Article

Women Living with HIV/AIDS: Psychosocial Challenges in the Indian Context

Journal of Health Management
19(3) 474–494

SAGE Publications
sagepub.in/home.nav
DOI: 10.1177/0972063416666347
http://jhm.sagepub.com

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Abstract

The main aim of this review article is to outline the factors linked to vulnerability of women to HIV infection and to understand the challenges and possible management of HIV among women. The review is a theoretical endeavour to understand women's experiences of living with HIV. This review primarily focuses on studies in the Indian set-up, but to further substantiate the arguments and describe the relevant concepts it also takes into account literature from other cultures.

On the basis of studies included in this article, it can be surmised that women are more susceptible to HIV due to cultural barriers, health vulnerabilities and social structures. They show less awareness about the treatment facilities, prevention strategies and perceived risk of infection. Women have to face numerous challenges after the infection, such as lack of social support, a higher level of stigma and discrimination, decreased quality of life, mental health issues and adverse coping. To prevent the spread of HIV among women as well as men, it is necessary to plan strategies which deal with empowerment of women, education and awareness regarding the vulnerabilities and knowledge and challenges of HIV infection. There is also a need to address the management of HIV among the infected and even those at risk. This article describes the possible interventions based on existing literature. The review also attempts to suggest certain future directions for the research.

Keywords

Gender, HIV/AIDS, vulnerabilities, awareness, challenges

Introduction

According to an estimation given by the National AIDS Control Organization (NACO, 2014), the number of people living with HIV/AIDS (PLWHA) in India is 2.089 million among which 0.816 million are women. The major population of PLWHA currently comprises the age group of 15–49 (NACO, 2014).

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The National AIDS Control Programme (NACP) has several interventions and prevention strategies targeting the people living with HIV as well as the general population. These efforts have yielded satisfying results demonstrating a reduction of 57 per cent in the new infections reported annually (NACO, 2014). Despite all these achievements, the United Nations Programme (2014) on HIV/AIDS in its report mentions that India has a large number of people (third highest in the Asia-Pacific region) living with HIV and 51 per cent deaths related to HIV/AIDS in Asia are reported from India. According to the World Health Organization (WHO, 2013), a major concern that deserves urgent attention is the increasing rate of infection among women; the number of women living with HIV is now coming close to that of men. The prevalence rate of HIV among adults is 0.27 in which women constitute 0.22 and men constitute 0.23 (NACO, 2014). Initially, the infection was mostly reported among the high-risk groups but now according to NACO Annual Report 2013–14, it has spread to the general population which was traditionally considered safe. Women and adolescent young girls appear to be more susceptible to HIV infection due to various biological and sociocultural factors prevalent in the Indian patriarchal society. Cultural norms, gender roles in society and reproductive tract infections (RTI) increase their vulnerability to the infection. Thus, there is a need to explore women's issues separately in the context of HIV as the women in India are already in a position of disadvantage. As noted by Dixit (2011, p. 1), 'Women's position in most societies is marginal and this leads to gendered discourse and stereotyping. These in turn lead to social constructions and social representations regarding women's and men's health.' This situation further complicates for women with HIV due to issues of morality and stigma.

This article attempts to present the crucial aspects of gender and HIV/AIDS with a major focus on studies in the Indian context. To fulfil this purpose, it primarily focuses on literature from the Indian cultural context, and wherever necessary, from other cultures and takes into account women's vulnerability to HIV: biological, social and cultural aspects. It explores the problems faced by women in approaching the treatment facilities, awareness among women, beliefs and attitude towards HIV and perception of risk. This article focuses on issues of stigma, discrimination, mental health, coping and quality of life among women living with HIV. It reports the literature which explores factors affecting the life of women living with HIV. Finally, based on the results of the review, the article provides inputs for future research and suggestions for intervention targeting the challenges encountered by women living with HIV.

Method for Literature Search

Published literature relevant for this article was searched through electronic medium using JStor, Science Direct, EBSCO Connections and Google Scholar. To perform a broad search, the keywords used were 'HIV' and 'Gender'. After initial readings of the selected articles, the issues faced by women were identified. In the second phase, literature search was done in the context of identified issues in relation to HIV/AIDS and women. The main focus of discussion is the Indian context. Studies from other cultures have been taken into consideration in order to substantiate the discussion. Results of the review have been discussed in following section.

Results

Relevant factors identified on the basis of review are organized into following sub-sections.

Gender

Gender and sex are two different aspects: Sex refers to the biological sexual differences, whereas gender is a social construct. Gender differences exist in relation to position, ascribed power, social roles, responsibilities and the nature of obligations of women and men in a society. Gender roles are so deeply rooted in the culture that people are born as males and females, but they learn to behave like men and women. These learned behaviours determine gender identity, roles and responsibilities of the individuals in the society. Gender roles and inequalities prevalent in societies make the situation even worse for women living with HIV/AIDS (WLHA). Women with HIV have to take dual responsibility, that is, self-living with HIV and as caregivers to husband, child or other family member (Hackl et al., 1997). Women emerge as primary caregivers in the Indian set-up and they receive very less support from their parental as well as marital homes (Kohli et al., 2012).

Women and HIV/AIDS Vulnerability

The vulnerability of women to HIV infection is due to three main factors: biological, social and cultural.

Biological Factors

Women have a receptive role in sexual relationships; this makes them more vulnerable biologically (four times more) to HIV infection than men (UNAIDS, 1998). The probability of a woman getting infected from a male with HIV is more as compared to vice versa (Higgins, Hoffman & Dwarkin, 2010). Adolescent girls are more at a risk of contracting HIV because their genital tract is immature. Forced sex is also among one of the factors, as sometimes it results in genital tearing making ways for the virus transmission. Women are also more vulnerable to HIV infection because of changes in hormones, physiological reasons, vaginal ecological features and higher rate of sexually transmitted disease (Quinn & Overbaugh, 2005). While biological factors are important, they alone cannot be held responsible for HIV transmission.

Social Factors

Social situations and expectations regarding gender roles in societies can also increase the risk of HIV transmission. Stigmatization (Tarakeshwar et al., 2007; Thomas et al., 2005), poverty (Kambou et al., 2007), lack of awareness regarding the ways related to HIV transmission (Pallikadavath et al., 2005) and lack of access to resources (Ghosh, Wadhwa & Kalipeni, 2009) are among the major challenges that are faced by Indian women when it comes to the risk of HIV transmission. Migration is considered to be an important factor for HIV infection in India; people who migrate for employment are more at risk of acquiring HIV and even putting their wives at risk back home (Population Council, UNDP & NACO, 2011). According to statistics, 75 per cent of women in India who are HIV positive are the ones whose husbands travel far due to work (such as truck drivers or migrant labourers) (UNAIDS, 2013).

Violence against women is another important factor among social factors responsible for women's vulnerability to HIV. Violence against women is, 'Any act…that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life' (UN Declaration on the Elimination of Violence against Women, 1993, A/RES/48/104). Several studies have shown that people with a history of gender-based violence (GBV) are at a higher risk of being infected with HIV (Gwandure, 2007; Kiarie et al., 2006; Straten et al., 1998; Wu et al., 2003). Researches around the globe reveal that experience of intimate partner violence (IPV) by women increases the likelihood of their acquiring HIV when compared to women who do not have such experience (Dunkle et al., 2004; Maman et al., 2001; Silverman et al., 2008). Sexual assaults and transactional sex destroy women's ability to negotiate safe sexual behaviour (Blanchard et al., 2005; El-Bassel et al., 2001; Miller, 1999). Gender-based violence is not only a risk factor for HIV but even vice versa is true. Several studies have reported higher rate of GBV among those women who are living with HIV (McDonnell, Gielen & O'Campo, 2003; Shelton et al., 2005). Fear of violence also decreases HIV testing and disclosure behaviour (Decker, Silverman & Raj, 2005; Koenig et al., 2002). A study on slum dwellers in Chennai demonstrated that those who experienced GBV chose to live with unsafe practices that increased the risk of HIV infection instead of being at the receiving end of violence from their partners (Go et al., 2003). Gender-based violence and HIV infection are linked to each other closely and share a bidirectional relationship.

Cultural Factors

Gender inequalities and role expectations from both the genders are such that in the Indian culture both men and women are at a risk of acquiring HIV infection. Relationship status is another crucial factor due to which both men and women are at a risk of acquiring HIV. Even if women practice monogamy, they are not aware of their husbands' sexual relation outside marriage, which increases the risk of infection. An ethnographic study shows that women choose being in the high-risk relationship over moving out of it, as the socio-economic consequences of the latter are more difficult to deal with (George & Jaswal, 1995). Many men practice polygamy or have multiple sexual partners because of several expectations from them. Even if a woman has only the husband as her sex partner, she has very less right and control over her husband's sexual relations (Clark, Bruce & Dude, 2006). Polygamy or multi-partner sex increases the risk of HIV among women (Saddiq et al., 2010). A study in the antenatal clinics in India reveals that two-thirds of people who visit female sex workers also have a regular sexual partner and therefore they pose a threat of HIV to themselves as well as to their regular partners (Ananth & Koopman, 2003). Women in India have very few rights over sexual practices. Studies have reported that they never ask their husbands to use condoms even if they know it is necessary and they are at a risk of acquiring HIV (Lawrence & Brun, 2011; Mahajan, 2008). Married women who were previously considered at low risk for acquiring HIV infection and were not a part of vulnerable groups, have emerged as an affected group (Gangakhedkar et al., 1997). Prevalent social and cultural expectations play a vital role in the formation of incongruous relations. In the Indian context, marriages are mostly arranged by parents who are unaware of their children's serostatus due to the stigma linked to HIV/AIDS; this further results in forming incongruous dyads (Newmann et al., 2000). In some of these cases, the infected partner does try to protect the other partner from contracting the HIV infection, but sometimes the societal pressure on these couples to have children is so much that they are forced to take the risk. Sometimes when they have to make a choice between the stigma of being HIV positive or being childless, they choose the former (Solomon et al., 2000).

There are power differences between men and women in most societies. Women are forced into marriages, not allowed to ask for divorce and have to suffer induced polygamy by the husband. These factors sometimes lead women into situations responsible for contracting HIV (UNAIDS & WHO, 2004). Economic decisions and resources are also controlled by the men in the family; these power differences do not leave much choice to the women other than accepting the decisions of their male partners. Early marriages, especially of young girls to older partners, result in power imbalance and control over sexual activities by the male (Population Council, 2008). According to the United Nations Children's Emergency Fund (UNICEF, 2014), half of the child brides in the world are from South Asia of which India accounts for 33 per cent. This puts forth that adolescent girls are more at risk of HIV (Santhya & Jejeebhoy, 2007) and if the husband is much older, then the risk increases even more (Clark, 2004). These are major factors because of which women are unable to negotiate for safer sex within marital relationships though in the recent past there have been several interventions to change the situation (Ghosh, Wadhwa & Kalipeni, 2009).

The factors discussed above play an important role in spreading the virus among women; along with these factors other aspects that deserve attention are attitude, awareness, treatment and prevention. The next section of this article will focus on the attitude towards HIV/AIDS and WLHA, awareness about HIV and the ways to prevent this virus from spreading further. This section will also take into account the difficulties and challenges women have to face while approaching for treatment and other care facilities.

Awareness, Treatment and Prevention

Voluntary testing of HIV status is the most recommended strategy for HIV prevention, but people in India hardly ever go for voluntary testing. In almost all cases, people go for testing when they are suggested to do so by the doctor. This usually happens after prolonged illness or after the diagnosis of one partner or a parent (in case of a child). Joseph et al. (2010) found that HIV testing for men under medical care was generally suggested by health care professionals if required. Men are advised to seek testing in private clinics and by the private practitioners. Women are most likely to be tested in public hospitals on the advice by a family member for clinical testing. Testing is advised for women when they are pregnant or when the husband is positive. When men are tested in private sectors, there are chances of receiving pretest counselling more than women. Men directly receive the information about their serostatus by the health professionals; this is irrespective of the sector in which the test is conducted. Women have shown less interest when it comes to HIV testing. There are several reasons behind this but the stigma associated even with the testing of HIV is one of the major reasons responsible for discouraging people from going for voluntary HIV testing.

It is yet not possible to cure HIV completely, but the advancement and progression of the virus in the body can be obstructed with the help of proper antiretroviral therapy (ART) and adherence to the prescribed lifestyle. Antiretroviral therapy inhibits the virus from spreading further and causing damage to the immune system. This would thus enhance the body's capacity to fight against various infections and illnesses. It has been reported that people are aware of HIV, but the awareness about testing, treatment and government services is low (Beattie et al., 2012). Women in India, who learn their serostatus during pregnancy, may get to know their being HIV positive before men. Many Indian women at a risk of acquiring HIV may not go for testing or to seek ART and other forms of clinical care even after they are tested positive for HIV. They are mostly worried about issues of confidentiality due to fear of rejection and negative responses from the family members and society (Roger et al., 2006). Studies have

identified that sometimes women who are asymptomatic are diagnosed earlier in the course of illness as their partners seek treatment and care for opportunistic infection at an advanced stage (Gangakhedkar et al., 1997; Newmann et al., 2000; Solomon, Card & Malow, 2006). Treatment seeking at an ART centre is also discouraged by several factors, such as the location of the ART centres which are located only in the district hospitals, lack of proper transport and cost of transportation. Context of life circumstances of women and related factors affect the use of these services. Poor homes, lack of education, scarce resources and individual-level attitudes which are shaped by past experience and community response, all influence treatment-seeking behaviour. According to the United States Agency for International Development (USAID, 2009), 'Delays in seeking appropriate care, difficulties in physically accessing services, and facing serious breakdowns in services at the facility level have been noted as the three crucial barriers that inhibit access to health care' (p. 10). In India, treatment-seeking behaviour is also affected by the prevalence of stigma in health care settings. A study by Ekstrand, Ramakrishna, Bharat and Heylen (2013) reports that stigma in health care settings is symbolized by conditions such as obligatory test for female sex workers and patients undergoing surgery.

Women adhere to the treatment physically as well as psychologically in a better manner when compared to men, but they are not encouraged to take proper treatment due to societal pressure and financial problems. Women are caregivers of family and their illness brings an additional physical, mental and emotional strain (Iwere, 2000). Women's health-seeking behaviour shows that women wait longer to seek health facilities than men (Türmen, 2003). Several studies show that women adhere better to the treatment than men but they suffer more from lack of awareness and comprehensive knowledge about HIV.

Knowledge and awareness about HIV are extremely necessary for the effective treatment and management of the illness as well as its prevention. Among the important factors fuelling the spread of HIV is the low awareness about the modes of transmission (UNAIDS, 2004). This seems to be true for all age groups and classes of women. Proper knowledge about the modes of infection can only help in the reduction of transmission and also the stigma attached to the illness. A survey in 13 states of India revealed that only one in every six married women had heard of AIDS (Balk & Lahiri, 1997). Female adolescents are significantly less knowledgeable about HIV/AIDS when compared to male adolescents (Sogarwal & Bachani, 2009). A qualitative study among female youths in Delhi and Hyderabad slums indicated low level of awareness and lack of information about HIV (Ghosh, Wadhwa & Kalipeni, 2009). Lack of proper knowledge also exists among schoolgirls even in the wake of compulsory sex education. A study observed that more than one-third of student participants of that study had no accurate knowledge of the signs and symptoms of sexually transmitted diseases (STDs) other than HIV/AIDS (McManus & Dhar, 2008).

In addition to this, the situation is not much better when it comes to the awareness among women receiving treatment at the ART centres. Women are less aware regarding HIV and other STDs when compared to men (NACO, 2008).

A study among women receiving ART in Maharashtra shows that 70 per cent of women in the sample know about vertical transmission, but only 10 per cent of them were aware of the ways of prevention (Vlassoff et al., 2012). Several organizations working in the field and making significant efforts towards PLWHA have recommended avoidance of all breast-feeding when replacement feeding is economical, reasonable, adequate, supportable and secure. Otherwise, exclusive breast-feeding is recommended for the earlier months of life (UNAIDS, WHO & UNICEF, 2009). One major issue in implementation of these guidelines is the low awareness and knowledge among the majority of WLHA about the advantages and disadvantages of infant feeding (Shankar et al., 2005). There is a need of appropriate knowledge and awareness not only among those living with the virus but also among the general

population. Adequate information about HIV, its modes of transmission, prevention and management will result in decreased stigma in the society. Stigma acts as a major barrier in disclosing one's serostatus to others.

Disclosure regarding one's serostatus is considered to be a critical decision. Such a decision is difficult since it can result in either positive or negative consequences. Factors that may influence this decision are fear of anticipated discrimination and breaking of relationships as well as anxiety about possible physical and verbal abuse. People may resist disclosure in order to protect themselves and their family from stigma. Non-disclosure of HIV status in several countries is criminalized under law (AIDS Law Canada, 2014; American Bar Association, 2011; BASHH & BHIVA, 2013). The decision of not disclosing one's serostatus is governed by multiple factors and prior experiences (Wei et al., 2012). Disclosure of HIV status to intimate partners enables them to make informed reproductive health decisions (Kalichman & Simbayi, 2003; Taraphdar, Dasgupta & Saha, 2007). In the Indian context, group and family associations play an important role in determining an individual's self-image. Therefore, disclosing one's serostatus results into greater risk when compared to the cultures where such associations do not play such a vital role. Thus, in India non-disclosure is preferred over revelation about one's seropositive status (Chandra, Deepthivarma & Manjula, 2003; Krishna et al., 2005). In India, the prevalent cultural and social norms restrict women's rights in general. Therefore, HIV positive men can conceal their HIV positive status from their intimate sexual partner without any fear of consequences (Seymour, 1999). Additionally, in such cultures, it becomes very difficult for women to voluntarily get tested for HIV and disclose serostatus to their male sexual partners and families. HIV is often linked to immorality, which in turn adds to stigma and discrimination (Bharat, Aggleton & Tyrer, 2001). In case a woman is tested earlier than her husband, then she is mistrusted and her moral character is challenged (Mawar et al., 2005). In a recent study, it is reported that most disclosures among PLWH are involuntary and women showed less readiness to declare their serostatus as the consequences can be potentially risky (Patel et al., 2012).

It has been observed that up to one-third of individuals do not reveal their serostatus to their partners after being diagnosed with HIV. These individuals have unprotected sex and expose their partners to infection who may not be infected (Kalichman, 2000; Wolitski et al., 1997). Sometimes, people do not reveal their serostatus in marital relationships when they are aware that their partner is negative (Patel et al., 2012). Disclosing one's serostatus in sexual relationships is one of the important factors in preventing sexual transmission of HIV. This also leads to safer sexual practices (Marks & Crepaz, 2001) but in cases of non-disclosure of the serostatus, people do not find the need to use condoms (Chakrapani et al., 2009). HIV positive women, caregivers of PLWHAs or widows of HIV positive men reported a higher level of stigmatization, isolation in the family and society when compared to their male counterparts. Women are even refused care and treatment. Sometimes, they have very little or no economic support (Mehta & Gupta, 2006; Pradhan & Sundar, 2006). These realities prohibit women from disclosing their serostatus to their partners and take up any HIV care (Bharat, Aggleton & Tyrer, 2001). Disclosing serostatus to intimate partners can be helpful in reduction of HIV transmission through sexual intercourse. Perception of risk also plays a pivotal role in the context of disclosing one's HIV status or seeking prevention strategies. The decision of disclosing one's serostatus is also influenced by the attitude and beliefs of the people in the society.

Attitudes and beliefs towards HIV/AIDS are very much influenced by people's awareness and these further influence various interventions and programmes for PLWHA. People in India have reported different kinds of attitudes towards PLWHA and beliefs regarding the spread of this virus. A study conducted among the female students revealed that they do not have much information about the illness, which in turn affects their attitudes and beliefs. They had rarely discussed about HIV with anyone;

participants in the study advocated the isolation of PLWHA and around 20 per cent of the participants did not have opinions about HIV (Gaash et al., 2003). In another study, women advocated that practice of monogamy is necessary to avoid the spread of HIV; some agreed that the use of condom is necessary, and a few of them were aware that sexual contact with high-risk groups and the use of infected needles should be avoided (Hazarika, 2010).

According to Adams (1995), risk is anticipation of an event about to happen or the perception of after-effects of the event. Most definitions of risk encompass an anticipated fear of a negative event (Brun, 1994). According to Adams (1995, p. 69), 'risk, according to the definitions most commonly found in the safety literature, is the probability of an adverse future event multiplied by its magnitude'. Perception of risk is one of the main concepts of health behaviour theories. Perceived risk is also called perceived anticipation or probability of an event (Conner & Norman, 1996). Theories of health behaviour have suggested that the perception of risk and expectation of negative consequences force people to take measures to reduce risk. However, a positive relationship between the two may not be the norm always. Studies have demonstrated that the relationship between perception of risk and actions taken by the people to deal with risk is inconsistent in nature. This relationship can be weak and negative (Gerard, Gibbons & Bushman, 1996). Given this inconsistency, the role of perceived risk in health behaviour needs to be further explored. The major issue that arises in the context of risk perception is the question whether perceived risk results in behaviour change.

Bernardi (2002, p. 6) identified three major determinants of risk perception in the context of HIV: 'knowledge of the mechanisms of HIV-spread, behavioural control, actual behaviour and social networks'. A study conducted among women in Mumbai reported that they were aware of HIV, but they did not bring about behavioural and lifestyle changes to avoid infection (Chatterjee & Hosain, 2006). An ethnographic study on female sex workers in Calcutta revealed that they do not perceive themselves much at a risk of acquiring HIV because they claim that they always use condoms with their clients (Sinha, 2014). Perceived risk of acquiring HIV is low even in the high-risk groups which further results in no efforts to bring about behavioural changes to avoid infection. Low-risk perception could be attributed to lack of knowledge and awareness.

These are certain factors which determine women's vulnerability to HIV and cause hindrance in availing treatment facilities. The following section will explore the psychosocial challenges faced by WLHA.

Challenges Faced by Women Living with HIV/AIDS

HIV is a health threat, which is associated with several psychosocial consequences. Thus, psychosocial implications need to be focused upon along with the physiological impact of the infection among women living with HIV. People living with HIV have to deal with the impact of infection along with the negative social experiences. HIV is not only a physiological illness but also a psychosocial condition which comes with a negative community response. Women have to face several difficulties when they are living with HIV, such as stigma, blame and lack of social support. Shame, guilt and fear dominate their lives. Living with HIV means dealing with the cultural and social impacts of the deficiency.

As noted by Watstein and Chandler (1998, p. 145),

> The psychological or internal challenges a person with HIV/AIDS faces vary from individual to individual. Not everyone will experience all of the emotional responses or stages of the emotional responses described. Each HIV/AIDS situation is as unique as the people involved. There are individuals who might face catastrophic

changes not only in their personal and job relationships, but in their physical bodies and in their self-images and self-esteem.

A person infected with HIV has to deal with several emotional responses and adjust to a new lifestyle. People living with HIV/AIDS are traditionally considered immoral and they have to work to reaffirm their sexual identities. HIV comes with a serious psychological impact. The following section discusses the studies related to challenges and experiences of women living with HIV. This section would focus on certain psychosocial challenges which women living with HIV have to deal particularly in the Indian setting. It will take into account stigma and discrimination, social support, mental health issues, quality of life and coping.

Stigma and Discrimination

Stigma is not a new concept in social science research. According to Goffman (1963, p. 104), 'Stigma marks an individual as being unacceptably different from "normal" people with whom s/he interacts.' Goffman (1963) argued that stigma results in a kind of 'spoiled identity' for the concerned person. Parker and Aggleton (2003, p. 16) investigated the concept of stigma in relation to HIV and noted that 'stigma is not an individualised process but should be understood in terms of power and domination that underlie inequality, it should be looked in the context of social and cultural processes and not only as cognitive phenomenon at an individual level. Gender inequality is one of the prominent factors leading to increase in HIV/AIDS among women; also women living with HIV experience gender inequalities (UNAIDS, UNFPA & UNFEM, 2004). Stigma attached to HIV/AIDS is one of the major factors recognized as a driver for increasing infection by limiting people's opportunities to care and treatment (Ogden & Nyblade, 2005; Rankin et al., 2005). Stigma inhibits many women from voluntarily investigating their HIV status. This happens due to the fear of violence and abandonment from the family members (Gaillard et al., 2002; Medley et al., 2004). Many men do not get themselves tested, as this could be considered as detrimental to their masculinity. In most cultures, being able to produce children is the most important aspect of being masculine. Thus, men tend to hide their serostatus since being HIV positive is a hindrance in producing a baby which in turn is associated with the possibility of death without leaving behind offspring. Men sometimes believe that their ability to produce children is a dimension to measure masculinity. In such cases, people tend to refuse or withhold their HIV status, as this is likely to hamper their prospects of producing children. If they disclose their status, it could result in not having children, thus not fulfilling their masculine objective of life (Skovdal et al., 2011; Wyrod, 2011).

In the Indian society, gender roles and power differences have become a part of the culture and the women infected with HIV are adversely affected by it. Stigma is one of the major factors that prevent many people from seeking HIV-related medical services. Stigma has adverse consequences for women more than men because of social and behavioural norms as well as their vulnerable status both economically and socially (UN, 2001). Diagnosis of HIV among women often results in blame (Bharat, Aggleton & Tyrer, 2001). Women are blamed for bringing HIV and the resultant sufferings to the family. Women are denied access to their husband's household, property and sometimes they are not even allowed to live with their children (Pallikadavath et al., 2005; Thomas, Nyamathi & Swaminathan, 2008). The in-laws' family generally does not support widows of HIV positive men. They have to seek support in their parental homes (Bharat, Aggleton & Tyrer, 2001; Pallikadavath et al., 2005). Life is relatively easier for men with HIV when compared to women as they are better accepted and have family support. Such support can be traced to the family-oriented culture of India (Bharat & Aggleton, 1999). In a study in Bangalore,

internalized stigma was higher among men. In this study, it was also observed that there were no gender differences related to enacted and felt stigma (Steward et al., 2008). A higher level of perceived stigma is one of the major barriers to HIV prevention and seeking treatment among women in rural India (Nyamathi et al., 2013). Women have reported more felt stigma when compared to men (Krishna et al., 2005). Studies claim that WLHA as well as their family members have to face more problems in the Indian society than men and their family members. Indian studies have demonstrated that experience of stigma is higher among women (Bharat, Aggleton & Tyrer, 2001; Doshi & Gandhi, 2008; Thomas et al., 2005). It may be noted that stigmatization of any illness/condition has consequences on social support provided by family, friends and community.

Social Support

The concept of social support is found to be rooted in the work of the nineteenth-century sociologist Durkheim (1984), who established the inverse relationship between social contacts and suicide. Decreased social contacts lead to increased number of suicides. The concept of social support has evolved with time. It originated with the term 'social ties' as used by Durkheim. According to Kaplan, Cassel & Gore (1977, p. 49), 'Social support are likely to be protective (of health) only in the presence of stressful circumstances.' The two main sources of social support discussed in the context of HIV are (i) social support from family and friends and (ii) community support and support from government organizations and agencies working in the health care (Shippy & Karpiak, 2005). The non-family support comes from people working in the health care system and this support is related to caring, fostering, nursing and serving (Cutcliffe, 1995). Counsellors and health care professionals provide informational support for livelihood and care to the PLWHA (Akinsola, 2001; Harris & Larsen, 2007). Researchers have identified that support from family and friends is helpful to counter stigma (Andrews, 1995; Galvan et al., 2008).

A study conducted in the southern part of India revealed that women experience lesser social support when compared to their male counterparts (Mahalakshmy, Premarajan & Hamid, 2010). In another study, no significant differences were found in the context of gender while accessing social support (Gohain & Halliday, 2014). Social support affects the ways people deal with mental health conditions.

Mental Health

According to the World Health Organization (2001, p. 1), mental health is 'a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community'.

The relationship between mental health and HIV is bidirectional; it is well established in the literature that PLWHA are more likely to develop mental health problems (Chandra et al., 1996; Jayarajan & Chandra, 2010; Stein et al., 2000) and people with mental health issues are more vulnerable to HIV infection (Chandra et al., 2003; Freeman et al., 2005). Researchers have identified certain mental health issues that are relevant in the context of HIV/AIDS: cognitive impairment due to increased viral load in the blood; anxiety and depression which can be a result of infection and illness; increase in the use of alcohol and drugs; side effects of ART resulting in mental health conditions; and social issues such as stigma and discrimination (Chandra et al., 1998; Tostes, Chalub & Botega, 2004). Mental health problems while living with HIV include fear, phobia, grief, neurocognitive disorders, etc., but

depression, anxiety and stress are more common. Mental health issues affect attainment of progressive goals, such as gender impartiality, empowerment of women, decrease in child fatality rate, increase in maternal health and decrease in spread of infection. Mental health awareness should be focused upon in health and social policy as well as health planning. For effective deliverance, such awareness should be a part of primary and secondary health care. Studies on mental health and gender among PLWHA have documented existing differences; certain studies show that women report higher level of anxiety, depression and trauma (Cescon et al., 2013; Sherr et al., 2012) and other studies documented no significant difference on the basis of gender in mental health outcomes (Kennedy et al., 1995; Moayedi, Hormozi & Tahamtan, 2015). In a study aimed at investigating the mental health of HIV-infected heterosexuals in India, it was revealed that they show signs of depression, anxiety and suicidal ideation but no significant sex differences regarding gender were found (Chandra et al., 1998). The concept of mental health and quality of life are, however, related and tend to influence each other.

Quality of Life

Health is one aspect of quality of life (QoL). The Constitution of the World Health Organization (1946, p. 100) defines health as 'A state of complete physical, mental, and social well-being not merely the absence of disease…' However, in a broad sense QoL is used to convey the overall happiness, well-being and life satisfaction. Thus, QoL is a multidimensional concept and its definition and measurement remain controversial. HIV/AIDS represents a high impact on all aspects of QoL. The theoretical framework for health-related QoL (HR-QoL) is based on the concepts of health and QoL as proposed by the World Health Organization. A study investigating the HR-QoL and gender differences among PLWHA living in the rural parts of India revealed that women show lower scores in domains, such as cognitive role and social functioning, when compared to the domain related to physical health. Men score better in domains such as perceived HR-QoL and health distress. Scores of factor analyses revealed that major factors associated with lower HR-QoL among women are lower level of education and separation or death of a partner (Vigneshwaran et al., 2013). A cross-sectional study in the southern part of India reported that persons with lower CD4 counts had low scores on QoL measures. Women had lower QoL scores than men despite having a less advanced disease (Nirmal et al., 2008). In another study, men reported better scores in four domains (positive feeling, sexual activity, financial resources and transport) of QoL and no significant differences were reported in other two domains of forgiveness and blame (Chandra et al., 2009). Economic difficulties, violence, stigma and discrimination are possible factors for lower QoL among women.

The above-mentioned aspects are among the major psychosocial determinants influencing the life of women living with HIV, with these factors, coping is another major determinant to have an impact on the life of WLHA.

Coping

The work of Lazarus and Folkman (1984) provides the research framework for stress and coping mechanisms. According to Lazarus (1981, p. 2), 'coping refers to cognitive and behavioural efforts to manage disruptive events that tax the person's ability to adjust'. Stressors such as problems with physical and social functioning, change in body image, treatment adherence and management of chronic pain are

related to chronic illness. According to Lazarus and Folkman (1984, p. 3), 'Coping responses are a dynamic series of transactions between the individual and the environment, the purpose of which is to regulate internal states and/or alter person-environment relations.' A study exploring coping patterns among men and women found that men tend to adopt the strategy of escaping from problems and detaching from stress provoking situations. They also try to control the situations or people around them. On the other hand, women seek social support and they also avoid conflicting situations. Thus, both men and women do not cope by acceptance of responsibility, planning, problem solving and positive reappraisal for improvement and personal growth (Shanthi, Damodharan & Priya, 2007). Another study conducted in the rural part of southern India found that higher level of felt stigma is associated with avoidant coping strategies (Nyamathi et al., 2013). Women have even reported higher use of blame in coping strategies (Vosvick, Martin, Smith & Jenkins, 2010).

Women living with HIV have to face several challenges related to biological, psychological and social issues. These issues have a different impact on women when compared to men. All the above-mentioned aspects regarding women living with HIV are related to women's social position and their ignorance. Thus, there is a need to develop specific management strategies. The interventions related to HIV need to incorporate management strategies for women living with HIV, women at risk as well as the general population. The next section attempts to comprehensively and succinctly outline the issues identified on the basis of the review presented above and proposes directions of future research and interventions.

Future Research and Interventions

In 1992, the first phase of NACP (NACP-I) was launched by the Government of India to encounter HIV in its very initial stage. However, due to the emerging trends of the pandemic, the focus of the programme had to be shifted in the successive phases (NACP-II launched in 1999 and NACP-III in 2007). The focus of this programme in the first phase was on bringing behavioural changes through awareness. In the second and third phases, the focus shifted from a decentralized response to ensuring the involvement of non-governmental agencies and networks of people living with HIV. As per the statistics now, women are outnumbering men in acquiring HIV infection (NACO, 2014). As a consequence, HIV-infected women may also transmit the infection to their infants. Women's vulnerability as well as their position and role expectations in the society brings about additional challenges which they have to face besides their illness. Future research needs to take several factors into account.

Future Research

On the basis of the above review of literature, following gaps are identified. There is a need for studies addressing women's vulnerabilities to HIV due to biological factors in the Indian context. Adolescent girls are more at a risk of HIV infection. There should be culture-specific studies addressing the issues of violence, early marriages and polygamy. In order to decrease the susceptibility of women to HIV, studies need to take into account factors influencing the behaviour of men (resistance to condom use, multiple sexual partners and alcohol and drug use) which leads them to take risk even when it can be dangerous to both. Studies show that women are less aware about the risks, spread, treatment and prevention of HIV. Studies in future should try to find out the ways in which relevant knowledge can be

increased among PLWHA and the interventions should come from the targeted communities. Their perspectives should be given primary importance so that interventions can be more influential within the targeted group. There is a lack of studies looking at general population and specifically young school and college girls. Stigma is one of the major challenges among WLHA; Indian studies show that women experience more stigma. Studies are required to identify the nature of stigma more prevalent among women and the ways in which it affects their lives. In the context of social support, studies have not yet identified the ways in which people try and get support from partners, family and community. Studies in the Indian context need to identify specific mental health challenges among women living with HIV. Studies addressing QoL report mixed findings but there is a need to find the factors majorly influencing QoL. There is a dearth of research in the area of coping and emotion regulation and studies need to identify the strategies used by women while coping with HIV. There is a need to design culture-specific assessment tools. Issues related to health and illness can never be explored without taking into account the influence of cultural factors and the traditional belief system of the society.

As noted by Dalal (2001, p. 339),

> A striking and obvious need is to more thoroughly investigate traditional Indian health beliefs and practices; religious and cultural beliefs not only related to border issues of life and suffering but also greatly influence our perception of health and disease, causality, treatment related decisions and long-term care.

Research needs to be done for population of women (such as adolescent girls, female sex workers, drug abuse, wives of truck drivers and migrant labourers) facing the risk of infection. Each of these groups has different sets of risk-taking behaviours and different issues of stigma, mental health challenges and seeking social support. The different risk groups may have different coping strategies and QoL perceptions. Thus, community-based interventions cannot have a generic structure and interventions for each risk group have to be aligned to their specific needs.

Suggested Interventions

Several intervention-based programmes are run by the government and NGOs among PLWHA. These programmes include knowledge about blood safety, injection drug use, sexual contact and avoiding contacts with high-risk groups. Counselling services are provided at ART centres. Also awareness campaigns have been conducted focusing on women. However, today there is a need to design proper interventions not only specifically for women but also for men so that the risk of HIV can be reduced among both men and women.

Women should be made aware about their rights and laws for them so that they do not become victims of injustice at the hands of their family and community members. Formal government plans for supporting women financially have to be formulated and executed. There should be special employment opportunities and skill training to make them financially self-sufficient. This also requires effective linkages between the health care providers, ART centres and government executive machinery at the nodal level. Emotional support is crucial to deal with negative aspects related to infection, while economic support becomes mandatory.

One of the major causes of HIV transmission is unsafe sexual practices; specific interventions are needed to address this issue especially in the Indian cultural context where discussing sex is still a taboo. This issue should be given importance on community platforms. Influential members of the community should be encouraged to discuss pertinent issues. Street plays targeting specific communities and general

population should be promoted. Commercial sex workers should be encouraged to demand condom use. Issues of male resistance to condom use should be taken into consideration, making the availability of male and female condoms easier. If needed, women should be given skill training in sexual communication. Several studies claim that adolescents are now at an increased risk of HIV. Parents, teachers and health care professionals should be encouraged to discuss safe sex and its importance. Not only women but also men need to be educated about the risk of HIV; they should be made aware about the consequences of unsafe sexual practices, forced sex and violence. There should be non-judgemental and friendly sexual health services for different groups.

To bring an effective change among women living with HIV, there is a need to work against the myths and false beliefs about HIV, because stigma increases due to misinformation. To reduce the discrimination of PLWHA, issues of moral judgement need to be tackled at family and community level. We not only need to work on community-based social support but also on the ways to increase family support. Quality of life can be increased by giving training for self-acceptance and self-enhancement. Therapies should be adapted for proper coping strategies, promoting interactions, supportive groups, exercises and hobby development. These changes can be brought about by skilful training of people, including media to promote interventions. People within the communities should work in a structured manner to improve the situation.

Future interventions in the field of WLHA must take into account the cultural belief systems and practices in the context of attitudes, empowerment, dealing with discrimination and family issues.

Conclusion

In conclusion, interventions aiming at AIDS prevention need to include gender-related contextual aspects in counselling and mental health services. There is a need for intervention to improve the position of women in society and effectively reduce women's exposure to HIV. Women have reported an inadequate knowledge and awareness of HIV. Thus, it can be concluded that women are more vulnerable to HIV and less aware about the preventions and precautions to avoid the infection. They face several psychosocial challenges after acquiring HIV.

The need is to focus on interventions that can help in empowerment of WLHA and bring in a social change to reduce the adverse social responses which they encounter. To bring a change in the society, it is necessary to educate, empower and facilitate the women about their social and legal rights. Awareness among women will definitely hamper the transmission of HIV and also enable them to ensure their own safety.

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