

Living in Silence: A Grounded Theory Study of Vulnerability in the Context of HIV Infection

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Clients with HIV infection have been conceptualized as a vulnerable population. Although some researchers have examined vulnerability with clients with HIV infection, a theory of vulnerability in the context of HIV infection is non-existent. The purpose of this study was to describe, using qualitative methodology, the process by which vulnerability occurs in the context of HIV infection. Grounded theory methodology was used to sample and analyze data from 15 qualitative interviews of adults with HIV infection. Data were collected until data saturation was reached. A theory that describes the process by which vulnerability occurs in the context of HIV infection, *Living in Silence*, emerged from the data. *Living in Silence* consists of four categories: *Confronting Mortality and Illness*, *Struggling with Change*, *Encountering a Lack of Psychosocial Support*, and *Experiencing Vulnerability*. Clients living with HIV experience vulnerability. Nursing interventions to decrease the risks of vulnerability should be directed toward the holistic needs of clients and toward increasing psychosocial support.

HIV infection, like all disease processes, impacts physical and psychological health. HIV is unique, however, in that infected individuals experience stigma and discrimination that impact mental health (Beer, Fagan, Valverde, & Bertolli, 2009; Logie & Gadalla, 2009). Both stigma and discrimination, at any point in the disease process, combined with the stress of living with an unpredictable illness may result in perceptions of vulnerability (Holzemer et al., 2009).

Up until the mid-1990s, HIV was a terminal illness. Progression to AIDS was inevitable and clients succumbed to opportunistic infections, neoplasms, or other infections from destruction of the immune system (Kartikeyan, Bharmal, Tiwari, & Bisen, 2007). Early in the HIV epidemic, clients with HIV were conceptualized as a vulnerable population because of the unique physical, psychological, and social issues surrounding HIV infection (Flaskerud & Winslow, 1998; Macklin, 2003).

Vulnerability is a concept with relevance for both clients with HIV infection and health care providers, as HIV/AIDS is an

international health problem affecting nearly 33.4 million people (World Health Organization, 2009). Because of the unique physical, psychological, and social issues that clients experience related to HIV infection (Flaskerud & Winslow, 1998; Macklin, 2003), nearly all clients with HIV infection are at risk for vulnerability during their disease course, especially those clients with HIV infection who reside in resource-limited countries where HIV care and treatment are not readily available.

With advances in treatment, HIV infection is a manageable, chronic illness. Research on vulnerability in the context of HIV infection is limited, and a theory that describes the process by which vulnerability occurs among clients with HIV infection has not been developed (De Santis, 2008).

REVIEW OF THE LITERATURE

Four English language studies were located that focused on vulnerability in the context of HIV infection. These studies were selected from CINAHL, ERIC, MEDLINE, LGBT Life, and PUBMED databases limited to the years of 2000 to 2010 using the key words of AIDS, HIV infection, vulnerable, and vulnerability. Research studies on vulnerability to HIV infection were excluded as these studies were not relevant to this study because clients cannot experience vulnerability in the context of HIV infection without infection with HIV.

The four available research studies on vulnerability in the context of HIV infection were used to develop the interview guide for the study. Van Servellen, Chang, and Lombardi (2002) used a quantitative approach to study 89 Hispanic men and women living with HIV infection. Vulnerability in this study was a combination of a lack of resources plus a decreased quality of life. Using regression analysis, clients most vulnerable were those with HIV symptoms, problems with HIV treatment, and HIV-related stress and these factors were related to poor quality of life (Adjusted $R^2 = .335$, $F(6, 76) = 4.75$, $p < .05$).

Ayers and colleagues (2006) used qualitative interviews to document vulnerability in HIV-infected adolescents ages 13 to 20 ($n = 22$) and their caregivers ($n = 13$) in Brazil. Vulnerability included the physical, mental, behavioral, cultural, moral, political, economic, and institutional factors that impacted clients

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with HIV infection. Three themes emerged from the study that contributed to vulnerability: individual dimensions, social dimensions, and programmatic dimensions. Individual dimensions included networking, intimate relationships, family relationships, and mental/physical health factors. Social dimensions included stigma, discrimination, and social support. Programmatic dimensions included governmental response, health care access, and HIV prevention services. All identified dimensions resulted in vulnerability, which influenced client health outcomes for those living with HIV infection.

Peretti-Watel and colleagues (2006) used a large data base of 1,809 heterosexual men and women and men who have sex with men (MSM) with HIV infection in France to study vulnerability. This quantitative study focused on the economic, social, and personal aspects of vulnerability. Heterosexual men ($OR = 1.44$, 90% $CI = [0.70-1.38]$) and women ($OR = 1.28$, 90% $CI = [0.70-1.38]$) were more likely to report material vulnerability such as money, food deprivation, and housing when compared to MSM ($OR = 0.99$; 90% $CI = [0.77-2.13]$). MSM and women ($OR = 1.44$, 90% $CI = [0.91-2.28]$) were more likely to express vulnerability in terms of discrimination, suicide attempts, and alcohol abuse when compared to heterosexual men ($OR = 1.11$; 90% $CI = [0.68-1.80]$). Female immigrants were more likely to be vulnerable to unsafe sex and non-adherence to medication therapy ($OR = 1.51$, 90% $CI = [0.95-2.53]$) when compared to both groups of men ($OR = 1.28$; 90% $CI = [0.77-2.13]$).

Lippman and colleagues (2007) conducted a qualitative study of people with HIV infection living in six cities on Brazil's borders. Individual interviews ($n = 430$), focus groups ($n = 75$), and direct observations ($n = 108$) were used. Data were used to explore the health care process of people living with HIV infection and to identify sources of vulnerability within a socio-cultural context. Five themes emerged from this study: lack of social cohesion, lack of mobilization, lack of government structure, economic inequity, and social division. Clients with HIV infection were vulnerable because of substandard medical care, disempowerment, alienation, isolation, and stigmatization.

Limited studies are available to document vulnerability in the context of HIV infection. A theory that describes the process by which vulnerability occurs in the context of HIV has not been developed; therefore, the purpose of this study was to develop a theory that described the process by which vulnerability occurs in the context of HIV infection.

METHOD

Design

Grounded theory was used to describe the process of vulnerability in the context of HIV infection. This type of qualitative research is used to generate a theory that explains an action, process, or interaction of phenomena (Creswell, 2007; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Grounded theory involves the process of collecting data, identifying categories or themes, connecting the categories or themes, and generating a

theory that explains the process of a phenomenon. The theory that is generated is an abstract description of a process that is grounded in the data (Glaser & Strauss, 1967).

Sample

A sample of adults ($n = 15$) with HIV infection was recruited using theoretical sampling. Theoretical sampling is the intentional sampling of a population with firsthand knowledge of the phenomena in order to generate a theory (Strauss & Corbin, 1990). Participants were recruited from the University of Miami's Adult Immunology Research Clinic. Each participant was compensated \$50 upon completion of the interview.

In order to participate in the study, participants had to meet eligibility criteria. Eligibility criteria included a diagnosis of HIV/AIDS; at least 18 years of age; and able to read, write, and speak English. The sample was comprised of 15 adults with HIV infection. This sample size was established by saturation of the data. Saturation is a subjective determination by the researcher that additional data will not result in new information, themes, or categories (Glaser & Strauss, 1967). In this study, saturation was achieved by the thirteenth interview, but two additional interviews were collected to ensure consistency among the data. Demographic data of the study participants is detailed in Table 1.

Data Collection

Data were collected using audio-recorded interviews that were conducted between August and December 2008. Data were collected using a semi-structured interview guide. Questions included in the interviews are included in Table 2. Consistent with grounded theory methodology, additional questions were added, deleted, or modified based on previous interviews (Creswell, 2007; Stauss & Corbin, 1990).

Interviews were 1 to 1.5 hours in length. Field notes were written at the completion of each interview. These were used to summarize the interview, list unanswered questions, and to describe the tentative themes (Mack, Woodson, MacQueen, Guest, & Namez, 2005). Interviews were then transcribed verbatim.

The study was conceptually based on the work of Rogers' (1997) concept analysis of vulnerability. Vulnerability included susceptibility to health problems, helplessness, requiring protection, and a loss of control that individuals experienced during transitions or life changes. Vulnerability also includes the person-environment interaction. Rogers (1997) defined vulnerability as an "experience that creates stress and anxiety which affects physiological, psychological, and social functioning" (p. 65). This conceptualization of vulnerability was used to guide the interview process and was the working definition used for this study.

Ethical Considerations

The study was approved by the University's Institutional Review Board. Participants signed an informed

TABLE 1
Demographic Characteristics of the Sample (N = 15)

Demographic	N
Age (range 24–61)	
20 to 29	1
30 to 39	0
40 to 49	3
50 to 59	9
More than 60	1
Years of Education (range 6–13.5)	
Less than high school diploma	5
High school diploma or equivalent	4
Some college	6
Number of Years since HIV Diagnosis (range 2–28)	
0 to 9 years	6
10 to 20 years	8
More than 20 years	1
Sex	
Female	8
Male	7
Race/Ethnicity	
Black	6
Hispanic	8
White	1
Employment Status	
Employed	2
Unemployed	6
Disabled	7
HIV Risk Factor	
High risk heterosexual contact	11
Intravenous drug use	2
Male-to-male sexual contact	1
Unknown	1
Currently Taking Medication Therapy for HIV Infection	
Yes	14
No	1
Most Recent CD4+ (T-cell) Count	
Above 200 cells/mm ³	9
Below 200 cells/mm ³	5
Unknown	1
Most Recent HIV RNA (Viral Load)	
Undetectable	8
Detectable	5
Unknown	2
Diagnosed Illnesses in Addition to HIV Infection	
Yes	10
No	5

TABLE 2
Interview Questions^a

- People with HIV infection may experience vulnerability because of HIV infection. Vulnerability is anything that causes stress and anxiety and affects the body (physiological), the mind (psychological), and relationships with others (social functioning).^b
- Tell me about time since you were diagnosed with HIV infection that you experienced vulnerability. (describing the phenomenon)
 - For people living with HIV infection, what does vulnerability mean? (describing the phenomenon)
 - For people living with HIV infection, where and when does vulnerability occur? (context of the phenomenon)
 - What promotes vulnerability? What inhibits vulnerability? (influences)
 - For people with HIV infection, how does vulnerability occur? (process of the phenomenon)
 - What happens to people with HIV infection who are experiencing vulnerability? (consequences of the phenomenon)

^aInterview questions are based on Grounded Theory methodology as described by Creswell (2007), Glaser and Strauss (1967), and Strauss and Corbin (1990).

^bBased on Rogers (1997).

consent that included permission to be audio-taped prior to participation.

Protection of confidentiality was an additional ethical concern. In order to protect confidentiality, participants were assigned a number upon enrollment. Participants were instructed not to provide names or any identifying information on the audio-tape so personal information would not appear on the transcripts. Consents were stored separately from the transcripts in a double-locked office.

To further ensure confidentiality, interviews were conducted in a private office free from interruption. Conduction of interviews in a private office was necessary not only to protect the confidentiality of the participants, but to ensure that participants felt safe in providing information about sensitive topics that emerged during the interviews, such as high risk sexual behaviors and substance abuse.

Data Analysis

The data were analyzed using content analysis. Transcribed interviews were read and analyzed by the first author using the constant comparative method (Glaser & Strauss, 1967). In the first level of analysis, open coding was used to group data into codes. Axial coding was then employed to group the first level

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codes into higher level themes and to explore the relationships among these themes. As each new transcript was read, it was constantly compared to analyzed interviews, which allowed data to be grouped in categories or themes and modified. Individual quotes from the interviews that supported categories and themes were identified to ensure that the data were not only credible, but that the theory was grounded in the data (Glaser & Strauss, 1967).

Rigor

Two methods were used to establish rigor and to minimize researcher bias during data analysis. These methods were clarifying researcher bias and peer review/debriefing (Creswell, 2007). Clarifying researcher bias is essential since the first author has extensive experience in providing care to this population of clients, which could have influenced the study results. In order to address this potential bias, the second author, who lacks clinical experience with this population, verified the categories and themes initially identified by comparing the themes and categories to the data.

Peer review/debriefing was conducted by having two nurse practitioners, who are certified specialists in HIV care and who are not affiliated with the HIV research center where the data were collected, to assist in confirmation of the findings. The results of the study as well as the study transcripts were made available to these two nurse practitioners to ensure that the analysis of the data was congruent with the nurse practitioners' clinical experiences. The comments made by the nurse practitioners were incorporated into the theory that was grounded in the data.

RESULTS

Participants provided rich descriptions of vulnerability in the context of HIV infection. Selected quotes from the interviews are included to illustrate the categories and subcategories of the theory. These descriptions illustrate the process of vulnerability in the context of HIV infection entitled *Living in Silence*. This process contains the categories of *Confronting Mortality and Illness*, *Struggling with Change*, *Encountering a Lack of Psychosocial Support*, and *Experiencing Vulnerability* (see Figure 1).

Confronting Mortality and Illness

Participants reported that the roots of vulnerability for people with HIV infection could be traced to two points in the disease trajectory: initial diagnosis or when diagnosed with an HIV-related illness. At diagnosis, participants reported feelings of susceptibility, risk for illness, denial of diagnosis, desiring to escape the diagnosis, fear that others who are not infected with HIV will never understand them, and doubt regarding the future and survivability. There was also a pervasive belief that life had been permanently altered.

The process of vulnerability could also begin upon diagnosis of a physical illness related to HIV infection. Regardless of whether vulnerability resulted from the initial diagnosis or a subsequent illness, the origination of the process of vulnerability in the context of HIV infection was summarized by one participant, a 61-year-old black female:

It [vulnerability] began when I got very, very sick. Like in 2003 I wasn't able to do anything for myself. I felt like everybody had to come in and do things for me. I couldn't walk my dog, I couldn't wash my dishes, I couldn't cook my food. I was in my bed and I couldn't get out. I got trapped in my bed and my bed was a prison. I couldn't get up and I was hurting. I was crying. I was screaming. Nobody heard me and I was trapped in my bed. I was trapped inside of myself, inside mentally and physically trapped. And what made it so bad I was scared. Scared to talk about it to my daughter. I was scared!

During this stage participants reported that the realization of the need to hide and conceal the diagnosis of HIV from others became evident. Not only was embarrassment and shame present, but participants also based the decision to conceal the diagnosis on observations of maltreatment of others with HIV infection in the communities where the participants lived. Embarrassment and shame related to the HIV diagnosis combined with the observed differential treatment of others with HIV infection provided the foundation for living in silence, as reported by the participants.

Struggling with Change

After being confronted with the initial diagnosis of HIV or an HIV-related illness, participants reported experiencing a number of changes that were physical, psychological, spiritual, and social in nature. Because these changes resulted in a significant amount of stress for the participants, this category was named *Struggling with Change*, and includes four subcategories.

Changing Physicality

Physical changes that resulted from HIV infection were easily identified by the participants. These physical changes were present throughout the disease process beginning with diagnosis, and were directly related to HIV infection, as well as the side effects of antiretroviral (ARV) therapy. Participants reported that they worried about physical health at diagnosis and during periods of physical illness related to HIV infection, as well as their ability to survive related to increased susceptibility to illness. The most common physical changes included weakness, loss of energy, and loss of physical strength. One participant, a 58 year old Black female described the physical changes that occurred to her body because of HIV infection:

When I walk it is not the same as before when I was ok [before diagnosis]. I had more energy. Maybe sometimes I have headaches. I feel nauseated. My stomach hurts because of all the medicines. I have pains in my legs and feet when I walk [HIV neuropathy]. It is more difficult for me and my body.

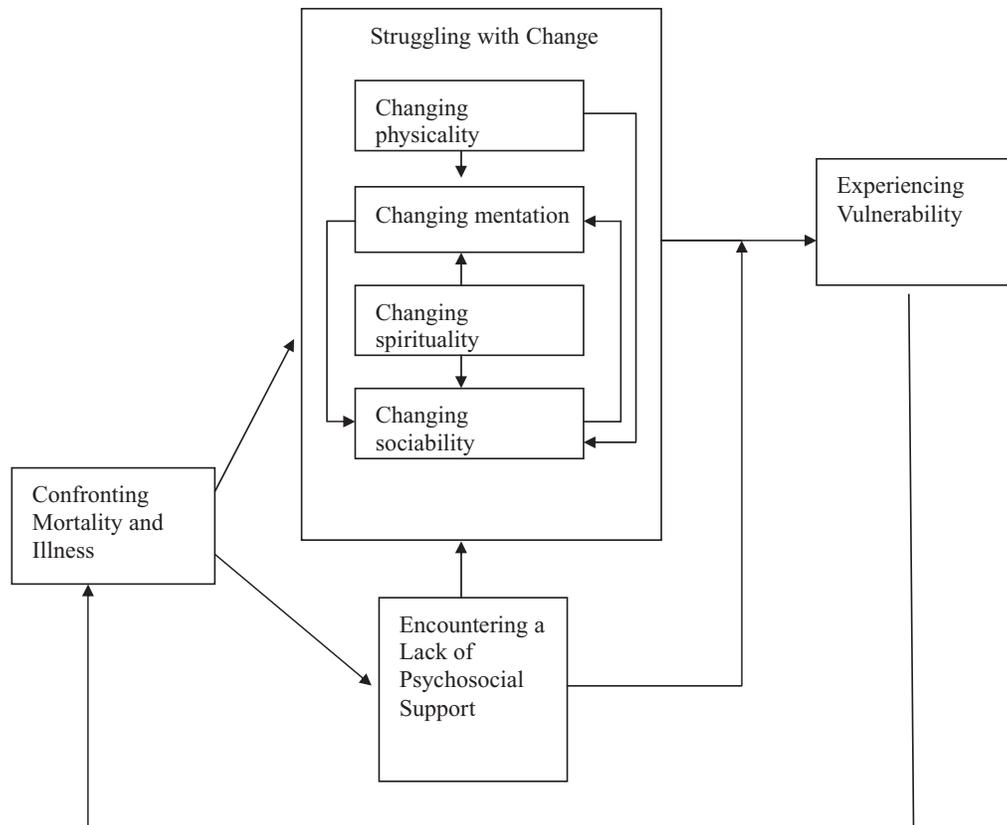


FIGURE 1 Living in Silence: A Theory of Vulnerability in the Context of HIV Infection

Nearly all of the participants were receiving ARV therapy for the treatment of HIV infection. Clients who had received ARV therapy for prolonged periods of time may be at increased risk of body habitus changes such as lypodystrophy. These changes were significant sources of vulnerability as described by one participant, a 54-year-old Hispanic male:

Like I had this hole in my face that could not be covered by glasses because it was indented . . . They [people in general] look at your face and you can see like, "I am sorry that you have HIV." By looking at your face they can read them [the changes in your body] and tell [that] you have HIV.

The physical change that most concerned the participants was weight loss. All participants reported unintentional weight loss at some point in the disease trajectory that was concerning. The concern regarding the weight loss stemmed from beliefs that unintentional weight loss was equated with illness, especially HIV infection. One participant, a 50-year-old Hispanic woman described her feelings regarding weight loss:

Sometimes you cannot gain weight. I could not gain weight. Like today, maybe I woke in a different way than I went last night to bed. Maybe today I say, 'Oh my God! What do I look like today? I look different from yesterday!'

Changing Mentation

All participants discussed the psychological changes that occurred related to HIV infection. Psychological distress was most common during initial diagnosis and was exacerbated during periods of illness that was related to HIV infection. Psychological distress was manifested most often as depression, as described by a 47-year-old Caucasian female:

Depression is something that if you don't know how to do it [deal with it], you will kill yourself. It breaks you down. It breaks down your self-esteem, which brings down everything, I think. You feel worthless. You are positive [infected with HIV] and so many things come to mind. "I have HIV, now what? How am I going to survive with HIV? Nobody will love me because I have HIV." That is terrible!

In addition to depression, participants stated that various emotions also occurred, including shame, self-pity, self-directed anger, frustration, worthlessness, negativity, decreased self-confidence, and insecurity. All participants voiced guilt that stemmed from behaviors that resulted in HIV infection like substance abuse and/or high risk sexual behaviors, and guilt related to the possibility of infecting others with HIV.

Depression and other emotions associated with HIV infection caused many of the participants to consider suicide. Active suicide was not an option for the participants, however, passive

suicide was a more reasonable alternative. Believing that death was inevitable from HIV infection, many participants reported becoming non-adherent to ARV therapy in order to hasten death. This process was described by one of the participants, a 55-year-old African-American female:

In my frustration I stopped all the meds. I stopped the HIV meds and all the other meds. I stopped everything that could keep me alive. I was waiting. I figured, you know, I am not going to jump off a building. I am not going to slash my wrists. I am just going to stop the meds, and something will turn up. Someone is going to wake up one morning and I will be gone. That was my idea.

Changing Spirituality

HIV infection resulted in changes in spirituality manifested as spiritual distress for the participants. All participants reported a belief in God or some higher power. When diagnosed with HIV or when confronted with an HIV-related illness, spiritual distress often resulted. This spiritual distress was ingrained in the pervasive belief that HIV infection was a punishment from God because of certain behaviors. Anger at God often ensued that resulted in a change in spirituality. Participants were also concerned that members of their religious congregations would become aware of their diagnosis. In order to conceal their diagnosis, participants reported disengagement from religious services and congregations. One participant, a 58-year-old Black female described the spiritual distress that resulted after she disclosed her diagnosis to her religious leader:

I found out I had it [HIV], and I told my pastor. I remember that the preacher said that "God gave the daughter HIV" and I feel that God has punished me or something like that. I am being punished. I was angry at God. And I don't feel God reaching deep into me yet because of this illness.

Changing Sociability

Participants reported a number of social changes related to HIV infection. This subcategory was named Changing Sociability. Once diagnosed with HIV infection, participants reported rejection, discrimination, stigma, and isolation. Many participants initially attempted to disclose their diagnosis to support systems, but this often resulted in verbal abuse, humiliation, and withdrawal of support. In order to avoid these reactions, participants chose to conceal their diagnosis. One participant, a 50-year-old Hispanic male, described the social changes that resulted from living with HIV:

If my [present] landlord found out that I had it we would probably be, well, somehow he would find a way to evict us. If your neighbors found out, it would be hard to live there anymore. So you hide from your neighbors. Your whole life is deceit. You tell your friends, your family, and that doesn't always work out to your advantage because they are afraid of you. So you don't tell anyone. You keep everything to yourself.

Within the category of Struggling with Change a number of relationships among the subcategories were noted. Depression

and anxiety that was experienced by participants was further impacted by physical changes that were occurring because of HIV infection. When physical changes such as weight loss occurred, many participants reported that they became overly concerned about physical appearance and discontinued social contact with psychosocial support networks, which contributed to further isolation and decreased psychosocial support.

A cyclical relationship was noted between mental health and sociality. As with any client who experiences depression, participants reported a tendency to isolate and decrease contact with family members and friends. As these social networks are lost, participants were at risk for declining mental health. As mental health continued to deteriorate, opportunities for psychosocial support through social networks also decreased.

Spiritual changes were related to mental health and sociability. Participants experienced spiritual changes and because participants relied on spirituality as a form of psychosocial support, participants were at risk for depression and isolation because of the severance of the relationships from religious networks. Without these psychosocial support networks, participants reported depression from detachment from spirituality, support networks, and from God, which often resulted in spiritual distress.

The physical, psychological, social, and spiritual changes experienced by clients further compounded the need for living in silence. The loss of physical and mental health and changes in social relationships and spirituality that were experienced by participants caused further isolation as participants attempted to avoid stigmatization and discrimination.

Encountering a Lack of Psychosocial Support

Participants reported that the physical, psychological, spiritual, and social changes that occurred because of HIV infection were significant life stressors, but these stressors could be managed if psychosocial support systems were available to mitigate the stress of living with HIV. Psychosocial support frequently was not available because support systems were severed or damaged when participants disclosed their diagnosis, or participants concealed their diagnosis and therefore could not access support systems. Either way, the lack of psychosocial support encountered by the participants was distressing, as described by one participant, a 52-year-old Hispanic female:

Even my family stopped helping me. I asked my daughter to rub my back [because of pain], and she was afraid to touch me, you know? I was dirty to everyone. She would not let my grandkids around me. It was awful! [It was] like I had leprosy, tainted. I lost all my support. Everyone disappeared. I was all alone.

The lack of psychosocial support that participants encountered provided an additional reason to live in silence. Based on past experiences of disclosing and in observing others disclose the diagnosis of HIV infection and receive negative reactions from support systems, participants reported that it was easier and less stressful for them to live in silence.

Experiencing Vulnerability

During the interviews, participants reported a number of consequences of vulnerability for people infected with HIV. Vulnerability perpetuated denial. Denial then impacted adaptive coping with their diagnosis of HIV as well as with the physical, psychological, spiritual, and social changes that occur in the lives of those infected. Maladaptive coping may include returning or turning to substance abuse. In addition to substance abuse, the vulnerable person with HIV is at risk for anxiety and depression, as well as the progression of HIV infection to AIDS.

Vulnerability also impacts adherence to ARV therapy and medical care. Ultimately, the vulnerable person with HIV infection, according to the participants, will be unable to function and care for themselves.

An additional consequence of vulnerability is self-silencing. When an individual engages in self-silencing, the person suppresses or conceals their feelings and needs and is unable to self-advocate or to seek support. Eventually the vulnerable person with HIV infection will continue to withdraw until illness or death results. One participant, a 47-year-old Caucasian female summarized the consequences of vulnerability for people with HIV infection:

Vulnerability makes us lose our health. Vulnerability can isolate you, especially if you live at home, have no social support, and no one to talk to, which I think is crucial. We need support, 'cause if you have no one to talk to, you keep everything inside and it's not healthy. It hurts your body physically. It hurts your mind. It hurts your attitude. You don't have anybody to help you or to remind you to take your medicines. You may start drinking alcohol because you're depressed or to forget about everything or do drugs, or whatever it is 'cause a lot of people do that. That's what vulnerability does to you. It destroys you because you're not going to take care of yourself. You're going to try and be in denial about it and you're gonna try and live without people seeing you that you're sick. Without help or understanding of the disease, you're gonna hurt yourself. That's basically what it comes down to. And that's from experience, I know that.

As participants experienced the consequences of vulnerability such as denial, maladaptive coping, substance abuse, non-adherence to ARV therapy, and disease progression, participants were once again confronted with mortality and additional illnesses. This continued or perpetuated the cycle of vulnerability in the context of HIV infection.

DISCUSSION

The study is the first grounded theory study of vulnerability in the context of HIV infection. From this theory, a definition of vulnerability in the context of HIV infection emerged. Vulnerability in the context of HIV infection is the process by which a person with HIV infection is initially confronted with the diagnosis of HIV infection, or diagnosed with an HIV-related illness in the absence of psychosocial support that is influenced by HIV-related stigma. The physical, psychological, spiritual, and social changes that result from HIV infection lead to the

subjective experiences of vulnerability, which renders the client at risk for additional negative health outcomes. For clients with HIV infection, vulnerability includes perceptions of susceptibility, weakness, helplessness, defenselessness, risk, stigma, and marginalization depending on the situational factors that occur at points during the disease trajectory.

When confronted with the initial diagnosis or an HIV-related illness, people with HIV infection often lack psychosocial support because of stigma and marginalization. Psychosocial support is essential to buffer the effects of illness, but if psychosocial support is not available, clients may become helpless and defenseless. The loss of psychosocial support combined with the physical, psychological, social, and spiritual changes that have occurred may result in physical weakness, psychological helplessness, social isolation, and spiritual distress, which place clients at risk for increased physical and psychological morbidity. This entire process is influenced by the stigma and marginalization experienced by people living with HIV infection.

The various forms that vulnerability assumes during each of the stages of the theory are consistent with the work of Rogers (1997). The concept of vulnerability contains many attributes and meanings such as susceptibility, helplessness, needing protection, and loss of control. These attributes and meanings are related to the abstract nature of vulnerability (De Santis, 2008), and are influenced by situational factors (Rogers, 1997) that are experienced by people with HIV infection. For example, at diagnosis and during periods of illness, clients' perceptions of vulnerability may equate to susceptibility. While during other phases of the disease process, vulnerability may equal risk or weakness. The multiple aspects of vulnerability and the situational factors that clients with HIV infection encounter are probably related to the changing perceptions, meanings, and experiences of vulnerability in the context of HIV infection.

The results of the study contain implications for nurses and other health care professionals who provide care to clients with HIV infection. Participants discussed the periods of time during the initial diagnosis and times of physical illness as the origin of vulnerability. The time period of initial diagnosis was especially challenging for participants, as they were confronted with a potentially fatal, stigmatizing illness that resulted in decreased psychosocial support that forced them to deal with their diagnosis in silence and without psychosocial support. At this point, vulnerability equates to susceptibility and risk for subsequent morbidity and possible mortality.

Perceptions of vulnerability were intensified during periods of physical, but not psychological, illness. This finding was interesting because participants identified both physical and psychological changes that resulted from HIV infection. One possible explanation for this contradiction may be rooted in the nature of HIV as it was manifested in the early days of the epidemic. HIV-related physical changes often were expressed as changes in physical appearance (i.e., weight loss) and were indicators of advancing disease (Cabrero, Griffa, & Burgos, 2009;

Reynolds, Neidig, Wu, Gifford, & Holmes, 2006). Because psychological changes are more easily concealed, clients with HIV infection may only be concerned about the physical changes associated with HIV infection, as these are easily visible to others and may cause the client to feel more vulnerable than psychological changes would cause.

The results of this study are congruent with the literature on vulnerability in the context of HIV that documents the physical (Ayers et al., 2006), psychological (Ayers et al., 2006; Peratti-Watel et al., 2006), and social aspects of vulnerability (Ayers et al., 2006; Lippman et al., 2007; Peratti-Watel et al., 2006; Van Servellen et al., 2002). In addition, the physical changes (Sharma, Howard, Schoenbaum, Buono, & Webber, 2006) combined with the psychological changes increase the risk of suicide (Chander, Himelhoch, & Moore, 2006). Social changes, including isolation, stigma, and discrimination that occur related to HIV are well-documented in the literature (Holzemer et al., 2009; Relf, Mallinson, Pawlowski, Dolen, & Dekker, 2005).

None of the previous research studies on vulnerability in the context of HIV included spirituality as a component of vulnerability, although a number of studies have documented spirituality in the context of HIV (Litwinczuk & Groh, 2007; Lorenz et al., 2005; Vance, Struzick, & Raper, 2008). From the interviews, spiritual changes are an important component of vulnerability in the context of HIV. Previous research on vulnerability in the context of HIV infection neglected to identify changes in spirituality that may result from HIV infection (Ayers et al., 2006; Lippman et al., 2007; Peratti-Watel et al., 2006; Van Servellen et al., 2002). With the inclusion of spiritual changes, a more holistic view of vulnerability in the context of HIV has emerged.

The consequences of vulnerability in the context of HIV provide some of the most clinically-relevant information for mental health nurses and other professionals who work with clients with HIV infection. Vulnerability has the potential to further compound physical and psychological health. Crucial periods of vulnerability include the time of initial diagnosis and times of physical illness, however, clients who lack psychosocial support are also at risk for the consequences of vulnerability. The influence of psychosocial support on clients with HIV infection to cope with their illness is well-documented (Grant, Prachakul, Pryor, Keltner, & Raper, 2009). Clients need thorough assessments of available psychosocial support. When support is not available or is not functional, referrals to support groups for clients with HIV infection may be necessary to assist clients in adapting to and coping with their diagnosis. Although support groups can never replace support that clients would receive from closer support systems, when these support systems are not available or when the client chooses not to disclose their diagnosis to their support systems, support groups may be a source of support for these clients (Walch, Roetzer, & Minnett, 2006).

The importance of psychosocial support in mitigating the physical, psychological, social, and spiritual attributes of vulnerability highlights the essential nature of psychosocial support

for people living with HIV infection. If psychosocial support is available, clients with HIV infection may be able to cope with and to adapt to the numerous changes that occur because of HIV infection. One of the most imperative interventions in the care of people living with HIV infection is psychosocial support. Clients can be instructed on the importance of accessing sources of psychosocial support including family, friends, and support groups (Walch et al., 2006).

Because of the chronic, manageable nature of HIV infection, current care of clients with HIV infection is focused on health promotion. Preventing illness and maximizing wellness within the context of a chronic illness is essential in preventing adverse health outcomes. Vulnerable clients with HIV infection may be at risk for physical and psychological health conditions including substance abuse (Chander et al., 2006), and those clients who lack psychosocial support may be at an increased risk of these health conditions (Grant et al., 2009). Mental health nurses and other health care providers who work with this population need to conduct thorough physical, psychological, and substance abuse assessments of clients so that health problems are identified and appropriate treatment is initiated to minimize the impact on the client's health.

If clients adhere to the medication regimen, HIV is a chronic, manageable illness. Adherence to the medication regimen is essential in controlling viral replication and disease progression. Non-adherence to ARV therapy may result in increased morbidity and mortality and impact the quality of life for people infected with HIV (Simoni et al., 2005). Adherence to ARV therapy is often a problem for clients with HIV infection (Simoni et al., 2005). Because participants reported that non-adherence to ARV therapy is a consequence of vulnerability, clients who are non-adherent may require additional education or psychosocial support to assist them with medication adherence.

A number of overlaps were noted among the categories and subcategories of the theory. This overlap is most pronounced concerning psychosocial support and social aspects of HIV infection. This overlap is most likely related to the profound impact of HIV-related stigma on social relationships and on the physical and mental health of people with HIV infection (Logie & Gadalla, 2009). Because HIV-related stigma has the potential to influence numerous aspects of health among people living with HIV infection, stigma should overlap into the various categories and subcategories of the theory.

Directions for further theory development can be drawn from the results of the study. The next logical step would be to design a quantitative study that would be used to test this theory as a middle-range descriptive theory that could further explain the process by which vulnerability occurs, and to explore the health-related consequences of vulnerability in the context of HIV infection (Fawcett, 1999).

In addition to theory development, directions for future research can be drawn from the results of the study. In light of the fact that in this study notes that vulnerability influences

health outcomes for people with HIV infection, more research is warranted. A method to assess or screen for vulnerability can be developed as an instrument or scale to assess the impact of vulnerability on health outcomes.

LIMITATIONS OF THE STUDY

This study was designed to develop a theory that describes the process of vulnerability in the context of HIV infection. There are a few limitations that need to be addressed. Recruitment of participants may have influenced the results. The sample was drawn from participants who receive services from a university-based HIV clinical research unit. All participants in this study have previous experience with HIV-related research and may be “research-experienced,” which may have influenced the results. Regardless of these limitations, the findings of this study are congruent with previous research and even provide some new information to the knowledge base of vulnerability in the context of HIV infection.

SUMMARY

Clients with HIV infection experience vulnerability from numerous sources. From the interviews, a theory that describes that process by which vulnerability occurs in the context of HIV infection has been developed that is grounded in the qualitative data. The results of this study add depth to the knowledge base of vulnerability in the context of HIV infection. With the inclusion of the spiritual changes that may result because of HIV infection and the role of psychosocial support in decreasing the effects of vulnerability, a more complete description of vulnerability emerged. Although the results of this study have provided information that fills some gaps in the knowledge base, more theoretical and empirical work is necessary to fully understand vulnerability in the context of HIV infection.

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REFERENCES

- Aranda-Naranjo, B. (2004). Quality of life in the HIV-positive patient: Implications and consequences. *Journal of the Association of Nurses in AIDS Care, 15*, 270–275.
- Ayers, J. R., Paiva, V., Franca, I., Gravato, N., Lacerda, R., Della Negra, M., et al. (2006). Vulnerability, human rights, and comprehensive health care needs of young people living with HIV/AIDS. *American Journal of Public Health, 96*, 1001–1006.
- Cabrero, E., Griffla, L., & Burgos, A. (2009). Prevalence and impact of body physical changes in HIV patients treated with highly active antiretroviral therapy: Results from a study on patient and physician perceptions. *AIDS Patient Care and STDS, 24*(1), 5–13.
- Chander, G., Himelhoch, S., & Moore, R. D. (2006). Substance abuse and psychiatric disorders in HIV-positive patients: Epidemiology and impact on antiretroviral therapy. *Drugs, 66*(6), 769–789.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- De Santis, J. (2008). Exploring the concepts of vulnerability and resilience in the context of HIV infection. *Research and Theory for Nursing Practice, 22*(4), 273–287.
- Fawcett, J. (1999). *The relationship of theory and research* (3rd ed.). Philadelphia, PA: F. A. Davis Company.
- Flaskerud, J. H., & Winslow, B. J. (1998). Conceptualizing vulnerable populations health-related research. *Nursing Research, 47*(2), 69–78.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Hawthorne, NY: Aldine.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*, 105–112.
- Grant, J. S., Prachakul, W., Pryor, E. R., Keltner, N. L., & Raper, J. L. (2009). Sources of functional social support provided to people with HIV. *Journal of Nursing & Healthcare of Chronic Illnesses, 1*(4), 331–338.
- Holzemer, W. L., Human, S., Arudo, J., Rosa, M. E., Hamilton, M. J., Corless, I., et al. (2009). Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the Association of Nurses in AIDS Care, 20*(3), 161–168.
- Kartikeyan, S., Bharmal, R. N., Tiwari, R. P., & Bisen, P. S. (2007). *HIV and AIDS: Elements and priorities*. Netherlands: Springer.
- Lippman, S. A., Kerrigan, D., Chinaglia, M., & Diaz, J. (2007). Chaos, co-existence, and the potential for collective action: HIV-related vulnerability in Brazil's international borders. *Social Science & Medicine, 64*, 2464–2475.
- Litwinczuk, K. M., & Groh, C. J. (2007). The relationship between spirituality, purpose in life, and well-being in HIV-positive persons. *Journal of the Association of Nurses in AIDS Care, 18*(3), 13–22.
- Logie, C., & Gadalla, T. M. (2009). Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care, 21*(6), 742–753.
- Lorenz, K. A., Hayes, R. D., Shapiro, M. F., Cleary, P. D., Asch, S. M., & Wenger, N. S. (2005). Religiousness and spirituality among HIV-infected Americans. *Journal of Palliative Medicine, 8*(4), 774–781.

- Mack, N., Woodson, C., MacQueen, K. M., Guest, G., & Namez, E. (2005). *Qualitative research methods: A data collector's field guide*. Research Triangle Park, NC: Family Health International.
- Macklin, R. (2003). Bioethics, vulnerability, and protection. *Bioethics*, 17(5-6), 472-486.
- Peretti-Watel, P., Spire, B., Schiltz, M. A., Bouhnik, A. D., Heard, I., Lert, F., et al. (2006). Vulnerability, unsafe sex, and non-adherence to HAART: Evidence from a large sample of HIV/AIDS outpatients. *Social Science & Medicine*, 62(10), 2420-2433.
- Relf, M. V., Mallinson, K., Pawlowski, L., Dolen, K., & Dekker, D. (2005). HIV-related stigma among persons attending an urban HIV clinic. *Journal of Multicultural Nursing & Health*, 11(1), 14-22.
- Reynolds, N. R., Neidig, J. L., Wu, A. W., Gifford, A. L., & Holmes, W. C. (2006). Balancing disfigurement and fear of disease progression: Patient perceptions of HIV body fat redistribution. *AIDS Care*, 18(7), 663-673.
- Rogers, A. C. (1997). Vulnerability, health and health care. *Journal of Advanced Nursing*, 26, 65-72.
- Sharma, A., Howard, A. A., Schoenbaum, E. E., Buono, D., & Webber, M. P. (2006). Body image in middle-aged HIV-infected and uninfected women. *AIDS Care*, 18(8), 998-1003.
- Simoni, J. M., Kurth, A. E., Pearson, C. R., Pantalone, D. W., Merrill, J. O., & Frick, P. A. (2005). Self-report measure of antiretroviral adherence: A review with recommendations for HIV research and clinical management. *AIDS and Behavior*, 10, 227-245.
- Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA: Sage.
- Van Servellen, G., Chang, B., & Lombardi, E. (2002). Acculturation, socioeconomic vulnerability, and quality of life in Spanish-speaking and bilingual Latino HIV-infected men and women. *Western Journal of Nursing Research*, 24(3), 246-263.
- Vance, D. E., Struzick, T. C., & Raper, J. L. (2008). Biophysical benefits of spirituality in adults aging with HIV: Implications for nursing practice and research. *Journal of Holistic Nursing*, 26(2), 119-125.
- Walch, S. E., Roetzer, L. M., & Minnett, T. A. (2006). Support group characteristics among persons with HIV: Demographic characteristics and perceived barriers. *AIDS Care*, 18(4), 284-289.
- World Health Organization. (2009). *World health statistics 2009*. Geneva, Switzerland: World Health Organization Press.