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POSITIONING FOR ACCEPTANCE: HOW WOMEN WITH HIV INFECTION MANAGE THEIR RELATIONSHIPS

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for the degree of

Doctor of Philosophy

By

Mary A Kozy

December 2007

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Mary A Kozy

2007

POSITIONING FOR ACCEPTANCE: HOW WOMEN WITH HIV INFECTION MANAGE THEIR RELATIONSHIPS

By

Mary A. Kozy

Approved November 2, 2007

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ABSTRACT

POSITIONING FOR ACCEPTANCE: HOW WOMEN WITH HIV INFECTION MANAGE RELATIONSHIPS

By

Mary A Kozy

December 2007

Dissertation Supervised by Professor Dr. Rick Zoucha

Even though the number of women with Human Immunodeficiency Virus (HIV) grows annually, medical treatment has rendered this illness a chronic but manageable disease. Nurses must expand their knowledge beyond issues of survival and end of life care and focus on ways to maintain health and well being in this population. The works of Miller (1986) and Gilligan (1993) underscore the significance of relationships in the emotional well being of women. Issues of stigma, sexual transmission and ill health render HIV infection a threat to social relationships. Published literature exists that explores aspects of relationship such as social support, motherhood and condom use but the management of relationships has not been studied. The purpose of this grounded theory study was to discover how women with HIV infection manage relationships. Individual interviews were conducted with 14 women. Positioning for acceptance emerged as the basic psychological social process (BSP) that explained how women

managed their relationships subsequent to the betrayal shame and isolation that came from being infected by a trusting partner who had withheld his diagnosis. The BSP was comprised of four strategies; manipulating the social context, finding purpose, securing support, and accommodating HIV infection. These strategies, which were both cognitive and behavioral, each contained two to three sub strategies and existed within contextual factors of health care, sexual intimacy, and a larger social network. The study has implications for practice, education and research.

DEDICATION

This study is dedicated to the memory of my father Mattison Wells Alderman; the first PhD in my life. While he was alive he made sure that I believed in my ability to accomplish anything. His spirit was present and guided me through out this journey of higher education. Dad, I know you would hood me if you could.

And

To the memory of my mother Betty Bury Alderman; the first RN in my life. She left a legacy of strength, determination and excellence that has served me well through my career and was absolutely essential as I pursued by doctorate.

And

To the women who participated in this study. You shared your stories as courageously as you live your lives. Your inspiration has been the light I have followed from the very beginning. It is an honor and a privilege to know you.

ACKNOWLEDGEMENTS

It is with gratitude that I acknowledge the following people.

Dr. Rick Zoucha, the chair of my dissertation committee whose patience and mentorship was invaluable and allowed me to persevere, even when I didn't think I could. He doesn't need me to make him famous.

Dr. Ellen Olshansky and Dr. Kathleen Sekula, committee members, whose faith in me never faltered; whose patience was beyond measure and whose knowledge and leadership kept me on the path to success.

Dr. Joan Duggan, Susan Carter, and Christie Clinton as well as the members of the HIV Care Team; who provided access to the women and offered invaluable advice and direction as I prepared and implemented this research project.

My sisters Kate and Sarah; for believing in me so completely.

Judy Didion; colleague, friend and fellow doctoral student; for knowing exactly when to give advice, and when to back off. Her own progress kept me going.

Martha and David, my children who despite evidence to the contrary insisted I was doing the right thing and had me believing that I was serving as a role model.

Jeff my wonderful husband; for being who he is. During this process he has been supporter, cheerleader, confidant, punching bag, chief cook and bottle washer, and god send. I simply couldn't have done it without him.

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CHAPTER I

INTRODUCTION

Background of the Problem

The purpose of the proposed study was to examine how women infected with Human Immunodeficiency Virus (HIV) manage their personal relationships. HIV infection represents a major health threat for women. Spread through sexual contact and intravenous drug use, the virus invades a woman's immune system and, if left untreated, creates symptoms of fatigue and pain, leaves a woman vulnerable to opportunistic infections, and eventually results in death. Until recently women with HIV infection were expected to live for only a few years, but the advent of highly active antiretroviral therapy (HAART) has transformed HIV infection into an incurable but manageable chronic illness. The success of current treatment therapies has changed the focus of nursing care of women with HIV infection from survival and symptom management to long term health and well being. Essential to the health and well being of women is their relationships (Gilligan, 1993; Miller 1986).

It is through close personal relationships that women begin to form an awareness of their unique personal reality (Miller, 1986), learn how to resolve moral and emotional crises (Gilligan, 1993), and claim knowledge of and understanding about the world around them (Belenky, Clinchy, Goldberger, & Tarule, 1986). Authenticity in relationships, the ability to represent needs and gifts honestly, allows a woman to foster

continuous personal growth and emotional health (Miller). HIV infection, because of the way it is transmitted and the way it is viewed by society, challenges the ways a woman establishes and maintains herself in relationships; and therefore her health and well being.

HIV is an infectious disease occurring within and affecting all aspects of personal relationships. It is spread through intimate contact, specifically sexual activity and needle sharing during intravenous drug use (IVDU). Once infected, a woman with HIV has the potential to infect others, specifically her sexual partners, her unborn children, and, if addicted, her needle sharing partners. HIV is also a highly stigmatized illness. Stigma, by its very nature, pushes those who are afflicted with the stigmata to the borders of society, limiting opportunities for social contact and affecting all manner of personal relationships.

Women react to perceived stigma in regard to their HIV infection by not seeking medical care, or initiating HAART for fear people will learn that they are ill (Carr & Gramling, 2004). They internalize society's perspective that their HIV infection makes them deviant and they express shame and guilt about their illness (Lawless, Kippax, & Crawford, 1996; Stanley, 1999). They suffer from depression, anxiety and chronic sorrow (Lichtenstein, Laska, & Clair, 2002). Mothers work hard to keep their illness a secret so that their children will not suffer negative consequences by their peers (Bunting, 1996; Ingram & Hutchinson, 1999b; Sandelowski & Barroso, 2003). Disclosure of their illness to others is risky. Women fear that the stigma associated with HIV infection will result in rejection by friends, families, and health care providers (Sandelowski, Lambe, & Barroso, 2004; Sowell, Lowenstein et al., 1997). Ultimately women report that they find

the experience of stigma to be isolating and lonely (Goggin et al., 2001; Moneyham et al., 1996; Sandelowski et al.; Sowell et al.).

When women make the decision to disclose their HIV status, some experience violence or rejection (Gielen, McDonnell, Burke, & O'Campo, 2000) and some find that they receive important social support. For women this social support affords both benefits and liabilities. The benefits of social support include emotional well being (Derlega, Winstead, Oldfield, & Barbee, 2003; Gonzalez et al., 2004; Hudson, Lee, Miramontes, & Portillo, 2001) and in some studies increased adherence to HAART (Gonzalez et al., 2004; Knowlton, Hua, & Latkin, 2005; Malcolm, Ng, Rosen, & Stone, 2003). The cost of social support stems from the potential for loss of independence and increased vulnerability to loss should the supporter leave or die (Brashers, Neidig, & Goldsmith, 2004). Social support, like relationships, is complex. But social support is not the same as relationship. The concept of social support is concerned with the people upon whom a woman relies. The concept of relationship implies mutuality; giving as well as receiving.

Physical intimacy and sexual contact is an aspect of relatedness that is directly affected by HIV infection. Studies show that many women opt for celibacy, at least initially after being diagnosed (Gaskins, 1999; Maticka-Tyndale, Adam, & Cohen, 2002). Many eventually return to normal and satisfying sex lives (Bova & Durante, 2003), but in order to so they must find ways to negotiate safe sex boundaries with their partners, decrease physical symptoms and avoid clinical depression (van der Straten, Vernon, Knight, Gomez, & Padian, 1998; van Devanter, Thacker, Bass, & Arnold, 1999).

Even the mothering relationship is affected by HIV infection. Although the probability has been greatly reduced in the last decade, women still risk infecting a

newborn child. If the child is born without HIV infection, the mother still worries about the possibility of her own premature death and leaving the child to grown up without a mother (Siegel & Schrimshaw, 2001; Wesley et al., 2000). Women must weigh these risks against their desire to have a child and become a mother. Stigma is visited upon women with HIV infection who decide to have children because they are perceived to be bringing harm on an innocent child (Sandelowski & Barroso, 2003). Women feel this disapproval as they weigh their decisions. Even women who have children prior to having HIV infection spend a great deal of energy protecting themselves and their children from the burden of societal judgment (Ingram & Hutchinson, 1999a; Sandelowski & Barroso).

Despite the challenges that HIV infection brings to women's relationships, some women do thrive. They find satisfying relationships and they proclaim their lives to be fulfilling. There is little in the literature that examines the processes involved in managing relationships for women who are HIV positive. Research has begun to shed light on specific aspects of relationships in women with HIV infection. Issues of stigma, social support, sex and motherhood have been explored. Despite the importance of relationships in the lives of women there is a paucity of research examining how women manage their network of relationships within the context of HIV infection.

Significance of the Problem

HIV infection has become a major health problem for women. Currently there are over 123,000 women living with HIV in the United States and that number grows at an estimate of 10% annually (Centers for Disease Control (CDC), 2005). For each woman diagnosed with HIV infection there is a significant impact on every close relationship.

Until recently research on women focused on issues of diagnosis, treatment and prevention. However, the advent of HAART has helped to transform HIV infection from an acute life threatening disease into a long term manageable illness and women are living longer more productive lives. Scientific inquiry needs to expand to help these women live the healthiest lives possible, while managing HIV infection.

Nurses assist people in the management of illnesses in such a way as to promote optimum functioning and well being. Recent literature has made explicit the importance of relationships in the mental health of women. Miller (1986) and Gilligan (1993) argue that it is within a network of relationships that women develop a sense of identity and worth. Relationships help create in a woman her sense of purpose and value as she receives and gives attention, affection, and validation. Nursing care of women must incorporate the knowledge of relationships. Effective nursing care must take into consideration a woman's place within relationships and strive to maintain and develop relationships that are essential to a woman.

Nurses are in a strategic position to address issues of relationships with women with HIV infection. Women with HIV infection are encountered in every aspect of their practice; in-patient settings, at primary and specialty care clinics, in drug abuse and rehab centers, and in counseling sessions with psychiatric mental health practitioners. Nurses in these settings deal with the women's concerns about sexual contact, mothering, and disclosure of HIV status; all of which impact the quality of a woman's relationships. In order to be effective as caregivers, nurses must be fully cognizant of the role of relationships in these women's lives. Nurses must also develop an understanding of how women manage relationships in light of the threats provided by HIV infection. Nursing

interventions should be designed in such a way as to support and strengthen these relationships. A study such as this one which explores how women with HIV infection manage their personal relationships provides nurses with essential knowledge to be able to render optimal care for women living with HIV infection.

Purpose of the Study

The purpose of this study was to discover how women with HIV infection manage their relationships. A grounded theory approach provided the method for data collection and analysis.

Research Questions

The research questions for this study were as follows:

1. How does HIV infection affect women's relationships?
2. What processes do women use to manage their relationships within the context of HIV infection?
3. What role does a network of social relationships play in the lives of women with HIV infection?

Definition of Terms

For clarification and consistency in interpretation of the study the following terms are defined:

1. Human Immunodeficiency Virus (HIV) infection- the presence of human immunodeficiency virus within a human being as verified by immune assay or RNA detection. For the purposes of this study a woman was considered to be HIV positive if she received medical treatment at a health care clinic dedicated to treatment of women with HIV infection or she attended one of

the community support groups for people with HIV infection. The terms HIV infection, and HIV positive were used interchangeably within this document because both refer to a person who has contracted the virus.

2. AIDS- Acquired Immune Deficiency Syndrome- the advanced progression of HIV infection as indicated by a CD4+ count of less than 200 per cubic millimeter of blood or the presence of one or more of the 26 opportunistic AIDS-defining opportunistic infections (National Institute of Allergies and Infectious Diseases [NIAID], 2005).
3. Stigma- A societal construct that implies a relationship between a person and expected norms. A stigma implies deviance from the expected norm and places the stigmatized individual outside the circle of societal acceptance (Herek, 1990; Herek, Capitanio, & Widaman, 2002).

Assumptions

This study was based on the following assumptions

1. The women knew and understood that they were infected with HIV.
2. The women were honest while talking about their experiences of HIV infection and their relationships.

Limitations

Women who have managed to connect with the health care system, a community service agency, or support group, may possess different skills or attitudes about managing their relationships than those who have not engaged with such systems. Study participants were recruited from HIV support groups and an HIV health clinic and as

such might not have been representative of the population of women with HIV infection as a whole. This may have influenced and caused bias during the study.

Summary

HIV infection is a growing health problem for women in the United States. Within recent years it has evolved from an acute fatal illness into one that can be managed successfully over many years. Despite medical advances HIV infection is still highly stigmatized and women who live with this disease risk rejection by health care workers, friends, family, and society at large. The experience of stigma jeopardizes important relationships within women's lives resulting in alienation and social isolation.

Women require a strong network of relationships in order to promote personal growth and development as well as a sense of well being. Research has begun to shed light on how women react to and maintain relationships within the shadow of HIV infection. To date there is little data to provide a meaningful framework in which to understand how women manage their network of relationships in the context of HIV infection.

The purpose of this study was to discover how women with HIV infection manage their relationships. Grounded theory, which is based on the philosophy of symbolic interactionism, was the methodology used to design the study and analyze the data.

CHAPTER II

REVIEW OF THE LITERATURE

The review of the literature in grounded theory bears some discussion. One school of thought posits that an extensive literature review should not be done prior to data collection (Glaser & Horton, 2004). This position is based on the belief that grounded theory is a purely inductive process in which the investigator needs to remain open to new and creative interpretation of the phenomena represented by the data. Others propose that a comprehensive review will identify gaps in the literature; help refine research questions and provide sensitizing concepts to be utilized during data analysis (Strauss & Corbin, 1998).

This investigator believes that a thorough review of the literature is necessary in order to justify the study by identifying areas appropriate for nursing inquiry. Furthermore, the presentation of broad survey of existing literature can serve as a form of disclosure for the reader. No investigator can enter into data analysis totally without prejudice. Constant comparison of the data is undertaken within the framework of the investigator's unique perspective which has been formed in large part by her knowledge of her science. This literature review serves the reader by illuminating the backdrop for the substantive theory that was constructed as a result of data analysis.

Three major areas of literature were explored during the conceptualization and development of this study. The first area concerned the function of relationships in

psychological, moral and intellectual development of women. The next area focused on HIV infection in women specifically the impact of the illness on health and social functioning. The last area delved into the role of social support and other relationships in women with HIV infection. This chapter presents the results of this literature review and makes explicit the conceptual milieu that provided the basis for the ensuing data collection and analysis.

Women in Relationship

The significance of relationships and the importance of relating and responding in a social context for women has gained a greater understanding within the last twenty years through the works of such authors as Jean Baker Miller (1986), Carol Gilligan (1993, 1995) and Mary Belenky (Belenky et al., 1986). The collected works of these authors emphasize that all aspects of women's emotional, moral and intellectual growth and development occur within and because of their connections with others. The following section explores these aspects of female existence.

Psychological, Moral and Intellectual Development

Jean Baker Miller (1986) describes how women are socialized to grow and gain strength by remaining in relationships. In her view the central context of relationship is an empathic understanding that grows out of the repeated interactions that a girl has, first with her mother and then with others. A girl learns from an early age how her actions affect others, and how others affect her. Over time a girl gains an understanding of herself as well as an awareness of her own needs and how they are met. She begins to learn how she affects people and their responses. The empathic response builds a form of mutuality. A woman is able to get her needs met, but she is also able to meet the needs of

others and therefore help provide joy, comfort, and support. She develops a sense of identity that is unique.

In the type of connectedness that Miller (1986) describes, authenticity is essential. Authenticity means presenting oneself honestly to those in one's social network. A woman must genuinely represent her needs and she must respond to others in a way that is true to her nature. Key to her ability to be authentic is to feel truly safe within her relationships. Miller proposes a paradox that is articulated by Gilligan (1993): women can only define themselves as separate and unique within the connections of personal relationships, and authentic relationships can only be experienced if women see themselves as separate and unique.

Miller (1986) describes the impact of relationships on healthy emotional growth and development. Gilligan (1993), on the other hand, explores the nature of feminine relationships in connection to moral growth and decision making. Gilligan describes that women develop an ethos of caring for others; a responsiveness to the needs of others starting at a young age. In one study girls were asked to give their reactions to a fictional moral problem, called the Heinz dilemma, in which a man must make a choice between stealing medication he cannot afford and allowing his wife to die. The responses to this dilemma revealed that the girls did not view this situation in terms of right or wrong or universal principles of justice. Instead the girls viewed the impact of the decision within the framework of the man's relationships. The girls expressed concerns for the wife should the man steal and go to jail. Questions arose as to how thoroughly the man had negotiated with the druggist selling the medication. Other feedback explored the possibility that friends or family might help provide the resources to purchase the needed

treatment. The girls' responses showed respect for maintaining and strengthening relationships as well using relationships as a source of support.

In order to explore the issue of moral decision making in adult women, Gilligan (1993) interviewed 29 women of various levels of education and social class, who were considering voluntarily terminating a pregnancy. In evaluating the women's interviews Gilligan was able to illustrate that women also make decisions in terms of their social context and are guided by a sense of responsibility. Women considered the impact of the abortion not only on the unborn child, but also other people in their lives and ultimately on themselves. Women who were able to successfully resolve the moral dilemma of abortion came to see the choice as theirs and not dictated by the wishes of others. They fully recognized the implications of terminating a pregnancy as terminating a life, but came to understand that giving birth required a commitment to another type of relationship and responsibility. The decision was made based on an authentic understanding of their own capacity to take on the responsibility of being a mother amidst their responsibility to other relationships and to themselves.

Adding further dimension to the role of relationship is an understanding of the role of relationship in intellectual development. In a landmark study by Belenky and her colleagues (1986) interviews with 135 women of various ethnic and socioeconomic backgrounds were examined to determine how the women came to know the truth about things, how they decided what to believe and whom they considered as authorities. The authors concluded that women who are allowed to develop intellectually eventually come to a state of "connected knowing" (p. 112).

Connected knowing is constructed knowledge. According to Belenky et al (1986) women come to realize that there is no absolute truth. Knowledge is constructed and the knower is part of the knowledge. Connected knowing builds on the constructivist idea by emphasizing that knowledge is also an experience that is shared with others. Knowledge, according to Belenky et al. involves a connection in which others speak and are listened to. At the same time a personal knowledge is shared and heard by others. In this work the quest for knowledge is identified in the philosophical sense as a quest for truth. The woman's genuine presentation of herself is essential for connected knowing to exist.

The writings of Miller, Gilligan and Belenky and associates did much to reframe our understanding of the growth, development and psychology of women. Theories that that had taken for granted a white male dominated world were challenged and reconstructed by acknowledging the experience of women. These writings, while presenting a much needed perspective, have been criticized for not taking into account the experiences of women of color in the United States (Henderson, 1997). Henderson points out that racism and colonization have influences that go unrecognized in the works of Miller, and Gilligan. The works of these authors fail to explore the intersection of race, gender and class as they relate to women's emotional health, growth and development.

Intersectionality

Intersectionality is a concept that has gained increasing recognition over the past 10 years and has relevance in understanding women with HIV infection (Epele, 2002; Osmond et al., 1993). The concept of intersectionality maintains that, at any given point in time, a person is positioned according to a number of social constructs. Even though

numerous social constructs can come in to play at any given time the relevant positions for women with HIV infection are gender, race (or ethnicity) and social class.

For women of color both cultural and ethnic factors strongly influence the concept of self. For example, Henderson (1997) describes how African American women are raised to be independent in order to cope with the probability that they will be heads of households due to the economic reality of being Black in America. At the same time their sense of interrelatedness encompasses black community. They understand that their actions reflect more than their family name, but black society as a whole. These are just two ways in which gender, culture and social class intersect to influence a sense of self in relationship for certain women of color.

The acknowledgement that multiple social constructs such as race, gender and social class influence both relationship and sense of self is significant for an understanding of women with HIV infection. HIV is an illness, but it is also a social construct. In addition to having an identity defined by society via gender, ethnicity, and social class a woman must now contend with an identity that is formed, in part, by her infection. The illness influences not only a woman's health but much of her social domain as well.

HIV Infection, AIDS and Women

Much has been learned about HIV and AIDS since it emerged as a new health problem 25 years ago. It is now common knowledge that it is transmitted through sexual activity and needle sharing and that if left untreated, destroys the immune system. A 20 minute test based on an oral swab can detect the presence of HIV antibodies (Liang et al., 2005; Truong & Klausner, 2004) and the progress of the disease can be monitored by

measuring viral load and CD_4^+ counts (National Institute of Allergies and Infectious Diseases (NIADA), "HIV infection and AIDS: An overview," 2005). Due to the development of new antiviral medications, treatment has evolved to the point where HIV infection is now considered a chronic, but manageable illness (CDC, 2004).

Highly active antiretroviral therapy (HAART) is a drug treatment regimen consisting of a combination of two or more antiretroviral medications and it is effective because it slows the replication of the virus and restores the immune system (Furler, Einarson, Walmsley, Millson, & Bendayan, 2004; Johns, Furtek, & Looney, 2004). As a result, mortality from HIV infection has declined and survival rates have increased significantly (CDC, 2004). Unfortunately, HAART also imposes a heavy pill burden, as many as 21 pills, which need to be taken at various times during the day. Because resistance to HAART develops quickly, dosing schedules must be meticulously maintained (Fumero & Podzamczer, 2003). Side effects can also be significant and include hepatotoxicity, lipodystrophy, hyperlipidemia, hyperglycemia and cardiac changes (Montessori, Press, Harris, Akagi, & Montaner, 2004; Saves et al., 2003). Lipodystrophy results in a redistribution of fatty deposits in the abdomen and chest wall which renders this side effect noticeable to friends and family.

Just as current technology has greatly improved the diagnosis and treatment of HIV infection, nursing care for such clients has undergone a shift of focus. Nurses must now understand and help clients deal with management of a chronic yet life threatening illness. This means understanding the impact of HIV infection, not only from a physiological perspective, but from a societal and personal perspective as well.

Women and HIV Infection

Women represent the fastest growing segment of new cases of HIV infection ("HIV Infection in Women," 2004). Furthermore, 83% of all new cases of HIV infection in women are African American or Hispanic (CDC, 2004). The majority of women with HIV infection are women of color, live in poverty, single heads of households (Gaskins, 1999) and have a history of being survivors of physical or sexual abuse (Brady, Gallagher, Berger, & Vega, 2002; Koenig & Moore, 2000). Of all the women living with HIV infection over 80% acquired the virus through heterosexual sex (Divisions of HIV/AIDS Prevention & National Center for HIV/AIDS, 2007). In our country today a woman with HIV infection is likely to be a poor woman of color, with experiences of violence, exposure to substance abuse trying to raise her children alone (Bova, 2000; Epele, 2002; Osmond et al., 1993).

In addition women with HIV infection generally do not do as well medically as their male counterparts. This is partially due to the fact that women are diagnosed later in the illness trajectory. Women do not fully realize the risk of heterosexual transmission. As a result the vague symptoms that are present in the early stages of the disease are ignored. At the same time physicians do not always consider women who are not prostitutes or intravenous drug users to be at risk, thus delaying diagnostic testing even in the presence of puzzling and persistent infections (Squires, 2003).

Women are less likely to receive the most effective treatments for HIV infection and have mortality rates that are higher than those of men with HIV (CDC, 2004; "HIV infection and AIDS: An overview," 2005). Some research indicates that the progression from HIV infection to AIDS in women occurs with lower viral loads and higher CD_4+ counts than with men (Squires, 2003). Because of these basic differences in diagnosis and

treatment women have shorter survival times after diagnosis than do men (CDC). Issues of poor access to health care and less than effective treatment in women with HIV infection reflect the general health care disparities faced by women of color living in poverty in the United States. The stigma associated with HIV infection, however, amplifies these health disparities (Carr & Gramling, 2004).

Despite or perhaps because of this stigma, women know what they want from health care providers. It is important that the care women receive is given in a compassionate way from understanding caregivers (Meredith & Delaney, 1997). They want adequate information to manage their disease and symptoms (Meredith & Delaney). It is well documented that emotional counseling is a necessary component of care (Meredith & Delaney; Morrison et al., 2002; Morrow, Costello, & Boland, 2001). Women do not want health care providers to stereotype them, assume they use drugs or are prostitutes because they are HIV positive (Bunting, 1996).

Existing literature sheds some light on how women experience HIV infection. Some experience HIV as an ongoing calamity full of misery and despair (Stevens & Doerr, 1997). Other women experience it as a path to personal growth and enlightenment (Crossley, 1998; Dunbar, Mueller, Medina, & Wolf, 1998). But all women experience it primarily within an environment of stigma that threatens their self-image, the lives of their children and families and their personal and professional relationships (Moneyham et al., 1996; Sandelowski et al., 2004).

Stigma

Stigma is a social construct that emphasizes deviation from expected societal norms. People who are stigmatized represent those attributes which a society or culture

does not wish to acknowledge and incorporate (Herek, 1990; Herek et al., 2002). According to Herek (1990) stigma surrounding HIV infection is both instrumental and symbolic. Instrumental stigma deals with concern that is associated with the nature of the illness; society fears contracting HIV infection, becoming ill or incapacitated and dying. Symbolic stigma arises from the reaction to the behaviors and lifestyles associated with HIV infection. Symbolic stigma of HIV infection is stigma that represents society's attitudes toward gay men, intravenous drug users and sex workers.

It has been inferred that the experience of stigma is universal in HIV infection; however women with HIV infection tend to be stigmatized more than men (Sandelowski et al., 2004). It has already been noted that women with HIV infection tend to be women of color and live in poverty, two categories that are already subjected to stigma in the form of discrimination (Bunting, 1996). In addition there has long been a subtle but prevalent stigma against women's sexuality (Bunting). Whereas a man might feel pride in multiple sexual conquests, a woman with a rich sexual history is more likely to experience shame. The fact that women have the ability to bear and infect children compounds the stigma attributed to women with HIV infection (Sandelowski et al.).

According to Herek (1990), stigma can be classified as either felt or enacted. Felt stigma is that which is perceived by the woman and is internalized. Felt stigma occurs when a woman fears rejection or believes that she will not be treated fairly if her HIV status is known. It is expressed through statements of self-blame and shame at being HIV positive. Enacted stigma encompasses those behaviors perpetrated on the woman in such a way as to convey her stigmatized status. These come in the form of rejection, avoidance, denial of treatment or access to care. Both forms of stigma serve to distance

women from friends, family and society, resulting in a sense of isolation and loneliness (Alonzo & Reynolds, 1995; Bunting, 1996; Lawless et al., 1996; Moneyham et al., 1996; Stanley, 1999).

Members of a stigmatized group are in a sense branded by society for their attributes. They are identified as deviant and different from those who are normal. An individual who is thus designated as undesirable actually incorporates or internalizes society's stigma into ones own self-image (Herek, 1990). In women with HIV infection this is evident in personal expressions of shame and guilt at being HIV positive (Carr & Gramling, 2004; Goggin et al., 2001; Herek ; Lawless et al., 1996; Moneyham et al., 1996). Some women have been known to express that they feel dirty or unclean (Lawless et al.).

People with HIV infection attempt to counter stigma through certain coping mechanisms (Herek, 1990). First they attempt to pass as normal and pretend they are healthy and not HIV positive. Another method of coping is to devalue the attribute designated as desirable. In the case of HIV infection this would be devaluing health or an HIV negative status. Lastly persons counteract stigma by entering into or developing a community of others with the same stigmatized attribute in order to compare oneself against a peer group, rather than society as a whole.

Evidence of these responses by women with HIV infection can be seen in the work by Stanley (1999). In this qualitative study examining how 15 white middle class women manage the stigma of HIV infection, women devalued the attribute of not having HIV infection by claiming their illness as a "gift from God" (p. 114). The women saw their illness as something that has been given to them to make them better than they were

before they became sick. This gift took the form of a greater appreciation for life and a journey of self-discovery. The women in Stanley's study also found a way to counteract the devaluing that stigma had placed on them, by referring to HIV infection as a calling. The women found that they had a need to educate others about HIV and AIDS, or become politically active on behalf of people with HIV infection.

Joining support groups with other women who were HIV positive is another way women manage stigma. Support groups provide a community in which HIV status is normal therefore allowing the women to compare themselves to their peers, rather than society as a whole (Alonzo & Reynolds, 1995; Kalichman & Sikkeman, 1996; Spirig, 1998; Summers et al., 2000). Joining a support group requires that a woman be able to accept her identity as a woman with HIV infection and disclose her HIV status to strangers.

Disclosure

Disclosure, for women with HIV infection, is closely related to stigma. The primary reason for not disclosing HIV status has been identified by women as fear of rejection (Comer, Henker, Kemeny, & Wyatt, 2000; Simoni et al., 1995; Sowell, Seals, Phillips, & Julious, 2003). In order to avoid rejection, or at least deal with it on their terms, women strive hard to have control over who learns of their HIV status and when (Herek, 1990; Sandelowski et al., 2004; Stanley, 1999). Women manage the disclosure of their HIV status by carefully deciding to whom they will disclose. They do not tell people who they fear will not be supportive, might reject them, or might perpetrate violence. They also withhold their diagnosis from people they believe will be hurt by knowing, like children or ill parents (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Kimberly,

Serovich, & Greene, 1995; Schrimshaw & Siegel, 2002; Sowell et al., 2003). Women choose to confide in people who they believe will be supportive and not likely to betray their confidence (Kalichman, Dimarco, Austin, Luke, & Difonzo, 2003; Sandelowski et al., 2004; Simoni et al., 1995; Sowell et al., 2003). Disclosure decisions are also based on a sense of obligation that comes from being in a particular relationship such as with mothers, sisters, sexual partners, or children (Kimberly et al.).

In deciding whether or not to disclose HIV infection women come face to face with the paradox of disclosure (Sandelowski et al., 2004). To disclose means risking the loss of social support because of stigma, shame and subsequent rejection. Nevertheless, authentic social support can not be secured unless women are able to share the fact of their illness with others. To disclose means that a woman has control over when her personal information is shared, but she also risks loss of control as others have the potential to talk about her diagnosis with casual friends and acquaintances. By disclosing her diagnosis, a woman can increase her self-esteem by being honest. However, exposure to the negative judgments of others can erode her confidence and positive self-image.

Consequences of disclosing an HIV positive status can be much as women fear. In one study all the women interviewed said that they encountered negative reactions from family, friends, or health care providers on at least one occasion (Serovich, Kimberly, & Greene, 1998). Another study indicated that violence occasionally followed disclosure (Gielen, McDonnell, Burke, & O'Campo, 2000). In general, reports of rejection or lack of support are not uncommon, but neither are reports of warmth and acceptance (Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Kalichman et al., 2003; Serovich et al.; Sowell et al., 2003).

From a health care standpoint there are numerous advantages to disclosing HIV infection. There is evidence that women who have disclosed their HIV infection to others seek appropriate medical care and have better adherence to medication regimens than non- disclosers (Koenig & Moore, 2000; Malcolm et al., 2003). Disclosure has also been linked to better mental health (Comer et al., 2000), and increased social support (Kalichman et al., 2003; Simoni, Demas, Mason, Drossman, & Davis, 2000). Disclosure to sexual partners is considered to be an essential element in containing the spread of HIV infection.

Sex and Women with HIV Infection

Sexual intimacy is one aspect of relatedness, and one that is directly affected by HIV infection. For some women sexual activity is a way to secure drugs or to earn money to maintain their families. At other times, sexual contact is the most intimate form of relationship. It can signify the bond and commitment made in a relationship with another. Whatever purpose sex serves, sexual activity is always affected in the presence of HIV infection.

The choice of whether or not to have sex is one of the first things to be considered after an HIV positive diagnosis. Loss of libido is common, though many individuals report that sex drive returns over time (Bova & Durante, 2003; Maticka-Tyndale et al., 2002; Siegel & Schrimshaw, 2003; van Devanter et al., 1999). Some individuals suffer from a permanent loss of sexual function. The reason for prolonged hypo sexual desire in women is unknown; it may be a side effect of medications or a direct effect of the HIV virus (Maticka-Tyndale et al., 2002). Even with a normal sexual desire, the choice of celibacy is not uncommon. Celibacy is chosen by women because of anger and distrust

related to becoming infected (Siegel & Schrimshaw), fear of infecting their sexual partners (Maticka-Tyndale et al.; Siegel & Schrimshaw; van Devanter et al.), and fear of suffering from stigma and shame by disclosing to potential sex partners (Gaskins, 1999; Maticka-Tyndale et al.; Siegel & Schrimshaw; van Devanter et al.).

The issue of being HIV positive causes concerns in heterosexual relationships. In a study of 41 primarily Caucasian couples, dealing with the sexual aspects of the relationship was listed as a primary concern (van Devanter et al., 1999). Sex was identified as a constant reminder of the presence of HIV infection. In another study of serodiscordant couples, communication about sex and sexual activity was identified as stressful and uncomfortable (van der Straten et al., 1998). When communication around sexual activity broke down, issues of safer sex could not be negotiated which further impacted the quality of the sexual relationship. This was particularly stressful for women whose partners refused to wear condoms despite the women's desire to protect them from becoming infected (van der Straten et al.).

Healthy sexual activity can and does return to relationships. This seems to be most likely in women who never used injecting drugs, have few HIV related symptoms and have a good quality of life (Bova & Durante, 2003). Couples who have been able to communicate openly about HIV infection and sexual needs, and have mutually agreed upon boundaries for sexual risk taking also have a better likelihood of regaining a satisfying sexual relationship (van der Straten et al., 1998). Sexual risk taking, which takes into account condom use during sexual activity, has been studied in women with some surprising results.

Two separate studies found that women who were HIV positive were more likely to use condoms consistently with casual partners than with steady partners (Maticka-Tyndale et al., 2002; Simoni, Walters, & Nero, 2000). Simoni et al. determined that the correlation between condom use and relationship was not straightforward. While women with steady partners, even live-in partners, were not consistent in their use of condoms, women in committed long-term relationships used described a more reliable use of condoms. Latina women in the same study had more inconsistent condom use than their African American or Euro American counterparts (Maticka-Tyndale et al.). These results call into question the influence of culture on relationships and sexual practices.

When culture and ethnicity are taken into account, the interplay of multiple factors within the sexual relationship becomes apparent. It has been suggested that poor women of color combat threats to survival on a daily basis, rendering HIV a secondary concern (Ciambrone, 2001; Epele, 2002; Osmond et al., 1993; Simoni, Walters et al., 2000). One woman, relating why she did not negotiate condom use with her African American partner, stated that she did not want to hassle him because of his daily battles with racism (Simoni, Walters et al.). Other authors have suggested that the meaning of condom use is a more significant factor than the possibility of HIV infection (Pivnick, 1993; Simoni, Walters et al.).

Condoms are thought to represent infidelity and lack of trust between partners. For women of color condoms represent a lack of procreative ability and perhaps an attempt at genocide by the dominant culture (Pivnick, 1993; Simoni, Walters et al., 2000). In light of the daily need to survive poverty, racism and violence within a

dominant culture, HIV risk reduction through condom use may take on less significance than trust between intimate partners and the ability to bear children.

One aspect that is noticeably missing in the literature is an examination of the impact of HIV infection on the non sexual aspects of relationships that women have with their intimate partners. Simoni, et al. (2000) posit that the persistent focus on women primarily as vectors of transmission for HIV infection has impeded the development of a meaningful theory of women in intimate relationships that takes into account the impact of culture, and social class. The forces that come into play for a poor woman, as she negotiates questions of sexual activity and reproductive decision making remain relatively unknown at worst and poorly articulated at best. It would be an injustice to assume that women of color negotiate condom use in the same way and for the same reasons as middle class white women.

Motherhood and HIV Infection

Most women with HIV infection are single parents and are of childbearing age which makes motherhood and reproductive decision making a key issue in their daily lives. Women who are HIV positive have a desire for children for most of the same reasons that women without HIV infection do. They would like to give their partner a child and see this as a natural extension of a loving relationship. They see motherhood as something that would complete them (Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2001). They anticipate that the joy of motherhood would come from caring for someone else, teaching them, and instilling personal values (Wesley et al., 2000). However, women with HIV infection also have unique reasons for desiring motherhood.

A significant number of women with HIV infection have been separated at least temporarily from their children because of substance abuse or homelessness (Theall, Mitchell, Ludwick, Brown, & Kissinger, 2004). These women indicate a desire for subsequent children because they missed out on mothering their previous children (Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2001) Some HIV positive women view having children as a way of leaving a legacy and being remembered after they have die (Siegel & Schrimshaw). Whatever the reason for desiring children, women with HIV infection express significant concern over the possibility of infecting their children, or dying and leaving a child without a mother (Ingram & Hutchinson, 1999a; Siegel & Schrimshaw; Wesley et al., 2000; Winstead et al., 2002). In reality the risk of perinatal HIV transmission and early death have been greatly reduced in recent years.

While HIV infection used to be considered a death sentence medications have now relegated it to a chronic illness that can be successfully managed for many years. In studies in the late 1990s a long-term survivor was a person who had lived with HIV infection for over three years (Barroso, 1997; Crossley, 1998). In more recent studies, the average time since diagnosis has been as high as 11 years, with some members of the sample living 17 years or more post diagnosis (Wood, Tobias, & McCree, 2004). By the same token, the risk of perinatal transmission, which was 25%, has dropped to 3% if a woman takes appropriate medications and is delivered according to CDC guidelines (Anderson, 2001). Even though women will continue to be concerned about infecting and orphaning their children the context for reproductive decision making has improved dramatically in the last 10 years.

The work of mothering with HIV infection has not lessened, however. Sandelowski and Barroso (2003) performed a meta analysis on 56 qualitative research studies in which mothering was an issue and outlined the experience of mothering while infected with HIV. According to the authors, mothers directed their efforts toward caring for their body and caring for themselves within stigmatizing society, while at the same time caring for children. Motherhood became a paradox in the battle against stigma. Motherhood tended to elevate a woman's position within society, yet women with HIV infection were more highly stigmatized if they chose to get pregnant because they were seen as harming an innocent child. The authors also pointed out that motherhood tended to exacerbate the symptoms of HIV infection, yet the presence of children was inclined to make the illness more bearable and helped the women ascribe meaning to HIV infection. Similarly it was harder for women to follow health care regimens to treat their HIV infection, yet the presence of children increased the woman's motivation for self-care.

The centrality of the role of motherhood in HIV positive women cannot be over stated. In analyzing 56 studies on HIV infection in women, Sandelowski and Barroso (2003) noted that 33 of the studies focused on variables other than mothering. The significance of motherhood was made manifest by the women themselves during the the study interviews. The women's need to maintain the mothering role by defensively redefining it within the context of a stigmatizing life threatening illness, underscored how essential the relationship was between the women and their children.

HIV Infection, Social Support and Other Relationships

Social support is one aspect of relatedness and incorporates a complicated network of individuals. Within the context of illness it is generally conceptualized as a

cluster of interpersonal relationships through which people are able to access and exchange resources related to their care (Knowlton et al., 2005). Members of the support network include family members, friends, partners, health care providers and the community. Support given to individuals comes in the form of money, information, transportation, acceptance and comfort. At any given point in time the availability of support can change. The mere fact that a woman is HIV positive may alter the kinds of support available to her in both positive and negative ways. However, relationship encompasses more than social support. Relationship is about mutuality and genuine connection. It is about engaging with people at various levels of intimacy in ways that define and nurture identity. Literature reveals that women frequently define the impact of HIV infection in terms of the effect it has on their relational network. This section will discuss the literature as it relates to social support as well as the broader category of relationship for women with HIV infection.

Social Support

The literature on the benefits of social support for persons with HIV infection is quite rich, but the majority of the findings have been culled from mixed gender samples. Studies involving exclusively female cohorts are fewer in number. The literature reveals results that are mixed and imply relationships between variables that are complex.

In women with HIV infection social support has been found to have a mixed influence on adherence to HAART. Although positive social support beneficially influenced medication adherence in some studies (Burgoyne, 2005; Gonzalez et al., 2004; Power et al., 2003), the presence of friends and family have were found to be a barrier in others. Women reported concern that others will learn of their HIV status if they are seen

with HIV medication (Powell-Cope, White, Henkelman, & Turner, 2003; Roberts & Mann, 2000; Sankar, Luborsky, Schuman, & Roberts, 2002). In other investigations the presence of numerous family members in the home and child care responsibilities were associated with poorer adherence (Mellins, Kang, Leu, Havens, & Chesney, 2003; Powell-Cope et al., 2003). It may be inferred from the inconsistency in the value of social support for women on HAART, that social support is a concept that takes into account more than the presence of certain people in a woman's life. Complexities of social support take into consideration which people in a woman's network provide what kind of support at different times and how the woman asks for support.

Knowlton, et al. (2005) studied the ways the structure, function, and relational aspects of social support related to medical services use in a population of HIV positive substance using men and women. In this study it was not the presence and perception of support that was under investigation but rather who made up the social network, how those people were related and what functions the support network provided to the client. In the sample of 295 men and women Knowlton et al. found that access to more females and to more sources of emotional, financial, and instrumental support was associated with use of a consistent health care provider, such as a primary care physician or an outpatient clinic. In the same study neither a supportive sex partner nor kin support was associated with consistent medical service use. The authors did not analyze differences between male and female respondents.

Knowlton and colleagues demonstrated the relationship between the structure of social support and health seeking behavior. Emotional well being, however, appears to be related to the way an individual relates to others and asks for help. An attachment style

that is secure and less anxious has been associated with positive state of mind (Turner-Cobb et al., 2002) and decreased perception of stress (Koopman et al., 2000). Direct methods of seeking support have been linked with receiving emotional closeness and problem solving help from friends, family and partners (Derlega et al., 2003). Derlega et al. label the way support is sought and given as "interactive coping" (p.120) implying the dynamic nature of the presence of others in a person's life as they learn to live with and manage HIV infection.

The nature of interaction is examined in a study looking at social support as a mitigator of the distress associated with the uncertainty of HIV infection (Brashers et al., 2004). In this study, distress was decreased as long as the support came from a relationship that was stable and the nature of the support coincided with the client's uncertainty management strategy. For instance, if the client chose to cope through denial distress was relieved if the denial was not challenged. In this same study, social support also came with costs; specifically the cost of decreased independence and increased vulnerability. On the one hand social support had its benefits, distress was decreased, but it necessitated the development of strategies to maintain independence and protect against possible loss should the support be withdrawn.

The literature on social support in women with HIV infection is inconsistent. No conclusions can be drawn about its benefit or harm because the nature of social support is multidimensional and complex. Quantitative studies frequently operationalize it as a score on a survey tool or instrument, but social support is really about relationships; the way women with HIV infection come into contact with the significant people in their lives. While the influence of social support may be documented and measured, the nature

and management of relationships involves risks and rewards, support and stress that are also worth investigating, but are harder to measure. Relationship, as opposed to social support, implies a kind of mutuality, a give and take, with others.

Relationships Affected by HIV Infection

It is now understood that growth, development, and emotional well being in women occur within the context of relationships; not just a single relationship, but a network of relationships (Belenky et al. 1997, 1986; Gilligan, 1993; Miller, 1986). The nature of relationships and the ability of women to find value and meaning within those relationships become the touchstone for women's identities. HIV infection and its associated stigma alter the relationships in women's lives. If managed poorly, the ability for women to grow and find meaning in HIV infection is threatened. There are numerous examples of women describing various dimensions of HIV infection within the context of relationship.

Relationships are central to the health care needs expressed by women infected with HIV. Women identify social support, love and understanding, and concerns for their children's future as more important than the need for information about HIV infection or the need for physical care (Bunting, Bevier, & Baker, 1999). When identifying ideal attributes of health care providers women stated that receiving personalized care and respect, and having someone to talk to about problems was paramount (Ciambrone, 2003; Meredith & Delaney, 1997).

When asked to describe in their own words both the positive and negative aspects of HIV infection women cite issues that are directly associated with relationships and social connections. Some women identify the loss of relationships through death or

rejection as the most detrimental affect of their illness (Goggin et al., 2001; Gray, 1999; Moser, Sowell, & Phillips, 2001). Women also mourn the loss of the ability to have children and feel guilty about the effect that their illness has on family members (Goggin et al.; Gray). Physical symptoms arising from HIV infection that interfere with care giving and sexual function are also distressing (Gray). The negative aspects of HIV infection experienced by women are frequently described in terms of the impact of the illness on important relationships. By the same token, the impact of the illness on relationships has been described as the best thing about having HIV infection. The positive influence of HIV infection includes developing closer ties with family members, expanding supportive networks, and increasing involvement in their communities (Goggin et al.; Moser et al.).

Disruption in the social network occurs immediately when a woman learns she is HIV positive. Stevens and Doerr (1998) interviewed 38 ethnically and racially diverse women and confirmed that for all the women involved, the initial diagnosis was traumatic. A small percentage of the informants eventually came to see HIV infection as an epiphany that helped them find clarity and meaning in their lives. The majority of the women in this study however, continued to see the illness as a calamity which had an impact of destabilizing personal relationships. It should be noted that these women were interviewed prior to the known effects of HAART. Life expectancy with HIV infection was still considered in terms of a few years. It is not known if their responses would be the same today.

Even as women live with and come to grips with their HIV infection relationships are affected. Dunbar et al (1998) interviewed 34 women in order to identify and articulate

positive aspects of HIV infection. One theme that emerged from the data was that of redefining relationships. In the wake of HIV infection the informants discovered a new affirmation for life which led them toward resolving and clarifying relationships with family and friends, bringing a greater degree of honesty to existing relationships and letting go of relationships that no longer met a women's needs. It was revealed that HIV infection forced the women to reckon with their impending death. Personal growth involved developing a perspective that was both life and self affirming. Strengthening the social network by resolving old grievances and eliminating unsatisfactory alliances came to be part of the process. The study by Dunbar et al. was done prior to the benefits that are now attributed to HAART. It is not known if women with HIV infection would respond the same way today, or if the themes identified by Dunbar et al. are still relevant.

A grounded theory study of nine women caring for siblings, partners, or children with HIV infection identified sustaining the relationship as the basic social process (Bunting, 2001). The women, three of whom were also HIV positive had assumed primary care giving responsibilities for loved ones with HIV infection. For these women the relationship with the loved one was central to the act of giving care. The women described the role transition that came about as the abilities of the loved one declined with illness. During caring the informants described strategies aimed at managing the behavior, balancing independence, and managing distance. The caregivers acknowledged that a significant aspect of giving care was the care they in turn received from their loved one. The relationship was neither static nor one sided. The care giving was reciprocal and involved mutuality. In short, while the woman provided support in terms of tangible care

giving tasks, the care recipient was an equally important part of the woman's social network.

Bunting's (2001) study does not address the issues of how women with HIV infection manage their relationships; however it does shed light on the nature of women's caring relationships. When one considers the significance of relationships to the growth, development and well being of women, the following question emerges: How do women with HIV infection manage their relationships?

Summary

Since 1960 the role of relationships has been explored and found to be significant for the healthy emotional, moral and intellectual development of women. HIV infection brings with it threats to physical and emotional well being. Treatments now extend life expectancy well past 10years, but the disease has profound impact on many areas of women's lives that include relationships with others. The pervasive presence of stigma and chronic illness impact who a woman tells about her illness, who she sleeps with and how she mothers her children. Social support has been found to be both beneficial and stressful in the lives of women with HIV infection. The concept of relationship encompasses more that social support and for many women with HIV infection it is the impact of the illness on relationships that is of primary concern. To date the literature has not considered the issue of how women manage their relationships in the context of HIV infection.

CHAPTER III

METHODS

The purpose of this study was to do discover how women infected with Human Immunodeficiency Virus (HIV) manage their relationships. Although studies have been published that are concerned with the effects of HIV infection on certain aspect of relationships, there is a dearth of literature that describes the networks of relationships for women with HIV infection. This study sought to examine this phenomenon using the qualitative methodology of grounded theory.

Grounded Theory

Glaser and Strauss (1967) proposed grounded theory as a research method in 1967. It is a primarily inductive process using raw data to generate new theories related to previously uninvestigated phenomena, or phenomena that were not accurately described by existing theory. Grounded theory utilizes a wide variety of sources as data such as interviews; field notes newspaper articles, art and other media. The role of the investigator is to engage in a constant comparative analysis of the data to discern the patterns and relationships which serve to explain what the investigator observes. Although grounded theory originated in the field of sociology it has been used with increasing frequency in the past three decades in order to advance nursing science (Benoliel, 1996).

The philosophical roots for grounded theory come from symbolic interactionism described by Blumer (1969). According to Blumer symbolic interactionism is based on three premises:

1. Human beings act toward things based on the meanings those things have for them.

2. The meaning is derived out of the interaction one has with others.

3. Meanings are handled in, and modified through, interpretive process used by the person in dealing with things he encounters.

Blumer posits that human beings deal with the meanings of things symbolically. They use words, body language, manner of dress and speech, among other things to, convey and respond to the world around them. Furthermore, objects and events have meaning only in the context of the social self that encounters others, in some form on a regular basis.

For example, a woman may view HIV infection as a threat and a life of misery, or she may view it as a challenge and ultimately a gift that allows her to grow into her potential. This meaning has been formed based on what she has heard and seen about HIV infection. The woman will react according to the meaning she has assigned to it. However, the meaning may be modified through interactions with others, what she reads in the papers or sees on TV. According to symbolic interactionism, the meaning of HIV infection for the woman is dynamic and it is shaped within a social world.

In grounded theory it is recognized that the investigator is not uncovering an absolute truth but is discovering a truth that is being expressed through symbols. Those symbols are the words that the informant speaks, tone of voice, manner of dress, body language, and to a certain extent what is not discussed. The investigator regards these

symbols as data which are then subjected to meticulous analysis with the intent to construct concepts that serve as the building blocks of theory.

Grounded theory methodology results in a substantive theory or conceptual model that is constructed by the investigator during data analysis. These data are a symbolic representation of each informant's truth, which is constructed within a social context. The theory that results is a symbolic representation of patterns evident in these multiple truths. It is a theory that is grounded in the data and is constructed inductively. The intent is not verification of existent theories or concepts but discovery of a truth that exists as revealed by a select group of informants.

Glaser and Straus (1967) state that one purpose of theory is to predict and explain behavior so that a practitioner may gain a sense of control over a clinical situation (p.3). The intent of this study was to discover, through systematic evaluation of data gleaned from face to face interviews, one theory of how women with HIV infection manage their relationships. It was hoped that such a theory would increase nurses' understanding of the experience of HIV infection as a chronic life threatening illness for women. It would be especially significant to advanced practice psychiatric mental health nurses who encounter women with HIV infection in their practice.

Setting

This study took place in northwest Ohio, a geographic area that consists of both rural and urban communities. Twenty five percent of all persons living with HIV in this area were women. The majority of women living with HIV infection in this area were women of color, primarily African American and Hispanic. A significant proportion of these individuals were dependent on public financial assistance for medical bills, food,

and rent (Ohio Department of Health HIV/AIDS Surveillance Program, 2005).

A university medical center, located in the largest city in the region, provided specialized health care for people living with HIV infection. A Ryan White funded clinic sponsored by the university medical center provided comprehensive care to men women and children with HIV as well as their uninfected family members. Within two years prior to conducting the study a community service agency (CSA) that coordinated social services such as transportation, links to low income housing, assistance with energy bills and food, for persons with HIV infection closed due to financial difficulties. The services remained available within the community but access to them was fragmented and offered through a number of different organizations.

Within the community a few support groups existed that were started by the original CSA. The support groups and the clinic were locations where people with HIV infection tended to gather. The number of women attending support group meetings regularly was far less than the number of women in the area that were known to have HIV infection. This suggests that for the majority of women with HIV infection living in the region, their network of relationships consisted primarily of people who were not other women with HIV infection.

Participants

The focus of this study was an in depth exploration of the relationships of women with HIV infection and was not concerned with the ability to generalize results. The purpose of the study was to construct a substantive theory of these relationships that emerged from the data. For that reason, issues related to a random selection of informants from the study population were not relevant.

Initially purposive sampling was used for the study. Purposive sampling is a non probability sampling technique in which the investigator selects participants for the study based on a judgment of who is most representative of the population under investigation (Polit & Hungler, 2001). Because the investigator had a professional relationship with a group of women with HIV infection who provided the impetus for this study, it was a logical way to begin the sampling process. Once the initial one or two interviews were completed, ongoing theoretical sampling drove the recruitment of additional informants.

Theoretical sampling is the primary sampling method in grounded theory and it is closely related to the process of data analysis (Glaser & Strauss, 1967; Hutchinson & Wilson, 2001). Data collection and analysis occur concurrently in this method. The investigator constantly searched for patterns of abstractions in the data. As patterns emerged the investigator critically appraised the emerging concepts and theoretical relationships between them. This appraisal determined from where data would next be collected. Informants were selected for their unique experiences intended to validate or challenge the emerging concepts.

Data collection continued until saturation was reached. Saturation represented the point at which new data was redundant to the theory and no longer informed the theory in a new way. For this study saturation was reached after 14 interviews. This was consistent with the tradition within grounded theory methodology.

Participants were recruited from two sources; the community HIV support groups; and the health clinic for women with HIV infection and their families. These locations were picked because they were dedicated to provide services to people with HIV infection. Therefore approaching a woman to participate in the study was not likely to

inadvertently reveal her diagnosis of HIV infection.

At all times the principle of the honest broker was honored and the investigator did not directly recruit any woman with whom she has had, or was likely to have a professional relationship. Recruiting fliers were available at both sites (See Appendix I). A facilitator recruited the women who attended the HIV support groups by addressing the group as a whole. Staff at the university medical center clinic approached women individually at the time of their appointment. If a woman agreed to participate in the study the clinic staff member introduced the woman to the investigator, who was on site but not directly involved in recruitment. At that time an appointment for an interview was set up. Two women opted to contact the investigator by phone. The women were offered information about the study to take home with them. All of the women who were approached by the investigator agreed to participate, however one of them called the investigator at a later date and cancelled the interview, citing a reluctance to share her personal story. The location of the interview was mutually determined by the investigator and the participant. The role of the investigator was to help the woman find a place that would be comfortable and assure privacy; the selection of the site was left up to the women. Eleven of the participants chose to be interviewed in their own home. Two women chose public restaurants and one interview took place in the investigator's office. Each participant was given $20 at the conclusion of the interview in appreciation for her time and assistance with the study.

Prior to recruiting, the investigator sat down with support group facilitators and clinic staff members to discuss the nature of the study and the responsibilities of the participants. Recruiters were given an information sheet outlining pertinent information

(See Appendix II). There was adequate opportunity for the volunteer recruiters to have their questions answered.

In order to be eligible for the study a woman had to be HIV positive, 18 years of age or older and speak and understand English HIV status was assumed to be positive if a woman was receiving care at the HIV clinic or attending one of the support groups for people with HIV infection.

Data Collection

In grounded theory data can come from an infinite number of sources (Eaves, 2001; Glaser, 1978; Glaser & Horton, 2004; Hutchinson & Wilson, 2001; Kendall, 1999). Field notes, literature, published news items, photographs, and personal interviews all yield important information. The primary source of data for this study was personal interviews with women over 18 years of age who have HIV infection. Additional data came from the investigator's field notes chronicling aspects of the interviews that were not captured in the verbatim transcripts of the interviews. Such things as the interview setting and environment, interviewer reactions, and the informant's non-verbal reactions were documented. In addition, a record was kept of the interviewer's reactions and emotional responses. This personal diary provided insight into the state of mind of the interviewer as well as moods and thoughts that may have influenced the informant's participation.

The informants participated in semi-structured interviews that were audio taped. The tapes were transcribed to facilitate recall and allow for coding and identification of the emergent concepts. The ideal of theoretical sampling was honored in that the open ended questions asked in the interviews were guided by the ongoing analysis of the data.

The initial interviews were very broad and began with such questions as "Tell me what it is like to know you have HIV infection," "How are things different for you since you have learned of your HIV infection?" and "Tell me about your relationships with people in your life since you learned that you had HIV infection (See Appendix III)." As the first interviews were analyzed and patterns emerged the interviews incorporated other, more focused questions that allowed the investigator to explore and refine emerging concepts. In order to understand and describe the sample the women were asked to provide basic demographic data (See Appendix IV) at the end of their first interview. Answers to the demographic questions were recorded on paper as well as included in the audiotape.

Protection of Human Subjects

The privacy and rights of all participants were protected by the standards set by the Institutional Review Boards of Duquesne University and The University of Toledo, (formerly Medical University of Ohio at Toledo) the institution that provided medical care for potential informants. No personal health information was sought from the participants and no such information was recorded during the course of the study.

All participants were required to sign a consent form agreeing to be interviewed for the study (See Appendix V). In order to assure that each participant understood the nature of the study and her role in it, the interviewer read the consent form aloud and solicited questions from each informant prior to signing. The interviewer stressed that participation was voluntary and that consent could be withdrawn at any time without penalty. It was also made clear that although risk from participation in the study was low, if the woman experienced emotional distress from recalling negative events, help was

available 24 hours a day from the agency listed on the consent form. A copy of the signed consent was given to each participant.

For tracking purposes each participant was assigned a number and a fictional name. The number was only recorded on the transcript and the demographic data sheet. It did not appear on the consent form. In order to maintain confidentiality and prevent the identification of specific participants with specific responses, signed consent forms were kept in a locked cabinet separately from the locked cabinet containing transcripts of the interviews.

The transcriptionist was required to sign a form agreeing to keep all information on the audiotapes confidential (see Appendix VI). She was also instructed to omit all names and other identifying data from the transcripts. All data was kept in a locked drawer in the office of the investigator. Only the investigator has been allowed access to the raw data. All raw data will be destroyed at the end of all activities related to the research project. Transcripts will be shredded. Women had the option of receiving their audio tapes. All audio tapes that are not hand delivered to participants will be destroyed.

Data Analysis

Data Analysis was done using the constant comparative method put forth by Glaser and Strauss (1967). In this method data analysis was done simultaneously with data collection. The investigator remained alert to potential patterns and concepts that emerged and acknowledged her ideas in memos. The emerging themes and concepts were constantly compared with other data to test for validity and fit. To reiterate what was stated earlier, in grounded theory everything can be considered data (Eaves, 2001; Glaser & Horton, 2004; Kendall, 1999) which means that not only was the investigator making

comparisons against other transcripts, but also against the literature, and other aspects of the world which she has come to know as "true." Transcripts were read and coding began immediately even while data collection continued.

This investigator used the coding method described by Strauss and Corbin (1998). Analysis began with open coding, which involved line by line analysis of the transcript. From this initial analysis concepts and their properties were constructed. Determination of meaningful categories of concepts also began in open coding. Axial coding occurred next. This level of analysis developed some of the dimensional and relational aspects of the concepts. Concepts were organized into meaningful subcategories in which causal conditions, context and consequences were identified. Selective coding refined the relationships of the concepts and allowed for the construction of a substantive theory. During this level of analysis core concepts were generated along with the basic psychological social process (BSP). It was the BSP which provided a coherent framework for the emergent theory and explained the data.

Grounded theory, by definition, deals with subjective data. The subjective nature of qualitative research does not, however, preclude a study that is both reliable and valid; or in qualitative terms, credible and trustworthy. Measures were taken to assure credibility and trustworthiness in this study. To account for subjective bias or reactivity the investigator kept a journal in order to identify the researcher's concerns surrounding emotional reactions, inequalities of power, complacency, loss of focus, and cultural biases that may have skewed collection and interpretation of the data (Paterson, 1994).

Auditability, is a way to insure creditability in a qualitative study (Hutchinson & Wilson, 2001; Sandelowski, 1993). The sequence of coding in grounded theory is not

linear because data collection and analysis occur simultaneously. To aid in ongoing analysis the investigator wrote memos highlighting ideas, perceived relationships, and insights as data was coded. These memos served as a point of reference during all levels of analysis and theory construction. Memos were retained during analysis and provided a way to assure auditability or creditability to the research project. Auditability was further assured through the retention of transcripts, field notes, coding, and journals.

Fit, or trustworthiness, was assured through a process called participant and expert checking-in. The constructs and the relationships which emerged in the process of data analysis were shared with a research participant and experts in treatment areas of HIV infection for acknowledgement of the researcher's conclusions. For this study checking in was provided by a research participant who also works as an outreach worker and service coordinator for people with HIV infection. Expert checking was provided by a social worker and a pediatric nurse practitioner both of whom work primarily with people living with HIV infection.

Summary

Grounded theory methodology was utilized to address the question of how women with HIV infection manage their relationships. The purpose of grounded theory is to explore the phenomenon in question and construct a substantive theory that explains the relationship between key concepts and core variables generated from the data. Data was collected in personal interviews with women who were recruited from a University clinic for women and children with HIV infection and support groups for people with HIV/AIDS. Strauss and Corbin's (1998) method of coding was used. Human subject' protection was assured by maintaining strict confidentiality of all data and obtaining

approval from the Institutions Review Boards of Duquesne University and The University of Toledo (formerly Medical University of Ohio at Toledo).

CHAPTER IV

FINDINGS

The purpose of this study was to discover how women with HIV infection manage their relationships. To that end 14 women were interviewed about their relationships and the impact HIV infection had on their lives. Interviews were audio taped and transcribed and the investigator wrote field notes and kept a diary of personal reactions during and following the interview. The women's words and the investigator's field notes and diary became the data that comprised the study. Data analysis was conducted according to grounded theory methodology in order to address the three research questions

1. How does HIV infection affect women's relationships?
2. What processes do women use to manage their relationships within the context of HIV infection?
3. What role does a network of social relationships play in the lives of women with HIV infection?

This chapter will present the findings of the study, followed by detailed descriptions of the concepts along with the supporting data. The relationships of the variables will be explained and the substantive theory will be articulated.

Results

Description of the Participants

A total of 14 women were interviewed over a three month period from Oct. 2006 to January of 2007. The women ranged in age from 19 to 53. Six of the women identified themselves as Caucasian, six self-identified as African American. There was one woman of Mexican heritage and one woman identified herself as being of mixed race. Only two identified themselves as married, the rest self-identified as single; four as a result of divorce and one had a husband die as a result of HIV infection. Ten women indicated that they were in a relationship with a significant other including one woman who identified herself as a lesbian. Two of the women were employed full time, the rest were unemployed. Additional descriptive characteristics can be found in Tables 4.1 and 4.2.

Findings

In grounded theory, the data should yield one or more core concepts that, according to Hutchinson and Wilson (2001), "illuminates the 'main theme' of the actors in the setting and explicates 'what is going on in the data'" (p. 222). The core variables clarify the relationships of the individual concepts as well as the properties and dimensions that the investigator discerns during data analysis. Concepts relate to each other in the form of categories and subcategories. If the study is successful the investigator will construct from the core variables a basic social psychological process (BSP).

The BSP is a significant core variable that serves as the basis for the generation of the grounded theory (Hutchinson & Wilson, 2001). It is a unifying concept that illuminates the social processes as they continue over time; regardless of varying conditions. More than any other concept or any category of concepts the BSP serves to make sense of the data. The BSP serves as a framework for understanding the phenomenon under investigation.

Table 4.1 Selected Demographics

Demographic	N
Race	
African American	**6**
Mexican	**1**
Caucasian	**6**
Mixed/Other	**1**
Age	
18-25	**4**
26-40	**5**
41-55	**3**
55-65	**2**
Years since Dx	
< 1	**1**
1-3	**6**
3-5	**2**
5-10	**1**
>10	**4**
Employment Status	
Employed	**2**
Looking	**9**
Unemployed not looking	**3**
Marital Status	
Married	**2**
Divorced	**4**
Single	**7**
Widowed	**1**
Number of Children	
0	**3**
1	**5**
2	**4**
3-5	**2**
Religion	
Catholic	**1**
Protestant	**10**
No Affiliation	**3**

Some schools of thought describe the BSP and other concepts in grounded theory as emerging from the data and in a sense that is true. The data should never be forced into the investigator's preconceived idea of what she believes should be revealed. In reality it is the investigator's expertise and familiarity with the data; her engagement in the process of data analysis, that recognizes and gives name to the concepts. In this way concepts in grounded theory are said to be constructed by the investigator.

Table 4.2 Fictional Names, Select Characteristics and Self-Reported Health

Fictional Name	Characteristics	Mode of Infection	Self-Reported state of health
Alice	Has lived with significant other and his 9 year old child for a few years. He is HIV negative.	Not shared with investigator	"good I guess"
Sophie	Lives Alone. Has been in a relationship with a man for a few months. He is HIV negative. One 7 year old child lives with her father.	Man who withheld HIV status from her	"Very tired"
Naomi	Lives with her husband of 7 years and their children ages 2 and 6. He is HIV negative	Man who withheld HIV status from her	"good"
Susan	Lives with husband of 12 years and two teenage children age 15 and 17. She says she infected him.	Not shared with investigator	" 6 on a scale of 1-10"
Pauline	Lives with another man for "a few years" but are no longer sexually intimate. She says she infected him. No children	Unknown male partner	"legs hurt" but "more concerned with my mental state"
Cassie	Lives alone. States there is a "man I love" who is HIV negative and a "man I sleep with" who is HIV positive. Grown child is out of the home.	Man who withheld HIV status from her	"improving"
Janet	Currently not in a relationship. Lives with 18 month old child	Man who withheld HIV status from her	"good"
Lisa	Currently not in a relationship. Lives with two children age 10 and 14.	Man who withheld HIV status from her	"OK" "I'm in a lot of pain"
Wanda	Currently not in relationship. Moved back to mother's house	Man who withheld HIV status from her	"tired and weak, but better"
Francine	Lives with long term partner who is HIV negative and 4 year old child who is HIV positive.	Unknown male partner	"Anxious, depressed." My blood pressure is real high"
Esther	Lives with grown daughter, her son-in-law, and her 6 year old grand child. Chooses celibacy. Fiancé died of AIDS.	Male partner who did not know his status	"I got a stomach ulcer" "My counts are good"
Ruth	Lives with 4 year old child.	Man who withheld HIV status from her	"healthy, I'm 4 months pregnant"
Bess	With husband of 16 years, 5 year old child, and 6 year old grandchild. Husband is HIV positive.	Male Partner who did not know HIV status	"Good" "Clean and sober for 5 years"
Irene	Lives with female partner of 27 years who is HIV negative. She has 4 grown children	Man who withheld HIV status from her	"Not as good as I would like"

In the current study, constructing the core concepts, including the BSP, was the result of a lengthy and meticulous data analysis and coding. Coding was the process by which the investigator examined the transcripts and recorded her reactions and thoughts in memos. Her ideas about the data were constantly evaluated against the rest of the data, what the investigator knew about the phenomena and about the world in general. This aspect of analysis is known as constant comparison.

The process began with open coding. Open coding started immediately and involved detailed examination of the data for ideas that appeared frequently or seemed to have particular significance. For example the word "god" was spoken frequently by the women and was noted as a concept. One woman used the term "labeled a slut." Reference to the investigator's field notes and memos revealed that when the participant used this phrase it seemed to carry a certain amount of weight. The investigator had an emotional reaction to the phrase. "Labeled a slut" was identified as a concept; even in the absence of other references to it in the data. Open coding yielded many concepts that were not well developed and the relationships were not clear. A list of concepts developed during open coding can be found in table 4.3.

Concepts were further refined and properties and dimensions developed during axial coding. Relationships among the concepts, categories and sub categories were also initiated during axial coding. A concept was considered to be well grounded if it appeared frequently in the data. Well grounded concepts were examined more closely to see if additional dimensions could be discerned. For instance the concept "acceptance" appeared frequently, however it was used in a number of different ways. The women talked about being accepted by others, accepting the fact that they had HIV infection,

Table 4.3 Results of open coding

Acceptance	Denial	Rejection	Feeling Dirty
Barriers	Be myself	Growing mentally	Betrayal
Caring for others	Health care providers	Fear of infecting others	Loneliness
Uncertainty	Fear	Medication	Educating others
God	Being strong	Being Stuck	Can't think
Moving away	Stay by myself	Shame	Be there for me
Children	Pain	Children	Family
Unconditional love	Trusting others	Girl friends	No one to love me
Finding work	Sex	Telling others	Depression
Labeled a slut	Being judged	Staying well	Support groups

accepting the need to take medication and acceptance being closely related to self-esteem. With this understanding the concept "acceptance" was understood to have density because it was related to a number of other concepts. All of the relevant concepts were eventually put into categories based on their relationship to each other.

Axial coding was also concerned with the dimensions of the concepts; if they demonstrated properties under different conditions which helped to explain variations in the women's behavior. New concepts were constructed that took into account properties and dimensions represented by clusters of other concepts. An example of this was the concept "controlling disclosure." Women discussed telling others their diagnosis in many ways. They considered who to tell, when to tell, and how to tell. Opinions about disclosure varied greatly. Women would talk about how their views on disclosure had changed over time and varied based on circumstance. The concept "controlling disclosure" was created to encompass the numerous ways that the data presented the subject of disclosure. The more properties and dimensions inherent in a concept the more

of the women's behaviors it explained. Concepts with the most dimensions explained the categories of concepts. Manipulating the social context, finding purpose, seeking support, and accommodating HIV infection were the concepts that represented the categories of concepts referred to here as strategies. Within each strategy were sub strategies. At this point the concepts of acceptance, sex, health care, betrayal, shame and loneliness, and social network remained as concepts with significant depth and dimension. Each of these concepts explained much of the data, but the relationships had not been clearly defined. Table 4.4 lists the results of axial coding.

Table 4.4 Results of Axial Coding

Categories (Strategies)	**Sub Categories (Sub Strategies)**			**Broad Concepts**
Manipulating the Social Context	Relocating	Controlling Disclosure		Betrayal
Finding Purpose	Considering Employment	Mothering	Aids Work	Shame and Loneliness
Securing Supports	Dealing with the Ignorant	Clarifying Current Relationships	Considering New Relationships	Sex
Accommodating HIV Infection	Defining HIV Infection	Reconciling Rejection		Acceptance
				Health Care
				Social Network

Selective coding represented the last stage of analysis in which conceptual relationships were refined in order to construct the substantive theory that best explained the phenomena. It was during this stage that the contextual concepts, core concepts and the BSP were constructed. Sex, Health Care, and Social Network were all constructed as contextual concepts. These concepts were articulated by the women in numerous and varied circumstances. They did not fall neatly into any category; rather they were present

in most of the categories. They provided the context in which the women needed to manage their relationships.

Consistent in all aspect of the data were references to betrayal, shame and loneliness and these emerged at core concepts apparent at every level of analysis. The conditions that necessitated the development of a process or strategy to manage relationships existed because of the betrayal the women experienced and the subsequent shame and loneliness they felt. These concepts were central or core to the phenomenon of managing relationships.

Positioning for acceptance was the concept that explained the process of managing relationships. It was the concept with the greatest depth and dimension and was created as the BSP. Women manipulated their social context by relocating and controlling disclosure. They found purpose through employment, mothering or aids work. Securing support was accomplished by dealing with the ignorant, clarifying existing relationships, and considering new ones. The women defined their relationship to HIV infection and reconciled the inevitable rejection in order to accommodate HIV infection. All these behaviors were undertaken in order to be seen as acceptable in the eyes of others. The results of selective coding are shown in Figure 4.1.

The rest of this chapter will present these findings in greater depth along with supporting data. The relationships will be more clearly defined and the substantive theory more thoroughly articulated.

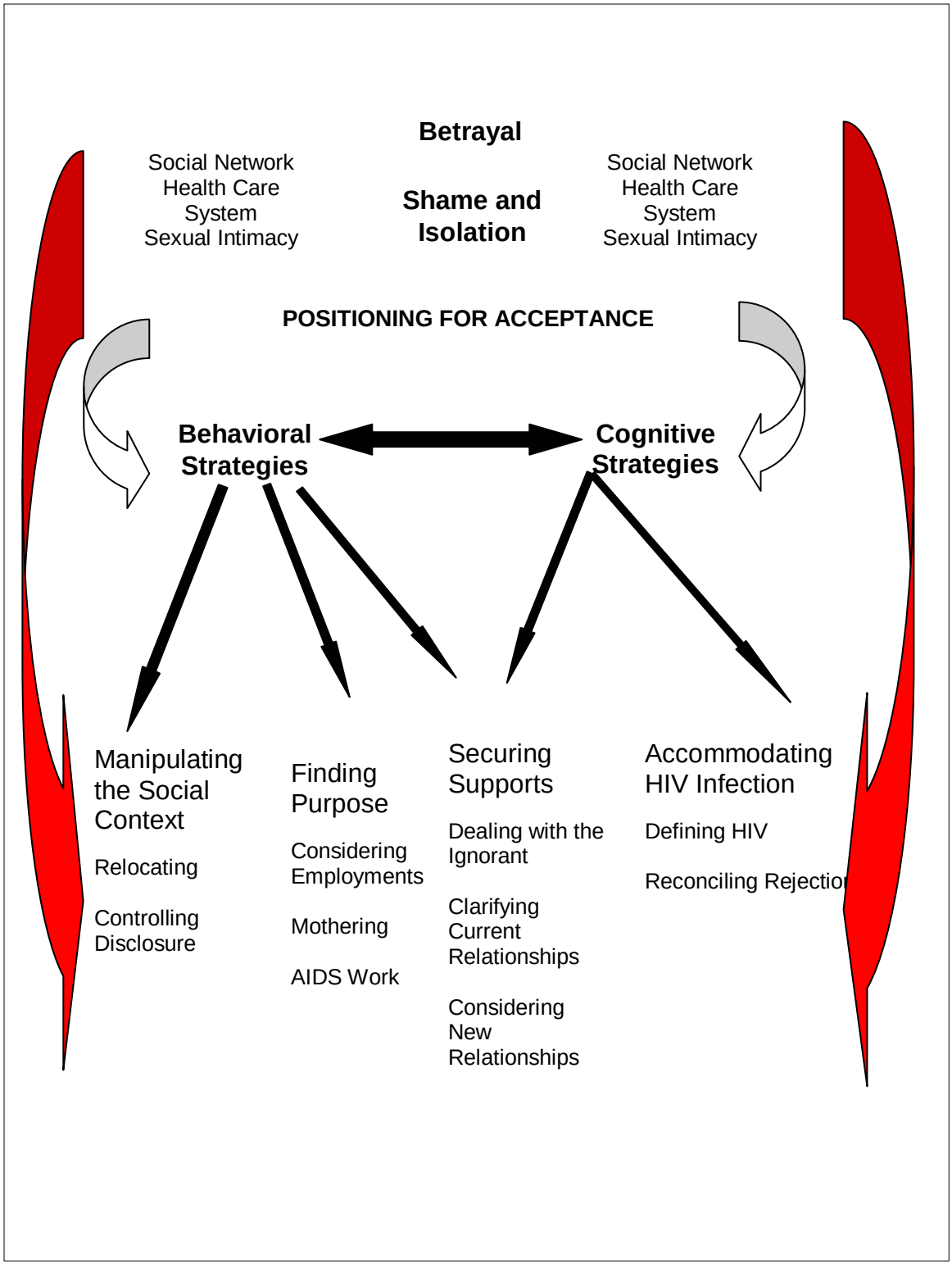

Figure 4.1 Positioning for Acceptance

Core Concept: Experience of Betrayal

Almost all the women experienced a significant betrayal subsequent to learning she had HIV infection. Betrayal came by deceit, rejection or in some cases when the women "betrayed" a loved one by infecting them. The majority of women experienced betrayal when they learned a lover had known of his HIV status, withheld that information, and failed to protect them against infection. Other women were rejected by friends or family because of their HIV infection. A few of the women committed an act of betrayal when they transmitted their HIV infection to a sexual partner or child.

For some women betrayal came when they were rejected by people they thought were friends. Wanda, a young woman of 25 had only learned of her diagnosis eight months prior to the interview. She was distressed to learn her friends' reaction to her illness, "And they say a lot of mean things; things that will scar me for the rest of my life and make it harder for me physically to deal with."

Rejection, for a number of women, meant a total end to a previously close relationship. Ruth had been very close to her boyfriend's parents. Around the Thanksgiving Holiday she disclosed her diagnosis and she said

> They freaked out the idea that I had it and freaked out at the idea that he was sleeping with me and that he could catch it. And I don't, yeah, like I said, they were, they're still very ignorant…They, it almost….they outcasted me because I have it.

Rejection represented not only a loss of relationship, but awareness that a woman had been stereotyped as promiscuous because of their HIV infection. Francine, Ruth, Lisa, Sophie and Naomi all said they were labeled as sluts and whores once people learned of their diagnosis. This was particularly hurtful in light of the fact that they became infected while in monogamous relationships with men they trusted.

Rejection and disloyalty at the hands of friends was disruptive and distressing but for many of the women the most distressing betrayal was learning that a lover had not informed her of his HIV status. The women described pain, shock, and hurt at learning that their partner had not disclosed their HIV status with the women prior to having sex. Janet explains.

> When somebody misleads you, it like, misleads you then leaves you, you're like, it just leaves you stuck. It leaves you without the words to explain it. You really can't explain that feeling that you get because it's just very hurtful.

For some of the women this betrayal was harder to take than learning about their diagnosis of HIV infection. Irene, who suffered from bi-polar disorder, stated she coped well after learning that a heterosexual affair resulted in her infection, but learning that her lover was aware of his own infection and did not disclose it to her was almost more than she could handle.

> I had more emotion when I found out, not that he had it, but that he had known about it for all those years. Um, I, oh my god, I went off the deep end. And my undiagnosed bipolar really kicked in. Really, really, really, from one manic to depression, I mean, it was awful. And that was the worst time of my life. And that's when Dr. ... said you have got to do something about this. And she sent me to a therapist and you have got to learn to deal…. you've never accepted it.

It was this betrayal that seemed to have a devastating effect on the women. It called into question all their other relationships. For Wanda "Finding out that I was betrayed is the hardest because I can't do nothing about it. You know. I trusted….oh, man….I trusted that person with everything I had." Lisa, who has experienced depression since learning her diagnosis, identified her partner's betrayal as impacting all her relationships, "Almost as if my trust in everybody has just gone behind one man."

While most women had been betrayed through deceit or rejection, some women experienced betrayal by being the traitor. These women had unknowingly passed HIV infection to a loved one. Two women had transmitted HIV infection to their lovers, and one woman gave birth to an infected child. All three women expressed feelings of guilt and shame around the act of transmission. These emotions influenced their behaviors in relating with others. While this was not described as an experience of betrayal on the part of the women, the investigator believes it was similar. In these situations the women violated or betrayed an implied social contract by harming someone they loved. Instead of being the victim, they became the traitor. The feeling of isolation and disconnection was similar to what the women felt who had been deceived.

When Susan tried to discuss the fact that she infected her lover of 12 years she became tearful and had trouble speaking. She eventually described it in one word, "terrible." She indicated that it was the worst thing about having HIV infection. Pauline described her housemate as "the man I infected." She did not give him a name. She cried when she described how much she loved him but insisted that she "cannot be with him" right now. He had not left her, but they were no longer sexually intimate by her choice. He slept with other women at the house they owned together and that hurt her. "But at least I do know that he is using condoms because when I go to clean up I see the empty wrappers and stuff. I feel a little better." She felt better because the man she infected was not infecting anyone else.

Francine learned that she had transmitted her infection when her daughter was 3 months old and hospitalized with a serious HIV related illness. As a result Francine experienced profound guilt.

> And I feel like slowly but surely I'm dying. Just because of stress and knowing I have HIV and knowing I gave it to my daughter and…..I mean it really stresses you out and it's really hard sometimes … Giving it to [my daughter] is what's really been the worst."

Francine believed the fact that she transmitted HIV infection to her daughter kept her isolated.

> Francine (F): I mean a lot of women are in the same situation that I'm in but they're not in the same situation I'm in with my kid.
> Investigator (I): And by that … you mean your daughter is HIV positive?
> F: Yeah.
> I: … I get the impression that you feel like you are very much all alone with that.
> P: Yeah, because nobody gave it to her but me.

Francine was overwhelmed with her child's care and her remorse at infecting her daughter was constant.

Christina Robb (2007) writes that psychological trauma is about "breaking betraying and hurting relationships (p. 274)." The result of that trauma can be a disconnection from the perpetrator of the betrayal and other people as well (Robb, p. 275). The betrayal these women experienced all came at the hands of relationships. Lovers and friends were lost to these women in ways that were painful and distressing. The result was self doubt and an altered view of who they were.

Core Concept: Shame and Isolation

The betrayal experienced by the women was accompanied by feelings of shame. Susan used words such as "embarrassed" and "ashamed" as she described reaction to her diagnosis. Lisa feared others could know she was HIV positive simply by looking at her. "I feel like there's a world-size sign above my head saying exactly what I have. Right here in color, the brightest colors you could ever possibly imagine." Other women

described feeling dirty or tainted. Sophie described it succinctly "I feel like I'm dirty now because of that disease … it's just a dirty feeling you know."

Robb (2007) quotes Judith Jordan speaking a Harvard Medical School Conference in 2000 saying "When we are in shame we long for connection but feel we are not worthy of connection" (p.322). This experience was echoed by the participants in this study. The shame these women experienced was coupled with the assumption and expectation of rejection when their diagnosis was revealed. Ruth wondered "whose gonna love me?" Wanda imagined herself as a loaf of bread and her HIV infection the mold that appeared on one slice.

> "Because if you open that loaf of bread and you got one piece in there with mold on it, it kind of spoils the rest of the batch. You don't want the rest of the bread because it's no good. If that one's spoiled then [others] are on their way."

Lisa, who is described above as feeling as if there was a sign over head, believed her rejection would be public "I feel like if somebody out there ever finds out I'm infected they won't let me in the store. Like they'd be all of sudden, bam, you can't come in." Francine, whose child was born with HIV infection, believed she would suffer violence or even be killed

> Somebody would probably try to kill me …And I think if them people were to find out they would probably hurt me. Like, oh, this nasty bitch has got AIDS and, no, let's just take her out so she can't mess with none of our other dudes.

Lisa was able to directly relate her feelings of isolation to her experience of betrayal. When asked what she thought might happen if other people knew of her HIV infection she replied, "That I would probably never be in a normal relationship whether it would be with a man. I would never be able to have anyone to talk to."

Judith Herman, a psychiatrist and a pioneer in relational psychology discusses the shame that follows psychological trauma. Christina Robb quotes her as saying "Shame is one's own vicarious experience of the other's scorn … Mutual acceptance and regard dispels the pain" (p.322). The participants in this study spoke of how they wanted and needed people in their lives that accepted them. Ruth explained what she is missing from relationships since learning her diagnosis

> It's almost like I yearn to want to open up to them but as soon as I do I've been rejected … not even 3 months ago … that I'm not ready to open up to any more people and accept any more rejection.

Janet who suffered depression and attempted suicide after her diagnosis explained

> "I need somebody that's in my corner that we can be together on some stuff. We can be friends. If you need me, I'm there. If I need you, then you're here. Not just a one way street. It's gotta be a two way."

Betrayal and subsequently the feeling of shame were identified as the central problems for the women in this study. Most of the women learned that their infection occurred as a result of a sexual relationship with a man they knew and believed they could trust. They felt betrayed to learn that their partner had deceived them by not disclosing their HIV status. Feelings of shame occurred as a result of the experience of betrayal. Accompanying the feeling of shame was also a sense of isolation, of being cut off from others.

The Basic Social Psychological Process: Positioning for Acceptance

During the interviews with the women and subsequent analysis of the transcripts a BSP, positioning for acceptance, was constructed that integrated and explained the range of behaviors described by the women. Positioning is a term used in business. It means creating a perception in the minds of the public in order to increase popularity and ultimately sales of a specific product (Tronstad, 1995). A product is said to be positioned relative to other products in the

same category to increase its appeal within a certain demographic. In the findings of this study positioning for acceptance, referred to the strategies used by the women to foster acceptance by others. Betrayal and its subsequent shame left the women feeling isolated. Some felt dirty and most felt unlovable at some point. They longed to reconnect with people, avoid rejection, and be part of an accepting relationship. They achieved this by employing one or more strategies of manipulating the social context, finding purpose, securing support, or accommodating HIV infection.

Strategy: Manipulating the Social Context

One strategy that was identified was manipulating the social context. This is primarily a behavioral strategy in which the women employed specific activities to create an environment that included people who would view them favorably. Two sub strategies for manipulating the social context were labeled relocating and controlling disclosure.

Relocating. An unexpected finding in this study related to the fact that since diagnosis almost all the women physically relocated since learning they had HIV infection. Relocating brought the women closer to family, away from people who judged or deceived them, or into situations to receive needed attention such as foster care or drug rehabilitation. Some women described moving in intentional and positive terms, others felt it represented a negative consequence of having HIV infection. A few women did not consciously associate their move with their illness.

Janet felt that a move was necessary in order to escape her old life.

> And you see I had to move. I stayed right down the street … And I think I had to just move from that neighborhood. Move away from the pointing and the talking. And just basically find what I wanted out of life.

Janet wanted to locate away from the labeling and rejection by her friends. She wanted to live in an area where she had a better chance of being tolerated. Janet made a conscious choice to move to be close to her mother and way from the scorn of others.

For some women changing locations occurred with the involvement of social service agencies. Both Naomi and Ruth were minors when they were diagnosed and ended up being placed in foster homes shortly after their diagnosis. Ruth puts it like this:

> So, I got to the point where I couldn't handle it so I moved out with … I hooked up with the Nurse Practitioner and I moved out … with some foster family because I couldn't do it anymore. I had to get out of [town]. I had to get away to even start thinking.

Bess learned she was HIV positive while pregnant with her youngest child. . At that time Bess was an active substance abuser and lost custody of her child at the time he was born. She entered a residential treatment facility after leaving the hospital in an attempt to get her child back. After she successfully finished the program or "got [herself] together" as she calls it she moved to a safer neighborhood.

Naomi, Ruth and Bess moved as a result of the involvement of Children's' Services. By moving these women entered into the care of others. For Naomi and Ruth they received parenting. Bess received treatment for substance abuse. The three of them admitted that their moves helped them get to a better place both geographically and emotionally. Naomi said her foster mother fostered her self-esteem by "encouraging me and with telling me I'm a good person ... care[d] about me for me. You know, stuff like that." For Ruth the move brought her to people that would take care of her and allow her to raise her infant. Residential treatment cared for Bess while she recovered from her addiction.

Other women moved as an indirect response to their HIV infection. Irene ended up retiring early as a result of physical problems brought on by her illness. She sold a home she loved because she could no longer afford to keep it. For her the move was an accommodation to an altered financial state that occurred as an indirect result of her infection. Some of the women moved in with relatives after they left the men who infected them. Others, like Irene, moved as a result of changed financial situations. The physical problems associated with their illness caused some of the women to lose their jobs and they relocated into less expensive and often public housing.

Moving, for these women was not a choice to alter a social environment, but rather an unplanned result of HIV infection. Unplanned though it was, moving still afforded these women an increased the likelihood of support or ongoing contact with important relationships. Wanda moved home with her mother, it removed her from the frequent contact with friends she knew prior to learning about her HIV infection, whom she now feared would reject her, and it allowed her family to help support her financially. Cassie disliked her small apartment because it was too far from her sisters; but she could maintain it independently, something she needed to do in order to eventually gain custody of her grandchildren.

Controlling disclosure. Controlling disclosure was the second sub strategy identified under manipulating the social context. If the women could control who knew their HIV diagnosis and when, then the women could surround themselves with people likely to accept them. If people were judgmental towards women with HIV infection then a woman could withhold her diagnosis and pass as normal. If individuals were accepting, a woman might choose to disclose her diagnosis and therefore enter into a more authentic relationship. This

strategy involved deciding who should know, when they should know, and predicting what impact disclosure would have on other important relationships.

Opinions about disclosure varied widely; some women wanted very few people to know; others felt comfortable with almost everyone knowing; but all the participants believed strongly that they alone should decide when and who should know their diagnosis. Controlling disclosure minimized the risk of rejection and increased the likelihood that the women could remain within a group that displayed social tolerance about their diagnosis.

When to tell was a significant concern when considering sexual relationships. Lisa tried to imagine a life with a sexual partner and it was very hard. She couldn't picture when she should tell someone she wanted to have sex with that she had HIV infection.

> 'And I guess I'm scared to….if I ever let a guy that close to me then I'm not even sure when I should tell them. Whether it should be right in the beginning, or before we get intimate, or right in the middle or… I have no clue.'

The uncertainty of telling sexual partners meant that some women avoided sexual relationships completely. This served as one method of controlling disclosure. If the women didn't allow themselves to get sexually involved then they didn't have to tell their HIV status. Naomi, who had known her diagnosis for 11 years, said that she "tried to dodge having a serious relationship with somebody for a while." Eventually Naomi began to delay having sex until a friendship had developed. She described the early relationship with the man who is now her husband "We were like really good friends for like five months. And, I think that helped because he really got to know me instead of knowing my HIV first. So I think that helps out a hundred percent." This decreased the likelihood sexual rejection. Other women who had been infected for more than a few years also used this strategy.

The women who learned they were HIV positive while involved in a sexual relationship felt the need to inform their sexual partner right away, but for some this was not easy. Pauline lived with a man who had a history of physical violence and she feared for her own safety. A public health official offered to tell her partner for her, but Pauline wanted to do it herself. She believed that it will be better for the relationship if there was no stranger involved

> "The only thing I could really think of was, how was I going to tell him? … He's very discrete and he doesn't really like … because he doesn't get along. He figures its best he be by himself. And then with this situation, I had to do it on my own. I could do it alone. And so I went and I told him and he was really surprised. He was quiet. But he held me he wanted to comfort me."

Controlling the circumstances surrounding disclosure helped assure Pauline that her partner would still accept her.

Deciding who to tell was as important as when to tell. Most of the women disclosed their HIV infection first to people they believed would support and accept them. Often these were female family members such as mothers and sisters. Many women with older and grown children told them first. Bess explained how she chose the people to whom she would disclose.

> Because they're the most important people in my life so that I need for them to know. That way that I would be able to deal with it better knowing that I have somebody there that is, you know, understandable with what may happen to me somewhere down the line, you know. Or, uh, how can I say it, um, I just felt that it was important to me that they knew what was really going on with me in my life, you know.

Controlling disclosure was not always about keeping HIV status secret it was about having the power to decide; to choose when to hide her diagnosis and when to reveal it. Esther thought, in general, that it was OK for people to know her HIV status but took exception to the state law requiring women to inform their sexual partners of their HIV status "I mean I can understand where they're coming from but then again, they have to understand, too, that if we don't want people to know that should be our right to tell it." Esther did not want anyone else

dictating who she should tell. She believed that individuals had to take the responsibility for not transmitting the virus "well if anyone got any common sense if you're gonna go to bed with somebody you're gonna use a rubber anyway," but she wanted the option to keep her HIV status unknown.

Lisa preferred that no one but her health care providers and certain members of her family be aware that she had HIV infection. She suspected an elderly Aunt was going to tell one of Lisa's neighbors "oh God, I don't wanna tell, I don't wanna tell. But I don't want them to get the satisfaction of everybody in the neighborhood finding out without me at least telling one person." In this case it was more important for Lisa to tell her neighbor than to keep her diagnosis a secret. Ruth, on the other hand, preferred that people know her HIV diagnosis because she believed it would cut down on the gossip "Actually it was … let 'em all find out at once. I'd rather have it that way than (whispering) 'did you hear did you hear'?"

Despite the fact that women wanted control of their disclosure; they took into consideration the feelings of others. For Naomi the decision about telling her in-laws about her HIV infection remained a major concern. After seven years of marriage she wanted her in-laws to know about her diagnosis. Her husband's reluctance influenced her ability to control her disclosure. "One of things that me and him struggle about is his family finding out. I'm at the point right now that I don't care. But he does." She kept her diagnosis private because she respected her husband's desires. Naomi opted for the acceptance and tolerance of her immediate family over her in laws "Because it's not just me in this relationship. It's him and the kids and stuff, so I can't be selfish."

Ruth, who didn't mind that her friends new about her HIV infection, talked about why she never came right out and told her grandfather about her HIV status

> Because he was old fashioned. I didn't know what he would think. I didn't want him to be, not so much him be ashamed of me, but kind of, I don't how to put it, like I just didn't want him to know, really. … He passed, I'm under the impression that he passed away knowing I had it, but I never told him I had it.

Ruth respected her grandfather's values. She knew he loved and accepted her. She didn't want to confront him with her diagnosis and strain the relationship. All the participants in the study used the strategy of controlling disclosure to increase tolerance and acceptance among their family and friends

Strategy: Finding Purpose

Finding purpose was a second strategy employed by the women in order to position for acceptance. This strategy involved identifying and engaging in meaningful work and it was primarily a behavioral processes. Finding purpose gave the women an opportunity to feel better about themselves and their day to day lives. It also put them in a position to be with people who accepted them. Sub strategies used to find purpose involved considering employment, mothering, and AIDS work.

Considering employment. All the women in the study referenced having a job as important to them. Only two of the participants were employed and most of the rest said they were looking for work. They believed that finding work would make their lives better. Surprisingly these women did not mention finances as the primary benefit of working; they indicated that they missed work because it gave them purpose; a reason to get up in the morning. Cassie was very ill when she learned she had HIV infection. She ended up losing her job while she was ill and struggled to make ends meet each month. She talked about why she was so anxious to return to work

> "I'm determined to go back to work … No, the money. I need the money, everybody needs money. But I just need something to do … Because it would give me something to do. It would give me some kind of meaning of life"

Bess also missed work "Just getting up, getting out, you know, knowing I got something; getting up; going to." The women saw employment as giving them structure and purpose as well as the financial means to survive.

When Wanda was diagnosed she was in her mid twenties and living a carefree life, hanging out with her girlfriends and dating boys. In the six months since her diagnosis she had begun to consider where her life was taking her. She talked about a group of male friends she enjoyed being with

> "because we talk about school, we talk about getting jobs, going job hunting together … We're all around the same age, so we're all looking at it like, man, our clock is ticking. You know what I'm saying (laughing). We're knocking at 30's door, you know. If we don't do something now are we ever gonna get it done?"

Most of the women wanted to be involved in gainful employment not only for survival, but to make acceptable use of their time. Women tended to reject the idea of employment if they were concerned that their health would prevent them from doing a job well, or if they had other meaningful work to do such as helping to raise grandchildren. Bess wanted work, but believed it was not as important as taking care of her young son and grandson "Yeah, but then I'm there with the children most of the time … because my daughter she's working, you know. So I'm kind of like a home, like her babysitter or whatever."

Mothering. Even though most of the women did not work all of them had found something in their lives that gave them purpose. Women who were raising children were very passionate about the significance of the mothering role. They wanted to be the best mother for their children. Like Naomi; they referred to their children as their

"everything." Janet who had attempted suicide shortly after learning she was HIV positive, described what mothering her two-year-old meant to her

> "Ain't nobody gonna take care of her like me. Don't nobody love this little girl like me, so I'm glad they was around [to save me] because I'm here for her now. And I realize … if I can't live for anything else, I can live for her."

Francine, whose daughter also had HIV infection, believed that her daughter's care required most of her attention.

> "I'd rather just go out there and get a job and be a manager again. That would be way easier for me, but then [my daughter] just got way too many doctors' appointments. I haven't figured out how to juggle a job and be a mother. And I wanna be the best mother that there is. Well, the best mother that I can."

At the time of her interview Francine complained of being depressed and anxious. In addition to caring for her daughter she had a relative with mental health needs move into her apartment. She had mixed emotions about her role as caretaker. She referred to herself as "the mother hen of the family" but also said that people "want more than I can give." It is this role as care giver that kept Francine going. "I feel, like I said, I feel like the "mother hen". Like I gotta take care of everything and if I don't take care of it, it's all gonna fall apart."

Bess believed her child and her pregnancy also gave her life. "Yes, he is a miracle. He changed my life. And if it wasn't for him, I don't know if I would be where I am today. And I may not even have found out that I was positive." Bess believed this about her child because it was during her pregnancy that she got an HIV test and made a commitment to stay healthy and go into recovery. For Bess and Francine motherhood brought a special status. It gave Francine a reason to keep living. It gave Bess an opportunity to become clean and sober and leave behind a life she did not value.

AIDS work. Many of the women felt committed to reaching out to others about HIV infection. Naomi was employed as an outreach worker for AIDS patients at a local clinic. Esther was a volunteer on two boards for agencies that managed AIDS related federal funds. Most of the women spoke to their children and relatives about the dangers of unprotected sex. At least three of the women made themselves vulnerable by speaking at public events about what it was like to have HIV infection.

HIV related outreach, in the form of education or public speaking was motivated by a desire to prevent others from experiencing the devastation they experienced. Cassie who claimed "I wouldn't wish HIV on my worst enemy" described an encounter with her teenage nieces when she learned they were sexually active.

> "I actually grabbed ahold of them and said, remember when your Aunt was in the hospital and you all thought I was gonna die … do you know how I got this way? I got this way by having sex with somebody that I trusted. And you guys are out there having sex. Are you guys using protection? … There is a lot of people out there that have it that you think that you can trust and that can give it to you. And then that's something that you have to live with for the rest of your life."

Women who spoke publicly also focused on helping health care professionals work more effectively with HIV infection. Cassie talked about her first public speaking engagement

> "Like my first speech that I went to at Planned Parenthood. I felt good because then the people that were there, we can let them know how we feel. If you're practicing to be a doctor, don't treat us like, how could I say it…..like you're scared of us. "

After Pauline was diagnosed she found that she could write poetry. The words came to her easily. Many of her poems were about being African American, surviving life struggles, and the healing nature of faith. She also found herself reaching out to street people, offering them prayers and trying to tell them of God's love. Her partner did

not want her to disclose her diagnosis to others but at the time of her interview she was trying to get the courage to write a poem about HIV infection. Pauline saw life in this way

> And I figure this is my purpose for everything that happened to me so that I can relate to the people that God wants me to reach out….like I'm one of His vessels. He put His soldier out there. He got a real strong soldier that ain't afraid, you know what I'm saying?

By finding a purpose the women believed their lives had meaning. They might have been deceived by someone they loved; they might feel dirty and alone; but their days had significance. They were able to do some good in the world.

Strategy: Securing Support

A third strategy for positioning for acceptance involved securing support. While manipulating the social context involved assuring a social environment for acceptance, securing support involved examining and structuring relationships in such a way as to be accepting. To a certain extent all of the women experienced a shift in their personal relationships. After being diagnosed with HIV infection, the women examined people in terms of whom they could trust and who they couldn't. They solidified relationships that were genuine and authentic and distanced themselves from people who were not. The sub strategies used in securing support included dealing with the ignorant, clarifying existing relationships and deciding on new relationships.

Dealing with the ignorant. Many women in the study referred to certain people as ignorant or uneducated about HIV infection. This term usually referred to people who spoke negatively about individuals with HIV infection and who bought into stereotypes about people who had contracted the illness. The women dealt with the ignorant by avoiding them, educating

them, or not disclosing their diagnosis to them. People who were not educated could not be relied upon for support. Naomi described what she meant by ignorant.

> Well, I think they stereotype people with HIV and think that we sleep around with everybody and that we got this disease because of we were sleeping around with people, or we deserve what we get. And just stuff like that and just being ignorant. Oh, I don't want to touch that because of that person. I don't want to go into that bathroom because them patients go to this clinic.

Wanda described disappointment with a long time friend

> Well, she told me she'd be supportive. She still contacts me and I go by her house and stuff like that. But she said a lot of hurtful things at first. She's not that educated about it.

Her father, on the other hand, was the person she felt most comfortable around and was the person she preferred to be with. She described him this way, "He'll call me and talk to me, make sure he tells me he loves me. He's more educated about it than a lot of other people are."

When a woman encountered someone who was ignorant, sometimes she chose to educate them about the illness. Ruth talked about her boyfriend's parents who still believed they could contract HIV infection through casual contact, "I mean, hello! So I'm in that process of trying to not so much as educate them but steer them off the ignorant path. That's pretty much where I'm at." Irene avoided people who were ignorant if she could help it. Naomi found it hard to know what to do when she encountered someone who was ignorant. She talked about why she withheld her diagnosis from her in-laws

> "The things they say about people with HIV and, the way they treat other people, it's not nice. And it kind of makes me feel uncomfortable. So in a way I'm kind of glad that they don't know about me"

However, Naomi believed she needed to speak up to her co workers, but was afraid because she did not want them to know her diagnosis

> I hear talk and stuff and it's very uncomfortable because a lot of our patients come to that clinic and it's just hard knowing what [some of my co workers are] saying on the side.

> You know and I would say something to somebody else, like, in our team, but not really to them people.

By dealing with the ignorant the women had a way of managing people who were likely to reject them because of their diagnosis. They kept them out of their circle of regular contacts, continued to have contact with them but with held their diagnosis; or they tried to change the mindset of the ignorant by educating them.

Identifying individuals as ignorant was also a cognitive strategy that was protective. If others believed the women were promiscuous, or highly infectious the women could know that the rejection came because of lack of knowledge and was unrelated to whom the women really were. Ruth's boyfriend's family was not really rejecting her; they were rejecting an idea of what they thought she was based on a lack of education. Ruth's strategy was to give them the proper facts in order to gain their acceptance.

Clarifying old relationships. In order to secure support the women also engaged in the sub strategy of clarifying existing relationships. Decisions had to be made about whether or not someone would remain close, if the relationship would become more superficial, or if the relationship needed to be dropped. After her suicide attempt Janet took a hard look at her life.

> And I said now what is it with me that's making me so sick and making me want to do things…..and I looked at my living situation, I looked at the neighborhood, I looked at the people that was around me and I said this is what's putting me down here … And I cut off all the people that was just out for them. I don't need people that's just out for them.

Many of the women found that their family relationships became more important to them. When asked to identify the important people in their lives all the women identified family members and children (if they had them). Some did not even mention their sexual partners or husbands. Female relatives like mothers, sisters, and grandmothers were frequently mentioned as being open and accepting. These were the

family members to whom the participants first disclosed their diagnosis. For some women, HIV infection strengthened their already strong bonds to female relatives. Other women referred to these relationships as strong even before their illness, but were grateful for the care and concern the relatives displayed. Janet talked about her mother

> "So with me and the disease right now, she's very over protective over me. Don't want me to go anywhere. Want me to save my energy and, you know, just very over protective, but if I needed anything … she's right there. If I'm sick or in the hospital, she's right there."

In evaluating existing relationships HIV infection became a barrier to intimacy for some women. Cassie had known about her HIV infection for about a year; one of her greatest regrets about her diagnosis was what it meant for her relationship with who she described as her true love "We can always remain friends. We can talk. We can go out to eat. [He] can come over to my house. We can visit, whatever, but we can never be the way we want to be; EVER." For Cassie the possibility of transmitting the virus precluded any sexual intimacy or emotional commitment.

Although, HIV infection sometimes served as a barrier it also helped women identify those relationships that were authentic. Janet put it this way, "When I got diagnosed I started seeing a lot of things different. I got to see who was my friends and who really was just using me." She described being hurt by girlfriends that had spread rumors about her, but she found friendship unexpectedly in a male friend.

> "I can call him any time in the night if I'm feeling depressed or whatever … And he's like … You know just come to me, talk to me. If you ever feel that you're about to hurt yourself, bring your daughter to my house and y'all come over here. And you sit and talk to me and get that out your physicalness. I mean like if you want to fight or hit anything, let me know. You can hit me. I'll just sit there."

Deciding about new relationships. The last sub strategy under securing supports was deciding on new relationships. Avoiding relationships was one tactic that almost all the women engaged in at some point. Some women, like Wanda, could give no reason for this other than they "didn't want to be with people." Some women, like Pauline, were able to articulate that they were afraid for people to know their diagnosis. Still others, like Lisa were afraid they would inadvertently infect someone else.

Establishing friends with others who had HIV infection was another option. The most frequent route for this was through area support groups. The women said that support groups offered them a place where they could be themselves, where others understood their problems and where they did not feel judged. Janet described that it is a place for her to go and not be lonely

> "I go to group for basically, because sometimes you can get alone, you be lonely, and…sometimes other people that's not in the same situation as you, don't understand why you might be in that funk or why you might be depressed or something."

For others the group was a place to escape being judged for her illness and to feel OK about strong emotions such as anger. Lisa described how it is for her

> "I even still feel like they are judging me because I have what they have. It's not the same kind of judge, judging. It's hard for me to explain it … I don't know, sometimes other women are mad and I'm like OK, I'm not the only one angry today. I'm not the only one stressed out and it kind of helps me to breathe."

For a few the support groups became a central focus in their lives. Esther, who had spent much of her energy raising a daughter and a grand daughter, says that now most of her time is spent with women from the support group. Other women stated that

the mixed support group, which also includes males, provided a safe place to meet men who already know their diagnosis.

If the women did not find value in the support groups they found friends elsewhere and these friends may not have known that the woman had HIV infection. Wanda and Janet rediscovered male friends. Wanda talked about these newly rediscovered relationships:

> I got like three guys that I grew up around. You know they were always around, in and out. Moved out of town, moved back into town. Still kept in touch with each other. We're all like best friends now. And it kind of freaks me out because I'm closer to them as best friends you know with dealing with this than I've ever been with …With anyone.

She believed it was easy to be with her male friends because she knew she did not want to have a sexual relationship. She also said that when she was with her men friends she focused on important things

> "But you know what, it's funny because we talk about school, we talk about getting jobs, going job hunting together, you know, eatin'. We talk about food (laughing). Just stuff that normally before wouldn't have been the main focus on our conversation."

Previous to her diagnosis her conversations were superficial. Since learning about her HIV infection her conversations centered on finding jobs and bettering herself. She went on to say that her girlfriends wanted to talk about boys and dating. Because she believed she could not date and she did not want people to know about her HIV status, social relationships with women had been replaced by platonic male relationships.

The strategy of securing supports was about the women deciding who they wanted to relate to and how, in order to have a supportive network of people around them. For a variety of reasons, almost all the women experienced a period where they

avoided people all together. Some women found that old friendships were not helpful and chose to reject them and establish new relationships with others. Support groups became one vehicle for establishing new and accepting relationships with others who also had HIV infection. In almost all situations the women identified at least one family member who accepted them and was an important part of their network of relationships.

Strategy: Accommodating HIV infection

The fourth and final strategy for managing relationships was accommodating HIV infection. Accommodating HIV infection was primarily a cognitive process which allowed the women to determine how much HIV infection would transform their lives. The illness had a certain significance that necessitated changes in life style and attitude in order to accommodate the imposition of HIV infection. There were two sub strategies; evaluating the meaning of HIV infection and coming to terms with rejection.

Evaluating the meaning of HIV Infection. All the women described HIV related attitudes that influenced their actions in relationships. These attitudes incorporated issues of disease acceptance, of personal identity, what HIV infection meant for them in the present and what HIV infection meant for their future. These attitudes were not fixed and women described that they had changed over the course of their illness.

All of the women talked about a time when they did not fully accept their diagnosis. They referred to it as a time of denial, not dealing with it or not accepting it. Susan, who had known her diagnosis for about a year and expressed her reaction to her illness as shame and embarrassment, said she was managing her illness well because she "doesn't think about it". She hung out with friends who didn't talk about it, most of whom did not know her diagnosis. Susan said she knew her parents accepted her because

they did not treat her differently and they did not ask her about her illness. She was most comfortable with people who did not acknowledge that she had HIV infection.

Naomi, who had known her diagnosis for 11 years, spoke of just beginning to accept her illness within the last two years. She said she had to grow up a great deal, marry and have children before she could begin to accept that she had HIV infection.

> I think when I was younger it was a lot harder for me, because I really couldn't accept or understand why it would happen to me. And as I've gotten older I've learned a lot about HIV and I've learned a lot about myself.

Denial spared the women from having to deal with the rejection that comes with being HIV positive. For periods of time a woman could believe she was like the rest of the people that she knew that had not been betrayed, were not sick and did not have to fear the scorn of others. Although all of the women experienced some level of denial, none of the women experienced total denial. They undertook the practical considerations of managing their illness, like keeping doctor appointments and taking medications.

As the women talked about how HIV infection had they sometimes discussed it in terms of how HIV infection had affected their identity. Lisa said that since she developed HIV infection she felt as if she was "different." Susan believed it made her dirty, and affected her whole being. Wanda's metaphor of HIV infection as a moldy slice of bread illustrated her uncertainty at how HIV infection would affect who she was. Cassie spoke of expressing relief when someone described what it meant to have her viral load undetectable "Your AIDS is blocked in a box and it's not spreading and you're getting better" AIDS, although still part of her, was contained. Other women however seemed to free themselves of being defined by their diagnosis.

Ruth described why she believed she was accepted by certain people "They've known me my entire life. This doesn't change me one bit." Bess described why she felt she could deal easily with her HIV infection at this point in her life. Part of this she attributed to the fact that her struggle to become free of her addictions was a more significant event in her life. But she also stated "Because I have more knowledge of it now than I did, you know, um. And I know I'm still the same person that I was before I was diagnosed."

The women sought to discover how much they were was defined by HIV infection. Was it "locked in a box" the way Cassie saw it or did it make them dirty the way Susan felt it did? Compartmentalizing the illness left the essence of the woman in tact and able to be more readily accepted by others.

In evaluating the meaning of HIV infection the women discussed how they managed the illness on a regular basis. The daily challenges imposed by HIV infection generated a range of responses from the women. A few described HIV as a terrible thing and they saw themselves as stuck. When asked in what ways her life might be better since learning about her HIV infection Susan could think of nothing. Lisa said her life was worse, she could not relate to people, she had lost her self-confidence, and she no longer wanted to be around people. Francine who had known about her HIV infection for four years talked about being stuck

> And I can't get it back. I'm, I really am, I'm smart, but I can't wrap it all together to get my ass back out here in this world and just keep it together … I just….I can't do it. I can't figure out how to do it … I'm very lost. I know I don't wanna be nothing for the rest of my life because I know I can be something but I don't know how to get out here and do it.

Women who felt stuck were also likely to describe themselves as depressed and preferring to be alone. There was a sense that the illness had stopped them in their tracks and prevented them from moving forward.

For some women the daily challenges of managing HIV infection were something they learned to take in stride. Esther said "whatever gets throwed my way, I just take it and go on." Ruth talked about being 16 pregnant and living with HIV infection, "I mean I was just drained all the way around. But I kept having to do it. I had no other choice." For Bess managing her illness was a small part of her day "All that I know is that I got to take my meds twice a day then I just continue to go on doing what I normally do."

Other women described the period of time since diagnosis as one of growth where they learned about themselves and the world around them in ways that made a difference and opened up doors. Irene described herself as more tolerant, more open minded. Naomi was particularly aware of how dealing with her illness had been a source of personal improvement

> I don't thank God that I have this disease but it has helped me grow in a lot of ways. Um, mentally. Mostly mentally. I think I look at life differently than some people who don't have to have a disease like this does. Like I live every day like it could be my last.

Pauline went so far as to call it a blessing

> And I'm thinking now it was a blessing because now I'm getting out into my community and I'm trying to help and I'm trying to inspire and whatever profit that I make I want to come back home and try to make up and clean up. You know what I'm saying?

The way the women accommodated to HIV infection seemed to impact how they managed their relationships. If they presented an attitude of acceptance, a belief that the illness was something manageable, or something that had challenged them to grow, then they expressed a likelihood that others would respond to them in a positive fashion. Women that felt defeated by

their HIV infection and allowed it to define them were more likely to expect rejection and therefore narrowed their circle of friends.

The women also described varied reactions to how HIV infection influenced their future. Sophie saw it as a death sentence in which suffering was inevitable. She wanted to spare her daughter from being witness to her decline and chose not to take medication.

> "But they can't promise me a lifetime, you know, if I take this medication. They can only promise me an X amount of years any way … I would love to have at least 12 you know with no problems. You know I mean what's another 12 years? … But that medication, it's terrible. It makes you sick and who wants to live like that for the rest of their lives, sick every day?"

Others adopted an attitude focused on living. There was a sense that HIV infection was manageable. Cassie:

> You can live to be, you can live a long life as long as you try to eat healthy, try to get proper rest, exercise, take your meds, you know and all that. You can live a successful life. You can live a long time with it.

Along with the belief in a manageable illness came a commitment on the part of many to focus on the positive and avoid negative thinking and depression. Naomi described her concern with the uncertainty of her future and followed it up with this "And sometimes that pops in my head every once in awhile. But when I get things in my mind like that I try to get rid of them fast; because it's not healthy." Adopting a positive attitude seemed to be a choice these women made and they worked to maintain it. Esther explains:

> "No. I don't never wanna be down. I've been down before. Not sick down, but down and I know how that feels and I don't like it … I really don't. And like I said, I think when [my fiancé] got sick [with HIV infection] and seeing him like that I think that just changed my whole attitude toward life. Even though I already knew you gonna die with something wrong with you, but you know you don't never think about that."

Reconciling rejection. The women also made a decision on how to deal with rejection. They either avoided situations in which rejection was possible or they rejected the rejecters. Wanda chose to avoid rejection

> "Like I might just as well be by myself for the rest of my life because I don't want everybody to know. I can't just tell somebody and then we don't end up together. Because I did that already. You know I tried that and it just didn't work out."

Lisa likened getting rejected to getting her teeth kicked in. She was very reluctant to have that experience again. For these women rejection was to be avoided at all costs.

While no one liked being rejected, some women did not find the experience to be devastating. Janet believed in telling people right away "I mean, you always can get rejected in something. So, I mean if you get rejected in sex that's not the biggest loss in the world." Esther echoed the same feeling but applied it across a broader range of relationships

> "And I feel like this, if that's the way they feel about it then hey, you can stay away from me, because I'm gonna go on with life. There's gonna be somebody wants to be around with me whether I'm HIV positive or not."

Women like Wanda and Lisa found rejection to be something greater than rejection of a personal characteristic. Being rejected meant being rejected as an individual. On the other hand, women like Esther seemed to experience being rebuffed as a rejection of her HIV status and not her as a person. HIV infection was a characteristic she possessed that could be accepted or rejected. This latter attitude seemed to allow some women to maintain a belief in their inherent acceptability in the eyes of others. A person could reject the illness, but that was simply a part of who the woman was. Esther maintained the belief that she was still acceptable to others.

Contextual Concepts: Sexual Intimacy, Health Care and the Social Network

In grounded theory it is understood that all concepts exist within a greater schema referred to by Strauss and Corbin (1998) as macro conditions. Macro conditions are those

elements which are in continual interaction with the identified concepts and processes and help account for variations an behavior. In this study three macro conditions or contextual concepts were constructed. These were the health care system, sexual intimacy and the social network.

Although the interview questions did not initially address either sex or health care the women spontaneously discussed these issues as they responded to questions about relationships. The frequency with which they were discussed highlighted the significance these issues had for the women in the study and revealed how these systems influenced the selection and implementation of the strategies of the BSP. HIV infection is an illness, identified, defined and managed within the context of the health care system. Sexual intimacy is also contextual for HIV infection. All of the participants acknowledged that they either contracted HIV infection through sexual intercourse or lived with concerns about transmitting HIV through sexual activity in the past or in the future.

Sexual intimacy. Sexual intimacy was identified by all the women as a significant aspect of relationship; in fact most of the participants anticipated that this topic would be the central focus of the interview. However, sex did not appear to be a central strategy for dealing with the problem of betrayal and shame. Women's treatment of sex reflected the other strategies involved in positioning for acceptance such as controlling disclosure, changing relationships, and reconciling rejection.

For most of the women sex became an issue of acceptance or rejection. Some women confessed that they had withheld their diagnosis from potential sexual partners in order to avoid rejection; others opted for celibacy. Others like Sophie, admitted that her feelings about sex had changed since learning she was HIV positive

> "I don't even crave it. Its just, if I gotta do it I gotta do it cause I'm in a relationship and he wants some, I just do it you know what I mean I just don't, I feel like I'm dirty now because of that disease."

Women who experienced satisfying sexual relationships described it in terms of acceptance. Susan described her relationship with her long term partner as unchanged because he loved her. Sophie described her relationship with her current partner who is HIV negative

> "He doesn't use protection because he accepts me for who I am, you know, I want him to because I have AIDS now but he refuses to use protection because he doesn't want to treat me any differently and he doesn't want me to feel like I'm being rejected."

Naomi learned after a series of rejections to wait before she told a potential partner about her infection.

> "I think one of the big things that helped was being friends with him for awhile before we even tried to be intimate or even say we was going out. We were like really good friends for like five months. And, um, I think that helped because he really got to know me instead of knowing my HIV first. So I think that helps out a hundred percent."

Naomi recognized that her identity was more than her HIV infection. It became important for her to make sure that a man had an opportunity to know her before he learned about her diagnosis. If he accepted her sexually after learning her HIV status he demonstrated his acceptance of all of her. Women who were not able to separate HIV from their identity tended to choose celibacy, believing that no one would ever want to have sex with them if the man knew their diagnosis.

The context of sexual intimacy was ever present to the women. They craved it, but feared there illness would prevent them from having it. At times they hid their diagnosis to avoid being rejected, or they resigned themselves to celibacy assuming that they would be rejected. Those who had taken the risk, disclosed their diagnosis and been accepted had the opportunity to change the view of how the illness affected them. An altered cognitive appraisal of HIV infection then led to the use of different strategies as they positioned for acceptance. In this way strategies of disclosure affected sexual intimacy, and experiences of sexual intimacy had an

impact on chosen strategies. This contextual factor was in constant interaction with chosen strategies involved in positioning for acceptance.

Health Care System. A unique theme in the participants' discussions with the interviewer related to receiving health care. All the women in this study received care for their HIV infection at the same out patient clinic with the same team of health care providers. All the women in the study praised the, nurses, physicians and other professionals that provided services to them and their children. They spoke of health care providers as accepting, honest and supportive. Ruth, who was 16 and pregnant when she learned her diagnosis, recalled the role the nurse practitioner had in helping her cope,

> I think the Nurse Practitioner actually …Seriously, she's like the greatest person I've ever met in my life. And I tell her this all the time but she's like my second gramma. It's almost like she showed me, I mean I was going through some really tough emotional things and she showed me that 'so what you have HIV?' Or 'I'm not looking at you any different'

Ruth also talked about the role the physician had in giving her hope.

> If it wasn't for Dr. [name] being the grateful doctor that she is and explaining just a couple of things; because I can pretty much find it on my own. But her being a doctor in the medical field for 11 years and saying, "Hey, I'm dead serious you're really not going to die." OK. I believe you. I have no reason why I shouldn't.

The women found the clinic to be a place where they could be honest and accepted. They identified outreach workers, social workers and nurses by name and explained the numerous ways these professionals provided support during the women's illness. The women also explained how they could be honest with the health care providers. They felt comfortable sharing information about not taking medications as prescribed and use of illicit drugs. Pauline said

> But then I was sitting there and I was saying Ah, Oh, because it was like deja' vu. It was the same high it was when I was sniffin'. I told Dr. [name], I told her… I was honest

> with her, I told her everything about drug use, I told her everything, and she respected me for it.

The support, respect, and tangible assistance given by the health care providers were taken as acceptance by all of the women in the study. This helped them to formulate their evaluation of HIV infection. At the same time the evaluation of HIV infection influenced their relationship with the health care system. Sophie believed that HIV infection had ruined her life and saw no need to take the medication suggested by her physician. Alice saw her HIV infection as a long term but manageable condition. She used it as an opportunity to take better care of all aspects of her health, like having annual gynecological exams, and flu shots.

Social network. The social network, for the women in this study, was both the stimulus and the goal of positioning for acceptance. Each woman had experienced a betrayal within their social network resulting in a sense of isolation. Each woman desired accepting and open relationships. As they employed the strategies of positioning for acceptance the reaction of the people who formed their social networks were appraised to determine the use of future strategies, which in turn influenced the response of people with whom they interacted. The interaction between positioning for acceptance and the social network was continuous.

Naomi described being rejected soon after she learned her diagnosis. Initially chose a strategy of dodging relationships and non disclosure. As she lived with the diagnosis she eventually disclosed it to non sexual friends who responded in supportive ways. Eventually she adopted an approach of becoming friends with potential sexual partners before sharing the fact of her illness. This resulted in not being rejected and the development of a satisfying and accepting sexual relationships. The process involved a continual interplay between her social network and her use of strategies in positioning for acceptance.

Relating the Concepts

Two core concepts and a basic social psychological process (BSP) were constructed during the analysis of the data. The two core concepts betrayal and shame and isolation, served to address the first research question, how does HIV infection affect women's relationships? Most of the women experienced betrayal as a result of learning their diagnoses. They learned they had been deceived by lovers or they were rejected by friends or family members the women believed would be loyal. This betrayal resulted in feelings of shame and isolation. The women had difficulty trusting others and they had difficulty trusting themselves. Some feared that they would never have another relationship again. HIV infection had the consequence, at least temporarily, of instilling feelings of shame and isolation, which resulted in a desire for acceptance and mutuality in relationships.

The BSP positioning for acceptance provided an answer to the second research question, what process do women use to manage their relationships within the context of HIV infection? Positioning for acceptance involved four strategies that employed both behavioral and cognitive processes in order to create positive perception in the minds of others. The four strategies, each with two or three sub strategies were labeled manipulating the social context, finding purpose, securing supports and accommodating HIV infection. The behaviors and cognitions of the four strategies of positioning for acceptance comprised the BSP which explained how women manage their relationships.

Two of the strategies, manipulating the social context and securing support were primarily behavioral strategies. In the former strategy the women engaged in activities, specifically relocating and controlling disclosure, in order to create a social environment that was more accepting of them. They moved away from negative environments which were in someway undesirable; to places of acceptance and care. Some women moved away from judging friends,

some moved toward friends and family, and others moved into situations where they could receive foster care or treatment for substance abuse. They also made conscious decisions on when and who to tell about their HIV infection. They wanted the people they told to be receptive to them despite their diagnosis. The women withheld their diagnosis and passed as normal to people who were thought to negatively judge people with HIV infection. This strategy involved behaviors geared toward creating an accepting environment.

Securing supports also involved primarily behavioral sub strategies in order to engage in accepting relationships. Unlike manipulating the social context, these behaviors were not geared toward the social environment, but instead involved actions taken with specific individuals. Most women spent some time avoiding relationships all together. This tended to occur shortly after a woman had experienced betrayal, in the early days of her diagnosis. The women also evaluated current relationships, minimizing those that were harmful or judgmental and opting to spend time with people who were able to enter into more genuine interactions. Some women actively sought out new friendships with others who were HIV positive; believing that they could truly accept and understand the woman's current circumstances.

Finding purpose was a strategy that was both behavioral and cognitive. The women actively considered employment and engaged in AIDS related work in order to give structure to their days. They also took care of the daily needs of their children. These activities gave the women purpose and provided them with a unique and singularly acceptable role in society. The cognitive aspect of this strategy involved how the women viewed their work. They believed that mothering was valuable; they saw their AIDS work as something positive that arose from their illness. The meaning that they assigned these actions is what made these actions significant and provided a level of acceptance in they eyes of the women.

The fourth strategy, accommodating HIV infection was primarily cognitive. With this strategy the women developed attitudes about HIV infection and how it would impact their lives. They also decided what it meant to be rejected by others for being HIV positive. Almost all of the women described some period of denial in which they could not truly comprehend that they were HIV positive. They chose to deal with it by ignoring it. Eventually some women viewed HIV infection as a death sentence. These women were more likely to view rejection globally. In this case the rejection indicated that a woman was unworthy of the esteem of others and anyone who knew of her HIV infection would likely reject her. Other women decided that HIV infection was manageable; some went so far as to consider it a blessing. These women were also more likely to compartmentalize rejection. In this case a woman would consider a rejection in an isolated sense, believing that acceptance would soon follow.

It is likely that the cognitive and behavioral strategies influenced each other. If a woman experienced rejection upon disclosure of her diagnosis, it was likely to influence how she viewed her HIV infection. Similarly a belief that her HIV infection was a death sentence likely influenced how a woman went about entering into relationships with others. Women like Naomi and Ruth, talked about how a single accepting person (a foster mother, or a nurse practitioner) influenced them to see the best in themselves and their diagnosis. Others, such as Lisa and Wanda, spoke easily about how a traumatic rejection (by boyfriends) left them distrusting of themselves and others. The data suggested that the outcomes of behaviors and cognitions influenced the use and results of different strategies involved in positioning for acceptance.

The contextual concepts health care system, sexual intimacy and social network were also in constant dynamic relationship with the BSP. The health care system influenced how the women experienced HIV infection, which in turn influenced how they entered into behavioral

strategies to elicit acceptance. At the same time relationships with others, and their appraisal of HIV infection influenced how the women utilized the health care system.

For most of the women HIV infection occurred within the context of sexual intimacy. Of the women who identified their means of acquiring their illness, all identified heterosexual sex. Fear of transmitting HIV to non infected partners was universally acknowledged by the participants. All of the women expressed a desire to be accepted as a sexual partner. The strategies used to deal with sexual intimacy, non disclosure, celibacy, avoidance, openness, were met with reactions of acceptance or rejection which in turn influenced the choice of future strategies.

The third research question, what role does a network of social relationships play in the lives of women with HIV infection, has also been addressed by the data. The social network was constructed as a contextual concept in constant interaction with the BSP positioning for acceptance. On the one hand an accepting social network was the desired outcome of the strategies. On the other hand it was the current social network that influenced which strategies and sub strategies would be utilized.

Naomi's description of her relationship with her foster mother is an example of how the social network shaped strategies within positioning for acceptance. Naomi related how her foster mother's positive disposition toward her helped Naomi develop an elevated self-esteem. This gave her the confidence to make new friends and break her pattern of being involved in abusive relationships. Naomi's foster mother represented Naomi's social network shortly after her diagnosis. Eleven years later, at the time of her interview, Naomi was married to man she described as totally accepting. She believed her self esteem was the reason she viewed her HIV infection as a manageable illness that represented only part of who she was as a person.

Francine, on the other hand, felt overwhelmed, in part because of her social network. She identified herself as a caregiver and at the time of her interview her family supported that view. A mentally ill relative had moved into her apartment so that she could care for him. Her role as care giver, defined and reinforced by her family, not only denied her needed support, but prevented her from socializing with friends because she didn't want to burden them with her illness. She relied heavily on the strategy of finding purpose to keep her going, but she accommodated her HIV infection by seeing it as a burden which shadowed every aspect of her life.

Ruth's story demonstrates a more complex interaction. Early in her illness she experienced rejection from important people and was reluctant to disclose her diagnosis again, at the same time an optimistic health care provider offered her reasons to hope for a good prognosis. The two experiences influenced how Ruth went about positioning for acceptance. She actively controlled disclosure by withholding her HIV status from her colleagues at work and from her elderly grandfather in order to avoid rejection. She also accommodated her HIV infection by considering it a chronic illness, established a new relationship with a sexual partner and became pregnant.

Summary

The purpose of this study was to determine how women with HIV infection manage their relationships. The data from 14 interviews revealed that HIV infection affected women's relationships by resulting in the experience of betrayal and feelings of shame and isolation. The BSP of positioning for acceptance was identified as the primary process the women used to manage their relationships in the context of HIV infection. Strategies within this process included manipulating the social context, finding purpose, securing support, and accommodating

HIV infection. Each strategy encompassed two or three sub strategies that were either behavioral or cognitive in nature. The data suggested that the cognitive and behavioral aspects of the strategies and sub strategies influenced each other as the women positioned themselves for acceptance. Contextual concepts, health care system, sexual intimacy and social network were in dynamic relationship with all the concepts both influencing and being influenced by the BSP. An accepting social network was the desired outcome of positioning for acceptance, but at the same time the response of people within this network influenced the strategies the women employed while positioning for acceptance.

CHAPTER V

DISCUSSION

The purpose of this study was to discover how women with HIV infection manage their relationships. The participants revealed that the diagnosis of HIV infection was accompanied by an experience of betrayal which led to feelings of shame and isolation. Positioning for acceptance was constructed as the basic psychological social process (BSP) used by the women in order to reconnect in relationships. The process involved four behavioral and cognitive strategies that were intended to decrease rejection and increase the possibility of being well received by others. The identified strategies were manipulating the social context, finding purpose, securing supports and accommodating HIV infection. Sexual intimacy, the health care system and social networks were recognized as contextual concepts; over arching issues identified by the women that form the context for understanding and managing their relationships.

The substantive theory positioning for acceptance is dynamic. The contextual factors of social network, sexual intimacy, and the health care system are in constant interplay with strategies and sub strategies the women employ to manage their relationships. Responses of lovers, health care providers, and friends influence how a woman views herself in relationship to HIV infection. She anticipates that certain future actions will either bring her acceptance or rejection and she selects her strategies based on this assessment. If her selections produce the

predicted results she adjusts her self-perception and further strategies accordingly. The feedback is continuous and dynamic. Each of the contextual factors provides varying degrees of influence at different times, but they are interrelated.

The interrelationship between context and strategies are significant as the theory is examined in light of the existing literature. Current publications have discussed many of the strategies identified in the present study. Personal responses to shame have been explored by other authors. Shame has also been examined in light of female relationships. Positioning for acceptance takes into account the interplay between personal identify, selected strategies, and existing contextual factors. This chapter will discuss the findings of this study in light of the current literature. Conclusions will be articulated and implications for practice, education and research will be discussed.

Betrayal and Shame

Martens (2005) writes "In shame we are rejected, separated from the others and thrown back on ourselves" (p.400). Shame creates a level of self-consciousness that prevents genuine participation in relationships; the kind of participation that is necessary for human growth and the capacity to feel joy (Hartling, Rosen, Walker, & Jordan, 2004). Yet HIV infection is an illness characterized by shame; primarily due to stigma (Dickerson, 2004; Duffy, 2005). The women who participated in this study brought to light an additional shaming aspect of HIV infection; the experience of betrayal.

The recognition of betrayal brings a new understanding to the feelings of shame for women with HIV infection. Shame has been an identified component of the experience of HIV infection but it has been tied almost exclusively to stigma (Dickerson, 2004; Duffy, 2005; Pryor, 2004). Stigma brings into a woman's consciousness the fact that she possesses an attribute that

is socially unacceptable. This realization may result in shame as the woman realizes she does not measure up to basic norms (Herek, 1990, 1999). The shame imposed from stigma isolates a person from normal society; however it need not isolate a woman from others who share the same attribute. Even if she cannot fully belong to the group of all women she still shares some aspect of community with women with HIV infection (Goffman, 1963; Herek, 1990).

A woman who has been betrayed experiences a different kind of shame than the kind of shame elicited in stigma. Whisman and Wagners (2005) describe the impact of betrayal on someone who is betrayed in a relationship . While stigma is directed toward a group of people possessing a common trait, betrayal is personal. It is not the attribute of HIV infection that is scorned, but the woman herself. By withholding the fact that he has HIV infection, her lover has deceived her and failed to honor the trusting relationship. The woman interprets this to mean that her lover did not care for her as much as she had presumed. The woman comes to question her value in the relationship and her value as a person. She may consider that there is something inherently wrong with her that allowed her to be manipulated so completely. She has been played for the fool and she experiences shame (Whisman & Wagners). The personal nature of the shame of betrayal alienates a woman from a reference group and may be more isolating than the shame of stigma alone.

Although it is not identified as a major concept within this study it must be understood that all the women's experiences existed within an environment of stigma. Indeed some of the women's experiences of betrayal were rooted in stigma. Even thought none of the participants in this study knew for sure why their lovers did not disclose, the literature identifies rejection from stigma as the primary reason men won't tell sexual partners that they are HIV positive (Derlega et al., 2002). Stigma, and the shame associated with it are acknowledged factors in the

participants' daily experience of HIV infection. Betrayal is an additional element that contributes both to the experience of HIV infection and to their feelings of shame.

The literature on the experience of betrayal for women with HIV infection is scant. One study reported that all 10 participants were women who had become infected by a male partner who had withheld his diagnosis (Mphande-Finn & Sommers-Flanagan, 2007). These women acknowledged the pain of the betrayal and, like the women in the current study, experienced isolation and alienation along with a desire for accepting and supportive relationships. The predominant emotions related to betrayal in the Mphande-Finn and Sommers-Flanagan study were hurt and anger, not shame. However, because the women contracted HIV infection in what they believed to be an honest and trusting relationship, the stigma of being stereotyped as sexually promiscuous was especially painful. The pain of betrayal was reinforced by stigma.

The experience of romantic betrayal in women with HIV infection needs to be explored further. Heterosexual sex is the primary method of acquiring HIV infection for women (Divisions of HIV/AIDS Prevention & National Center for HIV/AIDS, 2007) and nearly a third of men with HIV infection do not disclose their serostatus to their main sexual partners (Sullivan, 2005). The extent of romantic betrayal among women with HIV infection is largely unknown. The current study brings this phenomenon into awareness and begins to explore the impact of betrayal on women as they manage their HIV infection.

Positioning for Acceptance

Positioning for acceptance provides a conceptual framework for understanding how the study participants managed relationships in the context of HIV infection and ensuing betrayal and shame. Specific tactics are organized under strategies and sub strategies that give meaning to the women's behaviors and cognitions. Most of the strategies and sub strategies have been

identified previously in the literature as being used successfully in response to specific issues such as stigma (Sandelowski et al., 2004; Stanley, 1999), motherhood (Sandelowski & Barroso, 2003; Siegel & Schrimshaw, 2001), social support (Brashers et al., 2004; Derlega et al., 2003; Kalichman et al., 2003; Turner-Cobb et al., 2002) and coping (Ciambrone, 2001; DeMarco, Miller, Patsdaughter, Chisholm, & Grindel, 1998; Dunbar et al., 1998). The organizing framework of positioning for acceptance gives additional meaning to these tactics and it adds to our understanding of the participants' experience in relationships.

Goffman's (1963) classic work on stigma outlines how individuals handle social disapproval. Many of the management strategies he presents are similar to those in positioning for acceptance. Some of these strategies include, moving to a location where the individual is not known by former friends, controlling information about his or her stigmatized attribute and organizing social situations to reduce the tension his or her stigma generates. Goffman's strategies correlate with the process of manipulating the social context identified by the participants in this study. Study participants changed location and controlled disclosure in an attempt to distance themselves from people who would judge them for their illness and become closer to those who would accept them for who they were.

The strategy of securing supports mirrors Goffman's (1963) description of the "own and the wise" (p.20). For Goffman the "wise" are those who are in a position to understand the struggle inherent in living with a particular stigma. The HIV positive women classified their acquaintances as either educated (wise) or ignorant (unwise). Those who were educated understood that the women were not contagious and their diagnosis did not mean they had been promiscuous or addicted to drugs. The ignorant were those who relied on stereotypes and judged the women to be undesirable or dirty. The women had to deal with the ignorant, making choices

such as hiding their diagnosis from them, ignoring or educating them. According to Goffman, managing stigma also includes developing relationships with the own, those who share the stigmatizing attribute (in this case HIV infection). In positioning for acceptance, a sub strategy of securing supports includes making decisions about how much to associate with people who are HIV positive.

Another area that Goffman (1963) explores is that of resolving the ego conflict inherent in possessing a stigmatized attribute, much the way the women employed the strategy of accommodating HIV infection. He acknowledges that an individual must reconcile a personal attribute against social standards, just like the women needed to decide if HIV infection defined their identity and or if it was merely an attribute, something to be managed while they lived the rest of their lives.

A significant difference between Goffman's (1963) work and the current study involves the area of focus. Goffman is primarily concerned with how an individual manages a personal identity in the face of stigma. The current study looks at women in relationship. In some ways the area of interest in the two studies over lap. According to relational cultural theory identity is formed and reinforced in relationship (Gilligan, 1993; Miller, 1986; Robb, 2007). It stands to reason that the strategies identified by Goffman would feature ways of interacting with others. However, the end that Goffman envisions is a healthy identity. The goal of the women utilizing positioning for acceptance is a network that includes welcoming, non judgmental relationships.

Brown (2006), like Goffman (1963), looks at how people manage shame. Her focus is on women and unlike Goffman she is not concerned with stigma or any specific cause for shame. Similar to the current study she is also concerned with relationship. She posits that shame traps and isolates women and strategies of shame resilience frees and empowers women to relate in

genuine ways. Her shame resilience theory, like positioning for acceptance, identifies both behavioral and cognitive strategies employed in pursuit of breaking free of shameful feelings and entering into more authentic relationship with others. In order to become inured against shame, women engage in strategies that, among other things, involve reaching out to others to secure support. Shame resilience also involves developing an awareness of shame, the forces behind it and the impact it has on daily living, which is comparable to the work involved in accommodating HIV infection.

Brown (2006), while focusing on relationship, does not deal with the issue of reconciling shame within a stigmatizing society. Goffman (1963) elucidates the steps in negotiating stigma but focuses primarily on individual identity. Positioning for acceptance takes into account the dual impact of HIV infection as a stigmatizing attribute that has the power to disrupt relationships. It also acknowledges that at least part of the shame experienced within the illness may have causes outside of stigma and may already represent a relationship fractured as a result of betrayal.

Comparing Brown and Goffman a question arises, what roles social network and self identity play in reconciling stigma and shame? Is an accepting set of relationships required for a healthy identity; or is a sound sense of self imperative for a satisfying social network? The answer appears to be neither and both. Relationships and personal identity constantly interact at all times. Relational cultural theory (Hartling et al., 2004; Miller, 1986; Robb, 2007) holds this dynamic interaction to be central to healthy growth and development. It is within authentic relationship that we form our identity, yet a clear sense of identity is required in order to be genuinely present within those relationships.

The cognitive and behavioral aspects of positioning for acceptance reflect the interaction of self and relationship. How a woman thinks about who she is as a woman with HIV infection affects what strategies she employs. In turn the response she gets from others as she engages in specific strategic behaviors influence her understanding of who she is in the context of her illness. This process is ongoing and dynamic, more than a simple case of cause and affect.

Conclusions

The substantive theory positioning for acceptance adds to the body of nursing knowledge by providing a unique perspective on how women with HIV infection manage their illness. The model acknowledges the dynamic interplay of social context, behavior, and cognition in managing relationships. In this way it builds on the works of Goffman, (1963) who dealt with shame and personal identity, and Brown (2006) who considered shame and relationship in the absence of stigma. The strategies employed by the women in the study are not new but positioning for acceptance relates them in new ways. They are seen not merely as ways of coping with an illness, but rather ways of coping with an illness while managing a network of social relationships.

The women in the current study stressed the importance of acceptance in their lives in order to counter act the shame and isolation they feel. There is ample literature describing shame and isolation as an almost universal experience for women living with this life threatening illness, but these experiences have been linked almost exclusively to stigma. This study gives evidence that shame may also be linked to the more personal trauma of betrayal. The response to betrayal is a set of behavioral and cognitive strategies that serve to position the women to be accepted into relationships.

In light of this theory, the choices and behaviors of women with HIV infection take on additional meaning. Acceptance can now be acknowledged as a motivating factor in decisions about health care, medication adherence, disclosure, and safer sexual practices. As such nurses now have additional knowledge and understanding with which to design and implement care for this specific group of clients. .

Implications for Practice

The results of this study may provide nurses with a better understanding of women with HIV infection and how they manage their illness. The BSP positioning for acceptance provides a framework for understanding some of the behaviors and attitudes present in the women we treat. Women with HIV infection struggle to define themselves in the midst of an illness that exists alongside betrayal, shame and isolation. They seek to engage in meaningful activity that adds purpose to their lives. They seek support from others whose knowledge of HIV infection encompasses more than fear and stereotypes. Women with HIV infection need acceptance. Many of their actions are driven by this need. The data provided by the women who participated in this study included health care as a significant contextual factor.. The system and individual providers influenced and were targeted for positioning for acceptance. An awareness of the need women with HIV infection have for acceptance and an understanding of the ways that women strive to meet this need has implications for nursing practice.

On an individual level nurses need to be cognizant of attitudes and beliefs that may hinder their efforts to be genuine and accepting with clients. A personal inventory for the presence of stereotypes and the tendency to label clients needs to be taken. Behaviors and gestures that are employed in the act of providing care need to convey respect; it is important to make eye contact, listen actively, an offer appropriate non procedural touch.

Nursing care of individuals must also take into account that a woman may make health care choices based on the need for acceptance; rather than optimal disease management. Once a day dosing of medication may be more appealing than a first line medication that has a dosing schedule that affects the dinner hour, or occurs during times she socializes with friends. Despite warnings to the contrary a woman may refuse to insist that her HIV positive partner use condoms if the behavior is perceived to indicate a lack of trust. The mere fact that a woman with HIV infection must take medication daily may be a reminder of her betrayal and reinforce feelings of shame and isolation. Advanced practice nurses; psychiatric nurse practitioners or clinical nurse specialists can develop treatment plans that acknowledge the possibility of not only stigma, but betrayal and shame.

Health care delivery systems should be established that convey understanding of the needs of women with HIV infection and examined for the presence of institutional bias. For instance; women with limited resources for travel and time may opt to get care for their children at the expense of their own health care needs. Can the system adapt in a way to provide care for women and children in conjunction with each other? Where and when is the care for HIV positive women offered? Is it in conjunction with care given for sexually transmitted infections? Are clinic rooms segregated into older areas in need of remodeling? Is there a habit of limiting pain medication to women with HIV infection because of assumptions of substance abuse? Do these practices send subtle messages of rejection and judgment?

Support groups offer an avenue for acceptance and relationship building for many women with HIV infection. The results of this study provide an understanding that despite a profound sense of isolation a woman may not find a support group appealing if the shame she experiences has a stronger relationship to betrayal than stigma. Many women experience some period of

time after diagnosis in which they choose to withdraw and avoid relationships all together. On the other hand, a number of participants indicated that support groups were helpful and decreased a sense of isolation. If support groups are available they may need to be suggested repeatedly during the course of treatment in order to capture an individual woman's readiness to engage.

From a public health standpoint there is a need to find effective ways to help women protect themselves from HIV infection. Most of the women in the study left themselves vulnerable to the illness by having unprotected sex while involved in trusting relationships. Some of the women explained that they used condoms during one night stands and more casual encounters, but not in more monogamous relationships. The women in this study indicated they believed they had no need to protect themselves in a particular relationship. Current messages about risk and prevention do not appear to be effective. Nurses who work with sexually active women need to be cognizant of the risk and aware that most women in caring relationships do not consider their sexual activity to be risky. Nurses need to assess carefully and listen to how a woman perceives the threat of HIV infection. We need to offer her realistic ways to view her relationships and protect herself. Wide scale prevention efforts need to be modified to better reach this population.

Implications for Education

The women in the study frequently referred to individuals who were "ignorant" or "uneducated." Use of this term referred to people who held stereotypes related to how people became infected; and maintained unrealistic fears about transmission. Nurses must be educated about HIV infection. This education must go beyond the basic facts given to the public at large, or the concepts included in methods to control the spread of blood born pathogens. In order to

minimize stereotypes, education should focus on risk behaviors not "at risk populations" Nurses must come to understand that every woman who is sexually active is at risk for HIV infection, not just those with multiple sexual partners or substance use problems.

Nursing education should also strive to assist practitioners in becoming aware of values and biases that impede true acceptance and caring. As it relates to the treatment of women with HIV infection this needs to focus on issues related to minority populations, sexuality, drug use, and issues of class and socioeconomic status. It is not enough to teach about diversity; students must have an opportunity to learn to integrate acceptance of diversity within existing personal values and beliefs.

Advanced practice psychiatric mental health nurses might be better able to help women with HIV infection if they expand their understanding of shame and relationship betrayal. Though scant, current literature such as Brown's (2006) study of shame resiliency explores the idea from the perspective of feminine relationships (Johnson, 2006; Panos, 2002). Shame within the context of HIV infection has been exclusively associated with stigma. Understanding the interrelationship of shame, stigma, and betrayal provides a broader base for counseling women with HIV infection.

Implications for Research

This study provides new understanding of how women with HIV infection manage their relationships. Betrayal has been identified as a common experience and the interplay between relationships, behavior and social context has been articulated. As with all new knowledge, greater understanding of a phenomenon also poses new questions that give way to future research. Research questions arise related to shame and betrayal, health care delivery and theory.

Identification of betrayal as a common experience gives rise to several questions for further investigation. One question is how common is the experience of betrayal for women with HIV infection? Was this an event unique to this particular sample of women or is it a widespread phenomenon? If it is a widespread phenomenon then is there a relationship between betrayal, shame and health outcomes? Does the shame of betrayal influence health care and disease management choices for women with HIV infection? And what impact, if any, can nurses have on a woman's experience of shame and acceptance?

Most of the women in the current study spoke favorably about their health care providers. They spoke of their providers as accepting. All of the women who participated in this study received care from the same clinic. Why did the participants feel so accepted by their health care providers? What is it about the care they received? Is there something about the health care delivery at this clinic that promotes acceptance? Do health outcomes of women who receive care from providers they label as accepting differ from outcomes for women who do not believe their health care providers accept them? All these questions could serve as the basis for further scientific inquiry.

A substantive theory has been constructed from the data provided by the women who participated in the study, but the theory needs to be further articulated. Broadening the scope of the study to include greater geographic areas could help to refine the concepts and the nature of the relationships between contextual factors and strategies employed by the women. The concept of stigma was not directly addressed in this study. No questions about stigma were asked of the women and its role as a contextual factor was not made explicit. The role of stigma within positioning for acceptance needs to be clarified.

Lastly, the theory needs to be tested. The concepts need to be operationalized and methods for testing need to be devised. For instance, is the isolation that is felt due to the shame of betrayal quantitatively different from isolation experienced as a result of the shame of stigma? Are certain strategies more successful than others? Do women tend to utilize the strategies in any particular sequence? Do any of the contextual factors have a greater influence on behavior? Are there any nursing interventions that have a positive influence on the use and success of specific strategies? Does this same phenomenon of managing relationships exist with gay men or women of other cultures?

Summary

HIV infection continues to be a significant health problem for women. Fortunately treatment advances in the last decade have extended life expectancy and quality of life considerably. Ways in which mental health, well being and continued personal growth can be maintained in the face of HIV infection need to be explored. While the literature on women with HIV infection is vast, little attention has been devoted to how women manage their relationship in the context of this illness.

Using grounded theory methodology the investigator interviewed 14 women who shared personal experiences about their relationships since learning they were HIV positive. Common to all the women's stories were experiences of betrayal and feelings of shame. Isolation and feeling disconnected were issues that needed to be dealt with on a regular basis. Their stories revealed the strategies they used to manage their relationships. The investigator analyzed these stories and constructed a basic psychological social process of positioning for acceptance. Positioning for acceptance involved four strategies each with two or three sub strategies utilized

by the women to reduce the possibility of rejection and increase the likelihood of being favorably received.

Goffman's (1963) description of managing stigma and Brown's (2006) theory of shame resilience described strategies similar to the ones identified in the current study, but positioning for acceptance provides a more thorough explanation how the women in the study managed their relationships. Positioning for acceptance also acknowledges the mutual interaction between the social environment and the strategies employed to manage relationships. Relational cultural theory supports the evidence demonstrating the constant interaction between the social network and the strategies of positioning for acceptance. The study provides implications for practice, education and future research.

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APPENDIX I

Recruitment Flyer

Recruiting Women with HIV Infection to Join a Research Study

Women 18 years age or older who are HIV positive are being asked to participate in a research study about relationships

The study involves talking with a nurse for about an hour about personal relationships

If you are interested please tell your social worker or nurse
or call
Mallie Kozy RN at 419 383 5805

You will receive $20 at the end of the interview in appreciation for your participation

APPENDIX II

Instructions to Agency Staff about Research Study

Thank you for helping to recruit participants for this research study with women with HIV infection.

Purpose of the Study: To explore how women with HIV infection manage the relationships in their lives.

What it Involves: If a woman agrees to participate in the study she will be asked to speak with the study investigator for approximately 1-2 hours at a time an in a setting of the woman's choice. She will be asked questions about her personal relationships and how HIV infection has affected those relationships. Her interview will be audio taped.

Protecting the women's privacy: ALL INFORMATION GATHERED DURING THE STUDY WILL BE CONFIDENTIAL AND, EXCEPT FOR THE CONSENT FORM, THE WOMAN'S NAME WILL NEVER APPEAR IN ANY ASPECT OF THE STUDY.

The Benefits to Nursing: To help nurses understand more about women with HIV infection and their relationships so nurses can design interventions and offer support to women that strengthen and maintain relationships.

The Benefits to Clients: There is no guarantee that the participant will benefit from the study but $20 will be given to each participant at the end of the interview in appreciation for her time and cooperation.

Any Questions? Please call Mary Kozy at 419 383 5805

APPENDIX III

Semi-Structured Interview Questions

Questions 1- 7 represent the initial questions that will guide the interview with the participants. Additional questions will serve as probes to help guide the interview in such a way as to facilitate answering the research questions. As data collection progresses it is anticipated that the form of the questions will be modified.

1. Tell me about the relationships in your life.
    a. Talk to me about some of the important people in your life?
    b. In what ways are these people important?
    c. What kinds of people do you spend most of your time with?
    d. Who are the people with whom you would like to spend more time?
    e. Are there any reasons you can think of why you spend so much time with certain people and not enough time with other people?
    f. With whom do you feel comfortable?
    g. With whom do you feel ill at ease?
    h. How do you decide with whom you will spend your free time?
2. Tell me what it has been like for you since you have learned about your HIV infection.
    a. In what ways has HIV infection affected your life?
    b. How are your days different now? What do you do differently than you did before?
    c. In what ways do you think or feel differently about your self since you learned you have HIV infection
3. Tell me how learning about HIV infection has affected the relationships with the people in your life. .
    a. For instance, in what ways are your relationships different?
    b. In what ways do you act differently with the people in your life?
    c. In what ways do people act differently with you?
    d. Tell me the ways that you might think or feel differently about people now.
    e. Are there people with whom you spend more or less time than you did before you learned of your HIV infection? How do you feel about those changes?
4. What are some of the biggest obstacles that you face right now?
    a. What are some of the things in your life that are particularly difficult?
    b. What part, if any, does HIV infection play in trying to deal with these challenges?
5. In what ways is life better since you learned that you have HIV infection?
    a. What are some of the things you enjoy doing now?
6. How do you think you are doing managing your HIV infection?

APPENDIX IV

Demographic Data Collection Sheet

The following data will be collected during the interview with the respondent. Oral responses will be sought.

Date of Interview: Participant #:
Age:
Ethnicity:
Marital Status
Relationship with significant other:
Number of Children:
- Ages of children:
- Number of Children in the Home:
- Number of children living outside the home

Living status:
- Alone
- With others
  - Husband or significant other:
  - Parents
  - Siblings
  - Friends/other

Employment status:
- Full time
- Part time
- Not employed

Religious or spiritual affiliation:
Time since diagnosis of HIV infection:
Current medications for HIV infection:
How would you describe your current state of health?

Appendix V

Duquesne University
600 Forbes Ave
Pittsburgh, PA 15282

University of Toledo
3000 Arlington Ave
Toledo, OH 43614

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: **HOW WOMEN WITH HIV INFECTION MANAGE THEIR PERSONAL RELATIONSHIPS**

PRINCIPLE INVESTIGATOR: Mary Alderman Kozy MSN APRN, BC
University of Toledo, College of Nursing
3015 Arlington, Ave
Toledo, OH 43614
419-383-5805

ADVISOR: Dr. Rick Zoucha RN
Duquesne University, School of Nursing
521 Fisher Hall
Pittsburgh, PA 15282
412-396-6545
zoucha@duq.edu

What you should know about this research study:

- We give you this consent/authorization form so that you may read about the purpose, risks and benefits of this research study. All information in this form will be communicated to you verbally by the research staff as well.
- Routine clinical care is based upon the best-known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.
- We cannot promise that this research will benefit you. Just like routine care, this research can have side effects that can be serious or minor.
- You have the right to refuse to take part in this research, or agree to take part now and change your mind later.
- If you decide to take part in this research or not, or if you decide to take part now, but change your mind later, you decision will not affect your routine care.
- Please review this form carefully. Ask any questions before you make a decision about whether or not you want to take part in this research. If you decide to take part in this research, you may ask any additional questions that you may have at any time
- Your participation in this research is voluntary.

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in Nursing at Duquesne University.

NO TEXT THIS PAGE

PURPOSE: You are being asked to take part in a research of women with HIV infection. The purpose of the study is to discover how women with HIV infection manage their personal relationships. A total of 15-20 women will participate in this study. You were selected as someone who may want to take part in this study because you are a woman living with HIV infection.

DESCRIPTION OF THE RESEARCH: If you decide to take part in this study, you will be asked to interview with the primary investigator to answer questions about how you manage your personal relationships. You will be asked to permit me to tape record your answers, without use of your name.

The interview should last a maximum of one hour. A possibility exists that you may be asked to have a second interview to clarify and expand on some of your answers you provided in the first interview. If you are asked and consent to a second interview you may choose a site for the interview that is convenient, private and comfortable, such as your home, a room at a church, or an office at University Medical Center. You will be asked to sign a second consent form before the second interview. In the second interview you will again be asked to permit me to tape record your answers without the use of your name. The second interview will last a maximum of one hour. If you are asked to have a second interview you will be contacted within six months of today's date. After all interviews are complete, the findings may be published in order to assist nurses in helping others with HIV, however no names or other identifying information will be used in any reports or publications.

RISKS: Potential risks for participating in the study are minimal, but may include emotional distress in remembering certain things about your illness. This research poses no known risk to unborn children.

BENEFITS: We cannot and do not guarantee or promise that you will receive any benefits from this research, however, you may have a sense of satisfaction about talking about your illness and helping future women with HIV infection receive better nursing care.

COST TO YOU: The primary investigator assumes financial responsibility for taping and transcribing the interviews. Taking part in this research study will require no cost to you.

COMPENSATION: If you decide to take part in this research you will receive $20 at the end of every interview that you complete in appreciation for your time.

CONTINUE ON NEXT PAGE

CONFIDENTIALITY: By agreeing to take part in this research study you give to the Duquesne University, University of Toledo University Medical Center, the Principal Investigator and all personnel associated with this research study, your permission to use or disclose health information that can be identified with you that we obtain in connection with this study. We will use this information for the purpose of conducting the research study as described in the research consent form.

The information we use will be the content of your interview. Your name will never appear in the typed transcript of your interview. No personal identity will be made in the data analysis. In published reports of the research findings your responses may appear as verbatim quotes but no identifiers will ever be attached. Under some circumstances the Institutional Review Board and Research and Grants Administration of the University of Toledo and the Institutional Review Board and the Office of Research at Duquesne University may review your information for compliance purposes. You will be offered your tape after it has been transcribed and the data verified. If you do not want your tape it will be destroyed. All copies of the transcripts will be destroyed seven years after the end of all activities related to this research study.

The University of Toledo and Duquesne University are required by law to protect the privacy of your health information and to use or disclose the information we obtain about you in connection with this research study only as authorized by you in this form. There is a possibility that the information we disclose may be disclosed by the person we give it to, and no longer protected. However, we will encourage any person who receives your information from us to continue to protect and not re-disclose the information. The person who types your transcript will be required to sign a statement agreeing to keep all information from the interview confidential.

Your permission for us to use or disclose your personal health information as described in this section is voluntary. However, you will <u>not</u> be allowed to participate in the research study unless you give us your permission to use or disclose your personal health information by signing this document.

You have the right to revoke (cancel) the permission you have given to us to use or disclose your personal health information at any time by giving written notice to the primary investigator, Mary Kozy at the University of Toledo College of Nursing, 3015 Arlington Ave., Toledo, OH 43614, 419 383 5805. However, a cancellation will not apply if we have acted with your permission, for example, information that already has been used or disclosed prior to the cancellation. Also a cancellation will not prevent us from continuing to use and disclose information that was obtained prior to the cancellation as necessary to maintain the integrity of the research study.

Except as noted in the above paragraph, your permission for us to use and disclose personal health information has no expiration date.

A more complete statement of the University of Toledo's Privacy Practices are set forth in its Joint Notice of Privacy Practice. If you have not already received this Notice, a member of the research team will provide this to you. If you have any further questions concerning privacy, you may contact the person identified in the Notice.

RESEARCH RELATED INJURY: In the unlikely event of injury resulting from your taking part in this study, treatment can be obtained at a health care facility of your choice. You should understand that the costs of such treatment will be your responsibility. Financial compensation is not available through Duquesne University, or the University of Toledo University Medical Center. In the event of the injury

please contact Mary Kozy at 419-383-5805. Rescue Mental Health runs a 24 hour help line at 419 255 5925 should you experience emotional distress from discussing your illness and need to talk with someone.

VOLUNTARY PARTICIPATION: Taking part in this study is voluntary. If you decide not to take part in this study your decision will not affect your future relations with Duquesne University, the University of Toledo University Medical Center, its personnel, and associated hospitals or the HIV support groups. If you do decide to take part in this research, you are free to withdraw your consent and to discontinue your participation at anytime without any consequences to you.

NEW FINDINGS: You will be notified of new information that might change your decision to be in this study if any becomes available.

SUMMARY OF RESULTS: A summary of the results may be supplied to you, at no cost, at your request. This may take several years.

CONTINUE ON NEXT PAGE

OFFER TO ANSWER QUESTIONS:

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

SIGNATURE SECTION PLEASE READ CAREFULLY

You are making a decision whether or not to participate in this research study. Your signature indicates that you have read the information provided above, you have had all your questions answered, and you have decided to take part in this research.

BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PERSONAL HEALTH INFORMATION AS DESCRIBED IN THIS FORM

The date you sign this document to enroll in this study, that is today's date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study, but do not reflect how long you may participate in the study. Each page of this Informed Consent/Authorization Form is stamped to indicate the form's validity as approved by the University of Toledo University Medical Center and Duquesne University Institutional Review Boards (IRB).

_____	_____	_____
Name of Participant (Please Print)	Signature of participant or Legally Authorized Representative	Date

_____	_____
Relationship to Participant	Time AM/PM

If it is OK to be contacted for an additional interview, please give your telephone number (otherwise leave blank).

PHONE_____

Would you like to receive results of the study (please circle)? **YES NO**

Would you like to receive the tape from the interview or have the tape destroyed by the investigator (please circle)?

DESTROY TAPE **PROVIDE TAPE TO PARTICIPANT**

If it is OK to be contacted for an additional interview and if you want either the results of the study or the tape, or both and you DO NOT HAVE A PHONE please provide your address. A notice will be sent asking you to contact the primary investigator for an interview or to receive your tape or the study results. The primary investigator will hand these items directly to you. They <u>will not</u> be sent through the mail.

_____	_____	_____
Street address	City, State	Zip Code

_____	_____	_____
Name of person obtaining consent (Please Print)	Signature of person Obtaining Consent	Date

_____	_____	_____
Name of Witness to Informed Consent (When Required) (Please Print)	Signature of Witness to Informed Consent (When Required)	Date

YOU WILL BE GIVEN A COPY OF THIS <u>SIGNED</u> FORM TO KEEP

If you have any questions concerning this study or consent from beyond those answered by the investigator, including questions about the research, your rights as a research participant or research – related injuries, please feel free to contact the Dr. Roland Skeel, Chair of the University of Toledo University Health Science Campus Institutional Review Board at 419 383-6796, Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board at 412 396 6454, Mary Kozy at 419 383 5805, or Dr. Rick Zoucha at 412 396 6545.

APPENDIX VI

Transcriptionist's Consent to Confidentiality

I understand that as a transcriber for a study being conducted by Mary A Kozy of the School of Nursing, Duquesne University, under the supervision of Professor Zoucha, I am privy to confidential information. I agree to keep all data transcribed during this study confidential and will not reveal it to anyone outside the research team. I will return all documentation and audiotapes to Mary A Kozy and delete the original transcription from the hard drive of my computer whenever she instructs me to do so.

Signature: ---------- Date: ----------

Witness: ---------- Date: ----------