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Mental health needs of people living with HIV/AIDS in India: a literature review

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We describe the global conditions associated with the AIDS pandemic and its socioeconomic and psychological impacts. A systematic review was performed to investigate the literature on the mental health needs of people living with HIV/AIDS (PLHA) in India. The focus is on the prevalence, nature, and sociocultural factors of the epidemic in India. A conceptual framework is offered and the findings of this study are presented across three major domains: (a) prevalence of mental health disorders among the HIV-infected population; (b) mental health needs of PLHA; and (c) gaps in policies and programs addressing these issues. Experiences of HIV stigma and discrimination are also noted in this population. We conclude with implications for future research, interventions, and public policy.

Keywords: mental health disorder; people living with HIV/AIDS; developing countries; policy; India

Introduction

The HIV/AIDS epidemic remains among the most significant challenges to public healthcare systems worldwide (Catalan, Collins, Mash, & Freeman, 2005). Globally, there are 33 million “people living with HIV/AIDS (PLHA)” (UNAIDS/WHO, 2008), with 25 million AIDS-related deaths reported in the last 25 years (UNAIDS/WHO, 2007). The negative impact of HIV infection includes co-morbidities in individuals, such as substance abuse, depression, and posttraumatic stress disorder (PTSD; Boarts, Sledjeski, Bogart, & Delahanty, 2006) and it profoundly impacts families and communities. Social stigma, marginalization, and discrimination of PLHA lead to further risk and vulnerability that results in poorer physical and mental health (Jenkins & Sarkar, 2007). Co-morbidity among PLHA has been linked to treatment outcomes and problems with medication compliance underscoring the importance of addressing psychological symptoms (Chander, Himelhoch, & Moore, 2006; UNAIDS/WHO, 2008).

There has been a paucity of research investigating mental health among PLHA in India. While psychiatric co-morbidity is known to have a strong association with HIV/AIDS (Chandra et al., 2003; Treisman & Angelino, 2007), a research review is necessary to further understand the prevalence and impact of mental disorders among PLHA. The study therefore aims to review the relevant literature to identify gaps in research pertaining to India, which may aid national policy development.

HIV/AIDS in India: the epidemic profile

Since the first case of HIV was detected in 1986, the infection has rapidly spread across all Indian states. Over a billion population of the country makes the task of curbing the HIV infection more difficult. The growing epidemic has adversely affected the psycho-social, cultural, and developmental domains, hence making it a major public health concern. Contrary to prevalence estimates that there are 2.3 million PLHA in India (NACO, 2007a), UNAIDS (2006) reported that an even higher number (5.7 million) were living with the virus. Contrasting data makes it difficult to ascertain an accurate number of HIV/AIDS cases in India. Epidemiological studies, surveys, and surveillance systems are difficult to carry out because certain high-risk groups are reluctant to undergo HIV/AIDS testing and disclose their diagnosis. Research has identified certain demographic and social factors that contribute to this reluctance (e.g., ethnicity, oppression, and societal reactions; Chandra et al., 2003), as well as factors that predict reasons for refusing consent to testing (e.g., poor perception of risk, denial of spousal permission; Satyanarayana, Chandra, Vaddiparti, Benegal, & Cottler, 2009).

Generally, HIV/AIDS infection is concentrated among high-risk groups in urban areas, in younger populations (15–24 years) with lower education levels (NACO, 2007a). However, the epidemic has spread from urban to rural areas and from high-risk populations to the general public. Comparable statistics maintained by National Sentinel Surveillance...
System and National Family Health Survey-3 (NFHS-3, 2006) indicated that 2.47 million individuals were infected with HIV/AIDS by 2006. Approximately 89% were adults (7.5% of whom were ≥ 50 years) and 3.8% were children (<15 years). Of those infected, 39.3% were female and 61% were men (NACO, 2007a). HIV prevalence rates tend to be 6–8 times greater among high-risk groups, e.g., those who engage in risky sexual behavior, than the general population. Although the mode of transmission has been predominantly heterosexual contact (84.28%; Figure 1), intravenous drug use has been etiologically connected with the epidemic in northeast India (Shaukat & Panakadan, 2004). Men who have sex with men (MSM) were also found to be at high-risk due to drug use and risky sexual behavior (Go et al., 2004).

As in the other parts of the world, PLHA in India suffer from stigma and discrimination in several contexts: household, workplace, health settings, and communities (UNAIDS, 2001). The UNDP (2006) reported refusal of medical treatment; work place discrimination; physical attacks; rejection by families, partners, and communities; and in some cases denial of last rites before death to PLHA. Vulnerable subgroups of PLHA like CSWs, transvestites, and homosexuals face further discrimination.

The HIV/AIDS epidemic has existed for over two decades in India, yet mental health providers often do not have sufficient knowledge and experience to diagnose and assess the mental health needs of people with HIV infection. In some cases, providers only require HIV-specific training (Datye et al., 2006) and mental health issues are often neglected during planning and implementing AIDS interventions.

Methods
A systematic review of relevant published literature from 1986 to 2009 was undertaken. Studies were identified through keywords and author searches in electronic databases including PubMed, Sage, Springer Link, Informaworld, and Science Direct. The keywords included AIDS and mental health, mental health disorders among PLHA, mental health needs of PLHA, mental health policies, stigma discrimination, and counseling. References were examined and included when appropriate and not found on initial search. The international and national studies that significantly discussed mental health aspects of PLHA were incorporated and compared with other studies. With reference to India, data were obtained from secondary sources, such as National Family Health Survey, theoretical work, secondary analyses by experts and reports, articles, organizational reports, case studies, and gray materials.

Conceptual framework
The conceptual framework that guides the present study is illustrated in Figure 2. HIV infection is a life-threatening disease that can render PLHA vulnerable to mental health disorders. The research is conclusive that variables associated with psychosocial circumstances of PLHA, such as stigma, discrimination, and economic crisis, can cause mental health vulnerabilities. The presence of personal level variables, such as self-perceived stigma, reactions of society and suicidal thoughts, exacerbates the onset and progression of mental disorders. In addition, personal issues, such as disease-related anxiety, suicidal thoughts, occupational stress, and treatment and care issues, intensify this propensity. Knowledge of the prevalence of mental disorders may determine the type of interventions and services that are needed. These needs in turn help shape global policy for addressing mental health problems and the flow of international funds.

Findings
Mental health and HIV: prevalence and outcome
Studies have consistently reported a higher prevalence of mental health problems among HIV-infected people compared to the general population or hospital samples (Cournos & Forstein, 2000; Green & Smith, 2004; Hartzell, Janke, & Weintrob, 2008). Two categories have been identified: those with mental illness prior to HIV infection and those develop mental illness after HIV infection (Dwight et al., 2000; Goulet et al., 2000; Yovtcheva et al., 2001). Commonly reported co-morbidities included
advanced levels of clinician-rated depression (Jones, Beach, Forehand, & Family Health Research Project Group, 2003; Lipsitz et al., 1994; Miller, 2006; Pence, William, Kathryn, Joseph, & Bradley, 2006; general distress (Mellins, Ehrhardt, Rapkin, & Havens, 2000; Reece, Basta, & Koers, 2004); elevated level of PTSD (Martinez, Israelski, Walker, & Koopman, 2002; Pence et al., 2006); substance abuse (Pence et al., 2006); and general psychiatric morbidity in contrast with population norms (Milan et al., 2005; Tostes, Chalub, & Botega, 2004).

Collins, Hollman, Freeman, and Patel (2006) carried out a systematic review of studies which confirmed the high prevalence of mental disorder in HIV/AIDS care settings and treatment programs in developing countries. In Table 1, we draw from this work and describe the relevant Indian studies that identify the most prevalent mental disorders.

The five studies in Table 1 reveal that co-occurring psychiatric morbidity, including depressive disorders, anxiety, adjustment disorders, suicidal intent or attempts, and alcohol dependence, is highly prevalent among HIV/AIDS-infected individuals in India. Researchers suggest that depression leads to worse outcomes in PLHA (see also Hartzell et al., 2008). Patients with anxiety, mood, and substance abuse disorders are less responsive to antiretroviral treatment (ART) compared to PLHA without these mental health conditions (Mellins, Kang, Leu, Havens, & Chesney, 2003; Pence et al., 2006), and cause the progression of disease (Antelman et al., 2007; Ickovics et al., 2001; Mellins et al., 2003; Murphy, Marelich, Hoffman, & Steers, 2004). These disorders (especially major depression) profoundly affect adherence to highly active antiretroviral therapy (HAART) among HIV patients. Moreover, they increase vulnerability to HIV infection by provoking high-risk behaviors and it interferes with a patient’s ability to comply with protocols for the prevention and treatment of HIV infection (Treisman & Angelino, 2007). A significant number of researchers also suggest social stigma, discrimination, and social
isolation of HIV-infected individual cause greater psychological and emotional turmoil, which may ultimately lead to mental health problems (e.g., Simbayi et al., 2007; Wingood et al., 2008; Wu et al., 2008) and affect the quality of hospital care (Mahendra et al., 2006).

Mental health needs and services

The findings of this review underscore that HIV/AIDS and mental health disturbances must be treated concomitantly. Researchers have observed that due to the complex nature of medical care, patients with co-morbidity are expected to be hospitalized for longer periods and have recurrent readmissions and greater post-discharge aftercare needs (e.g., Cheng, Mijch, Hoy, Wesselingh, & Fairley, 2001). With regard to the impact of HIV/AIDS, the onset of mental health problems may manifest from the initial HIV diagnosis. Subsequently, adverse social circumstances and life stressors may exacerbate psychological symptoms while living with HIV, and certain HIV medications have negative mental health side effects (Global Initiative on Psychiatry [GIP], 2008). Difficulties may arise at each phase of HIV infection, such as during the time of testing, receiving a HIV-positive diagnosis, the symptomatic phase, beginning anti-HIV treatment, and the terminal care phase. Hence, it is crucial for PLHA to have easy access to mental health facilities to promote their health and well-being, and to prevent secondary transmission. Table 2 describes the rationale for providing mental health support services for PLHA, GIP (2006) cogently identifies the ramifications of untreated mental morbidity, which is considered both a mental health and human rights issue.

The HIV/AIDS pandemic is associated with low-treatment adherence often as a result of mental health issues as well as damaging personal, familial, and societal consequences (Table 2). These outcomes include co-occurring disorders, substance abuse, risky sexual behavior, stress on caretakers, economic breakdown/poverty, and breakdown of social support in communities. Despite the fact that mental

Table 1. HIV/AIDS and psychiatric morbidity in India.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study site</th>
<th>Sample</th>
<th>Study design</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kermode et al. (2008)</td>
<td>North-east India: Manipur and Nagaland</td>
<td>N = 74, IUD Widows</td>
<td>Cross-sectional study. No comparison group. Diagnostic/screening measures: HADS&lt;sup&gt;a&lt;/sup&gt;</td>
<td>70% experiencing a common mental disorder, such as depression or anxiety</td>
</tr>
<tr>
<td>Chandra et al. (2003)</td>
<td>South India, HIV counseling clinics and respite care centers</td>
<td>N = 68, men and women</td>
<td>Cross-sectional study. No comparison group. Diagnostic/screening measures: HADS&lt;sup&gt;b&lt;/sup&gt;</td>
<td>47% with depressive disorders; 25% anxiety disorders</td>
</tr>
<tr>
<td>Chandra et al. (1998)</td>
<td>India, HIV clinic</td>
<td>N = 51, men and women</td>
<td>Cross-sectional study. No comparison group. Diagnostic/screening measures: HADS clinical interview for ICD-10 diagnosis</td>
<td>40% with depression; 36% with anxiety by HADS; 35% with moderate anxiety and depressive disorders by ICD-10; 14% with persistent suicidal intent or attempt</td>
</tr>
<tr>
<td>Ahuja, Parkar, and Yeolekar, (1998)</td>
<td>India, general medical ward</td>
<td>N = 18, men and women</td>
<td>Cross-sectional study. No comparison group. Diagnostic/screening measures: structured clinical interview for diagnosis (SCID)</td>
<td>33.3% with major depressive disorders; 27.8% with adjustment disorder; 5% with psychotic disorder; 44.4% with alcohol dependence</td>
</tr>
<tr>
<td>Jacob, Epen, John, and John (1991)</td>
<td>India, AIDS referral and surveillance center</td>
<td>N = 46, PWA (N = 4) and HIVP (N = 42) men and women</td>
<td>Longitudinal study with two groups. Diagnostic/screening measures: psychiatric clinical interview</td>
<td>Baseline: 75% of PWA with any psychiatric morbidity and delirium or adjustment disorder; 21% of HIVP with any psychiatric morbidity. After knowledge of status: PWA, no change; 47.6% HIVP with any psychiatric morbidity</td>
</tr>
</tbody>
</table>

<sup>a</sup>General Health Questionnaire 12  
<sup>b</sup>Hospital Anxiety and Depression Scale.  
Source: Adopted from Collins et al. (2006) with updates.
health disorders are directly linked with HIV/AIDS, very little attention has been paid to this association (GIP, 2006).

Wang et al. (2007, p. 847) highlighted “disturbingly high levels of unmet need for mental health treatment worldwide, even for people with the most serious disorders”. There are undoubtedly worse outcomes in less developed countries where only a small proportion of people with serious disorders receive any form of care. Even in developed countries, approximately 50% of individuals with severe psychiatric illness do not receive adequate treatment (Wang et al., 2007). Patel et al. (2007) noted that in the low- and middle-income countries (LMICs), mental disorders constitute more than 11% of the disease burden, however, many countries invest less than 1% of the health budget to mental health services.

Numerous studies have found that mental health in developing counties has been seriously neglected, but with the advent of the HIV pandemic, researchers, policy-makers, and planners now consider mental health issues as a global health concern (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Freeman, Patel, Collins, & Bertolote, 2005; Saxena, Thornicroft, Knapp, & Whiteford, 2007). Mental health services are scarce in the LMICs and there is a dire need to address the gap in service provision (Lancet Global Mental Health Group [LGMHG], 2007; Saxena et al., 2007). Such services are particularly essential for people, like the PLHA, who are at risk of developing severe mental health disorders. Similarly, mental health in India is largely neglected and many psychiatric disorders remain undiagnosed and untreated. There are also many LMICs which lack a sound infrastructure required to support patients and provide treatment for mental illnesses (Saxena et al., 2007). Additionally, patient advocacy and mental health service provision are limited due to a lack of research evidence (Patel et al., 2007).

Although the UNGASS Country Reports (2008) highlight that the national governments of 52% of countries worldwide report that psychosocial support services are available in all districts, the non-governmental organizations report only 27% of these countries provide such services. Despite available treatment for mental disorders, the majority of the people with mental health needs in most developing nations do not receive required treatments or services (WHO, 2001). Further, there is a state of exigency calling for the integration of mental health components into the care and treatment of PLHA.

**Discussion**

**HIV/AIDS in India: assessment**

In the initial phase of the epidemic, it was reported, “Unlike developed countries, India lacks the scientific laboratories, research facilities, equipment, and medical personnel to deal with an AIDS epidemic. In addition, factors such as cultural taboos against discussion of sexual practices, poor coordination between local health authorities and their communities, widespread poverty and malnutrition, and lack of capacity to test and store blood would severely hinder the ability of government to control AIDS if
the disease did become widespread” (Ghosh, 1986, p. 29). This research review suggests that in order to promote improved public health outcomes and elicit behavioral change among PLHA in India, e.g., reduce risky behaviors, access to counseling, adequately trained medical professionals, community support, and government policies supporting mental health interventions are required.

**Programs and policies**

The international literature recommends addressing the mental health challenges of PLHA by ascertaining and meeting their mental health needs (Freeman et al., 2005; GIP, 2006; Saxena et al., 2007; Wang et al., 2007). This review of the literature finds that the data in India are not sufficient to either advocate or provide the services necessary to meet the growing mental health needs of PLHA. The challenge for the Government of India (GOI) will be to collect relevant data and develop appropriate programs to address this gap.

Clearly, the majority of persons with mental health needs in India do not receive needed treatments or services. Moreover, the mental health component is often neglected during planning and implementing AIDS interventions in the country. However, mental health needs of the PLHA could be addressed effectively through counseling, social support, and psychotherapeutic strategies (Catalan et al., 2005). Specifically, treatment adherence, depression, substance abuse, and high-risk sexual activity are significant issues that should be tackled in this population. Since HIV patients must visit clinics and hospitals regularly, healthcare providers have unique opportunities to assess these issues and intervene in the context of comprehensive care (Berg, Susan, Michelsona, & Safren, 2007). WHO (2008) also recommends that the mental health component must be incorporated within HIV/AIDS programs in the nation, which could bring about a remarkable improvement in the health of PLHA.

In 1986, the GOI initiated the NACP in 1987 with a special emphasis on surveillance, prevention and control, and testing of blood and blood products. Realizing the magnitude of the epidemic, the GOI established the NACO in 1992 with the support from the World Bank to augment and improve existing programs. Subsequently, in order to move toward decentralization and effective implementation of the program, NACO established State AIDS Control Societies. Nevertheless, to date there are no specific guidelines/policies of NACO on mental health of PLHA, there is only a cursory mention of providing psychological support and mental counseling to ART users (NACO, 2007b).

In India, “the National Mental Health Program (NMHP) serves practically as a mental health policy” (Khandelwal, Jhingan, Ramesh, Gupta, & Srivastava, 2004, p. 126). The NMHP (1982) aimed to address the inadequacies in the mental health infrastructure in order to tackle the burden of mental illness in the community. The strategies include integrating mental health with the general health systems, provision of tertiary care for treatment of mental health disorders, eradicating the associated stigma, and protecting the rights of the mentally ill patients (National Institute of Health and Family Welfare [NIHFW], 2009). However, the NMHP does not specifically deal with the mental health needs of PLHA.

The available data suggest that the main problem facing the country is the severe deficiency of human resources. It is estimated that for a population of 1 billion, there are only 3500 psychiatrists. This number is unequally distributed between urban and rural areas with three-fourths concentrated in the urban areas. The former Health Minister had admitted that there is a shortage of 1600 psychiatric social workers (PSWs) and 9000 psychiatric nurses (cited in Chatterjee, 2009). However, the Eleventh Five Year Plan (2007–2012) of the country has prioritized mental health and approved INR 4740 million. The funding shall be utilized for establishing 11 centers of excellence for mental health and neurosciences. Additionally, it is expected to support the addition of “100 psychiatrists, 400 clinical psychologists, 400 PSWs, and 800 psychiatric nurses to India’s health workforce each year” (p. 1161). Yet information is needed to help integrate trained human resources into successful provision of services and support.

**Conclusion**

There are few inadvertent barriers in the implementation of mental health policies in a country. There is a lack of sensitivity regarding mental health issues in India, and the country is short on adequate resources and trained personnel to carry out the provisions of such policies. Moreover, the availability of counseling and psychiatric services is inadequate. There is high prevalence of mental disorders amongst PLHA and the importance of mental health intervention must not be undermined. The most important role of mental health providers is to understand the psychosocial and sociocultural context of HIV, alleviate mental health problems, and ensure treatment adherence as well as prevention. Mental health
Providers should be an indispensable part of the multidisciplinary treatment team.

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