INNER STRENGTH IN WOMEN WITH HIV/AIDS

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DEDICATION

Be my heart's prop.
In the waste places be a shade-giving tree.
Be good to me!
The night is long, the dawn far away.
Be a small light, be a sudden joy,
Be my daily bread.

Rachel, 1966/1979

This work is dedicated to special people who were my heart's prop and shade-giving tree!

To my mother, who has more inner strength than any woman I have known.

To my father, who would have been proud to read every word.

To my husband and sons who loved and nurtured my inner strength.

To the physicians, nurse practitioners and physician's assistants who patiently taught me the art of HIV/AIDS caring.

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Our strength is often composed of the weakness
that we're damned if we're going to show.
Mignon McLaughlin, 1966 (as cited in Maggio, 1996)

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ABSTRACT

Significance. This phenomenological study generated descriptions of inner strength in women living with HIV/AIDS. Only two previous studies have investigated inner strength in women with illnesses. The study findings present a new perspective of health within illness and methods for nurses to assist women to identify and utilize their inner strength.

Methodology. This phenomenological study explored inner strength in nineteen women living with HIV/AIDS. Data were collected through use of semi-structured interviews. Data analysis of the audiotaped and transcribed interviews followed Colaizzi's (1978) procedural steps.

Findings. Inner strength is an innate and inherent potential among women living with HIV/AIDS. The diagnosis of HIV/AIDS in women can be a pivotal event, leading to positive growth and a new perspective. Inner strength that is identified and utilized by women in crises such as catastrophic illness can increase with nurturance.

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CHAPTER 1

INTRODUCTION

We say that we cannot bear our troubles
but when we get to them we bear them.
Ning Lao T'ai-t'ai, 1945/1979

Women make up the fastest growing population of new cases of human immunodeficiency virus (HIV) infection worldwide (Wofsy, 1995). By the end of 1997, a total of 121,526 female adolescents and adult women in the United States had been reported to have acquired immunodeficiency disease (AIDS) or HIV (HIV/AIDS Surveillance Report, 1997). Between 1990 and 1994, the rate of increase in incidence of AIDS in women was 89% compared to the 29% increase reported in men. Undeniably, the trend of the HIV/AIDS epidemic in women in the United States continues upward. This trend is occurring especially in women of color, women who are partners of injectable drug users, younger women and women outside major population centers such as those in rural Southeastern United States (Fowler, Melnick, & Mathieson, 1997).

The psychosocial impact of HIV/AIDS on women is formidable. Women who have contracted this infection face many uncertainties. They are living with a chronic illness frequently characterized by vague symptoms, rapidly changing medical management or philosophies and possible social isolation (Adair & Burian, 1997). Many of the 160,000 or more women estimated to be

living with HIV in the United States are also parents (Cotton, 1999). These women are faced with the challenge of coping with their own illness as well as caring for family members. Their abilities can be compromised by the stigma of their illness, isolation, denial, concealment of their HIV status and difficulty accessing health care (Matheny, Mehr, & Brown, 1997). Yet many of these women are long-term survivors, having had the infection for many years and successfully meeting these challenges.

Medical management of HIV/AIDS is becoming more focused on longevity and the chronic effects of viremia, as well as the complicated interactions of medications used. The need for women to deal successfully with these challenges in addition to those of everyday life presents opportunities for nurses to intervene and facilitate strategies for success. Effective health care for these women must include more than teaching about medication side effects and focusing on lack of adherence to prescribed treatments. Nurses must focus intensely on the psychosocial factors that support survival and those factors that nurses can influence (Strawn, 1995). Inner strength, a phenomenon described by various disciplines in the care of individuals experiencing challenging life situations, has been identified as a factor of psychological health, spiritual well-being and a dynamic component of holistic health (Dingley, 1997).

Past research on inner strength in women with illness has focused only on breast cancer and cardiac disease. Historically, research targeting women, whether healthy or ill, portrayed women as weak or focused mostly on their reproductive health aspects (Moloney, 1995). Because few women were initially reported as being infected with HIV, early clinical HIV research often did not include women. Therefore, neither the physical nor the psychological health of women living with HIV/AIDS was investigated (Adair & Burian, 1997).

The perceptions of women with HIV/AIDS assist health care providers to develop a more accurate understanding of what women with this infection must cope. With this information, health care providers caring for other women with HIV/AIDS can facilitate the identification or transformation of inner strength in each individual woman to complement and enhance her health status.

Problem of the Study

The purpose of this phenomenological investigation was to explore and describe inner strength as a lived experience in women with HIV/AIDS. The descriptions of women living with HIV/AIDS were examined and analyzed in the context of their consciousness of existence and interpretation of their experiences. The role the health care provider in relationship to inner strength was examined.

Rationale for Study

In 1993, the National Center for Nursing Research identified five important issues for study in the area of HIV nursing: physiologic nursing care, psychosocial nursing care, delivery of nursing care, prevention of transmission and applied ethics (Flaskerud & Ungvarski, 1995). After reviewing the topics of over 30,000 papers on HIV/AIDS indexed in MEDLINE from 1981-1990, Elford, Bor and Summers (1991) recommended that one of the areas of research priority be the psychological aspects of HIV/AIDS.

AIDS has become the fourth leading cause of death in American women of childbearing age and the number one cause of death in women ages twenty-five to forty-four. It is estimated that more than 160,000 women in the United States are currently living with HIV or AIDS (Cotton, 1999). A majority of these women are young, indigent and faced with multiple social challenges. In the United States, heterosexual transmission of HIV has become the dominant mode of transmission, surpassing intravenous drug use as the leading mode of transmission to women (Cotton, 1999). HIV in women is truly a family disease, as this woman may be a member of an infected family. She is often the primary caregiver for other family members and women in these circumstances often ignore their own needs (Cotton, 1999).

The psychological impact of the diagnosis of HIV/AIDS is as pervasive and profound as the physiological effects of this chronic and/or terminal illness. It has been recognized that the psychosocial and emotional sequelae associated with a diagnosis of HIV significantly affects a woman's quality of life, social support systems, relationships, health status, and the ability to follow medical protocols (Munjas, Oliver & Luna, 1998). This observation supports the need for more scientific inquiry in this area. Munjas, Oliver and Luna (1998) have stated that persons with HIV/AIDS may follow a psychosocial trajectory with transitions along the trajectory junctions, similar to the disease trajectory. However, most texts and research have focused on responses such as fear, anxiety, coping and perspectives of quality of life.

Fewer studies have investigated internal resources such as attitude, resilience, hope, and hardiness, although it is known that psychological factors influence functioning of the immune system (Strawn, 1995; Munjas, Oliver & Luna, 1998). Rose first described inner strength in healthy women in a phenomenological research study of the psychological health of women in 1990. Perceptions of women's inner strength based on women's own ideation and experiences relating to their healthy functioning were absent in the literature prior to this time (Rose, 1990). Roux and Keyser (1994) researched inner strength in women with breast cancer, identifying themes that depicted

the process, the needs of the woman and possible interactions by nurses to facilitate the growth of inner strength. Moloney (1995) used a Heideggerian hermeneutical approach to examine patterns in the development of inner strength in older women. Her research suggested that assisting women to verbalize their strength may help them visualize themselves as strong in a way that could potentiate health (Moloney, 1995).

Katz (1996) found that individuals with HIV seem to grow in a positive way and find a new perspective on life as a result of their HIV diagnosis and its inherent uncertainty. Katz, however, did not define this as inner strength specifically. In 1995, Coward identified eight themes related to self-transcendence in women with HIV/AIDS, with finding of inner strength being one of these eight themes. This theme of finding inner strength was not further defined, however. Neither the specific phenomenon of inner strength in women with HIV/AIDS nor the process of developing or finding inner strength has been previously documented.

Theoretical Orientation

Phenomenological investigations do not seek to confirm a theory or establish occurrence, but rather to understand a human experience and its meaning to the person. Phenomenological investigation is based on the belief that essential truths about reality are grounded in one's lived experience (Polit

& Hungler, 1999). Phenomenology does not seek to show cause and effect, but attempts to make human phenomena explicit through analysis of participant descriptions. Phenomenology aims to show the essential features of a process in order to understand the phenomenon. In qualitative research, a phenomenon is the abstract entity or concept under investigation and the term phenomenon is often used in lieu of the term variable (Polit & Hungler, 1999). Appropriate phenomena to be studied include human circumstances related to health and illness (Habermann-Little, 1991).

Phenomenology, being existential and based on philosophical anthropology, seeks to uncover the ground structures of situations through the analysis of experiences (Lynch-Sauer, 1985). The philosophical underpinnings of phenomenology come from such philosophers as Heidegger, Sartre, and Merleau-Ponty. Heidegger believed that people are situated in the world and that their understanding of the world comes from their experiences in the world (Moloney, 1995). Phenomenology calls for appreciation of the human being and a sensitivity to the human condition (Gortner, 1997). This appreciation and sensitivity is reflected in nursing theories that incorporate a commitment to personhood, holism and humanistic attention, and a philosophy of nursing as a science of caring, such as the framework by Jean Watson (1979).

Qualitative research is primarily associated with human science and naturalistic paradigms and is concerned with the nature of the meaning. The following basic paradigmatic assumptions apply to qualitative research.

1. Reality is dynamic and multiple. Multiple meanings can be derived from similar experiences. Meanings may change over time.
2. Phenomena must be studied in context. Researchers do not manipulate or control variables to obtain data or results.
3. The researcher is an integral part of the research process (Haberman-Little, 1991).

In contrast, phenomenology is philosophical and emphasizes that experience is a valid, fruitful source of knowledge and the basis of human behavior. Becker (1992) described the following phenomenological assumptions.

1. People are active, intentional subjects who are aware of their worlds.
2. Each person is inherently tied to a context and to other people, and these factors help define the person.
3. A person is a unity of mind and body, a perspective scholar, and a co-creator of meaning who embraces and transcends throwness

(being born or thrown into a given world) by exercising situated freedom.

4. Unique experiences generate common themes that illuminate the essential structures of life.
5. Experiential time and space differ from clocktime and measured space (Becker, 1992, pp. 23-25).

Phenomenology provides an ideal method to study and understand the lived experience of inner strength in women with HIV/AIDS. The people with whom these women interact have defined them or affected them in ways that influence their inner strength. Their experiences also are framed with what happens in their bodies as well as the effect of their illness on their thoughts and emotions. The individual and unique experiences of each woman illuminate common and recurring themes that define essential aspects of the phenomenon of inner strength.

Uncovering the ground structures of the situations in which women with HIV/AIDS live provides understanding of the woman as a human, whole person. Through phenomenological inquiry, women with HIV/AIDS can relate the lived experience and their perceptions of inner strength, providing an important and relevant body of knowledge for all health care providers.

Knowledge of a phenomenon such as inner strength leads to a human understanding that nurses may apply directly to their practice.

Research Questions

Using a phenomenological approach, the following research questions were asked.

1. What is the lived experience of inner strength in women living with HIV/AIDS?
2. Does the health care provider have a role in facilitating the attainment of inner strength?

Orientational Definitions

Orientational definitions are guides to study the domain or areas related to the theoretical orientation. The following orientational definitions were used.

1. Women with HIV/AIDS are females age eighteen or older with a diagnosis of HIV infection or AIDS for one year or more.
2. Lived experience is the individual personal situation identified and described by each woman participating as an informant of the research investigation.
3. Health care providers are physicians, nurses, nurse practitioners, physician assistants, social workers and other counselors or educators.
4. Inner strength refers to the different ways women with serious illnesses

experience and describe the deepest, existential resources available to and used by them to cope with, if not control, severe risks to self-integrity.

Summary

The purpose of the study was to explore and describe the phenomenon of inner strength in women living with HIV/AIDS. The qualitative study utilized a phenomenological approach. The analysis of what was understood about the lived experience of inner strength from a deep and existential framework in women with HIV/AIDS allowed the identification of a holistic, human and effective approach to the health care of women with HIV/AIDS.

CHAPTER 2

REVIEW OF THE LITERATURE

To be desperate is to discover strength.
We die of comfort and by conflict live.
May Sarton, 1953 (as cited in Maggio,1996)

Qualitative research generally requires two literature reviews serving separate purposes. The initial literature review, which is not exhaustive in nature, identified gaps in knowledge and supported the need for the research. An in-depth literature search was deliberately avoided prior to field research to circumvent bias and thwarting of the creative efforts of discovery. A preliminary literature review also familiarized the researcher with practical and theoretical issues applicable to the area of interest (Polit & Hungler, 1999). A second literature review was done concurrently with data collection and analysis. The secondary literature review included both professional and nonprofessional literature. Professional literature was nursing-related and from other health science disciplines, while nonprofessional literature included information from sources such as poetry, novels or classical literature. This chapter discusses the outcomes of the initial literature review. A more in-depth discussion of relevant literature derived in the secondary literature review follows. Topical areas in this review include hardiness, resilience, transcendence and examples of inner strength.

Initial Review of the Literature

Conflicting opinions and ideas have been reported by qualitative researchers regarding the performance of a literature review prior to the outset of the study (Polit & Hungler, 1999). Exhaustive literature reviews prior to data collection potentially can bias research and constrain the discovery process. Addressing objectivity in phenomenological research, Colaizzi (1978) suggested that personal inclinations and predispositions can bias how and what is investigated. Therefore investigators must take care to recognize biases that can hamper discovery. Adopting this philosophy, the researcher investigated previous studies addressing the topic of inner strength in order to validate the need for this study.

The initial review revealed that recent literature on women and HIV/AIDS in general was more plentiful than in the earlier years of the epidemic. Gender differences of the disease, such as survival and clinical manifestations, were initially based on small case studies and anecdotal reports, often yielding conflicting data. In the past, women were excluded from clinical trials and access to promising drugs based on teratogenicity concerns (Cotton, 1999). Currently, two large, federally funded cohort studies of women with HIV/AIDS in the United States are being conducted. The Women's Interagency Cohort Study and the HIV Epidemiology Research Study were

designed to provide more detailed data on the gender differences of the natural history of HIV in women, with some information expected within a few years (Cotton, 1999). However, these studies tend to focus on mechanisms of disease and treatment. Few examine topics related to living with and managing HIV.

Only three published studies were found that addressed the topic of inner strength in women. Rose (1990) utilized phenomenology to examine inner strength in nine healthy women. Through unstructured interviews, she identified nine essential themes of inner strength that represented psychological health. These themes constantly merged and overlapped with one another; therefore she suggested none be interpreted alone. Rose identified those themes with the following terms.

1. Quintessencing, or the most perfect embodiment of self, included recognizing, becoming, accepting and being one's true self.
2. Centering, a process of focusing and balancing outside events with inner self.
3. Quiescencing, or being calm, quiet and at rest.
4. Apprehending intrication, or knowing and understanding that which is complicated.

5. Introspecting or gaining awareness of self and own psychological processes.
6. Using humor.
7. Interrelating, a personal, intimate, open and reciprocal process.
8. Having capacity, including the ability to heal, solve problems, stay present, face pain and recognize a lack of capacity.
9. Embracing vulnerability, a process of accepting, acknowledging and integrating one's imperfections and humanness (Rose, 1990).

Rose's results described the holistic, health-focused phenomenon of psychological health in women, which was termed inner strength.

In 1995, Moloney interviewed twelve women over the age of 65 to elicit stories from their lives that exemplified being strong. This study utilized a phenomenological approach in which three constitutive patterns emerged in the analysis. Different themes comprised each pattern. Themes of living with loss, living through hard times, being different and putting it behind you comprised the first pattern, identified as surviving. The second pattern, finding strength, was characterized by themes of being close to others, drawing strength from others, being at home and feeling good about self. The third pattern, called gathering the memories…seeing the patterns, was

representative of the process of telling the stories themselves. Moloney's investigation illustrated to nurses and their female clients the benefit of understanding strength from a woman's perspective and the power of storytelling itself. Moloney also concluded that there was value in exploring the lives of women that are marginalized (1995). These findings further supported investigating inner strength in women with HIV/AIDS as these women are often marginalized due to their diagnosis.

Roux and Keyser (1994) investigated inner strength in eighteen women with breast cancer and found that their experiences of inner strength were manifested in the following four major themes.

1. Coming to Know.
2. Strength Within of She Who Knows.
3. Connection of She Who Knows.
4. Movement of She Who Knows.

These themes were representative of stages through which the women passed following a diagnosis of breast cancer—i.e., facing and accepting the diagnosis; acceptance of accompanying pain that opens the passageway for her strong spirit; a passionate connection of her instinctive life with her true loves; and finally, a passage through wandering and searching to inner strength used for moving, harmonizing and facilitating a desired change.

Salient needs of the woman with breast cancer were identified and opportunities for potential nursing interactions to foster holistic, healthful living were offered as a result of this investigation.

In her unpublished thesis, Dingley (1997) utilized grounded theory to examine inner strength in women with coronary artery disease. She described a multidimensional and multidirectional process of growing in inner strength that encompassed the total being, occurring at the physical, mental, emotional and spiritual levels. Dingley described five interrelated constructs in the process of growing in inner strength in women recovering with cardiac disease. The first was allowing for nurturance , which involved receiving and accepting psychosocial support. Dwelling in a different place involved a process of focusing self outside of illness. Balancing the search was representative of balancing and assimilating new understanding, meaning and direction in their lives. The fourth construct, healing in the present, represented the process of creating a new normal for self in the present. Finally, connecting with the future occurred as women extended themselves to support and help others. The processes represented by these five constructs were thought to be identifiable in women with HIV/AIDS.

While none of these studies examined the phenomenon of inner strength in women with HIV or AIDS specifically, they did support the premise that women with HIV might also exhibit some of the same characteristics and behaviors of women in other studies of inner strength. This supported the rationale for nursing research on the topic of inner strength in women with HIV/AIDS.

Secondary Review of the Literature

Throughout data collection and analysis of results, an ongoing second literature review was in process. Literature from the health sciences and other health disciplines, as well as literary works such as poetry and prose, were included. Reinharz (1983) noted that there are many ways to change experience into knowledge, including artistic, experimental and human scientific methods. As a phenomenologist examines experiences to derive consensually validated knowledge, all of these methods may be used (Lynch-Sauer, 1985). This literature review served to link research and theory with the concepts and information discovered during the research process. “Qualitative researchers often strive to develop a conceptualization of the phenomena under study that is grounded in the actual observations made by the researcher.” (Polit & Hungler, 1999, p. 106).

An analysis of qualitative research of client roles and elements of chronic illness in the past two decades revealed a shift in the client role from focus on loss and burden to a focus on experiences of health within illness, transformation and normality (Thorne & Paterson, 1998). Jones and Meleis (1993) and Katz (1996) found evidence that illness may stimulate personal growth. Nonphysical dimensions of being, such as psychological, social, and spiritual dimensions, may grow and strengthen during illness or transition (Jones & Meleis, 1993). Research and articles exploring inner strength and similar concepts associated with nonphysical dimensions were sought. The three published studies of inner strength in women were carefully explored while data collection was occurring. Descriptions of the processes of inner strength in women with breast cancer, coronary artery disease and psychological health were compared with processes described by the women with HIV/AIDS.

The second literature review revealed that multiple studies and publications addressed HIV/AIDS in relationship to stress, coping or social support concerns but these studies were not always specific to women. Because of the limited research published addressing inner strength, the second literature review was expanded to include concepts similar to inner

strength. These concepts were hardiness, transcendence and resilience. Examples of inner strength were also sought and are presented.

Hardiness

Inner strength was defined for this study as the way women with serious illness experience and describe their deep existential resources to be used to cope with or control severe risks to self-integrity. Hardiness can be considered similar to inner strength in that hardiness has been described as an attitude, personality characteristic and psychological construct that serves as a resource for resisting the negative effects of stress (Carson, 1993). In 1993, Carson published results from her quantitative study of 100 subjects with HIV/AIDS that demonstrated a positive relationship between hardiness and long-term survival with perception of health, use of prayer and meditation, and healthy habits such as exercise and special diets. Prayer (r = .233; p< .010) and meditation or imagery (r = .2621; p< .005) were positively correlated with hardiness, as were health promoting behaviors such as exercise (r = .3345; p =.000). Individuals perceiving greater physical health (r = .3567; p = .000), emotional health (r = .3729; p = .000) and spiritual health (r = .2932; p = .002) also exhibited greater scores on hardiness . Although more than half of the sample rated their participation in AIDS-related activities, such as supporting other people with AIDS, as high, none of these activities were

positively related to hardiness. Carson concluded that a positive attitude or perception of one's health was associated with hardiness. It was expected that these characteristics of hardiness might also be found in the descriptions of the lived experience of inner strength in women with HIV/AIDS.

In a similar study with a sample of forty-seven men and three women with HIV or AIDS, Nunes, Raymond, Nicholas, Leuner and Webster (1995) examined the interrelationship between social support and quality of life. Utilizing two different instruments for measuring perceived social support and sense of well-being in life, the researchers identified a significant intercorrelation between social support and quality of life ($r = 0.81$; $p < 0.0001$) and perceived health status ($r = 0.64$; $p < 0.0001$). Quality of life also significantly correlated with immune function based on CD4 lymphocyte cell counts ($r = 0.36$; $p < 0.02$) and perceived health status ($r = 0.64$; $p < 0.0001$). Perceived health, social support and immune status were all factors in this study that were expected to be important aspects related to inner strength.

Strawn (1995) reviewed scientific and anecdotal reports in alternative literature to explore the role of nursing in long-term survivors of people with HIV/AIDS. A set of criteria was given for classification as a long-term survivor of HIV/AIDS. She reported that the possible factors associated with long-term survival with AIDS could be attributed to individual immune response, genetic

differences, psychosocial realms such as internal resources and social affiliations, and differences in coping. Additional research on this topic from a wellness perspective was indicated, especially in those populations of the second wave of the epidemic that include women, children, intravenous drug users and people of color. Specifically, she recommended qualitative studies that let individuals tell their stories as an important step in the exploration of things perceived to be important to survival. The current study incorporates this method and includes several women who meet the criteria for classification of long-term survivor.

Hardiness can be considered similar to inner strength as a resource that emerges for resisting the adverse effects of stress and illness. These studies demonstrated that hardiness could be positively correlated with perception of health status, one's immune status, prayer and meditation and health habits such as exercise. Social support, quality of life and immune status were also found to contribute to one's hardiness. Reviews of information of long-term survival in people with HIV/AIDS indicated genetic differences, internal resources and differences in coping may also be factors in hardiness and survival.

Transcendence

Realizing the role of self in the phenomenon of inner strength, literature addressing the existential self was sought. Kotarba (1984) wrote:

> The most obvious reason why the self is grounded in a constant state of becoming is the embodiment that forms the core of our existence. The body is not only the source for unending and ever-changing feelings and emotions and the criterion by which we evaluate the objects in our world; it also provides life-events that may either threaten the self or open the way to self-fulfillment…Since the experience of becoming is inherently problematic (i.e. unpredictable), we are liable at various times in our lives to encounter discrete yet critical episodes that threaten the security of self and often require massive reconstruction of one's sense of being (p. 227).

Frankl (1969) believed that self-transcendence was an inherent characteristic of being human and that transcendence happened in three ways. Giving to the world through family, occupation and creative works and taking from the world through receptiveness to others and the environment were the first two ways. Frankl stated that the third way to transcend was reflected in the way one faces a predicament, unchangeable situation or adversity when deprived of the creative or experiential ways to find meaning.

Choosing how to face adversity was an opportunity to transcend or reconstruct one's sense of being.

Coward (1995) based her work on self-transcendence on theories of Viktor Frankl (1969). Her investigation described the lived experience of self-transcendence in ten women with AIDS. She identified eight themes related to self-transcendence during the women's pursuit of meaning and purpose in their lives. She defined self-transcendence as "reaching out beyond the boundaries of the self to achieve broader perspectives and behaviors that help one discover or make meaning" (Coward, 1995, p. 314). She found the experiences of women since their diagnoses of AIDS were all similar in one of two ways. In transcending, women either reached beyond self and personal concern or reached inward to understanding. Both resulted in connectedness, increased self-esteem or increased meaning and purpose in life.

Coward (1995) identified the following themes related to self-transcendence.

1. Experiencing fear and aloneness.
2. Experiencing uncertainty.
3. Using others as role models.
4. Finding inner strength.
5. Reaching out to give and receive.

6. Making a difference and having a purpose.
7. Viewing AIDS as an opportunity.
8. Having hope.

This transcendence study was the only one found that specifically used the term inner strength in relationship to women with HIV or AIDS, although Coward did not define what was meant by finding inner strength.

Katz (1996) examined the experience and consequences of uncertainty after an HIV diagnosis. Analysis of focused in-depth interviews with ten persons with HIV revealed five core experiences that contributed to the formulation of new perspectives. Those experiences were surviving the HIV diagnosis, taking care, living in the present, seeking support and appreciating the positive. Katz stated that all ten individuals described their HIV diagnoses as pivotal events that changed their lives, leading to positive growth that they believed would not have occurred without HIV as an impetus. Katz concluded that individuals with HIV infection seem to grow in a positive way in response to the uncertainty inherent in living with HIV/AIDS. Experiencing uncertainty, having hope, viewing AIDS as an opportunity and finding inner strength were all themes related to self-transcendence as described by Coward (1995). Some respondents in the current study on inner strength also stated that HIV

diagnosis was a pivotal event that led to positive growth with characteristics of self-transcendence.

Tsevat (1999) and six colleagues surveyed fifty-one persons with HIV/AIDS. Questions were asked regarding health status, quality of life, life satisfaction and attitudes toward family and friends. They found that seventy-one per cent of respondents indicated they were delighted, pleased or satisfied with their lives. Women and persons at peace with God and the universe were more likely to respond that they were satisfied with their current life. Further results of the survey indicated factors other than health were found to be more important to a sense of satisfaction and a will to live. Improved living conditions, drug and alcohol treatment and addressing psychological and spiritual issues appeared to have an equal or greater effect on quality of life than medical care alone. Seventy-four per cent of women that responded to this survey indicated they felt their lives were better now than before they knew they were infected with HIV. These results contrasted with only thirty-nine per cent of men answering yes to the same question (Tsevat et. al., 1999). This finding might suggest women deal with catastrophic illnesses much differently than men in their perception of effect on and meaning to their life.

DeMarco, Miller, Patsdaughter, Chisholm, and Grindel (1998) addressed transcendence in a report of data extracted for secondary analysis from a larger study on experiences and needs of persons living with HIV/AIDS. They utilized transcripts from three focus groups and six individual interviews with fourteen women living with HIV/AIDS. Their objective was to understand the transition from silencing behavior to action behavior as a process of reacting to a threat to self. Data indicated that most women exhibited silencing behaviors early in their HIV trajectory. Some women stated their HIV diagnosis was a catalyst to speak for themselves and become more assertive in shaping their own lives. Some found peer or professional counseling as the starting point for transition. These same processes were described in various forms in the stories told by the women with HIV/AIDS who were interviewed for this study.

Transcendence appears similar to inner strength. It was believed to be inherent and was expressed when an individual was faced with adversity, unchangeable situations or threats to self. Transcendence was described in terms of opportunity for choice, growth, transition and the formulation of new perspectives.

Resilience

Literature on a similar concept, resilience, also was reviewed. In an ethnographic study, Barroso (1995) identified self-care activities that might contribute to the long-term survival of fourteen men and six women with AIDS. Self-care was defined as taking care of oneself through focused activities that participants used to enhance their mental and physical health. These activities were identified as discontinuing negative habits such as substance abuse, undertaking health-promoting activities such as nutritional changes, being responsible for one's health, implying an internal locus of control, and decreasing stress by making efforts to remove harmful stimuli from their lives. Taking care of themselves gave these participants a sense of control within the context of the uncertainty of HIV/AIDS. The participants had a strong belief that what they were doing positively enhanced their mental and physical health. Aspects of these self-care activities are expected to be found in women with inner strength.

Andrews (1995) described social support as a buffer to stress in her article focused on urban mothers with HIV. She identified three ways women experience HIV as a stressor. HIV was seen as a stressor within the context of poverty, because of the stigma constructed from the current image of HIV disease and due to the challenge it presents to individual psychological coping

mechanisms. She concluded that survival for these particular women was possible because of help and strength from their social support networks and strength from within themselves. Surviving incorporated managing daily life, raising children, dealing with spousal illness and caring for elderly parents. The description of help and strength from within the women was similar to the concept of inner strength and their social support served as a source for that strength.

Barroso reported similar findings in 1997 when she published a second paper based on her previous ethnographic interviews with the same twenty individuals. This investigation examined social support and long-term survivors of AIDS. Barroso's findings indicated these individuals reconstructed their lives within the context of their HIV disease. Five essential dimensions and coping strategies within the dimensions utilized for survival were described. Normalizing, focusing on living, taking care of oneself, being in relation to others and triumphing were dimensions described. These five dimensions were representative of the cognitive, attitudinal, behavioral, interpersonal and existential realms of the lives of those living with AIDS.

Most of the participants reported developing a relationship with a higher power subsequent to their diagnosis, carefully distinguishing this from

organized religion. The participants identified social support as a subset of persons upon whom they relied for socioemotional aid or instrument aid. Their developed network for social support helped them cope more effectively, therefore affecting their survival. Barroso stated the findings suggested women form affiliations for social support and utilize them differently than men. “For example, the women in the study relied heavily on their children for support and found in them a reason to live.” (Barroso, 1997, p. 569).

Hunter and Chandler (1999) described resilience as an individual internal resource that allows one to be able to overcome adversity through use of developed internal and external protective mechanisms. Researchers have proposed that resilient individuals successfully meet the challenge of trauma and that resilience may be fostered through intervention (Moreno & Simoni, 1997; Hunter & Chandler, 1999).

Hunter and Chandler (1999) utilized a triangulated research design to explore resilience in adolescents in a group of inner-city adolescents. The adolescents in this pilot study believed self-reliance, defending themselves and not being dependent were necessary for survival. The researchers concluded that surviving and being defensive are strengths of personhood even if the way in which one uses them to survive appears maladaptive. They

suggested that resilience possibly exists along a continuum between less than optimum and optimum resilience, possibly varying with developmental stages. It was proposed that strengths of personhood, with appropriate interventions, could be used to facilitate achievement of healthy resilience. Although this study looked at resilience in adolescents, the implications may apply to adults.

Moreno and Simoni, at the 1997 National Conference on Women with HIV, presented data about stress and resilience gathered through a focus group with twelve Latina women with HIV. Their study confirmed that coping mechanisms of Latina women need to be understood within individual and cultural contexts. Coping mechanisms utilized by these women were spirituality, non-traditional healing cures, therapeutic support groups that addressed their culture, gender and current situation and the presence of significant others in their lives. These coping mechanisms were also found to be important aspects of inner strength.

Using a holistic approach, Zorilla and seven colleagues (1996) designed a pilot project to encourage resiliency by empowerment of women living with HIV. Strategies of self-help groups, a two day seminar and part time voluntary compensated work were utilized in the project with eighteen women with HIV. The project was deemed successful as the women with HIV attained personal changes directed towards healthier and assertive behaviors. This

healthcare strategy that encouraged resilience was presented at the 1996 International Conference on AIDS (Zorilla et. al., 1996). These same strategies could be identified as helpful resources of inner strength.

Resilience has been described as an internal resource that allows one to overcome adversity through use of internal and external protective mechanisms. Self-care, social support, spirituality, alternative healing methods and therapeutic support groups that are gender, culturally and age-appropriate may facilitate strengthening of resiliency and a woman's inner strength and in turn bring about healthier behaviors.

Examples of Inner Strength

Respondents in the current research project described the importance of family in contributing to their inner strength. Women with HIV/AIDS and their family members with whom they chose to disclose their disease experienced dramatic changes in their lives. Respondents expressed much love and appreciation for their families. A poem by May Sarton (1988) describes these feelings of love and appreciation that are expressed by women with HIV/AIDS.

AIDS

Closed lives open to strange tenderness.
We are learning the hard way how to mother.
Who says it is easy? But we have the power.
I watch the faces deepen all around me.
It is the time of change, the saving hour.
The word is not fear, the word we live,
But an old word suddenly made new,
As we learn it again, as we bring it alive:
Love. Love. Love. Love. (p. 36-37.)

In her introduction to Circle of Stones: Woman's Journey to Herself (1989), Judith Durek wrote the following about her personal experience.

> Sometimes dreams alter the course of an entire life.
>
> In the summer of my forty-sixth year, one day before my birthday, I had a dream that did not so much alter the course of my life as it did confirm in the deepest possible way, its pre-existing course—confirm that which my life already, however gropingly, was becoming.
>
> For two years before the dream, a series of images had come to me around the motif of women seated in a circle, coming together to understand their lives…They named themselves the Circle of Stones.

> Into this, then, came the dream. It took that which I cared most deeply about in myself and my work and turned it over slowly and thoughtfully, reflecting various aspects of it and pointing out its validity and meaning. The dream said to me that what I was doing, my life, my ideas, and my work, were coming out of a center inside myself. It said that I needed to trust the truth of that process and to let it come out more fully…
>
> Many times I faltered or held back, through lack of faith or self-doubt…
>
> The dream's final scene portrayed a young woman of today newly come to her new voice, newly come to her authority in outer affairs, while remaining grounded in her inner feeling values. It completed the circle.
>
> This writing attempts to reflect the intertwining of the initiating images, the dream, and women's experiencing of them. (pp.xvii-iii).

Ms. Duerk (1989) expressed her inner strength in a creative way in her writing of the Circle of Stones series. Although not faced with a serious illness of which the reader is aware, the writing represented her ability to reach inward to her deepest existential resources and successfully achieve, despite the risks to her self-integrity.

Dr. Peter Selwyn, author of the book Surviving the Fall: The Personal Journey of an AIDS Doctor (1998), described women he treated who exhibited inner strength. One woman described was Delia, a young Puerto Rican woman found to be HIV positive a few months prior to her first pregnancy. At six weeks gestation, her boyfriend and father of the baby was shot and killed. At ten weeks gestation she experienced bleeding and a threatened abortion. Terminating the pregnancy was never considered as an option in her thinking. Dr. Selwyn wrote the following about Delia.

> After the bleeding episode, she did well during the remainder of her pregnancy and was proud of the progress that she was making. Delia became close with Carmen, who was pregnant at the same time, and Magaly, who played the role of the wise older sister to the other two, having already been through this several times. I still remember the three of them walking into my office in the clinic one day, arm in arm, laughing as they kept interrupting each other in excitement to tell me about an idea they had to start a support group for pregnant women with HIV (Selwyn, 1998, p. 88).

This is an example found in literature of a woman's inner strength—when confronted with the adversity of loss and an HIV diagnosis, she sought her

deepest existential resources to cope with and control the risks to her self-integrity.

Summary

A preliminary review of the professional literature on the topic of inner strength in women with HIV/AIDS revealed a gap in the current knowledge base. Women were found to have not been included in any studies in the area of HIV/AIDS until recent years (Cotton, 1999). Only three qualitative studies in current literature have explored inner strength in women. A secondary exhaustive literature review revealed studies regarding similar characteristics or qualities that might be part of the inclusive description of inner strength. Scholarly literature was reviewed concurrently with data collection and analysis. It enhanced discovery throughout the methodological approach without precipitating bias or preconceptions.

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

You may trod me in the very dirt
but still, like dust, I'll rise.
Maya Angelou, 1978 (as cited in Maggio, 1996)

This phenomenological study was an investigation of the lived experience of inner strength in women with HIV/AIDS. Phenomenological investigations are done to explore the reality of persons who have experienced the phenomenon of interest. Nursing practice, based upon a holistic belief system, is rooted in the caring of human minds, bodies and spirits as a whole rather than caring only for a part of the human being. Knowledge of the phenomena of living with HIV/AIDS as a woman today and the development of inner strength in this situation was deemed important to nursing. The foundation of this phenomenological inquiry was the exploration of the lived experience of inner strength with women that could tell their stories, providing rich and descriptive data.

Qualitative research is almost always a collaborative endeavor, with the investigator and the informant becoming colleagues or coparticipants in the research. Four investigators with a mutual interest in the phenomenon of inner strength in women with HIV/AIDS formed a collaborative research team for this study. As stated by Tripp-Reimer, Sorofman, Peters & Waterman in 1994,

"This investigator-team model is the norm for research that combines the expertise of investigators from different disciplines or with different methodological expertise" (p. 319). The team consisted of a graduate student, two college of nursing school faculty members and a professor of sociology. The graduate student was experienced as a health care provider for women with HIV/AIDS; one college of nursing faculty member was an experienced psychotherapist and the other had experience as the director of an AIDS education and training center in a school of public health; and the professor of sociology was a publicized author of previous qualitative research in HIV/AIDS. At different phases of the research, the expertise of different team members provided guidance and insight for the other team members.

Setting

This study was conducted in a large metropolitan area of approximately three million people in the south central United States. Interviews were done in mutually agreed upon sites that were comfortable and convenient for both the informant and the researcher. These sites were usually the informant's home, the researcher's home or another location that assured privacy and comfort for the informant. All interviews were conducted with only the researcher and informant in the room to protect the privacy and confidentiality of the informant. The chosen settings facilitated the development of rapport

and trust needed to encourage the informant to disclose intimate and emotional descriptions. All interviews were audiotaped and notes were taken in the field by the researchers.

Population and Sample

Purposeful sampling was used to recruit and select the women for this study. Phenomenological inquiry dictates this type of sampling in order to retrieve informative and rich data. Study participants were chosen based on their knowledge of living daily with HIV/AIDS and for the purpose of sharing information of central importance to the study (Streubert & Carpenter, 1995). The population for this study was all women living in the metropolitan area that were diagnosed with HIV/AIDS. Sample selection occurred through identification of possible respondents by various AIDS Service Organizations, educational centers and care providers in the metropolitan area. The women in the sample were 18 years of age or older and were infected with HIV for one year or longer. All respondents were English-speaking although neither race nor ethnicity was used as selection criteria.

Adequate sample size was achieved when researchers experienced repetition or redundancy in statements expressed by the participants living the experience or phenomena of interest. Therefore, predetermination of a sample

size in phenomenological inquiry was not possible (Streubert & Carpenter, 1995). Interviews were conducted with nineteen women, at which time it was determined that no new essences or responses were emerging from the participants. This saturation determined the final sample size.

Protection of Human Subjects

This large joint research project, conducted by researchers from several local universities, received approval from the Committee for the Protection of Human Subjects at the University of Texas School of Public Health and Texas Woman's University. Potential risks of unpleasant emotions such as anxiety, embarrassment, and fear of improper release of information were addressed. Provisions were made to decrease anxiety and embarrassment. Researchers allowed the respondent to choose the site for the interview and allowed adequate time for questions or concerns to be addressed. Respondents were reassured that the interview could be stopped at any time. Confidentiality was ensured by not using any names on tapes, forms or notes from the field. Only initials or pseudonyms of their choice identified participants. No names were used anywhere in the study results in connection with direct quotes. The women were assured that audiotapes and any written material referring to them would be kept in a locked file, not available to anyone but the

researchers. Audiotapes will be destroyed no later than two years after completion of the study.

After approval to conduct the study was received, prospective participants were contacted by phone and asked to participate in the investigation. The women were informed of the nature of the study, the time commitment for the study and the method of data collection. After agreeing to participate, arrangements were made to conduct the interview in a place of their choice. At the time of the interview, the researcher presented a verbal description of the study. If the woman was willing to join the study, the researcher provided a written consent for them to read and sign that allowed the researcher to conduct the interview (see Appendix A). After the consent was read, signed and witnessed, the interview was conducted and audiotaped. Once they had agreed to meet with the researcher, all participants consented to participation in the study, although opportunity was given to withdraw without effect to any services or care they were currently receiving. Participants were paid $50.00 at the time of the interview to compensate for their time, transportation and child care costs. This $50.00 stipend was made available by the research department of a pharmaceutical company.

Data Collection

Phenomenology relies predominantly on interviews as a source of data and to develop knowledge. Interviews provide forums for the exchange of verbal and nonverbal information (Hutchinson & Wilson, 1994). The interviews in this investigation were conducted in a semi-structured research format. Specific demographic data was obtained at the onset of the interview and recorded on a general information form (see Appendix B). As suggested by Streubert and Carpenter (1995), the researchers obtained descriptions of the experience using open-ended, clarifying questions without leading the discussion. Semi-structured interviews provided opportunities to explore personal experiences with each respondent in an individual way that prompted descriptions of experiences as they remembered them.

The researchers for this investigation developed sample questions to be used during the interview process. The semi-structured research format allowed for selection of the questions needed in each individual interview to collect the information (see Appendix C). Paraphrasing of questions was allowed for purposes of clarification. Probes such as “tell me more about that” were used for obtaining more detail.

Rigor and trustworthiness address aspects of reliability and validity in qualitative research. Rigor in this research project was demonstrated through

the researcher's attention to discovery and confirmation of accurately represented experiences of those studied. Rigor can be accomplished through the operational techniques of credibility, confirmability and transferability (Streubert & Carpenter, 1995). Credibility—validating the circle of inquiry—can be established by activities that increase the probability that credible findings would be produced (Streubert & Carpenter, 1995; Ray, 1994). Returning to the participants to validate findings as being true to their experiences would exemplify this, although it was not possible in this study. Confirmability refers to the repeated participatory and documented evidence obtained from the primary informant source. Obtaining repeated affirmations of what the researcher has heard or experienced in the study of the phenomenon demonstrated confirmability. Restating ideas or interpretations of thoughts of those women who had already shared experiences was a method to accomplish confirmability (Leininger, 1994). Regular meetings of the research team for sharing and feedback sessions were used to ensure confirmability. The probability that the findings have meaning to other potential users of the results that can be transferred to another similar context or situation exemplifies transferability. Transferability must preserve the particular meanings, interpretations and inferences from the completed study (Streubert

& Carpenter, 1995; Leininger, 1994). Other researchers determine actual transferability as they make use of the findings of the study.

According to Colaizzi (1978), the trustworthiness of the questions used in an investigation depends on the degree to which they tap the subject's experience separate from the subject's theoretical knowledge of the phenomenon. The researchers assumed that the participants of the study told the truth about their experiences as they lived them. Participants were asked for a negative description of inner strength to enhance establishment of trustworthiness. Researchers used this mechanism to verify that their findings were real, true and authentic.

An extensive review of the literature was postponed until after data analysis began to promote neutrality. Streubert and Carpenter (1995) stated that consistent use of the method and bracketing prior knowledge would help ensure pure descriptions. Bracketing required deliberate identification and suspension of judgements or ideas about inner strength and what the researchers already knew about the phenomenon prior to and during the investigation. The conditions of the inquiry and a lack of bias, motivation or special interest further determined neutrality by the researchers (Hutchinson & Wilson, 1994). Streubert and Carpenter (1995) suggested that the fewer

preconceived notions the researcher has about the phenomenon, the less likely it will be that the research will be affected by biases.

The research team addressed the trustworthiness of the method in multiple meetings throughout the investigation. Purposeful decisions were made to identify women from a variety of settings, with varying socioeconomic levels and stages of disease progression. Similar responses tested the reliability of the descriptions that were given by the women in this study. The questions that were developed and used by the research team addressed trustworthiness and authenticity by asking for descriptions of someone with no inner strength, and by inquiring about the varying levels of their inner strength and threats to their inner strength. Findings during the data collection were confirmed with other study participants and were found to be consistent. A final test of applicability of the research findings will be evaluation for "fit" outside the contexts of the study situation (Munhall, 1994).

This phenomenological investigation aimed to gain a deep understanding of the informant's experiences and was accomplished through active listening and flexibility of the researchers during the semi-structured interview process (Habermann-Little, 1991). After the respondent signed the consent to participate in the study, audiotaping was started and interviews began with collection of demographic data (Appendix B). During this exchange

of information, rapport was established with the woman as a basis for the rest of the interview. More meaningful data was shared after a trusting relationship developed between the researcher and respondent. Each participant was approached in an individual manner, permitting exploration of leads and cues provided by the participant. Broad questions were used initially, with most interviews becoming more focused based on each individual's responses. Interviews averaged sixty to ninety minutes. Field notes were taken during the interview or immediately after the interview in supplement to the audiotaped interview. As soon as possible after the interview, the audiotape was replayed and transcribed by that interviewer. Research meetings were held approximately every two weeks and included all researchers on the collaborative team. During these meetings, team members shared information and collaboratively planned any refining of the interview process in order to collect the richest possible data.

Treatment of Data

The researchers analyzed tape recordings, individual transcriptions and field notes. Data analysis began with data collection, as is common in phenomenological investigations (Streubert and Carpenter, 1995). The procedural steps outlined by Colaizzi (1978) were used to collect and analyze the data. The following steps were methodically used for data analysis.

1. A description of the phenomenon of interest by the researcher.
2. Collection of the subjects' descriptions of the phenomena.
3. Reading all the subjects' descriptions of the phenomenon.
4. Returning to the original transcripts to extract significant statements.
5. Attempting to derive the meaning of significant statements.
6. Categorizing the aggregate formalized meanings into clusters or inventories.
7. Writing an exhaustive description.
8. Returning to subjects for validation of the description of the phenomenon.
9. Incorporating any new data revealed in the validation into the exhaustive description (Colaizzi, 1978, pp. 58-62).

As delineated in the procedural steps, the informants' descriptions were read after transcription and a general feeling of the content was acquired. Meanings were formulated from significant statements and descriptions. Extractions of significant statements, phrases and descriptions as they pertained to the phenomenon of inner strength were organized into categories or inventories (see Appendix D) that represented analytic dimensions of the lived experience of inner strength in women with HIV/AIDS. These inventories were not identified until interviews were completed, keeping with the no a priori hypothesis necessary of qualitative researchers. Themes or essences were

identified from the aggregate formulated meanings and common descriptions in the inventories. Finally, an exhaustive description of the lived experience of inner strength in women with HIV/AIDS was integrated and a role for the health care provider in the facilitation of inner strength was described. In this study it was not possible to return to the subjects for formalized validation of the final description of the phenomenon of inner strength.

Summary

Semi-structured interviews were utilized to collect rich information from the women with HIV/AIDS that were identified as appropriate respondents for this investigation. The research team met regularly to review transcribed information extracted from the interviews. Colaizzi's (1978) procedural steps were utilized for analysis of data obtained. A compilation of experiences and stories were utilized to identify ways inner strength was activated and integrated in the lives of women living with HIV/AIDS.

CHAPTER 4

ANALYSIS OF DATA

> Woman grounds herself in being as she nurtures the elemental,
> caring for her own matter through rest and through touch.
> Judith Duerk, 1989

A phenomenological approach was used to study the phenomenon of inner strength of women with HIV/AIDS. Data for this study were collected by means of nineteen in-depth, semi-structured, biographical interviews. Interviews were audiotaped for later transcription and analysis in the exploration of the phenomenon of inner strength in women with HIV/AIDS. A description of the respondents and the aggregate description of the phenomenon as analyzed are presented.

Description of the Sample

The respondents were all women living with HIV or AIDS in a large metropolitan area in the south central United States. In order to achieve diversity of the sample, two methods were utilized to recruit respondents. Initially, women who were known to the researchers through education and care settings were recruited. As data collection continued, the research team realized the sample lacked women with late or end stage AIDS and women who were not actively seeking care for their illness. Respondents that fit those criteria were recruited through other agencies and professional contacts.

Nineteen women shared their perceptions and experiences related to

living with HIV or AIDS. Respondents ranged in age from 19 to 54, with an average age of 33.6 years. Sixty-three per cent of the women identified themselves as African American; additionally, the sample included Latinas, Anglos and a woman who had recently arrived from an African country. More than fifty per cent of the women identified themselves as being single, separated or divorced and sixty-eight per cent had living children. Sixty-eight per cent of the respondents had either private insurance or Medicaid, but thirty-two per cent were truly indigent and received their care in government-funded clinics. Only one woman had not attended any high school or received her GED. One half of the sample had either attended or graduated from college. Only seven women stated they were totally unemployed. However, one respondent worked as a prostitute and two had temporary work at the time of the interview.

Years of being infected with HIV ranged from one to twelve years, with the average time of infection being 5.6 years. Four of the respondents were known to have the diagnosis of AIDS based either on CD4 counts or AIDS-defining illnesses. Five women were not taking any antiretroviral medications at the time of their interview, although three had taken medications previously. One respondent described herself as a long term nonprogressor, stating she

had been diagnosed nine years ago, currently having a nearly nondetectable viral load and a CD4 count greater than 1000 without ever taking medications.

Description of Findings

This phenomenological investigation examined ways women with HIV/AIDS activated or failed to activate inner strength in terms of their experiences and through their own words. The following two assumptions were made in the exploration of the phenomenon:

1. Inner strength is an innate and universal potential among women that can be developed for use in crises such as catastrophic, life-threatening illness.
2. Inner strength is necessary for successful coping with catastrophic illnesses such as breast cancer and HIV/AIDS.

The stories told by women with HIV/AIDS were examined to derive definitions and meanings of the concept of inner strength, the source of their individual inner strength and the effects of inner strength on the management of their illnesses. All women interviewed were able to describe an entity or feeling they equated with inner strength. Some women knew they had always had inner strength and that this strength had only grown stronger, maturing with the diagnosis of HIV/AIDS. Others were able to identify and utilize their strength as a specific, definite result of the HIV/AIDS diagnosis. The women gave personal definitions and descriptions of inner strength that were similar to

each other, having comparable meanings for the women. Yet the descriptions reflected uniquely developed strategies that were representative of each woman's individual inner strength and the ways she might utilize her individual strength to deal with the various problems and issues related to HIV/AIDS. Examples of these meanings and strategies are presented. All respondents are referred to by pseudonyms.

Identifying and Connecting

Women interviewed for this investigation were asked what inner strength meant for them. Indicators of inner strength were defined for the respondents as a way of knowing that one had inner strength. Some women's personal descriptions of inner strength were related to an internal force or a characteristic of self. Some described being resourceful, stubborn or willful even in childhood. Other women felt their strength as a transcendental force within themselves.

Inner Strength as a Trait of Self

Dawn, a 40-year-old African American divorced mother of two, spoke of her capabilities and how she felt about herself in describing her inner strength. In referencing capabilities, she stated that inner strength is "allowing something to happen and not letting it break you down." She reported that

indication of her inner strength is evidenced by her ability to focus, pray and "not let it get me down."

Hope and self-reliance were terms Gail used to define her inner strength. This 36-year-old woman came from an African country in which polygamy was an accepted practice, probably being infected through her husband's relationships with multiple concubines. Women in that country often remain dependent on men for their existence despite their education. Gail stated, "I was hopeless…And it's in this country that I discovered you can be self-reliant without any help from anybody. But what kept me there was that I was dependent." Upon arrival in this country, she was depressed because of her "crowded marriage" and was physically wasting from AIDS. She exhibited inner strength through her regained physical strength, positive outlook and vocalization of her hope for the future.

Transitioning from being a victim to a survivor and then to a thriver was the description Stephanie gave for her inner strength. Having been a victim of her father's incest from age nine to age sixteen, this 36-year-old Latina woman has survived the effects of incest, including overcoming her alcohol, food and sex addictions. Her survival began with her resourcefulness at age sixteen when she planned ahead by saving money to leave her abusive home.

> I think survivor mode kicks in during an instance of like when I found out I was HIV+…I was thinking, 'now I know why I remember all those things that happened in that house when I was growing up.' God was telling me 'you've been through worse, you know.'…I'm one person who believes where the mind goes, the body follows. Having a lot of hope is what counts, if you want to call that inner strength.

Stephanie stated she had to have inner strength to disclose her HIV status and to "be able not to pick up the shame, guilt and stigma that society puts out there…"

Other women described connecting with their inner strength and identified it as motivation to go on in the face of adversity, having a mental attitude the opposite of giving up, being comfortable with who you are and knowing your decision is right and being able "to get on with it."

Inner Strength as a Transcendental Force Within

Definitions that contrasted self-reliance, motivation and self-will were usually related to reliance on God. Gay, an African American woman who is an AIDS educator, did not have an overt definition of inner strength, but associated it with trust in God. "I will have strength and I can be strong as long as I have God." Her interviewer interpreted that her inner strength might also be defined in part by saving other people, as she referred to "always helping

anybody and everybody, and to always put a hand out" to others. She related a strong indicator of her inner strength as being able to ask for help for herself when she felt like hurting herself.

Like Gay, Jackie defined inner strength in terms of "being blessed…with the grace of God." Jackie, a 45-year-old married African American woman, determined her ability to stay alive and survive "with the grace of God" was indicative of her inner strength.

Donna also related a strong link between her inner strength and God. Despite using drugs and alcohol to dull the pain from a brutal gang rape at age 16, she turned her life over to Christ three years ago. Donna stated that inner strength was from God, since everything good comes from God. She reported that her positive attitude was based on God's love and grace; His plan provided her strength to get through all she has had to overcome. She gave an example and indicator of this strength in her experience in 1997. She had been diagnosed with an opportunistic infection and told she had two months to live. Her status dramatically changed from being placed in hospice to die peacefully from AIDS to gaining over sixty pounds and having her virus become nondetectable in just four months. Donna attributed this to prayer and reliance on the grace of God.

In stark contrast to the previous examples of self-reliance, motivation or hope and faith in God, respondent Bobby defined inner strength as just "good luck." This 28-year-old prostitute with a daily crack habit was not actively seeking treatment for HIV. She was unable to describe any characteristics of inner strength that were similar to other respondents. Bobby stated that she had good luck when she was able to avoid problems associated with her drug use. "All day long you get ripped off…by dealers and pimps and men…I know I got good luck when I can get my drug, not get beat up, and get through another day."

Nurturing Inner Strength

Each individual woman was able to relate her source for development or nurturance of inner strength. Sources of inner strength were those places, persons or experiences that provided fortification of a woman's innate or inherent inner strength. All sources for inner strength were personal to the individual women responding to the inquiry.

Transcendental Forces

One of the first and most commonly reported sources was God, a higher power or other transcendental force. Linda, a 20-year-old mother of three children whose husband was incarcerated at the time of her interview, stated, "I believe in God…God is the only healer on earth…God does talk to

you if you have an open mind." Deborah, a 30-year-old mother of one, was infected eight years ago. Deborah felt that "God will take care of me and protect me." God was also indicated as a primary source of inner strength for Glenda. She stated that research on her true name revealed it meant "the Lord will be with me through the deepest fear and as long as I have him on my right hand, I will have the strength and I can be strong." Another woman stated that God helped her through a guardian angel.

Stephanie's first source of inner strength was God or her higher power although she does not consider herself religious. In talking about her childhood, she stated, "I'd go to church on Sunday and then get abused (incest) on Monday night—that never made any sense to me…I would think, 'OK, where is God?' Now I know where God was because I was always taken care of one way or another." She admitted that she continues to feel this way as she relies on her Higher Power and listens to God. Kay had to first accept her anger with God when she learned of her HIV status, but now she acknowledges God as a source of strength, stating God is "with me." These women did not believe organized religion provided them the same source of strength provided by their personal God or higher power. Most of these women did not attend any church services on a regular basis.

Religion and Related Sources

Religion, ministers or other religious leaders and the Bible were found to be sources of inner strength for other women. Soon after her HIV diagnosis, Susie was caring for the man who had infected her. She related trying to pass her strength on to him—to will him to live. Although she did not attend church regularly, during this time she attended Bible classes at an interdenominational center that taught a lot of the old Hebrew ways. These classes were interesting but not really a source of strength. However, Susie reported communicating at least three times a week by email with a friend who was previously a nun whom she described as "now turned lesbian." These communications provided "a boost in inner strength." Kay similarly related that a nun through the AIDS ministry of her diocese became an important source of inner strength for her initially and many years after her diagnosis.

People and Places

The third common source for nurturing inner strength that respondents indicated was family. The women living with HIV/AIDS discussed relationships with many family members as sources of strength, but most specifically mentioned were children and mothers. Susie, a 38-year-old mother and wife as well as an AIDS educator, discussed her family's role as a source for inner strength.

> It's my family—they're there with me day to day…Not the doctor, not the nurses, not the social worker…There's a lot of love in our house. A lot of acceptance. Thankfulness that I'm still around…They tell me things like 'my God, you're marvelous' and 'Mom just hang on.'

Glenda reported that her daughter was a primary source for inner strength, stating, "She was my lifter." She also indicated her family of origin as a source of strength. "My family really loved me to where I could not let them down."

Several women lived in an apartment community with other HIV positive women with their children. These women reported this arrangement to be a significant source of inner strength and support. Dawn, in reference to this community, stated, "I know I have a job to do that requires success, and I have to abide by the demands (rules)." JoAnn, a 34-year-old mother of two whom has been infected for seven years, expressed a similar sentiment. She found living in this apartment community a tremendous source for nurturance of her inner strength. This arrangement ordered her life, provided security and support from other HIV positive women and caused her to focus on her family rather than the chaotic life she previously led as a substance abuser. Other women indicated that support groups, twelve step programs and individual therapists were additional sources for enhancement of their inner strength.

Only two respondents specifically mentioned their spouses as a significant source for inner strength. Kay indicated that her husband, who is also HIV positive, was a strong and important source of nurturance for her strength. Susie's husband is not HIV positive but also serves as a strong source of inner strength for her. She gave the example that because he gave her support and encouragement that increased her inner strength, she was able to complete the AIDS walk this year.

Linda, who had listed God as her primary source of support, discussed her husband's role in her attainment of self-esteem and her inner strength. Her husband was incarcerated at the time of the interview because he broke his parole and was physically abusive to her. Prior to that, she had discovered he had slept with her mother, prompting her to call his parole officer. Her three-month-old baby was the result of a different relationship she had while he has been incarcerated. Yet she stated, "He's accepted the baby—the baby is named after him. It took a lot for him to forgive me, just like I forgave him. People don't understand everything…I had no self-esteem. My husband gave me my self-esteem and my self-worth."

What remained largely unstated was that in most instances, women with spouses or significant others did not state they were significantly

supportive or the primary source of their inner strength. Women were generally reluctant to talk about non-supportive spouses. The researchers did not probe deeper in this area when women did not seem comfortable discussing their lack of or obviously missing support from a spouse. The researchers determined that possible reasons for this lack of reported support could include spouses that were incarcerated or estranged.

Bobby indicated that inner strength for her was simply good luck in her life as a street prostitute with a crack cocaine habit. She was unable to identify her source of inner strength and she stated, "I really don't know where (good) luck comes from. I guess you just have to keep trying…" The researcher determined that the luck she identified was really a secondary source or a transcendental source of inner strength for her. She relied on it as other women relied on their relationship with God or their Higher Power.

The women in this investigation clearly did not report nurses as a specific source of inner strength or support. Several women noted that their doctors had been sources of support, as were their therapists and case managers. None spoke of any instance in which a nurse supported her or helped her identify and utilize her own inner strength to meet the challenges of living with HIV/AIDS.

Finding Balance

In some interviews, a level of inner strength was identified and self-determined by the women respondents. The researchers defined levels of inner strength as situations in which inner strength might vary or waver. Most women did not identify a specific level—i.e., high, medium or low levels of inner strength—but rather described situations in which their inner strength had increased and decreased.

Kay, a 36-year-old Anglo woman, was married, had a college degree and a position as a data base manager. Her family knows of her HIV status, but not all of her husband's family has been told that they are both HIV positive. They have chosen not to disclose to most of their close friends. "For them to think, 'well you have HIV and you're not worth anything to me anymore'" prevented disclosure. She felt this rejection, if it happened, would likely decrease her inner strength. In contrast, she felt her inner strength increased when she had to "speak up for myself" with health care providers or family and even her husband. She told of her experience writing her annual Christmas letter the year she had been diagnosed. She decided to tell all of her extended family about her HIV status in the letter. One great aunt never

spoke to Kay or to her mother again until there was a death in the family. Kay was making calls to family members for her mother and she had to call this particular aunt. When Kay identified herself to the aunt, the response from the aunt was, “You’re still alive?” in a disbelieving tone. Because her inner strength had increased with the initial disclosure letter, Kay believed she was able to laugh about the remark and educate her aunt through this experience.

Rejection and the possibility of rejection were factors that could cause decreased inner strength for other women also. Stephanie felt her inner strength had wavered with rejection in a previous dating situation when she disclosed her HIV status. Susie felt the ignorance of others could be draining to her inner strength, particularly the unwillingness of some of her husband’s family to understand the infection.

In contrast, feeling in control, trying to “get life back together,” staying clean from addiction and successful accomplishments were all identified by others as instances that increased their perceived levels of inner strength. Dawn discussed her especially high level of inner strength after completion of a special program. “I felt so good! Imagine—an addict like me achieving that!” She also related experiences that “build my self-esteem, make me feel loved and wanted” and those that focus on her spiritual life as increasing her inner strength.

Some women who strongly related their inner strength to God seemed to feel their level of inner strength stayed high since they were in God's control. Others felt inner strength could vary with God's changing will. Jackie had related that her inner strength was a result of being blessed with the grace of God, but she also spoke of the way "evil spells" can lower her inner strength. JoAnn felt her inner strength varied because it was related to "God's will and He changes all the time." In contrast to this perception, since Dawn found God as her source of strength, she has felt her strength stays high all the time since it depends on Him. Ann, an Anglo woman infected since age 18, reported her sources of inner strength as her strong faith and spirituality and her inherent willfulness. She believed that because of these sources that nurtured her inner strength, her level of inner strength was usually quite strong.

Constance, a 34-year-old African American woman with AIDS, recently experienced near death, and was ready to give up and go to hospice. Her inner strength was low. She was not able to care for herself and her children. Consequently her children had to go live with their grandmother. Her inner strength improved when God spoke to her in a dream, telling her that He wasn't through with her yet. Although her inner strength varies with her illness, she felt God had given meaning to her life, which has caused her inner

strength to continue to grow. This has given her the will and ability to keep fighting.

There appeared to be a relationship between the self-perception of high levels of inner strength, women's ages and the ability to feel some control in their experiences with HIV/AIDS. Evie, who at age 54 had been living with HIV for eight years, equated her inner strength with her will to live. She stated in her interview that inner strength was always there whenever she needed it, such as in times of depression, loneliness and fatigue. Feeling in control of her medical plan of care and doing what she feels is best—i.e., "chewing ginger to feel better rather than taking a pill"—instead of giving up control to the doctors keeps her level of inner strength high.

Susie related she usually had consistently high levels of inner strength which were also maintained by being in control. She attended a Women Organized to Respond to Life-Threatening Diseases retreat in 1994. "That is where I really learned to take charge." She shared that one of her methods to maintain control is keeping her own personal copies of all her medical records—"my war notebook"—that would provide an organized, compartmentalized picture of her HIV history should she not be able to give accurate information herself.

"Being able to overcome it (HIV) instead of it overcoming me" was part of Kay's description of her inner strength. Her ability to "speak up for myself" maintains her sense of control and adds to her feeling of higher levels of inner strength.

Linda and Sissy illustrate the opposite of these examples. Twenty-year-old Linda admitted that her level of inner strength varies with her current situation and feelings. As a result, she attempted suicide because of marital problems and dwelling on sad things. Sissy was recently incarcerated for breaking parole and relapsing with her addiction. It was suspected that she was infected within the past two years and although she was 34 years old, the level of inner strength she described and displayed frequently varied. During the interview her inner strength changed multiple times, evidenced by the following remarks in response to a question about her current level of inner strength.

> It's just now that I'm finally getting my life together and I'm realizing values and what I want to do in life. I'm like, God, why now? I mean I was ready to be sincere about a lot of things...Sometimes I feel like I don't (have inner strength). I want to keep dwelling on life, and...I don't know—every time I start feeling sorry for myself it scares me...But I

> don't think there's much of nothing that's going to make me just give up. But if they tell me I'm in the full-blown stage, I think I would just die! Because I feel like once you're in that stage, you're pretty much gone…and I don't want to reach that stage.

Both Linda and Sissy reflected other women's responses in which they felt their inner strength varied according to their stage of illness.

Responding to Threats

Possible factors that could weaken inner strength to the point it seemed insufficient for the crisis were defined as threats to inner strength. Threats could be classified as either internal or external. Frequently reported threats to inner strength were fear of failing health, deterioration or loss of relationships, temptations of relapsing into substance abuse and other psychosocial stressors such as depression or suicidal ideations. Women living with HIV/AIDS described experiences and situations in which inner strength was insufficient to deal with these threats.

Health-related Threats

As a woman working closely with AIDS organizations in her employment, Ann verbalized that seeing reality at times has been a threat to her inner strength. She referred to the statistics about HIV/AIDS and death and her development of some medication resistance as realities she has

experienced. These things caused Ann to temporarily experience loss of inner strength and subsequent depression. She related there is “a fine line between hope and reality” and she has had to fight fear at times to keep a positive attitude. She has been able to do this through spirituality and strong will. Constance stated that the atmosphere around her has the capability to pull her down. The fear of death and the thought that one day she may not come out of the hospital has threatened her ability to focus on the meaning God has now given to her life. JoAnn has also felt threats to her inner strength at times when her condition worsened or she was hospitalized.

In relationship to health and threats to inner strength, Evie stated, “I have more problems with doctors than anything else. They don’t know as much about HIV as you do!” She also felt the time when her inner strength was the most insufficient was when she experienced strong side effects related to medications, but she utilizes many alternative therapies for overcoming side effects. Dawn experienced a temporary threat to her inner strength when she was unable to obtain her HIV medications due to lack of money. Finding help through an organization with funding for this purpose re-established her inner strength.

Loss of Significant Relationships

Many of the respondents experienced relationship problems and loss of significant persons resulting from HIV/AIDS. They reported these experiences to be a threat to their inner strength. Although not typically pessimistic or one to "wallow" in self-pity, Deborah was depressed after her divorce and HIV diagnosis. She stated it took more than two years to completely recover and overcome this depression. Even though she reported that her inner strength was usually strong, the threat of loss of relationships or being out of control of the situation were felt by Deborah to be current threats to her inner strength. Dawn viewed relationship problems as a threat, describing instances such as "when my significant other won't agree, won't see reality…won't hear me." These situations decreased her inner strength, resulting in feelings of disorganization and lack of concern for her appearance.

Carol, a 19-year-old single African American woman, experienced the death of her first child as the biggest crisis she ever faced. Feeling her inner strength was insufficient for this crisis, there were times she felt she did not want to go on. She viewed her ongoing grief for this baby and a potential loss of her boyfriend to HIV/AIDS as threats to her inner strength that caused her to struggle with maintaining balance.

Gail voiced concern over the problems with her husband if she should be forced to return to her country. She works with an attorney and social services to overcome the threat she feels about having to return to her husband.

> We do talk over the phone, but he's mad. He wants me back. But I don't think he would look after me. It's very expensive for a person admitting to having HIV over there. It would cost over $400 a week just to get the basic medicine…There you are somebody's property—you are not the boss of your own self. He dictates the terms—you are part of his property.

Kay stated her inner strength prior to her HIV diagnosis was performance-related and dependent on success in her professional life. She found this type of strength was insufficient for the crisis of being diagnosed with HIV, stating that she "crashed." Her subsequent withdrawal from family and friends and her inability to concentrate at work resulted in termination from her job. Through self-determination and the realization she needed to take care of herself, her inner strength re-emerged in a different, stronger form. External threats in the form of rejection or disapproval from significant friends and family members were thought to be potential threats to Kay's inner strength now.

Psychosocial Threats

Examples of other psychosocial stressors that threaten inner strength included bouts of depression, suicidal ideations and the temptation to relapse into chemical or substance abuse. Sissy found her inner strength insufficient six months ago when she relapsed to her crack habit. She attributed the cause of the relapse to her boyfriend's incarceration and other family stressors. With her current level of inner strength varying, she admitted that the temptation to relapse is strong again at this time when she sees other people in her group home dying of AIDS. However, she verbalized she was sure she had some inner strength. She attributed this assurance to living with a woman she considered to have no amount of inner strength. Sissy stated, "…this girl staying over here, cause to me she's practically given up…she won't get up and do for herself…I think she's the most negative person that I've met since I've been diagnosed." She attends support meetings to overcome addiction and threats to her inner strength.

Women who felt that their inner strength was not in their control did not find they had any threats to their inner strength. An example was Donna who felt everything came from God. Therefore, she was unable to identify threats to her inner strength; everything was all in God's will. Paradoxically, Bobby defined her inner strength as luck and therefore was not sure how she got it.

She was able to identify a threat to inner strength. “You can lose your good luck by acting a fool…by being stupid. Like, when you let a man run you.”

Inner Strength as a Component of Holistic Health

Inner strength identified and sufficiently nurtured in these women with HIV/AIDS allowed them to successfully cope with the stressors associated with their life-threatening illness in most cases. Women perceived positive effects of inner strength that benefited them holistically with improved health of body, mind and self or soul. Self in this analysis included both spiritual and emotional aspects. When women described how inner strength had affected their health, happiness, relationships and meaning in their lives, they generally addressed one or more of these aspects of holistic health.

An example of improved health of the mind as a result of inner strength was found in Jackie’s experience. Jackie had been incarcerated for a felony conviction in the past and had been a crack cocaine addict. She was currently working to increase her inner strength through a recovery program. She was dealing with these problems in addition to living with HIV/AIDS. She stated, “Inner strength can help you to be a good person when you are trying to be bad.” She explained this contradiction by saying that she had seen herself as a good person, even when using and selling drugs. Inner strength, however,

had helped her realize, on a cognitive level, that the activities that perpetuated and spread drug use were bad.

Inner strength had allowed Stephanie's mind to heal from incest so that she is now able to have healthy relationships and goals for the future. She stated she believed inner strength had improved her mental health over the past nine years, contributing significantly to her current state of good health and immune status. As proof of this she offered that her CD4 count was 1250 and her viral load was nearly undetectable without ever taking antiretrovirals.

Glenda stated inner strength helped her to keep her mind focused so she could care for her daughter even when it was very difficult. Her inner strength has also helped her to see herself on a mission to help others as she works with others living with HIV/AIDS.

Those women who feel their inner strength totally related to God and spirituality also felt that their inner strength directly affected the happiness and meaningfulness of their lives. Donna stated God and religion were the sources of her inner strength. Because of inner strength, she felt her life had meaning and she felt happy with herself and all things in her life. With God in control and keeping her doing the right things, Carol felt hope and freedom from depression. Since God and inner strength are much the same thing to JoAnn, she felt her inner strength helped her to be a good Christian. Her faith in God

helped her fight temptation, but at the same time, to prepare for the worst. Constance voiced similar feelings about the effect of inner strength in her life. While she was introspective in analyzing her self and her life, she stated that her life has meaning because of the inner strength she received through God's message to her in a dream.

Several women spoke of their physical health in terms of their immune status and the role that inner strength played in keeping them physically strong. Linda stated her inner strength motivated her to eat right—i.e., fruits and vegetables instead of junk food—exercise regularly, not smoke and avoid alcohol. Dawn perceived her inner strength as helping her know that if she "gets too stressed, depressed or frustrated, that I could break my immune system down and go into full-blown AIDS." Both Susie and Kay stated their inner strength was instrumental in helping them remain adherent to their medication regimen, thereby improving their immune systems and physical health. Kay, who knew positively she had only missed three doses of medication in the past two years, felt her inner strength has given her incentive to take care of herself in the best way she can. She expounded on this aspect, discussing her opportunity to plan for children because her physical health is excellent. Although Linda admitted she had not taken her medications for over two weeks, she denied this was related to weakened inner strength.

One woman felt that there were limits in her ability to continue to maintain inner strength on her own. Evie conceptualized inner strength in terms of meaning for her life. The researcher felt HIV/AIDS permeated Evie's entire life and self, implying the importance for inner strength and how she actively seeks it. Although physically and spiritually strong, she admitted that having a significant relationship would add a source of inner strength to her life.

It could be said that without developed and nurtured inner strength, a woman with HIV/AIDS might not reach optimal health. For example, Bobby commented on the effects of inner strength (good luck) on her health and life.

> I just don't have time to worry about my HIV. When I get sick and I think it's from my HIV, I go down to (the county hospital clinic) and they give me some cocktail. I stop taking my medicine when it makes me feel bad. I feel bad enough from my habit; I don't need no more feeling bad.

Another example of the effects of under utilized inner strength was evident in Bobby's admitting to waiving the use of condoms with customers if they insist and will pay her more money.

A diagnosis of HIV would be devastating to many women; yet three women discussed the positive changes this diagnosis had made in their lives. Deborah found she had been introduced to important people who had given her life more meaning as a result of having HIV/AIDS. The infection has provided her with opportunity to do work that makes her life meaningful. She stated, "I do not know where I would be today if this whole thing hadn't happened to me."

Living with HIV/AIDS has also provided Susie with opportunities for growth. She volunteers at a center for women who are living with HIV/AIDS, most of whom are prostitutes or intravenous drug users. "Inner strength allows me to find some common ground with them and relate to their struggles to survive." She felt inner strength had allowed her to learn to be more kind and giving to others.

Perhaps Kay best described the relationship of her inner strength and meaning to life in these remarks.

> When I'm asked if I could relive my life, would I change anything? My answer is that I wouldn't wish this disease on anyone and yes I wish I didn't have it. Would I do anything different? No. I've become a much stronger person; I've dealt with a lot of issues besides HIV within

> myself. I like myself better. I'm not as angry as I was...People like me better.

Experiencing Health Care

The women with HIV/AIDS offered important suggestions for nurses and other health care providers to enhance women's inner strength through positive health care experiences. Many women reported that the worst thing to be asked is "How did you get infected?" When helping women newly diagnosed with HIV, rather than asking how they were infected, Stephanie suggested the following.

> The most important thing is to help them get through the shame and guilt of it...Society says 'you're either a whore or a slut, or shooting up drugs or having sex with gay men.' So the shame, guilt and stigma society puts out there—that's probably going to be the thing that's going to be detrimental, especially to a woman.

Stephanie offered that a sensitive and appropriate opening with a new patient should be, "'So, since you've found out about being HIV positive, what are some things that have happened that might have hurt you?' That's being sensitive to the client so you don't open your mouth and say the one thing that is going to hurt her the most." Being insensitive brings shame and discourages

women from returning for care. It was suggested that nurses help educate doctors to be sensitive to the woman's issues.

Ann cautioned nurses to take care in the words they use to provide comfort to a woman with HIV/AIDS. "People tried to comfort us by telling us that nobody knows when they'll die, that we could all get hit by a bus on the way home. This did not help. They were invalidating my feelings and this made me angry." Ann also recommended that nurses not ask questions out of curiosity—i.e., "How did you get infected?" or "How did your boyfriend get infected?"

Preserving a woman's self-esteem was also important to the women living with HIV/AIDS. Several indicated that nurses have the power to help women feel normal and loved. They suggested that to not treat them differently because of their HIV status would show this type of caring. Jackie felt that nurses, as people who work with those living with HIV/AIDS, must understand the importance of self-esteem. To her, those that did understand "made me feel like I'm not a bad person." Linda offered that a way to show care was to not "use me as a lab rat."

Several women emphasized the value of touch in caring and preserving self-esteem. Constance stated, "The only time I got my feelings hurt was when a nurse offered to help me bathe but then wouldn't touch me. I think she thought my HIV would rub off on her." Touch was also important to Kay, who stated she does not return to any health care provider who does not initially shake her hand or touch her in a comforting way.

The right to have hope was valued by women living with HIV/AIDS. Therefore, helping women preserve hope was a suggestion for health care providers. Ann discussed the fine line between reality and hope, pointing out that women often have to fight to keep a positive attitude when they are dealing with those in health care. Stephanie offered the following points.

> There are some people who will say 'you're not allowed to have hope.' I heard a doctor that was speaking say, 'I encourage my women patients to not get pregnant.' Then you are taking away their hope…That's basically saying you're not allowed to have that dream…one of the worst things that a counselor, therapist, lay person or a nurse can say to a person is, 'Well what are you hoping for?' and try to take away somebody's hope…To take away someone's hope is to take away their livelihood and their spirit.

Summary

The findings of this investigation included rich descriptions of the lived experience of inner strength from nineteen women living with HIV/AIDS. The sample respondents were between nineteen and fifty-four years old, from multiple ethnic and socioeconomic groups with varied life experiences. These women indicated inner strength might manifest as a characteristic of self or from transcendental forces such as God. Women found their inner strength to be nurtured or fortified through God or a higher power, religion or related sources and through relationships with people. Inner strength was a dynamic force in these women, wavering with threats such as fear of failing health or loss of relationships and increasing with success in accomplishments and positive relationships. Inner strength may affect all dimensions of health and health care providers may affect one's inner strength.

CHAPTER 5

SUMMARY OF THE STUDY

Everything nourishes what is strong already.
Jane Austen, 1813 (as cited in Maggio, 1996)

Inner strength is the way women with serious illnesses such as HIV/AIDS experience and describe the deepest existential resources available to them and used by them in coping or controlling the severe risks to self-integrity that illness may bring. Women universally have an innate or inherent potential for inner strength, although it may not always be evidenced or necessarily utilized until faced with a devastating diagnosis or other crisis. A need exists for nurses and other health care providers to understand the lived experience of inner strength in women with HIV/AIDS. Insight into the experience of inner strength can provide a basis for more effective care for women with HIV/AIDS. As nurses are able to assist women to identify their inner strength and facilitate identification of sources for nurturing new or existing inner strength, quality of life and holistic health might improve for women with HIV/AIDS.

Summary

Inner strength in the lives of women with HIV/AIDS and the role of the health care provider were explored using a phenomenological approach. Data were collected from nineteen women living with HIV/AIDS in a metropolitan

area in the south central United States. A purposive sample was utilized to obtain respondents with a wide range of age, ethnicity, socioeconomic status and disease stage. Data collection occurred through semi-structured interviews utilizing sample questions developed by the researchers (See Appendix C). Researchers had flexibility in the questions asked according to information being given; most respondents were simply asked to tell their story of what their life had been like since their HIV/AIDS diagnosis. Sampling ceased when redundancy in the data was achieved.

Audiotaped and transcribed interviews were analyzed using Colaizzi's (1978) method. The secondary literature review was done concurrently with data collection and analysis to prevent bias. The research team met every two weeks for purposes of reviewing data obtained and discussion of possible meanings of the data. Significant statements from the transcripts were extracted and the researchers attempted to derive meaning from these statements. The aggregate meanings of the significant statements were categorized through the use of inventories developed by the researchers. Inventories included definitions of inner strength, indicators of inner strength, sources for increasing inner strength, threats to inner strength and contribution

of health care providers to inner strength. Statements regarding descriptions of negative or lacking inner strength were also extracted from the transcripts. Finally an exhaustive description was written that utilized four identified themes of inner strength comprising the lived experience of inner strength for women living with HIV/AIDS. Beneficial elements of the role of the health care provider were identified.

Discussion of Findings

The diagnosis of HIV/AIDS in women can be wrought with uncertainty and devastation of self-esteem. Initially, the researcher expected that inner strength in women living with HIV/AIDS might develop in a trajectory similar to the women's illness trajectory, with women possibly being in one of four groups. These possible groups were inner strength that was present prior to illness that continued to develop over the disease trajectory; inner strength that was never present in the past but could be developed through education or support; inner strength that was present prior to illness which actually decreased over the disease trajectory; and women with missing or no inner strength at all. Instead, the findings of this study suggest that women living with HIV/AIDS have an innate or inherent force termed inner strength that can serve as a resource to protect self-integrity as they live with this catastrophic illness. Inner strength had not been needed or identified prior to HIV diagnosis

for some women. Other women had utilized inner strength prior to their diagnoses to overcome crises such as incest, incarceration and addictions. Dealing with HIV/AIDS was a continuation of utilization of those resources they determined were their inner strength. The experiences described by the women with HIV/AIDS both illustrated and expanded the previous conceptual definitions of inner strength in women.

Rose (1990) described inner strength as a function of healthy psychological functioning. She described themes that involved inner strength in a centering, integrating and balancing function that led to self-awareness and understanding of the whole of things. The women living with HIV/AIDS were different from Rose's sample because these women were diagnosed with a chronic, possible terminal illness. A theme Rose termed quintessencing involved recognizing the real self, becoming true to that self, accepting the woman she was and acting from that acceptance. Many women living with HIV/AIDS related experiencing similar processes. Kay, for example, stated she had discovered who she was and she liked the woman she had become and being able to speak for herself. Other themes Rose described that were also seen in the women living with HIV/AIDS were centering and quiescencing, which correlated with prayer and focusing on God. In their descriptions of living with HIV/AIDS, all of the women except Bobby, gave examples that

illustrated the other themes of apprehending intrication, introspecting, using humor, interrelating, having capacity and embracing vulnerability that were outlined in the work by Rose (1990).

Similar to Moloney's (1995) assumption, an underlying assumption for this study was that all women in our culture possess a potential to develop inner strength through living in the world to which they are born, although this inner strength varies according to life experience. The women in Moloney's investigation were older and not ill, which differed from the current study. However, the themes that emerged from their stories—surviving, finding strength, and gathering the memories…seeing the patterns—were all reflected in some way in the various descriptions of the experience of living with HIV/AIDS. Surviving, which involved living with loss, living through hard times, being different and putting it behind you, were all found in the descriptions obtained in this study. An excellent example was Stephanie's recounting of having survived incest, subsequent addictions to food, alcohol and sex, and her current self-image as not just a survivor but a thriver, despite her HIV diagnosis. As a result of their life experiences, all the women living with HIV/AIDS were able to connect with a source of inner strength. These life experiences resulted in seeking nurturance and support from God, people and positive experiences, reflecting the themes of identifying and connecting and

nurturing inner strength in this study. The pattern Moloney identified as gathering the memories…seeing the patterns was similarly exhibited in the women with HIV/AIDS as they told their stories, with the storytelling itself being a way to examine life (Moloney, 1995).

Roux and Keyser (1994) determined that inner strength in women with breast cancer erupted in the coming to know and accepting of self that occurred as women connected with themselves, with God and with loved ones. Reaching a new normal and a new self in this process created movement toward triumph and a sense of harmony. The themes described by Roux and Keyser (1994) were definitely a process that women progressed through to reach this sense of triumph and harmony. Although the women living with HIV/AIDS who shared their stories described some of the same experiences as the women with breast cancer, there was not an obvious process or progression that emerged for each woman.

One way to view this difference between the women with breast cancer and those with HIV/AIDS is that women with breast cancer can be cured and can be called cancer survivors. Currently, there is no cure for HIV/AIDS. Although a woman who is a long-term nonprogressor is sometimes referred to as a survivor, she is still not cured of HIV/AIDS. Another possible explanation was the differences found in the samples. The respondents to Roux and

Keyser's 1994 study were primarily white, middle class women with only one African American participating. The respondents for the current study were primarily African American, many in a lower socioeconomic class. The way a woman develops her illness could also account for differences in the two studies. Women with breast cancer often discussed their illness as a legacy or an inherited disease. The fact that a majority of women have breast cancer for unknown reasons also removes any blame in having the diagnosis. In obvious contrast to this are the ways women contract HIV/AIDS. Exposure to the virus from either sexual intercourse or intravenous drug use can both imply blame. Although the results of both studies show that women with serious illnesses have inner strength, the way women described their experiences living with HIV/AIDS do not follow any certain progression in identifying or exhibiting that strength.

In her unpublished thesis, Dingley (1997) defined inner strength as a dynamic and integral reality that can be observed in individuals facing challenging life experiences. She identified inner strength as a factor of psychological health and spiritual well being that was a dynamic component of holistic recovery in women with cardiac disease. A similarity of Dingley's (1997) study and the current investigation was found in the following statements.

> The chronicity of heart disease was experienced by participants as they moved through the recovery process which began with an acute event or point of diagnosis, but did not end with a cure. Thus, the chronic nature of heart disease became the impetus for the creation of a new normal as they experienced healing over an unlimited amount of time (Dingley, 1997, p. 41).

Another similarity to the current study was the necessity for adjustment and reorientation in all dimensions of their lives due to the implications of living with a new normal related to their diagnoses. Similar to the women living with HIV/AIDS, the women with cardiac disease grew in inner strength through allowing themselves to be nurtured, receiving physical support and psychosocial care as needed from others, choosing to dwell on health rather than illness and finding strength within themselves. Although not all of the women living with HIV/AIDS chose to release control or relinquish power, some found this important to their inner strength, especially if their strength was related to God and God's will. Other women with HIV/AIDS, like Evie and Susie, actually found releasing control and power to be a threat to their inner strength. The inner strength aspects of maintaining physical and mental health were important to both groups of women. Similar to the construct Dingley (1997) identified and described as connecting with the future, many of the

women living with HIV/AIDS have become involved in AIDS-related activities and employment. Several were AIDS educators and volunteered in AIDS service organizations. For these women, AIDS-related activities that give their lives more meaning and help them connect with the future, have become sources of inner strength.

Because of the nature of cardiac disease in women, the sample participants in Dingley's (1997) study were all women over the age of 65, which differed from the women with HIV/AIDS. Another difference in the samples was that all but one woman in Dingley's sample was white and in the middle class socioeconomic group.

The descriptions given by the women living with HIV/AIDS illustrated the change in client roles and shift in focus from the burden of disease to a sense of health within illness that was described by Thorne and Patterson (1998). Very few women referred to themselves as being ill and they tended to focus on positive aspects of their health. Several women identified their HIV diagnosis as a pivotal event, with their lives having changed for the better as a result. Many had learned to control harmful stimuli and stressors and abandoned harmful substances in an effort to improve their physical and mental health. A number of the women living with HIV/AIDS gave illustrations

of positive growth and change in their lives, similar to those described by Jones and Meleis (1993) and Katz (1996).

The women living with HIV/AIDS exhibited and described characteristics of hardiness in their stories describing their inner strength. In the literature, hardy individuals practiced health-promoting behaviors such as exercising regularly and being attentive to their nutrition (Carson, 1993). Hardy persons perceived their spiritual and emotional health to be greater which were also evident in the perceptions of many of the women in this study. Participation in AIDS-related activities was rated high by participants in the hardiness study, although no positive correlation with these activities was found in relationship to hardiness scores (Carson, 1993). However, women interviewed for this study did indicate that they perceived their AIDS-related activities contributed to their inner strength.

Strawn (1995), in her review of investigations of long-term survivors, suggested that further exploration of long-term survivors telling their stories might reveal important correlations. Several respondents for the current study indicated that speaking to other women and telling their stories had contributed to their inner strength. Two women told this researcher that in participating in the interview for this investigation, they felt energized and

better for having told some of the details of their lived experience since diagnosis with HIV/AIDS.

Transcendence in the respondents for this study was a similar process to one of the three ways Frankl (1969) described. Women living with HIV/AIDS were faced with an unchangeable situation. Some transcended through their occupations that were often AIDS-related, such as Ann and Kay. Other women experienced self-transcendence through creative outlets such as singing and being a praise dancer at church. They all were presented with opportunities for choice in facing adversity and reconstructing their sense of being. All of the women except Bobby seemed to grow in positive ways and transcend their adversity as described by Coward (1995). Some women looked inward to characteristics of self or spirituality for inner strength; others reached outward to support groups, therapists, and family in connecting with their inner strength and transcending their unchangeable condition.

Like the women that were interviewed by DeMarco, Miller, Patsdaughter, Chisholm, and Grindel (1998), some women in this investigation indicated that early in their disease trajectory, they were hesitant to disclose or discuss their HIV diagnoses. However, many indicated that the transition from silence to speaking out for themselves was a contributor to their developing inner strength.

Resilience and inner strength were found to be similar. Self-care activities and use of social support associated with resilience were described by Barroso (1995; 1997). The women living with HIV/AIDS often reported these activities as contributing to their inner strength. The description of help and strength from within her in the context of resilience (Andrews, 1995) seemed very similar to descriptions of inner strength and the anecdotal examples given by women in this study. Inner strength, as described by the women living with HIV/AIDS, was also similar to the resilience continuum that Hunter and Chandler (1999) described. Many of the women related situations and instances in which their inner strength varied, which could be compared to the resilience continuum. Finding balance and responding to threats, themes that emerged in the current study, contain illustrations similar to this continuum.

Conclusions

The experiences of women living with HIV/AIDS provide an alternative view of women living with chronic and life-threatening illnesses. The findings of this study contribute to a cumulative body of knowledge necessary for establishment of a substantive theory of inner strength in women. The findings of the current study allow the following conclusions to be made.

1. Women living with HIV/AIDS have the potential to identify their inner strength for utilization in responding to the challenges and crises of their illness.
2. Women may continue to develop and increase in inner strength that was present and utilized prior to the diagnosis of HIV/AIDS.
3. Women may experience HIV/AIDS as a pivotal event which provides them with an initial opportunity to identify and utilize their inherent inner strength in response to the crisis of an HIV/AIDS diagnosis.
4. Some women may fail to develop their inner strength or may exhibit consistently low levels of inner strength that are insufficient for successful management of the crises of living with HIV/AIDS.

Implications

In this investigation, it was observed that women had a wide range of definitions for inner strength and many different ways of talking about the concept. Cultural differences could explain some of these variations. Women who had been attending church their entire lives or who had become spiritually strong often discussed their inner strength from this perspective. Current life situations determined and influenced individual meanings of and sources for inner strength. This was especially relevant in women with children. These women often cited a will to live for their children as part of their definition of

inner strength as well as a source of inner strength. This was previously recognized by Barroso (1997) and nurses must be cognizant of this factor when assisting women in utilization of their social support network.

The individual meaning of inner strength was likely influenced by the amount of time a woman had been living with HIV/AIDS and her associated experiences during that time. It was noted that women living with their diagnosis for longer times and those who worked or volunteered in HIV/AIDS organizations were more articulate in conceptualizing inner strength, but this was not necessarily correlated with whether their inner strength could be subject to threats. Nurses should be aware that all women might not use the same language or terms in verbalizing their inner strength.

It was observed in this study that no woman identified a nurse as a source of her inner strength. Barroso also noted this in her 1997 study of social support and long-term survivors. Nurses have a unique opportunity to benefit women in their identification of inner strength and by being a source of nurturing of that inner strength once it is realized. Nurses could create a role for themselves as facilitators of inner strength that would not necessitate taking on another role such as pastor or therapist. Listening to what women say about their inner strength in their own language or words could significantly influence women's health when living with HIV/AIDS. The

importance of such a role can not be underestimated. Helping a woman realize and utilize her inner strength could potentially impact survival, which is especially important when a woman is also a mother of children.

The women who participated in this study showed that their individual perceptions of their levels of inner strength might vary at any given time. Inner strength is likely to change since it seemed to be a dynamic process as described by the respondents living with HIV/AIDS. The challenge of keeping inner strength at consistently high levels throughout crises or daily life presents potential for intervention for nurses. A sensitive and perceptive nurse could utilize strategies similar to those employed by Zorilla and colleagues (1996) to empower women to verbalize their needs. This would be beneficial to facilitating, strengthening or maintaining of higher levels of inner strength.

Nurses should remember that women living with HIV/AIDS face multiple problems on a daily basis (Cotton, 1999) that might threaten their inner strength. Their HIV may be only one of multiple problems that must be prioritized and dealt with successfully to maintain health. Nurses who are perceptive to these issues and threats may intervene by helping women develop strategies to keep health, with all of its holistic aspects, as the number one priority for most of the time.

Preserving dignity and self-esteem in women living with HIV/AIDS must remain a priority. Resisting temptation to give in to curiosity and not asking how the woman contracted HIV/AIDS is one way to not cause shame and guilt, thereby helping to preserve her self-esteem. Unless the knowledge of the mode of transmission will change a nurse's plan of care or strategy for increasing inner strength, or specific forms for reporting need to be completed, the question is not necessary.

To remain alive and healthy, complicated regimens of medications will be necessary for most women with HIV/AIDS for the remainder of their lives. Having sufficient inner strength to endure the possible side effects and toxicities of antiretrovirals may be an important factor in women's health. Two women in the current study stated their inner strength helped them to remain adherent to their medication regimen; another found she needed her inner strength to deal with the side effects the medications can cause. These findings suggest that nurses who provide care and education for women with HIV/AIDS need to be cognizant of the potential role inner strength might have in the important area of adherence.

Roux and Keyser (1994) identified salient needs of women with breast cancer and interventions to increase inner strength in these women. The

implications for nursing and health care providers are apparent. Many of the interventions identified by Roux and Keyser (1994) are deemed appropriate for women living with HIV/AIDS. Based on the findings of this investigation, the adapted interventions for nurses and other health care providers working with women living with HIV/AIDS are delineated.

1. Encourage sharing thoughts and feelings.
2. Explore fearful feelings of knowing about the illness; clarify misconceptions and unrealistic fears.
3. Encourage discussion with other women living with HIV/AIDS through support groups and social organizations specific to HIV/AIDS.
4. Help women discover their skills, strengths and resources for nurturing inner strength.
5. Encourage women to do what is important for them to maintain and improve self-esteem and inner strength.
6. Encourage release of energy through playful and recreational activities.
7. Encourage communication that allows asking for help, support or expression of needs.
8. Encourage outlets for self-expression and creativity as well as physical exercise.

9. Facilitate the minimizing of stressful stimuli and encourage women to put Themselves first.

These interventions could positively influence the inner strength of women living with HIV/AIDS.

Recommendations

From the findings of this qualitative study of inner strength in women living with HIV/AIDS, the following recommendations for future research are suggested. Results of suggested investigations could add valuable information regarding inner strength for both educators and providers of health care.

1. Research that further investigates the value of inner strength in a woman's adherence to the prescribed medical regimen would benefit women living with HIV/AIDS and their health care providers. Due to the chronicity of HIV/AIDS, this information could also be of value in other chronic diseases such as diabetes and hypertension when patients are not always adherent to their prescribed treatment plan.
2. Investigation of the possible correlation of inner strength in women with HIV and long-term nonprogression to AIDS could add further clarity to the phenomenon of long-term nonprogression. This research might include the interrelationship of inner strength and immune status markers. These

findings would potentially benefit women living with HIV/AIDS and their health care providers.

3. The question remains whether inner strength can be taught or learned. If inner strength is inherent in all women, but not always identified or utilized, investigating possible ways that women could learn to find and use their inner strength would be of value.
4. The development and testing of an assessment tool for inner strength would be valuable to nurses and other health care providers that interact with women living with HIV/AIDS. Research that proved the value of such a tool could be incorporated into early intervention and education programs for women with HIV/AIDS. This information could lead to earlier identification of inner strength in women, thereby facilitating the maintenance of or improvement of their holistic health.
5. Further investigation of inner strength and hardiness, resilience and transcendence would possibly clarify the relationship of these phenomena in women living with HIV/AIDS. Must a woman have identified and utilized her inner strength to be hardy, resilient and self-transcendent in her condition with HIV/AIDS? Or must the characteristics of hardiness, resilience and self-transcendence be present to have inner strength?

Whether there is a true correlation and how that correlation exists could influence interventions meant to fortify inner strength.

6. Outcomes research in the area of psychosocial health, such as investigation of interventions that could potentially increase or fortify inner strength, is necessary. Documentation of successful, theory-driven interventions that demonstrate increased inner strength would add to a body of knowledge important for evidence-based nursing practice.

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APPENDICES

APPENDIX A

INFORMED CONSENT

You are being invited to participate in a research study called "Inner Strength in Women with HIV/AIDS" conducted by Drs. Brenda Haile, Peggy Landrum, and Joseph Kotarba of The University of Texas School of Public Health, Texas Woman's University, and The University of Houston, and Ms. Debra Trimble, a TWU Masters nursing student. Your decision to participate is voluntary and you may refuse to take part, or to stop participating at any time. A decision not to take part, or to stop being a part of the study will not alter any services available to you from any agency.

You may refuse to answer any questions, during the interview or on the written forms.

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Houston Health Science Center.

This study is being done to examine "Inner Strength" , or the ability to accept illness or a change in health and continue on with a meaningful life in women with HIV. It may be beneficial to nurses and others in the healthcare profession to know how this inner strength is developed and if there are ways of making the process easier.

If you decide to participate in this study, you will meet with an interviewer at a place of your choosing where you will be comfortable and can talk quietly for a period of time. The interviewer will ask you to tell her about your life and your HIV infection, basically tell your story. What you say will be audio-taped so that your words may be written down after the interview and read carefully by the researchers.

This interview will last approximately 1-2 hours, or until you feel you have told all you have to tell. You may stop at any time.

You will receive $50 at the time of the interview which will cover the cost of your transportation, any child care costs, and also compensate you for time spent in the interview process. You will receive this money even if you do not decide to complete the interview.

The tapes will be destroyed after they are written and the written words will not have your name or any way to identify you connected to them. They will be kept under lock and key by Brenda Haile and will not be made available to anyone other than the researchers under any circumstances.

I have read the above and agree to participate in this research project. I have been given an opportunity to ask questions and understand all that has been explained to me.

_____Participant _____Date
_____Witness

CPHS Statement:

This study (HSC-SPH-98-121) has been reviewed by the committee for the Protection of Human Subjects (CPHS) for the University of Texas Houston Health Science Center. For any inquiries regarding research subject's rights, or to report any research-related injury, call the CPHS at 713- 500-5827.

APPENDIX B

GENERAL INFORMATION FORM

DATE_____ INITIALS_____

This information is confidential, and will not be connected or identified with you in any way.

1. When did you find out you were HIV +? _____(Date)

2. Your date of birth_____Telephone #_____

3. What is your marital status?

Single_____Divorced/Separated_____Married_____

Live with partner_____Widowed_____

4. How many children do you have?_____ Ages_____

5. What is your living situation?

Live with spouse or partner_____Live with children (under 18 yrs)_____

Live with children (18 and over 18 yrs)_____Live alone_____

Live in group setting_____ (please describe)_____

6. What is your ethnic identification?

Caucasian (non-Hispanic)_____Hispanic_____

African American_____Asian_____

Other (please specify)_____

7. What is the highest grade of level you completed in school?

8th grade or less_____9-12th grade_____

High school graduate_____Some college_____

College graduate_____Technical/trade school_____Graduate school_____

8. Are you employed outside the home? Y___N___

What is your occupation? _____

9. How is your medical care paid for?_____

10. Have you been a member of an HIV support group? Yes_____ No____

11. What is your source of income? _____

12. What medication are you on now for HIV or opportunistic infections?

_____

How many doses do you think you miss in one week?

13. What was your latest viral load? Your last CD4 count?

APPENDIX C

SAMPLE QUESTIONS FOR INNER STRENGTH INTERVIEW

The semi-structured interview may include any of the following general questions. Paraphrasing will be allowed for purposes of clarification.

1. Tell me about your life since your HIV diagnosis.
2. What has been a source for your inner strength since your HIV diagnosis?
3. Tell me about a specific instance that you feel relates to your inner strength.
4. How did that experience affect you?
5. What things have you done to help increase your inner strength?
6. Has any health care provider done anything to help or hinder your inner strength?
7. Tell me about things—from inside yourself or from outside—that threaten your inner strength?
8. Are there situations in which you feel your inner strength varies or wavers?
9. What effects has inner strength had on your happiness, health, relationships, or meaning of your life?
10. Would you say inner strength has always been there or has it grown since your HIV diagnosis?
11. What kind of a childhood did you have? What was your personality?

12. Who or what helps you get through the rough times?
13. Who or what do you use for support?
14. What did you know about HIV before you were infected? What have you heard since then?
15. Do you know someone who you think has no inner strength? What makes you think so?

APPENDIX D

Inventories Template

Respondent: Date:

Interviewer:

I. General Information (on form)

II. Three Process Analysis (options)

- The respondent develops Inner Strength over the course of her HIV/AIDS trajectory.

- The respondent transforms the Inner Strength present in her before she contracted HIV/AIDS.

- The respondent loses Inner Strength during her HIV/AIDS trajectory.

III. Inventories

- Definitions of Inner Strength

- Indicators of Inner Strength (i.e. how a respondent knows she has it)

- Crises and critical situations in which Inner Strength emerges, is useful, saves the woman, is insufficient, etc.

- Sources of Inner Strength (e.g. family, religious/spiritual counselors, or health care providers)

- Threats to Inner Strength (e.g. from others, from within)

- Levels of Inner Strength (e.g. situations in which IS varies)

- Effects of Inner Strength (e.g. on health, on happiness, on relationships with others, or on the meaning of life)