to encourage you to participate.

You may receive a synopsis or summary of this research when completed.

IV. EXTENT OF ANONYMITY AND CONFIDENTIALITY

Your anonymity will be protected in relation to the interviews. At no time will I release the interviews to anyone other than individuals working on the project without your written consent. The written transcripts of your interviews and written or oral reports of the research will only use your pseudonym.

The interviews will be audio taped. These tapes will only be reviewed by Anne Gosling and will be erased after the research is completed. If a research assistant is hired to transcribe the tapes they will sign a pledge of confidentiality and agree to withdraw from transcribing tapes of anyone who is known to the assistant.

V. COMPENSATION

If as a result of this project, you or the investigator decide that you could benefit from counseling there will be counseling available through Family Services of Roanoke Valley.

VI. FREEDOM TO WITHDRAW

You are free to withdraw from this study at any time without penalty.

VII. APPROVAL OF RESEARCH

This research has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University, by the Department of Family and Child Development.

VIII. SUBJECT'S RESPONSIBILITIES

I know of no reason why I cannot participate in this study.

Signature

IX. SUBJECT'S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this study.

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

Should I have any question about this research or its conduct, I will contact:

Anne Gosling 381-0976
phone

Victoria Fu, Faculty Advisor 231-4796
phone

Chair, IRB 231-6077
Research Division phone

Appendix B

Notice of Study in Newsletter

Seeking HIV positive Women to tell their Stories

Many research studies about HIV/AIDS have focused on men or on AIDS prevention for both men and women. It is important to hear the stories of women who are living with HIV/AIDS so that people may be more aware of women's experiences and needs. I am conducting a study at Virginia Tech on this topic. I am seeking women who are HIV positive, and interested in telling their story. Please contact me at 381-0976 for more information. Calls will be kept confidential. Anne Gosling

Appendix C

Interview Guide

Diagnosis

Disclosure of HIV status

Discrimination

Employment

Economics

Medical care

Sexuality

Reproductive issues

Children

 present

 future plans

Relationships

Orientation to future

 past dreams

 present outlook

What to tell others

Effect of the research

Appendix D

Demographic Information

Narrative Name

Phone _____ leave message?

Birth date _____ age _____

Education

Ethnicity/race

Employment

Source(s) of income

Grandparents

Parents

Other important family

Siblings (in birth order)

Friends

Marital/partner status and history

Number of living children girls _____ boys _____

Deceased children, miscarriages, abortions

Children:

Name sex birth date death date

Living arrangements

Diagnosis date and circumstances

Current stage of infection

Appendix E

Research Assistant's Confidentiality Statement

Title of Study: Pain, Courage, and Wisdom: Stories of Women Living with HIV

Primary Researcher: Anne Gosling

Confidentiality Pledge

I understand that the information being collected in this study is sensitive, personal and is strictly confidential. I hereby pledge that I will keep all such information confidential. I also pledge to withdraw immediately from further involvement with a particular interview if I discover that the participant whose interview I am transcribing is an acquaintance of mine or known by me in any way.

Signature

date

Appendix F

Interview Questions

Diagnosis

What was it like when you found out you were HIV positive?

Disclosure of HIV status

What has it been like to share this information with others?

Discrimination

In what ways have you been treated because you have HIV/AIDS?

Employment

In what ways has living with HIV/AIDS affected your work?

Economics

In what ways has living with HIV/AIDS affected your finances?

Medical care

What has your medical care been like?

Sexuality

In what ways has living with HIV/AIDS affected your sexuality?

Reproductive issues

In what ways has living with HIV/AIDS affected your decisions to have children?

Children

present: In what ways is your relationship with your children affected by your HIV?

future plans: In what ways have you made plans for your children in the future?

Relationships

In what ways has living with HIV/AIDS affected your relationships?

Orientation to future

past dreams: In what ways does living with HIV/AIDS affect the way you see the future?

present outlook: In what ways does living with HIV/AIDS affect the way you see the future now?

What to tell others

If you were able to tell others what you have learned in living with HIV/AIDS what might that be?

Effect of the research

In what ways has being a co-researcher on this project effected you?

Is there anything about the research you would like to change?

ANNE GOSLING
220 South Hill Drive
Christiansburg, VA 24073
(703) 381-0976

EDUCATION

- Ph.D. Family and Child Development, 1995**
Marriage and Family Therapy, College of Human Resources
Virginia Tech, Blacksburg, VA
Dissertation: Pain, Courage, and Wisdom: Stories of Women Living with HIV
Advisor: Dr. Victoria Fu
- M.A. Theology, Pastoral Counseling, 1980**
Episcopal Divinity School, Cambridge, MA
Including coursework in Adult Development
Harvard University Graduate School of Education
- M.S. Dance/Movement Therapy, 1976**
Hunter College, New York, NY
Thesis: A Scale of Movement Characteristics for Hyper- and Hypo-Active Children
Including coursework in Psychopathology, Group Process, & Child Development
- B.A. English Literature, 1971**
University of Michigan, Ann Arbor, MI

PROFESSIONAL CLINICAL EXPERIENCE

FAMILY SERVICE OF ROANOKE VALLEY, Roanoke, VA 1994-present
Marriage and Family Therapist
•Counseled individuals, couples, children and families
•Co-led a groups for women from the battered women's shelter

THE COUNSELING CENTER, Roanoke, VA 1989-91
Counselor
•Developed individual treatment plans
•Counseled clients and provided movement therapy

NEW ENGLAND REHABILITATION HOSPITAL, Woburn, MA 1980-82

Movement Therapist, Physical Therapy Department

- Evaluated and led outpatient back pain management groups
- Evaluated and treated stroke patients and brain-injured adolescents and adults
- Led family meetings and participated in team meetings and family conferences

ACADEMIC TEACHING EXPERIENCE

VIRGINIA TECH, Blacksburg, VA 1991-1993

Graduate Teaching Assistant, College of Human Resources

Course: Professional Seminar

- Lectured 150-200 undergraduates
- Taught sections for seven departments including Family and Child Development
- Taught Family and Child Development independent study sections
- Supervised and advised individual independent study students
- Advised undergraduate students 10 hours a week
- Graded 150-200 weekly assignments, including resumes, letters, class assignments and exams

HOLLINS COLLEGE, Roanoke, VA 1989

Lecturer, Dance Department

- Designed and taught a three credit undergraduate course
An Introduction to Movement Therapy

AWARDS

Jessie Bernard Award

for Outstanding Contribution to Feminist Scholarship 1993

National Council on Family Relations

Virginia Tech Department of Family and Child Development

Certificate of Merit 1993

For Contributions to College Administration and to Undergraduate Instruction

CLINICAL INTERNSHIPS

FAMILY SERVICE OF ROANOKE VALLEY, Roanoke, VA 1993-present
Marriage and Family Therapist, Intern

- Counseled individuals, couples, children and families
- Co-led groups for women from the battered women's shelter and adolescent girls

CENTER FOR FAMILY SERVICES, Blacksburg, VA 1992-93
Marriage and Family Therapist, Practicum, Virginia Tech

- Counseled individuals, couples, and families
- Co-led a women's group

NEW ENGLAND REHABILITATION HOSPITAL, Woburn, MA 1979-80
Chaplain, Field Education, Episcopal Divinity School

- Counseled chronic pain and stroke patients

UNIVERSITY OF MICHIGAN PSYCHIATRIC HOSPITAL, Ann Arbor 1979
Chaplain, Clinical Pastoral Education

- Counseled psychiatric and pre-operative patients with intensive in-depth verbatim group and individual supervision

THE ASHBOURNE SCHOOL, Elkins Park, PA 1974-75
Dance/Movement Therapist, Clinical Internship, Hunter College

- Led and co-led therapeutic groups for learning disabled children ages 6 to 18

BRONX STATE HOSPITAL, Bronx, NY 1974
Dance/Movement Therapist, Field Education Program, Hunter College

- Co-led therapeutic groups for adult psychiatric inpatients and emotionally disturbed outpatient children

CLINICAL TRAINING

POST-TRAUMA INTERVENTION, Roanoke, VA 1994 (Two day training)
A. Ward West, M.A.

REWRITING LOVE STORIES: BRIEF MARITAL THERAPY
Richmond, VA 1994 (One day training)
Patricia O'Hanlon Hudson, Ph.D. & William Hudson O'Hanlon. M.S.

TRAINING IN THE TREATMENT OF SUBSTANCE ABUSE

Roanoke, VA 1994 (One day training, and monthly supervision)
Ted Petrocci, M.A., L.P.C.

TREATING SURVIVORS OF SEXUAL ABUSE AND OTHER TRAUMAS

Lynchburg, VA 1994 (One day training)
Yvonne Dolan, M.A.

INVESTIGATION AND PROSECUTION OF CHILD SEXUAL ABUSE

Roanoke, VA 1994 (One day training)
Children's Justice Act Training/ The American Prosecutors Research Institute
National Center for the Prosecution of Child Sexual Abuse

BRIEF SOLUTION-ORIENTED THERAPY, Roanoke, VA 1993

(One day training)
Steve Miller

KIDS POWER:

IDENTIFYING AND TREATING CHILDREN OF ALCOHOLICS

Christiansburg, VA 1992 (Workshop)
Jerry Moe, M.A.

MARY STARKS WHITEHOUSE INSTITUTE

Northampton, MA 1982-83 (One year full-time)
Intensive training in Authentic Movement with Janet Adler, M.A.

EFFORT SHAPE MOVEMENT ANALYSIS

Cambridge, MA 1981 (Monthly session/one year)
Basic training in Effort Shape with Carlotta Willis, Ph.D.

BOSTON GESTALT INSTITUTE, Cambridge, MA 1979-80

(Weekly training/one year)
Training in Gestalt Therapy with Richard Borofsky, Ed.D.

PSYCHOSYNTHESIS INSTITUTE, Cambridge, MA 1979

(Two four day trainings)
Basic professional training in Psychosynthesis

ADDITIONAL PROFESSIONAL TEACHING EXPERIENCE

AMERICAN RED CROSS, Roanoke, VA 1994

Workshop co-leader, Family Service of Roanoke Valley

- Emotional dimensions of informing persons of HIV positive status

FAMILY SERVICE OF ROANOKE VALLEY, Roanoke, VA 1994

Inservice co-leader, Family Service of Roanoke Valley

- Yvonne Dolan's solution-focused work with survivors of sexual abuse

EPISCOPAL DIOCESE OF NORTH CAROLINA, Brown's Summit, NC 1992

Workshop leader, Commission on Ministry Spiritual Development Program

- Authentic Movement as Spiritual Process

YMCA FREE UNIVERSITY, Blacksburg, VA, Spring 1991 and 1992

Teacher

- Introduction to Authentic Movement

HOLLINS COLLEGE WOMEN'S CENTER, Roanoke, VA 1990

Teacher

- Movement for Mothers and Toddlers
- Creating a Space To Be

INTRODUCTION TO AUTHENTIC MOVEMENT, Roanoke, VA 1989

Workshop Leader

- Authentic Movement for Counselors and Psychotherapists

EPISCOPAL DIOCESE OF SOUTHWESTERN VIRGINIA, Roanoke, VA 1986

Coordinator, Convivencia

- Global Awareness Conference

OLD STURBRIDGE VILLAGE, Sturbridge, MA 1976-78

Costumed Interpreter, Historic Interpretation Department

- Taught early 19th century life to museum visitors
- Developed and led Crafts-at-Close-Range weekend workshops
- Performed early 19th Century song and dance

SERVICE AND OUTREACH

- **Virginia Tech, College of Human Resources**
Goal setting and time management for undergraduates
Blacksburg, VA 1993
- **Southeastern Family and Child Development Symposium**
The Use of Movement with Families in Therapy
Virginia Tech, Blacksburg, VA 1992
- **Creating Confidence in Women Conference, Women's Research Institute**
Moving into Confidence
Blacksburg, VA 1992
- **Women's Program, Lewis-Gale Outpatient Clinic**
Movement Therapy for Women in Transition
Roanoke, VA 1990
- **Activities Therapy Department, Catawba Hospital**
Catawba, VA 1989
- **Women in Ministry in the Virginias Conference**
Camp Bethel, Fincastle, VA 1986
- **Women in Ministry in the Roanoke Valley**
Hollins College, Roanoke, VA 1986

PROFESSIONAL MEMBERSHIP

American Association for Marriage and Family Therapy, Student Member
International Family Therapy Association
National Council on Family Relations, Student Member

PUBLICATIONS

Gosling, A., & Palonis, M. (1978). A scale of movement characteristics for hyper- and hypo-active children. In C. Schmais & F. Orleans (Eds.), Dance therapy research, New York.

Gosling, A., & Zangari, M. E. (in press). Feminist family therapy and the narrative approach: Dovetailing two frameworks for therapy. Journal of Feminist Family Therapy.

PAIN, COURAGE, AND WISDOM:
STORIES OF WOMEN LIVING WITH HIV

by

Anne Gosling

Victoria R. Fu, Ph.D., Chair

Department of Family and Child Development

(ABSTRACT)

This is a descriptive study of women with Human Immune Deficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS). Women have been neglected in social science research and literature on HIV/AIDS (Anastos & Marte, 1989, Corea, 1992). Unfortunately even when women with HIV/AIDS have been studied it has been in relation to their role as transmitters of the disease (through prostitution and child birth) not as sufferers of the deadly disease themselves (Carovano, 1991). This study recounts an insider's perspective of the learnings, strengths, and challenges of women living with HIV through their stories. Themes identified through qualitative analysis in these stories provide policy recommendations for practitioners and directions for further social science research.