

Review Article

Women Living with HIV in India: Looking up from a Place of Stigma, Identifying Nexus Sites for Change

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ABSTRACT

For women living with HIV infection in India, stigma is a pervasive reality and the greatest barrier to accessing treatment, quality of life and survival. Defining stigma according to Goffman as a socially conceived abnormality, this paper then draws on Engel's biopsychosocial model for chronic disease to show the pervasive nature of stigma as a continuum affecting all dimensions of life for married, monogamous Indian women with positive HIV sero-status. Two distinct perspectives were identified in the literature: 1) Public: social and relational stigma, or 2) Private: internalised psychological stigma. Only four of the twenty published works reviewed noted interrelationships between these public and private spheres. Only one of those employed an ethnographic methodology to understand stigma from the perspective of the women themselves.

While concepts associated with stigma among women

living with HIV are diversely employed in research, by considering them as a whole through an intersectional biopsychosocial lens, this paper attempts to provide a basis for implementing integrated and tailored responses. Once the manifestations and interconnected causes of particular groups of HIV-positive women's marginalisation are identified from their perspective, corresponding HIV-care programs and research activities can be designed. Such programs can be tailored with dual objectives: 1) to respond in a coordinated manner to the particular women's own identified and prioritised daily needs across biomedical treatment and social and psychological support, and 2) to work to promote change in social constructions of stigma that form barriers to care.

Keywords: HIV; Gender; India; Stigma; Women living with HIV; Biopsychosocial model; Intersectionality

Current knowledge

- For people living with HIV infection in India, stigma is a pervasive reality and the greatest barrier to accessing treatment, quality of life and survival.
- However, women and men experience stigma differently. Despite typically contracting the disease through marital sexual relations, married monogamous women are also subject to stigma resulting from moral blame.
- Stigma affects women both in public spheres of social relationships and in private through psychological stresses. These spheres are typically considered in isolation not as interrelating.

Novel information

- In order to go beyond consideration of discrete public and private arenas of stigma, this paper applies Engel's biopsychosocial model on chronic disease experience as promoting an understanding of the effects of illness on women across their biomedical, social and psychological life arenas. Use of Engel's approach resists binary separation of private and public experiences of HIV related stigma and encourages care responses to address a whole-of-life continuum.
- By gaining information from particular groups of HIV-positive women about the whole-of-life situations where they experience stigma related constraint, inter-relationships between stigma sites can be mapped and specific root causes of marginalisation identified.
- In the complex context of establishing programs of care for women living with HIV, arranging qualitative information on lived experiences in such a way as to identify interacting barriers to care, can assist in tailoring multifaceted HIV-care programs that address the particular needs of specific groups of women. Such customised programs would embody dual objectives: 1) to respond to the women's own identified and prioritised needs across biomedical, social and psychological arenas in a coordinated manner, and 2) to work to reduce stigma as a barrier to care.

Background

With access to effective antiretroviral drug treatment, HIV infection can now be experienced as a survivable chronic illness, allowing long-term health management to focus on maintaining quality of life and infection containment [1,2]. Given the effectiveness and availability of treatment, it might be assumed that the stigma experienced by the 2.1 million Indian people living with HIV (PLH) would be reducing as they receive: testing and treatment; education about disease management, virus transmission and life strategies; and social support no longer constrained by fear of a deadly infection [1,3]. And yet, stigma has not only survived the advent of antiretroviral drug treatment in India, but remains pervasive, affecting life patterns and disrupting biomedical interventions [1,3]. While stigma is experienced by all PLH, cultural beliefs and unequal power relations make Indian women particularly vulnerable [4].

In 2014, women represented 41% of Indians diagnosed with HIV, a percentage that continues to increase [5,6]. The number of Indian PLH had decreased over the preceding five years, both in total and among the segments of the population at greatest risk: sex-workers, men who have sex with men, and injecting drug users [5,7]. Representing an estimated 1.5 million persons, these at-risk groups are at the forefront of advocacy and treatment campaigns [5]. However, this focus, evidenced for example in preventative educational advertisements [6] and statistics on advances made in controlling HIV in India [5], reinforces vernacular perceptions that HIV is on decline, and is a disease afflicting only people who engage in immoral behaviours [8]. Over time such associations become accepted societal truths [8]. Rahangdale et al. reported interviews where PLH described their fear of being treated as a new kind of unclean, immoral, social outcast, describing themselves using the historically caste-laden term *untouchable* [9], an attitude and language which has also been found in mainstream media [10,11]. Yet despite this pervasive cultural association, 90% of new infections in Indian women do not involve sex-work [12]. Instead these new infections result from matrimonially sanctioned sexual relations [13].

Although HIV disease progression is not related to the biological sex of an individual patient, Indian women's illness experience is reported to differ from that of Indian men: for example, women are 30% less likely to access antiretroviral drug treatment (ARDT) than men, men are typically diagnosed at a more advanced stage of the disease, and women experience greater social stigma than men [3,6,14]. The major factor limiting regular use of ARDT by women living with HIV (WLH) is stigma [1,3]. In order to probe for reasons as to the differences in the experience of being HIV-positive for Indian women and men, a number of studies utilised sex disaggregated quantitative data [1,14,15]. The potential risk of this approach is that some groups of women or men with particular social risk factors may not be identified if analysis of the data assumes a binary male: female biological sex paradigm and conflates it with social constructions of gender (different groups of, and social conventions about, diverse women and men). For the purposes of this discussion, an Indian woman's gender is understood to be

formed by the hegemonically defined norms of living within her particular socially constructed, patriarchal, relational hierarchy, cultural myths, rituals and folk beliefs. Gender behaviour is learned via socially sanctioned gender roles, institutional gender constraints, and norms of behaviour for Indians identifying as a particular sex. In order to develop care interventions that result in equitable health outcomes for different groups of women and men, it is important that manifestations of gendered inequalities that marginalise particular groups are identified.

Recognising an HIV stigma continuum

In examining HIV-related stigma, the reviewed literature refers to the foundational work of Goffman [16] who defined stigma as a *cultural belief* about a *social abnormality* which degrades the value of the identity of any individual possessing that abnormality: in this case the stigmatised person's value is degraded through exhibiting an abnormality (HIV infection) to the socially defined and preferred norm (HIV free) [4,17,18]. Ho and Holloway (2016) identified two cultural beliefs which are universally mobilised to stigmatise WLH: 1) that being HIV-positive always indicated immoral behaviour of which the individual should be ashamed and for which she deserved to be punished, and 2) that the HIV-positive individual posed an unmanageable infection risk as she could transmit a disease understood to be incurable. Ho and Holloway [2] also identified that manifestations of stigma for WLH could be collated as public or private via: socio-cultural, relational and psychological spheres. The information provided by Ho and Holloway [2] is interpreted diagrammatically here in Figure 1.

Like Ho and Holloway [2], Parker and Aggleton [17] also noted that in studying PLH, researchers typically separated private and public life experiences, and prioritised the private or psychological experience. Such an approach seeks to understand the PLH psychological experience, and identifies the need to educate both the uninfected (wider society and health care professionals) to be more tolerant, and the infected to understand their illness, access medical care and develop coping strategies [1,4,9,13,18]. Parker and Aggleton's criticism of this approach is that it ignores Goffman's insight that stigma is a *public cultural belief*, a social construction of *degraded identity* where power is wielded to exclude individuals on the basis of *undesirable difference* [16]. It is therefore not restricted to the psychological realm, but compromises social functioning and all inter-human relationships.

Although Ho and Holloway [2] and Parker and Aggleton [17] identified the operation of HIV related stigma in both public and private spheres, only Van Hollen [6] conceives of a stigma continuum permeating all aspects of the life of a WLH. It is proposed here that such a continuum is aligned with Engel's [19] *biopsychosocial complex model*. While working with women and men with chronic disease, Engel [19] noted that focussing exclusively on biomedical factors failed to explain why some individual's experienced debilitating illness while others could manage their condition as a routine problem to be addressed [20]. Considering each individual's experience from their particular perspective of living within the

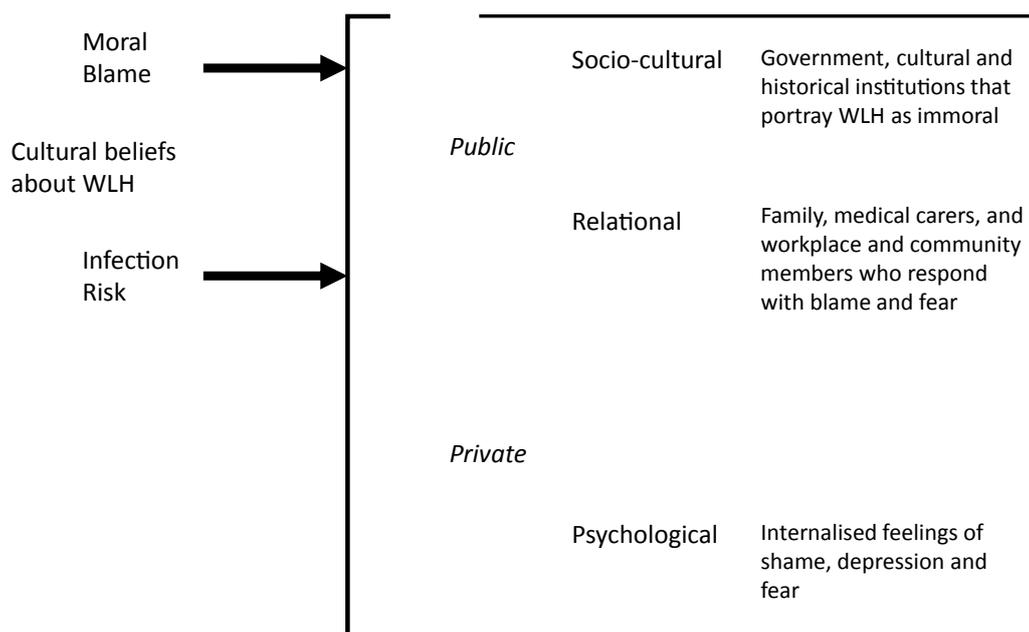


Figure 1: Stigma continuum.

limits of their disease, Engel identified the criticality of social relationships and psychological resilience [19]. While critiqued as impractical in the clinical setting, Cohen and Forstein [21] considered the approach vital to physicians developing a compassionate and integrated approach to health care. Borrell-Carrió et al. [22] argued that when considered for a defined population, the biopsychosocial complex provided an important perspective on the ways “...suffering, disease, and illness are affected by multiple levels of organization, from the societal to the molecular”.

Also evaluating the effects of multiple levels of social organization at the macro or group level, is the theory of Intersectionality, an approach that considers how a group’s place in social hierarchy is simultaneously constituted by constructions including ethnicity, gender, class/ caste, religion and age [23-25]. Recognising that stigma “feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality”, Rahangdale et al. [9] noted that Indian cultural and historical institutions often stigmatise all women with positive HIV sero-status [13]. Applying an intersectionality lens to interpretation of the lived biopsychosocial experience of particular clusters of Indian WLH, is suggested here as a means for researchers to gain an over-view of the unequal social power dynamics that result in a spectrum of biomedical, social and psychological stigma manifestations for those groups of women.

Returning to the public: private dichotomy presented by Ho and Holloway [2], Parker and Aggleton [17] and reimagining it according to the biopsychosocial model, demonstrates that WLH experience a whole-of-life stigma continuum (Figure 2). As noted above, for Engel [19] the aim was for the physician to work with the woman or man such that their chronic disease would be experienced as a routine factor of life to be managed. As can be seen in Figure 2 for a WLH or a population of WLH to have the resources to experience HIV infection as a manageable

chronic condition, would require overcoming stigma in every context of life: biomedical/health care, psychological/personal ideations, and social/relational interactions [19,26].

Women in India living an HIV: The pieces of a stigma riddled life

Mitra and Sarkar [15] and Vlassoff et al. [13] report that in India, a husband’s exposure to HIV commonly results from having participated in high-risk heterosexual behaviours such as having multiple sexual partners. Diagnosis then follows development of advanced symptoms of AIDS, a related sexually transmitted illness, or often after developing a comorbidity with tuberculosis [18,14,27]. Vissandjeé et al. [28] and Sinha et al. [14] note that while no consensus has been reached as to causality, men typically have higher infection rates for tuberculosis than women. Whether this relates to biological sex related disease factors or results from social constructions of gender, women’s reduced incidence of tuberculosis symptoms with attendant tuberculosis and HIV testing and diagnosis means that for women, one opportunity for HIV testing is removed and diagnosis potentially delayed.

Unless tested for during pregnancy, HIV-positive monogamous married women often remain undiagnosed until their husband is terminally ill or deceased [4]. Many women in South India, particularly poor rural women, are unaware of the risk of HIV transmission from their husbands [6,15,26]. Furthermore, cultural and historical expectations of a wife’s subordination to her husband mean that women often have little control over marital sexual activity or safe-sex practices [12,26]. It is reported that HIV tests are often performed without the woman’s consent, with results communicated to her husband’s family, so, even after diagnosis the woman may not be advised of her condition or receive treatment [1,6,15]. Family resources are typically prioritised toward the husband’s care by the wife

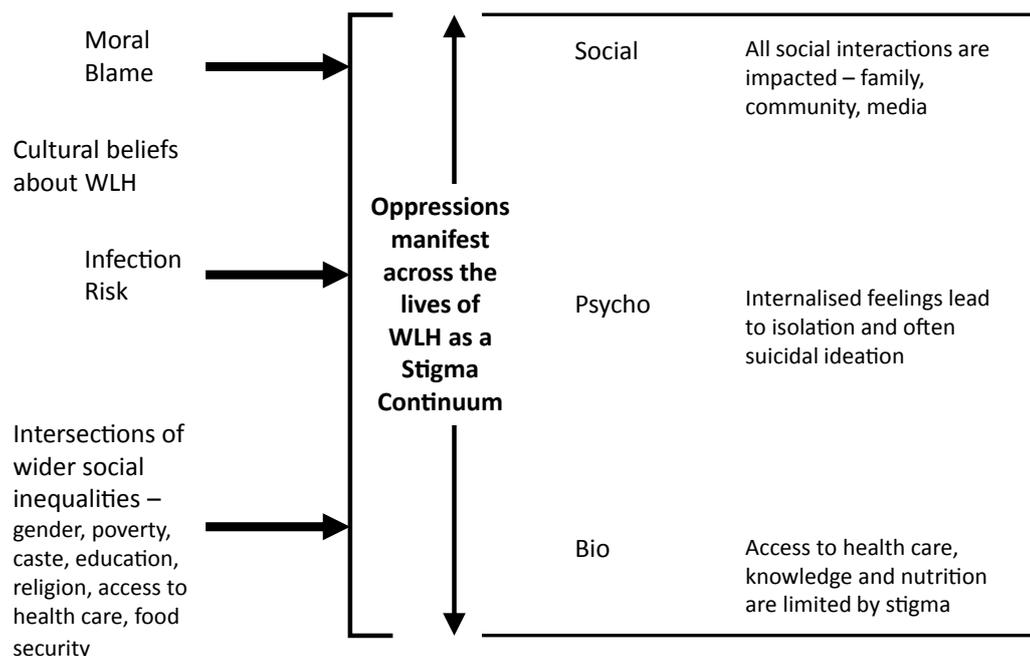


Figure 2: Biopsychosocial stigma continuum.

and the husband's family [26]. While the wife may blame a sex-worker for luring and infecting her husband, within the family unit the wife herself is typically blamed for engaging in immoral behaviour, infecting her husband and shaming his family [6,9,26].

Entrenched patriarchal loyalty is rationalised by gendered folk myths which connect a basic understanding of HIV as transmitted in blood and sexual fluids, with traditional cultural notions associating blood with impurity and death [6]. Van Hollen [6] described a gendered South Indian folk logic which imagines menstruation as a means whereby women are temporarily purged of the HIV virus, and which is claimed to explain why husbands typically die before their wives. Van Hollen [6] identified two social motives for accusing the wife of introducing HIV: as protection of family honour by shifting shame onto a scapegoat, and as justification for expelling the 'aberrant widow' and thereby avoiding the economic burden of medical costs, child support and inheritance.

In rural communities there is little understanding of the mechanisms and risks of virus transmission, and minimal education about disease management [26]. Information is instead gleaned from rumour, government statements, cultural institutions and media [9]. Such a lack of accurate biomedical knowledge, combined with widely held social perceptions of HIV as an immoral, deadly, highly-contagious women's disease, generates fear and focuses shame on women, be they sex-workers or wives [6,9].

Noting her husband's diagnosis, and where not tested by the family, to avoid the stigma of being known to be HIV-positive WLH attempt to keep their HIV sero-status secret [15,18]. However secrecy often results in non-attendance for ARDT, attempts to disguise symptoms, social isolation and women travelling large distances on unreliable public transport to access

care in remote centres with hopes of anonymity [18,29]. Regular absences for treatment also take women away from the work of caring for the family and incur travel costs, both of which may further limit resources available to purchase medication and nutrition [26]. On seeking care, many WLH meet disinterest, fear of infection and moral condemnation at the hands of medical staff [3,14,26,30]. Nyamathi et al. [26] and Rahangdale et al. [9] both described WLH who experienced neglect, were told that they were not worth treating as they would soon die, were publicly shamed, and whose confidentiality was breached by staff. However, it is also reported that such behaviour can be reduced by engaging nursing staff in training to provide infection information and opportunities to discuss concerns, beliefs and behaviours [14,30].

The resources WLH can access to deal with daily stigma directly affect their mental health [29]. Diagnosed with a disease that is anecdotally understood to be immoral and fatal, fearing stigma, and lacking both the education and support to make informed choices about disclosing their HIV sero-status, WLH in India report anxiety, depression and suicidal ideation [1,18,26]. Depression is recognised as being a strong predictor of poor ARDT adherence and declining quality of life [31]. Most married, monogamous WLH report that their internalised stigma is associated with feeling that they have failed their families by needing to receive care, rather than providing care to the family as social roles teach that a woman should [1,6,14,26,31]. To minimise the risk to their children, nursing mothers reported implementing avoidant coping strategies, eschewing maternal acts such as breastfeeding or touching their infants, strategies which further reinforce feelings of maternal failure [29]. Women also reported fearing that their children would be ostracised and would have reduced opportunities for education and a better future [9,26].

Stigmatised women: Looking up through an intersectional biopsychosocial lens

This is the complex situation of the WLH: a world structured by socially constructed notions of gender, defined by the behaviours and relationships constituted appropriate for her as a woman and a wife in Indian society, and inculcated by folk beliefs and partial truths about a disease that will define the rest of her life. And so her illness experience and disease progression diverges from that of men in ways not predicted by biomedicine alone.

In February 2017, The World Health Organisation’s Human Reproduction Programme released a woman-centred approach to care for women living with HIV [31]. Key to the recommendations are involving WLH as “active participants in, as well as beneficiaries of, trusted health systems that respond to women’s needs, rights and preferences in humane and holistic ways”, and the guideline provides a framework to guide good practice. Developed for this paper, Figure 3 provides one possible schema to allow researchers to map ethnographic or qualitative questionnaire responses from a group of women about experiences of stigma [32]. Once mapped as shown in

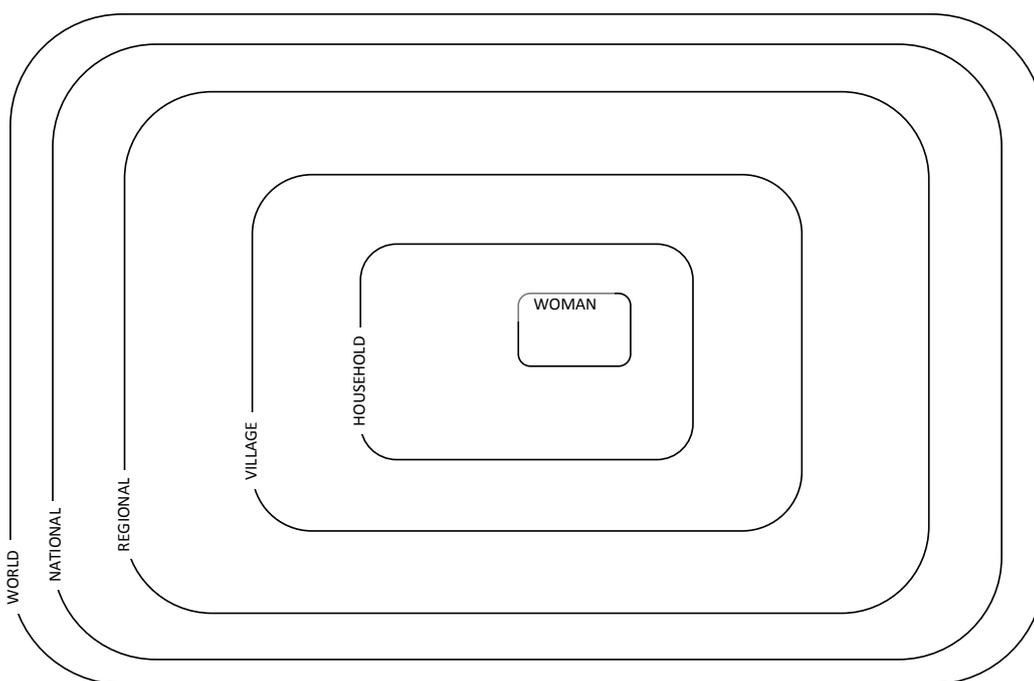


Figure 3: Schema for centring the experiences of stigma for Indian WLH

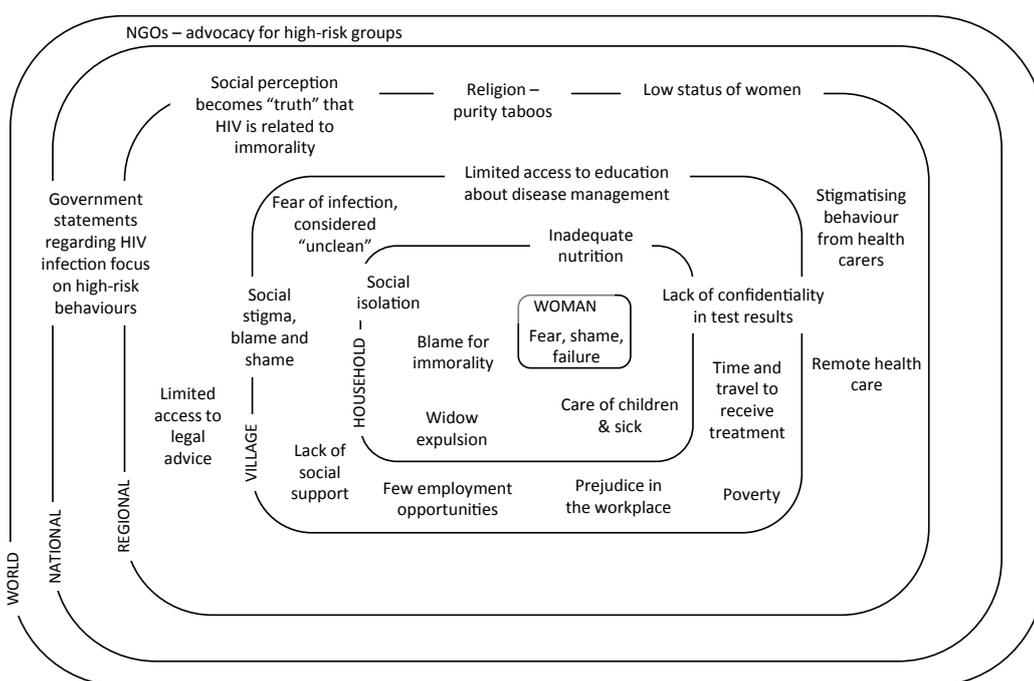


Figure 4: Mapping expected multiple sites of stigma for Indian WLH

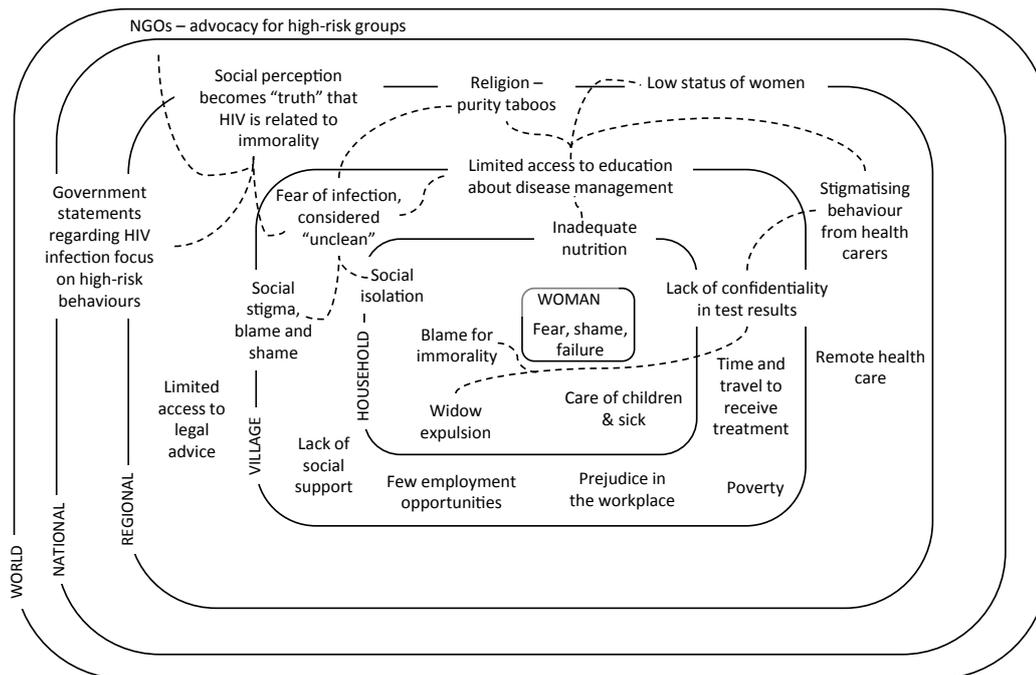


Figure 5: Identifying linkages and possible nexus points

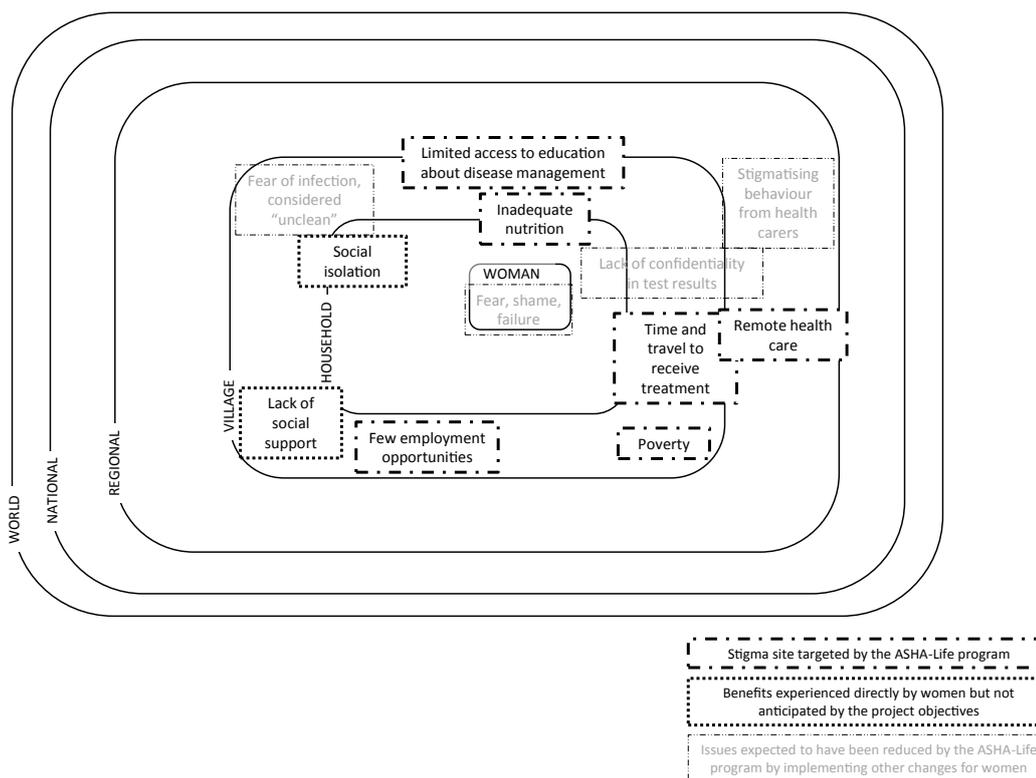


Figure 6: Analysing Nyamathi et al [26] and mapping impacts for Indian WLH

Figure 4, common themes, clusters of stigma manifestations, and potential root causes can be identified and linked as shown in Figure 5, allowing further evaluation of opportunities to maximize the effects of social change. In this way, the schema proposed in Figures 3-6, becomes a means not only for mapping reported experiences, but for identifying nexus points, and then coordinating and prioritising care and assistance initiatives.

The findings of data analysis, and critical confirmation of

the mapped results of questionnaires or ethnographic surveys, could then be used to design multi-faceted systems of care. Such systems would be inherently tailored to respond to specific, identified sites of need and aim to reduce limits imposed by stigma. A multi-faceted care program will respond not only to daily tangible and biomedical needs of WLH, but also to provide social and psychological support, and/or promote change in social constructions of exclusion and poverty.

While not using the terminology of intersectionality, or a biopsychosocial complex, the principles of this approach are demonstrated in base-line research and an Asha-Life village intervention reported by Nyamathi et al. [26,29,33]. In the most recently reported focus group study [26], a group of 16 South Indian, rural WLH met regularly with ASHA (Accredited Social Health Activists), trained local advocates and were provided with; transport to trusted medical therapy; tangible support in the form of high protein food, cooking oil and money; vocational training; and, education regarding management of their condition. Based on the publication these initiatives are mapped. In addition to achieving quantifiable health benefits, the women who participated in the Asha-Life program stated that the sense of community engendered was “powerful and transformative” [26]. One participant said: “I am not thinking that I am an AIDS patient. I just feel like [a] normal person” and another: “I was not alone” [26]. The participants described “improvements in their mood and their feelings of self-efficacy” [26]. These additional benefits of the program are mapped in Figure 6. While this intervention did not aim to directly change the ideological social structures that so constrain WLH, it demonstrated that coordinated attention to biomedical (treatment and nutrition), psychological (counselling and empowerment), and social (economic independence through skills development, and belonging to a community) arenas generates real benefit in improving women’s quality of life and health outcomes. This initiative demonstrates that in order to achieve equitable health outcomes, these particular WLH need care programs “which emphasize nutritional knowledge, while reducing barriers to receiving ART and [provide] physical, emotional, and financial support” [26].

A biopsychosocial intersection: turning away from stigma

While PLH around the world experience stigma and not all PLH experience equity in accessing ARDT, women in India who live with positive HIV sero-status are particularly engulfed by stigma [3]. Employing Engel’s biopsychosocial model and considering the intersection of mutually constitutive unequal and inequitable power relations that limit a WLH life, allows researchers to perceive the experience of stigma as a continuum [19]. Stigma that otherwise forms a self-reinforcing hegemony which separates WLH from ARDT and social support, reduces their quality of life and increases the likelihood of terminal illness outcomes and infection transmission [15]. Recognising the interrelated nature of stigma suggests that single-point care initiatives may do little to improve the overall quality of life for WLH and instead tailored, multi-faceted approaches are required.

In the complex context of establishing programs of care for women living with HIV, arranging qualitative information on lived experiences in such a way as to identify interacting barriers to care, can assist in tailoring multifaceted HIV-care programs that address the particular needs of specific groups of women. Customised care programs aim: 1) to respond to the women’s own identified and prioritised needs across biomedical, social and psychological arenas in a coordinated manner, and 2) to

effect social changes that result in a stigma laden environment. The imperative to further develop, test and implement such women-centred, multi-disciplined care initiatives originates in an appreciation that HIV-related stigma is the greatest constraint on the lives of almost one million Indian women today.

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