

# Factors affecting psychosocial well-being and quality of life among women living with HIV/AIDS

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## Abstract

Women who are infected with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) represent a major public health priority due to the disease impact on health, family, and society. Despite the growing number of empirical studies in this area, particularly from developing countries, there are few review articles that explore the psychosocial challenges faced by women living with HIV/AIDS. This clinical review describes prominent factors that influence treatment and quality of life among this target group. Implications and recommendations highlight therapeutic interventions that provide immediate psychosocial and psychophysical support. The review also proposes a conceptual model that may serve as a psychosocial management tool for mental health practitioners in developing countries who counsel women living with HIV/AIDS.

Keywords : HIV/AIDS; Stress; Stigma; Coping; Social support

## Introduction

Globally, the human immunodeficiency virus (HIV) pandemic has infected approximately 35.3 million persons, where women constitute nearly half of this population (1). When compared to their male counterparts, women living with HIV experience greater stigma (2), significant decline in quality of life (QOL) (3-5), and greater incidence of psychopathology and psychiatric co-morbidity (6-8). In the developed world, where HIV has changed from a sub-acute and fatal infection to a chronic illness, largely due to the initiation of highly active antiretroviral therapy (HAART), health priorities now emphasize early identification and

management of psychosocial issues that ensure better treatment and QOL (9).

In India, the National AIDS Control Organization (NACO) reported that 2.9

million people are living with HIV/AIDS (PLWHAs), where 39% are women (10). Although the rapid spread of infection among women has largely been attributed to heterosexual contact (10), overall awareness about unsafe sexual practices and HIV transmission is as low as 2.7% [3]. Without appropriate health promotional campaigns to increase knowledge about sexually transmitted infections (STIs), women may continue to be a high-risk group for STIs and related psychiatric co-morbidities (11).

This review aims to synthesize the literature related to psychosocial issues faced by women living with HIV and identify the factors influencing their treatment access and quality of life. Although social stigma and support among women living with HIV have been widely published, there is limited evidence about the role of coping mechanisms, quality of life and well-being. The review also proposes a conceptual model that may serve as a psychosocial management tool for mental health practitioners who counsel women living with HIV/AIDS.

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## Results

### I. Stress

Unlike individuals afflicted with other chronic illnesses, PLWHAs experience multiple stressors. Psychologically, they experience distress that roots from concerns about disclosing their personal HIV/AIDS diagnosis, living with a chronic illness, complex medical treatments, and fear of infecting a friend or family member (12-14). Physiologically, they may endure diminished appetite, insomnia, weight loss (12), and weakened immunological resilience that hastens AIDS onset and progression (15-17). Both physical and psychological stress levels induce different complications in PLWHAs, such as substance abuse, risky sexual practices, suicide attempts, and reduced adherence to pharmacological treatment (15, 18, 19). However, the nature and causes of stress related to HIV/AIDS infection among women differ from those reported among men (13, 18).

Routine challenges in HIV-positive women include enduring systemic forms of oppression and marginalization, when compared to HIV-negative women (20). In a comparative study among urban and rural, HIV-positive (N=216) and HIV-negative women (N=243), Gupta et al (21) found that HIV-positive women were significantly more likely to report marital dissatisfaction, history of forced sexual intercourse, domestic violence, depressive symptoms and husband's extramarital sexual affairs, when compared to HIV-negative women. Various social, cultural and economic factors may play a significant role in contributing to HIV transmission among Indian women, such as power hierarchy in society, child marriage, lack of awareness about transmission (22), inability to freely communicate about sex and sexuality, pressures of bearing the family heir, implicit marriage threats for the infertile woman (23), and sexual victimization and coercion (24).

An extensive review by Jayarajan and Chandra (25) highlighted the higher HIV/AIDS prevalence among women who reported sexual coercion in comparison to those women who did not indicate sexual coercion. Abused women reported high risk sexual behavior and

consequently had higher risk of HIV transmission. Socio-cultural norms and marriage subservience reinforced by violence and abuse can compromise the woman's ability to protect herself from illness or seek medical care.

#### 1.1. Stigma and discrimination

Herek et al (26) defined HIV stigma as "the prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or HIV and at the individuals, groups, and communities with which they are associated" (p. 36). HIV stigma includes the perception of societal attitudes toward HIV as well as the personal experience of attached stigma (27), or *felt stigma* and *enacted stigma* (28). Felt stigma (perceived or internal stigma), is understood as the individual's real or imagined fear of persecution and sense of community disapproval, upon being labeled (29).

Women reported higher rates of both felt and enacted stigma, especially from intimate partners (30). In India, Newmann et al (31) reported that as high as nearly 90% of women under HIV care were monogamous, where sexual intercourse with their husbands was their primary risk factor for HIV/AIDS transmission. Once infected with HIV/AIDS, women have been reported to face severe abuse, discrimination and stigmatization within the home and in society, limiting their ability to access HIV/AIDS treatment and resume a life with dignity in the Indian society. Unlike developed countries, India practices abandonment of such women in cases of the husband's death due to HIV/AIDS infection (32).

Research highlights that women living with HIV/AIDS perceive maximum stigma and discrimination by the immediate family members and friends upon disclosure of their HIV status (2, 33-35). Lack of regard from staff in municipal places like hospitals, welfare offices and prisons has been identified as another factor for perceiving discrimination (36, 37). When health care providers display stigmatizing attitudes towards these patients, withdrawal often minimizes the scope of how this population seeks treatment (38).

An HIV-positive diagnosis has implications on a woman's moral life (39). A married woman who was infected by her husband could be regarded as being an innocent victim. However, a woman with multiple premarital sexual relations may be stigmatized with immorality (40).

One study examined stigma dynamics linked to HIV/AIDS infection, highlighting that those PLWHAs who were infected through sharing needles or through sexual intercourse with multiple partners were viewed more negatively than those who were infected through sexual intercourse with one partner (26). Other significant factors contributing to stigma towards women living with HIV are low education levels (41) and low income (42).

Compounding factors of illness and social discrimination may yield high risks of developing symptoms of depression and anxiety among women (19, 34, 43-46). Socially, this could prevent women from disclosing their HIV status (2, 47), which would further likely inhibit their ability to seek and adhere to treatment programs (48-50). More specifically, at an individual level, this may influence metastasis (51).

### 1.2. Intimate partner violence

Research highlights that violence and sexual coercion by intimate partners are major factors for HIV diagnoses among women (52-55). Independent of the reason underlying HIV/AIDS diagnosis, women have reported experiencing several forms of discrimination and violence from intimate partners. Several global studies have reported higher instances of domestic violence in women diagnosed with HIV/AIDS (56-59).

### 1.3. Sexuality and reproductive health

Sexuality is a fundamental aspect of every individual's life. The World Health Organization (WHO) estimates that 17.6 million women living with HIV/AIDS were reported to be in their childbearing age (1). Along with familial and societal discrimination, medical disclosure of HIV-positive status causes elevated stress because of its impact on their sexual and reproductive health, including pregnancy, sexual intercourse, contraception and breastfeeding (60). Both

marriage and childbearing, which are considered to be the vital aspects to women's life, may be curtailed because of their HIV-positive status (61).

In one general survey conducted among PLWHAs in Argentina, women reported a heightened need to experience motherhood. Furthermore, it was revealed that 55% of women had children after their HIV/AIDS diagnosis (62). Despite knowledge about the risk of vertical transmission and the possibility of orphan hood, they desired sexual intercourse and motherhood (63, 64). Another study that targeted HIV-positive Brazilian women showed that they considered breastfeeding as an essential component in their role during the childbearing process (65).

### II. Social support

Social support is broadly defined as 'assistance and protection provided to others' (66). Studies have indicated the necessity for social support among women living with HIV/AIDS (2). Research findings have depicted that women with social support from family members show higher levels of resilience towards the illness (36), which correlated with enhanced mental health (67-69) and treatment adherence (70, 71).

Greater emotional support has been associated with reduced negative and increased positive affect (72, 73), reduced psychological distress, and higher quality of life and self-esteem (74, 75). Those perceiving low levels of social support were reported to experience increased distress (76).

### III. Coping

Lazarus and Folkman (77) defined coping as the "constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person" (p.141). For many women, an adaptive coping strategy allows them to incorporate the HIV diagnosis into their identity (78) and results in better treatment adherence (70). A positive relationship between passive (or avoidance) coping strategies and negative mental

health outcomes has been reported (16, 79).

Studies have further identified factors that facilitate adaptive coping among PLWHAs (e.g. physical ailments, feeling responsible for children, support group participation, forming supportive relationships) and reduce levels of perceived stigma and discrimination (80). Also, feeling forgiven and forgiving others have been highlighted as being an effective mode of coping with the HIV-positive status. Expressing forgiveness in the context of one's own HIV infection was associated with decreased likelihood of placing others at risk through unprotected sexual intercourse (81).

Individual resilience or psychological strength is another important factor for coping with negative situations. Taylor's (82) Cognitive Adaptation Model proposes that mastery and control over one's illness and self-esteem are instrumental in adapting to illness. Research among PLWHAs also substantiates this model, demonstrating that greater psychological strength and resourcefulness are associated with increased social support and decreased depression (71, 83, 84).

#### IV. Psychiatric co-morbidity

Studies have reported a greater incidence of psychiatric co-morbidity, including clinical depression, among women living with HIV/AIDS, when compared to their male counterparts living with HIV/AIDS (6, 85). Cross-cultural studies have highlighted that the frequency of major depressive episode among women living with HIV ranges from 4.5% to 61% (71, 86-89). Van Servellen et al (90) reported that fatigue was the most frequently reported depressive symptom for 98% of African-American women living with HIV. Depression indexes using Beck Depression Inventory (BDI) stressed that social interactions and physical symptoms affected women living with HIV (91).

In addition, researchers noted that African-American women living with HIV/AIDS reported more psychiatric symptoms (92, 93) than their HIV-positive male counterparts. In an American cohort, HIV-infected women reported greater levels of generalized anxiety (4) and post-

traumatic stress disorder (94). Studies from India showed that women living with HIV had a high risk of developing post-traumatic stress disorder, depression and anxiety spectrum disorders, when compared to men living with HIV (2, 95, 96).

High risk behaviors were also found prevalent among African-American women attending AIDS counseling centers (97). Luseno et al (98) reported high rates of substance abuse among South African women living with HIV. General psychological distress that failed to meet the criteria of a psychiatric diagnosis was commonly found among women living with HIV (68, 69, 99-102).

Empirical studies show that the high prevalence of psychiatric disorders among women is associated with various factors, namely, high levels of perceived stress (103), events of discrimination (44), low social support, and low income (94, 104). Psychiatric morbidity in women living with HIV resulted in reduced utilization of health services, poor adherence to anti-retroviral treatment (98, 105), high risk sexual behavior (106), poor quality of life (104), increased decline in CD4+ count, and faster metastasis (107, 108).

From this review, it is evident that these factors are inter-related. These outcomes can be either positive (e.g. better quality of life, well-being, and treatment adherence) or negative (e.g. poor quality of life, well-being, and poor treatment adherence).

#### V. Barriers in seeking medical help

Despite universal and free access to antiretroviral treatment (ART), women infected with HIV have reported reduced treatment access (109, 110) and ART adherence (75), when compared to men. Studies reported that women have experienced enhanced ART side effects (111). Challenges encountered in accessing treatment may be due to lack of awareness regarding the illness and insight about HIV/AIDS status, transmission mode, and treatment access (98, 112-114).

Studies also show that HIV-positive women who had three or more stressful life events during the previous six months

were at least 2.5 times more likely to have missed a medication dose within the past two weeks, when compared with women without such events (115). Researchers also indicated that women with young children were more likely to delay seeking medical care due to caregiving responsibilities, when compared to men (116). In addition, one study conducted in South Africa reported that HIV-positive women who reported drug abuse had reduced likelihood of seeking health services (98).

#### QOL and well-being

The WHO (1995) (117) defines QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 1403). Researchers have suggested the need for empowering afflicted women as a strategy for improving health-related outcomes (118). Women were found to be more vulnerable towards increased HIV/AIDS symptoms, demonstrated poorer functioning and had greater disruptions in physical and psychosocial well-being (119). However, women living with HIV were further reported to be more accepting and forgiving when afflicted with the illness, when compared to men (120, 121).

Recent studies in different regions of India have examined QOL among HIV-infected men and women, and have documented gender-based differences (50, 122, 123). Women reported significantly lower QOL scores than men (122). Men reported better QOL in the environment domain, while women had higher scores on the spirituality, religion, and personal belief domains (81).

Among various socio-demographic variables, full-time employment had a positive relationship with QOL (4). European studies have highlighted challenges faced by a single parent or a new immigrant to the country as being significant predictors of lower mental health-related QOL among women living with HIV/AIDS (124). Age and marital discord were also found to be inversely related to health-related QOL (124, 125).

Women with HIV are known to experience frequent episodes of low self-worth, self-esteem and poor resilience, which subsequently results in QOL decline (126). Among women with HIV, better mental health-related QOL was predicted by practical coping style and increased social support (127).

#### Discussion

Women diagnosed with HIV/AIDS face multiple risk factors, such as the HIV/AIDS diagnosis, physical effects on QOL, stigma and discrimination, fear of rejection and violence from intimate partner, and concerns about sexuality and reproductive health. Various socio-economic factors, such as gender-specific roles related to motherhood, homemaking, socio-economic inequalities, and minority grouping, determine the degree to which stigma is faced by women living with HIV/AIDS. They perceive heightened discrimination in health care settings and intimate relationships. These factors may have personal and social implications, such as poor psychological well-being, lack of treatment adherence, and high risk sexual behaviors. Sexual and reproductive health care also greatly affected due to higher stress levels in women living with HIV/AIDS.

Empirical studies have shown that various mediating factors, such as social support, individual coping and resilience, are instrumental in reducing the impact of this stress. Women have been reported to experience a higher need for social support when compared to male counterparts. A positive relationship has been linked between social support and QOL among women living with HIV/AIDS. Effective coping strategies among women must accompany acceptance of the HIV diagnosis, so that they can develop higher resilience and enhance self-esteem toward increased QOL and general well-being.

Higher prevalence of psychiatric co-morbidities among women living with HIV/AIDS has also been reported. Although depression has been reported as the most prevalent condition among the afflicted group, anxiety spectrum disorders, psychological distress and substance dependence have been highlighted as other major diagnostic conditions. Social discrimination, poor social

support and inadequate coping mechanisms may be underlying factors that have influenced the high prevalence of these psychiatric diagnoses.

These factors are known to have lasting consequences on treatment adherence and QOL among women living with HIV/AIDS. Though ART is instrumental in improving life expectancy, overall functioning of women living with HIV may be disrupted because of poor physical and psychosocial QOL, which can lead to faster metastasis.

Research within the Indian culture elucidates the gender disparity with respect to psychosocial issues faced by PLWHAs. Within this socio-cultural scenario, women are left in a state of compulsion to conceal their illness due to fear of spousal and familial rejection. This has been reported as a major barrier in treatment access and intervention.

Psychosocial issues faced by women living with HIV/AIDS have emerged of significant and immediate concern among their health care providers. Based on the Transactional Model of Stress and Coping by Lazarus and Folkman (77), we propose a conceptual model for the psychosocial issues faced by women living with HIV/AIDS (Figure 1). This model will provide a comprehensive understanding about the various factors affecting psychosocial well-being and QOL among women living with HIV/AIDS.

Future directions

Until recently, health care providers working with people at risk or afflicted with HIV/ AIDS have mainly focused on various primary- and secondary-level psychosocial interventions. Women at risk for developing HIV were prompted to use condoms in primary prevention strategies (128), whereas counseling services were provided on

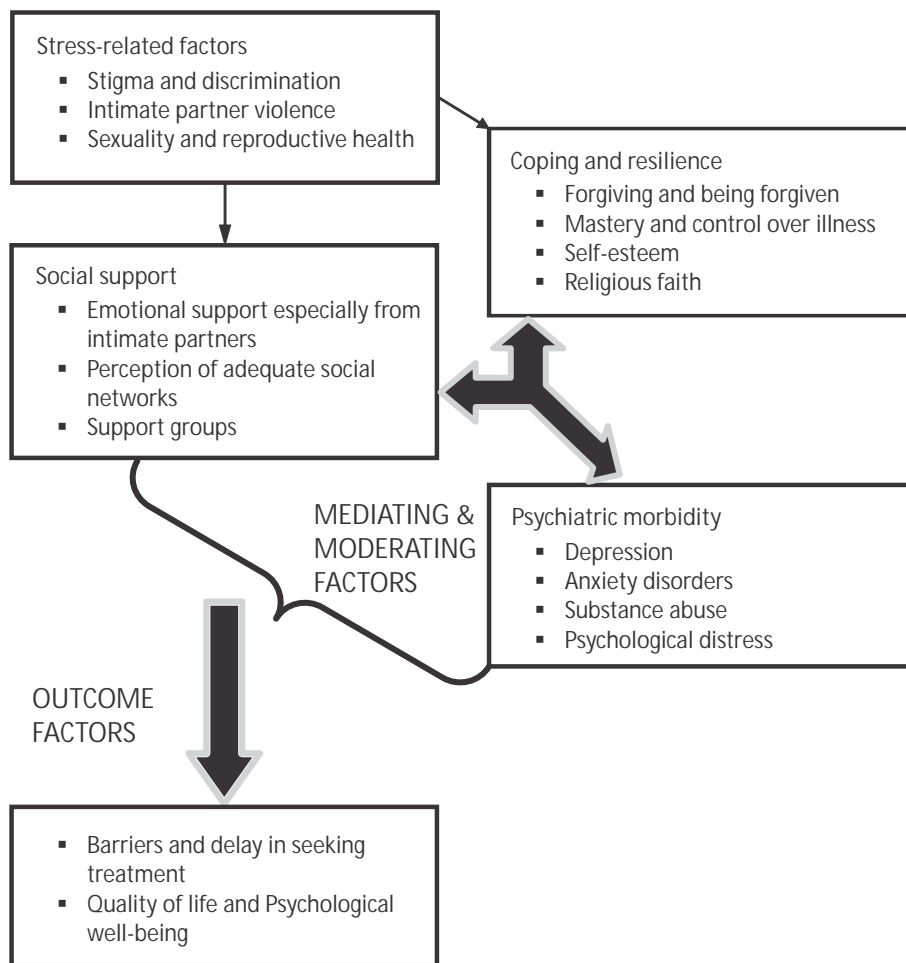


Figure 1 : Diagrammatic representation of the conceptual model

family planning and contraceptive methods to prevent HIV transmission from the target women to others in secondary prevention strategies (60, 129, 130). Although few studies have targeted tertiary-level psychosocial interventions, these strategies were more commonly found among men living with HIV than among women (131, 132). The lessened focus on tertiary-level interventions could be attributed to the lacunae in public health policies and intervention strategies addressing the mental health needs of PLWHAs (133).

A recent WHO report (134) suggests the need for a comprehensive psychosocial intervention among people living with HIV that can include individual and group counselling, peer support groups, family counselling and support, and home visits to reduce the risk of HIV transmission, promote adherence to prophylactic and therapeutic regimens, and minimize the socioeconomic

impact of HIV on households. Literature clearly suggests that the high risk sexual behavior, psychological well-being, QOL and treatment adherence among women living with HIV are dependent on various psychosocial factors. The socio-cultural and economic scenario in which these women live determines the amount of gender disparity faced by them. In addition to aiding in educating about STI transmission, health care providers should be able to recognize and manage psychosocial conditions among women living with HIV, which will enhance overall QOL, well-being and treatment adherence. Future research should highlight culturally appropriate, effective psychotherapeutic interventions among women living with HIV. To achieve this target, mental health professionals in HIV clinics must sensitize and train other health professionals on psychosocial factors as well as provide appropriate psychotherapeutic interventions to women living with HIV.

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