# BREAKING THE SILENCE: MESSAGING AROUND HIV PREVENTION FOR SOUTH ASIAN WOMEN IN TORONTO

By

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# ABSTRACT

In recent years, the number of HIV infections among South Asian women in Toronto contracted through heterosexual transmission has been increasing, potentially attributable to a number of factors and vulnerabilities. This situation will be examined including a review of trends since 1980 and an in-depth analysis of contributing factors. Regarding a general increase in infections among women in Canada, it appears that greater efforts are required to improve awareness around HIV prevention, and one widely used method has been public messaging through poster campaigns. As a result, this paper proposes that a poster campaign, which has previously not been explored or launched targeting this community in particular (South Asian women in Toronto) would be useful. It suggests elements that should be included in a campaign, how the issue should be addressed, what the messaging should look like, and broader goals of such a campaign for the community.

Key words: South Asian women in Toronto; HIV prevention; poster campaigns; poster messaging

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# INTRODUCTION

Throughout the world "more than four-fifths of all HIV-infected women have contracted the virus through heterosexual transmission" (Hunter, 2006; UNAIDS, 2004; ASAAP, 2004). In recent years, the number of HIV infections among women has been increasing, pointing to a higher vulnerability and risk that should be addressed through prevention initiatives. In particular, South Asian women in Ontario have been identified as a high-risk group for HIV transmission through heterosexual intercourse, due to a number of factors that increase their vulnerability. These women have immigrated here from South Asian countries mostly over the last 40 years, or are born to immigrant parents, and as such experience HIV infection risk uniquely. Gender norms and expectations especially as they intersect with cultural norms, a reluctance to engage in open discussion around sex and sexual health, cultural identity conflict, power imbalance in relationships, and often a lack of knowledge or choosing not to practice safe sex are all determinants of risk in this particular community of women.

The Alliance for South Asian AIDS Prevention (ASAAP), a community-based organization in Toronto, has recognized this slowly growing problem and has chosen to actively respond. Although this paper speaks of "South Asian women" as a group, it should be noted that the term does not adequately convey the heterogeneity of the group in reality. By engaging with women in the community through focus groups and seeing what they feel would be the most effective manner to address the issue, ASAAP has determined that a knowledge awareness campaign on HIV prevention would be a progressive first step – especially as a means to facilitate open community dialogue. This paper examines the problem and uses information collected through ASAAP's focus groups to suggest what a poster campaign for this community should look like, particularly as it has never been explored before. Although such an initiative may not resolve the issue on its own, by breaking the silence and fostering conversations on topics the community has been silent on for so long, it may help move toward ultimately changing the broader societal context that exacerbates the risk of these women to HIV infection, as well as other health and social inequities.

### BACKGROUND

# Epidemiology

Heterosexual women are now considered an at-risk group for HIV, both in Canada and worldwide (HIV Prevention Research Team, 2007). A 2009 report on HIV/AIDS in Ontario trends until December 2007 demonstrates that the proportion of diagnoses made up of females has risen between 2001 and 2007 from 15% to 25% (Liu & Remis, 2007). The only report done on HIV epidemiologic trends in Ontario based on race and ethnicity by Robert Remis in 2007 looks at data from 1985 to 2004 for Toronto and further stratifies these results by sex . Ethnicity data is not routinely collected on the HIV test requisition, however, it is included on the reporting form collected by health units for case management (Liu & Remis, 2007). Even so, there may be ethnicity underreporting due to the stigma associated with having HIV/AIDS among groups such as South Asians.

The group "South Asian" includes individuals originally from countries such as India, Pakistan, Sri Lanka, Bangladesh, Nepal, and Bhutan. Among South Asian females, the number jumps from 1 HIV infection between 1985 and 1989, to 10 infections reported between 2000 and 2004 (Liu & Remis, 2007). In addition, 25.9% (29 out of 117) of HIV infections among South Asians were attributed to heterosexual transmission, second only to MSM exposure at 53.7% (58 out of 117) (Liu & Remis, 2007). Among the 16 (of 18) infections reported with a known exposure in South Asian females in Toronto, 12 (75%) were as a result of heterosexual transmission – by far the highest risk among this particular population; the remaining 4 cases are linked to exposure in an endemic country (Liu & Remis, 2007). Looking solely at trends in heterosexual transmission among the South Asian population in Ontario (both sexes), the numbers increase from 2 infections from 1985-1989 to 28 infections reported from 2000-2004 (Liu & Remis, 2007). Comparing ethnic groups with respect to heterosexual transmission of HIV, South Asians (from 1980-2004) had the fourth highest number of infections – after whites, blacks, Asians (only one less) (Liu & Remis, 2007).

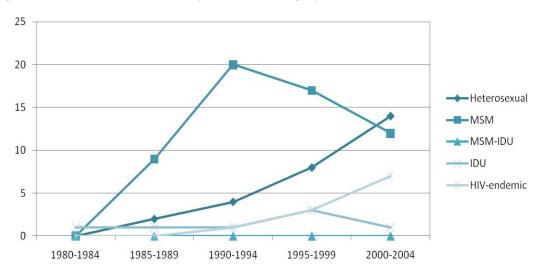


Figure 1. Number of HIV cases by exposure category - South Asian, Toronto, 1980-2004

Source: Dr. Robert S. Remis - Public Health Sciences, University of Toronto Note: Data incomplete for 2004

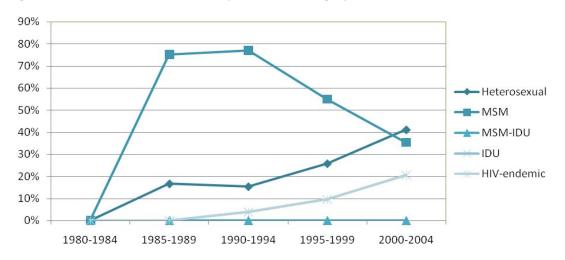


Figure 2. Proportion of HIV cases by exposure category - South Asian, Toronto, 1980- 2004

Source: Dr. Robert S. Remis - Public Health Sciences, University of Toronto Note: Data incomplete for 2004

From this report, it is clearly evident looking at the trends over 25 years (1980-2004), the number of HIV infections among South Asians in Toronto have become less attributed to MSM as an exposure category, and more related to heterosexual exposure (Figure 1 and 2) (Liu & Remis, 2007). Over 40% of HIV cases reported between 2000 and 2004 were attributable to heterosexual exposure, whereas in the five-year period directly before, this number was less than 30% (Figure 2) (Remis, 2006). Worldwide, heterosexual contact has

been identified as the leading risk factor for HIV infection among women, and it appears to be the same in this population as well (UNAIDS, 2004; Hunter, 2006; HIV Prevention Research Team, 2007).

#### Factors related to South Asian women's vulnerability

As defined by the United Nations Joint Programme on HIV/AIDS, vulnerability means "to have little or no control over one's risk of acquiring HIV infection or, for those already infected with or affected by HIV, to have little or no access to appropriate care or support." (ASAAP, 2001) To gain a better understanding of women's prevention needs, it is essential to look at the factors that contribute to their vulnerability. There are a number of interacting reasons women are more susceptible to HIV infection, which range from increased biological vulnerability to social and gender inequities that put them at greater risk (UNAIDS, 2004; HIV Prevention Research Team, 2007; Webber, 2007). For South Asian women here in Canada, these reasons are intersected and compounded by additional factors related to migration, culture and class.

#### Gender norms and expectations

"The social construct of gender, which differentiates the power, roles, responsibilities and obligations of women from men, significantly impacts on women's ability to take precautions against acquiring HIV" (Webber, 2007). Throughout public health literature, it has been noted that "gender-based inequities and disparities in expectations generate the exposures, or acquired risks, and the risk factors that adversely affect women's health" (Wingood, 2000). Gender norms and expectations, and the resulting power dynamic within relationships expose women to greater risk of infection by predisposing them to certain risk behaviours, or increasing their likelihood of exposure to infection (Webber, 2007; Wingood, 2000). If a woman wants to request that a partner use a condom, she would need to assert a dominant position; this usually goes against cultural norms dictating sexual encounters (Gomez & Marin, 1996). Married women may be even less able to negotiate the use of condoms with their spouses, as this may be construed as a sign of distrust, or questioning her partner's fidelity – both of which in many cases are unacceptable. Different gender expectations pertaining to women's traditional role in South Asian societies also usually mean women act in a manner benefitting others, rather than solely pleasing

themselves (Bhattacharya, 2004). This interaction of gender norms with cultural norms, especially in sexual interactions, can increase women's vulnerability to HIV infection (Gomez & Marin, 1996).

#### Silence on sex

The discourse around sex, sexual behaviour, and sexual health is mostly absent among the South Asian community at large, despite a new generation of immigrants and young men and women born to South Asian parents who have immigrated here over the past 30 or so years. Although the second generation may have greater exposure to sexuality and related issues through media, school and peers, these conversations are often absent in the home, and in the cultural community, resulting in a ubiquitous silence around a very important topic.

Traditionally, marriage is the institution which "permits" women to initiate and engage in sexual relationships (Bhattacharya, 2004). Without being told explicitly that being sexual before marriage is "bad", continued perception of sex as a taboo, and that unmarried women who engage in such behaviour incur a bad reputation and bring shame upon their families, places the health of young women at greater risk. For instance, in speaking with a service provider from ASAAP, a community organization, it was noted that although condoms are available from a jar at a community centre where they are easily accessible to South Asian youth, no one takes them or feels comfortable enough to – despite the undeniable fact that such relationships are happening (ASAAP personal communication, March 4, 2010). Often, youth discuss their problems and concerns with their peers, and thereby influence each other's behaviour. If these discussions are absent altogether, especially among those in the same peer group because people feel ashamed, youth may not really know or understand their risks, or how to go about modifying them.

While peer influence traditionally may be the strongest during adolescence, it also has a hold among South Asian women in various age groups, and this is attributable to the culture. What others think, and how others perceive them or their families is often ceded a great deal of importance and works as an informal social control. Discussing personal sexual behaviour conflicts with cultural norms, and as a result, women may hesitate to ask questions of a sexual nature, fearing censure or judgment by women in their social circle.

Religious, cultural and social beliefs impose restrictions on discussions around sex among South Asians, but moreover, HIV/AIDS is often viewed as an issue linked to Western culture, homosexuality, drug use and promiscuity (ASAAP, 1999; ASAAP, 2001). Often, people still do not see the connection between personal risk and HIV and therefore fail to acknowledge there is a problem (Bhattacharya, 2004). Taboos around HIV/AIDS also extend into other aspects of women's reproductive and sexual health, which may disempower them from making decisions affecting their lives. Young women brought up in Canada may have the option of learning about their bodies through sexual education classes, but parents may choose to prevent their children from attending, believing that such knowledge may encourage sexual behaviour (ASAAP, 2001). Likewise, women who immigrate to Canada from South Asian countries may never have even been exposed to knowledge about sexuality and effective contraception (ASAAP, 2001; Gagnon et al., 2010). Additionally, those who are infected may feel the necessity to hide their status, primarily fearing ostracism by their cultural community; with newer immigrants for who English may not be a first language, losing connections to their ethnic communities may be a scary thought (ASAAP, 1999; ASAAP, 2001).

#### Cultural value conflict

From adolescence onward, young South Asian women may face dual pressures, and be unable to reconcile them. On one hand, there are the expectations that are internalized as a result of their cultural and religious upbringing which place a very high value on chastity and fidelity to one's spouse (after marriage). This is challenged by the desire to explore and experience sexuality and relationships as their peers do, and perhaps also express their commitment to their current partners (who may or may not end up their husbands in the future). In wanting to please their partners, negotiating safe sex may not place highly on a young woman's list of considerations before engaging in a sexual relationship (Gavey, 1999). However, her partner may have been with other partners, or may be unaware of his own HIV status and therefore may place her at increased risk of infection, not to mention the always potential risk of pregnancy.

"Cultural value conflict" has been studied among South Asian women in North America and is defined as "an experience of negative affect resulting from dealing

simultaneously with values and expectations internalized from the culture of origin and those imposed from the new culture (e.g. dominant White culture) (Inman, 2006). Here, first generation South Asian women are classified as women migrating to North America after the age of 20, and second generation as women either born here, or migrating before the age of 12. Different social and cultural pressures are prevalent among either group; especially for the first group of women, traditional responsibilities around upholding cultural values and expectations within the home and family are strong (Inman, 2006; Dasgupta, 1998). To promote and safeguard such values, informal social controls such as fear of community censure are pervasive, and continue to feed into the cycle (Dasgupta, 1998). However, as these women try to integrate into the dominant society and take on its values, areas where they experience the greatest acculturative stress and cultural conflict include intimate relations and sex-role expectations (Krishnan & Berry, 1992). With regard to intimate relations, the context in which they are expected to occur are conflicting between cultures; traditionally, such relations only occur among married couples, as opposed to freely dating and exploring intimate relationships with multiple partners (at different times or simultaneously) (Vaidyanathan & Naidoo, 1991).

These two types of conflict are experienced to different degrees among both groups; first generation women appear to feel more pressure around values regarding intimate relations. For example, premarital relations are associated with having a "loose character", therefore the woman would fear being judged by her community and losing their support. Second generation women seem more stressed by sex-role expectations, and being seen as "too American" – an alternate reason for losing credibility and membership within their respective communities (Inman, 2006). Often, religion further compounds these stresses by imposing greater patriarchal views and restrictions around dating/premarital relationships, especially since religion and culture are closely intertwined in South Asian cultural practices (Inman, 2006; Ibrahim et al., 1997).

As women who migrate at an older age have already internalized values and identities from their homeland, exposure to a new culture that is somewhat incongruent with those values results in tension (Dasgupta, 1998; Inman et al., 1999). This stronger internal ethnic identification was found to create greater intimate relations conflict (Inman, 2006; Ibrahim et al., 1997; Prathikanti, 1997). Although there is a certain degree of adaptability required to

succeed in their new country (learn the language, career goals), they still often retain their cultural values relating to dating and marriage, and therefore intimate relations. As a result, conflict manifests between two seemingly opposite sets of choices: upholding cultural values like marrying within one's community, along with maintaining chastity and modesty in sexuality, versus exploring the contrasting values of dominant culture, such as engaging in premarital sex.

For second generation women, external ethnic identity plays a significant role – this includes racial dimensions such as the visible aspects of their heritage that relate to their experience of power dynamics within dominant society (Inman, 2006). For instance, if second generation South Asian women face racial stereotypes or prejudices in dating relations while they engage in ethnic activities (such as speaking their language, which is related to external ethnic identity) that preclude certain types of behaviour or demeanour, there may be a greater conflict around sex-role expectations, and this may have a spill-over effect into intimate relations (Inman, 2006). Cultural behaviour becomes a proxy for cultural identity and while trying to maintain this identity in a racially diverse dominant culture, certain gendered behaviour may be judged or looked adversely upon, once again resulting in conflict and stress for these young women, and perhaps also feelings of isolation and inferiority.

The greater struggle remains around internal ethnic identity though; core values related to intimate relations which de-emphasize sexuality are considered fundamental to that identity, and the threat of transgressing against these expectations with the subsequent shame that may befall the family creates a significant amount of internal tension for the women (Inman, 2006). These issues of "selective acculturation among first generation women... and impact of racial socialization among second generation women" result in dilemmas between personal identity and group membership, and the need for both (Inman, 2006).

#### Power dynamic in relationships

Power is defined as having the "capacity to influence the action of others..." (Wingood, 2000) Much of early HIV prevention programming targeting women has been around changing behaviour related to condom use however this may not take into account

the complexity or power imbalance of their sexual relationships (Webber, 2007; Gomez & Marin, 1996). In most heterosexual relationships, men are seen as the active, decisive partner, and women take on a more passive, responsive role (Gavey, 1999). Even the risk behaviour itself (e.g. wearing a condom) in a relationship is different for a man and woman (Amaro, 1995; Webber, 2007). For the man, he is required to wear the condom, but for the woman, she must persuade her partner to wear it, or deny intercourse if he refuses to (Amaro, 1995). However, to enact either of these options successfully requires a certain degree of power within a relationship, and in many sexual relationships, women lack this power (Gavey, 1999; Soet et al., 1999). This difference in gender roles and actions to arrive at the same outcome is illustrative of a power dynamic; men make the choice often only considering themselves, whereas women have to push men to behave in a manner that takes the health of both partners into consideration (Webber, 2007; Gomez & Marin, 1996). Cultural gender norms influence the power women wield and exercise in relationships, which directly affects their ability and willingness to enforce condom use (Webber, 2007; Wingood, 2000). As a result, promoting a measure such as condom use alone can be insufficient as it tends to overlook or overestimate women's roles and power in relationships.

In addition, for immigrant women it is suggested that factors such as marginalization, family separation and social isolation may lead to increased dependence on their partners and consequently, less power in their relationships (Webber, 2007). On the other hand, moving to a more gender-egalitarian society as one would find in Canada may provide women with more opportunity and thereby slowly "dissipate the women's vulnerability to HIV through increasing their relationship power, or increase their access to community resources (Webber, 2007)." In this manner, migration may be a positive force in HIV prevention for some women (Webber, 2007).

#### Being married

As mentioned earlier, a number of gender norms are linked to women's role in marriage. Among married couples, sociocultural factors may very much influence attitudes, beliefs and therefore likelihood to engage in risk behaviours, or abstain from protecting oneself, for example, through condom use. Culturally, one of the primary purposes of marriage is to procreate, and since condoms are mainly thought of as contraception, married

couples may refrain from using them (Bhattacharya, 2004). Especially in South Asian culture where childbearing and leading a family life is given a lot of importance, condom use would appear counterproductive. Condom use has also generally been associated with extramarital relations, so women may fear suggesting their partners use them – either because it may seem that she is accusing him of having an affair, or that he may accuse her of being unfaithful (Bhattacharya, 2004). With marriage being traditionally seen as protective and safe, women may tend to believe they are unable to get HIV from their husbands, which also means they are unlikely to use condoms (Bhattacharya, 2004). Particularly among women of South Asian heritage, marriage is a relationship where the husband is held in high esteem, and the needs of women are often seen as subservient to that of her partner. In cases where women have been legally sponsored to come live in Canada by their spouses, the feelings of obligation may be even greater, making it more unlikely that she will assert herself with regard to safety around sexual health Webber, 2007; Gagnon et al, 2010).

#### Varying knowledge, attitudes and practices

A Canadian study looking at the knowledge, attitude and practices of migrant South Asian women in Montreal around STI and HIV prevention based on gender disparities in decision-making power found that fewer women feel they have that power within their marriages, and that knowledge around sexual health varied widely among the women (Gagnon et al., 2010). As mentioned earlier, women who migrate here may have a different level of, if any, knowledge of sexual health and contraception. 55% of the women responding had been in Montreal for 5 or more years, with about 70% of these women being independent or family class immigrants, i.e. non-refugees. 31% of women had not heard of HIV, and about 50% were unfamiliar with STIs. Only 44% of women felt they could prevent themselves from getting an STI if their husband had one, which indicates a lack of knowledge around preventive practices. There were also stigmatizing attitudes around HIV, with large proportions of women (>50%) feeling that teachers should not continue teaching if they had HIV, or that they would not buy from a shopkeeper who had HIV (Gagnon et al., 2010). There were more positive attitudes toward prevention strategies, and about 63% of women felt they could negotiate condom use with their husbands. When survey items were examined in relation to (self-perceived) power category (high vs. low), more high power women knew about HIV, felt they would disclose their status and felt they could ask their partner to use a condom. Women who held "higher" power in their marriages, tended to be more knowledgeable about STIs and HIV, along with women who had been in the country longer than 5 years (Gagnon et al., 2010). Also, in concordance with other literature, this study found that women who felt they had high power in their marriages were more likely to feel comfortable enough to ask their husbands to use a condom (Gagnon et al., 2010; Blanc, 2001). The study's limitations lie in having a somewhat smaller sample size (n=81 women), and that women participating in general may have been more "open" – proven by difficulties faced in recruiting women who would discuss/answer questions related to sexual practices, and also high non-response rates to questions asking about condom use and sexual acts (Gagnon et al., 2010).

#### Lack of and barriers to testing

HIV testing is crucial to ensuring that the spread of HIV is reduced and that affected individuals receive the proper care to slow down disease progression. As such, it also becomes an important form of prevention. However, in a community where the discussion around sexual health barely exists, how can such an important issue be brought to light and addressed? There are a number of additional barriers to testing: stigma and discrimination, finding an appropriate service provider, fears around confidentiality, fear of violence, fear of being ostracized from community, assumptions around risk taking behaviour, etc (ASAAP, 2001; ASAAP, 1999). For instance, if a woman was discovered to be HIV positive, despite the fact she may have been fully faithful to her partner or spouse, the initial assumption among others might be that she must somehow have strayed, rather than questioning the husband's fidelity first, if at all (ASAAP, 2001). Also, the possibility of a positive diagnosis may further prevent women from seeking testing and counselling services. If they find out they are positive, a whole new set of issues come to light, including first coping with the diagnosis on their own, and then seeking support, which may or may not include disclosure to family members (ASAAP, 2001; Abraham et al.). Without a proper safety net, or the feeling that they will still be secure and accepted among their family and community unconditionally, women may be even less likely to access testing, preferring and considering ignorance as the lesser of two evils.

#### Summary

The complex layering and range of factors that impact South Asian women's vulnerability to HIV has culminated in the current trend where heterosexual transmission is occurring more frequently, especially in larger North American cities like Toronto. To reverse this trend, local organizations can start by taking an active role in raising awareness of the risks for women, since in the past this has been done more specifically for traditional high-risk groups. A goal of any prevention campaign is for the audience to understand their risk and learn how they can work to reduce that risk. However, South Asian women as a whole are a rather heterogeneous group, and with the interplay of factors contributing to their risk prevention campaigns must be comprehensive and strategic in addressing them through their messaging.

#### Health communication around HIV prevention

Numerous sources of literature highlight the significant role of health communication campaigns in preventing HIV infection worldwide by providing information and education to the public since there is no effective vaccination or cure for the disease (Hunter, 2006; Airhihenbuwa, 2000; Agha, 2003; Maibach, 1993). While there are a range of prevention interventions available, HIV/AIDS organizations often use poster campaigns to educate and raise awareness as they work well to reach a broad audience (Hunter, 2006). If these campaigns are able to effectively help people recognize their risks and how to mitigate them, while motivating them to do so, they become a valuable tool in disease prevention and health promotion. However, the difficulty lies in constructing a campaign that incorporates all the right elements, because assuming that mere exposure to health information will bring about behaviour change is much too simplistic. The desired behaviour change is often a long-term process, which often means gradual or incremental changes over time (Maibach, 1993).

There are a number of factors to consider but to begin with, at-risk populations for HIV are usually quite heterogeneous. Even to say "South Asian women", and assume homogeneity of identity, as well as risk profile and risk perception, would be erroneous. These women are diverse among themselves, so targeting prevention initiatives and messaging "must set different objectives, use different communication strategies and have

different measures of success ", along with presenting different options (Rugg, et al., 1990). Another important goal of prevention campaigns (especially for these women, as they do not fall under the traditional definition of "high risk") is to prevent high-risk behaviour from being initiated in the first place (Maibach et al, 1993). This would mean particularly targeting young women, right from early adolescence, since their sexual behaviour and practices "will largely shape epidemic pathways in the next decade" and beyond (Cleland & Ali, 2006). Furthermore, this could be tied into a general approach to open up the discourse around sexuality and sexual health in the community.

As an example for youth, it has been suggested that three types of approaches used concertedly may be most effective – one that is universal and includes providing information widely, a second that places more emphasis on self-esteem and building communication skills, and a third more directed and personalized approach that is geared toward changing the behaviour of those who may already be involved in high-risk behaviours (Maibach et al, 1993). Again, the point to note here is that using multiple, mutually supportive strategies in parallel with providing knowledge tends to produce the greatest long-term effect.

A number of behaviour change models are used to explain why people act in ways that protect or harm their health, and these can be used to inform health communication campaigns (Witte et al, 1998). One strategic health communication campaign model provides a framework for developing a campaign using five stages and certain issues for consideration (Maibach et al, 1993). The stages are as follows: planning, use of theory, communication analysis, implementation, and evaluation/reorientation. The first two stages involve assessing who is at risk and determining campaign objectives, and then moves into looking at theories of human behaviour at various levels to decide on which techniques may be most effective (Maibach et al, 1993; Amado, 1995). For example, an audience's perception of costs and benefits can influence how willing they are to adopt certain practices and behaviours. Benefits do not necessarily have to be material – for example, they can be one's desire for acceptance, and these elements need to be incorporated into poster messages. From here however, it becomes essential to move from being general toward being more specific in terms of target audience.

Audience segmentation involves splitting the larger at-risk population into smaller, more focused populations to be reached, who may also have input into development of the campaign (Maibach et al, 1993). HIV campaigns in particular are thought to be more effective if they target homogenous audiences, as this allows for planning campaign goals specific to certain populations, and designing messages according to that population's needs. This also makes it more likely that the audience will notice and internalize the campaign messages, and adopt the recommended behaviour. Segmentation can occur in any number of ways – geographic, demographic, psychographic – and can also complement each other (Maibach et al, 1993).

Next, formative research is performed to design appropriate and effective campaigns. This can be done in the form of focus groups, interviews, surveys, etc. with members of the target audience to determine which messages will have the greatest impact and can also be quite useful in ensuring that they are both culturally sensitive and specific (Maibach et al, 1993; Pulley et al, 1996). Since the process works as a feedback loop, it allows for modifying and improving the campaign over time as may be relevant. This is an important part of the last two stages, whereby campaigns are implemented and evaluated. Evaluation not only assesses the strengths of the campaign, but also examines the shortcomings, and why certain objectives may not have been met. This becomes vital in guiding the development of new campaigns and directing future prevention efforts.

Strategically planned communication campaigns can have an important role in HIV prevention – but they require a great deal of planning done with the participation of the target audience, should "attempt to influence the audience's motivation to engage in behaviour change... and be sustained for a sufficient amount of time to promote long-term behaviour change" (Maibach et al, 1993). However, literature has also shown that knowledge is not enough to change behaviour on its own, especially without offering strategies to maintain the changed behaviour (Airhihenbuwa, 2000; Witte et al, 1996). Culture needs to be incorporated simultaneously, and this includes considering the social environment and context within which the behaviour occurs (Amaro, 1995).

#### Canadian poster campaigns on HIV prevention targeted toward women

While a number of HIV prevention campaigns are directed at prevention among high risk groups like MSMs, ad campaigns targeting women are less common and less frequently analyzed, especially with respect to the depictions of gender and sexuality. Hunter (2006) compares representations of males and females in HIV/AIDS poster campaigns in Canada from 1986-2005 by Health Canada, the Canadian Public Health Association (CPHA), the Ontario Ministry of Health and the AIDS Committee of Toronto (ACT), and how these vary based on the individual sponsoring organizations. By looking at these posters to examine how visual representations of gender and sexuality are created, Hunter (2006) argues that there are differences in the way campaigns target and represent men and women. With men, the messages suggest a positive approach with safer sexuality, whereas this approach seems to be absent in posters targeting women. Despite being highly pervasive in popular culture and commercial marketing, women's sexuality is fairly repressed and absent in most HIV/AIDS prevention campaigns. Most posters for women were not found to promote confidence in women around safer sex, which Hunter (2006) states is synonymous with the state of women in Canadian culture at large; women are not empowered in their efforts around communicating and negotiating safer sex or decisions around sexuality.

Posters are a representation of the organizations that create them as they express certain ideologies and beliefs, so it becomes important to analyze and understand how they in turn promote and enforce these messages among their audiences (Miller, 1989). Generally, it appeared that governmental posters tended to use fear and avoidance of sexuality in their HIV/AIDS awareness posters, while community-based posters appeared to promote an approach of safer sexuality (Hunter, 2006). For example, a poster "If Mr. Right refuses to wear a condom, he's Wrong" (a yellow heart with an arrow against a red background) by Health Canada may raise feelings of doubt or anxiety, which partly raises awareness of the issue, but fails to offer suggestions on how to better communicate with one's partner(s) about safer sex (Hunter, 2006). Without providing proper support or advice on how to handle these issues, such posters may overwhelm people. Posters may also indirectly end up promote stigmatizing attitudes around HIV while they are in fact trying to change it. Portraying images of isolation (with the intent of educating people to be more accepting) may again evoke audience feelings of fear, and confusion around the unknown (Hunter,

2006). Instead, if themes of acceptance were highlighted, showing a woman being accepted by her peers and family, more positive messages are promoted and reinforced.

More recently, CPHA has produced a poster with the words "Change the world" showing a young woman in bed with her partner producing a condom from her purse, which is intended to promote a message of empowerment with the woman taking charge – this is a more positive message for women to be exposed to (Hunter, 2006). Posters produced for men by ACT, a community-based organization, tended to show sexual partners taking a safe sex approach, promoted condom use, informed men on how to take control of their sex lives and also included congratulatory messages to continue to promote safer sex. When producing posters that targeted lesbian and bisexual women, even ACT's posters initially dealt with women's sexuality as something that was hidden, and used the word AIDS (which is believed to elicit more fear). Over time however, these posters have become more similar to the ones for men with positive messages around taking responsibility and promoting empowerment (Hunter, 2006). Generally, Hunter (2006) notes that most poster campaigns targeting women do not positively portray female sexuality or agency, where women appear to freely make demands and take control, in contrast to posters for MSMs, where the "taking control" message is highlighted.

Another important observation about the messages promoted to the heterosexual population revolves around men and women being presented as opponents around safe sex negotiation (Hunter, 2006). By saying "If Mr. Right refuses to wear a condom, he's wrong", it appears that the partners have opposing views, and that it is the woman's responsibility to convince him otherwise to protect both of them (Hunter, 2006). However, no suggestions on how to effectively do this are offered up, leaving women in a somewhat precarious position as to how they can change the situation. Combined with the fact that societally, sex is often linked to men's needs, it remains difficult for women to always assert themselves sexually (Hunter, 2006; Holland et al., 1992). Many factors result in increased risk and diminished opportunities for women to negotiate the decisions involved in their sexual interactions, not the least of which are unequal power dynamics, sex-role expectations, and dependence on partners for social and economic resources. When culture is thrown into the mix, successfully preventing HIV/AIDS through effective messaging becomes an even more complex feat. To promote positive, empowering messages for women around sexuality and

safe sex negotiation, communication between partners needs to be emphasized through HIV/AIDS awareness and prevention posters (Hunter, 2006). While the explicit goal of these poster campaigns is to prevent HIV, an underlying goal is to empower heterosexual women to better communicate and make decisions in their sexual relationships.

#### The Alliance for South Asian AIDS Prevention (ASAAP)

ASAAP is a non-profit, community based organization in Toronto that works to provide health promotion, support, education and advocacy in a non-discriminatory manner for those who identify as South Asian living with and affected by HIV/AIDS (ASAAP, 2001). Until recently, ASAAP primarily worked with MSM within the South Asian community, as this has traditionally been a high risk group for HIV infection and transmission. Lately however, there has been increasing attention devoted to outreach programs for women in the community, in line with the increasing rates of infection in this group, through heterosexual exposure. In addition, the clientele of ASAAP has been changing over time, with a reported 30% increase in the number of women accessing their services over the past two years (ASAAP personal communication, March 4, 2010).

The types of clients using the organization's services are also an indicator of where needs are, or where a gap exists in the community, and with more women contacting the agency for HIV/AIDS related services and resources, this has been taken as a sign that the range of services offered need to be diversified to cover a broader population at risk (ASAAP personal communication, March 4, 2010). The majority of new women clients are between the ages 25-40 (HIV Prevention Research Team, 2007). This is consistent with Liu and Remis' (2007) findings looking at HIV trends in Toronto from 1980-2004, where looking at a 25 year trajectory that over time, the number of HIV infections have become less attributed to MSM as an exposure category, and more attributable to heterosexual exposure. As result, ASAAP has decided to expand its community outreach to women as a target population. The organization recognizes factors discussed above in the vulnerability section as fuelling the problem, and therefore proposes opening up community discourse around sex and sexual health as one of the primary steps in mitigating it. An initial exploratory analysis looking at ways to do this has been conducted by ASAAP with women in the target population, the results of which are discussed below.

## **METHODS**

In order to respond to the changing face of HIV/AIDS in the South Asian community in Toronto, ASAAP has been consciously trying to widen its outreach programs to women, and to do this in an effective manner, workers have used focus groups as a way of identifying issues and assessing the community's needs as they see them. Using the insight gained through these focus groups, the organization seeks to launch a widespread HIV awareness/prevention campaign for the South Asian community in Toronto at large. In addition, the organization aims to later supplement this campaign through workshops and other initiatives, along with creating a resource toolkit for other agencies and service providers that addresses major needs with regard to HIV and AIDS as identified by the women themselves.

Three focus groups were held in 2009; the first and second groups were conducted in January and February of 2009 with 7 women each, and the third group was held in March 2009 with 4 women. The first focus group was held to determine what women felt were key thematic areas for the organization to address or promote within the community. Questions were asked regarding their perceptions of needs, what they felt might be effective methods of community outreach, and also actual images and messages or slogans that they felt could be included in a community awareness campaign.

The second focus group session consisted of a presentation on women and HIV/AIDS, reading and responding to a handout on the topic specific to women in Ontario, followed by a series of slides with a number of posters/images used in HIV prevention campaigns by other organizations targeting women, to gauge the reactions and responses they elicited in the participants. Participants were asked to fill out a handout answering questions about: demographic information (age, sexual identification, class status, HIV status); notes and thoughts on an infosheet provided "Women from Asian and South Asian Countries" (McWilliam, 2008); opinions on which three slides had the most and least impact on them; thoughts on which means would be the most effective way to get the three themes (prevention, education and support) out to the public; any other thoughts or notes on discussion questions.

The handout "Women from Asian and South Asian Countries" (McWilliam, 2008) briefly outlines how we know that women from these countries are at risk, what puts women from these countries at risk, HIV prevention efforts for women from these countries, and finally a number of recommendations. It begins by presenting numbers of infected women in these countries followed by the situation in Canada. There is the additional caveat that these numbers are likely underreported because not all provinces collect ethnicity data, and other issues include the likelihood that a large number of Canadians living with HIV are undiagnosed at present because they have not been tested, especially in communities where cultural taboos prevent open communication around HIV and sexual health. The increased risk of infection for women from these countries is attributed to a number of factors, mostly the same as those discussed in the background section of this paper. For example, challenges in negotiating condom use and accessing information on HIV due to cultural taboos around discussing issues related to sexuality and sexual health leaves them less able to make informed decisions that may affect their health and well-being (ASAAP, 1999). Gender issues further complicate these difficulties, with expectations and norms around gender roles, possibility of violence, as well as social and economic inequalities that increase women's risk of infection (McWilliam, 2008). To better understand the prevention needs of women from these communities, the authors of this handout suggest that ethnicity data should routinely be collected in epidemiological reporting, as well as building partnerships between community organizations since there is still a paucity of information about the unique HIV prevention needs and issues of the populations they serve (McWilliam, 2008).

The third discussion was held with four younger South Asian women following the production of images from ASAAP's photo shoot for a poster campaign, and issues raised here were used to supplement the discussion from the prior two focus group sessions. These images included a pregnant woman, the upper half of a married woman's face (with the traditional markings of a bindi and sindoor) mainly focused on kohl-rimmed eyes, a woman's foot adorned with silver anklets, the back of a topless woman with a small tattoo, the exposed midriff of a woman wearing a sari, and the joining of three women's hands wearing bangles.

### RESULTS

During the initial focus group session, participants discussed the relevance and utility of a poster campaign to launch this new angle of community outreach and just get the word out. Posters were identified as a useful resource since they are generally non-invasive, can reach and spread awareness/information to the masses, and somewhat force people to see and read information. Participants were shown a number of images ASAAP had taken with the intent of creating an ad campaign, and the group identified three themes – prevention (e.g. through safer sex), education (e.g. facts, FAQs, misconceptions and stats about HIV/AIDS), and support (e.g. for women with HIV/AIDS). Difficulties were primarily related to the heterogeneity of women even within the South Asian community; these women speak/read different languages, respond to different images based on their age/background, and ability to act after reading and receiving the message.

The women in the second focus group were briefed on the discussion and findings from the first group, and then were asked what they felt would be the best way to get these three themes out to the public would be. Suggestions included promoting prevention through large posters, education through booklets and support through providing a list of resources. The session concluded with a general discussion around thoughts women had after viewing all these images, what they felt they could most relate to, and what they felt would have the most impact.

The second focus group consisted of 7 participants, ranging from 26 to >50 years of age, varied sexual orientation (heterosexual, queer, N/A), class (lower-middle, middle, middle-upper, N/A) and all with negative or unknown HIV status. Participants' thoughts on reading the handout were generally that this information was useful, and more needed to be done to get this information out to women in the community. One participant mentioned that it might be useful to have this handout translated into a number of South Asian languages so that more people could understand it without interpretation, and also that an FAQ-type resource on common taboos/myths specifically related to HIV/AIDS and South Asian culture/women might also be helpful. A couple of participants mentioned that age would be an important factor to consider alongside gender; different campaigns targeted to women who are born or raised in Canada versus women who are immigrants might be

necessary, and also that it would be important to open up this dialogue among women of all ages in the community. Another consideration along this line might be for expanding outreach to immigrant mothers so they can begin talking to their daughters about sex and sexual health. One participant also raised the issue of questioning not only cultural taboos, but religious taboos, and doing this by engaging more with faith-based community organizations (as well as cultural ones). Violence against women was also raised as an important co-issue; since HIV/AIDS can also be a violence against women issue, using lessons learned or strategies used in such campaigns may be helpful in raising awareness around both problems.

The women's opinions were quite varied when it came to deciding which posters had the most and least impact on them, but certain types of images/messages appeared to women differently based on their demographic and background, emphasizing the heterogeneity of women in general. For example, a poster with the image of a woman's hand sewing a button onto a shirt was one of the slides that had most impact on two of the women who were 50+, and was also mentioned by one of the younger women as an image she felt would appeal to older women. On the other hand, an image of a young woman in bed turned away with only her back exposed in the background, her partner zipping up his jeans and wearing a shirt that says HIV in the foreground, and a slogan that says "Just because you can't see it, doesn't mean it's not there", was perceived as having greater impact by two of the younger women. One poster that produced an impact among women across age groups simply had the black-and-white message "(in larger text) Women are not equal. (in smaller text) In AIDS prevention" on a red background, perhaps suggesting that little, yet powerful information could be quite effective. When answering about which images had the least impact, again the difference between women of different age groups became evident. A poster with a topless woman on her knees giving oral sex to a man with a gun replacing his penis was recorded by all three of the older women (and none of the younger women) as a slide that registered the least impact. The other women mostly found images with lots of pink, or painted images of happy/thoughtful women to have less impact. Again, it appeared that one of the key factors determining impact of the poster was whether the images in the posters were ones women could relate to.

When asked about the most effective means or medium to get messages about prevention out to the community, the women unanimously suggested and agreed upon posters. Large posters with strong, provocative (but inoffensive) messages were believed to be very effective, and one participant suggested that they also work well when distributed in "surprising" places (e.g. bathrooms). To spread messages around education, pamphlets were suggested as a more passive option, but most women felt that active workshops and community outreach where people would go to schools, youth groups or places of worships would be more effective. A couple of participants suggested advertisements for TV/radio, and one participant mentioned popular theatre as another potential method to educate the community about HIV.

With regard to messaging around support, the suggestions mainly involved brochures or postcards in multiple languages, distributed widely to ensure maximum access. One participant suggested that these should also include resources for talking to one's husband/partner, as well as links to other community organizations and women's groups dealing with related issues like violence. A general concluding thought around campaigns was that it was important to have different material geared toward different age groups in order to successfully target a wide range of women; to reach all demographics effectively with one campaign would be an extremely difficult task.

Among the third group which consisted of younger, second generation women, the findings were also similar. One problem with the imaging again was that it might not be relatable not only to women from different age groups, but also different cultural groups (Sri Lankan, Pakistani women). Images of fair-skinned, attractive young women may not appeal to, or cover all kinds of South Asian women, and may also look more like an advertisement for a Bollywood movie as opposed to a campaign for health. Workshops were again raised as a great form of outreach, and one suggestion was to make them more focused on health as opposed to only HIV/AIDS. Here, it would again be important to target the fact that there is a lack of discussion around all these issues, and it could be a good platform to educate women on how to start talking to their kids, parents, partners and families. This could also be a place to educate women and discuss other ways they may be able to protect themselves from STIs, highlighting that while they may be in monogamous relationships, their partners might not always have been, or even still be. Additionally, women could be informed of ways

to take control of protection within their relationships. Getting community and faith based leaders involved are once again suggested as an important connection to make in order to reach a greater audience, and here again, the focus could be on health in general.

Finally, suggestions around education mostly revolved around targeting and advertising to different generations, for example, providing a website for younger people and maybe producing brochures for older people. Images are important, so producing something with fewer words and more images, including ones that show women how to protect themselves, since the dialogue is not often present. One potential drawback with brochures was that women may not want to, or be able to go out and physically get this information, so they may not actually get picked up or read.

# DISCUSSION

A number of initiatives will be required over time to expand ASAAP's outreach to women, but having identified three key areas helps determine how to focus their approach. Presently, developing and launching a poster campaign to raise awareness about HIV prevention appears to be an initial initiative with the necessity, drive and resources behind it. As a result, determining what such a campaign should look like, and what elements are important to include based on the background research and focus group findings will be the focus of this section.

To begin with, it is clear from focus group results that a "one-size-fits-all" approach will not necessarily work for this community, as it ignores the heterogeneity of women that belong under the larger umbrella term – South Asian women. These women come from different countries, or even different parts of the same country, speak different languages, and as such respond differently (or not at all) to the same images. This dictates the need for posters to be culturally appropriate and developed in multiple languages in order to be accessible to a greater number of women. Furthermore, these women are of all different ages, some having immigrated to Canada as adults, and others born and brought up here their entire lives. Either way, a single poster/image may not effectively capture the attention or interest of all these women, nor will it be representative of them or women they may know. As such, it may not be easy to settle on one image for all the posters, but the message that these posters should try and promote should be similar.

Communication and emphasizing its importance is an essential theme to be included. Since ASAAP is a community-based organization, their poster messaging should generally focus on promoting themes of safer sexuality. In the context of prevention, this includes communicating with one's partner about safe sex, and encouraging communication between mothers and daughters about sex to move past the persistent cultural silence around such topics. It is a fact that many young South Asian women are engaging in relationships and exploring their sexuality, so opening up this discussion across age groups may be one way of transcending cultural barriers. To date, it has been felt that to discuss something like HIV must mean that a person has it, or else why would they want to talk about it, but unless such

stigmatizing attitudes begin to break down, women will continue to be at risk as they may remain uneducated about how to protect themselves.

To move past this, conversations on sexual health and HIV need to be normalized so women do not feel scared or ashamed to raise such topics and in turn learn more. A related factor may be that women also need a safe, encouraging environment to start having these conversations, so it may be necessary to make condoms (along with other methods of prevention) and counselling available in places easily accessible to women without them feeling embarrassed or needing to explain themselves to male family members. In addition, testing was discussed earlier in the paper as a means of prevention; with this comes the need to incorporate post-test counselling into HIV prevention messaging, and again this needs to be culturally appropriate. By making this an open community topic, these posters may implicitly encourage the development of an inclusive, supportive community in which one can feel safe and comfortable to disclose their status and seek help if need be.

Women of all ages experience different types and levels of vulnerability, but if using the previously mentioned definition where it means to have little or no control over one's risk of infection, they need to be educated at the very least about their bodies, STIs and safe sex options. As the Montreal study showed, many women are unfamiliar with STIs and HIV, and seem to be unaware that they can do something to protect themselves (Gagnon et al, 2010). Knowledge, attitudes and practices are all interrelated, so while the first may not equal the other two, there is a greater chance that it will have an influence. With regard to safe sex options, methods of prevention that are female-controlled also need to be encouraged. As is often the case with mainstream poster campaigns on HIV prevention, condoms tend to be exclusively promoted, but this ignores the fact that in many relationships, power dynamics may prevent a woman from imposing protection on a man and therefore leave them unprotected. If women are aware of ways to protect themselves that do not depend on their partners, then they do have control over their risk of infection, and therefore their vulnerability is decreased.

#### Limitations

A limitation of the data collected by ASAAP is that the focus groups are rather small in size (only 7 participants each), and therefore may not adequately capture the actual

demographic and ethnic diversity of South Asian women in Toronto. Especially when looking at participants' responses to images they were shown, it was evident that responses varied by age – the strength of these observations could hold greater weight if observed among even more women. Also, the observation that an image might not appeal to all South Asian women just because they were South Asian only surfaced in the smaller, third group, where the participants came from different backgrounds. Especially in North America, Bollywood and popular Indian culture has become symbolic and representative of South Asian culture as a whole, but this ignores the fact that South Asia is made up of a number of countries other than India, and even within India, there are a countless number of subcultures. One image may not universally appeal to all South Asian women, and further research with more women, from different sub-communities may help strengthen this finding. In addition, the objective of the focus groups was to determine the best methods for community outreach, however there is still no real data on how women in this particular community perceive and respond to their risk. This should definitely be explored further, especially to help discern and evaluate change over time, and assess how much of this change can be attributed to increased knowledge and awareness.

As noted, knowledge and educating people on how to modify their risk can seem too simplistic an approach at times, and can be faulted for suggesting people are able to act completely of their own agency. With the immigrant South Asian community in Toronto, and particularly with women, a number of factors contribute to what decisions they make regarding their health, and how they make these decisions. As discussed throughout this paper, decisions around sex are often predominantly made by men, whether directly or indirectly as a result of gender norms and power dynamics, and this impacts the ability of women to modify their risk of contracting HIV from their partners.

It is important to acknowledge that posters are only an initial step in the right direction. Hopefully they will help move past the silence among this community and culture as a whole around issues like sexuality, sexual health and HIV/AIDS simply by making these topics "common", as opposed to taboo. At the very least, value in posters and the images they carry as a tool for promoting health lie in their ability to provoke thoughts and conversations on these subjects. However, since posters generally represent a one-way flow of information, it becomes essential to also expand and supplement outreach by including

initiatives such as workshops, speaking at schools, and theatre as potential ways to open up and facilitate active dialogue between community members of all ages. Finally, it must be noted that this problem is only one part of a larger picture where women are still unable to fully recognize their rights and the rights they have over their own bodies. Violence against women remains an associated and equally important risk that should be addressed. All of this requires much more than breaking the silence and educating women; it is dependent on a shift in gender roles and attitudes within the culture itself. It is difficult for desired changes in behaviour to occur in the absence of changes in a broader social and cultural context. Traditional mindsets need to be challenged if we are ever to see any truly sustainable change in the empowerment, and ultimately the better health of women – South Asian women in Toronto, Canada, or even simply women worldwide.

#### Reflection of self as a public health practitioner

As a young Canadian woman of South Asian heritage myself, I felt an affinity to the problem which made me curious to investigate it further. While studying the factors contributing to Canadian South Asian women's increased vulnerability from an academic standpoint through published literature, I found that I could instinctively list and sometimes even identify with them firsthand. Born and brought up in Toronto, I fit the profile of a typical second generation South Asian woman, and the cultural value conflict discussed earlier in the paper is certainly something I have experienced. Despite having studied science and public health and knowing all that I do about risk and disease prevention, I can understand why a silence on topics such as sexual health still exists.

For many young South Asians like me, our parents are still making the transition toward bridging the culture they grew up in, and the one they have moved into. Although the situation may vary when comparing families, very few South Asian families openly discuss sex because such discussions would have been unheard of when and where they were growing up. Compared to many of my female South Asian peers, I feel fortunate to have grown up in a very liberal family, yet I feel there are also certain cultural values I have somehow internalized, again without explicit discussion or expectation. For the current generation, sex is much more visible in mainstream culture, and whether we talk about it or not because we still fear judgment by others in our cultural community, engaging in

premarital sex and risky sexual behaviour is more predominant now than among our parents. This is where I feel my responsibility to public health steps in and takes over; although I never did while growing up, I now feel that open discussion about such topics is imperative if youth are going to learn to be safe. Since risks can be socially constructed, they can also be deconstructed and removed, if people are aware of them and know how. If the current generation begins taking these steps, slowly the situation can improve for future generations.

Another factor discussed throughout the paper was gender norms and expectations, and how changing these are imperative to dissipate the gender-based power dynamic that exists in many relationships. Fortunately, Western society and culture is more emphatic about promoting women as equals, and viewing them as people who can make decisions and act by themselves, for themselves. Hopefully, as people from other cultures assimilate into this society, they begin to also adopt some of the more gender egalitarian beliefs and attitudes prevalent here. Again, I have observed this more among young men and women like myself who have lived here for all or most of our lives, and as a result, I feel these are the values we will promote in our own families, when we begin raising children. As a public health practitioner, when choosing to study a phenomenon related to one's own background in any way, I feel one can bring certain strengths to the table. In this case, I felt that my cultural background worked as a unique lens with which to view and analyze the problem, as it allowed for overlapping of both academic and non-academic knowledge and experiences.

# CONCLUSION

As Webber (2007) aptly states, "the context of HIV prevention for women includes their biologic risk intersecting with their gender (socialized position in society) in the setting of their personal relationships, community, and the structural setting." Here, the term relationship encompasses issues such as power and communication between partners, community includes health resources as well as protection and access to these resources, and structural setting is determined by factors like stigma, socio-cultural norms and policies. Ethnic identity influences and is influenced by all three, and therefore cannot be overlooked when trying to promote any kind of awareness to a cultural community at large, but particularly awareness around sensitive topics such as sexual health, HIV and AIDS. As this is a somewhat novel population to target with HIV prevention messaging, there is no real precedent to follow, nor is much known about what may be effective in producing change. Promoting behavioural change to any extent is never easy, especially in isolation or without the support of greater societal change with regard to gender roles and cultural norms. An awareness campaign for the South Asian community is merely an initial step, and starts to scratch at the surface of the public health problem. If we can overcome the upstream barriers and break the silence that has been imposed on such issues, hopefully we can move toward not only preventing HIV, but also toward promoting more equitable health outcomes for women overall.

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