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WHAT INEZ KNOWS: A QUALITATIVE, LONGITUDINAL CASE

STUDY OF ONE WOMAN'S JOURNEY THROUGH THE MAZE OF LIVING

WITH HIV AND A SERIOUS MENTAL ILLNESS


by

Linda Austin


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WHAT INEZ KNOWS: A QUALITATIVE, LONGITUDINAL CASE STUDY OF
ONE WOMAN'S JOURNEY THROUGH THE MAZE OF LIVING WITH HIV
AND A SERIOUS MENTAL ILLNESS

by

Linda Austin

The University of Wisconsin-Milwaukee, 2014
Under the Supervision of Professor Patricia E. Stevens

Although more than thirty years have passed since AIDS was first diagnosed in the

U. S., the HIV/AIDS epidemic continues and the prevalence and incidence statistics

remain alarming. Twenty-five percent of the people living with HIV in the United

States are women, but only half of these women are in care and even fewer women

(42%) have viral suppression. Women of color continue to carry a disproportional

disease burden with African American women comprising 64% of newly reported

HIV cases in women in 2010. HIV prevalence among adults with a serious mental

illness range from 3-23% compared to the general population prevalence (.4-.6%).

Based on these facts, there is continuing need to explore the dual experience of HIV

infection and serious mental illness in women. Research that focuses on the women

and seeks to understand the particulars of their lives may offer greater insight into how

the health care community can improve their outcomes. Inez (pseudonym) is an

African American woman dually diagnosed with HIV infection and a severe and

persistent mental illness. She was one of 55 participants in the qualitative study, *In-
Depth Longitudinal Study of HIV-Infected Women* (National Institutes of Health, Grant

#R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN). In this

secondary analysis, her narrative data were segregated from the original study,

analyzed, and used to develop an in-depth, longitudinal case study. The purpose of this

study was to uncover Inez's perceptions of what it means to live with HIV and a serious mental illness. Through this single case study replete with experiential detail from two years of interviews, we are given an extraordinary view into how one individual lives with HIV and a serious mental illness, what she needs from the health care community to successfully manage her illnesses, and how mutually respectful relationships built over time are key to overcoming internalized and enacted stigma. Inez's story confirms the importance of therapeutic, respectful communication, and stability of care provided in an environment of cultural safety where the perspectives of health care consumers are prioritized. In addition to these practice implications, this research-based case study could be used in problem-based classroom learning environments to inspire students to consider ways to improve the experiences of women who are similar to Inez.

**α**

To the women who shared their stories in the original study,
To Inez who is the heart of this current study,
I give thanks.

To Pat who offered enduring guidance and patience,
To all committee members and colleagues who shared in this experience,
I give thanks.

To my friends from the four corners of our world,
To my family who are the center of my world,
I give thanks.

**Ω**

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Chapter 1

There are approximately 270,000 women in the United States living with HIV, with women of color disproportionally represented in that number (Centers for Disease Control and Prevention, 2013, 2014b). There are approximately five million women over the age of seventeen in the United States living with a serious mental illness diagnosis (National Institute of Mental Health, 2012). While it is not known how many of these women are seropositive, HIV prevalence among adults with a serious mental illness is estimated to range from 3-23% compared to the general population prevalence (.4-.6%) (Agenor & Collins, 2013; Blank et al., 2011). These estimates represent a group of women who are under recognized in HIV research and thus their voices are silent. Using a qualitative feminist approach, I explored the experiences of one woman who was dually diagnosed with HIV and a serious mental illness by conducting a secondary analysis of a subset of data from *An In-Depth Longitudinal Study of HIV-Infected Women* (National Institutes of Health Grant 1R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN).

*Statement of the Problem*

In 2011 the Centers for Disease Control and Prevention (CDC) (2014b) reported a slight decrease in the number of newly diagnosed HIV cases in women. Of the estimated 47,500 newly diagnosed cases in the United States, 20% were women. A decade ago, women represented 28% of the estimated number of newly diagnosed HIV cases in the United States. This same report revealed that of the women who were diagnosed and linked to care, approximately one half of them remained in care after one year and only 42% achieved viral suppression. Historically these statistics

compared unfavorably with what was found in the male population, who experienced a steady decrease in incidence until 2010 when the number of newly diagnosed males increased but decreased in the female population (Centers for Disease Control and Prevention, 2014a). These numbers can be interpreted to show that the HIV epidemic has not been contained in any population, but that there continues to be an ebb and flow to the numbers of new cases. Until the epidemic is controlled, further research may provide clues about how the lives of those affected by HIV can be improved.

The statistics about mental illness are equally disconcerting. Serious mental illnesses are those that carry the greatest degree of disability and are persistent across the life span. The disorders classified as serious, often with the additional descriptor "persistent," include schizophrenia and other psychotic disorders, bi-polar disorders, and major depressive disorders (Walkup, Satriano, Berry, Sadler, & Cournos, 2002). It is estimated that 9.6 million adult U. S. citizens carry a serious mental illness diagnosis and more than one half of this number is women (National Institute of Mental Health, 2012). The burden of serious mental illness was defined in the *Global Burden of Disease Study,* a collaborative effort of The World Health Organization (WHO), the World Bank, and Harvard University. This group estimated that the burden of serious mental illness, measured as Disability Adjusted Life Years (DALY) or the sum of the years of life lost due to premature death and years lost due to disability, accounts for 15 % of the total disease burden in established market economies. To put this number into perspective, 15% is greater than the disease burden of all cancers (National Institute of Mental Health, 2012; The World Bank Group, 2006).

The statistics for women who are HIV positive and carry a serious mental illness diagnosis were difficult to determine, mainly because gender differences are not well reported in the statistical literature (Cournos & McKinnon, 1997). What is known is that individuals who have a serious mental illness are at an increased risk for acquiring HIV when compared to the general population (Agenor & Collins, 2013; Birch, Lavender, & Cupitt, 2005; Blank et al., 2011; Bogart et al., 2006; Cournos, McKinnon, & Rosner, 2001; Meade & Sikkema, 2005; Rosenberg et al., 2003; Satriano, McKinnon, & Adoff, 2007) and that women carry an equal (Rosenberg et al., 2001) or slightly higher risk (Stoskopf, Yang, & Glover, 2001) then men. The HIV prevalence rate is estimated to be nine times greater in the seriously mentally ill population than in the general United States population (Rosenberg et al., 2003), but this rate increases significantly when sub-groups, such as homeless individuals or individuals in drug addiction centers are reported (Cournos & McKinnon, 1997). The explanation for these findings is related to both contextual and psychiatric factors. Contextually, this population is more likely to be homeless or have transient living arrangements, to be socially and economically marginalized, and to experience frequent hospitalizations that interrupt stable relationships (Cournos et al., 2001; Dyer & McGuinness, 2008; Meade & Sikkema, 2005). The psychiatric factors include impaired judgment coupled with poor impulse control, increased incidence of substance use or misuse, impaired communication skills, and impaired reality testing (Cournos et al., 2001; Devieux et al., 2007; Dyer & McGuinness, 2008; Weiser, Wolfe, & Bangsberg, 2004). When combined, these factors increase the individual's vulnerability to acquiring HIV (Dyer & McGuinness, 2008).

It is not known how stigma complicates the lives of HIV-infected women who have a serious mental illness, but stigma has been documented in the extant literature as a force in the lives of women who carry a stigmatizing condition such as HIV or mental illness. The outcomes of stigma have been identified and include discrimination, prejudice, and lost opportunities (Chernomas, Clarke, & Chisholm, 2000; Khakha, 2003; Kinch & Jakubec, 2004; Rosenfield, 1997; Stevens & Hall, 1988; Walker, 2002), rejection and shame (Chernomas et al., 2000; Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002), stereotyping and social distancing (Buseh & Stevens, 2006; Lee, Kochman, & Sikkema, 2002; Reif, Mallinson, Pawlowski, Dolan, & Dekker, 2005; Shambley-Ebron & Boyle, 2006b), and fear of disclosure (Shambley-Ebron & Boyle, 2006b; Wahl, 1999a). Additionally, The New Freedom Commission on Mental Health (2003) identified stigma as a barrier that individuals must cross to access health care.

Given the above statistics and research findings, it remains unknown how women who live with both diagnoses perceive their health care experiences. Further, it is not clear how the women respond to their stigma experiences. As a psychiatric nurse generalist and as a nurse educator, I am convinced that the significance of this problem and the implications for this lack of knowledge transcends these statistics and research findings. From the perspective of a psychiatric nurse, I find the lack of knowledge about HIV-infected women who have a serious mental illness troublesome and question how patient outcomes are influenced by what is unknown. From the perspective of a nurse educator, I wonder what students are missing in their education

that should prepare them to provide high-quality, holistic care to all patients, including these vulnerable women.

*Purpose of the Study*

The purpose of this study was to conduct a secondary analysis of the life stories of Inez (pseudonym), an African American woman dually diagnosed with HIV infection and a severe and persistent mental illness, as told in a series of ten interviews over two years with particular attention to her health care and stigma experiences. The stories that emerged from this analysis were translated into knowledge that will be useful to nursing and other professions that provide health care to women as they manage the complexities of their lives.

The research questions that guided this study were:

• How does a HIV-infected woman who has a serious mental illness describe her health care experiences?

• How does a HIV-infected woman who has a serious mental illness describe stigma experiences and her responses to those experiences?

Chapter 2

The health care experiences of HIV-infected women who carry a serious and persistent mental illness diagnosis are tangled together with the singular experiences of having HIV and having a serious and persistent mental illness. These experiences were pulled apart to gain insight into the threads that make up the tangle and presented as a prologue to the exploration of the center of the tangle, i.e., what is known about the health care experiences of HIV-infected women who have a serious and persistent mental illness. However a discussion of the nature of stigma must come first because references to stigma are woven throughout the health care experiences literature, and stigma is presented as a "central force" (Fife & Wright, 2000, p. 229) against which the women must contend.

*Review of Stigma Literature*

An examination of the stigma literature usually begins with Goffman (1963), and his theoretical description of stigma as a spoiled identity. It is this theory that has served as the foundation for stigma research by the social sciences to explore stigma and mental illness (Corrigan, 2000; Dickerson et al., 2002; Holmes & River, 1998; Wahl, 1999a), and the stigma of HIV/AIDS (Herek, 1999; Poindexter & Linsk, 1999; Relf, Mallinson, Pawlowski, Dolan, & Dekker, 2005; Sandelowski, Lambe, & Barroso, 2004). Although Goffman's (1963) theory is from a sociological perspective, and, as such, is concerned with the study of a stigmatized person's "corporate life," (p. 22), he suggests that a "language of relationships" (p. 3) is necessary to the understanding of stigma within a society. Thus stigma must be revealed on both a cultural or societal level and on an individual level (Herek et al., 1998). In the context

of relationships, those who are stigmatized manage their relationships based on a dual perspective of stigma. These perspectives are that the stigmatizing condition is either evident or visible upon entering a relationship, or it is covered or not perceived by others upon entering the relationship (Goffman, 1963). HIV infection and some mental illnesses are usually unseen stigmas, although symptoms of advanced disease processes may make the disorders visible or discredited. Individuals with HIV infection and/or mental illness manage their relationships through social withdrawal, selective or discriminate disclosure (Buseh & Stevens, 2006; Holmes & River, 1998; Poindexter & Linsk, 1999; Shambley-Ebron & Boyle, 2006b), living a secretive life (Ingram & Hutchinson, 1999; Relf et al., 2005), or holding silent (Sandelowski et al., 2004).

*Defining the Components of Stigma*

A conceptualization of stigma that expands on Goffman's (1963) suggestion that stigma is a relationship between attribute and stereotype is provided by Link and Phelan (2001). These authors propose that stigma is the interrelationship of six components: labeling, stereotyping, separation into categories, status loss, discrimination, and a power hierarchy. Without power labels, stereotypes and categories are benign, and status loss and discrimination cannot exist. A discussion of each component follows.

*Labeling.* A basic assumption of any stigma definition is that for stigma to exist, something is deemed different from what is considered the norm. This component of stigma is an evolution of Goffman's (1963) terminology. Goffman used mark or attribute as a definition for the difference, the stigma, found in an individual.

An attribute is an inherent characteristic that is closely associated with an individual (*Merriam-Webster's Collegiate Dictionary*, 2003) and this term positions the difference in the individual. Labeling connotes that the stigma is affixed to the individual by others, and thus labeling places responsibility for assigning the stigma outside the stigmatized individual (Link & Phelan, 2001). Labeling is relational and changes within different social contexts (Crocker, Major, & Steele, 1998), such as how the label "witch" is considered today versus in the 1600's. The consequences of being labeled can lead to another component of stigma, stereotyping.

*Stereotyping.* When a label is linked to a set of undesirable characteristics, a stereotype of the stigmatized target is created. These stereotypes facilitate "cognitive efficiency" (p. 369) and may be useful when making split-second decisions (Link & Phelan, 2001). This cognitive representation of stigma is usually from the perceiver's point of view (Ottati, Bodenhausen, & Newman, 2005) but may be internalized by the targets of the stereotype and is known as self-stigma (Corrigan & Kleinlein, 2005) or internalized stigma (Lee et al., 2002). Stereotypes are unjustified in that they reflect inaccurate thought processes such as over generalizations, are based on an incomplete set of facts, are rigidly applied without consideration of individual differences among group members, and are used as a rationalization for a prejudicial attitude or discriminatory behavior (Biernat & Dovidio, 2000). If a difference is labeled as undesirable and is then linked to a stereotype, the next component of stigma becomes evident. The individual is separated from the in group, those who are labeled normal, and an environment of "us" versus "them" is set in place (Link & Phelan, 2001).

*Separation.* This component of stigma has roots in social identity theory. This theorist proposes that separation from others and affiliation with a specific group shapes an individual's social identity, which is the part of a person's self-concept that comes from the knowledge of being a member of a group and the value and emotional significance of that membership (Tajfel, 1982). Members of the in group, the group that is positively stereotyped or labeled normal, establish a social identity that focuses on the differences between the two groups and ignores the similarities. This focus on differences becomes the rationalization for devaluing, rejecting, and excluding members of the negatively stereotyped group (Link & Phelan, 2001).

*Status loss and discrimination.* In an environment of separation or a mind set of "Us" and "Them" the focus is on differences and away from similarities. This environment is often adversarial (Devine, Plant, & Harrison, 1999) and is ripe for the surfacing of discrimination and status loss (Link & Phelan, 2001). Status loss and discrimination speak to devaluing, rejecting, and excluding others. When individuals are labeled as possessing an undesirable characteristic and then separated into a "Them" group, they are then perceived as residing in a lower status station; the person is not just different but is viewed as "less" (Link & Phelan, 2001). This lessening of a person is a prejudicial affective response that leads to discriminatory practices, or negative behavioral responses (Ottati et al., 2005).

There are two categories of discrimination, individual and structural (Link & Phelan, 2001). An example of individual discrimination is when a woman with schizophrenia is refused housing, and structural discrimination is when an HIV-infected woman cannot get her medications because funding for her drug assistance

program has been cut while other programs remain fully funded. The discrimination experiences of individuals with a mental illness include the loss of rightful opportunities such as housing and employment, distorted experiences with the criminal justice system, and discriminatory practices within the health care system, including denial of insurance and limited access to care (Corrigan & Kleinlein, 2005; Jensen, 2004; Lundin, 1998). HIV-infected women initially experienced discrimination in that they were not included in diagnostic guidelines for AIDS until 1993 (Bunting, 1996) and in fact were mostly ignored at the beginning of the HIV epidemic (Barroso & Powell-Cope, 2000; Stevens, 1995). Documented discriminatory practices against and lost opportunities for HIV-infected individuals include mistreatment and indifference from health care providers, pressure from health care providers to forgo having children, decreased housing and employment opportunities, lack of social support, and denial of health insurance (Carr & Gramling, 2004a; Chesney & Smith, 1999; Ingram & Hutchinson, 1999; Woodhead, 2003). These lists of discriminatory practices are not exhaustive, but are representative of what is reported in the HIV and mental illness literature.

*Power.* "Stigma is entirely dependent on social, economic, and political power—it takes power to stigmatize" (Link & Phelan, 2001, p. 375). In the absence of a power hierarchy stigma cannot exist because it is power that supports the consequences of the discriminatory practices that spring from labeling, stereotyping and separating. To have power a group must have the ability and resources to impact the outcomes of another group, such as when one group controls housing opportunities or health care accessibility or treatment options (Khakha, 2003). Additionally, the

relationship between the groups must be involuntary. This involuntary relationship is seen between patients and health care providers when there are limited choices of health care providers (Jones et al., 1984).

*Dimensions of Stigma*

The identification of the components of stigma is one layer of understanding stigma. Another layer of understanding is found in the dimensions of stigma. The components of stigma could be likened to threads of a tapestry that are woven together to create a durable, strong covering. If one thread is broken, absent, or not woven into the tapestry, the tapestry looks different. All of the threads (components) are necessary to the creation of a strong covering (stigma). To extend this image of stigma as a tapestry, dimensions of stigma could be likened to the variations within the tapestry. The tapestry (stigma) exists, but an examination of the tapestry reveals variations (dimensions) that are embedded in the construction of the tapestry (stigma). The image of a tapestry was chosen not because stigma is a beautiful creation such as the tapestries that hang in museums, but because tapestries are one of the heaviest coverings that can be imagined.

Link and Phelan (2001) took Goffman's (1963) caveat that stigma needed a language of relationships and applied it to the relationships among the components of labeling, stereotyping, separation, status loss, discrimination, and power. From the psychological perspective Jones, et al (1984) expanded Goffman's theory and applied this caveat to the role of stigma in interpersonal relationships. The authors identified six dimensions of stigma that are present in relationships and are found in varying degrees depending on the specific stigma. These dimensions are concealability,

course, disruptiveness, aesthetics, origin, and peril and are considered in the context of how interruptive they are to interpersonal relationships.

*Concealability.* This dimension is similar to Goffman's description of discredited or discreditable (1963) as mentioned previously. However concealability also refers to the extent to which the mark (the term used by the authors to describe a stigma) can be hidden or controlled. When the option for concealment is present, those who are marked tend to exercise the option (Jones et al., 1984) through explaining away the signs of the stigma (Shambley-Ebron & Boyle, 2006b), living a secret life that involves lying about the stigma (Anderson & Doyal, 2004; Hayne, 2003), and strategic disclosure of the stigma (Buseh & Stevens, 2006; Chernomas et al., 2000).

*Course.* Course speaks to the expected pattern of the mark over time, i.e., will the mark improve, get worse, or stay the same? A stigma that is expected to improve or disappear, such as adolescent acne, causes less interruption to a relationship than a stigma that is expected to be permanent or fatal, such as a serious mental illness or HIV infection.

*Disruptiveness.* The extent to which a mark interferes with an interpersonal relationship is known as disruptiveness. According to Jones, et al (1984) this dimension differs from the others in that disruptiveness is less dependent on the presence of the other dimensions, is not clearly defined, and is not attended to by all students of stigma research. Therefore, the authors concede that the utility of this dimension is questionable. However disruptiveness is noteworthy when considering the stigma of mental illness. This dimension is said to be present in individuals who have a behavior that interferes with a relationship, such as stuttering or the poor eye

contact or unpredictable behaviors such as may be seen in individuals who have a mental illness.

*Aesthetics.* This is the primitive affective response to the mark and asks the question, "Is the mark repulsive?" The response to this dimension is rejection, revulsion, and disgust. Although health care providers may attempt to cover or hide their affective response to a stigmatized individual, the attempt may be sabotaged by the provider's nonverbal behaviors such as when a HIV-infected woman reports that health care providers "All of a sudden they got to put gloves on before they can talk to you" (Buseh & Stevens, 2006).

*Origin.* Origin of the stigmatizing condition is an evaluation of whether or not the individual who has the mark is somehow responsible for that condition. This dimension of stigma would be different for the individual who was infected by HIV through a blood transfusion versus the individual who was infected through a shared needle while injecting illegal drugs.

*Peril.* This is the last dimension. It is an evaluation of whether or not the mark presents a threat to others (Jones et al., 1984). This dimension is relevant when considering individuals with a mental illness because of the perception of unpredictable behavior and when considering individuals with a contagious disease such as HIV infection.

Just as the health care experiences of HIV-infected women with a serious mental illness are not easily seen but are tangled together with other experiences, the definition of stigma is not easily seen but is veiled under multiple layers. It is not sufficient to merely uncover the components and dimensions of stigma to determine a

definition, although the importance of understanding these components and dimensions cannot be discounted, for knowing that an imbalance in power is an essential component of stigma is vital to understanding stigma from a feminist perspective. There are other layers to consider such as the wide range of stigmatizing conditions that have been investigated, the contextual and relational characteristics of stigma, and the various conceptualizations of stigma found in research conducted by different disciplines (Heatherton, Kleck, Hebl, & Hull, 2000). An effort to uncover a definition of stigma that is useful for understanding women's health care experiences from a nursing perspective is risky considering that experts have stated that "any attempt to summarize the essential elements of stigma either structurally or functionally will inevitably fall short"(Heatherton et al., 2000, p. 9). Therefore a concise definition of stigma remains elusive. However because health care experiences are relational, and because the dimensions of stigma reside in relationships (Jones et al., 1984), and because a power hierarchy is often perceived by one or both actors in a health care experience (Carr, 2001; Worthington & Myers, 2003), it is reasonable to accept that the components and dimensions (Jones et al., 1984; Link & Phelan, 2001) of stigma can serve as the foundation for this review and for the future development of a conceptualization of stigma as applied to the nursing discipline.

The next step was to look at how individuals experience the central force of stigma in their lives (Fife & Wright, 2000). I attempted to pull apart the stigmas of being infected with HIV and being diagnosed with a serious mental illness before considering the health care experiences of women from each group. Although the emphasis of this review is on women's experiences, stigma does not respect gender

but surrounds all members of the stigmatized group. However, some experiences are unique to women, such as childbearing (Ingram & Hutchinson, 1999), and some are universal, such as discrimination (Chesney & Smith, 1999; Corrigan & Kleinlein, 2005; Lundin, 1998; Woodhead, 2003). As much as possible women's stigma experiences were pulled out and examined, but to avoid a cumbersome and confusing discussion that is filled with gender identifiers, the bulk of this portion of the review is written without gender identification. However the final sections of this review of literature focused on the health care experiences as reported by women because it is their experiences that are at the heart of the proposed study.

There are three issues central to the understanding of any stigmatizing condition (Poindexter, 2005). These issues are internalized stigma, what it means to the stigmatized individual; associative stigma, what it means to those who care for or are associated with the stigmatized individual; and stigma management, what the stigmatized individual will do about it. These three issues will serve as a frame for the review of HIV stigma literature and mental illness stigma literature.

*Stigma and HIV*

Early in the HIV epidemic, the term "AIDS-related stigma" was coined to describe a particularly virulent type of oppression and discrimination that was experienced by individuals with AIDS and their caregivers (Herek & Glunt, 1988). We now know that individuals navigate through the same stigma environment regardless of whether they have just received a HIV positive diagnosis or have been diagnosed with AIDS (Chesney & Smith, 1999; Poindexter, 2005). Therefore, the term HIV stigma is used throughout this review.

When HIV was first recognized, the disease was associated with groups that were socially ostracized such as homosexual and bisexual males (Shilts, 1987) and intravenous drug users (IDU). This misconception added an additional layer to HIV stigma, symbolic stigma. Symbolic stigma means that others use HIV stigma to express prejudicial attitudes towards the groups most often associated with the disease, namely gay males and IDU's, and as a cover for racism and sexism (Herek, 2002). For symbolic stigma to be present, the individual must carry two or more stigmatizing conditions. Symbolic stigma is in contrast to instrumental stigma which speaks to how members of the non-stigmatized group react to a HIV-infected individual with fear and avoidance in an effort to protect themselves from acquiring the infection. The outcomes of instrumental stigma include disregard, shunning, avoidance, rejection, and discrimination (Buseh & Stevens, 2006; Carr & Gramling, 2004a; Chesney & Smith, 1999; Herek & Capitanio, 2002; Hines, Decker, Witt, Marconi, & Singer, 1997; Khakha, 2003). This layer is interwoven with the dimensions of origin, peril, and course as described by Jones, et al (1984).

Although HIV is now known to infect members of all groups, some individuals continue to associate HIV exclusively with substance misuse, homosexuality, and sexual promiscuity (Walker, 2002) and to assign blame to the individual for acquiring the infection. The dimension of origin or responsibility for the stigma is positively correlated to the degree of stigmatization experienced by an individual who carries the stigma (Herek & Capitanio, 2002), and it helps to explain why research suggests that HIV is more highly stigmatized than any other disease (Burrage & Rocchiociolli, 2003; Lee et al., 2002) with women being more vulnerable to the stigma burden

(Moneyham et al., 1996; Sandelowski et al., 2004) than men. Suggested reasons for

this increased burden for women include the unfounded assumption that women who

are HIV positive are drug users or sexually promiscuous (Sandelowski et al., 2004),

the reality that many HIV-infected women are socially and economically marginalized

(Buseh & Stevens, 2006; Moneyham et al., 1996; Plach, Stevens, & Heidrich, 2006;

van Servellen, Sarna, & Jablonski, 1998), and the often unrecognized  lack of support

for HIV-infected women that is found in the community of HIV-infected males

(Lichtenstein & Clair, 2002; Moneyham et al., 1996), a community that is

predominately comprised of males who have sexual contact with males (Buseh,

Kelber, Hewitt, & Stevens, 2006). In fact, the burden of HIV stigma is so heavy that

women may fear the stigma more than the disease to the point of not seeking any

treatment (Walker, 2002).

    *Internalized stigma.* This heavy stigma burden that is projected as fear is

evident when women report that having HIV leads to a redefinition of self (Carr &

Gramling, 2004a; Fife & Wright, 2000) in an attempt to make sense of how the social

construction of HIV fits with their lives. The social construction of HIV varies across

cultures and is contingent upon the culture's beliefs and values about gender,

sexuality, drug use, and disease (Herek et al., 1998). The dominant culture in the

United States has assigned immoral, deviant, and polluting qualities (Stanley, 1999) to

HIV infection and holds to the heterosexual community assumptions that HIV-

infected females are either prostitutes or IDU's and therefore a threat to the

heterosexual community (Lichtenstein & Clair, 2002). Then through a process of

internalizing society's view of the disease (Lee et al., 2002), the HIV-infected woman

will expect to lose intimate and social relationships and family ties through rejection

(Carr & Gramling, 2004a; Chesney & Smith, 1999) and may experience despair and

isolation (Buseh & Stevens, 2006; Relf et al., 2005) which can lead to self-hatred, self-

silencing, guilt, shame, and self-destructive behaviors (Aranda-Naranjo, Barini-

Garcia, & Pines, 2005; Herek, 1999; Stevens & Hildebrandt, 2006). After all, she will

believe that she is immoral, deviant, and polluted (Stanley, 1999) so of course others

will reject her; but only if she discloses what she sees every time she looks in the

mirror. "I no longer see Sonya (pseudonym). I see a woman with HIV disease"(Carr &

Gramling, 2004b). The issues related to disclosure are presented in the stigma

management discussion, but "Sonya's" reflection is useful as a way to see how the

central issues of a stigmatizing condition are intertwined.

It is important to note that not all women internalize society's assigned beliefs

about HIV or are buffeted about to the same degree by the forces of stigma, but this

phenomenon is seen predominately in groups of women who possess "respected

symbolic capitol" (p. 317), a term used to describe white, heterosexual, married,

and/or middle class women (Grove, Kelly, & Judith, 1997). It is not that these women

escape HIV stigma; rather their symbolic capital is recognized by society, and they are

more likely to be labeled "innocent victims" (Grove et al., 1997; Stanley, 1999). The

"innocent victim" label carries the connotation that others are "guilty" or deserving

victims (Grove et al., 1997) of the disease and reflects back to society's assignment of

meaning to being HIV infected. Although it may appear that carrying symbolic capital

is consistently beneficial, it opens the door for "medical profiling"(Poindexter, 2004).

In non-health care settings, profiling often refers to the practice of targeting particular

groups when law enforcement agencies are searching for criminals or terrorists. In medical profiling, health care providers make decisions based on stereotypes versus fact, at the risk of failing to suspect HIV infection. This leads to a delay in HIV testing which in turn negatively impacts the women's prognosis and in fact can be deadly (Gramling, 1996; Poindexter, 2004; Stanley, 1999). "They only gave me an HIV test after they had exhausted all other possibilities. It never occurred to them that a White, married woman in Coronado could have AIDS. I almost died" (Stanley, 1999, p. 110). This information about women who carry symbolic capital is presented as further evidence that although stigma experiences vary across groups, stigma is ever present in the lives of women who live with HIV.

*Associative stigma.* How people who are infected with HIV choose to navigate through this stigma environment speaks to the central issue of stigma management or information control (Goffman, 1963), but a brief discussion about associative stigma is needed first because stigma management is employed by those with HIV infection as well as by those who care for and care about them. Goffman (1963) uses the term "courtesy stigma" to describe the stigma experienced by family members and others who are associated with the one who carries the original stigma. This is a rather benign description of the hurtful experiences of associative stigma that can leave family members feeling isolated, invisible, afraid, and stressed (Poindexter, 2005), and the isolation adds to the grief and work burdens of caregivers by increasing anxiety and stress (Bunting, 2001). To avoid associative stigma, family members and caregivers of HIV-infected individuals may choose to not disclose the status of the family member. The stigma is avoided but isolation remains because of decreased

social and emotional support (Herek, 1999; Poindexter & Linsk, 1999). Isolation then leads to the same internalized stigma as seen in the HIV-positive individuals (Poindexter & Linsk, 1999). The family member is left to provide care in an atmosphere of fear, loneliness, and isolation as expressed by this daughter. "I get no help at all from family members or relatives. And as you know, if I should inform them about my mother's condition and the fact that I need help, they will by all means want to know the actual cause of her sickness and the moment they get to know it is AIDS, they will shun her"(Mwinituo & Mill, 2006, p. 377).

*Stigma management.* Humans use interactions or relationships with others as a means of understanding themselves and their place in the world (Poindexter, 2005), and stigma impacts all interactions. This interplay between stigma and interactions creates an adversarial environment of "Us" versus "Them" (Devine et al., 1999). Because women experience relationships differently from (Gilligan, 1993, 1995; Surrey, 1991) men, this adversarial environment intensifies HIV-stigma in women (Sandelowski et al., 2004). HIV stigma leads to rejection, isolation, despair, experiences of pity that reinforce the differences between "Us" and "Them," and discrimination towards the stigmatized individual (Anderson & Doyal, 2004; Buseh & Stevens, 2006; Carr & Gramling, 2004a; Herek, 1999; Khakha, 2003; Lichtenstein & Clair, 2002; Moneyham et al., 1996; Relf et al., 2005; Stanley, 1999; Surlis & Hyde, 2001) or family members and caregivers (Bunting, 2001; Ingram & Hutchinson, 1999; Mwinituo & Mill, 2006; Poindexter, 2005). In an attempt to manage the impact of stigma on their relationships, HIV-infected people employ information control through nondisclosure, strategic disclosure, or full disclosure of their HIV status.

The issue of disclosure is complex for HIV-infected individuals and is surrounded by fear and increased stress as the dilemma of telling, not telling, or selective telling is resolved. Fear has an ironic position in a discussion of HIV stigma in that it plays a pivotal role in assigning stigma and in managing stigma. Because stigma occurs only when there is an imbalance of power, the dominant group can assign a level of peril to the stigma based on fear and label and segregate those who are feared (Jones et al., 1984; Link & Phelan, 2001). Thus they have created an avenue to avoid what they fear. On the other side of the power gradient, HIV-infected individuals fear stigma (Sandelowski et al., 2004; Walker, 2002) and its dreadful outcomes. Their avenue to avoidance of the fear of stigma is through nondisclosure.

Nondisclosure may increase stress, especially if the women or caregivers strive to maintain a protective layer of made up stories that explain away the symptoms of HIV infection (Carr & Gramling, 2004a; Ingram & Hutchinson, 1999). "It is really hard leading a double life. I lost my husband [to AIDS] in '92, and he was really sick for a long part of that [time]. I constantly had to lie about what he had, make stories up for the kids" (Ingram & Hutchinson, 1999, p. 96). The made up stories, considered lying by some, are justified as a means of survival in the context of stigma management, and offer a sense of accomplishment when the cover is effective, but require the expenditure of great emotional energy to uphold the double life at a time when such energy is often taxed to the limit (Ingram & Hutchinson, 1999). Additionally not telling automatically removes any potential social support for the individuals, and this loss of support is an additional source of stress (Herek, 1999; R. S. Lee et al., 2002). Individuals who do not disclose to health care providers or

insurance companies because of the fear of discrimination at the work place or a breach of confidentiality in the health care setting (Moneyham et al., 1996) may not receive full benefit of available services and will shoulder an increased financial burden for their disease as they pay for services out of pocket rather than disclose to insurance companies (Chesney & Smith, 1999). Adding to the stress of disclosure decisions is the reality that although no one can predict how others will respond when they learn of another's positive HIV status (Berger, Ferrans, & Lashley, 2001), there is an expectation, a fear, that they will be hurt by stigma (Sandelowski et al., 2004).

However, most HIV-infected women do eventually tell others of their status (Gielen et al., 2000). The telling is sometimes a tactic to reduce the risk of transmission, although research is lacking on this approach (Stevens & Galvao, 2007), and sometimes as a way to gain a level of control over stigma (Buseh & Stevens, 2006). This means that they are willing to risk losing important family and intimate relationships or custody of their children if they were infected through illegal activity (Buseh & Stevens, 2006; Carr & Gramling, 2004a; Chesney & Smith, 1999), to risk indiscriminate disclosure by others who would breach confidentiality (Moneyham et al., 1996), and quite possibly to increase their risk of intimate partner violence (Anderson & Doyal, 2004; Gielen et al., 2000). At this juncture it should be noted that although HIV-infected women are encouraged to inform their partners, family, and health care providers of their HIV-positive status (Bova, 2000; Gielen et al., 2000) and are judged harshly by society for not telling and possibly spreading the infection to children and males (Ciccarone et al., 2003; Stevens, 1995), little support is available to women regarding how to disclose safely (Stevens, 1995).

When women do disclose, it is with the hope of enlisting social and familial support, gaining control or power over stigma, authenticating their relationships, finding relief from the stress of hiding or concealing their HIV status, and discovering meaning for their new life as HIV-infected women (Buseh et al., 2006; Sandelowski et al., 2004; Stanley, 1999). To increase the chances that these hopes will be realized, women often choose to strategically disclose their status to members of their families or spiritual support systems. Unfortunately the reality that no one can predict how others will respond to learning of another's positive HIV status (Berger et al., 2001) seems harsher in what should be a safe environment, when the disclosure leads to negative consequences. Some women report that it feels like an ambush when family members or members of the religious community respond to the disclosure with fear and rejection (Anderson & Doyal, 2004; Buseh & Stevens, 2006; Poindexter, 2005; Relf et al., 2005). Fear can be expressed as an exaggeration of the risk of non-contact transmission of the virus through requiring the HIV-infected individual to use only special utensils and dinnerware (Carr & Gramling, 2004a) or refusal to eat food prepared by the HIV-infected individual (Anderson & Doyal, 2004), and rejection as shunning, "…None of my family members would let me stay with them…I was really roughly rejected…" (Buseh & Stevens, 2006, p. 9). A component of feeling ambushed in the religious community is that women report a lack of freedom to discuss their HIV status with those who purport the healing powers of prayer and faith. In fact some women were silenced or asked to leave the church when their HIV status was revealed (Anderson & Doyal, 2004), but women did not report this as being ambushed by their God, but rather by the people in their churches (Relf et al., 2005). It should be noted

that while women agree that telling is difficult, especially telling their children

(Goggin et al., 2001), they do not all experience fear and rejection but rather improved

relationships and increased support (Buseh & Stevens, 2006; Goggin et al., 2001).

A particularly disturbing ambush comes from the health care community, the

place where help and compassion are expected. To be ambushed by a health care

provider means that instead of respect and support, an individual is met with disgust,

fear, stereotyping, and disregard  (Buseh & Stevens, 2006; Carr & Gramling, 2004a;

Plach, Stevens, & Keigher, 2005; Relf et al., 2005), violation of patient confidentiality

(Hines et al., 1997), and discrimination (Khakha, 2003). Fortunately these are not

universal experiences (Ingram & Hutchinson, 1999; Surlis & Hyde, 2001). This

particular type of ambush will be explored in greater depth in the discussion about

health care experiences.

*Stigma and Mental Illness*

Unlike HIV/AIDS, that was discovered and named amid much controversy and

fear in the early 1980's (Shilts, 1987), mental illness has no identifiable beginning. It

is as if mental illness has always been in our midst even before recorded history

(Burns, 2007) along with the attending stigma of mental illness that stands as "an

unwelcome bed-fellow of the mentally afflicted throughout history and a subject that

must be confronted in any discourse on mental illness" (Burns, 2007, p. 2). To

confront the subject of the stigma of mental illness, the central issues of internalized

stigma, associative stigma, and stigma management (Poindexter, 2005) will serve as

the framework for this review of the extant mental illness stigma literature.

Mental illness is a broad term. The *Diagnostic and Statistical Manual of Mental Disorders,* Fifth (DSM-V) (American Psychiatric Association, 2013) lists eighteen classifications of mental disorders with many subtypes of each disorder. The literature available on all mental illnesses is enormous, and an extensive review of all disorders is not reasonable. Therefore, this review is focused on a specific population, individuals who have a serious mental illness.

The terms serious mental illness (National Advisory Mental Health Council, 1993; New Freedom Commission on Mental Health, 2003; Wong, 2002), severe mental illness (Chandra, Deepthivarma, Carey, Carey, & Shalinianant, 2003; Diaz-Caneja & Johnson, 2004; Green, Hayes, Dickinson, Whittaker, & Gilheany, 2002; Onken & Slaten, 2000), and serious and persistent mental illnesses (Ackerson, 2003; MacHaffie, 2002) are used interchangeably in the literature. The disorders that are mentioned consistently in these studies come from two of the sixteen major diagnostic classes of mental disorders found in the DSM-IV-TR (American Psychiatric Association, 2000), i. e., schizophrenia and other psychotic disorders and mood disorders. The disorders classified as serious, often with the additional descriptor "persistent," include schizophrenia and other psychotic disorders, bi-polar disorders, and major depressive disorders. The term serious mental illness will be used throughout this study. Following is the official description of this category of diseases.

> …persons age 18 and over, who currently or at any time during the past year, have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria…that resulted in functional impairment which substantially interferes with or limits

one or more major life activities (New Freedom Commission on Mental Health, 2003, p. 2).

It is easy to get covered up and weighed down by the vast amount of literature that defines and explores mental illness stigma. In a further effort to lighten the weight of the literature, this review will focus on the actual experiences of the stigmatized individuals rather than on the literature that attempts to measure stigma (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004; Schumacher, Corrigan, & DeJong, 2003), or to view stigma from the providers' perspectives (Markham, 2003; Servais & Saunders, 2007), or to advance a political or research agenda for the elimination or reduction of stigma (Brown & Bradley, 2002; Corrigan, 2004b; Sayce, 2008). These topics are not excluded from this review because they do add to the understanding of mental illness stigma. Rather these topics will serve in supporting roles to the main actors, the stories of the individuals who live with the stigma, such as the following story of how a young woman realizes the stigma of her mental illness.

I perceived myself, quite accurately unfortunately, as having a serious mental illness and therefore as having been relegated to what I called 'the social garbage heap.'…I tortured myself with the persistent and repetitive thought that people I would encounter, even total strangers, did not like me and wished that mentally ill people like me did not exist. Thus, I would do things such as standing away from others at bus stops and hiding and cringing in the far corners of subway cars. Thinking of myself as garbage, I would even leave the sidewalk in what I thought of as exhibiting the proper deference to those

above me in social class. The latter group, of course, included all other human

beings (Gallo, 1994, pp. 407-408).

Reading this account from an analytical perspective, the components of stigma

are discernable. The author was labeled as mentally ill, and she internalized the

stereotype of mentally ill individuals as being "less" than "us." It may be argued that

lost opportunities were self-imposed, perhaps by distorted thinking that may be a

symptom of her disease, or perhaps the lost opportunities were imposed by her belief

that she was "less." However the analytical perspective overlooks the great impact that

stigma has on the individual (Corrigan & Kleinlein, 2005).

The impact of mental illness stigma is experienced as rejection, labeling, lost

opportunities, shaming, devaluing, isolation, and stereotyping (Chernomas et al., 2000;

Corrigan, 2004a; Dickerson et al., 2002; Lundin, 1998; Onken & Slaten, 2000; Prince

& Prince, 2002; Sayce, 1998; Weiss, Jadhav, Raguram, Vounatsou, & Littlewood,

2001). Moreover individuals who have a mental illness report feeling stigmatized by

the general community, family, coworkers and classmates, mental health caregivers,

employers or supervisors, and friends (Birch et al., 2005; Brown & Bradley, 2002;

Chernomas et al., 2000; Hayne, 2003; Liggins & Hatcher, 2005; Prince & Prince,

2002; Schneider et al., 2004; Wahl, 1999a). A major consequence of the stigma of

mental illness it that it interferes with treatment seeking behaviors (Brown & Bradley,

2002; Corrigan, 2004a; Muhlbauer, 2002a; Okazaki, 2000; Sirey et al., 2001) and is

one of three major obstacles that prevent Americans with a mental illness from

receiving the highest level of health care. Unfair treatment limitations and financial

requirements attached to private insurance mental health benefits and a fragmented

mental health service delivery system are the other identified major obstacles (New Freedom Commission on Mental Health, 2003).

It is known that stigma can lead to lost opportunities (Corrigan, 2005b), but to the individual living with the stigma of mental illness lost opportunities means being told by "a doctor about ten years ago…I would never work again. I tore up my resumes." (Chernomas et al., 2000, p. 1518), or having a job offer withdrawn after the employer learned that the individual was on lithium, a mood stabilizing agent used in the treatment of bipolar disorder (Lundin, 1998). Lost opportunities also means that individuals cannot find safe, affordable housing that allows for a feeling of community belonging because neighborhoods are resistant to the construction of apartments or group homes in their "backyard" (Perese, 2007). Lost opportunities are not confined to the individual. Our communities suffer the consequences of stigma that limits the resources that individuals with a mental illness can contribute to the community and undermines the ethical assumption that all individuals should have equal opportunities (Corrigan & Kleinlein, 2005).

Stereotyping that is at the center of the stigmatizing process (Jones, et al., 1984) can be experienced as either a direct or as an indirect stigma experience. Direct stigma targets a particular individual, e.g. a woman who dresses eccentrically is taunted by others as "crazy." Indirect stigma is experienced when an individual is subjected to negative comments or jokes about mental illness in general, often without the speakers knowing that their audiences includes individuals who have a mental illness (Wahl, 1999b), although this does not excuse the speaker. Print media is guilty of inflicting indirect stigma anytime words like "psychotic killer," "nut case," or

"crazy terrorist" are used to describe criminals, political extremists, or enemies of a country. These stereotypes, indirect stigma experiences, are hurtful (Dickerson et al., 2002; Wahl, 1999a), foster fear by portraying individuals with a mental illness as dangerous (Wahl, 2003), and can cause confusion and fear when an individual is diagnosed with a mental illness as seen in the following first-person account. "All I knew were the stereotypes I had seen on television or in the movies…Dr. Jekyll and Mr. Hyde, psychopathic serial killers, loony bins, morons, schizos, fruitcakes, nuts, straight jackets, and raving lunatics…and what terrified me was that professionals were saying I was one of them"(1993).

Perhaps the most devastating outcome of this stigma is that it assumes the rank of "master status" trait (p.138) and forever changes how others interact with the individual (Jones et al., 1984). The mental illness diagnosis is used by others to evaluate the individuals' parenting skills (Diaz-Caneja & Johnson, 2004), contributions to society, educational successes or failures (Wahl, 1999b), and even their ability to manage their health care (Chernomas et al., 2000; Edwards, Staniszweska, & Crichton, 2004). The individuals are seen as mentally ill parents, mentally ill students, mentally ill employees, or mentally ill patients instead of parents, students, employees, or patients. However there are times when it is necessary to identify an individual as one who has a mental illness, but this naming should not become labeling. Goffman (1963) used the common term "schizophrenic" to describe an individual with a serious mental illness. In 2007 this term was replaced with "person with a severe mental illness" (Corrigan & Lundin, 2001, p. 12) or "consumer of mental health services" (Wahl, 1999b, p. xvii). Both identifiers have been endorsed

by individuals who have a mental illness (Corrigan & Lundin, 2001; Wahl, 1999b), but the former will be used throughout this review for consistency.

*Internalized stigma.* "I lived in utter fear that people would find out" (Corrigan & Lundin, 2001, p. 269).

Serious and persistent mental illnesses, such as psychotic disorders and bipolar disorders, are usually diagnosed in early adulthood (Wahl, 1999b), and the individual who is diagnosed has had ample time to learn and internalize the stereotypes and beliefs about mental illness that are at the center of the stigmatizing process (Jones et al., 1984). There have been some positive changes over the past half century in the beliefs and stereotypes held by the general public, mostly because of an increase in knowledge about the scope of mental illness (Muhlbauer, 2002a; Phelan, Link, Stueve, & Pescosolido, 2000). At one time, mental illness was synonymous with psychotic disorders. Now the public recognizes that the scope of mental illnesses includes depression, addictive disorders, personality disorders, anxiety disorders, attention deficit disorders, etc. (Phelan et al., 2000). It is likely that broadcast and print media have facilitated this positive change through their coverage of interviews with Hollywood or political celebrities who struggle with mental illness or through news stories about new treatments for certain mental illnesses. This apparent positive finding of increased understanding of mental illness has set up a "hierarchy of diagnoses" (Muhlbauer, 2002a, p. 81) with psychotic disorders as the most stigmatized, followed by bipolar disorders (Angermeyer, Beck, Dietrich, & Holzinger, 2004; Corrigan, 2004a; Muhlbauer, 2002a). Individuals who are diagnosed with one of the highly stigmatized mental illnesses are aware of this hierarchy and may resort to

silence or lying to avoid an increase in stigma as found in the words of a woman when she learned that her diagnosis was changed from bipolar disorder to schizoaffective disorder. "I'm not telling anybody that, Mom, that sounds real bad. I'm just going to tell them I'm manic-depressive" (Muhlbauer, 2002a, p. 81). Unfortunately, the vicious beliefs that individuals with a severe and persistent mental illness are dangerous and should be avoided or that they are incapable of leading productive lives and should lower their life expectations persist are also facilitated by the broadcast, entertainment, and print media (Dickerson et al., 2002; Phelan et al., 2000; Wahl, 1999a, 2003). When these vicious beliefs and their accompanying stereotypes are internalized, individuals experience fear and confusion (Wahl, 2003) and decreased self-esteem and self-efficacy (Corrigan, 2004a). Then their behaviors are driven by the beliefs that they internalized, and the individuals may withdraw from social interactions or act defensively in an attempt to avoid the rejection that they anticipate (Angell, Cooke, & Kovac, 2005).

In the mental illness stigma literature, the term self-stigma expands on the definition of internalized stigma, the process of internalizing society's view of the disease (Goffman, 1963; Lee et al., 2002), to include the idea that the negative attitudes are turned against "self" (Wahl, 1999b). The phrase self-stigmatization was coined by Gallo (1994) as she described how internalized stigma affected her sense of self (Angell et al., 2005). "I perceived myself, quite accurately unfortunately, as having a serious mental illness and therefore as having been relegated to what I called 'the social garbage heap'" (Gallo, 1994, p. 407). With such a negative self-assessment it is not hard to imagine that the individual would avoid family support, community

involvement, medical treatment, and self-care. Consequently the individual will have greater disabilities and more hospitalizations than the individual who does not engage in self-stigma (Corrigan & Lundin, 2001; Wahl, 1999b). Fortunately not all individuals who have a mental illness hold onto self-stigma (Corrigan & Lundin, 2001); some rail against the stigma environment by becoming activists for change or serve as role models for others who hate the "…painful aspects of mental illness and the consequent stigmatization" (Gallo, 1994, p. 408).

*Associative stigma.* "I had one guy that I worked with ask me about him (one of his sons) one time, and I says, 'Which one are you talking about?' He says, 'The one that's a nut'" (Muhlbauer, 2002a, p. 80).

Mental illness stigma reaches beyond the individual and affects family members who are often caregivers, friends (Hall & Purdy, 2000; Muhlbauer, 2002a), and health care providers (Halter, 2002, 2008; Malhi et al., 2003). The importance of understanding this central issue resides in knowing that a person's recovery is closely linked to family and social support (Hall & Purdy, 2000; Jensen, 2004; Levine & Ligenza, 2002) and in knowing that the availability of qualified health care providers is negatively impacted by associative stigma (Halter, 2002, 2008). Family caregivers who find that they are responsible for helping their loved ones navigate the health care environment (Jensen, 2004) may choose to ignore the symptoms of mental illness and delay treatment (Chiu, Wei, & Lee, 2006) and remain silent about their family member's mental illness (Muhlbauer, 2002a). Family members also avoid social support out of fear of rejection (Rose, Mallinson, & Walton-Moss, 2002) and thus carry out their responsibilities in isolation. Providers may choose a practice area other

than psychiatry to avoid associative stigma (Halter, 2002) and the need to defend their choice of practice against charges that their provisions for care are futile, lack a scientific base and are mostly custodial, and are carried out in a dangerous environment (Halter, 2008; Malhi et al., 2003).

Individuals with a serious mental illness feel invisible or unheard because of internalized stigma (Chernomas et al., 2000). Family members may also internalize the stigma and believe that what they experience does not matter; their loved one's experiences should not be discussed; and that silence is their best option (Jeon & Madjar, 1998) as a way to avoid stigma (Muhlbauer, 2002a). These beliefs and behaviors lead to treatment delays and to an increased burden for the caregivers who care for their family member in isolation. Associative stigma may also present as guilt when the relative feels responsible for causing the illness (Chiu et al., 2006; Rose et al., 2002), or rejection and blame by feeling like an "outcast at the hospital…a necessary evil" (Muhlbauer, 2002b, p. 1085), or shame for somehow allowing the illness to exacerbate (Muhlbauer, 2002a). "In the back of my mind I was worrying that if I took her in, that whoever I took her to would think I was crazy, so I took her home…" (Muhlbauer, 2002a, p. 79). These words characterize how family members may feel shamed into silence about their loved one (Angell et al., 2005). Individuals manage associative or internalized stigma through information control, and this topic will be discussed under the last central issue, stigma management.

*Stigma management.* "…It's a strange thing about us, the mentally ill, we've got to disguise ourselves a lot…"(Goldberg, Killeen, & O'Day, 2005, p. 463).

Although not always a conscious decision, individuals who experience the stigma of mental illness manage the stigma through information control strategies and resistance strategies (Corrigan, 2005a; Goffman, 1963; Muhlbauer, 2002a; Wahl, 1999b). These two management strategies are found consistently in the stories of individuals who live with and struggle to manage the stigma of mental illness (Angermeyer et al., 2004; Corrigan, 2005a; Diaz-Caneja & Johnson, 2004; Goldberg et al., 2005; Lundin, 1998; Muhlbauer, 2002a; Wahl, 1999a, 1999b; Weiss et al., 2001).

*Telling is Risky Business* (Wahl, 1999b) tells the combined and individual stories of over 1,300 individuals who participated in a nationwide survey that asked questions about stigma and discrimination. Over 100 of these participants were also interviewed directly; their stories explain why telling (disclosure) is a risky but worthwhile business. The risk resides in the real possibility of increased stigma experiences. To avoid this risk of increased stigmatization and the resulting discrimination, individuals may choose to not tell. However by not telling they live with the fear of being found out, and this fear may increase the very symptoms they are trying to hide, e.g. anxiety, depression, or paranoia (Wahl, 1999a). No evidence was found that supported non-disclosure as a positive choice for individuals with a mental illness, but quite the opposite was found.

Nondisclosure leads to treatment delays (Prior, Wood, Lewis, & Roisin, 2003), lost opportunities as the individual avoids situations that may involve inadvertent disclosure such as filling out a job application (Angermeyer et al., 2004), increased isolation, and charges of betrayal if the disease is disclosed in the future (Muhlbauer,

2002a). In fact truthful and full disclosure (Lundin, 1998) is the recommended disclosure strategy with the caveat that the telling should be selective and strategic (Corrigan, 2005a; Goldberg et al., 2005; Lundin, 1998; Muhlbauer, 2002a; Wahl, 1999a; Weiss et al., 2001).

Selective disclosure involves telling those who are mostly likely to understand (Weiss et al., 2001) or to be supportive (Corrigan, 2005a) and deciding how much to disclose, for example telling co-workers about taking medications for anxiety but not mentioning that anxiety control is vital to management of the symptoms of schizophrenia (Goldberg et al., 2005). Strategic disclosure means that the individual chooses the circumstance of the telling. For example, an employee may not disclose until after proving to be a valuable employee (Goldberg et al., 2005), or a person would choose to disclose during a time of symptom-free health (Wahl, 1999b). Learning how to disclose is vital to this process (Muhlbauer, 2002a; Wahl, 1999b) and fortunately there are available resources that include self-help support groups such as NAMI (formerly National Alliance for Mental Illness) and books such as *Telling is Risky Business* (Wahl, 1999b) or *Don't Call me Nuts!* (Corrigan & Lundin, 2001).

Individuals choose to disclose in the hopes of finding understanding and support. However, sometimes a disclosure is met with rejection, prejudicial statements, discriminatory behaviors, or complete disregard. These reactions are particularly hurtful and disheartening when they come from close friends and family members (Muhlbauer, 2002a; Wahl, 1999a) or health care providers (Diaz-Caneja & Johnson, 2004; Muhlbauer, 2002a, 2002b; Prior et al., 2003; Shattell, McAllister, Hogan, & Thomas, 2006). When those who should be accepting and supportive, i. e.,

family and health care providers, react negatively, individuals are silenced and less likely to ask for help (Diaz-Caneja & Johnson, 2004; Shattell et al., 2006) or to resist stigma through advocacy (Wahl, 1999a). They may experience confusion from the apparent abandonment and rejection of their closest friends (Muhlbauer, 2002a) or relatives (Wahl, 1999a).

If the disclosure is presented without shame or non-apologetically, the response is more likely to be positive and can lead to further discussions about mental illness or reciprocal self-disclosure (Muhlbauer, 2002a). However before a positive and informative discussion about the mental illness can take place, individuals must learn how to manage any internalized stigma that they may continue to carry (Muhlbauer, 2002a). Mental illness education for the individual and the family members helps to decrease internalized stigma, and often leads to a sense of empowerment and a desire to confront stigma (Corrigan, 2005a; Muhlbauer, 2002a; Wahl, 1999a). Although it is encouraging that individuals with a serious mental illness are finding some relief from the effects of stigma through the use of these strategies, the numbers are distressingly small. Less than 25% of the participants in the largest study to date on the experiences of mental illness stigma (Wahl, 1999a) report successful stigma resistance while 95% continue to report lasting consequences of stigmatization, most notably a loss of self-confidence and increased social isolation.

For those who do employ resistance strategies, the support found at self-help organizations is invaluable (Wahl, 1999a, 1999b). The sense of shared experiences is empowering and can lead the individual into the role of advocate (Wahl, 1999a). Advocacy through public education that challenges the myths about mental illness is

often listed as the most effective way to resist stigma (Wahl, 1999a; Watson & Corrigan, 2005). A significant finding regarding education, is that individuals who have a mental illness indicated that "people in general—and mental health caregivers in particular—needed to be better informed about mental illness for stigma to be reduced"(Wahl, 1999a). Other resistance methods include protests and confrontation of direct stigma (Muhlbauer, 2002a; Wahl, 1999a; Watson & Corrigan, 2005).

*Metaphorical Representation of Stigma*

Metaphors, giving something a name or the characteristics of something else, have been used since ancient times (Aristotle, 4th Century BCE/1961) to paint a mental picture of the concept under discussion. They are pervasive in our everyday thoughts, words, and actions (Lakoff & Johnson, 1980), and it is suggested that we cannot think without using metaphors (Sontag, 1988). Therefore it should not be surprising that a metaphorical representation of stigma was brought to mind while reading about the constant force of stigma (Fife & Wright, 2000) and how it becomes a relentless part of the environment through which an individual must travel. I pictured a woman leaning into the wind as she walked along. While it may be a disservice to those who live with these stigma experiences to take this picture and set up a metaphor of their lives as a symbol of their illnesses (Sontag, 1988), metaphors do help to paint a picture for those of us who would seek a way to relate to the experiences. With that in mind, I respectfully suggest that stigma is like the consistently windy environment in which those who are stigmatized must live. Although my thoughts as presented in the following verse about the wind are benign, they should not be interpreted to mean that stigma is benign. Rather the verse is presented with the understanding that

everyone encounters the wind regardless of the journey, the wind affects everyone

regardless of circumstances, and everyone is forced to make a choice on how best to

content with the wind.

<div align="center">

Sitting, standing, resting, running, playing

On a porch step, on the ocean's edge, in a swaying hammock, in a back yard

The wind is ever present and tends to

Toss my hat, mess my hair, push me along, or hold me back

I have no choice except to

Turn aside, ignore the ride, hoist a sail, hide away

Or struggle through

Because I have no choice

</div>

*HIV-Stigma and Mental Illness Stigma Together*

Does the wind blow harder or swirl about more erratically when there is more

than one identified stigma at work in the environment? Carrying more than one stigma

is known as layered (Herek, 1999; Reidpath & Chan, 2005; Walkup, Cramer, & Yeras,

2004), multiple (Crandall, 1991), or doubled (Grossman, 1991) stigma. There are

suggestions that the effects of multiple stigmas may be synergistic or greater than the

sum of the two stigmas (Reidpath & Chan, 2005) or compounded (Worthington &

Myers, 2003). However the voice of one who carries these burdens refutes these

descriptors, for if they are layers, cannot layers be removed? Cannot multiples be

divided or doubles split apart? "I cannot separate my being Asian Pacific, from my

being lesbian, from my being a woman who has a chronic illness " (Stevens, 1994, p.

220). Although the descriptors may be misleading, it is important to recognize that co-

existing stigmas do add to the tangle of threads that surround the individuals'
experiences. It is equally important to recognize that it is less clear how or if co-
existing stigmas change the intensity or direction of the wind in the environment
through which the individual must struggle (Walkup et al., 2004).

*Health Care Experiences*

There is a growing interest in understanding the experiences of individuals as
they travel through the health care environment as a means of improving health care
delivery and thus patients' satisfaction with their care (Anderson et al., 2001;
Edwards et al., 2004; Williams, 1998). The health care experiences studies, also
known as interactions, encounters, or relationships (Alexander, 2004; Browne &
Fiske, 2001; Kuzel et al., 2004), focus on utilization of services, barriers to access, and
availability of providers (Anderson et al., 2001). The experiences are explored from
both the provider's (Collins, 2001; Johnson, Bottorff, & Browne, 2004; King et al.,
2007; Servais & Saunders, 2007) and the patient's perspectives (Carr, 2001;
Chernomas et al., 2000; Diaz-Caneja & Johnson, 2004; Kuzel et al., 2004; Liggins &
Hatcher, 2005; Relf et al., 2005; Stevens & Hall, 1988; Worthington & Myers, 2003),
often with an emphasis on the role of stigma in the experience. The researchers seek to
understand not only the one on one interactions between the patient and the primary
care provider, but also to understand the whole experience, from initial contact with
the health care system to interactions with all members of the health care team to the
relationships that are built over time (Kuzel et al., 2004). This review will focus on the
patients' perspectives of what it is like to interact with health care providers as they
navigate through the health care environment.

From the stigma literature we know that individuals do not step inside, out of the wind, when they enter the health care environment. Rather they carry their stigma burdens with them. As a HIV-infected woman who also has a serious and persistent mental illness travels through the health care system, she continues to contend with the tangled threads and the windy environment of stigma as identified above. Therefore, it is not surprising that the findings about health care experiences are tangled up in the literature about stigma or about living with a stigmatizing disorder. A look at what is known about the health care experiences of women who are bound by each of the threads will be presented first, and then an exploration of the experiences of women who are constrained by both of the threads will be discussed.

*Health Care Experiences of HIV-Infected Women*

Because HIV stigma occurs during all stages of the disease, it is important to look at health care experiences from the time of diagnosis forward. It is known that in the initial stages of the disease, health care may be avoided out of fear of the stigma over the fear of the disease (Chesney & Smith, 1999). The dread of stigma, of becoming one of the "other," can cause an individual to ignore physiologic changes that accompany the HIV infection in deference to attention to the psychosocial ramifications of the disease. Fear of disclosure and dread of the diagnosis then become barriers to making healthy choices including the decision to seek treatment. This delay in starting treatment has a negative impact on the long-term prognosis for an HIV-infected individual (Carr & Gramling, 2004a; Chesney & Smith, 1999; Herek et al., 1998).

Being tested for HIV carries the risk of having to confront a dreaded disease that carries a dreaded stigma, and therefore, the testing site is often a woman's important first health care experience related to HIV. If the provider is unhurried, relaxed, and at ease with providing information, the woman is likely to experience less anxiety and report less stigma than if the provider displays a judgmental attitude (Worthington & Myers, 2003). The same holds true when a woman receives her test results. When positive test results and accurate information are given in a safe atmosphere of acceptance and support while looking at and perhaps touching the woman (Ingram & Hutchinson, 1999; Stevens & Hildebrandt, 2006), the experience is described as compassionate and of high quality (Anderson & Doyal, 2004; Relf et al., 2005). This is in direct contrast to experiences where the test results are spoken bluntly, "It doesn't matter anyway. You're gonna die" (Carr & Gramling, 2004b, p. 34) and without any signs of interest, through touching or eye contact, in what the results mean to the women (Aranda-Naranjo et al., 2005; Ingram & Hutchinson, 1999). Such negative experiences undermine individuals' trust in health care providers (Relf et al., 2005) and have ramifications for future health care experiences (Carr, 2001). It is interesting to note that even when the test results are given gently, if "tangible assistance" is not provided, the experience may not be perceived as positive (Stevens & Hildebrandt, 2006).

Descriptions of negative health care experiences have been described as "ambushes" because they are unexpected from the community of care providers (Poindexter, 2005). Instead of finding respect and support, a woman is met with disgust, fear, and discrimination, and she will leave the health care experience feeling

devalued, demeaned, and disenfranchised (Buseh & Stevens, 2006; Khakha, 2003; Relf et al., 2005) sometimes without having her health needs met as described by one woman who did not receive much needed pain medication when her regular physician was out of town. "I went in to see the doctor on call, and he would not give me anything. He basically told me that I was a drug addict" (Plach et al., 2005, p. 544). There are also reports of broken confidences (Hines et al., 1997; Surlis & Hyde, 2001), refusal to care for the patient (Carr & Gramling, 2004b; Moneyham et al., 1996), and even abandonment after care is initiated (Carr & Gramling, 2004b). Acts of insensitivity are especially hurtful such as when a pregnant, HIV-infected woman is exposed to public services posters that proclaim the pictured infant "has her daddy's eyes and her mother's AIDS" (Ingram & Hutchinson, 1999, p. 101). Equally hurtful to women are times when physicians encourage women to forego pregnancy or to have a tubal ligation to protect future children from infection (Ingram & Hutchinson, 1999; Neely-Smith & Patsdaughter, 2004). Fortunately, these negative experiences are not universal. Women report their health care experiences positively when the providers instill hope (Stevens & Hildebrandt, 2006), show respect by listening to the women and asking their opinions about treatment options (Aranda-Naranjo et al., 2005; Carr, 2001), or are treated as equals to other patients who are not HIV positive (Surlis & Hyde, 2001). However, there are more reports of unsatisfactory health care experiences than positive experiences.

There are clues as to why there are more reports of negative health care experiences than positive ones. The health care experiences are surrounded by stigma, and a power inequity is a necessary component of stigma (Link & Phelan, 2001). This

power differential is evident in the health care setting (Browne & Fiske, 2001; Shambley-Ebron & Boyle, 2006b; Stevens, 1996a). For example, women of color with HIV or who are caregivers of children with HIV behaved passively and answered questions with one syllable responses and did not maintain eye contact in one study (Shambley-Ebron & Boyle, 2006b). These behaviors are consistent with other research findings that suggest that women with HIV employ such behaviors that support self-silencing as a coping strategy against an imbalance of power in a health care environment and act as barriers to becoming actively involved in their health care planning (DeMarco, Miller, Patsdaughter, Chisholm, & Grindel, 1998; Walker, 2002). Although Shambley-Ebron and Boyle (2006b) situated this behavior in the context of the Southern culture, they did encourage researchers and health care professionals to examine their biases and to not ignore the issues of hierarchical relationships and gender and racial disparities (Shambley-Ebron & Boyle, 2006a).

Another clue to the majority report of negative experience relates to the attitudes of health care providers. Even with their higher levels of education, health care providers hold negative attitudes about HIV-infected individuals at levels similar to those held by the general population (Chesney & Smith, 1999). The only offered explanation for this finding is that perhaps the negative attitudes expressed by health care providers are the expressed reactions to the fear of contamination that is a known risk for health care providers rather than expressions of stigma (Chesney & Smith, 1999). Although this is an area that could be explored in the future, perhaps knowing the reason why stigma maintains such a strong influence over women's health care

experiences is less important than knowing that it does, and that HIV-infected women do have to navigate through their health care experiences against the winds of stigma.

*Health Care Experiences of Women Who Have a Serious Mental Illness*

It is known that stigma is a key reason why individuals avoid health care and fear being diagnosed with a mental illness (Brown & Bradley, 2002; Corrigan, 2004a; Muhlbauer, 2002a; New Freedom Commission on Mental Health, 2003; Okazaki, 2000; Sirey et al., 2001), but what happens after a woman is diagnosed and becomes bound by the thread of mental illness stigma? What is it like for her to seek care primary care or specialty care such as psychiatric or women's health services? Unfortunately the stories of women who seek such care are scarce (Birch et al., 2005; Liggins & Hatcher, 2005; Schneider et al., 2004; Shattell et al., 2006) and are often buried in the bigger stories of living with a mental illness (Chernomas et al., 2000; Diaz-Caneja & Johnson, 2004; Edwards & Timmons, 2005; Hayne & Yonge, 1997) or are part of a caregiver's story. Caregiver experiences seem to mirror the patient's experiences (Chiu et al., 2006; Levine & Ligenza, 2002; Muhlbauer, 2002a, 2002b), perhaps as a mechanism of associative stigma, and therefore are helpful in uncovering about what is known about how women with a serious and persistent mental illness describe their health care.

Although not explicit, the women's stories support that their mental illnesses have assumed the role of master status (Jones et al., 1984). "…everything about you starts being attributed either to the mental illness diagnosis that you have…or the medication…You're not seen as a whole person" (Shattell et al., 2006, p. 238). Health care providers seem to see the mental illness before or instead of seeing the patient

(Edwards & Timmons, 2005; Hayne, 2003; Levine & Ligenza, 2002; Liggins & Hatcher, 2005; Muhlbauer, 2002a). The women feel invisible and unheard (Chernomas et al., 2000; Muhlbauer, 2002a), their physical complaints are discounted as being symptoms of their mental illness (Liggins & Hatcher, 2005; Shattell et al., 2006), or they are silenced with threats of being locked up if they continued to talk about their troubling symptoms (Hayne, 2003). Sometimes they are met with stereotypes that interfere with the their ability to access services as when a psychiatrist who believes that individuals with schizophrenia are lazy refuses to provide help secure financial assistance (Muhlbauer, 2002a).

When women with a serious mental illness seek care or information about their reproductive health or childbearing, they are often met with frustration and hurt. Providers either discourage pregnancy, ignore childcare issues when planning treatment, or do not provide answers (Birch et al., 2005; Chernomas et al., 2000; Diaz-Caneja & Johnson, 2004; Edwards & Timmons, 2005). An interesting finding is that women who reported satisfaction with their psychiatric health care qualified that satisfaction with the exception of when questions were asked about reproductive health (Birch et al., 2005; Diaz-Caneja & Johnson, 2004). No explanation was provided for this finding.

Not all reported experiences are negative, but from the literature that was reviewed only three studies report positive comments. These are in addition to the positive findings that were qualified in the above paragraph. Clear communication is at the heart of the positive experiences (Schneider et al., 2004; Shattell et al., 2006) along with expanded access to services (Levine & Ligenza, 2002). When a woman's

feelings are validated through verbal expressions or non-verbal encouragements (Shattell et al., 2006), she is more likely to adhere to the treatment plan and to make good decisions about self care (Schneider et al., 2004), and to take advantage of all the services available (Levine & Ligenza, 2002).

It is discouraging to read that women have to contend with the harsh realities that stigma imposes on their health care experiences. How can these reports persist? Why is mental illness stigma as prevalent in health care as it is in the general public (Brinn, 2000; Halter, 2008; Malhi et al., 2003)? Halter (2008) suggests that the stigma persists because students are educated and socialized in an atmosphere that supports mental illness more as a personal flaw instead of a brain disorder. Others suggest that it is more of an image problem that may be resolved by changing the focus in education from clinical signs and symptoms to an improved of quality of life (Malhi et al., 2003). Regardless of the reason, the stigma exists and continues to buffet women as they enter into relationships with health care providers.

*Health Care Experiences of HIV-Infected Women with a Serious Mental Illness*

HIV infection rates among individuals who have a serious mental illness are higher than for the general population (Bogart et al., 2006; Meade & Sikkema, 2005; Satriano et al., 2007) with more women than men being affected (Stoskopf et al., 2001). Providing treatment and care for this growing population is a public health issue (Bouis et al., 2007) that is difficult to manage under the current fragmented mental health care system (Andersen et al., 2005; Bouis et al., 2007; Fremont et al., 2007). HIV-infected individuals with a serious mental illness who seek care under this fragmented system experience difficulty in accessing care, dissatisfaction with care,

and increased number of disability days compared to HIV-infected individuals who do not have a serious mental illness (Fremont et al., 2007). While this information is valuable as a starting place for understanding the health care experiences of HIV-infected women who have a serious mental illness, the voices of these women are absent in the literature.

Only two studies were found to shed some light on how these women describe their health care experiences (Keigher, Stevens, & Plach, 2004; Tangenberg, 2002). Tangenberg (2004) combined personal narratives with published research and professional observations to start a dialogue about the mental health needs of women over 50 who have HIV. A description of the actual health care experiences of HIV-infected women who have a serious mental illness is limited to a general dissatisfaction with mental health services because of barriers to access and providers who are insensitive to the unique needs of these women (Tangenberg, 2002). One participant in the second study (Keigher et al., 2004) reports adequate access to health care for her complex medical needs, including bi-polar disorder, with Medicare and Medicaid lightening the financial burden of her care. However, in both studies the voices of the women are silent on the topic of their health care experiences as defined in this review, their perspectives of what it is like to interact with health care providers as they navigate through the health care environment.

*In Conclusion*

The purpose of this review was not to determine how HIV stigma and mental illness stigma experiences are similar or different, but there are some compare and contrast findings from this review that deserve mention. Mental illness has been with

society since before recorded history (Burns, 2007), and AIDS was identified less than

forty years ago (Shilts, 1987). However Americans report that they know more about

AIDS than mental illness (Wahl, 1999b) and it is suggested the knowledge about a

disease is a powerful deterrent to stigma (Corrigan, 2004b). Discovering the driving

force for this finding would have implications for educators, policy makers, and self-

help support groups. A disheartening similarity revealed in the HIV and mental illness

literature is that the women's reproductive health needs and mothering concerns are

not being met (Birch et al., 2005; Chernomas et al., 2000; Diaz-Caneja & Johnson,

2004; Edwards & Timmons, 2005; Ingram & Hutchinson, 1999; Neely-Smith &

Patsdaughter, 2004), although it is possible that this is an experience that is common

in other stigmatized groups. Regardless of the extent of this phenomenon, until health

care providers hear and heed the voices of women regarding their unique health care

needs, the women will not have all aspects of their health care addressed.

However the purpose of moving through this body of literature was to discover

what is known about the health care experiences of HIV-infected women who have a

serious mental illness. The process has revealed that health care providers hold

attitudes towards HIV and mental illness that is similar to what is held by society

(Brinn, 2000; Chesney & Smith, 1999; Halter, 2008; Malhi et al., 2003), so it is not

surprising that what is known about the health care experiences of HIV-infected

women and women with a mental illness is that the experiences are surrounded by

stigma. The implication of this finding is that until stigma is reduced, individuals will

continue to be ambushed (Poindexter, 2005) by health care providers. Health care

providers are well represented in this body of literature (Collins, 2001; Johnson et al.,

2004; King et al., 2007; Servais & Saunders, 2007), however the actual voices of the

women who must contend with the stigma of HIV and mental illness remain silent.

Research studies that are designed to give voice to these women are needed to shift the

focus from the provider to the women.

Chapter 3

A secondary analysis of an existing qualitative data set was conducted to uncover how one HIV-infected woman who also lives with a serious mental illness described her health care experiences. As her stories unfolded, the role of stigma in how she described her experiences was also considered. In this chapter a discussion of the philosophical underpinnings of this research design will be presented first followed by a discussion of the original study. The specific design of the current study will then be presented.

*Feminist Qualitative Underpinnings*

All research is interpretative (Denzin & Lincoln, 2005). The researcher observes or is drawn to a phenomenon that is bound by the prevailing cultural, societal, economic, historical influences and then interprets what needs to be known about that phenomenon. Then the researcher interprets what is known about the phenomenon and develops a research question. The interpretative process will drive the research design, data collection, data analysis, and report of findings. Each interpretative decision is guided by the researcher's beliefs or interpretative framework (Denzin & Lincoln, 2005; Guba, 1990). This framework stands on a combination of four guiding philosophical principles: ontology, epistemology, methodology, and axiology. Ontology asks questions about the nature of reality and human beings. Epistemology asks about the relationship between the researcher and the known, and methodology asks questions about how we can know the world (Denzin & Lincoln, 2005). Axiology asks questions about the role of values in the

knowing process and addresses ethics, religion, and aesthetics (Guba & Lincoln, 2005).

Qualitative research "is a situated activity that locates the observer in the world" (Denzin & Lincoln, 2005, p. 3) taking the ontological stance that there are multiple realities that are the subjective experience of individuals (Boyd, 2001) and the epistemological stance that a partnership between the individual and the inquirer, the known and the knower, is the means to knowledge construction about reality (Denzin & Lincoln, 2005; Munhall, 2001). Without the known (HIV-infected women) the knower (investigator) could not give voice (create knowledge) that would offer guidance to others (Buseh & Stevens, 2006; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Stevens, 1996b, 1998; Stevens & Galvao, 2007). Methodologically, qualitative methods are inductive, flexible, and contextual, and the axiological principle that supports qualitative studies allows for the inclusions of values thus allowing for a holistic understanding of the participant's experience (Guba & Lincoln, 2005 ).

A feminist perspective highlights the lived experiences of women in a patriarchal society (Hutchinson & Wilson, 2001) as a way to give voice to women who may be silenced, oppressed, unheard, or disregarded (Gilligan, 1995; Neely-Smith, 2003; Stevens, 1995, 1998). This perspective also honors vulnerable groups who may otherwise remain unheard because of socioeconomic standing or race (Denzin & Lincoln, 2005; Flaskerud & Winslow, 1998). A qualitative feminist design allows the investigators to approach the participants subjectively versus objectively as the investigators seek to give a voice to the women by allowing them to ask questions

and to "hear" their stories in the context of their individual environments (Chase, 2005). Upon reflection of each of the philosophical principles and how they translate to qualitative methods and upon consideration of the feminist perspective, the qualitative feminist approach that was chosen for the original study was carried forward to the current study as this approach fits well with the study of women's experiences (Chernomas et al., 2000; Diaz-Caneja & Johnson, 2004; Edwards & Timmons, 2005; Sandelowski et al., 2004; Stevens, 1996b; Stevens & Hall, 1988; Walker, 2002).

*Original Study*

The original study, *An In-Depth Longitudinal Study of HIV-Infected Women*, is the source of the data that was used in this current study. Data collection occurred between 2000 and 2003. A repeated qualitative narrative interview design was used to follow 55 multi-racial, HIV-infected women living in rural and urban Wisconsin. This study was conducted with full approval from the University of Wisconsin-Milwaukee's Institutional Review Board and under the guidelines of a confidentiality certificate issued by the Department of Health & Human Services. Prior to data collection, informed consent was obtained, and the participants received a modest payment of $30 at each interview (*In-Depth Longitudinal Study of HIV-Infected Women*, National Institutes of Health Grant #R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN).

The aims of the original study were to "1) examine the meaning and impact of HIV/AIDS in the lives of HIV-infected women; 2) describe the overall health needs of HIV-infected women, including subjective symptom experiences and symptom

management strategies; 3) explore personal and contextual factors that influence HIV-infected women's capacity to initiate and adhere to treatment regimens; 4) explore personal and contextual factors that influence HIV-infected women's capacity to reduce risky sexual and substance use behaviors; and 5) analyze participants' accounts of using health care, drug treatment, and social services, identifying how structural and interpersonal factors in care delivery and social welfare systems support or hinder HIV-infected women in accessing resources." A semi-structured interview guide was designed to elicit information related to these study aims during the interview process.

Participants were recruited using a purposive sampling technique, targeted chain referral, that works well for recruitment into studies that investigate sensitive topics such as HIV (Biernacki & Waldorf, 1981). All participants were at least 18 years old, conversant in English, and HIV positive by self-report (Buseh & Stevens, 2006; Stevens & Galvao, 2007). The women were scheduled for ten face-to-face interviews over two years, two to three hours each, at a private location that was chosen by the participant and with the same interviewer (Buseh & Stevens, 2006). This strategy created a safe environment for the participants that facilitated the development of trust between the investigator and the participant. Forty-four women completed all ten interviews (Stevens & Hildebrandt, 2006).

NVivo™ data management software , a specialized computer software package that was developed to assist in the management of qualitative data (Richards & Richards, 2003), was used to manage the large amounts of data that were generated. . The interview tapes and field notes were transcribed verbatim and imported into NVivo™. As the researcher read and coded the data, the coded text was assigned to

different nodes, the software storage areas for the codes that were assigned by the researcher. The software's search engine was then be used to track the themes or ideas located in the different nodes (Richards & Richards, 2003).

A within-case, across-case analysis was used to analyze the data. The specific process was devised by the Principle Investigator and is well described in the literature (Stevens, 1993, 1994, 1996b, 1998). Within-case analysis started with an initial read through of all transcripts, and then a Threshold Analysis, first engagement with the data, was done to find the major content that directly related to each original study aim. This content was coded using the Code Book for Targeted Specific Aims Analysis. Next a Narrative Summary was constructed using a template that allowed the investigator to fill in a description for each topic on the template. This summary was used to inform other team members about the participants. The final step was to do a Narrative Elements Analysis using the Code Book for Narrative Elements Analysis. During this step, content that was directly relevant to each code was identified. Careful memos of analytical decisions were kept throughout this process.

The across-case analysis was completed by looking at the similarities and differences among the participants' stories that were coded during the Narrative Elements Analysis. Qualitative matrices that plotted the story elements across the participants and compared the individual experiences against the experiences of other participants were constructed and helped identify patterns across the cases. The final step was to select exemplar narratives and interview excerpts that best displayed the patterns (Buseh & Stevens, 2006; Plach et al., 2005; Stevens & Galvao, 2007; Stevens & Hildebrandt, 2006). Throughout the analysis the investigators used inter-rater

reliability activities, referred back to the transcripts to ground the data, kept memos of all analytical decisions, and conducted participant validation (Buseh & Stevens, 2006; Stevens & Galvao, 2007; Stevens & Hildebrandt, 2006) to assure that the participants' stories were authentic and that the analytical process was auditable.

Although the data collection part of the parent study is completed, the research team continues the analysis of the rich, in-depth interviews that form this large data set and to publish the findings (Buseh & Stevens, 2006; Plach et al., 2005; Stevens & Galvao, 2007; Stevens & Hildebrandt, 2006). Additionally, the Principle Investigator has made the data available to doctoral students who can ask new questions of the data while learning the research process.

*Current Study*

*Study Design.* The current study is a secondary analysis of the data from *An In-Depth Longitudinal Study of HIV-Infected Women* (National Institutes of Health Grant 1R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN) that explored the experiences of one woman who lives with HIV and a serious mental illness. The richness of narrative data makes them amenable to secondary analysis as either new questions can be asked of the data (Shattell, Starr, & Thomas, 2007) or a focused analysis of a subset of the data (Buseh & Stevens, 2006; Keigher et al., 2004; Plach et al., 2005) can be conducted while maintaining a link to the original study's aims (Hinds, Vogel, & Clarke-Steffen, 1997).

One of the aims from the original study was to analyze the participants' accounts of using the health care system. For the current study a subset of the interview data was analyzed to explore this aim from the perspective of a participant

who also has a serious mental illness. Additionally, there is evidence from the original study that particular groups such as African American women experience stigma on multiple levels and that their responses to stigma may hold information for how to assist women to manage stigma (Buseh & Stevens, 2006). Just as this unique group of women merit a focused exploration of their stigma experiences, so do women who carry a mental illness because they also hold a position in society that has been marked by disregard (Chernomas et al., 2000; Diaz-Caneja & Johnson, 2004; Edwards & Timmons, 2005). Therefore, the purpose of this study was to listen to the stories of a HIV-infected woman who has a serious mental illness and then to translate her stories through narrative analysis into knowledge that will be useful to nursing and other professions that provide health care to women as they manage the complexities of their lives.

*Research Question.* The current study was guided by the question, "How does one woman describe her experiences as a HIV-infected woman who has a serious mental illness?" Because it is known that stigma is a central force in the lives of HIV infected women who have a serious mental illness (Fife & Wright, 2000), it was reasonable to expect that stigma experiences would be included in the data. For that reason, a second question was "How does a HIV-infected woman who has a serious mental illness describe stigma experiences and her responses to those experiences?" These questions evolved from the literature review that revealed the complexities of women's health care experiences that are tangled up with the experiences of having HIV and having a serious mental illness and surrounded by stigma.

*Data Selection.* To take full advantage of the longitudinal nature of the original study, the interview data from the women who completed all ten of the scheduled interviews over the two-year data collection period year were considered. This criterion maximized the exploration of an individual's experiences of living with a disease as this topic was reintroduced at each interview (Buseh & Stevens, 2006). Inclusion criteria for this study were:

1. Completion of all ten interviews.

2. Self report of being diagnosed with a serious and persistent mental disorder disorder (e. g. , psychotic disorders including schizophrenia and schizoaffective disorders, bipolar disorder, major depressive disorders).

3. At least some of the following circumstances apparent in the interview data:

    a. Mention of taking psychotropic medications such as antipsychotics or mood stabilizers.

    b. Inability to express thoughts logically or use of a disjointed communication style.

    c. Reference to a psychiatric hospitalization.

    d. Labile affect

    e. Reference to or display of a functional impairment that would keep the woman from managing money, living successful in the community, or maintaining a household

    f. Hallucinatory experience.

    g. Paranoid behaviors.

Adequate sample size in qualitative research is not based on a number but is based on the investigator's judgment of the quality and quantity of the data that will allow for a "deep, case-oriented analysis…" while uncovering "a new and richly textured understanding of experience" (Sandelowski, 1995, p. 183). In consideration of the richness of the data sets that spanned two years, selection of one participant, Inez, was made under the guidance of Dr. Patricia Stevens, Principle Investigator.

*Data Management.* An electronic copy of the complete data set that had all identifying information removed was saved as a Microsoft Word document file on a password-protected laptop computer that resides in my home office. All back-ups of the data and analysis files were saved on a dedicated USB flash drive that was secured in a locked file drawer in my home office. Any hard copies of the data that were made during the analytical process were stored in the same locked file drawer.

A clean copy of the data set was maintained, and the analysis was conducted by using a working copy of the data. The word processing options available on Microsoft Word were used during analysis. Keywords were indexed to assist with coding; bookmarks were used to delineate stories; and color-coded highlighting provided visual cues to specific text. Additional files were created as needed using the copy and paste option. Annotations/comments assisted with documentation of reflexivity and analytical journaling, which was done electronically. However I also maintained a handwritten journal that was stored in a locked drawer when not in use. After working with hard copies of the data, my notes or digital voice recordings were added to the electronic copy of the record as soon as possible after the reading. A code book was started as the data set was opened and initially included the broad categories

of health care experiences and stigma experiences, as operationalized in the following section. The code book evolved into an electronic file folder labeled "intriguing elements."

*Data Analysis.* The first step in the analysis of this single case study was to meet the data through an initial reading followed by a more careful line by line reading. I used a dedicated digital voice recorder to record of my thoughts during the initial engagement with the data, and the recording was transcribed and added to the data document as annotations as soon as possible after a reading session. However I changed to handwritten notes in the margins of the hard copies with subsequent readings. The act of writing, rather than speaking, allowed me freedom to work outside my office without breaching confidentiality by speaking my thoughts.

Stories were the unit of analysis, and I set out to demarcate the health care experience stories and stigma stories. Text that includes the structural elements of orientation, complication, evaluation, and resolution (Labov & Waletzky, 1967) were be named a story. Orientation refers to a specific beginning, complication is the story actions that are temporally or causally linked, evaluation statements suggest the participant's understanding of the experience, and resolution is the identified end of the story (Stevens, 1998). Health care experience stories were operationalized as reference to any interaction with a health care provider, including telephone conversations as well as personal contact. Stigma stories were operationalized as mention of being made to feel guilt, blame, or shame for having HIV or a mental illness, reference to discrimination (e. g., as a barrier to health care, housing, employment, educational opportunities, etc.), rejection, stereotyping, or oppression.

As stories were identified, they were placed in a separate document file labeled "intriguing elements" as subfolders for each main category of story.

The data were then opened up (Richards, 2005) by analyzing the stories dialectically to evaluate the events as well as Inez's understanding of the events. With careful respect for her unique storytelling styles (Riessman, 1987), an adequate paraphrase of each story was constructed to call attention to the main plot and context of the action, all actors involved in the action, and her evaluation of the story (Polanyi, 1985). However Inez's unique storytelling techniques created a challenge when attempting to pull her stories from the data.

Although the elements of a story were located in the data, they were found with difficulty because of Inez's unique storytelling techniques. Her stories were often embedded in the seemingly disconnected details of the circumstances that surrounded the story she was relating. This resulted in lengthy, unbroken sections of data that did not include paragraphing, voice inflection, or other cues that the she was changing topics. To delineate her story elements, and thus to clearly hear her stories, a textual analysis, based on feminist principles, was developed. The textual analysis was conducted by placing the text in a table. The number of columns and rows was determined by the content of the text and evolved during the analysis as her topics of discussion were discovered in the data. Thoughts or sentences of similar subject matter were placed in a column dedicated to that idea with each thought in a separate row cell. When a different thought was introduced in the text, that thought was placed under a different column in the next open row. This created open cells in the columns but maintained the original flow of the text. The open cells were visual reminders that

Inez changed direction in the story she was relating. After all the data were inserted

into the table, the content of the columns was read, and a title was assigned to the

column based on the general theme of the content. This process created an extensive

table. It also created a way to untangle her stories from the surrounding details by

reading the text vertically all the while being aware of her intervening thoughts. This

process also revealed that although lengthy and disjointed, these large sections of text

often held a main topic along with rich details of surrounding circumstances that

elsewhere in the data became the main topic. From this process, data that held

elements of the same topic were identified and segregated into files (See Appendix A).

The next step was to code the elements of the stories. Qualitative coding is

used to retain, versus reduce, the data by identifying relevant or interesting categories

that emerge from the data and then segregating the coded text from the data document

(Richards, 2005). The coded text was identified by category and by interview number.

This allowed me to see how her reflections on a topic changed or stayed constant over

time. After I segregated and identified the coded text, I examined it for themes and

patterns that were similar or different from interview to interview. During this process

the coded text was labeled as an "intriguing element," e. g. suicide, living

arrangements, or Michael. All data that related to each intriguing element were placed

in a folder and organized into one story.

*Rigor.* To assure scientific adequacy, this study adhered to the standards of

rigor in feminist research (Hall & Stevens, 1991) including reflexivity, credibility,

coherence, complexity, honesty, and dependability. The evidence of adherence to

these standards is as follows. 1) Reflexivity focused on the data-researcher

relationship. Because the researcher is in partnership with the participant, or the data in the case of the current study, evidence of reflexivity is important to the accuracy and relevance of the results. I reflected on how Inez was similar to or different from me and how these differences and similarities played out as I interacted with the data. I considered how my interaction with the data influenced analytical decisions, and if the interaction was hiding or uncovering the research question (Christman, 1988). A reflexivity journal was maintained throughout the study. 2) Credibility of the findings was validated with the original investigator as the analyses were conducted. 3) Coherence of the emergent intriguing elements was checked through documentation of analytical memos that were discussed with the original investigator. 4) During analysis, the participant's unique experience was honored through adherence to the standard of complexity which demands that the dissimilarities be afforded the same analytical consideration as do similarities. 5) Honesty in reporting the findings was assured by returning to the original data to ground my findings and by collaborating with the original investigator. 6) The standard of dependability was met through careful documentation in a methods/analytical journal (Rodgers & Cowles, 1993). Documentation of analytical decisions, validation of identified patterns and exemplars of the stories with the original investigator as the analyses were conducted further enhanced the authenticity of the findings from this study.

At first glance the tasks of adherence to standards of rigor may seem awkward considering that I was "hearing" the narratives from an "invisible" woman by reading her interview data, but that is an appropriate analogy to the purposes of this study. It is

not seeing a woman that allows others to know that woman's experiences. It is hearing

that woman's experiences.

*Ethical Considerations.* Confidentiality, honesty, and protection of human

beings are the three major ethical considerations in this study. I did not have access to

the original, recorded interviews in compliance with the IRB approval for the original

study. I did have full access to the transcribed interviews and field notes, and this data

did not include any identifiers that could link the data to the actual participant. I

maintained the security of the data and continued the chain of confidentiality that was

started during the original study when pseudonyms were assigned to each participant.

Another layer of confidentiality was added by assigning pseudonyms to all of the

people that Inez discussed and by changing or removing the names and addresses of

the places that she mentioned. Electronic files were stored on a password-protected

laptop computer, and back up files were saved on a dedicated USB flash drive which

was stored in a locked cabinet in my home office along with the hard copies of the

data. Having no contact with Inez did not absolve me from holding to the ethical

principle of honesty. The findings were reported openly and honestly. I do not hold

direct power over Inez and thus cannot deceive her openly, but I do hold power over

the data, and I am obligated to publish my findings honestly (Hall & Stevens, 1991;

Munhall, 1988).

This study was approved by the University of Wisconsin-Milwaukee Internal

Review Board. Because I used existing, de-identified data, I was granted exempt status

approval (See Appendix B). As I engaged with the data, I considered the protection of

my emotional welfare. I did this through journaling my reactions to the data and by

performing self-assessments to recognize any emotional distress that I may have

encountered.

Chapter 4

Inez, 45 years old when data collection started in 2000, is an African-American mother and grandmother who lived in a Midwestern urban area throughout the data collection. Inez is physically described as short and stoutly built with light brown skin. She likes to dress as stylishly as her circumstances allow, often in bright colors and always in pants or leggings except for one time when she was not feeling well and was wearing a dressing robe. She wears jewelry in her ears and nose, and she occasionally wears wigs so her hairstyle changes often. Inez smokes cigarettes, but not in the presence of the interviewer. At times Inez speaks words that express strong emotions, but she usually sits quietly during the interviews without displaying those emotions. Her affect is sometimes incongruent with the content of the conversation, and there are times when she fills her dialogue with language that is sexually explicit. Inez's speech is usually soft, and it is compromised by a constant grinding of her teeth which may be a side effect of her medications. Inez is HIV positive, and she has a serious mental illness, and this is her story.

Inez mentions how she would have her story told. "If you going to study, you have to study right to know all our problems down to the other to get a true understanding of those."

Inez did her part by telling her story. She faithfully completed all ten interviews even when she was not feeling well, was living in a chaotic household, was trying to communicate through her delusions or hallucinations, or was quietly withdrawn into herself. My part was to listen to her words, without hearing her actual

voice, and my challenge was to give a voice to her words through the findings from the data.

*A metaphor for organizing the data*

Moving through the data was much like moving through a labyrinth, an ancient symbol for a journey along a purposeful path towards wholeness. An individual can walk through a labyrinth either figuratively or literally by engaging in reflective thought while moving from the labyrinth's entrance to the center and then back out again. The beginning and ending of a labyrinth are at the same place, but the traveler is different after exiting the labyrinth for the path leads into and out of the center. Upon entering the labyrinth, the traveler may consider the events that precipitated the desire to explore the center where defining experiences often reside. The walk out of the labyrinth then becomes a time of reflection on what was found at the center and how those discoveries have changed the traveler.

The journey through the labyrinth of Inez's narrative data included twists and turns, but there was always a path that led to the heart or center of her stories and then back out again. There is no reason to believe that Inez engaged in this reflective exercise when considering what or how she would discuss her life with the interviewer for the data indicate that her path was not always purposeful, obvious, or without dead ends. The labyrinth metaphor is a device to explain how her stories were organized. The path to the center symbolizes Inez's life before the two life-changing experiences, being diagnosed with a serious mental illness and later being diagnosed as HIV positive, she describes throughout the data. This path into the labyrinth adds context to the center. The center holds the stories of Inez's first psychiatric hospitalization and

the day when she was diagnosed as HIV positive. Then Inez's stories about how she experiences life as a HIV-positive woman with a serious mental illness are the path out of the labyrinth.

From this wandering into and out of the labyrinth with the narrative data, the findings were clarified. Although the initial intent of this studywas to uncover Inez's health care and stigma experiences, the depth and intensity of the data intrigued me to explore beyond that narrow focus as I attempted to gain the "true understanding" that Inez would have others know. Therefore this in-depth case study is presented starting with a chronology of Inez's life before she was diagnosed with a serious mental illness and then later as HIV positive before moving to her reflections on how she lives with these two life-altering diagnoses.

*Preparing for the journey into the labyrinth: Uniquely Inez*

When Inez reports her experiences she does so with idiosyncratic speech patterns reflective of her unique way of thinking about the world. She randomly repeats a particular phrase that may seem nonsensical to the listener, and she often provides all the particulars of the many appointments she must keep and the decisions she must make. At other times Inez displays a circumstantial pattern to her speech as she tells all the details and surrounding events before returning to the main point of her story, and sometimes Inez misuses words and mixes up metaphors. Because these patterns are found to some degree across the ten interviews and are evident in the direct quotes that are a part of the analytical findings, a description of the idiosyncratic speech patterns follows.

*Inez's phrase: "down to the other."*

You see, because umm, my baby, he was properly fed, he was properly cared for down to the other. I always burped Michael. I put Michael on the bed, down to the other. You see, down to the other to make sure that he is not wet down to the other, previous to him going to sleep cause I have a habit of laying down with my baby. I always layed him on my breast to make sure. But this particular day, I had put the baby in the baby bed. And I woke up and the baby wasn't breathing. I called the paramedics down to the other…(Inez).

In this brief excerpt, Inez describes a painful experience from her past. Her repeated use of the phrase "down to the other" can be distracting as it seems to jostle the reader in and out of her story. Inez uses this speech pattern frequently and randomly across all of the interview data. It does not appear more often when she discusses stressful topics, and while it is sometimes used as filler in her conversations, there is no reason to think that it is used when she is at a loss for words. Her stories continue freely. However this phrase may be a barrier to understanding Inez's stories unless it accepted as a part of Inez's speech pattern and that it holds significance only to her.

*Details.*

Lisa Greene, when I first went over there to get my blood test, 'cause I have to have a blood test done every three months and um Lisa Greene. I think it's g-r-e-e-n-e. Registered case. Registered nurse case manager…That's at [name removed] Medical Clinic. And her telephone number is 37280, extension 119…(Inez).

This information was not read to the interviewer; it is information that Inez memorized and shared when asked about her recruitment into the study. This was not an isolated incidence, for Inez shared similar details about most of her appointments, her past and present living arrangements, and dates of significant events in her life. For example, instead of saying she changed apartments, she said, "I left [address removed] N 31st Street and went to [address removed] N 52nd, Apartment 4. " Instead of mentioning her niece's name, she said, "Her daughter name is Nikesha Wendy Rene Canon. Okay. Now it's Nidesha Wendy Rene McKnight 'cause she married to John Aaron McKnight. In '96 she got married to him. May the 6th they got married."

These many details intrude into the storyline, making it difficult to decide if the details are central to the story or not. Perhaps she uses the technique of repeating details as a reminder of an event or appointment. Considering the number of people she contacts to secure her health care, her financial support, her living arrangements, and her emotional support system, this is a likely possibility for this storytelling device. There is no reason to think that the details are included to impress anyone with her ability to recall the information or that she considers the details useless, although she never gives clues to the importance she assigns to the details. It is also possible that Inez's inclusion of many details is her attempt to "get it right" as she tells her stories so that we "study right to know all our problems…"

*Surrounding circumstances.* Sometimes Inez fell into a pattern of circumstantial speech, making it difficult to follow her storyline. Her answers to the interviewer's questions were covered up by surrounding stories that she wanted to share. While this form of speech is seen in individuals with thought disorders, there is

no way to know for sure that Inez was experiencing such a disorder. However, because there were occasions in the data when she responded directly without inclusion of the many circumstances, it is possible that she was experiencing some cognitive disturbances when she adopted this speech pattern. An example of Inez's circumstantial speech pattern from the data and how that data were analyzed is presented in the Appendix. However it is mentioned here to explain why some of Inez's quotes in this chapter contain multiple ellipses as specific stories are pulled out from her lengthy, circumstantial responses.

*Inez's unique use of words and metaphors.* Inez's unique use of metaphors and her misuse of other words are not barriers to hearing her stories. Rather they offer us a glimpse into her expressive style as she attempts to help us understand some important events. For example, when Inez tells us that she enjoys being in a support group for individuals living with HIV, she says that while in this group setting she is comfortable because she is not "I guess you wanna say, being a sore thumb or being a needle in a haystack that stickin' out that don't fit in. " And then "just out of the clear blue moon" she will let us know that some event happens unexpectedly and infrequently. At other times she lets us know what she is feeling by misusing a word, such as when she tried to fully explain what it was like to live in a chaotic household by saying, "It's like living in the bewilderness, you know. . . "

With an understanding of Inez's unique storytelling devices, there is a decreased chance of misunderstanding her words that could cause something "…like bewilderness down to the other" as we first consider the significant events in Inez's

life that she has asked that we "study right to know all our problems down to the other to get a true understanding of those."

<center>*Inez*</center>

Inez freely shared stories about her past and about her hopes for the future. These stories include details of the events that hold great significance to her. She expresses the significance of these events implicitly by returning to them from time to time across the data or by relating them in great depth during one telling. Inez's stories of hope for the future revolve around her desire to benefit others through the telling of her life experiences and her longing to reclaim her old self. "Then I thought I got to get a life. I need a life. I need my old self back. " Interestingly the woman Inez hopes to reclaim is not free from HIV or mental illness. The woman Inez wants to reclaim is an independent woman who is free to live in an environment that is nourishing to her health and her family relationships. "You see on my own I know I can do better…Everybody that I know that got their own place they are full of life and joy. They have their good days and bad days and that's what I really want. I want my own."

By telling us that she hopes to "get her old self back," Inez is also telling us that she feels as if she has lost parts of herself, piece by piece, over time. References to loss are included in the stories that Inez revisits time and again across the data such as the stories about her chaotic living conditions immediately before and after she was diagnosed as HIV positive; the day she was diagnosed as HIV positive, including accounts of how she struggled with suicidal thoughts; her experiences with residual nerve pain after contracting shingles; and her relationships with men including her

perceptions of the man who she believes infected her with HIV. The stories that Inez shares only once, but in great detail, are about the time she participated in the Job Corps as a young woman, and about the death of her last-born child, Michael, and the subsequent deterioration of her mental health. All of these stories are surrounded by details of her family relationships, and all of these stories carry elements of her health care experiences. Therefore all of these stories are important to the discovery of one woman's experiences of traveling through the maze of living with HIV and a serious mental illness as she longs to reclaim her "old self."

*Into the labyrinth*

Few details are found in the interview data about Inez's childhood experiences. However we do know that she is one of four siblings. Roberta is her older sister, Donna is her younger sister, and William is the youngest child in the family. We also know that their childhood experiences included physical abuse "I was got a hold of with an ironin' cord or somethin' like that" and alcohol misuse. "Cause my mother, she was an alcoholic down to the other. She had abusive man in her relationship…But it was hard for her." She explains the paucity of childhood stories and perhaps even gives insight into how she is able to weather the ups and downs she has with her family members when she says, "It's kind of hard to explain. I try not to think about it 'cause it's a lot of pain in the back. So I'd rather go forward and let the past lay down."

Conversely the stories of Inez and her siblings as adults permeate the interview data. Roberta and Donna are often central to the stories that Inez shares, but William does not appear in the data with any consistency. Inez explains this by simply saying

that they were "not close." These sibling relationship threads were woven through the story of Inez's life that unfolded as the data were analyzed.

As a teenager, Inez participated in the Social Spring Job Corps for Women in Kansas. Inez talks about how she was skipping school and because of this "my little wild tail was shipped out to job core." Inez talks freely and positively about this highly-structured, military style program that allowed her to finish her high school courses while learning the skills to be a certified nursing assistant. In fact she remembers this time in her life and this experience as a "beautiful thing." The women in this program were required to work on their high school courses, to learn a technical skill, and to do household chores such as cooking, laundry and cleaning. They slept in a bunkhouse and were responsible for the general upkeep of the facility, but their hard work was rewarded by weekend passes to a nearby town that housed an army base. Inez seemed to enjoy her time with the job corps and states that she "had a ball of fun, I had a ball of fun." However, before she completed the program she made the decision not to return to school after a regular weekend visit to the nearby army base.

I ran away from job core. That's how I got pregnant you see. I thought I was in love with someone, and he was good to me. He had his own apartment, down to the other and everything, he was my little gangster, and he was working hard, down to the other, and everything, so I just didn't want to go back (Inez).

Inez stayed with this man for four months. During these four months, Inez called her friends at the Job Corp and eventually realized that she missed her teachers and the companionship of the other women in the program. Also, she worried.

"…cause we be like we were in the military, we had the MP . . . , military police be knocking at my door, knocking at my door." So he took her to the bus stop, and that was the last time Inez mentions her "little gangster." She returned to the Job Corps. When it was discovered that she was "more than three months pregnant with my child, down to the other, so I could not have no abortion, which I did not want no abortion." Inez was dismissed from the Job Corps and sent home to St. Louis. However because she was at the end of her training, she was awarded a high school diploma and was certified as a nursing assistant.

Inez was 19 years old when she returned to her family in St. Louis. There is no information about the reception that she received, however she did not stay there for very long. Her Aunt Minnie, who lived in a different city and who had two foster children under her care, died about the time Inez left the Job Corp. So Inez moved to help care for these foster children. She talks about the many cousins and neighbors who helped her during this time, and it was into this "one big happy family" that her first child, Gene, was born.

As is often the case for Inez, this time of stability and happiness was interrupted by circumstances over which she had no control. Inez's uncle made the decision to relinquish care of his two foster children. She believes that he made this decision because the woman he was with did not want the children around. However it is possible that the children were removed from this home because the dynamics of the family changed when Aunt Minnie died. Regardless of the reasons, Inez was emotionally hurt by this decision, and although she moved out of her uncle's home she maintained ties to her extended family.

Inez worked as a waitress or as a nursing assistant when she was no longer needed as a child caregiver for her uncle. Her mother and her extended family helped with childcare. Then Inez met the man who fathered "a bunch" of her children; she names six children across the data but does not mention the fathers' names. This period of her life was filled with children and work and stress. One of her children "did not develop fully" and lived nine years on a machine. It is perhaps this child that she eventually "let my child's father raise him. Because it was hard for me. I had already had three children." There is also a reference to a child who was raised by a friend, but I wonder if she is referring to the child who was raised by the father. It seems that Inez has cared for children, hers and others, off and on most of her life.

*Approaching the center*

Inez names six children in the data. They are Gene, Felicia, Claude Jr., Pamela, Andrew, and Michael. She also mentions an unnamed child who was a triplet to Felicia and Claude Jr., and another child who was Michael's twin. However, she only identified six children by name. Although she mentions her children off and on across the data, she provides little information about her relationship with each child with one exception, the story of Michael.

Michael's story is different, for the story of his short life is tied closely to one of the life changing experiences that reside at the center of this analysis. Michael's story leads to the day she "snapped" and was hospitalized for the first time because of a serious mental illness. Inez was hospitalized in a mental health facility off and on for at least nine years after Michael died. She also admits to misusing alcohol during this same time period. The entwining of these two life experiences with the occasion of

Michael's death may explain why his story is told in greater detail than the stories of her other children.

When he was about five weeks old, Inez lost Michael "to crib death and I never could get over that. I never could. I never could get over it." Inez walks through the memory of Michael's death first by detailing the care she gave him.

…my baby, he was properly fed, he was properly cared for

down to the other. I always burped Michael.  I put Michael on the bed,

down to the other.  You see, down to the other to make sure that he is

not wet down to the other, previous to him going to sleep cause I have a

habit of laying down with my baby.  I always layed him on my breast

to make sure (Inez).

Then she moves to the day when her care did not keep Michael safe. She awoke, checked on Michael, and he was not breathing. She called the paramedics who questioned her about the circumstances of Michael's death, an experience that she describes as a "third degree." It seems that Inez did everything that she knew to do to keep Michael safe, yet he died. Her mind could not safely process her grief, and she "completely snapped." Instead of planning and attending her son's funeral, she was admitted straight away to a psychiatric hospital for the first time in her life.

*At the center of the labyrinth*

Inez was 25 years old, her youngest child had just died from crib death, and she was unable to cope. "…I was out there on the crazy ward hospital for quite some time until I could come back…" Thus began a nine-year period when Inez was in and out of the psychiatric hospital.

The stories of Inez's confinement are not included in the data, but she indicates that her family cared for her children when she was unable. "My mother, my uncles, they was there for me off and on with them.  I didn't just raise them by myself." Additionally she does not tell us much about her life during those times when she was released from the hospital. She only briefly mentions that she did some traveling with a man, and that she was out of town with him when her mother called to tell her that she [mother] was diagnosed with colon cancer. It was also during this time that Inez had another child die, a son who was "born with a brain tumor, down to the other…we had to pull the plug on him when he was nine years old. Um hum." This child was never in Inez's direct care, and perhaps that explains this rather unemotional statement of his death. Or perhaps her mental state during this time was such that she was unable to fully process this loss. Regardless of the reasons, there is very little information about this life-changing period in Inez's life, with one exception, the story of how she grieved for Michael.

Inez weaves together the stories of how she coped with Michael's death and her alcohol misuse. The alcohol was consumed under almost ritualistic conditions, for a specific purpose, and in isolation. She introduced this topic quite simply.

> …then there was the alcohol…I thought, I thought I would see
> my child. But my child was nowhere to be found. And I got to the place
> at Evergreen Cemetery…I wouldn't allow no one to go around
> Michael's grave, the other kids and stuff as they was growing up…I got
> me a blanket and I got to always have me some liquor…long as I was at
> the cemetery down to the other.

Eventually Inez named her solitary drinking behaviors as destructive, and she moved forward as she remembered her needs and the needs of her other children.

I was coming along but I was destroying myself without knowing that my other children needed me just as much as he needed me, although the Lord had took him from us… Don't you know I was probably going to destroy myself for nine years. Nine years went by and all that hurt and that pain. No one gave a damn about me.

It should be noted that Inez clearly states that she was hospitalized off and on for nine years and that she abandoned her self-destructive grieving behaviors after nine years. She does not clearly state which came first, the realization that she was destroying herself or the end of her psychiatric hospitalizations.

*At the center with Inez, a woman with a serious mental illness.* These nine years of grieving, alcohol misuse, and intermittent psychiatric hospitalizations were also included in Inez's self-described wild days, and although her self-destructive grieving behaviors stopped at the end of the nine year period of psychiatric hospitalizations, her wild days continued. Inez was working when she could as a waitress or as a nursing assistant, but she said that she was a "wild coyote" and talked about these days with bravado, "I was hot, I thought I was hot to trot, I was going out, I was drinking, I was partying down to the other." Meanwhile she relied on her mother, who lived close by, to keep "a tight rope on them [children]" although they still managed to skip school, smoke marijuana, and stay away from home for days at a time.

September, 1991 was a particularly difficult time for Inez during these wild days. Within a two-week period Inez was "emotionally upset" from an unidentified surgical procedure, her mother died creating a sense of being alone and without support, and her first grandchild, Christopher, was born. Although Inez's mother was in failing health for some time, her death on September 10, 1991 took Inez by surprise and sent her into an emotional tailspin.

> I got a phone call, they say that she was dying and she was dead down to the other.  Funeral arrangements was made. I don't know if I was there or not, you see.  At this particular time no one, no one gave a damn about me or my kids.

From this final statement it seems that Inez did not receive consistent help and support from her family, that at this particular time she was feeling alone, and that her memory of this time is incomplete.

In the years following the death of Inez's mother, the family experienced several crises that finally put an end to Inez's wild days. These crises centered on Inez's children and grandchildren who were living with her. Felicia and Pamela, her daughters, used illegal drugs off and on and one son spent some time in jail. Felicia, "like to lost her life" when she ran away from home and was subsequently arrested on drug charges. Inez was left to care for Felicia's infant daughter along with Pamela's oldest son, Christopher, who lived with Inez from the day he was born. Inez managed to hold her family together through this crisis. Unfortunately, the next crisis came quickly, and Inez's world "crashed in," and her wild days ended because she felt as if she had "lost everything."

Inez's world crashed mid-1995. Felicia and her daughter are not mentioned during this crisis, so it is possible that they were not living with Inez at this time. However Pamela and her two sons, Christopher and Jerrell, lived in Inez's home. One day when Inez was not at home, Jerrell, who was six months old, was "kidnapped" by his father. The police were notified, but it was determined that Jerrell was safe with his father. Conversely it was determined that Pamela was unable to care for her children. The proper authorities were notified and were in the process of removing Christopher from the house when Inez came home. She was met by the police who questioned her, and it seems that Inez was unable to remain calm for she believed that she had custody of Christopher and that he should not be removed from her home. Subsequently Inez and Pamela were arrested on unknown charges, and Inez was evicted from this apartment. Throughout the interviews Inez continued her quest to reclaim what she lost that day, her grandson and her home.

There are few details of Inez's life from the time she "lost everything" until she was diagnosed as HIV positive in 1998. She did not have stable housing, sometimes living with her older sister, Roberta, and sometimes living with her children; and she was sick all of the time with a cold. As she talks about the events leading up to the day she received her HIV diagnosis, Inez tells us that she and her youngest daughter and granddaughter lived with a relative, Debbie, as part of a mutually beneficial agreement. They were given a place to stay in return for providing childcare for Debbie's children. Unfortunately Inez's relationship with Debbie disintegrated, perhaps because Inez's physical and mental health were declining. For example Inez expressed some obsessive thoughts about her belief that Debbie, along

with several other family members, was bisexual. She also conveyed paranoia that someone was tampering with her mail. Inez's daughter moved from Debbie's household to live with her Aunt Roberta, and Inez's physical health worsened to the point where she required hospitalization. It was during this hospitalization that Inez was identified as HIV positive.

It is also during this portion of her journey that Inez first introduces her relationship with Dr. Casey, a man she describes as her friend, lover, physician, and the one who infected her with HIV. However Inez's beliefs about this relationship are puzzling. She weaves this relationship into stories about her health care experiences, her daily routine, and her hopes for the future, yet his actual role in her life remains unclear. Perhaps consideration of the things that Inez values in her relationships can shed light on her beliefs about Dr. Casey.

When Inez talks about the men in her life, she does not talk with emotion-laden words. She does not discuss any regrets or joys she may have about these relationships. Rather she just tells us her recollections, and it is from these recollections that it is possible to catch a glimpse of how the characteristics she values in a relationship affect some of the decisions she has made. Inez chose to stay with the father of her first child whom she describes as "good to" her. In a different relationship, Inez chose to give up a child to the child's father whom she describes as someone who wanted to "carry the load" for her. Then she describes Thomas, one of two men that she identifies by name, as "hardworking and honest." Thomas is the man she wanted to marry and share her dream home with as soon as her Social Security was arranged. All of these descriptions seem to indicate that Inez was attracted to men

who took care of her, and all of these descriptions seem to set the stage for how she recalls Dr. Casey.

Dr. Casey is credited with "announcing" to Inez that she was HIV positive. He is also credited with intervening when she expressed suicidal thoughts after being told of her diagnosis by introducing her to Albert Graham of Family Health Services, referring her to Social Security for financial support, and referring her to a HIV specialist. Dr. Casey's actions set Inez on a path to healthier living with her illnesses, and perhaps she accepted his actions as a demonstration of caring. Could this acceptance have led to the development of a fixed delusion about her relationship with Dr. Casey?

Inez talks about Dr. Casey more extensively than she does about any other man, and restates seven times that she considers him "my physician, my friend, and my lover." The exploration of this relationship is further complicated for often she discusses this relationship during times when she is having problems with her "emotions," which is how Inez describes her psychiatric symptoms. Additionally, several of the details about Dr. Casey overlap with her brief account of the other man she identifies by name, Thomas.

Inez believes she was infected with the HIV through sexual intercourse, and she frequently names Dr. Casey as the man who infected her. She also mentions Thomas, "a hard working honest man every day," who is HIV positive. Thomas was a part of her life when she was first diagnosed as HIV positive and as she worked through the process of securing her Social Security benefits. The disconnect in the story is that the first time Inez talks about hearing she was HIV positive, she just says

that "he" did not tell her sooner because "he" did not want to hurt her. "Baby I got

somethin' to tell you. He said, you HIV positive just like I am. I would've had told

you but, I didn't want to hurt you." Inez accepted this information calmly. However

later when she mentions Dr. Casey as the one who "announced" that she was HIV

positive, she was upset, angry, and suicidal. Are these two separate events that

somehow became confused in her mind, or was "he" really Dr. Casey? Subsequent

data indicate that it could have been either Dr. Casey or Thomas for there are other

similar stories about these two men. For example, at different times Inez names each

of them as the man she was traveling with in the 1980s, Inez voiced plans to marry

both of them, and both men are tied to stories about her interactions with the Social

Security offices.

Inez presented Dr. Casey as a major character in the experiences she described.

However she veered from her usual presentation of rich details, aside from his position

as Director at the clinic where she receives her health care, when she talked about him

which is somewhat surprising considering the emphasis she placed on her relation

with him. There are no data to indicate that she talked to her family about Dr. Casey,

and his name is not mentioned when she reported conversations she had with other

health care providers. Therefore it is difficult to know the true nature of the

relationship she had with him, but it should be assumed that the recollections she

shared about him are ones that she holds as true. These memories may be based on the

comfort she derives from having a steady and caring presence to help her make

decisions and to offer her advice, especially during times when her mental illness

symptoms are exhibited, even if the relationship is based on a delusion. Regardless,

the role that Dr. Casey played in this part of Inez's story is presented as Inez remembers it.

*At the center with Inez, March 6, 1998, diagnosis day.* There are moments or events in almost everyone's life that are unforgettable. The details of such moments are imprinted on the memory and when recalled can often provoke not only the particulars but also the emotions of that day. For Inez, one such day was her diagnosis day, March 6, 1998. Inez refers to this day throughout the interview data. It is a central component of her health care experiences, but also holds significance because it introduced the story of when she was suicidal. Inez also surrounded the story of this day with references to her living arrangements, her family relationships, and stories about her relationship with Dr. Casey, Director of the clinic where she receives most of her health care. Inez believes she was infected with the HIV by having sex with Dr. Casey. Although the details of this relationship are sometimes contradictory, and sometimes there are details of this day that do not fit together neatly, there is no contradiction or confusion about the exact date when Inez first heard that she was HIV positive, March 6, 1998.

Inez was hospitalized at the end of December 1997, but she was not told that she was HIV positive until March 6, 1998. While hospitalized, she was very sick and was in and out of consciousness. She offers the suggestion that she was not told about her HIV status because she was very sick and "they" did not want to upset her. Unfortunately, she was upset by not being told any specifics although she knew something was wrong. She remembers that at least one doctor told her that she should be told, but she was not told what the doctor was talking about. Inez imagined that she

had cancer, high blood pressure, or diabetes. So regardless of what she was or was not told, Inez knew something was wrong. She was told that there was something "in her blood," that she would receive a letter in the mail, that the doctor would tell her what was "in her blood," and that she should follow up at a clinic.

So Inez waited. After her discharge from the hospital, she went to the clinic in January and again in February, but she was not told anything about what was "in her blood." While waiting, Inez was feeling hopeful that nothing was seriously wrong. "I was just as happy as I could be. I just got a cold. I just got a cold. I just got a cold."

Then Inez went to the clinic on March 6, 1998 and at this appointment "…Dr. Casey announced it down to me in the office…that I had the virus…" She spoke of her diagnosis day in five of the ten interviews, sometimes with statements of calm acceptance and sometimes with words that conveyed feelings of intense emotional distress. This distress was evident through her expressions of anger, guilt, worry, and fear and by the words she used to describe herself, e. g., vulnerable, irritable, full of rage, and schizophrenic. She expressed the contradiction of having no one to talk to yet not wanting to talk to anyone for she would not have known what to say. In fact, Inez said that hearing that she was HIV positive "was worstest thing in the world" that she could imagine. In response to these feelings and thoughts, Inez decided suicide was her only option.

The details of Inez's suicide plan emerged in the re-telling of this story in five different interviews. Initially she was not going to tell anyone about her diagnosis; she was just going to overdose on her medications or find a limousine and driver and have the driver drive the car into the river. Then she thought about her children and

grandchildren. Inez realized that she did not want to leave these family members without a legacy or without their knowing about her diagnosis. That is when she expanded her suicide plan into a potential murder-suicide. She was going to get her children and grandchildren together in a car and tell them about her diagnosis. If they could not accept it, she would just "get it out of the way."

Inez always tied her suicidal thoughts to the day she was diagnosed as HIV positive, "I was not diagnosed as suicide, it was just that, it was just a thought, right then and there, at the time…," she did not act on these thoughts. Each time these thoughts were mentioned in the data, Inez also described how she found relief from the suicidal thoughts through the assistance she received. The physician gave her medication for depression and to help her to calm down; she was referred to the resources she would need, such as financial support, group therapy, registration with the State. As she received support, her suicidal thoughts decreased. Another time it was a preacher on the radio or TV whose words of hope inspired Inez to follow the doctor's advice and to live. Inez is adamant that her suicidal thoughts were not persistent, and that she eventually developed "a different aspect about it… It *(suicidal thought)* was in the beginning" of her life as a HIV-infected woman with a serious mental illness.

Although Inez assigns her suicidal thoughts to her diagnosis day, it is not clear that her plan was developed on that day. Rather the data support that her suicide plan developed over time. When she remembered that day, conceivably while talking with her health care providers who were undoubtedly monitoring her mood and self-harm intention closely, Inez could fill in the story of her plan to act upon her suicidal

thoughts. Perhaps Inez is reporting these recalled conversations when she tells the story of being suicidal on the day she received her HIV-positive diagnosis.

Inez's story of feeling suicidal eclipses some of the other details about the day she was diagnosed. When she calmed down after hearing her diagnosis, Inez wanted to talk but did not know who to talk to or what to talk about. Her nurse showed her some slides and charts that depicted what happens as the disease progresses through different stages. While receiving this information Inez said that she was very frightened by what she was hearing and immediately related what she learned to what she was experiencing. "…a person was HIV and they did not take care of they selves, they skins look like sores had came out on they skins and I noticed my skin is very dry." Then Inez talks about what else took place that day. She was referred to the appropriate social services and to a HIV specialist. She received tetanus and flu shots along with an unknown "HIV shot." A blood sample was taken, and she was started on Viramune and Combivir. Inez said that by the end of this appointment she was "sore all over my whole body." Surprisingly she then says that she left the clinic and returned to work.

During this one visit, Inez received a life changing diagnosis and experienced an emotional crisis. Her physician talked with her until she calmed down, and then she spent some time with her nurse to learn about HIV. This information caused her to become frightened, but she was told that if she took care of herself and adhered to the medication regimen she could live a "normal life." The injections and blood draws added a dimension of physical pain to her emotional pain, and before she left the clinic she was given prescriptions for new medications and appointment cards for future

visits. Inez received an overwhelming amount of information and then went to work and then returned to her chaotic home.

*Moving out of the labyrinth: Inez living with HIV and a serious mental illness*

At the end of data collection, Inez had been living with the knowledge that she was HIV positive for approximately four years, although her symptoms at diagnosis suggest that she unknowingly carried the HIV for a longer period of time.  As Inez recalled these years, she focused on her move from chaotic to stable living conditions, her interactions with the health care system as she managed her chronic and acute health concerns and her relationship with Dr. Casey, the man she identified as her lover who infected her with HIV. Inez learned much from these experiences and consequently she developed some very specific ideas about what it means to live with HIV, how she can stay healthy, and her obligation to do what she can to help others stay healthy including, her participation in the original study. However a chronological look at these experiences is not practical because of the way the stories weave together and overlap. For example the chaos in her living conditions was created by family members, and her thoughts about Dr. Casey were often woven into her health care experiences which include insight into where she receives information about her health. Therefore Inez's story will continue as a topical presentation of these stories that hold meaning to Inez as indicated by their prominence in the data. Her thoughts on what it means to her to be living with HIV and a serious mental illness will then follow.

*Leaving the labyrinth: Living with family in chaos*. Inez's interviews were conducted in the relative calm and safety of her living space in the basement of her

uncle's home. However, she tells us of times when her living arrangements were quite different. After she "lost everything," and until she moved into her uncle's home, Inez mentions at least four separate moves. She lived off and on with her older sister Roberta, her niece Debbie, and an unnamed cousin. Sometimes her children and grandchildren lived with her, and sometimes other family members were a part of the household. In these chaotic living arrangements Inez's mental and physical health suffered for she was unable to take her medications regularly, and she experienced the stress of living with individuals who were misusing alcohol and drugs and engaging in prostitution and other illegal activities. Tangled up in these moves are several circumstances that caused Inez much distress when she learned about them; her name was put on an apartment lease without her knowledge, her sister Donna was named as her payee, and she lost most of her material possessions while moving from place to place.

After leaving the hospital, Inez did not return to Debbie's home. Instead she moved in with her sister Roberta, where her daughter was also living. Inez was living with Roberta immediately before her "rescue" and subsequent move to her uncle's home. She does not provide a linear story of her time with Roberta; instead she shares a tangle of stories that she introduced by saying, "the atmosphere was not fit for a dog to be in. " She mentions that she was verbally abused and "treated like dirt…like I was a hereditary germ," and she describes incidences of how other household members misused alcohol and drugs or participated in prostitution and other illegal activities such as when her pain and HIV medications were either tainted or stolen from her purse. Although she did not like it, Inez tolerated the verbal abuse and the substance

misuse and prostitution, but she could not abide the issues with her medications. When the situation escalated to make it impossible for her to take her medication safely and confidently, Inez had to endure not only a decline in her health but also an interruption in her relationship with her physician who thought that she was not adhering to her medicine regimen.

Cause I had just had it with the atmosphere, just completely just had it. I'm tired of my medication a walking, then when I go to the doctor the doctor would tell me, "Inez, you ain't got no medication in you. " "What was I takin'?" … they had me on the capsules that you can just pull apart and put what you want in it and then put the capsule back together. That is what they did, put plain flour in there…

At one point while living with Roberta in this chaotic household, someone put Inez's name on the apartment lease, possibly to avoid eviction and a move to a homeless shelter or possibly because Inez was receiving Social Security disability payments. Her name remained on the lease even after she moved out to live in her uncle's home. When she learned of this, Inez was angry and felt that Roberta betrayed and used her. Although Inez recounted this event three separate times in the data, she never provided more details about the circumstances. However she always expressed her feelings of anger and betrayal which highlights how much she values honesty in her relationships.

During this time of living in chaos, Inez's Social Security Disability was arranged, and her sister Donna was named as her payee. Because Inez was living in unstable households during this time, the paperwork explaining this may have been

lost or not remembered. Consequently there were four months when Inez thought that Donna "was doing a good Samaritan thing" by buying her clothes and groceries, paying her bills, and negotiating the rent on her apartment in her uncle's basement. Inez felt blessed by the support she was receiving and did not realize that Donna was fulfilling her role as Inez's payee. However during a visit to the Social Security office "all hell broke loose August 18th …" This was when Inez learned that Donna was her payee and was using Inez's money and was not just being a Good Samaritan. Inez was informed during this visit that the paperwork was sent to her, but she denied receiving it. She was furious with Donna and called her immediately for an explanation. Inez eventually calmed down, as both Donna and the Social Security personnel requested, but she did not let the matter drop. Instead she set out to have that decision reversed. She gained support from her psychiatrist; and by the end of the study period, she had control of her Social Security funds and her relationship with Donna was strained but peaceful.

Inez's loss of her personal belongings was another stressor related to her moving from place to place. Occasionally she reflected on what she missed, and eventually she did retrieve some of her belongings from Roberta's home with help from her uncle and Donna.

Other than that, I wouldn't know, cause like I told her [Roberta], I would like my radio…I have curtains over there.  I have clothing over there. It is getting cold.  The shoes on my feet, I got to try to get me some more shoes to put back on my feet.  She got all my material things…

In spite of Inez's strained relationship with her younger sister, Donna, it was she who played a significant role in moving Inez out of chaos and into a living space in her uncle's unfinished basement. In this new environment Inez found a measure of emotional and physical security which was distinctly different from her previous living arrangements.

*Leaving the labyrinth: Living with family in constrained security.* The contrasts between the two environments are startling. Inez moved from a home where walking around the block or even sitting on the front porch seemed dangerous to an area where she could "Go where I want to go and come back and I can be safe. " Her uncle took Inez to the grocery store and encouraged her to attend church. Inez remarked that her belief in God and the support she received at church were sources of comfort to her, something that was lacking while living in chaos.

Although Inez felt gratitude for the security and support she experienced while living in her uncle's basement, she also felt physically and emotionally limited. The basement was partitioned off, and Inez's windowless, one-room living space did not have private kitchen or toilet facilities. These facilities were located outside her partitioned-off room and were shared with other family members who lived in this communal basement space from time to time. Additionally she did not feel free to have her children and grandchildren with her, although in the face of homelessness her daughter, son, and one granddaughter did stay with her on two separate occasions. While her children were with her, Inez worried about disturbing her uncle and aunt and perhaps in response to the increased stress of these worries, she voiced resentment

of their perceived interference in how she related to and cared for her children and grandchild.

At the end of the interviews, Inez was living in constrained safety at her uncle's house, and her family relationships, especially with her sisters, improved significantly. Roberta was living "around the corner," and they visited one another regularly to play cards, shop, watch a movie, or to share a meal. Inez and Roberta were friends. This is in stark contrast to their past antagonistic relationship. Inez's only explanation for this change was that their relationship "kind of fell apart" when Roberta was misusing drugs, a habit that she "just stopped." Donna was no longer living in the same city with Inez, but she and Inez had maintained contact. Donna was living closer to their father who was recently diagnosed with cancer. Inez visited her father and said that he was doing "okay," and she relied on Donna to keep her informed of his wellbeing. Although the data are quiet regarding the real emotional disposition of this relationship, it seems that Inez did not hold onto the anger she expressed about the time that Donna was acting as her payee.

It was into this constrained but safe space that Inez welcomed the interviewer as she candidly talked about her experiences. It is from this constrained but safe space that Inez hopes to move into "a place of her own." Regardless of the state of her family relationships, she still hopes to live on her own. She describes this longing as something she has to do, perhaps as a necessary step if she is to reclaim her old self.

It would be a change. Because I got to start from scratch. I got to start all over again. . . get furniture and stuff like that, down to the other. And then I have to be on my own for a while…

These are Inez's stories that could be chronologically organized using the labyrinth metaphor which will now be set aside. This metaphor was presented as a reminder that Inez was following a specific path and timeline as she moved from young adulthood to her current circumstances. The remaining stories are not chronologically presented; rather they are presented as her significant life experiences as a woman with HIV and a serious mental illness.

*Interactions with the health care system*

Inez's specific health care interactions are not easily uncovered for she not only wraps them up in the stories about Michael's death, suicidal thoughts, chronic pain experiences, her living arrangements, the day she received her HIV diagnosis, and her relationship with Dr. Casey, she also weaves them into many of the details that she describes while talking about her life. However, once unwrapped, Inez's interpretation of her health care experiences provides a picture of what she needs from these important relationships.

Inez intuitive understanding of what she needs from her health care interactions was discerned as her health care stories were analyzed collectively. She would like to have a mutually respectful relationship with a provider who hears and sees her and not her symptoms, and she needs consistency in her care. A look at how she describes being pulled "all over the place" provides the oppositional view of the consistency she desires. An examination of how Inez and her providers communicate offers clues to how others hear and see, or perhaps do not hear and see, Inez during an interaction. These elements are not mutually exclusive for both are often evident in her description of a specific interaction. However they will be separated so that the role of

each can add detail to Inez's picture of the respectful relationships that she seeks.

*All over the place.* Early in the data, while talking about her health care, Inez uttered this phrase in response to being told that she would be scheduled to see a different physician. She planned to "tell Dr. Johnson I prefer…my regular doctor…because I am all over the place." The phrase does not appear at any other time in the data; however, this idea of being all over the place permeates Inez's health care stories as she talks about the many appointments she must arrange, the multiple providers she has seen over the years, and the problems created because"…they have me running one minute to the other, one minute to the other."

Much of Inez's time is spent managing her many appointments that take her all over the place. She regularly sees a HIV specialist, a primary physician, a nurse case manager, a psychiatrist, and a therapist. She makes a separate trip to the clinic to have her blood work drawn before some appointments, and a separate pharmacy visit is sometimes necessary after appointments. She attends a weekly HIV support group, and she visits her dentist, eye doctor, and pain specialist as needed. Additionally she continues to make regular contact with Social Security to finalize her disability income and Children's Services as she continues to seek custody of her grandchildren. Each interaction requires at least one phone call to arrange vouchers for taxi or bus transportation, and sometimes the phone call is to a family member who may take her to an appointment. It is not surprising that there are mix-ups from time to time.

…I was all scheduled today, I was all scheduled because

my cab came at 8:00 in the morning when it was supposed to came

at 9:30 to pick me up down to the other.  They had the address

wrong. . . I said "no I ain't supposed to go there until tomorrow morning at 9:15. "…The cab driver, well he was trying to be nice about it and not to argue with me. So he called the Independent Care Company and told them "you have her all scheduled wrong. " They said they took the information backwards. They was kind of tired. So he told me I could stay in the cab and he took me to [name and address removed] Medical Clinic. Then I called the cab back and the cab came and brought me back.

In addition to her health care appointments, Inez was scheduled for a study interview on the day of this mix-up. She did not complain about having such a "full day" of appointments or about the complications. Rather she was thankful that she could keep her interview appointment and accepted that mistakes happen and even offered a possible excuse for the error, "They said they took the information backwards. They was kind of tired." Then she made the most of the situation, "So he told me I could stay in the cab and he took me to…the [name removed] Medical Clinic. Then I called the cab back and the cab came and brought me back." This positive attitude serves Inez well as she takes care of herself by fitting these arrangements into her daily routine.

Managing her many appointments is a part of Inez's life. She knows that to stay healthy, she must see her health care providers. She knows that to regain control of her finances and custody of her grandchildren, she has to stay in contact with social services. She knows that to help others and to help herself, she needs to participate in support group meetings. It seems that she knows that to regain her "old self," she must

prove to others and herself that she can manage her daily routine and for now that includes these many appointments.

Another component of being all over the place is the connotation of being in a state of flux or unexpected change. Although she did not express these exact words, perhaps that is what she felt when she discussed the many different providers she saw over the years. From the data, we know that over the four years since she was diagnosed as HIV positive, her HIV physician and her primary care physician each changed three times. However Inez's words not only reflect these many changes, but also the frustration she experienced because of the changes. "I have cared and . . . I have been to almost 17 quacks. You know, to see exactly what some of my – I'm in and what stage [HIV stage]. "

With all of these changes and multiple providers, and we cannot forget the specialist that Inez saw for chronic pain or the physicians who treated her on an emergency basis, it is not surprising to know that there was tension from time to time among the providers; or at least that is how Inez perceived the situations. For example, Inez found herself in the middle of a disagreement between two providers regarding the medication she should take to help her sleep.

> Because, see, on those sleeping pills I had said that one time I could not sleep…But then I said, well, take me off of them. He took me off of them. Then when I went to go see Dr. Joyce Lohr, Dr. Joyce Lohr told me to tell Dr. Gary Simpson to put me back on the sleeping pills. He said, oh, no, just take the two – just take the narcotics that I have already given you.

In contrast, Inez did not report any changes in her mental health providers during the data collection time although a change was suggested at one time. Inez's therapist mentioned that a new psychiatrist should see her. Inez does not mention if this change occurred, but she does offer her opinion on why this change should not occur.

It's just that I don't want to have to keep going back over and over and over and over. Like the pastor was saying at church, you know, why go in the past when this is the present. You know, the past ain't got nothing to do with the present. It's just like you just depressed from the past.

Each time Inez's provider changed, she had to develop a new relationship, and she had to adjust to the new provider's plan of care. These required changes seemed to be painful for her. Perhaps the process of developing new relationships, along with the tension she sensed among her providers, adds some context to her complaint about being all over the place.

Another thought about being all over the place is reflected in how she reports actual interactions with her providers and how her concerns are addressed. For example, Inez was experiencing a dry mouth and chapped lips. Her psychiatrist, Dr. Simpson, told her to mention it to her medical/HIV doctor, Dr. Johnson. Unfortunately Dr. Johnson was on vacation and this is when Inez declared that she perhaps they would "let me go back to see Dr. Casey." For one problem, Inez mentioned three different providers. There is some irony in this encounter. The first doctor she mentioned was her psychiatrist who prescribed a medication that may have contributed to her chapped lips for she said that the medication caused her mouth to

"stays dry a lot. I guess it is the side effects of those two pills that the clinical psychiatrist had gave me. . . It is nothing more than the medication that I was going to talk to them about it. " Inez stated a concern and had insight into the cause of that concern, yet instead of being allowed to talk about the side effects, she was told to tell her medical doctor. Being all over the place, in this instance, was also a hindrance to her ability to communicate with a provider.

Then there is the issue of getting her medications. On at least two different occasions, Inez mentioned having to go back and forth from pharmacy to pharmacy to get her prescriptions filled. Again she was required to go all over the place to get the medication that she knows is vital to her health.

> I know the pharmacy didn't fill it. We been running back and forth, back and forth. Because they closed down – let me see. [name removed] Clinic Pharmacy. And they closed down half of [a different] pharmacy. So right now I'm between Walgreen's and back between [name removed] Hospital to pick up my meds…Because my schedule just been – they have me running one minute to the other, one minute to the other,

As her health stabilized, Inez's health care interactions fell into a routine that seemed less complex, although still all over the place. By the end of the data collection period, she was having her labs drawn and her HIV medications evaluated every six months, she visited her primary physician every three months, and she had an appointment with her mental health provider monthly. According to Inez this schedule is different and represents a positive change. "I had a lot of appointments, but right now I don't have a lot of appointments…Things are going much better down to the

other, because I kept all my appointments down to the other, is that they gave me a break."

*Communications with providers.* The data do not hold the providers' words. Rather the data hold Inez's interpretations of her conversations with her doctors and nurses and therapists. She provides both sides of the conversations so we never really hear or read the providers' voices; we hear Inez's interpretation of the conversations. Therefore it is unreasonable to think that Inez is telling a word for word record of her interactions, but it is reasonable to conclude that she is repeating the essence of what she took from those interactions. From there it is possible to discern Inez's beliefs about how she is seen and heard by those who direct her health care.

The phrase that captures Inez's feeling of not being heard is "calm down." She hears this phrase from her family, [Donna] "said, Inez, calm down, calm down," her contact at the Social Security office, "She said, Inez, she said, you calm down so I can talk to you," and from other individuals who help her along the way, like her support group leader, "She said, Inez, just calm down, calm down, calm down, calm down." And she hears this phrase from her health care providers.

When placed against the backdrop of her interactions during times when she was experiencing "problems with her emotions," which is how she describes some of her mental illness symptoms, perhaps this phrase was appropriate and helpful. However, if Inez's emotions or concerns were discounted or minimized by telling her to calm down before knowing why she was upset, then the phrase becomes unhelpful and perhaps even harmful. For example at one time Inez went to her psychiatrist because she was having a hard time managing her emotions. On this occasion she was

anxious, perhaps even delusional, about lesbianism and the people in her life who may or may not be gay.

> I just say, oh, my God. Oh my God. Dr. Gary Simpson help me. Help me, my head is hurtin' down to the other…He says, you gonna calm down? I said, yes, I'm gonna calm down soon as I can get all these other problems and see I come in a talk to him…And my doctor's thinks, they say, calm down, calm down, calm down.

And during a different appointment with this physician, this phrase appeared to have a paradoxical effect. Inez said,

> Dr. Gary Simpson gave me that [medication] and told me to calm down…Only thing Dr. Gary Simpson is doing is giving me that medication right there. He said, how you doing Inez? I said, fine. How's the medication doing? Okay. Well, god bless you. I see you next month. That ain't helping me one bit.

In these examples Inez implicitly or explicitly needed to talk about her emotions. She expressed her frustration with not being heard by saying, "…you want to talk but it's no one to talk about. It all bottles, with Dr. Gary Simpson, it all bottles up inside me…" Consequently, she remembers that she was told to calm down, but she does not remember if her needs were addressed.

Inez was also frustrated when she did not receive information about how she was doing, beyond her lab results, or what she should be doing to maintain or improve her blood levels. In fact it seemed that Inez did not have an opportunity to tell the physician how she felt she was doing, physically or emotionally, for he was focused

only on her lab results. Inez remembers this visit as reassuring because she believed she was "doing pretty good," yet she also felt frustrated for she believed that the doctor did not hear her.

> and my HIV specialist, he say, "Well, you're doing pretty good. " Do you ever ask what do I need to . . ,do I need to take something different to bring it up or do I need to take something to, you know, to make it don't be so low, whatever. But they never tell me anything. He always says, "Well, you're doing pretty good. Doing pretty good. Doing pretty good. " So I believe I'm doing pretty good, long as I got the medication.

In contrast to being told to calm down, calm down, there were times when Inez was encouraged to express her feelings. She found this freedom at her support group meetings. "Sarah she let us. . . . . . if you want to cry, you know, who want to cry, she said cry, you know…you all want to holler. We holler. " She also enjoyed this freedom during her interactions with her therapist and at times with her primary care provider, and each time that Inez talked about being heard and allowed to talk about her problems, she reported finding relief from the current stressor or situation. Inez remembers these interactions as positive because the provider took the time to listen. The importance of having the freedom to freely express herself without fear of judgment and without the fear of having her feelings discounted or minimized was not lost to Inez. She viewed them as ways of giving and receiving strength! "If anything was bothering me then they would listen to me after the other, so we take each other problems on, give each other strength."

Unfortunately there were times when Inez was not told to calm down, but she still was not allowed to express her feelings or to discuss her care freely. For example, she says her visits with her psychiatrist consist mostly of him asking questions and that he does not welcome family members' involvement even though Inez wanted to share information with her immediate family. When Inez asked if he would talk to her family, she said that he offered his "time is money" philosophy and told her that "if your family really wanted to see me they would have to pay for that interview for that day."

I need to talk about my problems. Only thing Dr. – the Gary Simpson is doing is giving me that medication right there. He said, how you doing Inez? I said, fine. How's the medication doing? Okay. Well, god bless you. I see you next month. That ain't helping me one bit…You know, you want to talk but it's no one to talk about. It all bottles up inside me…like if I'm ready to explode.

Inez remembers these interactions as unhelpful and frustrating.

*Respectful relationships.* Throughout the interview data, Inez talks about the importance of respect. She describes respect as a learned behavior that eventually resides in an individual as a "respectful part" that compliments or is a part of an individual's intelligence. Respect for others is demonstrated by not intruding into another's life, by considering the feelings and needs of others, by acknowledging the rights of others including the right to speak and the right to be heard, and by responding to others "with yes ma'am and no sir." Additionally Inez describes self-respect as taking care of self and never forgetting that "you is somebody."

Inez talks freely about respect when discussing her family and acquaintances but not when discussing other interactions. However she does talk about demonstrations of respect, particularly with regards to the consideration of other's needs and feelings, the right to be heard, and the responsibility to hear others. When these expressions or respect are missing, she questions the helpfulness of the relationship. There were times when she believed that the provider was not interested in helping her or her family understand her illnesses.

However when these expressions of respect are present, Inez is content in the relationship, as she was with the interviewer during data collection and with her therapist, Dr. Lohr. "She's there for me and she likes to listen to me and see exactly what's what down to the medicines that guy [psychiatrist] has put me on…" Not only did Inez mention that this provider listend to her, she sensed that the provider liked to listen to her. She expressed similar thoughts about the time she spent with Dr. Stevens during the interviews and contrasts it vividly with how she viewed the time she spent with one of her physicians.

> …he's speaking in terms like, you want to say, a foreign tongue down to the other instead of, you know, he's there but does he really listen to me? See you take the time to listen and then I was feeling sad, you feel sad with me. See, you let me know that I'm not alone.

*Putting it all together in one health care interaction.* Following is the story of Inez and a pain specialist. This story is unique in that it is complete; there is a beginning and ending. This story is briefly presented to help clarify Inez's interactions with her health care providers and what she expects to receive from those interactions.

Inez endured episodes of both chronic and acute pain. She mentions having migraine headaches and pain from a pinched nerve or from arthritis that was experienced as crushing pain in her back and extremities that hit her suddenly and limited her movements. However the pain that caused her the most distress was residual pain from shingles.

Inez was diagnosed with shingles one month after learning that she was HIV positive. At first she treated her "itch" with an over the counter powder, but within four days, she was covered in blisters so she went to her doctor for treatment. The "driving pain" from the rash started to subside after three months, but she complained of residual pain for much longer. Inez recalls that she complained of severe pain for seven months before her complaint was addressed, and she was referred to a pain specialist.

When Inez arrived at the pain clinic, she was first seen by ancillary staff who took her vital signs. While with the nurse, Inez had an episode of not being able to move her fingers. The doctor was present during this episode, and Inez remembers that at this point she was rushed to the procedure room. First she was examined by the doctor and then positioned for the procedure. Before the injection she was told that there would be a "pinch…Well, it was a pinch, but when that needle went up in there, boy!  Did it hurt!" Inez was discharged home within 30 minutes.  She left his office knowing that the medication was put directly into her spine to help relieve her nerve pain, that she made a good decision to have the injection, and that she would have to take the pain medication for a while but would gain relief over time.

Inez was given several new prescriptions from the pain doctor, and she knew

the importance of keeping her medications organized. An interesting side story that reflects the trusting relationship between Inez and her interviewer is that Inez called UWM and left a message for Dr. Stevens. She called to ask for a "medication bag…'Cause I need it for my meds, 'cause see, I went and had a spinal tap done Friday." Serendipitously, Inez had a study interview scheduled within days of her first injection. During this interview, she and Dr. Stevens had an opportunity to discuss the new medications including the dosing schedule and the expected effects of the medications. Although she was told to start her medications immediately, she was unable to fill her prescriptions immediately because the pharmacy closed before her insurance coverage could be confirmed. For Inez, it is often not her resources but the process that keeps her from getting her medications.

After Inez's second spinal injection, she experienced a similar issue at the pharmacy with her pain medication. This second experience arose because after her spinal injection she fell and had to go the emergency department where she was given a different pain medication for a wrist injury. The pharmacy would not fill her new prescription although it was approved by her insurance, and Inez did not understand why there was a problem. However it is probable that the pharmacy did not fill this prescription because of a possible drug interaction. In this instance, the process looked like a barrier when quite possibly the process was a safety net to keep Inez safe while adhering to her complex medication regiment.

This story of her experience with the pain specialist is similar to the interactions she describes with her other providers in that she was all over the place, particularly in her dealings with the pharmacy, and that she felt cared

about through respectful treatment, particularly when she was allowed to express her emotions. However there were also differences. This story has a beginning and an ending. She explained her pain, her attempt to find relief, and finally her interaction with the pain specialist. Alternatively when she talks about her other providers, she does so by providing snippets of the conversations she has with the providers. This difference is likely because she did not have a long-term relationship with the pain specialist; but she did have a relationship, and that is the crux of what can be gleaned from this story. We learn that regardless of the length of time she spends with a provider Inez feels cared about when she is heard; that she is not deterred when the process is cumbersome; and that she is once again all over the place.

*Inez explains what she knows about living with HIV and a serious mental illness*

Inez does not necessarily see herself as a woman with HIV and a serious mental illness. Instead she discusses all aspects of her life without categorizing her actions as being driven by either of her diagnoses. She has lived as a mentally ill woman most of her adult life but as a HIV-positive woman for only two years when she enrolled in the original study. However because she understood the focus of the original study, her thoughts often moved towards the experiences that she tied to being HIV positive, and thus this section of her story has a strong component of what she knows about living with HIV. However just as Inez did not separate her emotional state from her physical state, this part of her story holds elements of what Inez knows about living with HIV and with a serious mental illness and how she manages her life to keep emotionally and physical healthy.

Since learning that she was HIV positive, Inez has assembled specific ideas about HIV, how she needs to manage her life while living with the infection, and what it means to her to be HIV positive. These ideas seem to be based on the information she has learned since she was diagnosed as HIV positive, although in the final interview she says that she did not know more about HIV at that time than she did when first diagnosed with the exception that, "…we talk about it in the open, down to the other, and we all go through stages of HIV positive, down to the other. And then we have to accept it." However there is evidence throughout the data that suggests that what she knows about HIV was progressively learned as she lived with the disease.

Inez knows that she has a blood infection, it is a disease much like other chronic diseases, and that she has to take medication for the rest of her life. Inez knows that she must be honest with her sexual partners; that she must carefully follow certain rules to keep herself and others healthy; and that there are "laws" she must follow because she is HIV positive. Additionally she knows that she must maintain her peace of mind by attending to her "emotions" beyond relying on medications to manage her symptoms. Inez frames these thoughts with the belief that having a HIV infection is not a death sentence and that each person who has the infection is a unique individual who is "gold."

Inez makes sense of her infection by likening it to other chronic diseases.

"I know I got a blood infection that I gotta deal with it the rest of my life…So I have to take the medications, just like a person have anemia, down to the other, they have to be on medication, down to the other. When a person is a diabetic, they have to be on medication, down to the other. So I try to put it

in that – in a medical expectation.

Although she does not offer her thoughts about the prognosis of other chronic diseases, including her mental illness, she recognizes HIV as "a deadly disease" but that she can live a "normal life as anybody else…" To have this normal life, Inez understands that the medications that she will have to take for the rest of her life may keep her healthy but will not cure her of this infection.

> I have a bacteria germ that's into my white and red . . . in my
> system, that's why I have to take my medication for the rest of my life
> to make sure they can break down the bacteria germ, but they can never
> remove the germ…There's nothing wrong with taking your meds.

When Inez talked about her need for medication, she reflected on how at one time she labeled individuals with diabetes as "junkies" because of their need for daily shots. Now she sees herself as a "pill popper." Both of these terms are commonly heard in reference to drug misuse, and Inez seems to have taken what she knew or experienced earlier in her life and applied it to her current circumstances. Why is this important to note? Words are powerful, and the meaning that the speaker assigns to that word may be quite different from the meaning assigned by the one who hears the word. So although she may say that she is now a "pill popper," she does so in the context of her dedication to remaining healthy through adherence to her medication regimen.

*Medication adherence 101: Inez style*

Inez recognizes that she has some level of control over her chronic illnesses by taking her medications as prescribed.

If you want your health to be, if you want to be healthy and be all right with your health, you've got to take your medications down to the minute, because if you can go in there and get a glass of water, if you going to drink the water you know you can take a pill. Just like if you got go in there and you want to eat and the way your stomach is growling. It's just like you got to take a pill, so my best advice is that it's best, you can do your everyday duties down to your chores, you can also take your meds. There's nothing wrong with taking your meds.

Inez has quite a lot to say about medication adherence and how she has incorporated her medication regimen into her daily routine. While exploring the data for medication adherence information, several layers of her understanding were identified. These layers are what medications she takes and why she takes them; how she fits her medication schedule into her day-to-day activities; and her motivation, support, and barriers to adherence to her medication regimen.

Inez takes medication for her HIV and mental illness diagnoses, and for her chronic pain. Her HIV medicines remained constant across the data, Combivir and Viramune. She also received an injection every six months for HIV and an annual "pneumonia injection." At one time she took Tylenol with codeine for chronic pain associated with shingles, but this was discontinued after her medications were stolen from her purse while living in an unsafe environment. Her pain was eventually managed by a pain specialist who performed at least two spinal injection procedures and prescribed Neurontin and Vioxx for chronic pain management. Her psychiatrists prescribed two different antipsychotic medications, Zyprexa and Risperdal, the

sedative flurazepam (Dalmane), and nortriptyline (Pamelor) for depression. After her first spinal injection, she was also taking amitriptyline (Elavil) for an unspecified length of time.

In addition to her chronic conditions, Inez reported several acute problems, flu-like symptoms including a cough and sore throat and two different skin conditions, a vaginal rash and "bumps" on her scalp and subsequent hair loss. She always consulted her primary physician when she was sick, and she mentioned taking cough syrup and antibiotics for her "flu" symptoms. Her primary physician prescribed a cortisone cream for the vaginal rash, but it is unclear if she was treated by the physician for her scalp condition which eventually resulted in a significant hair loss.

> I bought some Head and Shoulder. I bought the medicate Head and Shoulder. I also bought the Glover's. One's a medicate shampoo. And I washed it with it. It did clear up a lot. It wasn't itching as much, but I noticed when the scalp get dry down to the other, the bumps will come back and it irritates me at times. I can't. . . . I could just be a grease my head and I just get to scratching. So I broke off all my finger nails and stop it from making it bleed…they can do somethin' about it. 'Cause it's irritable.

Inez's scalp rash was irritating, but it did not make her irritable. Instead she was very easy going about her hair loss. She often wore a wig, and laughed when she removed her wig to show her scalp to Dr. Stevens.

In addition to her prescribed medications, there was mention of Inez possibly using over the counter medications.

> I bought some pills down here at the Jewels Osco that was called stress

pills. I ran out of 'em, but if I go down there I get a bottle and I just put it in

the medicine bag and I just keep it for you and I can show you. That's helped

a lot. It's called stress pills. I was taking two in the morning. I was taking

two in the evening. Taking two at night and I felt myself just winding down. I

found myself eventually just drifting off with a good thought down to the

other.

It is possible that these "stress pills" were her prescription medication,

however when she described her dosing schedule there were no medications that fit

with how she describes taking these "stress pills." Considering all of the medications

that Inez has to take, it is disconcerting to think about her taking anything without her

physician's knowledge and approval.

Inez often recognizes the desired effects of her medication. For example when

Risperdal was added to her medication regimen, she admitted "Yes, I'm much calmer

than what I was." She also understands how Zyprexa helps her to control her

behaviors. "…when I didn't have the medicine I wanted to fight. I tried to punch their

lights out. And then – then they said that, Inez, you can be charged with assault and

battery. But I didn't start it."

During a different conversation, Inez tied her medication adherence to a better

night's sleep. "Now I know I am on the right track now, down to the other, with the

medication. Because I noticed I sleeps like I supposed to sleep from the medication."

Perhaps most importantly she grasps the interaction between taking her HIV

medications as prescribed and the health of her immune system.

My blood level was up to the normal. My T-count was up to the normal

count that it's supposed to be at this particular time.  But taking the medication she was warning me of that that I got enough of the medication into me…But other than that, I guess it's where the infections is, my white corpuscles and my red corpuscles in my blood stream has the infection.  I guess it's supposed to break the germ down.  Which I know I can never get the HIV out of my blood system.  So I will be on medication for the rest of my life.

However, Inez does not always know why she takes specific medications, but that is the exception rather than the rule. This exception occurred after she had her first spinal injection and was given several new prescription medications. On this occasion she seemed overwhelmed with the new medications. During the next interview, Inez had a better understanding of her new medications.

There was one other occasion when Inez indicated that she did not know how her (HIV) medications were supposed to work when asked this question specifically. "No, no more than I'm supposed to take it twice a day." However in her unique storytelling style, she then proceeded to provide information to the contrary.  "But other than that, I guess it's where the infections is, my white corpuscles and my red corpuscles…I guess it's supposed to break the germ down. Which I know I can never get the HIV out of my blood system."

*How Inez fits her medication regimen into her daily routine.* Inez has built medication adherence into her life now that she is living in a stable environment. "Get up in the morning; take care of my medication and stuff…to make sure that I stay on track. Then I have to get up and clean up the house…to make sure everything is on the up and up." Prior to this arrangement, she found it hard to take her medications

because of a lack of daily routine and concern about her safety and the integrity of her medications.

Because the focus of the original study was the experiences of HIV-infected women, it is not surprising that Inez had more to say about adherence to her HIV medications than she did to adherence to her psychiatric medications. She consistently reported taking her HIV medication as prescribed. When asked if she ever forgets a dose, she states clearly "No, I have to do it so I get up and do it every morning. And I do it in the afternoon." However from the following quotes, it seems that Inez includes all of her medications in her daily routine.

Well, it just like takin' a vitamin every day. Down to the other, previous I put it in a sense of a one-a-day vitamin 'cause I take one Combivir. And then I take one Viramune and that's in the morning. Then I take another round about 3 o'clock. So I take four pills a day and that's no more than normal…Like one medication, I'm supposed to take once a day, that's once a day, a twenty-four hour medication for ten days. The next medication I'm supposed to take twice a day. That's twelve hours, that's twice a day and then the other medication like I can't say it, I take that twice a day, that's every twelve hours so I try to stay on track with that and the other one. I can't say that it start with a Z [Zyprexa], I take that twice a day, one in the morning and one at night. So everything is every twelve hours like if I get up at eight o'clock in the morning by nine o'clock I should be on schedule. I take my medication at nine o'clock in the morning. Then I turn around and take my medication at 10:30 at night.

Building her complex medication regimen into her daily routine did not seem to be a problem for Inez, and she did not indicate any behaviors that she had to change because of her medications. However, there was a time in Inez's life when she misused alcohol, and she indicates that she can never go back to that behavior and interestingly labels this as a side effect of the medications. Since learning of her HIV-positive diagnosis, she has avoided alcohol; she understands that she cannot drink alcohol while taking her medications.

Don't supposed to have no liquor what so ever …It would cause a bad reaction or down to the other so, I am not going to mess around with alcohol…That is why I can't drink alcohol medication. And that is even good because I don't even crave for alcohol. I cannot have no alcohol with none of that medication, right there. It would cause a bad reaction or down to the other so, I am not going to mess around with alcohol.

Inez seems to include all of her medications in this alcohol ban. However when asked directly about recent alcohol consumption, she admits that she "had a beer about a month ago. I had a nice cool beer about a month ago, other than that, that is when I didn't have the medication."

*Motivation, support, and barriers*. Inez's motivation for taking her medications is clear. She knows that by taking her medication she can achieve optimal health and extend her life. "I want to live." Her motivation seems to be directly related to her expressed desires to "get her old self back." Her "old self" is independent and living where she can enjoy her family.

There are four areas of support for medication adherence, with none identified

as more important than any other. The first is financial support in the form of insurance and government programs.

> …by me having um, straight blue ford insurance card and I got eye care
> to cover in case you want to say the copayment was a little more expensive
> than what I can afford.  Now, other than that, I shouldn't have no problem with
> my medication…Because one bottle of medication can run, for me, almost a
> thousand dollars…

The second is the personal involvement of Albert Graham who is mentioned throughout the data as her contact person with Family Health Services. When Inez was diagnosed as HIV positive, Dr. Casey arranged for Inez's referral to Family Health Services. "You know, 'cause Albert Graham came out to my house and told me that Dr. Casey had turned my name in that I was HIV positive." During this initial visit Albert Graham also helped Inez understand about her diagnosis, her medications, and the role of Family Health Services in her care. "Albert Graham…told me that um, you know, the virus is real.  He wanted to see what's I'm on the type of medication.  And is there anything that I need down to the other that he could provide?" Inez relies on Mr. Graham' advice and often calls him to verify information or to make sure things are being done correctly. For example when there was a question about who should have "custody" of Inez, she said, "Cause see, I got so upset and angry I called Albert Graham and I told Albert Graham these people names and stuff 'cause my sister says, 'I'm gonna get custody. I'm gonna have custody of you.'"

The relationship between Inez and Albert Graham carries the components of the respectful relationship that Inez desires to have with her health care providers, and

that may be the key to why she identifies him as a support for her medication adherence. Mr. Graham is "easy to talk to," allows her to express her concerns freely, and provides tangible help. Additionally, he is a constant in her life.

The third support for adherence is family. Inez's family support includes her aunt and uncle, her children, and her sisters. Her aunt and uncle provide a stable living environment that enhances her medication adherence. "That's why I'm glad I have my auntie 'cause I can lock my pocketbook up, take my medication, just like I did a few minutes ago. Go where I want to go and come back and I can be safe." Her children provide encouragement for her to take her medications, although they were not initially afforded an opportunity to support Inez because she delayed telling them of her diagnosis.

My daughter was the first one to find out about it, down to the other. She was scared for me, down to the other. She wanted to know how did I get it, what was I doing to get it, what – what is it, down to the other. So I told her it's a blood infection… Then I told my son. My son, he took it pretty well, down to the other.

However after telling them, she was pleased and seemed surprised at their responses.

Well, my kids cared more than what I thought down to the other. That's been a change. They just said they need to be in my life… she [daughter] didn't judge me. She hugged me. And she told me, it's going to be all right, Mama…[my son] talks to me and things like that, down to the other, to make sure I take my medication. They remind me of it every time they

come. Mama, did you take your medication today? I said, yes…they want to

see my medication bottles, down to the other, to make sure I got the right type

of medication to take.

Additionally, her sisters' provide support, but it is sometimes hidden in the

complexities of their relationships. However, Inez recognizes their support for

medication adherence when she recounts how Donna said,

You know you're supposed to be going to the doctor to be getting your

medication, you know we're already upset.  We don't want to lose you.  You

know we got mamma is gone.  You know we lost Daddy and now we gonna

lose you.

The final factor that supports Inez's medication adherence is her personality

and attitude. Inez attends to details, and this trait helps her as she organizes the dosing

schedule of her medications. Also, she has learned how to ask for help and she does

not hesitate to seek help when needed. For example, when her pain specialist added

several medications to her regimen, she contacted the UWM School of Nursing and

asked if she could get a "medicine bag" to help her keep track of her medications.

The barriers that Inez must rise above to maintain adherence to her complex

medication regimen include dealing with the pharmacies, medication side effects, and

maintaining the integrity of her medications.

Inez has financial resources to pay for her medications, and she has adequate

transportation to the pharmacy. However, these resources are not always adequate

when she needs to interact with a pharmacy. Sometimes coordinating everything

interferes with her ability to get her medications, and sometimes she just feels

frustrated with the whole process that pulls her all over the place.

> The pharmacy . . . see, Friday, at the pharmacy, my insurance company, I Care, had to have been called . . . that's speak with Jenny Neslon…'cause Jenny Nelson did not call the pharmacy back until between, you want to say six or seven o'clock.  But [the] pharmacy's open from seven o'clock to seven o'clock P. M. at night.  So the call came in at seven o'clock.  I could not get my medication until . . you want to say, this week that's coming up, for me to pick it up…

And sometimes it is just too difficult for Inez to arrange everything so that she can get her medication in a timely manner.

> I'm supposed to be picking up the Viox and the one with the M on Friday at [name removed] Hospital. I was supposed to have picked it up on the 18th but I didn't… Because my schedule just been – they have me running one minute to the other, one minute to the other, behind all this unnecessarily crap that's going on.

Another barrier to adherence is medication side effects. Considering the medications that Inez takes, she reports only a few side effects, and she does not identify which medication she believes is causing her side effects. She mentions feeling sedated sometimes, having a dry mouth, and experiencing increased joint pain. These side effects did not cause her to be become non-adherent to her regimen. Rather she identified them, talked about how to manage them, and attempted to discuss them with her providers.

Inez talked briefly about one medication that was prescribed to calm her down.

She said that this medication caused her to fall asleep during group therapy. "…like today at meeting, I had took my morning medicine . . . which is the one I take three times a day. . . and I was noticing that it (pooped me out?) so when they . . . "Wake up!" I woke." Inez also described how a different medication made her mouth dry and caused her to have chapped lips. From her descriptions, these side effects were from some of her psychotropic medications.

> And I also noticed that my mouth stays dry a lot. I guess it is the side effects of those two pills that the clinical psychiatrist had gave me. And that keeps a nasty mouth taste. I sucks on toothpaste but it would go away for a while, but it come back. It is nothing more than the medication that I was going to talk to them about it. It leaves a nasty taste in my mouth.

She attempted to discuss her dry mouth and chapped lips with her psychiatrist, but this was an occasion that Inez remembers as one when she was not heard and was referred to a different provider.

On at least two different occasions, Inez reported some numbness and tingling in her hands and increased joint pain that she believed to be caused by her medications. None of these complaints caused her to stop her medication, but she did report them to her physician. "I think I have a side effect…because my leg has been bothering me a little more than normal. Just hurting. It's the hip right there. It hurts right there. It just started about a month ago."

*Safety of medication.* There was a time when Inez was unable to take her medications because of her living environment. While living with her sister, who was misusing drugs and engaging in prostitution, Inez felt unsafe and her insurance card

and medications were stolen or tampered with by someone in the household or by a visitor to the household. Her blood work indicated that she was not responding to the medication, and it became a very distressing situation for Inez as she tried to explain to her physician and her family that she was taking her medication as best she could. This distressing period in her life remained important to her because she referred it on numerous occasions across the interview data.

Cause see, I had slacked up down to the other, cause like I said, my insurance card walked up out of my purse. I did not have the right type of medication in me down to the other. The medication was always coming out to bein' stolen down to the other. But here, I get the right doses. . . Because like I said, it's a, it's a shame that I can't put my purse down or my medication and come back and get it. Because they can tell with my blood work when they did if I took three pills…So I thought I was gonna completely go out of my mind…It was walking, it was like it would be there, but it is not the medication, it would be some generic medication down to the other because I know Dr. Casey kept getting on my tail. '[Inez], this is why we keep drawing blood. [Inez], you is not taking the medicine. ' 'Yes, I am. ' 'You are not taking the medicine. ' I prove it, I am taking the medicine, I brought it in. And it was some pills that you buy at Arty for 99 cents. Supposed to be 500, 5 milligram pills that's what I was taking. The other pills, he had it on like the capsule green pill, the white pill, there was some water you want to say flour in the capsule

Her journey to her current, stable living arrangement is documented in previous sections, and the insecurity of her medications actually played a role in alerting her family to her need for a safe place to live and to get healthy. Since living at the home provided by her aunt and uncle, Inez has faithfully taken her medications. "So, since I got my medication here I can leave, come and go as I please, and it will be there. It will be there. I think I am on the right track right now" So although this barrier has been overcome, from the way she recounts the incidence of living in an unsafe environment, it is likely if she ever moves again, she will consider the safety of her medications.

*Behaviors to protect self and others when living with HIV*

Although Inez has not been in an intimate relationship since she was diagnosed as HIV positive, she discussed that possibility and identified three rules that she would carefully follow should she choose to enter a relationship. She would disclose her HIV status to her sexual partner; she would try to choose a partner who is in the same disease stage; and she would always use condoms.

> I meet a person and I tell them I'm HIV positive down to the other…We can talk about it and if we want to be intimate we can really be intimate in the way where we both know that we will still be taking precautions with birth control, the rubber down to the other… You want to say my HIV might be in one stage like it's in stage 1 and his HIV might be like in stage 2. I got to be very cautious by keeping it in stage 1. . . I think I got eight bags of rubbers down to the other for the protection down to the other, because my virus is my virus and his

virus is his virus…

In this quote, Inez infers her understanding about how HIV lives in her body. She knows that the disease is progressive and has different stages based on her symptoms and viral load. Individuals at different stages may manifest different symptoms, and because of this she would be cautious. Further insight into how Inez views her HIV status is found in how she makes a distinction between having HIV and having AIDS. Throughout the data she is explicit that she is HIV positive which is different from having AIDS. "There's no way I got AIDS. I have HIV." Her expression of this clear distinction between HIV and AIDS is consistent with the terminology used when HIV was discussed during the time of data collection. Additionally she believes that she was assigned a different physician because she does not have AIDS and her doctor "…went from not being HIV specialist. He is working with all AIDS patients right now. " It is not clear if Inez understands what this means to her specifically for she did not voice concerns about being diagnosed with AIDS even though she understands that her illness could cause her death. Instead she relies on her medications and her healthy lifestyle to keep her alive "until the doctor is God, call me home. Other than that, there's nothing to worry about."

Inez recognizes the importance of following these rules and places an emphasis on the disclosure rule. She believes that it would be the same as murder if she infected another with HIV through sex without disclosing to the other that she was HIV positive.

It's just that I got to be more careful and take more protectoral

awareness of things than anybody else do or the next person do because

other than that I can easily infect somebody else's life…They can take

a life and that life is just like if I took a life I committed murder

myself…I should have told the person that I slept with that I was HIV

positive.

Inez knows that the HIV is transmitted through sexual contact and through

contact with blood and body fluids, "HIV blood cannot mingle with another person

blood because they can easily become [infected]. …I cannot have anything bloody

laying around, down to the other. I cannot let anybody else come into contact with my

blood." However she also believes that she must be careful and "clean" as a way to

keep herself and others safe. She injects thoughts of cleanliness into her narratives as

she talks about ways to stay healthy. For example, when sharing a drink, "I make sure

that I keep my straw down to drink and my mouth does not touch the glass…That way

I can be-- it's called cleanliness.  I have to understand that." While her ideas about the

HIV transmission via drinking after someone who is HIV-positive seems erroneous,

she relates this idea to cleanliness as a means of keeping herself healthy rather than as

a way to promote the health of others.

Always make sure your system is clean…I have to be very cautious and

clean…It is just that you got to be more clean then what you was before…But

as long as we keep ourselves clean and make sure we is, to represent yourself

as you are, down to other, we, don't harm anybody else by trying to infect

somebody else, we'll be all right.

In addition to the rules that Inez says she has to follow to keep healthy and to

keep from transmitting the HIV to others, she also talked about "laws" that must be

obeyed. She does not relate the laws to an infringement on her privacy or to a way of

tracking the HIV. Rather she talks about the laws as procedural and protective should

she ever have another child or form an intimate relationship.

> We can live a normal life as anybody else if we want a child, uh
>
> children, down to the other. Our children will have to register with the
>
> state by Albert Graham. (Wisconsin Family Health Services)... so, the
>
> baby has like a 90% chance to be normal and 10% to carry maybe HIV.
>
> Now, other than that, there's nothing else to worry about…It's just that
>
> I got a blood infection and you don't. And by the state law, I cannot
>
> just jump in and out of bed with any man down to the other 'cause it's a
>
> highly risk to the man…And that's a state law… they do not want me
>
> to come on contact with the syphilis or gonorrhea, which now they call
>
> Black Draw, cause it could aggravate my HIV to a state where it can
>
> almost cause me to go cripple. So, I have to be very cautious about
>
> everything.

*Attending to her emotions*

Because she hears "calm down" from so many individuals who she

depends upon and respects, it is not surprising that Inez has adopted this phrase

to explain how she manages her emotions. Or maybe the phrase is a reminder

to use her coping skills so that she can make good decisions. For example

during a particularly stressful period in her life when she was living in chaos,

she just wanted to "be able to adjust and try to calm down as much as I can."

And at another time when talking about why her daughter and granddaughter

were living with her, she mentioned that she "mainly concerned… for [all] to calm down, get the baby back in school, and then we'll find them a house." But ultimately this phrase is used by Inez as a reminder to cope with her problems and emotions. "I had to calm down, because if I don't I could end up in the hospital, and what is the hospital going to do for me?"

Although Inez takes medication to help her manage her emotions, Inez also relies on certain behaviors that she has developed over time. These include faith in her religious beliefs, attention to self-care, and helping others. She tries to use these behaviors not only during times of stress but on a daily basis as a way to stay emotionally healthy.

*Faith.* Inez was baptized into the Baptist faith as a child, and her faith has been a part of her life since that time. However, it has not always been a source of comfort for her. Sometime between childhood and her current life, she identified herself as "a stray for a long time. It's like living in the bewilderness…" During this time, Inez experienced many struggles including being diagnosed as HIV positive and with a serious mental illness. She also struggled with her faith. She said that God was always in her heart but she was only saying "God, God, God…It's like God must don't like me because why do I have to suffer so hard. . . I didn't do anything to inflict harm upon others. Why is all the harm inflicted upon me?" Inez has experienced many struggles throughout her life, so "the harm" cannot be identified. She continued to question her relationship with God until her uncle helped her connect with a local Missionary Baptist Church. Now she has reclaimed the title of a "church going woman," and when she is unable to attend services, she "cuts the tube on [to watch] a

gospel program…and then after I pray with them down to the other. " Through this reconnection to her faith and to a local church, Inez finds that her spirits are lifted as she remembers that her life "is in God's hands."

During times of emotional stress, Inez relies on her faith to help her calm down and to see beyond her current situation by "putting it [circumstances] back in God's hands." She finds reasons to be grateful every day, accepts and does not judge those who cross her path, prays for others and allows others to pray for her, and forgives. These attitudes and actions are evident in the following philosophical statement that she made when reflecting on her routine, day-to-day life. "I try to keep my thoughts good, not bad thoughts. I try to keep a millstone where it was a rock and try to break that rock down into small chips of rocks, don't build a big wall." Although she did not declare this to be her philosophy, she agreed with Dr. Stevens who mentioned that this statement sounded like a good philosophy of life.

When the phrases and analogies in her statement are examined in the light of how Inez describes her beliefs and actions, a tie to her faith can be found. Inez believes that "good thoughts" are thoughts of happiness and gratitude for the smiles she receives from her family and friends and from knowing that her children and grandchildren are happy. Good thoughts are also reminders to take one day at a time for tomorrow "is not promised to you." Bad thoughts are those that would "drag me down and look like I'm in a rut and hard place. . . so I'm locked in. One hell hole" and are opposite of "lifters" that she experiences when she puts "it back in God's hands." Good thoughts help her to keep rocks, the problems she encounters, from becoming heavy burdens such as a "millstone around the neck." Then through prayer,

acceptance, and forgiveness, even the rocks can be chipped away so that they cannot be used to build walls. Perhaps the walls relate to her relationships; Inez's family relationships changed over time because she chose to forgive and "to go forward and let the past lay down."

*Self-care.* Inez has taken care of her children, her relatives' children, and her grandchildren all of her adult life when she was physically able. She has now learned how to take care of herself. "I got to learn to worry about Inez and don't worry about somebody else. . . I got to worry about what is Inez going to do… because I got to always put myself first before I can put another person first." She does this by caring for her physical needs as well as her emotional needs through exercise, proper diet, adequate rest and relaxation, meditation, and setting boundaries.

When she is able, Inez likes to walk. However her walks are more than exercise for she walks to a local museum or a park which she describes as places of peace and beauty. She walks to a senior center where she "could always find someone to talk to, or someone to lean on." She also walks so that she can be alone and think before she returns to her home, tired and ready to rest. Inez knows the importance of adequate rest and tries to "rest as much as I can. The doctor say it's good for me." To relax Inez likes to watch TV, read, play cards, and shop; she enjoys staying busy as much as possible. She also mentions that she tries to eat a "proper diet," and mentions how much she enjoys taking meals with her family. Perhaps for Inez, a "proper diet" includes the social aspects of her meal.

To tend to her emotional needs, Inez practices meditation and prayer. The only meditation technique that she mentions is one she learned in group therapy. She counts

backward from 100 and that by the time she reaches zero, she is calm. Another way

that she cares for her emotional needs is through setting boundaries. She knows that at

times she "needs a little time to think," and she lets her family know when she is

taking such a "time out." However she is also careful about not extending her "time

outs" so that they become periods of withdrawal and isolation.

> I was getting to the place, you know, at a certain time, uh, evening, I don't like
>
> the TV. I just want to be left alone. I might get over there in a corner and just
>
> sit there for two or three hours. And then I get mad about sitting there, because
>
> once I'm sitting there trying to relax my mind, but then I get those bad
>
> thoughts going back through my mind down to the other.

When this happens, Inez recognizes that she needs to make a change and will

seek help from her psychiatrist in case she needs a medication change and she will

also try to reflect on her good thoughts. Because she can make these changes when she

is in this "place," Inez demonstrates that she has developed some powerful coping

skills.

*Helping others.* Inez is involved in community AIDS awareness programs and

offers her time and advice to others, particularly women, who are HIV positive. She

does this through her weekly support group meetings, by joining a "Stump Out AIDS"

awareness program, and through participation in the original study. She does these

things in the hope that other women can learn from her experiences and to help them

"cope with reality."

One way that Inez hopes to help others is through her participation in the

original study. She wants her story to be told, and to be told carefully. "If you going to

study, you have to study right to know all our problems down to the other to get a true understanding of those." Embedded in her story is the advice or help that she would offer other women who are "still running wild." Quite simply she says that they should "tone their heels" and "just be careful" and to know that "who you lay down with is clean."

Inez's weekly support group is another way for her to help others. At these meetings the members can speak freely about their concerns and learn about their infection and the resources available to them, and Inez reports general statements about how she participates in the group. She mentions that she has told group members about her HIV providers, about Albert Graham, and about the original study. Although it is not clear how this information is received or used by other group members, it is clear that these meetings and the concept of helping others are important to Inez and are useful coping behaviors for she "feels a little more better about myself with those meetings. I think if I didn't have that I probably would have fell apart."

*Stigma: Unexpectedly uncommon*

So far, Inez's story is rich with details of her daily life and how she manages her illnesses. However there are very few data about how Inez experienced stigma. The word "stigma" does not appear in Inez's narrative data, and there are only four references that could be viewed as stigma experiences, and these experiences were not described extensively or clearly. From these brief references it seems that Inez experienced internalized stigma as being fearful, an outcast, and different; however these feelings were never the focus in the stories she related.

*Being fearful*. When Inez was first diagnosed as HIV positive, she did not want to tell her children. She said that hearing that diagnosis was the "worstest thing in the world" and that she would rather die and kill her children than live with knowing that they could not accept her illness. This appears to be a form of internalized stigma, for she was not afraid to die. She was afraid of rejection. Although no longer suicidal, Inez continued to carry this fear and came to realize that others shared this feeling. During her support group meetings, she learned that, "I'm not the only one that say "I'm afraid to say I'm HIV positive." Everyone in the room is HIV positive. So we can talk in the open." With this statement, Inez reveals that she was learning to manage her fear and to perhaps lessen the stigma that she internalized. The timeline is not clear so it cannot be determined if this support group revelation had a role in her decision to tell her children about her diagnosis. However when Inez did tell her children that she was HIV positive, she was surprised at their responses of acceptance and gained their support as she learned to live with HIV.

*Feeling like an outcast*. When asked directly if she was ever discriminated against because she was HIV positive, Inez responded that "one time I was. I guess I was an outcast down to the other because there nobody know what HIV was. " She softened the idea of being an outcast by saying that it was because others did not understand or know about the disease. She did not explain what it meant that she was an outcast, but at a different time she mentioned that she was treated badly because of her HIV status. "Because some people when you tell them that you're HIV positive they look at you like oh! oh! They treat you like dirt…My sister, she treated me like dirt. Like if I was a heredity germ… Oh I'm HIV, you can't touch me." We do not

know if Inez was socially shunned, ignored, abused, or ridiculed. We just know that she felt mistreated.

*Different from normal*. When discussing the advice she would give women who were "kicking up their heels" and having sex with different individuals, Inez encouraged them to be careful and cautious before entering into a relationship. She said, "Because it ain't what you see what you get. 'Cause just looking at a person, if they know I was HIV positive, I guess they took me as a normal person." What did Inez mean by saying that she was taken as a "normal" person? The inference is that because she is HIV positive she is not normal. She put herself into a category that was different from individuals who were "normal." Again, this seems to be a form of internalized stigma, but Inez never repeated this idea again in the data so perhaps she is unaware that she feels this way or perhaps it is just her way of self-identifying as HIV positive.

Inez's brief statements that may be related to stigma are noted here because this is an unexpected finding considering the known levels of stigma that those with HIV or a mental illness usually report. This is a surprising finding that may be best explained by considering it in light of what is known about Inez. Inez is kind; she does not judge others and does not expect others to judge her; and she often chooses to see the best in others. Perhaps that is why she chose to not dwell on the few stigmatizing experiences that she mentions in the data.

*Gold*

Inez frames what she knows about HIV with beliefs that it is possible to live with HIV; that it is not a death sentence; and that each person who has the infection is a unique individual who is "gold."

> People are born HIV positive every day, every second, every minute. People are also born with AIDS. They are living and proof. God has not given up for them…We can live a normal life as anybody else…[and]I'm a human being just like you. It's just that I got a blood infection and you don't.

When talking about the importance of the original study, Inez said that individual stories must be heard because each individual with the HIV is unique and special. Inez also believes that in addition to the uniqueness of each person with the HIV, each person is also valuable, "…it is because you have to think of yourself as valuable as God's most valuable thing is life itself." Each person is also special for "God has chosen this here for me for a particular reason to make me realize life can be good, life can be miserable, life can be up and down." Inez's analogy for this valuable uniqueness is to "Let them know that I am gold" and collectively HIV-positive individuals are gold mines.

> It's changes, it doesn't really change anything but it changes my expectations and my thoughts to be more gentle and be more careful than ever than I was before I came to be part of, if you want to say, Fort Knox, a gold mine.

At one time Inez described an "old self" that she longed to reclaim. Her "old self" was living independently "with my grandchildren spending the night or my children spending the night. I can picture family gatherings down to the other." She has not

given up on this picture becoming reality, for she remains on a waiting list for low-income housing and she has regained some control of her finances. However while she is waiting, she remains kind, forgiving, outgoing and outspoken within the confines of her "emotions," and willing to help others by sharing her experiences. There have been some changes in her expectations and behaviors, yet she believes that she is still Inez, a HIV-positive woman with a serious mental illness who believes that she and others should, "Just try to be an understanding person with life and not to be a cast out. That's my understanding, because ah, I'm a human being just like you. It's just that I got a blood infection and you don't." Perhaps Inez makes these statements because she knows that even if she can never fully reclaim her old self, her current self is content, looking forward to the future, and is as precious as gold.

Chapter 5

The original study from which the data for this in-depth case study were drawn explored the impact and meaning of HIV/AIDS on the lives of HIV-positive women. Areas of interest included the participants' health needs, medication adherence, access to and utilization of health care, reduction of risky behaviors, and stigma (*In-Depth Longitudinal Study of HIV-Infected Women,* National Institutes of Health Grant #R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN). While all of these areas are included in this study, it is the unique voice of Inez as she describes what she knows about living with HIV and a serious mental illness that complements the original study.

In this chapter the findings from the case study are discussed, conclusions are drawn from the findings, and implications for education, practice, research, and theory are presented. However I believe that my first presentation of these items should be to Inez for she has been my constant companion through this process and as such should have this metaphorical first look. Therefore I have framed this chapter with a letter to Inez. All readers are invited to figuratively look over her shoulder and read along as each component of this chapter is presented, but for the sake of clarity, the letter that frames this chapter is in italics unlike the more detailed discussion in each section.

*Dear Inez,*

*I think that perhaps it is time for me to introduce myself to you, at least in this letter for I know that we can never meet face to face. My name is Linda, and Dr. Stevens (who you described as your "professor and friend") introduced you to me about six years ago. The introduction was made through*

*the sharing of the transcripts of the discussions that you and she had during the data collection period of that important study she was conducting. I suspect you remember that she wanted to learn as much as possible about women who are living with the HIV infection. You graciously allowed Dr. Stevens to share your words with her students, like me, so that we also can learn about women with HIV from the real experts, namely women like you.*

*So I am writing this letter to thank you for many things, but mostly for allowing me to read your stories. What I read, and I read the transcripts from your ten interviews many times, captured my attention, my curiosity, and my heart. Since the first reading of your words, I have been trying very hard to use your words and thoughts to create a word picture of how you have managed your life, and sometimes how life seemed to manage you, as you learned to bring into your life all that having HIV means to you.*

*Perhaps I should insert a few thoughts about myself here. I am a nurse and I currently teach nursing at a small university in the southeast. Just as you find meaning and hope in your desire to help other women who have HIV, I find meaning and hope in my desire to help individuals with a mental illness. At one time I did this by working directly with these patients, much like "your nurse" Lisa who worked at the clinic where you first learned about HIV and where she gave you information about Dr. Stevens' study. Then I became a teacher, and I taught student nurses about the different mental illnesses and how to take care of people who were having problems managing their illnesses. Ever since I met you through your interview data, my curiosity has*

*been stirred. Among other things I am curious about how what you have learned can be useful to others who must live with HIV, or other chronic illnesses, while continuing to manage their emotions.*

*So you see Inez, your stories are very important to not only me, but to other nurses and health care providers. You are one expert from whom we can all learn! You recognized this, I believe, when you told Dr. Stevens that, "If you going to study, you have to study right to know all our problems down to the other to get a true understanding of those." I hope that the word picture that I have created from your stories will help others as they work alongside women, such as you, to build respectful, helping relationships.*

*Inez, below is the "Summary of findings" where you will find a distillation of what I learned as I constructed the word pictures of your life. I formed it into a case study that carries the rather long title of "What Inez knows: A qualitative, longitudinal case study of one woman's journey through the maze of living with HIV and a serious mental illness." Dr. Stevens and I agree that this title captures the notion that you have greatly helped us learn from this case study created from your stories. And now my hope is that others who read the case study will learn from you as well. In what follows you will see that I am talking to doctors and nurses about your life.*

*Summary of findings*

The case study about Inez's life was created by pulling apart and then reassembling the common themes from her two years of conversations with Dr.

Stevens about her family, her losses, her hopes, and her health care experiences from the perspective of a woman living with HIV and a serious mental illness.

From this case study, we know that Inez wants to be seen and heard above the "noise," or symptoms, of her HIV infection and mental illness diagnoses. She believes that this can only occur if she can establish mutually respectful relationships with her family and health care providers. Then from this place of mutual respect, Inez can reclaim her "old self." Her old self would live independently and enjoy being with her family; her old self would make independent financial decisions; and her old self would confidently follow the treatment plan that was designed to bring her to optimal physical and mental health. Inez also knows that she is now "more" than her old self; she accepts that she is unique and perhaps even "golden" because she has learned to live with HIV and a serious mental illness.

However there are difficulties that Inez encounters as she tries to reclaim her old self through the establishment of mutually satisfying relationships. Her living arrangements are "all over the place." And, her health care encounters are "all over the place." The former was an issue before her family intervened and moved her to stable, safe housing at her uncle's home; the latter remains a multifaceted problem. Her health care providers are located across multiple facilities, meaning that she is physically all over the place. Inez's health needs are complex and include providers who treat her HIV infection, her mental illness, and her other physical health needs including management of acute and chronic pain. While trying to talk with her health care providers about a specific complaint, Inez sometimes senses tension related to treatment options, and she becomes frustrated when a provider refers her to a different

provider instead of addressing her complaint. Thus she feels that her treatment choices are also all over the place. The feeling of being pulled all over the place heightens her feeling of being unheard and having her complaints minimized. Additionally she often ties being unheard to hearing the phrase "calm down, calm down." Inez has the insight to know that she needs to be calm when trying to explain herself, and in fact uses "being calm" as a barometer of how well she is managing her mental health. However, she also feels that at times others lead with this phrase instead of listening to why she is upset. Therefore the phrase becomes a way to silence Inez instead of a way to remind her that she should assess her emotions and use her coping skills so that she can communicate more effectively.

In spite of these difficulties, or perhaps because she has had to learn how to persevere through them, Inez has developed some clear ideas about how a woman can live with an HIV infection and a serious mental illness. Inez knows that being HIV positive means that she has a "blood infection" and must take medication for the rest of her life. Inez knows that she must be honest with her sexual partners and that she must carefully follow certain "rules and laws" to keep healthy and to guard against infecting others with HIV. As a woman with a serious mental illness, she knows that she will need to maintain a relationship with her psychiatrist and take medications to help her manage her emotions. Additionally she knows that she must maintain her peace of mind by monitoring her emotions and practicing coping skills such as prayer, exercise, thinking positive thoughts, and moving outside herself by helping others. Inez does not categorize her actions as being driven by either of her diagnoses,

therefore she knows that all of these ideas and actions work together to keep her physically and mentally healthy.

Inez does not refer to her past experiences or her diagnoses with regret. Rather as much as possible she focuses on what she has gained from her experiences. She sees herself as a strong woman who has wisdom to share with others. Her family relationships are now perceived as avenues of support instead of barriers to healthy living, and she continues to believe that one day she will live independently and not only reclaim her old self but find that she is even "more" than her old self.

An unexpected finding from this case study is that Inez does not readily identify stigma in her life. However she suggests that she has internalized stigma when she talks about being fearful of disclosure, feeling like an outcast, and being different. Her brief statements related to stigma lack the rich detail that she often provides in her conversations and may be best explained by placing these statements in the context of what is now known about Inez. Inez is kind; she does not judge others and does not expect others to judge her; and she often chooses to see the best in others. Perhaps that is why she chooses not to dwell on the few stigmatizing experiences that she mentions in the data.

> *Inez, the above distillation of your story is what I believe you would have others know about your experiences as a HIV-positive woman who also has a serious mental illness. But there are other things that I "found" while creating the word picture of your story. For lack of a better word, I think of the following things as serendipitous learning, for I did not expect to learn these*

*things! Initially I was focused on what you said, and then I realized that how*

*you told your story over a two-year period was an equally important finding.*

*Serendipitous learning.* The process of working with Inez's narrative data was

challenging and frustrating. Learning to work with the data was rewarding and

instructive, however, and thus is presented as a serendipitous learning experience. This

experience confirmed that all words carry meaning and each word should be

considered carefully so that the true meaning can be discerned. Another discovery was

how the longitudinal data added to the strength of this study. Having access to Inez's

data that spanned a two-year period enriched my understanding of Inez's stories and

allowed me to follow the evolution of a mutually respectful relationship with the

interviewer. I cannot think of a better way to emphasize the importance of these

findings except by sharing them in the continuation of my letter to Inez.

> *Inez, your interviews were conducted over a two-year period. During*
>
> *that time you had periods of physical sickness, family upheavals, and*
>
> *emotional disturbances that may have interfered with your thoughts, but you*
>
> *were always faithful to meet with Dr. Stevens and speak openly in answer to*
>
> *her questions and about whatever you felt was important at that time. Before I*
>
> *elaborate on the importance of this longitudinal interview process, I need to*
>
> *confess that your ways of constructing stories and speaking were challenging,*
>
> *frustrating, and intriguing as I tried to understand exactly what you wanted*
>
> *others to hear. At times it seemed that your mind was pushing ahead, urging*
>
> *you to add details or to insert a side story. At other times you seemed to be*
>
> *silently withdrawn into your thoughts and chose to answer the questions or tell*

*your stories in what I came to think of as the "Dragnet Style." Do you remember the old TV show Dragnet? Sergeant Friday's catch phrase was, "Just the facts, Ma'am." During these times, you responded without the rich details that I expected; instead you just provided the facts. And sometimes you seemed to have a hard time managing your emotions, which is how you described the reason for your relationship with a psychiatrist and for your prescribed psychotropic medications. During these times, your speech patterns seemed to reflect some thought distortions or delusions, but I do trust that everything you reported was an accurate assessment of your reality at that time. Dr. Stevens and I spoke about this from time to time, and we reached the consensus that all of your words should be honored as your truth.*

*These unique storytelling styles caused me to consider unique ways of organizing the data, your stories, into accurate depictions of the experiences that you wanted others to hear and understand. The most challenging was when your responses to Dr. Stevens were lengthy and contained many different story lines. The method I used to analyze these lengthy, richly-detailed sections of data was a method that I used to help nursing students understand therapeutic communications; I segregated the data into untitled columns with each column representing a different story. After the data were segregated, the columns were titled based on the content of the story in that column. I admit to being surprised when I realized that what at first appeared to be a tangle of disconnected stories often emerged as several separate accounts of different experiences that added specific details to the topic at hand.*

*The most frustrating aspect of working with your data was when your responses were "just the facts." I was accustomed to hearing rich details and colorful descriptions of your interactions and experiences; reading one word responses troubled me. I even felt a sense of betrayal because you were not doing as I expected. These feelings told me that I had lost my perspective on the work I was trying to complete. I lost sight of you, Inez. To reconnect with you, and your data, I re-read the field notes from the interviews when you responded briefly, and I talked to Dr. Stevens who reminded me to trust the data. Your short responses helped me to realize that you always responded the best you could, and that this work of learning from you was about you, not me.*

*And then there was the intriguing element of what seemed to be the insertion of delusions or thought disturbances into your stories. There was no way that I could have or should have made any judgment regarding the objective truth of some of your statements or beliefs. For example, I do not know if you had a relationship with one of the physicians at the clinic where you received your care. I do know that you talked about such a relationship. What was I to do with the layers of detail that were added to your stories by these possible delusions? Surprisingly, the answer was that I simply had to acknowledge these thoughts as your current assessment of reality. After the construction of your stories and the identification of the meaningful findings from these stories, I realized that all of your thoughts supported the findings. To use the example from above, your thoughts about having a relationship with a physician supported your desire to engage in mutually respectful*

*relationships. So while I am still intrigued about your thought processes and how you incorporate your "emotional problems" into your life, I know that my role in the reporting of your story was to "trust the data" and allow your story to unfold.*

*Before I move on to tell you why it was so very important that you completed all ten interviews across two years, I want to mention two expressive idiosyncrasies of your speech that added a distinctive flavor to your storytelling. The first is that you sometimes, no I think it is more accurate to say that quite often you inserted the phrase "down to the other" into your sentences. At first this puzzled me, and I tried to figure out when and why you used this phrase for I thought that I needed to know this to understand what you were saying. I think I was wrong. As I became more familiar with your storytelling style by re-reading the narrative data, that is what Dr. Stevens and I call the transcripts of your interviews, I realized that the phrase did not add or detract from what you were saying. It was just something that you said; and before long, as I read your words, I found that this phrase became a mental signal that reminded me that Inez was speaking. It kept me focused on you. Now when I read through the data, that phrase is as natural for me to read as the phrases that alert me to other speakers. For example, when I read "The game is on" I know that Sherlock Holmes has found a new mystery to solve but the phrase itself is not a mystery. However, there are others who will read your words but one time, and those readers need to learn quickly what I learned*

*after many hours of reading the data. Otherwise they may spend too much time puzzling over that phrase and miss the salient points of your story.*

*The second expressive style was your (mis)use of certain words and how you mixed some metaphors. I mention this here only because I want you to know that these expressions caused me to smile and to think about how I use metaphors and words. I think that your way of mixing two sayings together may not be a more efficient way to express your thoughts, but it certainly is more memorable than a simple statement of your feeling. I clearly understood and remember your feeling of acceptance when you said that at a group meeting you were not, "I guess you wanna say, being a sore thumb or being a needle in a haystack that stickin' out that don't fit in." It is a memorable statement of your feeling!*

*So, Inez, these were the challenges, frustrations, and fascinations that I realized while I attempted to honor your guidance to "…study right to know all our problems down to the other to get a true understanding of those." All of these thoughts are explained in greater detail in Chapter 4.*

*Previously I mentioned that having access to interview data that spanned two years was important to me, although I did not initially recognize the full value of such data. Did you realize the importance of your devotion to the interview process? Because you shared your experiences over a two-year period, the details of the major events in your life deepened with each telling of the story. Additionally, the longitudinal nature of the data offered me the opportunity to hear how your concerns, circumstances, needs, and health*

*changed over time. For example, as your living arrangements changed from chaotic to stable, your self-care and family relationships improved. Therefore your stories are rich in details that may have been lost had you and Dr. Stevens spoken only once.*

*The creation of the case study from your stories was not without challenge. The stories that seemed to matter the most to you, the stories you re-told several times across the interviews, held different details with each telling. Additionally, your stories often intersected. Therefore I learned to rely on a spreadsheet that included dates, names, addresses, and other details that were tied to a specific event. From this spreadsheet, I constructed a timeline of these significant events in your life. These documents provided confirmation of how some stories were insular, like your interactions with the pain specialist, and how some stories tied together; i. e. the story of your chaotic living arrangements was tied to your HIV diagnosis day.*

*There is another important aspect of the longitudinal nature of your data that fits easily with one of the findings from this case study. I refer to your desire to engage in mutually respectful relationships and how your relationship with Dr. Stevens evolved over time into such a relationship. The relationships that you described in the data are reported with your words. Mutual respect could be implied or denied from your descriptions of what the provider or family member said or how that person responded to your presence. From this information, you helped me to understand what you desired in a relationship and how you would know when you experienced*

*mutual respect. I was able to learn about both sides of the relationship when it came to your relationship with Dr. Stevens. I had access to your descriptions of her interactions with you and the transcripts of her statements to you. Additionally I had her field notes that contained her assessments of your behaviors, the emotional climate of the interview, and her thoughts about what you told her. Therefore I could follow how your relationship evolved and why you determined that she truly cared about you. In short, you described your relationship with Dr. Stevens as the mutually respectful relationship that you desired to have with your health care providers and with others who you needed to interact with routinely. The longitudinal data afforded me this "insider" perspective on how your mutually respectful relationship evolved.*

*I mentioned earlier that I am curious about how what you know can be useful to others who must live with HIV while continuing to manage their emotions. This is where I stretch my thinking about what you have taught me and draw some conclusions from the findings. These conclusions will assist nurses and doctors as they care for other women who are living with HIV and a serious mental illness.*

*Conclusions*

*Conclusion #1.* Through this single case study replete with experiential detail from two years of interviews, we are given an extraordinary view into how one individual lives with HIV and a serious mental illness. For Inez, learning to deal with complex medical and emotional issues required support from trusted individuals, an environment of physical and emotional safety, and a reliance on her foundational

strengths- a sense of positive self-worth and a motivation to reclaim her life. By expending time and effort to learn about individuals' life stories, no matter how idiosyncratically told, health care providers might come to better understand patients' capacities, values, and needs; and collaborate more effectively with them as they seek care for physical and emotional problems.

*Conclusion #2.* Stability of care over time may be especially important for persons living with HIV and a serious mental illness. The individuals and places that comprise the health care of persons like Inez include not only care providers but also the ancillary services that assist with access to care and social and financial resources. For Inez stability of care in each of these areas was the difference between feeling unheard, distressed, or confused and feeling valued, heard, and in control. Stability of care allowed her to establish trusting relationship with the persons and places that comprise her health care.

*Conclusion #3.* Narrative knowledge of individuals' lives built consistently over time in mutually respectful relationship may be key in overcoming internalized and enacted stigma. By listening closely to Inez's story, the shadows of stigma were discerned but not explicitly expressed. In a mutually respectful relationship, both parties can safely bring the topic of stigma into the light to see what it looks like and feels like to individuals such as Inez. Without knowing that it exists, it cannot be overcome.

Each of the conclusions includes the idea of a mutually respectful relationship, and the elements of such a relationship are found in the extensive literature that addresses the provider/patient relationship. Terms such as connectedness, presence,

intimacy, person-centeredness, and empowering are used to explain a relationship that

is mutually beneficial (Anderson, 2007; McCormack, Karlsson, Dewing, & Lerdal,

2010; Mitchell, 2007; Nygardh, Malm, Wikby, & Ahlstrom, 2011; Phillips-Salimi,

Haase, & Kooken, 2012; Stavropoulou et al., 2012). Each concept intimates that the

provider and the patient are responsible for building the relationship, and recognition

of the patient as an individual and trust are common themes in these descriptions.

However acknowledgement of the unequal balance of power in the relationship, which

tends to tip in favor of the provider (Delmar, 2012), is not always evident in these

concepts. Bell and Duffy (2009) report that this unequal balance of power places the

patient in a vulnerable position as the patient extends trust in the provider's

competence and believes that the provider makes decisions that are in the patient's

best interests. It therefore becomes the provider's responsibility to acknowledge that

the asymmetrical relationship exists, to recognize the risk that the patient is taking by

trusting the provider (Bell & Duffy, 2009), and to provide "sensitive attention" versus

paternalistic "overcaring" (Delmar, 2012, p. 242). The extension of this relationship

from mutually beneficial to one that is mutually respectful is missing in the literature.

The notion of stability of care is also inherent in the conclusions for such

stability allows for the development of relationships that are mutually beneficial.

Stability of care is documented in the literature under the guise of problems associated

with a fragmented care delivery system. Fragmented care may be presented as a

structural barrier to access when care is provided in multiple locations (Joo & Huber,

2013; Philbin et al., 2014) or when ancillary services are not in place when individual

enters into a health care relationship with a primary care provider (Mutchler et al.,

2011). Stability of care certainly includes the importance of a centralized location for care that would lessen the feeling that Inez described as being "all over the place," but the findings also suggest that it is equally important to have consistent providers of care. Mutchler et al (2011) presented the idea of a "treatment advocate," a trained individual who facilitates the growth of the client-provider relationship. A treatment advocate (TA) would be a constant member of the health care team and could add some consistency to the patient's experiences.

Examples of what is known about patient-provider relationships are provided in the preceding paragraphs, but none of these examples capture the essence of Inez's experiences. As I read the literature and then reflected on the data and field notes, I realized that Inez felt secure and sheltered in her mutually respectful relationships which is different from what I found in the literature. When I mentioned this to Dr. Stevens, she suggested that perhaps what I found in the data was similar to the concept "cultural safety." I learned that the concept of cultural safety was introduced in the early 1990s in New Zealand by indigenous Maori nurse leaders (Anderson et al., 2003) to address the inequities in access to health care and life opportunities experienced by the Maori. Outside of New Zealand cultural safety has served as the framework of intercultural research in Canada (Lynam & Young, 2000), cultural nursing education in Israel (Arieli & Friedman, 2012), and others suggest that it is useful as a socio-ethical model for nursing practice (Woods, 2010) or as an expansion on the cultural competence model of practice (Mortensen, 2010) with global implications (Baker, 2007).

Cultural safety has not been explored in the context of HIV-positive women with a serious mental illness as a cultural group, but the following definition merges nicely with what I learned from Inez about mutually respectful patient-provider relationships. Cultural safety is a place "which is safe for people; where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening. " (Williams, 1999, p. 213).

*Limitations*

Inez was one participant in the original study that included a total of 55 women, and one of the aims of that study was to examine the meaning and impact of HIV/AIDS in the lives of HIV-infected women (*In-Depth Longitudinal Study of HIV-Infected Women*, National Institutes of Health Grant #R01NR004840, Principal Investigator, Patricia E. Stevens, PhD, RN, FAAN).The data generated from the original study provided rich details about many aspects of the participants' lives, but it was not designed to be a case study investigation. Inez's data were identified serendipitously as amenable to a single case study after review of the data that fit with the original intent of this study, which was to examine the lives of HIV-positive women who also had a serious mental illness. The decision to present a single case study was based on Inez's vivid descriptions and attention to detail and on the thorough field notes included with the narrative data. This case study, therefore, supports the aim of the original study but it is limited because the content of the narrative data was set prior to the start of this current study. Additionally, the data

were collected more than ten years ago. Although the truth of Inez's story holds across time, her stories are bound by time and should therefore be understood in that context.

The analysis of words without ever hearing the voice of the speaker was a challenge. There were many layers of interpretation between me and Inez's conversations with the interviewer in the original study. The words were spoken, recorded, transcribed, read, and then interpreted for meaning; and written words are flat, one dimensional, and open for interpretation by the reader. Part of the interpretation process involves putting a voice to the words, or hearing the original speaker, which adds another dimension to the words. However what happens when it is not possible to hear that actual voice? Quite often the reader puts a voice to the words, and that voice is usually the voice of the reader. As you are reading this, if you do not know me personally, what sound is in your head? Whose tone and inflections are you hearing? What about an accent? Therefore the reader truly becomes the interpreter of the words. By keeping this phenomenon in mind each time I read Inez's words, I proceeded with the analysis. However the crux of the challenge resided in how to stay true to the data and Inez's words without ever hearing her actual voice.

This challenge was met through adherence to the standards of rigor in feminist research (Hall & Stevens, 1991) by verifying my analysis with the interviewer, Dr. Patricia Stevens, who heard Inez's actual voice and witnessed her non-verbal voice as well. However I still had to recognize that my voice could intertwine with Inez's, thus creating a bias in the findings. To address this I practiced reflectivity through journaling and conversations with Dr. Stevens. There was one question that I asked myself throughout the analysis. "What did Inez say, and did I interpret her words

based on my experiences or on her experiences?" Through this practice, I believe that the final presentation of Inez's story is true to the data and captures the essence of what it was like for Inez to live with HIV and a serious mental illness.

Although working with narrative data was challenging, I believe that being forced to see only words allowed me to identify my personal prejudices and biases. For example Inez mentioned reading some professional articles about HIV, and I was surprised. Upon reflection I realized that I had created a mental image of Inez that did not include her having the capacity to understand professional writings. This led me to take a second look at some other responses I had to what Inez said or did. Did her words evoke memories of patients I met while working in a mental health setting, and did those memories lead me to assign more or less to her words than a non-biased reading of her words would have produced? Had I heard and seen Inez, it is possible that I would have missed this opportunity to examine my responses as closely as I did during the narrative analysis.

Limited generalizability of findings from a case study is often reported as a limitation, and it is true that these findings should be applied cautiously to other individuals. Rather than generalizability of these findings, the value of a this case study is that it provides an opportunity to know the unique or particular because the "trouble with generalizations is that they don't apply to particulars" (Lincoln & Guba, 2000, p. 27). Nurses are always cautioned to individualize care, or in other words, to recognize the particulars.

*Implications*

"Sometimes we simply have to keep our eyes open and look carefully at individual cases—not in the hope of proving anything, but rather in the hope of learning something" (Eysench, as cited in Flyvbjerg, 2011, p. 303).

*Practice.* Discovery of what Inez needed as she learned to live with HIV and a serious mental illness was possible because she was given time to tell her story and because someone listened to that story. Although Inez's story unfolded over a period of two years and practicing nurses would seldom have that luxury of time, I believe that a health care provider can achieve the same outcome with other patients who have complex needs. Learning about a patient's capacities, values, and needs takes time and effort beyond an initial assessment and should be accomplished in collaboration with the patient, for it is possible that the patient is as unaware of these things as is the provider. This discovery process is like the concentric circles that grow outward from a pebble dropped into a still pool of water. The pebble is an assessment question and the resulting concentric circles represent an increasing understanding of that initial assessment. The pebble may be a simple question like, "Where do you live?" The circle of discovery then grows as the patient may off handedly mention that her neighborhood does not have a local grocery where she can purchase fresh foods, or she may raise her voice angrily when responding to a particular question. This process requires careful attention to words and behaviors, and the provider and patient should be free to ask for clarification of what is heard or the meaning behind the behavior.

However Inez taught us that this process can change from the image of a quiet pool with ever-expanding ripples into rough waters as multiple providers, seeking the same information, drop pebbles into the pool. The ripples start to crash into one

another and a patient may experience what Inez called being "all over the place." For the benefit of the patient and the provider, the waters need to "calm down," and the pebbles dropping into the pool should be controlled. Stability of care can be that control. This stability may not be available under our current system of fragmented care delivery or because of confounding access to care issues, such as lack of financial resources or availability of providers. However when planning to meet the health care needs of individuals with known emotional concerns, stability should be considered perhaps through the use of an identified advocate or case manager who would serve as a constant presence or contact for the patient.

> *Inez, I wanted to talk to you briefly about how your interviews can help nurses, doctors, and other health care providers learn to do a better job talking with their patients. Some nurses and doctors may not realize they need to improve on how they communicate, but your stories about getting health care contain a lot of advice about this. How providers talked to you was the basis for how you perceived your relationships with them. You have shown us that no matter how efficient and competent we think we are being, if we don't listen for what the patient needs at a particular time, and try to connect our response to that need, we may be failing him or her. Because your data emphasized the importance of communication, it is prudent that I do the same, perhaps as a reminder to all providers who may care for a person with multiple health care needs.*

The health care provider is responsible for creating the emotional environment in a relationship and carries much of the communication burden in this discovery

process. This significant responsibility can be effectively realized through basic

therapeutic communication techniques which include an element of self-knowledge.

Just as focused listening allows one person to understand another, reflection allows a

person to understand "self" including personal values and biases. An emotionally safe

environment cannot be created without this process of dual understanding. Then,

within this safe environment, the nurse, physician, or other provider can provide

information, taking care not to overwhelm the patient, and offer care in answer to the

patient's condition and concerns. Mutually respectful relationships can develop and

thrive in such an environment.

*Education.* Nurse educators have long recognized that a well-developed case

study offers students a safe way to explore the complex needs of patients before they

encounter a "real" patient (Popil, 2011). Therefore it is incumbent on our profession to

assure that the case studies used are relevant, based on actual circumstances, and

stimulate further conversations about the phenomenon that is presented (Gomm,

Hammersley, & Foster, 2000). Additionally, case studies are often presented in a

narrative style that includes multiple direct quotes, metaphors to help explain complex

themes, and holistic accounts of the individual or group under consideration

(Donmoyer, 2000; Lakoff & Johnson, 1980; Stake, 2000). Therefore analysis of a case

study as a way to apply the facts, protocols, and disease descriptions that are described

in textbooks can help students understand the complexity of care they are likely to

encounter after graduation.

Inez's case study captures the unique circumstances of her life and logically

leads the reader to ask additional questions, such as "What if…?" It is exciting to

consider using her story in the classroom and to imagine the ensuing discussion as students reflect on what is required of a nurse to care for a patient with multiple physical and mental health needs. Of particular interest would be the development of reality-based scenarios from this research-based case study. Such a scenario would serve as the focus for problem solving in a problem-based learning environment (Lee & Uys, 2005). The reality-based scenario, based on a health challenge, would be presented to the students, perhaps in written form or perhaps verbally to mirror a nurse's shift-to-shift report. The students would be guided to ask new questions about this issue and to discover what was and what was not answered in the study. Existing literature related to this health challenge would be used to guide a discussion of similar challenges. Finally students would develop a plan to meet the challenge with the patient. These activities could inspire students as they practice reflective journaling to clarify their beliefs or identify any biases that entered their consciousness while working through the problem-solving activities. These are but a few of the innovative ways this research-based case study or others that may be developed using this as a model may be utilized by nursing educators.

Individual case study research would support the education of nurses and other providers. The individual case could be one person or it could be a community of individuals. Regardless, research-based case studies that include a depth of data similar to this case study could provide learning opportunities across a semester or course as all aspects of a person's life are presented to students. Students would learn about the illness while gaining knowledge of what it means to an individual who lives with that illness. If the individual case study addressed a community or group, students

would gain information about the impact of illness on a wider population and on the community at large.

 *Research.* Although more than thirty years have passed since AIDS was first diagnosed in the U. S., the HIV epidemic continues and the HIV statistics remain alarming. Twenty-five percent of the people living with HIV in the United States are women, but only half of these women are in care and even fewer women (42%) have viral suppression. Women of color continue to carry a disproportional disease burden (Centers for Disease Control and Prevention, 2014b). HIV prevalence among adults with a serious mental illness range from 3-23% compared to the general population prevalence (. 4-. 6%), although these statistics are not gender specific (Agenor & Collins, 2013; Blank et al., 2011). Based on these facts, there is continuing need to explore the dual experience of HIV infection and serious mental illness in women. Research that focuses on the women behind these statistics, that seeks to understand the particulars of their lives, may offer greater insight into how the health care community can improve outcomes for women with serious mental illness. Based on quantitative findings showing poorer viral load suppression and medication adherence in individuals dually diagnosed with HIV infection and serious mental illness (Blank et al., 2011), there is growing support for intensive case management for this population. However the patient perspective is missing in the analysis. There is also qualitative evidence that multidisciplinary models of care are effective in mental health care delivery, but structural and personal barriers may keep providers from adequately assessing reproductive and sexual health for these women, limiting HIV education and screening (Agenor & Collins, 2013).

What tends to be missing in extant research about the intersection between HIV and mental illness is the patient perspective. A qualitative research study could be designed to capture the patient perspective and start to fill this gap in understanding. A secondary analysis of an existing, rich qualitative data set would be one way to address this gap. Just as this secondary analysis of qualitative data proved valuable in learning from one woman, other data sets could be analyzed to discover new information about topics beyond the intent of the original study. The key is to locate sources of data from well-designed studies that yielded rich narratives.

As an alternative to additional secondary analyses, new studies could be designed. Further research to explore the transferability of the findings from this single case study is recommended. Studies that explore the experiences of individuals, male and female, dually diagnosed with other chronic conditions, such as diabetes hypertension, would provide additional insight into what these patients need from providers to improve their lives.

*Theory.* Individuals who provide HIV care may benefit from designing practices that adhere to the principles associated with cultural safety. The concept of cultural safety assumes that any relationship between a health care professional and individual seeking care is "unique, power-laden and culturally dyadic…[and] involves the convergence of two cultures…" (Papps & Ramsden, 1996, p. 494). Cultural safety is based on the broadest definition of culture to include individuals' age or generation, gender, sexual orientation, socioeconomic status, ethnic origin, religious or spiritual belief, and disability. The provision of quality, patient-focused care is impossible if providers hold unknown biases or negative attitudes towards patients who are different

from them in any of these categories. These negative attitudes and biases cannot be identified without deliberate self-reflection. Unknown biases and negative attitudes towards HIV positive individuals create barriers to provision of quality of care and negatively affect patient outcomes (Bennett, 2007; Bryson, 2012; Papps & Ramsden, 1996).

The experiences of Aboriginal HIV-positive women in New Zealand (Bennett, 2007) and HIV-positive Aboriginal women with a mental illness in Canada (McCall & Laurisden-Hoegh, 2014) were explored and the principles of cultural safety were infused throughout the report. Although cultural safety was developed as a way to improve the care of Aboriginal people, the authors of these studies suggest that all people should have the freedom to access care in an environment of safety and respect. All women who are HIV positive and have a mental illness belong to a cultural group that is often marginalized and stigmatized. Those who provide care for this cultural group can learn how to develop mutually respectful relationships by applying the principles of cultural safety.

*Policy.* In a statement outlining the National HIV/AIDS Strategy, President Obama reminded citizens that all of society, including members of health care professions and people living with HIV, must take part in the effort to make the United States a country where "new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination" (Office of National AIDS Policy, 2010, p. vii). The number of providers trained to offer evidence-based care to

individuals with comorbid conditions, such as HIV and a mental illness, must increase, and they must be allowed to practice unencumbered by a fragmented system. These goals are included in The Patient Protection and Affordable Care Act (ACA) (Druss & Walker, 2011).

To achieve these goals and to answer the President's call to action, nurses can make the most of their power to shape public policy at all levels of government through individual actions or through collective actions as members of professional organizations who support lobbyists. Nurses can also seek out opportunities to work alongside people who live with HIV in educational efforts that may reduce the stigma associated with HIV (Buseh & Stevens, 2006). By taking part in such strategies, nurses will demonstrate a united effort to reduce the burden of HIV stigma while enhancing the lives of HIV-positive individuals by influencing public policy.

However, policymakers are the mechanism for change. Individual's stories presented in research based case studies, placed in the hands of these policymakers, could guide them to "close in" on real-life situations (Flyvbjerg, 2011) and to connect a problem, such as fragmented health care, to a person.

*Final Thoughts*

*Dear Inez: I am closing out my dissertation research. This process has caused me to stop and think about the person I was before I met you through the data, about our time together, and about the person I am now because of meeting you and completing this dissertation research. The before and after pictures have not changed significantly on the surface, but our time together (the research process) has created*

*many changes in how I view others, myself, and our places together in the world. These many changes hinged on one defining lesson from the research process.*

*I was drawn to qualitative research because of my love of words, stories, writing, and my curiosity about how other people experience life. Nothing in that list has changed. However working with your data on this case study has changed my "curiosity perspective." Unconsciously I was curious about how people were different from me so that I could feel separated from them. I had some serious negative attitudes that rose to the surface of my consciousness through the self-reflection that is a part of the narrative analysis process. Since embracing self-reflection as a personal habit, I find that my "curiosity perspective" has shifted; I now seek to understand others so that we can work together on a problem or live together in my neighborhood or learn together about almost anything! You did that for me, and that is what I value most from this dissertation research process.*

*Knowing you through this research has also inspired me to consider other stories that may be held by women who do not have the opportunity to be heard. You are unique, Inez, but you are also a part of a larger community of women with HIV and a mental illness. I want to hear other women's stories. I want to figure out how their stories come together or move off into different directions. I want to stay connected to your community and share what I learn in the hope that the lives of all members of your community are better. Working through this research process with you has prepared me to do these things. Thank you.*

*Thank you, Inez, and farewell,*

*Linda*

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Appendix A: Textual Analysis Example

| Inez | Inez talking about Roberta | Inez talking about Donna |
|---|---|---|
| It was really hard because she wanted to be in charge down to the other. | | |
| | Instead she would take the truth and twist the truth in order to make it a lie, order for my little bitty sister, | |
| | | which I always say we called her the baby girl, but she's not little. We call her Duck because she's real beautiful. But that was the name my Grandmother gave her was Duck, little ducklet. She's a really beautiful down to the other. |
| | She had to have gone to the phone booth and telling her lies on top of lies. | |
| | | Here come Donna, she's steaming mad, hot and furious. Don't give me time to talk. Everybody is whooping, hollering and screaming. |
| My head is going donta, donta, donta. | | |
| | | She was so upset. You don't take your medication, you know you're supposed to be going to the doctor to be getting your medication, you know we're already upset. We don't want to lose you. You know we got mamma is gone. You know we lost Daddy and now we gonna lose you. It's not right, you could do better… |

Appendix B: IRB Approval

UNIVERSITY of WISCONSIN

UWMILWAUKEE

Department of University Safety & Assurances

Benjamin J. Kennedy, MA
*IRB Manager*
*Institutional Review Board*
Engelmann 270
P. O. Box 413
Milwaukee, WI
53201-0413
(414) 229-3182 *phone*
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## New Study - Notice of IRB Exempt Status

**Date:** October 16, 2008

**To:** Patricia Stevens, PhD
**Dept:** Nursing

**Cc:** Linda Austin, RN, MSN

**IRB#:** 09.099
**Title:** How Do HIV Infected Women Who Have a Serious Mental Illness Describe Their Health Care Experience?

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been granted Exempt Status under Category 4 as governed by 45 CFR 46.101 subpart b.

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol which may impact the risk level to the participants must be reviewed by the Institutional Review Board before implementation.

Please note that it is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the University of Wisconsin – Milwaukee and its Institutional Review Board. It is the principal investigator's responsibility to maintain proper documentation of its records and promptly report to the Institutional Review Board any adverse events which require reporting.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,

Benjamin J. Kennedy
IRB Manager

CC: Study File

CURRICULUM VITAE

Linda Austin

Place of birth: Boynton, PA

Education
> B.S.N., University of North Alabama, May 1998
> Major: Nursing
>
> M.S.N., University of Alabama in Huntsville, December 2000
> Major: Nursing Administration

Dissertation Title: What Inez knows: A qualitative, longitudinal case study of one woman's journey through the maze of living with HIV and a serious mental illness.

Professional Organizations:
> American Nurses Association: Member/2003-Present
> American Psychiatric Nurses Association: Member/1998-Present
> Sigma Theta Tau International Honor Society of Nursing:
>> Beta Phi; Member/1999-Present
>> Upsilon Omicron: Member/2008-Present; Past President; Director
>> Eta Nu: Member/2012-Present
>
> Phi Kappa Phi--University of North Alabama: Member/1998-Present

Presentations:
> Invited speaker: Student Nurses' Association, University of North Alabama: March 2, 2010. Topic: Overview of Forensic Nursing with an emphasis on the role of a Sexual Assault Nurse Examiner (SANE).
>
> Invited speaker: Community Networking Group, Florence, AL: March 10, 2010 as part of National Women and Girls HIV/AIDS Awareness Day. Topic: Overview of nursing research related to women and HIV with an emphasis on the stigma experiences of HIV-infected women who also have a mental illness.
>
> Presenter: Professional Development seminars: Quality and Safety in Nursing Education; February 8, March 8, April 5, and May 5, 2011. University of North Alabama, College of Nursing and Allied Health. Each session approved by Alabama Board of Nursing for 1.5 CEU.
>
> Invited speaker: NU325: Health Care Lecture Series, November 2, 2011. Topic: 30 Years Later; Living with HIV.
>
> Poster presentation: STTI Regional Research Conference, Jackson, TN, October 26, 27, 2012. Poster: A qualitative longitudinal case study of one woman's description of living with HIV and a serious mental illness.