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Exploring the Concept of HIV-Related Stigma

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Abstract

BACKGROUND—HIV infection is a chronic, manageable illness. Despite advances in the care and treatment of people living with HIV infection, HIV-related stigma remains a challenge to HIV testing, care, and prevention. Numerous studies have documented the impact of HIV-related stigma among various groups of people living with HIV infection, but the concept of HIV-related stigma remains unclear.

PURPOSE—Concept exploration of HIV-related stigma via an integrative literature review was conducted in order to examine the existing knowledge base of this concept.

METHODS—Search engines were employed to review the existing knowledge base of this concept.

CONCLUSION—After the integrative literature review, an analysis of HIV-related stigma emerged. Implications for future concept analysis, research, and practice are included.

Keywords

AIDS; concept analysis; HIV; stigma

Introduction

In the United States, over 1 million people are living with HIV infection (Centers for Disease Control and Prevention [CDC], 2008). Men who have sex with men (MSM) are currently at greatest risk of acquiring HIV, as this group composes nearly half of the total number of HIV cases (48.1%) (CDC, 2008). Second in terms of risk for acquisition are individuals engaging in high-risk heterosexual contact who make up 27.6% of all HIV/AIDS cases, whereas persons using injection drugs make up the third highest risk category (18.5%) of all HIV/AIDS cases (CDC, 2008).

Racial and ethnic minorities experience a disproportionate number of HIV infections in relation to their total numbers in the United States. Despite making up only 12% of the population, African Americans compose nearly half (46%) of all individuals living with HIV in the United States (CDC, 2010a). Hispanic Americans are similarly affected. At 15% of the population, Hispanic Americans compose 17% of all individuals living with HIV in the United States (CDC, 2010a).

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Nationwide, more than 2,000 professional nurses are formally engaged in HIV care (Association of Nurses in AIDS Care, n.d.). In addition, countless family members and friends provide care to people living with HIV infection. These healthcare providers and informal caregivers may be affected by HIV via various means because of their close proximity to individuals living with HIV infection.

HIV treatment and testing advances have shifted HIV infection from an acute to a chronic disease, allowing for an increased lifespan for individuals who test and enter treatment early in the disease process (CDC, 2006). However, stigma is a recurring challenge to HIV testing, care, and prevention (Office of National AIDS Policy, 2010), and may be compounded by the unique effects of stigma among persons belonging to traditional high-risk groups. Stigma associated with gay identification and resultant social discrimination may present difficulties in HIV prevention intervention design and implementation (CDC, 2010b). Black and Hispanic men may be unable to self-identify as gay because of cultural factors (Flores, Mansergh, Marks, Guzman, & Colfax, 2009; Mimiaga et al., 2009), and consequently do not participate in interventions delivered to gay communities. Some black men may self-identify as heterosexual even while engaging in same-sex activities, because of homophobia and stigma (Jerome & Halkitis, 2009). Hispanic MSM may be unable to disclose sexual orientation because of unique Hispanic cultural factors or because family members express negative beliefs regarding MSM (Finlinson, Colón, Robles, & Soto, 2006).

Women also experience HIV-related stigma. In addition to an increased susceptibility to HIV infection caused by biological differences, women experience social differences and gender disparities that present prevention challenges. Included may be the inability to negotiate condom use or to ask about a partner's high-risk behaviors (Billy, Grady, & Sill, 2009).

As an important concept in HIV treatment and prevention, HIV-related stigma has been examined. However, the concept comprises a number of components, and differs by country (Herek et al., 1998). The purpose of this integrative literature review is to explore the concept of HIV-related stigma as experienced by individuals affected by HIV/AIDS, defined as persons living with HIV, intimately involved with or related to someone living with HIV, or caring for individuals living with HIV in the United States. A clearer understanding of HIV-related stigma is the foundation for development of interventions that address HIV-related stigma.

The Importance of Concept Exploration

Concepts form the foundation of a theory. A theory provides a depiction of the relationships or interrelationships among concepts. The development of concepts is important in order to expand nursing knowledge, as concept development is a form of nursing inquiry that expands and develops the knowledge base of nursing and related disciplines (Rodgers & Knafl, 2000).

Concepts are generally abstract, and in order for nurses to understand and use concepts in clinical practice, clear definitions of concepts are necessary. Vague terminology, vague definitions, ambiguous definitions, inconsistencies among definitions, and inconsistent use of concepts inhibit the usefulness of concepts. Concept development is essential to develop clarity and precision in the concept's definition. With clarity and precision, the concept's essence can manifest. A concept's essence is the boundaries, context, and domain of the concept (Rodgers & Knafl, 2000).

Even when concepts have been developed, clearly defined, and are shown to be clinically useful, concepts development is never fully completed. This is rooted in the premise that

concepts are dynamic, infinite, change and evolve over time. Concepts are also influenced by history, breakthroughs in clinical care and treatment, and the emergence of new health conditions and diseases. These facts provide support for continual development and refinement of concepts (Rodgers & Knafelz, 2000), by using the integrative literature review to understand and perhaps clarify the concept of HIV-related stigma.

Method

An integrative literature review for the development of concepts (Broome, 2000) was used to gain an in-depth understanding of HIV-related stigma by reviewing previous research.

This method of concept development is based on the principle that concept development requires knowledge of previous research, is focused on methods and limitations of previous work, and seeks to explore unanswered questions (Broome, 2000).

An integrative literature review for concept development gathers theoretical, methodological, critical, and integrative reviews using computerized search engines. Questions guiding the integrative literature review include: (a) how has the concept been previously defined?; (b) what perspectives have been used to study the concept?; (c) how can previous work be expanded?; (d) what relationships exist between the concept of interest and other concepts?; (e) and what research methods have been used to study the concept? (Broome, 2000).

This method of concept development requires an organized approach in order to provide a critical evaluation of previous work. Methods are detailed to assist in evaluating the rigor of each study and deciding whether to include or exclude the study in the review. Each included study can be coded to analyze the quality of the study by reviewing research questions, sampling techniques, and results. Evaluating each study's rigor is necessary to determine the usefulness of the study for inclusion in the integrative literature review (Broome, 2000).

An integrative literature review for concept development was used to examine the existing knowledge base of HIV-related stigma. Research studies conducted in the United States that focused on HIV-related stigma from the years of 2000 to 2010 were included in the review, which included the advent of widespread anti-retroviral therapy use in the United States (CDC, 2010c). Literature from nursing and related disciplines was included so that a comprehensive conceptualization of HIV-related stigma can be explored. The integrative literature review used the search engines of PubMed, CINAHL Plus, and PsychInfo. Key search terms included HIV-related stigma, HIV related stigma (without hyphen), AIDS-related stigma, adults, older adults, people living with HIV/AIDS, gay men, bisexual men, MSM, women, caregivers, African Americans, Hispanics, and healthcare providers.

Findings on HIV-Related Stigma as Experienced by Those Affected by HIV

Many of the researchers identified in the following literature review cite or derive definitions of HIV- or AIDS-related stigma from the work of Erving Goffman (1963), who defined stigma as an attribute or characteristic that is profoundly discrediting to the individual possessing the attribute or characteristic. A distinction is made between *discrediting*, meaning others perpetrate stigma, and *discreditable*, in which case a person is dishonorable or of disreputable character (Goffman, 1963). A substantial discrepancy may exist between how people view themselves and the views of others. Goffman termed this discrepancy *virtual and actual identity*, and believed this inconsistency negatively influenced one's social identity, leading to social isolation. The issue of greatest concern to the stigmatized individual is *acceptance* (Goffman, 1963).

Influenced by Goffman, Herek (2002) defined stigma as a lasting, negatively valued circumstance, status, or characteristic that discredits and disadvantages individuals. Herek's (2009) definition of AIDS-related stigma is stigma directed at people living with HIV/AIDS (PLWHA) and/or associated with PLWHA. Stigma is manifested through four factors: *prejudice, discounting, discrediting, and discrimination* (Herek, 2009). The differences between prejudice and discrimination are delineated by Herek. Prejudice is defined as a judgment against a group, whereas discrimination is an act or a behavior (Herek, 2002). These attitudes and behaviors, as manifestations of stigma, create extensive damage to stigmatized persons.

HIV-Related Stigma Experienced by People Living With or Affected by HIV Infection

A review of the literature concerning stigma experienced by people living with or affected by HIV infection reveals variation in sources of stigma and in the manner in which stigma is experienced. Studies suggest HIV-related stigma may be experienced by individuals either externally and internally simultaneously, or stigma may be experienced externally or internally separately.

HIV-Related Stigma Experienced by Individuals and Families

In a grounded theory study ($n = 26$) of adults living with HIV, Block (2009) found participants experienced felt stigma (the fear of stigmatization or discrimination; Scambler, 1998) and enacted stigma (actual experiences of negative behaviors, such as discrimination; Scambler, 1998). Participants responded to felt stigma by choosing to either not disclose their HIV serostatus or to devise a systematic method for disclosure (i.e., when, how and whom to disclose status). Participants reported being rejected and blamed for their serostatus, and felt shame, loneliness, and anger in response to poor treatment by others (Block, 2009).

HIV-related stigma experienced from both external and internal sources by people living with HIV and their families ($n = 61$) was explored qualitatively by Bogart et al. (2008). Felt, enacted, and courtesy stigma were described by participants. Felt stigma was most exemplified by a fear of disclosure of HIV serostatus, in anticipation of resultant discrimination, as well as by fear of discrimination against children of parents living with HIV, and secrecy, prejudice, fear, isolation, ostracism and lack of support. Enacted stigma included discrimination in the forms of rejection, verbal insults, and ostracism perpetrated by family members and friends, and was manifested as avoidance related to fears of infection, judgment, and an inability to understand why spouses or caregivers would choose to remain with people living with HIV. Courtesy stigma (stigma caused by an association with an individual living with a stigmatizing condition) was experienced by participants' children via avoidance by friends and family members because of unfounded fears of infection. In addition, many people living with HIV and their families themselves experienced initial internalized negative attitudes regarding HIV, but later became more accepting of individuals living with HIV after becoming better educated about HIV (Bogart et al., 2008).

Rao, Pryor, Gaddist, and Mayer (2008) assessed whether cultural differences existed in terms of responses to the Berger HIV Stigma scale for black ($n = 224$) and white ($n = 317$) adults. Although one group was not found to feel more stigmatized than the other, the groups reported experiencing HIV-related stigma differently. Black individuals living with HIV were more concerned with discrimination and being judged in terms of their morals,

whereas white individuals living with HIV were more concerned with rejection (Rao et al., 2008).

In a qualitative study of low income men and women living with HIV ($n = 48$) exploring stigma, Sayles, Ryan, Silver, Sarkisian, and Cunningham (2007) identified four domains of HIV-related stigma related to blame and stereotypes, fear of infection, disclosure, and social contracts. *Confronting blame and stereotypes of HIV* included participant descriptions of self-blame for their HIV serostatus, in addition to blame from family, friends, strangers, and healthcare providers. Stereotypes included contraction of the disease through unacceptable behavior or sexual orientation. *Encountering fear of contagion* included the unfounded fear others have of contracting HIV via casual contact with individuals living with HIV infection. *Negotiating disclosure of a stigmatized role* included participants' concerns about disclosure, of assessing the risks and benefits of disclosure, and fear of rejection. *Renegotiating social contracts* involved finding safe environments and avoiding unsafe places, deemed places individuals living with HIV were likely to find judgmental people. These places often led those living with HIV to resort to withdrawal and isolation (Sayles et al., 2007).

Among individuals living with HIV, using illicit substances and attempting to restructure their lives while taking antiretroviral therapy, Ware, Wyatt, and Tugenberg (2006) found several themes emerged during qualitative exploration of these issues ($n = 52$). *Social marginalization* included marginalization caused by homelessness, past incarceration, mental illness or disability, as well as participants' shame caused by drug use, or isolation from the gay community because of serostatus. *Loneliness and the desire for connection* included increased fear of rejection, while attempting to establish relationships, caused by disclosure of HIV serostatus. To avoid this, some participants went to great lengths to hide their serostatus (e.g., avoiding HIV-identified housing or long commutes to pharmacies to avoid being seen). *Fear of disclosure and adherence* included the conflict between medication adherence and disclosure; some participants dealt with medication issues by telling others the medications were needed for other health issues besides HIV (Ware et al., 2006).

In the qualitative portion of a mixed methods study examining gender and depression among men and women living with HIV ($n = 21$), Lichtenstein, Laska, and Clair (2002) reported some highly depressed participants were socially isolated, in part caused by stigma. Others reported having been rejected by family and friends, and some did not disclose their serostatus because of fear of rejection, or in an attempt to protect their families from distress (Lichtenstein et al., 2002).

HIV-Related Stigma Experienced by Older Adults

Older adults have reported experiences with various aspects of HIV-related stigma. In a mixed method study examining HIV-related stigma, Emler (2007) found rejection, fear of infection, and social isolation were components of personalized stigma, as participants reported experiencing rejection by friends, family, and religious communities. One participant told of his physician's fear of HIV infection. While performing a hip replacement on the participant, the physician sustained a needle stick, and one of the first issues discussed at the participant's follow-up appointment was this incident, causing the participant to feel as if he needed to apologize to the physician. Other participants felt socially isolated as a result of their HIV serostatus, whereas others reported negative self-image. One participant described feeling as if he were "radioactive" (Emler, 2007). Secrecy, or disclosure concerns, emerged as another related issue. Silence regarding HIV status was used to protect participants from anticipated discrimination and stigma. Having to eventually disclose HIV serostatus was a cause of concern for participants. For some, the hope of

support from others or beginning a relationship created a need to disclose, but included a fear of the reaction or backlash that disclosure might elicit (Emlet, 2007). In addition, stereotyping due to age was another source of stigma for these participants. Some individuals expressed frustration with attitudes expressed by healthcare providers, such as older people should “know better” than to acquire HIV (Emlet, 2007).

In a mixed methods study ($n = 24$), Foster and Gaskins (2009) found that among older African Americans living with HIV, internalized shame was the only type of stigma these participants reported experiencing. Participants reported taking great care in choosing to whom they disclosed their serostatus, and participants concealed their status from others at places of worship. Many reported having no friends, and keeping to themselves, but not experiencing stigma directly. These participants reported overhearing insensitive comments made by others about people living with HIV infection, and one man reported learning to “hold his head high” when he heard these conversation so no one would suspect him as living with HIV (Foster & Gaskins, 2009).

HIV-Related Stigma Experienced by Women

Buseh and Stevens (2006) qualitatively examined HIV-related stigma among African American women living with HIV ($n = 29$), who experienced existential despair, shunning, and institutional disregard. Existential despair, a component of internal stigma, caused participants to experience feelings of receiving a notice of certain death upon learning of the diagnosis of HIV. Additional elements of internal stigma were selfblame and shame, as participants described refusing to touch anyone, hiding, and feeling as if becoming infected with HIV was something that was deserved due to past behaviors. Participants experienced shunning, insensitive treatment, and rejection by others and rumors about participants led to self-imposed social isolation. Institutional disregard referred to the perception that staff in hospitals or other institutions such as prisons treated participants with disrespect. In some cases, disclosure was an issue, as staff revealed participants’ HIV serostatus to others without the participants’ permission.

In a qualitative study designed to understand disclosure of HIV status among African American women ($n = 109$), Black and Miles (2002) found these women carefully constructed a method of disclosure, in which they evaluated the risks and benefits of disclosing their serostatus based upon experience with social stigmatization. These experiences included disclosure of their serostatus by family members or healthcare providers, rejection by community and church members, fear of losing custody of children, and being treated as if HIV were their defining characteristic.

In a cross-sectional study, Wingood et al. (2007) assessed perceived HIV discrimination experienced by African American and white women living with HIV ($n = 366$). Nearly 16% of the sample reported experiencing HIV discrimination, in the forms of losing a job (5.3%), being denied medical care because of HIV serostatus (4.4%), or having to move (6.2%). Further, for African American women, a significant association was found between experiencing HIV discrimination and not accessing HIV-related medical care in bivariate analysis (Wingood et al., 2007).

HIV-Related Stigma Experienced by Caregivers

In addition to HIV-related stigma that may be experienced by people living with HIV infection, family, friends, and partners who provide care for people with HIV infection also experience stigma. In a qualitative case study that detailed one mother’s experience of courtesy stigma, as she cared for her dying son, manifested as rejection by family members and disparaging remarks by a community member about individuals living with HIV

infection (Poindexter, 2005). In response, this caregiver disclosed her son's status to the community member in order to let the person know she was offended by the insensitive statement, and she informed family members of her disgust with the treatment her son received. This caregiver, as opposed to some individuals living with HIV, combated stigma with disclosure.

HIV-Related Stigma Experienced by Men Who Have Sex With Men

HIV-related stigma may be experienced or perpetrated by gay or bisexual men. In the qualitative piece ($n = 250$) of a mixed method study of the effect of perceived stigma experienced by gay and bisexual men living with HIV, Courtenay-Quirk, Wolitski, Parsons, Gomez, and The Seropositive Urban Men's Study Team (2006) found fear of disclosure, avoidance, fear of infection, rejection, discrimination, social isolation, and judgmental attitudes to be examples of stigma experienced by participants. Participants reported being avoided by men of HIV negative serostatus, related to fears of acquiring HIV, and as a result many of the participants living with HIV chose not to disclose their status, and instead lived in social isolation. Other participants, who were formerly open regarding serostatus, reported being forced to adopt a non-disclosure stance after being avoided by others upon disclosure (Courtenay-Quirk et al., 2006).

Among young men who have sex with men ($n = 42$), Dowshen, Binns, and Garofalo (2009) found the total Berger HIV Stigma Scale scores to be significantly and positively correlated with social support and self-esteem. The Disclosure Concerns subscale was correlated with romantic loneliness, which suggests the participants of this study may avoid relationships due to fear of the stigma that may accompany disclosure of HIV serostatus (Dowshen et al., 2009).

HIV-Related Stigma Experienced by Individuals in Rural Areas

Experiences of external stigma for individuals in rural areas with low HIV/AIDS rates were examined by Zukoski and Thorburn (2009). In this qualitative study ($n = 16$), the authors posit that stigma may be worse in rural areas due to less acceptance of individuals who differ. Three stigma-related themes emerged from participant interviews: social rejection; being asked to adhere to specific directives due to living with HIV; and differential treatment. Family and friends rejected people living with HIV, and stigmatizing actions included refusing to touch participants' hands or to let participants touch and hold young children. A common response to being stigmatized was shame and conflict over whether to disclose serostatus to others. These participants weighed the pros and cons of disclosure, with some resorting to isolation and ceasing sexual relations for fear of rejection.

In a qualitative study ($n = 40$) assessing facilitators and barriers to HIV care, rural women living with HIV reported HIV-related stigma as a major impediment to adherence to scheduled medical appointments (Kempf et al, 2010). Women without childcare missed appointments, rather than take children who could read with them to the clinic. Many feared the questions these children would ask regarding their serostatus. Participants were also afraid of being recognized at the clinic and took measure to hide their identities, such as wearing hats.

Individuals living with HIV infection in rural areas often lack access to clinical trials. In a qualitative study designed to construct a HIV-related stigma conceptual model and to assess HIV clinical trial implementation in a rural area (PLWHA $n = 35$), Sengupta et al. (2010) found that some individuals living with HIV experienced isolation, differential treatment, violence, and concerns regarding disclosure of serostatus that could be potential barriers to participation in clinical trials.

HIV-Related Stigma and Medication Adherence

In a qualitative study ($n = 20$) examining medication adherence issues among primarily African Americans with low incomes living with HIV, Konkle-Parker, Erlen, and Dubbert (2008) found stigma adversely affected medication adherence. The authors determined this perceived stigma caused barriers related to the environment. Described in terms of social relationships, these barriers focused on social stigma and shame. One participant described taking medication as not personally difficult, but the challenge was in listening to derisive comments made by others as a result of their own ignorance. Concealing one's HIV status was connected to a sense of shame, and one participant was reluctant to take medication while at work for this reason. Another participant felt shame so profoundly that filling prescriptions for medications at a pharmacy became a great difficulty for that participant.

HIV-related stigma may affect even the most adherent of those living with HIV. In a qualitative study exploring medication adherence among gay men living with HIV ($n = 24$), Brion and Menke (2008) found that although this group of participants was highly adherent to their antiretroviral regimens, fear of disclosure caused some to alter their medication schedules or to miss doses to avoid revealing serostatus. Participants feared the effect of disclosure on other areas of their lives, such as on employment, and many felt it was less difficult to conceal their HIV serostatus prior to taking medications. However, in a quantitative study examining HIV-related stigma among homeless and unstably housed PLWHA ($n = 637$), Wolitski, Pals, Kidder, Courtenay-Quirk, and Holtgrave (2009) found HIV-related stigma was not associated with current use of an antiretroviral regimen, but perceived HIV-related stigma was associated with missing medication doses in the past 2 days.

HIV-Related Stigma Experienced or Perpetrated by Healthcare Providers

HIV-related stigma may be experienced by healthcare providers. In a qualitative study examining rural HIV healthcare providers' experiences of stigma when connecting people living with HIV and substance abusers with appropriate resources ($n = 39$), Yannessa, Reece, and Basta (2008) found the providers and their clients experienced multiple forms of stigma. Four stigma-related themes emerged: stigma from referral sources; physician stigma; stigma from physician specialists; and stigma perceived by clients. Referral source stigma was perpetrated by the healthcare staff in the form of indifference to clients, a lack of acceptance of clients living with HIV and with substance abuse issues, and stigma due to assumptions made about these clients. Physician stigma manifested as reluctance of primary care physicians to provide care for people living with HIV and substance abuse. Primary care providers referred clients to specialists to avoid caring for clients; some claimed their practices were full. Specialists in rural areas also exhibited stigmatizing behavior toward clients living with HIV. Infectious disease specialists sometimes refused to care for these clients, made stigmatizing remarks to these clients, and some claimed that a lack of knowledge of HIV precluded them for caring for these clients (Yannessa et al., 2008).

Sayles et al. (2007) found among low income women and men living with HIV ($n = 48$), the categories of stigma experienced in other aspects of their lives (*blame and stereotypes, fear of contagion, disclosure, and social contracts*) were experienced in their interactions with healthcare providers also. Participants reported avoiding obtaining medical care for fear of disclosure of their serostatus, and some reported receiving inferior medical care due to living with HIV, such as when obtaining emergency care. Healthcare providers displayed an abnormal level of fear of infection with some participants. One participant described a healthcare provider putting on a mask and double gloves to take a blood pressure reading. Participants described feeling as if they were "contaminated" (Sayles et al., 2007).

Measuring HIV-Related Stigma

Instruments and questionnaires have been developed to measure HIV-related stigma, but definitions of HIV-related stigma vary from study to study, as does the focus on specific components of stigma (see Table 1). Assessments and exploration of HIV-related stigma include the use of semi-structured and in-depth interviews in qualitative and mixed methods studies. Examples of items include: “How would you define HIV-related stigma?” (Block, 2009); “Could you tell me about a time that you felt discriminated against or mistreated because of being older and having HIV disease” (Emlet, 2007); and “How have others reacted to you?” (Buseh & Stevens, 2006). Some authors narrowed their exploration of stigma, such as Wingood et al. (2007), who asked three questions about perceived stigma of participants. Some researchers did not directly ask questions about HIV-related stigma at all (Courtenay-Quirk et al., 2006), and others directed their questions toward specific issues such as disclosure and HIV transmission (Bogart et al., 2008), or medication adherence (Brion & Menke, 2008; Konkle-Parker et al., 2008; Ware et al., 2006).

The instrument used most often to assess HIV-related stigma was the Berger HIV Stigma Scale (Berger, 1995; Berger, Ferrans, & Lashley, 2001), which focuses on external and internal sources of HIV-related stigma. Perceived HIV stigma is described as actual or potential experiences of diminished social acceptance, opportunity, and negative shift in how others perceive the person living with HIV infection (Berger et al., 2001). Psychometric analysis of Berger’s HIV stigma scale indicates four underlying factors exist within perceived stigma: personalized stigma; disclosure concerns; negative self-image; and concern with the attitudes of others regarding people living with HIV. These factors were correlated with each other, indicating they compose a single construct within stigma (Berger et al., 2001).

Analysis of the Integrative Literature Review

A working definition of HIV-related stigma, formed from the distinct categories of HIV-related stigma emerging from the data from the integrative literature review, is: HIV-related stigma is the collection of adverse attitudes, beliefs and actions of others against people living with or affected by HIV, which may result in deleterious internalized beliefs or actions taken by persons living with or affected by HIV infection that may result in negative health outcomes.

A regrouping of these themes into a more inclusive definition of HIV-related stigma consists of two categories (Figure 1). External HIV-related stigma, conceived as the attitudes or actions expressed toward people living with HIV, includes rejection, avoidance, intolerance, stereotyping, judgmental attitudes, discrimination, disrespect, physical violence or verbal derision, and a lack of HIV transmission knowledge leading to unfounded fears of infection. Internal HIV-related stigma includes the feelings, beliefs or actions within or instigated by the person living with HIV/AIDS, such as shame, self-blame, secrecy related to fear of disclosure, self-isolation, despair, and great concern over the thoughts and attitudes of others.

HIV-related stigma may result in a number of negative health outcomes for people living with HIV infection. These negative health outcomes include mental health issues, medication adherence issues, accessions of healthcare services, employment issues, housing issues, and physical violence and verbal abuse.

In terms of mental health, HIV-related stigma results in decreased social support (Dowshen et al., 2009), rejection (Block, 2009), despair (Buseh & Stevens, 2006), loneliness (Ware et al., 2006), decreased self-esteem (Dowshen et al., 2009), and isolation (Sengupta et al.,

2010). These mental health consequences of HIV-related stigma further impact available support and serve as a source of additional psychosocial stress for people living with HIV infection.

HIV-related stigma impacts adherence to antiretroviral therapy. When stigma is experienced, people with HIV infection often fail to adhere to prescribed medication regimens. This lack of adherence with antiretroviral medications is often related to the need to conceal the diagnosis of HIV infection from others (Brion & Menke, 2008; Courtenay-Quirk et al., 2006; Ware et al., 2006). Without medical care and antiretroviral therapy, people with HIV infection are at risk for morbidity, mortality, and decreased quality of life (Simoni et al., 2005).

An additional component that is influenced by HIV-related stigma is adherence to appointments for HIV-related medical care. Medical care for HIV infection requires regularly scheduled appointments not only with HIV providers, but other specialists as needed to manage this chronic illness. People with HIV infection who are experiencing stigma often neglect to adhere to medical appointments that because of the need to conceal their diagnosis from others living in their households (Kempf et al., 2010; Wingood et al., 2007; Yannessa et al., 2008). Failure to adhere to medical appointments has the potential to further impact the physical health of those living with HIV infection (Wingood et al., 2007).

HIV-related stigma may impact employment. This includes, but is not limited to the fear of losing employment if employers become aware of the person's HIV status (Wingood et al., 2007). Losing employment could impact not only the person's socioeconomic status, but may have an impact on insurance or funding issues related to HIV-related medical care.

Housing issues may result from HIV-related stigma. People with HIV infection often perceive that they may be forced to relocate if landlords or housing communities become aware of their serostatus (Wingood et al., 2007). In addition, people with HIV infection with clinical AIDS may be eligible for government-assisted housing, but often forego this benefit in an attempt to conceal their diagnosis (Ware et al., 2006).

The last consequence of HIV-related stigma is the risk of violence and/or verbal abuse. People with HIV infection may be at risk for or may have experienced physical violence (Sengupta et al., 2010). Verbal insults and verbal abuse directed toward people with HIV infection or their caregivers may also occur (Bogart et al., 2008; Poindexter, 2005). Both forms of abuse have the potential to further impact available psychosocial support and the mental health of people with HIV infection and their caregivers.

People living with HIV infection are likely to experience HIV-related stigma at some point in the disease process (Berger, 1995; Herek, 2002). HIV-related stigma has been studied with various groups of HIV-infected individuals. A synthesis of all studies included in this integrative review of the literature revealed that because HIV-related stigma is a universal phenomenon for people infected with HIV, further research with HIV-related stigma should focus on this concept with the entire population of HIV-infected individuals rather than stratifying the study of HIV-related stigma by primarily studying the concept with various subpopulations with HIV infection. In order for this concept to be further developed, more research is needed that examines the commonalities across subgroups of people with HIV, versus comparing the concept of HIV-related stigma among the subgroups.

Another salient finding from the integrative review of the literature on HIV-related stigma involves the available instruments to measure HIV-related stigma. A number of instruments have been developed to measure this concept. Despite the fact that these instruments have been developed and tested, few instruments have been extensively utilized. It appears that

HIV-related stigma has been studied more with qualitative methods than quantitative methods. A few of the studies reviewed used mixed methods to study this concept. Because a number of instruments are available to measure HIV-related stigma, little research has been attempted to compare or to correlate these instruments. This would strengthen each individual instrument and would lead to the development of a more comprehensive measurement of HIV-related stigma. The most important piece of information that was noted in the integrative review of the literature involves the health outcomes of people with HIV infection that experience HIV-related stigma. A few studies have noted the influence of HIV-related stigma on adherence to ART (Brion & Menke, 2008; Konkle-Parker et al., 2008; Wolitski et al., 2009). No research is available that examines the influence of HIV-related stigma on other health outcomes, including mental health indicators such as self-esteem, depression, and anxiety. With the likelihood that people with HIV infection will experience HIV-related stigma during their lifetimes (Berger, 1995; Herek, 2002), HIV-related stigma probably has an impact on mental health, although this cannot be known for certain as research to document this relationship has not been conducted.

Limitations and Unanswered Questions

Limitations

From the analysis of the studies of the integrative review of the literature on HIV-related stigma, some limitations and unanswered questions were identified. The concept of HIV-related stigma is well-documented in the research literature; however, gaps have been identified that impact the utility of this concept.

The first limitation and probably the most essential is a lack of a clear and consistent definition of HIV-related stigma. Despite previous work on this concept, definitions of HIV-related stigma vary and are not consistently used. Without a clear and precise definition of HIV-related stigma, the concept cannot be clinically useful (Rodgers & Knafl, 2000).

The second limitation involves the relationship of HIV-related stigma to other concepts. Although a number of studies have documented HIV-related stigma, these studies have failed to identify concepts that are related to HIV-related stigma. The relationship of HIV-related stigma to other concepts is important to note as concepts form networks of related concepts that provide a background for the concept and significance to the concept of interest (Rodgers & Knafl, 2000). Without knowing which concepts are related to HIV-related stigma, it is impossible at this point to know which concepts are related and how these other concepts influence or impact HIV-related stigma.

The third limitation involves measurement of the concept of HIV-related stigma. As previously noted, instruments to measure HIV-related stigma have been developed and tested. Each individual instrument measures components of HIV-related stigma, but none of the available instruments measure all components of this concept. In addition, none of the instruments that are currently available to measure HIV-related stigma appear to be useful in measuring this concept across all populations that are affected by HIV. It is generally accepted that people living with HIV will experience stigma at some point in their disease trajectory (Berger, 1995; Herek, 2002). Would it be possible to develop an instrument that measures the general aspects of HIV-related stigma across all populations of people living with HIV, or are the populations of people living with HIV too diverse that one instrument cannot encompass all populations?

The fourth limitation concerns stigmatization of race/ethnicity, illicit substance use, and sexual orientation among PLWHA and experiencing HIV-related stigma. HIV-related stigma in terms of concept exploration/development is particularly needed for Hispanic

Americans, given the lack of literature currently available. However, the large scope of these issues precludes in-depth discussion in this article. Further research is required to understand how individuals experience and are affected by these potentially layered stigmata.

The final limitation that is apparent is the lack of clinical utility of the concept of HIV-related stigma. As previously noted, at this point the concept of HIV-related stigma is not clearly defined, not consistently measured, and remains too abstract for clinical use. Despite the fact that HIV-related stigma has an impact on client health outcomes in terms of medication adherence (Konkle-Parker et al., 2008), this concept cannot be applied clinically because of its abstract nature. More theoretical and empirical work needs to be conducted with this concept in terms of clarifying the concept. When concepts are clarified, nurses can make generalizations about the concept, develop an operational definition of the concept, and develop a model that places the concept in perspective with existing theories. Once a model has been developed, hypotheses related to the concept can be tested with research (Rodgers & Knafl, 2000). Qualitative research studies need to be conducted with people with HIV infection who have experienced HIV-related stigma to gain a view of this concept from the perspective of clients. From this research, a more clearly articulated definition of HIV-related stigma can be developed. The perspectives of the client could be useful in making the concept less abstract by asking clients how nurses and other healthcare providers can develop interventions that will address HIV-related stigma. This could be the first step in moving the concept of HIV-related stigma from abstract to more clinically useful and clinically relevant.

Summary

An integrative review of the literature was conducted to clarify the concept of HIV-related stigma. Numerous sources have documented HIV-related stigma with various populations of persons living with HIV infection, and instruments have been developed to measure this concept. A more complete definition of HIV-related stigma was developed from the literature that included external, internal, and the consequences of HIV-related stigma. More research and additional concept work is necessary to further develop HIV-related stigma, and to explore the relationship of HIV-related stigma to other health outcomes for people living with HIV infection.

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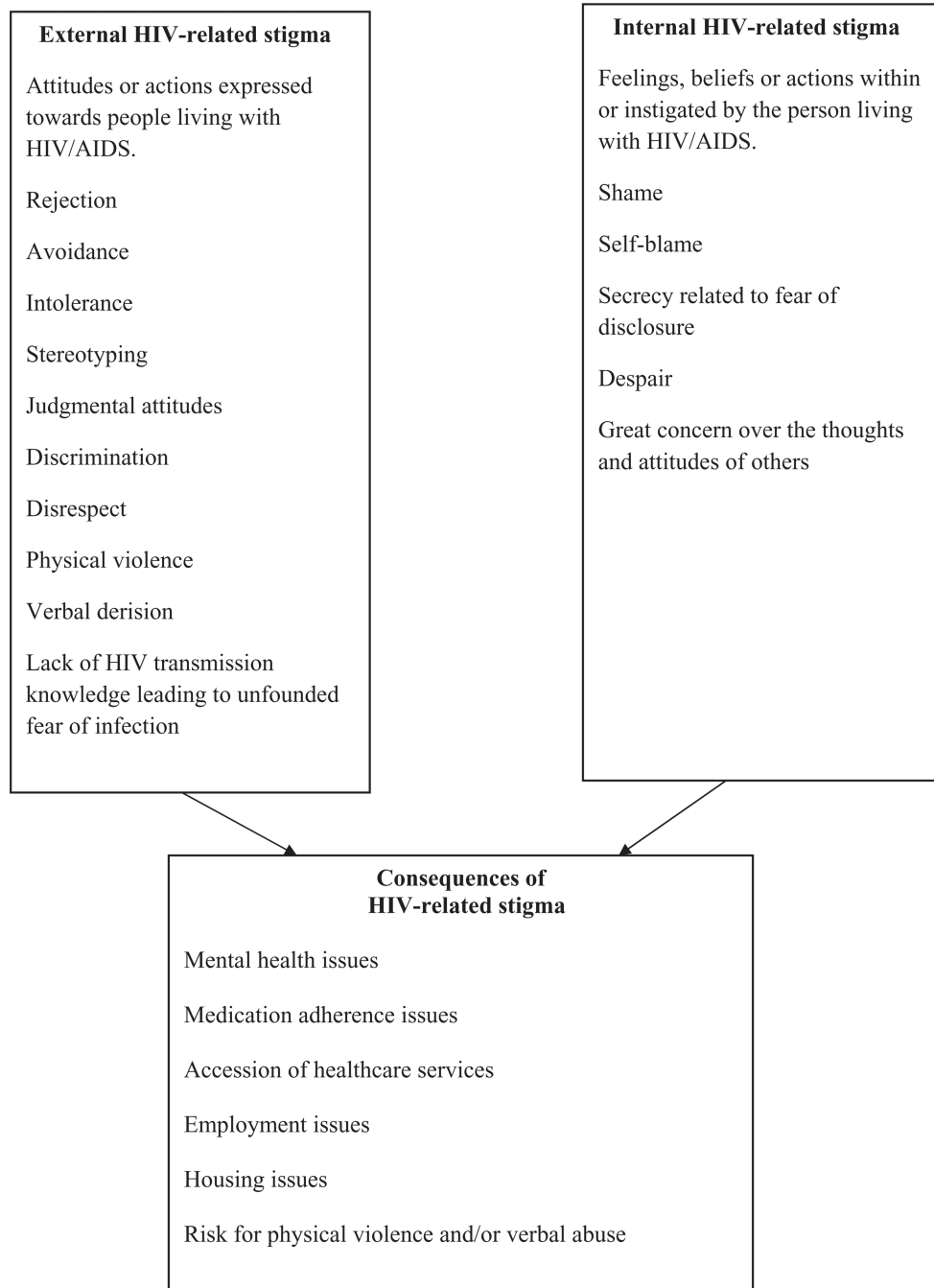


Figure 1.
External, Internal, and Consequences of HIV-Related Stigma

Table 1

A Summary of Research on HIV-Related Stigma

Author	Measure	Study type	Results
Kempf et al. (2010)	Broad, open-ended interview guide	Descriptive qualitative study exploring barriers and facilitators to health care among rural women living with HIV	Feared disclosure to children, feared recognition, hid identity when attending clinic.
Sengupta et al. (2010)	Semi-structured interview guide	Qualitative study to construct a conceptual model of HIV-related stigma and impediments to clinical trials in rural North Carolina	Isolation, differential treatment, violence, serostatus disclosure concerns all stigma-related potential barriers participation in clinical trials.
Block (2009)	Semi-structured interview guide	Qualitative study of felt HIV-related stigma among adult people living with HIV/AIDS (PLWHA)	Felt stigma and enacted stigma. Devised systematic methods for serostatus disclosure. Rejection, blame for serostatus. Shame, loneliness, anger in response to poor treatment.
Dowshen et al. (2009)	Berger HIV Stigma Scale	Quantitative study exploring HIV-related stigma, depression, self-esteem, loneliness, and social support among young men who have sex with men	Total stigma scores were significantly and positively correlated with social support and self-esteem. Disclosure Concerns subscale was correlated with romantic loneliness.
Foster and Gaskins (2009)	Self-Perceptions of HIV Stigma questionnaire; Stigma Impact of HIV questionnaire; semi-structured interview guide	Mixed method study of older African American PLWHA in the South	Internalized shame experienced, care in serostatus disclosure, with whom they disclosed their serostatus; isolated.
Wolitski et al. (2009)	Internal and perceived stigma scales adapted from Berger IV Stigma Scale; scales shortened and reworded to focus on social networks	Quantitative study examining effects of HIV-related stigma on mental health, risk behaviors, physical health, and HIV serostatus disclosure of homeless and unstably housed PLWHA	HIV-related stigma was not associated with current use of an antiretroviral regimen, but perceived HIV-related stigma was associated with missing medication doses.
Zukoski & Thorburn (2009)	Open-ended interview guide	Qualitative study of stigma and discrimination in social and healthcare settings as experienced by PLWHA	Social rejection by friends and family, expected to follow rules due to serostatus, differential treatment, avoidance, fear of infection, judgmental attitude.
Brion and Menke (2008)	Open-ended key questions	Qualitative study exploring medication adherence among gay men living with HIV	Disclosure fears caused disruption of medication schedule or missed doses, easier to conceal serostatus prior to starting medication regimen, fear of effect of disclosure on other areas of lives.
Bogart et al. (2008)	Semi-structured interview guide	Qualitative study of HIV-related stigma experienced by people living with HIV, their families and caregivers	Felt stigma: discrimination, disclosure fears, isolation, ostracism. Enacted stigma: verbal insults, avoidance, isolation, rejection. Courtesy stigma: irrational fear of infection, questioning why caregivers remain with PLWHA. Internalized negative attitudes about HIV present in some.

Author	Measure	Study type	Results
Konkle-Parker Et al. (2008)	Key questions	Qualitative study of perceived barriers and facilitators for HIV medication among African American women.	Environmental barrier: perceived stigma, shame, social rejection, fear of disclosure, embarrassment, derision by others due to HIV status, denial of HIV due to social stigma.
Yannessa et al. (2008)	Semi-structured interviews	Qualitative study examining issues impacting care of people living with HIV and substance abuse in rural areas.	Stigma from referral sources: indifference of staff, lack of acceptance, assumptions. Physician stigma: reluctant to accept patients into practice, "pass off" clients to specialists. Specialist stigma: refused to care for patients, claimed lack of current HIV knowledge. Perceived stigma: lack of HIV knowledge, double stigma due to HIV and substance abuse, homophobia (HIV as "gay disease," afraid to be labeled gay).
Emlet (2007)	Berger HIV Stigma Scale; two semi-structured questions	Mixed methods study of HIV-related stigma experienced by older adults.	Personalized stigma: rejection, fear of infection, isolation. Negative self-image: apart from society, low self-worth. Disclosure concerns: silence as protective measure, unexpected, expected and inappropriate disclosure concerns. Public attitudes: age stereotyping, homophobia.
Sayles et al. (2007)	Open-ended questions	Qualitative study to explore stigma and its impact on health and health care among PLWHA	Four categories of HIV-related stigma: <i>confronting blame and stereotypes of HIV encountering fear of contagion, negotiating disclosure of a stigmatized role, and renegotiating social contracts</i> ; these components of stigma were found in interactions with healthcare providers also.
Wingood et al. (2007)	Three questions related to perceived HIV discrimination	Quantitative study assessing HIV discrimination and health outcomes among African American and white women living with HIV	15.9% reported experiencing HIV discrimination: job loss (5.3%), denied medical care due to HIV positive serostatus (4.4%), or having to move (6.2%). Significant association between HIV discrimination and not accessing HIV/AIDS medical care for African American women.
Buseh and Stevens (2006)	In-depth interviews	Longitudinal qualitative study of African American women living with HIV, experience and response to stigma.	Internal stigma: despair due to equating HIV diagnosis with death, shame, self-accusation, hiding, deserving of HIV. Interactions with others: shunning, rejection, insensitive treatment, social isolation. Institutional disregard: disrespect, inappropriate disclosure.
Courtenay-Quirk Et al. (2006)	Perceived stigma in the gay community questionnaire; no direct questions regarding stigma in qualitative study	Mixed methods study of perceived stigma by MSM living with HIV and relationship between stigma and risky behaviors.	Division within gay community by serostatus: avoidance, fear of infection, rejection, discrimination, judgmental attitudes, social isolation, disclosure concerns.
Rao et al. (2008)	Berger HIV Stigma Scale	Quantitative study using IRT to assess cross-cultural differences between black and white PLWHA's responses to items on	Black PLWHA concerned with discrimination and being

Author	Measure	Study type	Results
Ware et al. (2006)	Structured interviews, followed by semi-structured interviews	the Berger HIV Stigma Scale Qualitative study of medication adherence among illicit substance using PLWHA	judged, white PLWHA concerned with rejection. Social marginalization: due to social issues, shame from drug use, or isolation from the gay community due to serostatus. Loneliness and the desire for connection: fear of rejection, hiding of serostatus. Fear of disclosure and adherence: conflict between medication adherence and disclosure.
Poindexter (2005)	Open-ended interviews	Exploratory qualitative study of HIV-affected caregivers	Courtesy stigma: rejection by family members, disparaging remarks by community members, caregiver disclosed son's status to convey her sense of disgust at offensive treatment by others, fought stigma with openness.
Black and Miles (2002)	HIV disclosure goals discussed during intervention delivery	Descriptive qualitative study to identify the process of HIV serostatus disclosure among African American women	Constructed disclosure method, evaluated risks and benefits of disclosure based on social stigmatization.
Lichtenstein et al. (2002)	Semi-structured interviews	Qualitative portion of missed method study examining depression and gender among PLWHA	Socially isolated, rejected, fear of disclosure, attempted to protect families from distress.