South Asian Women Living With HIV/AIDS

BY THE ALLIANCE FOR SOUTH ASIAN AIDS PREVENTION

Des membres de l'Alliance pour la prévention du sida en Asie du Sud (ASAP) se sont regroupées pour partager généreusement leur vécu et leurs expériences, parler de leurs peurs, de leurs angoisses tout autant que de leur courage et de leur force de résistance.

> *I will not die. I will not kill myself over this. Trust me, you will see me with gray hair.* (Simran)

Estimates based on the 1996 census figures suggest that approximately 439 South Asian adults may be infected with HIV in the Greater Toronto Area. The gender breakdown is not precisely known but three South Asian women living with HIV/AIDS recently shared their experiences with the Alliance for South Asian AIDS Prevention (ASAP).

Fifty-three-year-old Ayesha found out that she was HIV positive in 1992 when her husband was hospitalized with AIDS-related complications. She has kept her diagnosis a secret from her family back home in Tanzania, and the only two people who know about it are her adopted son and daughter-in-law with whom she currently lives in Canada.

Thirty-three-year-old Simran found out she was HIV positive ten years ago, five days before her daughter was born. Unknowingly infected through a blood transfusion in India during a prior pregnancy, she subsequently passed on the virus to her husband. Her ten-year-old daughter has tested HIV negative.

Twenty-four-year-old Kalyani was not as lucky and has an infant son who tested HIV positive. Kalyani got the virus from her husband who is not sure how he got it, but presumes it was through the use of unsterilized needles in a South Asian hospital years before he met and married Kalyani.

These women's accounts of how they contracted the virus are not uncommon. UNAIDS estimates that more than four-fifths of all infected women (approximately ten million out of the 25 million HIV infected adults worldwide) get the virus from a male sex partner. The rest become infected from a blood transfusion or from injecting drugs with a contaminated needle.

ASAP's experience of working around HIV/AIDS in South Asian communities has shown that prevailing religious, cultural, and social beliefs often restrict open discussion about sex amongst South Asians. Discussions about HIV/AIDS are further limited because this issue is perceived to be a western phenomenon linked with homosexuality, drug use, and promiscuity. These three women's lives do not fit the South Asian preconception of the type of people who contract HIV. However, as a result of such stereotypes about who gets HIV, all three women have hidden their condition from their friends and extended families. Simran uses "cancer" as a shield. Ayesha, too, has instructed her adopted son and daughter-in-law that if she ever has to be hospitalized, they are to tell her family in Tanzania that she has leukemia.

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> *Sometimes my brother calls asking how I am feeling, and I lie to him. I hate living this lie but if my family comes to know they'll die before I do.* (Ayesha)

The primary factor influencing this deception amongst South Asians living with HIV/AIDS, both men and women, is the fear that their families and friends will ostracize them. In Canada the situation is compounded by the fact that many newer immigrants do not speak English as their first language, and may not be economically self-sufficient, and therefore cannot afford to alienate connections within their ethnic communities.

Although these women are forced to hide their condition from their families and friends, the three women show tremendous optimism in the face of an illness that is considered by many to be socially taboo and can often be extremely physically debilitating.

> *I lost my vision for two years and I still do not know how I got it back. It's a miracle. I was pronounced dead for 45 minutes but I recovered. I have had every opportunistic infection you can think of but I am still here.* (Simran)

These women live full lives, looking after their homes and children, socializing, and keeping themselves busy. As a measure of their hopefulness about the future, Simran and her husband want to have another child.

After my daughter was born ten years ago, I became pregnant again almost immediately. But because of my HIV status I decided to have an abortion and had my tubes sewn. Now I wonder why I did that, so I recently had the tubal ligation reversed. I am now on fertility drugs. In 1992, there was a 70 per cent chance of passing on the virus from mother to child. In 2001, it's 20 per cent. And of course you can take other precautions like medication for the mother and the baby. You can have a Cesarian section and not breastfeed the baby. All of this will drastically reduce the chance of transmission to the baby. (Simran)

"I learned about the condom at ASAP's support group, after I had been infected with HIV. I had never seen or heard about a condom before."

One of the main factors influencing their positive outlook has been the knowledge that they are not alone. For those who have disclosed their HIV status to their immediate family, the response has surprisingly been extremely supportive. For others, having the support of other South Asians living with HIV/AIDS has been instrumental.

If there was no support group, I would have died years ago. Not because of HIV, but because of the loneliness and isolation. (Ayesha)

The taboo surrounding HIV/AIDS in South Asian communities often extends to other aspects of women's sexual and reproductive health as well, including infertility, other sexually transmitted diseases, and sexual abuse. This is not only true amongst South Asian communities, in the Indian sub-continent, and in the Afro-Caribbean diaspora, but also amongst South Asians settled in the West. Young South Asian women are often at a disadvantage because their parents may not give them permission to attend sex education classes, assuming that it will promote promiscuity. The double standard about dating and premarital sex continues to exist and women are expected to remain chaste, while men are tacitly permitted to have multiple partners. It is not surprising then that women are unwilling to bring up sensitive issues like safer sex or HIV /AIDS.

If you talk about HIV/AIDS or other sexually transmitted infections, people will assume you have it. Otherwise why would you want to talk about it! (Kalyani)

One of the consequences of the social restrictions around talking about sex is that many young women grow up with little knowledge of their reproductive system, intercourse, or the mechanics of HIV/AIDS transmission and prevention.

I learned about the condom at ASAP's support group, after I had been infected with HIV. I had never seen or heard about a condom before. (Ayesha)

These and similar circumstances characterize ASAP's experience of women's vulnerability in the context of HIV/AIDS. According to 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."

One of the major ways to overcome women's vulnerability is to combat their lack of knowledge about their own bodies, sexually transmitted diseases, and options for safer sex. It is also important to make condoms and sexual health counselling available in places where women can go without feeling embarrassed, and/or having to make explanations to male family members.

In spite of the availability of resources and services in Canada, for many South Asian women these facilities are linguistically inaccessible and/or culturally inappropriate. For instance, prevention methods suggested in mainstream HIV/AIDS campaigns, such as condom use, abstinence, and monogamy, may only be available in English, and may be beyond the control of some South Asian women who often have little say in how and when they have sex. This situation is especially common amongst South Asian women who are financially dependent on their husbands. Such women cannot afford to risk losing their husband's support by denying sex, even if they suspect he might be HIV positive. Ironically enough, sex trade workers who routinely insist that their clients use condoms often have more protection than housewives who do not feel they have the right to ask their husbands for safer sex.

Until such time when men and women are ready to share the responsibility for protecting themselves, their partners, and their children from HIV, more research into female-controlled HIV prevention methods is urgently needed. At present, the male condom is the most common barrier method available for HIV prevention. However, in an unequal power relationship, microbicides (virus-killing creams or foams that women can insert vaginally before intercourse) and female condoms can reduce risk without affecting the status quo.

Another powerful tool in the movement to prevent HIV transmission is to reinforce women's empowerment more generally. Women need to recognize they have rights, including rights over their bodies as well as their sexual and reproductive health. This can only occur if more women begin to question and challenge the "traditional," restrictive roles assigned to them. However, none of these strategies can be achieved in isolation. We must always keep the larger picture in mind. Social, geographic, and economic conditions also affect women's health, as do religious and cultural values and norms prevalent in our

communities. Thus, achieving optimum health can only happen if there is a shift in the way society perceives women.

The article is the joint product of staff and volunteers working at the Alliance for South Asian AIDS Prevention. For purposes of confidentiality, names and personal details have been altered.

The Alliance for South Asian AIDS Prevention (ASAP) offers a range of HIV/AIDS services to South Asian communities, including HIV Prevention Education and Outreach, HIV Testing, HIV/AIDS Resource Centre/Library and Advocacy. We also provide confidential services for South Asians living with HIV/AIDS, including case management, health promotion and community development. Our services are available in Tamil, Punjabi, Hindi, Urdu, Gujarati, Bengali and English. All of our services are free of charge. For more information, please call us at (416) 599-2727 or email us at aids@interlog.com. Visit our website at www.asaap.ca for more information.

CAMARA BROWN

Miscarriage

you have left me with new
 woman breasts
 tight water balloons
 these wine soaked stained mummy areolas

a mother's rounded pumpkin belly
 a learned womb

you left me
 with my irredeemable
 my pen, my paper
 my dirty water running out

Camara is 22 years old and lives in Kingston, Jamaica, She is a student of the applied sciences and a closet writer. This is her first publishing effort.

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