Trauma, Mental Health, Distrust, and Stigma Among HIV-Positive Persons: Implications for Effective Care

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Individuals living with HIV often have complicated histories, including negative experiences such as traumatic events, mental illness, and stigma. As the medical community in the United States adapts to managing HIV as a chronic disease, understanding factors such as these negative experiences that may be associated with poorer adherence to treatment regimens, greater HIV risk behavior, and lower patient quality of life becomes critical to HIV care and prevention. In less wealthy nations, these issues are also critical for addressing quality of life as well as medication adherence in the areas where antiretroviral therapies are being made available. This article presents a review of the literature regarding the following psychosocial factors as they relate to HIV/AIDS in the US and globally: traumatic events; mental illness, including depression, anxiety, and posttraumatic stress disorder; lack of trust in the healthcare system and government; and experiences of stigma among individuals with HIV disease. These factors have been found to be prevalent among individuals with HIV/AIDS, regardless of gender or race/ethnicity. Traumatic events, mental illness, distrust, and stigma have also been linked with poorer adherence to medication regimens and HIV risk behavior. Key words: HIV, traumatic events, depression, anxiety, PTSD, adherence.

INTRODUCTION

Individuals living with HIV often have complicated histories, including negative experiences such as traumatic events (1–3), mental illness (4–7), and stigma (8,9). HIV care providers may be unaware of their patients’ histories and the effects these experiences can have on health behaviors and health outcomes. As the medical community in the United States adapts to managing HIV as a chronic disease, understanding factors that affect patient quality of life and predict poor adherence to treatment regimens and HIV risk behaviors becomes critical to HIV care and prevention. Knowledge regarding psychosocial factors related to HIV disease and their associations with health behaviors can be translated into more effective treatment protocols that address these factors, which may subsequently decrease poor adherence and reduce the spread of disease. This information is also critical to addressing medication adherence in the less wealthy nations where antiretroviral therapies are currently being made available.

This article presents a review of the literature regarding the following psychosocial factors as they relate to HIV/AIDS: traumatic events; mental illness, including depression, anxiety, and posttraumatic stress disorder (PTSD); lack of trust in the healthcare system and government; and experiences of stigma among individuals with HIV disease. These factors have been found to be prevalent among individuals with HIV/AIDS and have been associated with poorer health outcomes. We will further examine how trauma, mental health, distrust, and stigma are associated with health behaviors including adherence to medication regimens and HIV risk behavior, such as unprotected sex and needle sharing.

Women, minorities, and other disenfranchised individuals, particularly those living in poverty, are now undeniably those most affected by HIV worldwide (10–14). For this reason, acquiring a better understanding of the influence of stigma and negative life circumstances on health behaviors among these groups is particularly critical. This review presents literature regarding differences in stigma, trust, and mental health by demographic characteristics and discusses social and cultural issues affecting women that put them at greater risk for contracting HIV. The literature presented in this review is primarily from the United States and Western Europe; however, it also includes mention of research regarding trauma and other psychosocial factors that is beginning to emerge from less wealthy nations.

Trauma and Mental Health

Trauma History

Studies indicate that a history of trauma is relatively common among HIV-positive persons (3,15–19) and substantially exceeds that of the general population in the US (20–23). One study of 357 HIV-infected persons in the US found that 45% of participants (68% of women and 35% of men) reported a sexual assault after age 15 years (24). Among those experiencing sexual assault, 80% were assaulted two or more times with a mean of almost 10 such events. In addition, sexual abuse occurring between the ages of 7 and 15 years was reported by 32% of women and 47% of men whereas sexual abuse occurring under the age of 6 years was reported by 19% of women and 17% of men. Furthermore, 34% of women and 27% of men reported a history of childhood physical abuse. No differences in history of trauma were identified by race/ethnicity, age, or education; however, self-identifying as gay or bisexual was associated with greater abuse among HIV-positive men. The Coping with HIV/AIDS in the Southeast (CHASE) study, a cohort study of 611 HIV-positive persons receiving HIV care in the Southeastern US, found that one quarter of participants had been sexually abused before the
age of 13 years, one third had experienced lifetime sexual abuse (30% of men and 38% of women), and over half had been sexually or physically abused (3). Women and gay or bisexual men were more likely to experience abuse. Furthermore, the vast majority (>90%) of these patients reported at least one severe traumatic event (e.g., abuse, parental neglect or death of a spouse) in their lifetime (25).

The rate of trauma seems to remain elevated even after HIV diagnosis. Data from the national HIV Costs and Service Utilization Study (HCSUS) showed that 20.5% of women, 11.5% of men who reported having sex with men, and 7.5% of heterosexual men reported physical assault by a partner or someone important to them after having been diagnosed with HIV (26). Younger age, homelessness, and history of drug dependence were associated with a greater likelihood of experiencing violence after HIV diagnosis. Race/ethnicity and income were not associated with experiencing violence post diagnosis (26). Results from the CHASE study found even higher levels of post-diagnosis abuse, as 33% of HIV-infected women in the CHASE study reported experiencing physical or sexual assault after their HIV diagnosis (25). Finally, the HIV Epidemiology Research Study of women with or at risk for HIV documented an incidence rate for violent events (defined as being physically attacked or raped) of 6.2 per 100 person-years over a 5-year period (27). Similar to the HCSUS study, this study found that younger age and illicit drug use were associated with violence. Study results also indicated that higher CD4 count, being single/widowed/divorced, prior physical or sexual abuse, depression, and having multiple sexual partners were associated with a greater incidence of violent events.

Experiences of sexual and physical abuse and other types of trauma may have lifelong effects on the health and behaviors of individuals. Sexual and physical abuse are associated with higher levels of mental illness including anxiety, depression, PTSD, and symptoms of borderline personality disorders, and consequently poorer quality of life among HIV-infected individuals (24,28–30). Findings among HIV-infected individuals parallel those in the general population, where sexual and physical abuse histories have been associated with depression and other psychiatric illness (31,32). Trauma and abuse have also been shown to be associated with poor treatment adherence and HIV risk behavior (24). CHASE study results indicated that having more lifetime trauma is highly correlated with poorer medication adherence, even when controlling for current mental health symptomatology and substance abuse (33). There is a large and consistent literature among men and women, patients from sexually transmitted disease clinics, and in HIV-positive and -negative samples showing that sexual and physical abuse history is positively associated with 1) sexually transmitted diseases, 2) risky sexual behavior (e.g., unprotected sex, multiple partners), 3) alcohol use, and 4) needle sharing (24,34–38).

**Mental Illness**

A high prevalence of mental illness has been detected among HIV-infected individuals (25,39,40). Results from HCSUS indicated that nearly half (48%) of these HIV-infected individuals had a probable psychiatric disorder (39). The CHASE study of individuals living with HIV/AIDS in the Southeastern US documented that a majority (54%) of participants had a probable mental disorder (25). The level of mental health problems detected among HIV-positive individuals is substantially higher than that of the general population (41). HCSUS results indicated that Whites were more likely to have a probable psychiatric disorder in the past year compared with African-Americans (42). In addition, being unemployed or disabled, having more HIV-related symptoms, and drug use were associated with greater risk for a psychiatric disorder (42). Although women in the HCSUS study were not more likely to have a probable psychiatric disorder, they did have a higher level of symptoms of mental illness (43). A study of the women involved in the HCSUS research indicated that women who were dependent on income assistance were more likely to have experienced psychiatric comorbidity (44). No statistically significant differences in having a probable mental disorder were detected by race or gender in the CHASE study (25). One study of HIV-infected individuals receiving medical care found differences by race in type of symptomatology. African-Americans were less likely to present with depression and anxiety and more likely to present with somatization and paranoid ideation (45).

Comorbid mental illness and substance abuse are also found at higher levels among HIV-infected individuals in comparison with the general population (42). HCSUS research findings indicated that 13% of study participants had both mental health and substance use problems (39). A study of psychiatric comorbidities among HIV-infected individuals receiving care at infectious disease clinics in North Carolina (n = 1358) found even higher levels of comorbid mental illness and substance abuse, as 23% experienced symptoms of both disorders (46). HCSUS study findings indicated that males, Whites, and heterosexuals were more likely to have experienced comorbid psychiatric symptoms and substance abuse (39).

Among HIV-infected individuals, mental illness has been associated with lower likelihood of receiving antiretroviral medication (47). Among those who receive antiretroviral medications, mental illness has been consistently related to poorer medication adherence (48–50). Mental illness has also been associated with unsafe sexual and drug use behaviors (51,52) and substantial societal costs including productivity loss, injury, and healthcare expenditures (43,53–55). Emerging research on providing treatment for HIV-infected individuals with mental illness has demonstrated that treatment can be effective in reducing psychiatric symptoms, improving adherence, and reducing costs of care (56,57).

**Depression**

Depression is one of the most commonly occurring mental disorders identified among HIV-infected individuals. Findings from the HCSUS indicated that 36% of HIV-infected individuals screened positive for depressive symptoms in the previous year (42). The CHASE study found similar levels, as 35% of participants screened positive for depression (25). Neither
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HCSUS nor CHASE research detected significant differences in depression by sexual orientation or race. HCSUS results identified only slightly higher levels of depression among women (58). Additionally, smaller studies of depression among individuals with HIV infection have also found high levels of depressive symptoms, ranging between 26% and 49% (59–62). Despite these high levels of depression, the HCSUS study showed that 45% of those with a diagnosis of major depression did not have this diagnosis documented in their medical records (63). Study participants with more outpatient visits and higher levels of education were more likely to be diagnosed (63). Depression has been consistently associated with poorer medication adherence among HIV-infected individuals (59,64–66). In addition, depression has been associated with being less likely to receive antiretroviral medication (47) and with HIV risk behavior (51).

Anxiety and PTSD

HCSUS study findings indicated that 16% of individuals with HIV in this national study had symptoms of generalized anxiety disorder and 10.5% percent screened positive for a history of panic attacks (42). The CHASE study of HIV-infected individuals living in the Deep South of the US found that over one quarter (29.5%) had significant levels of anxiety (25) as reported on the Brief Symptom Inventory (67). In the HCSUS study, symptoms of anxiety were only slightly higher in women (58) and no differences in gender were identified in the CHASE study (25). However, in the CHASE study, African-Americans were less likely to have symptoms of an anxiety disorder (25). Several studies have found that anxiety symptoms have been associated with less optimal HIV medication adherence (68,69).

A high prevalence of PTSD, which greatly exceeds that of the general population, has been found among HIV-infected individuals, ranging between 16% and 54% (25,59,70–73). This is consistent with the high rates of abuse and trauma reported previously. One study also documented a substantial co-occurrence of depression and PTSD (37% of study participants had both diagnoses) (59). Several studies identified that African-American race was associated with a lower prevalence of PTSD but did not detect any notable difference in PTSD by gender (25,73). A study of PTSD among women with HIV disease did not find differences in PTSD prevalence by race/ethnicity or any other demographic characteristics; however, the results of this study indicated that PTSD was associated with less social support and a greater number of traumatic experiences (72). Consistent with the associations of depression and anxiety with health behavior, a number of studies have identified an association of PTSD with poorer medication adherence (59,74,75) and greater HIV risk behavior (70).

Trauma and Mental Illness in Less Wealthy Nations

Several studies have examined traumatic experiences, mental illness, and/or PTSD among individuals with HIV disease in less wealthy nations. A preliminary study of the prevalence of traumatic events among HIV-infected individuals in Moshi, Tanzania conducted by the authors of this review found that 25% of the 59 study participants reported sexual abuse (76). Nearly all respondents had experienced a life-threatening illness other than HIV/AIDS and approximately 75% had experienced the death of a close relative or friend or witnessed a violent death. When compared with a US sample of HIV-positive persons matched by traumatic events to the Tanzanian sample, on average, the individuals from Tanzania reported greater mental health symptomatology and poorer health status. Poorer mental health scores were consistently associated with decreased physical health composite scores. Because this study was cross-sectional, directionality of causation cannot be determined. These findings are consistent with studies conducted in the US that identified that mental distress is associated with poorer health status (77). This study did not include a comparison of traumatic experiences to a sample of individuals not infected with HIV to assess for differences in trauma prevalence. However, the results from a study of violence among women in Tanzania indicated that women with HIV disease reported greater lifetime violence than women who were HIV-negative (78).

A study of individuals with a new HIV diagnosis in South Africa found high levels of mental illness that were comparable with that identified in the US, as 56% had at least one psychiatric disorder (79). The most common disorders were depression (35%) and PTSD (15%) (79). Female gender and history of sexual abuse were associated with a PTSD diagnosis (80). One study in Zimbabwe found that 71.3% of HIV-positive individuals endured psychiatric disorders in addition to having a higher prevalence of alcohol use/misuse (81). A study in Nigeria found that 59% of HIV-positive individuals participating in the study had a comorbid psychiatric disorder (82). This prevalence was significantly higher than that identified among similar individuals who were not infected by HIV (19%). Psychiatric disorders were associated with less social support and greater disease progression (82).

Trauma and Mental Illness Summary

The extensive body of literature regarding trauma and mental illness among HIV-infected individuals consistently shows a high prevalence of these factors despite differences in the proportion of affected individuals between study samples. Disparities between studies are likely due to differences in study samples and measurement of trauma and mental illness. The literature regarding trauma and mental illness also consistently describes the relationships of trauma and mental illness with HIV medication adherence and risk behaviors—factors that may subsequently affect morbidity, mortality, and the spread of disease.

Although the research on traumatic experiences among HIV-infected individuals is fairly consistent in reporting higher levels of trauma among women and gay or bisexual men, the literature regarding mental illness is less consistent in identifying a role of demographic characteristics, such as race, gender, or sexual orientation, in predicting the presence of...
ment of mental illness among HIV-infected individuals. The etiology of mental illness among HIV-infected individuals may be multifaceted, depending on a number of social, behavioral, and biological factors (7,28,29,72). In addition, trauma, depression, anxiety, and PTSD factors frequently coexist and their individual effects on quality of life and health outcomes are difficult to separate. Additional research is needed to determine the independent and synergistic relationships of demographic, psychosocial, and biological characteristics with psychiatric comorbidity among HIV-infected individuals as well as the individual and synergistic effects of multiple psychiatric comorbidities.

Despite the extensive body of HIV literature showing the prevalence and negative impact of trauma, depression, and other mental disorders on medication adherence and risky sexual behavior from the US and Western Europe, few studies have examined the prevalence and outcomes of these comorbid factors in less wealthy nations. Most studies concerning trauma in less wealthy nations have taken place among refugees or in war-torn areas (83), but as we have seen in the US, trauma and mental illness are highly prevalent in most HIV-infected populations (3,42).

Distrust

Lack of trust in medical care providers and the government can be a barrier to HIV prevention and appropriate use of medical services. Many studies have noted the reluctance of African-Americans to participate in medical research, medically sanctioned prevention practices, and treatment programs, in part due to distrust of providers and beliefs about the government’s role in the spread of HIV and other diseases (84–87). The injustices of the past, including the Tuskegee syphilis experiment (88), may lead many individuals to expect dishonesty from medical researchers and professionals (89–92). Furthermore, there is a vast body of empirical evidence showing that African-Americans, regardless of income and insurance status, do not receive the same quality of care as their White counterparts (93–96). Belief in conspiracy theories about HIV disease is relatively common and has been found to be more prevalent among African-Americans, those with less education, and lower income (97,98). For example, in the CHASE study of 611 HIV-positive persons in the South found that 23% of minority and 11% of nonminority respondents thought AIDS was created by the government to kill minorities (99). These rates increased to 47% for minorities and 23% for nonminorities when the response category “not sure” was included. In addition, more than half of the minority respondents and one third of the nonminority respondents agreed that a significant amount of information about AIDS was being held back from the public. Again, these rates increased to nearly three quarters of minorities and more than half of nonminorities when “not sure” was included. The study also found that 10% of respondents did not trust their doctor or clinic to provide them with the best care possible.

Regardless of minority status, trust in one’s care providers was positively associated with more clinic visits, medication adherence, and better physical and mental health status among the HIV-positive individuals in the CHASE study (99). In addition, trust in the government was associated with better mental and physical health. Few studies have examined the role of trust in the government and belief in HIV/AIDS conspiracy theories with sexual risk behavior. One such study found that belief in HIV/AIDS government conspiracies (e.g., AIDS is a form of genocide against African-Americans) was related to less positive attitudes toward condoms for birth control and greater numbers of partners in the past 3 months (100).

Issues Affecting Women With HIV

Globally HIV is primarily a heterosexual disease that infects nearly as many women as men and in some parts of the world, more women than men. For biological reasons, women are more susceptible to HIV than men during any given sexual encounter (101). Added to the biologic susceptibility are physical and wealth power dynamics that make women at higher risk than men for sexual exploitation or simply lack of ability to negotiate the mechanics of sexual relationships. These dynamics are experienced around the globe.

In the US, although rates of HIV among men have decreased, they have increased among women, particularly among African-American women (102). In some parts of Africa, the majority of those infected are women and if current trends in new infections continue, the majority of those infected worldwide will be women within the next decade (102). The majority of women infected with HIV in India are in monogamous relationships with their husbands (102). In these areas, it is more often accepted culturally that men have multiple sexual relationships even when married, making it easier for one infected man to infect several women. Women around the world exchange sex for money, shelter, food, and safety for their children (106,107). These exchanges make it difficult for women to demand the use of condoms. Further, in areas of conflict in less wealthy nations and in isolated cases in the US, HIV has been used as a vehicle for torture and violence. The ability of HIV to incapacitate, particularly where treatment is rare, has been capitalized on and turned into a potent weapon of war. HIV has been described as a psychological and biological weapon in recent conflicts in Rwanda, Sierra Leone, the Democratic Republic of Congo, and Liberia through mechanisms of widespread rape by infected militia members (108). During the Rwandan genocide, women were raped and intentionally infected with HIV to ensure prolonged suffering, a painful death, and social ostracism (108,109). Other sexual practices in various African nations also seem to be abusive and potentially traumatic for women in those countries. Such practices include men having sexual relations with young virgins so as to rid themselves of HIV (110) and women being forced by tradition to have sexual relations with their brother-in-law when their husband dies (111). Studies are beginning to explore spousal battering and female sexual abuse in less wealthy nations (112) and rates seem to be considerable.
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Stigma

Another complicating and often compromising facet of living with HIV is HIV-related stigma. Stigma has been defined as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society” (113,114). Stigma may either be directly experienced by an individual or may be perceived, which is an individual’s fear or concern that negative attitudes or discrimination would occur if HIV status were known. Both perceived and experienced stigma are discussed here, given the evidence in the literature demonstrating their effects on the individual reporting them (115–124). From the beginning of the epidemic, stigma has played a role in the realm of HIV disclosure as well as in HIV/AIDS education and treatment. Gay men, in particular, faced unrelenting stigma in the early years of the epidemic, thus creating an environment of secrecy and difficulty accessing social support (125).

Recent research demonstrated that HIV-related stigma continues to be pervasive in the US (122,126). For example, a majority of individuals involved in a Kaiser Family Foundation survey reported some discomfort with the idea of working with someone who was HIV-positive, as 30% were “somewhat comfortable” and 21% were “not too comfortable” or “not comfortable.” This survey also identified high levels of misconception about HIV transmission and found a relationship between these continuing misconceptions and stigma (126). The high levels of stigma identified in the general population are reflected in the experiences of individuals with HIV. For example, in a study of women and men living with HIV in New York, 41% stated that others had acted negatively toward them after learning of their HIV status (117). Rintamaki and colleagues found that 56% of men reported moderate-to-high levels of concern for stigma as a result of taking HIV medications (122). Greater HIV stigma has been identified in rural areas of the US in comparison to more urban areas (127,128). High levels of stigma and discrimination have also been identified in less wealthy nations (116,123,124). In a study of HIV-infected individuals in South Africa, one third of participants reported experiencing discrimination because of their HIV status and over half reported fearing negative responses if they disclosed their HIV status (116).

Research regarding the presence of stigma and the effects of HIV-related stigma among individuals with HIV/AIDS has identified links between stigma and depression, PTSD, and increased risky sexual behavior (115–118). Simbajy and colleagues in their study of individuals with HIV/AIDS in South Africa found that greater occurrence of perceived stigma and experiences of discrimination were associated with being less likely to disclose HIV status to a partner (116). Several studies also described an association of stigma with medication adherence among individuals living with HIV/AIDS. In a study of HIV-positive persons living in rural areas in North Carolina, individuals reported that they would not take their HIV medications in public for fear of undesired disclosure (119). Several studies conducted in urban areas of the US have also found associations between perceived or experienced stigma and poorer medication adherence (117,120–122). An association between stigma and poorer medication adherence has also been identified in studies in less wealthy nations (123,124). Although there has been recent attention given to the issue of stigma both internationally and domestically and calls to eliminate stigma toward people living with HIV/AIDS, there is little consensus about how to confront and eradicate stigma beyond providing HIV education.

Clinical and Policy Implications

In this review of published literature high rates of trauma, depression, anxiety, stigma, and distrust were identified among HIV-infected individuals regardless of race, gender, or sexual orientation. These findings indicate that significant attention to these issues in the context of HIV treatment and prevention is warranted. The need for a focus on these factors and a modification of treatment practices to adequately address them is particularly compelling because of their relationships with HIV-related behaviors including medication adherence and HIV risk behaviors. As indicated in the article by Leserman in this issue (77), these psychosocial factors have also been associated with poorer disease outcomes. One consideration for addressing trauma would be the development of standardized trauma protocols for infectious disease providers that assume most patients have experienced some form of trauma and would benefit from clinician sensitivity to potential trauma triggers. For example, important tenets to working with patients who have been sexually abused include seeing the patient clothed before the examination, encouraging questions and explaining all parts of the physical examination and any needed procedures, and allowing patients to opt out of any or all parts of a physical examination. In addition, acknowledging the high prevalence of trauma helps the patient feel more comfortable when asking about trauma history. Explaining that the same questions are asked of all patients is an important step in creating a safe environment for the patient.

The critical need to address mental health issues has been recognized globally and in the US; however, significant deficiencies in access to mental health care remain for the general population and for people living with HIV/AIDS (127,129). Results from the HCSUS study indicated that at least one third of individuals who need mental health treatment were not receiving it (130). This figure is likely an underestimate of the unmet mental health need as this study was conducted with individuals receiving medical care, thus excluding individuals who are not accessing medical care due in part to mental health problems. The significant associations of mental health and prevention and care issues presented in this special issue and the lack of universal access to mental health services for these individuals clearly warrant commitment of resources to effectively address mental health needs. Healthcare funding mechanisms, such as Medicaid and Ryan White funds, may need to be broadened to provide comprehensive mental health coverage for persons with HIV. Such policy changes could result in financial savings due to improved health outcomes.
and decreased emergency room visits and hospitalizations. This is supported by one study showing that provision of mental health services for HIV-infected individuals with psychiatric disorders resulted in decreased treatment costs and improved health outcomes (56). Innovative approaches to address issues of stigma and distrust in the medical community and government are also needed to improve HIV care and prevention.

Although this review of the literature is clear in identifying the substantial levels of mental illness, trauma, stigma, and distrust among HIV populations, further research is needed regarding interventions to address these problems. Longitudinal research is necessary to determine the causality of the relationships identified in cross-sectional studies. For example, whereas the direction of the relationship between sexual abuse in early childhood and the development of sexual risk as an adolescent is clear, the direction of the relationship between adult trauma and risk behaviors or between stigma and risk behaviors is more opaque. In addition, further research is needed to elucidate the extent of unmet needs for mental health services for HIV-infected individuals with psychiatric disorders. Evidence (56) shows that innovative approaches to address issues of stigma resulted in decreased treatment costs and improved health outcomes (56). Innovative approaches to address issues of stigma and distrust in the medical community and government are also needed to improve HIV care and prevention.

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