

Into the Shadow: A Reflection on the Stigma of Human Immunodeficiency Virus (HIV) in Singapore

Dear Editor,

In 1984, early in the days of the acquired immune deficiency syndrome (AIDS) epidemic, Ryan White, a 13-year-old haemophiliac who was infected with human immunodeficiency virus (HIV) after receiving a blood transfusion, was refused entry to school even though he posed no risk to other students. The ethical battles that ensued inspired one of today's most iconic and poignant posters drawn by Jack Keeler in 1986. This poster of a child with outstretched hands speaking the words 'I have AIDS, please hug me, I can't make you sick' has now become an internationally recognised symbol which has helped to address the psychological, social and emotional issues surrounding AIDS.

Even though children with HIV are no longer refused entry into public schools, the stigma of HIV infection remains very much alive due to the myths about transmission that are insidiously perpetuated within the community. A study conducted among Singaporeans in 1996 demonstrated that even though more than 90% of respondents correctly indicated that HIV could be transmitted via sexual contact, as many as 40% thought that HIV could be contracted by sharing utensils with or being sneezed or coughed on by people with AIDS.¹ Even though these figures show improvement compared with a survey done with 1987, with nearly 70% believing HIV could be contracted by sharing utensils and 56% believing it could be contracted by being sneezed or coughed on, the high prevalence of such fallacies only seek to contribute to further stigma.² Bishop suggests that such beliefs may stem from the misconception that since HIV is a communicable disease, it can be spread like other viruses such as the flu or chicken pox.¹

One of my first clinic encounters in the Communicable Disease Centre (CDC) was with a middle-aged woman who had been referred by the Ministry of Health to undergo contact screening as her husband had been diagnosed with HIV. For her, the greatest worry about having HIV was that she would not be able to carry her grandchild or eat with her family. I was fortunate to be given the opportunity to allay her fears, but there are still so many misconceptions about HIV in Singapore.

Among the healthcare professionals who care for HIV patients on a daily basis, there are too many stories of patients

ingrained in their mind who have succumbed to AIDS; not because of the failure of antiretroviral therapy, but because the stigma of HIV has led them to avoid treatment in an attempt to preserve their social circles. Yet these fears are not unfounded. John* is a patient who was diagnosed with HIV in 2005. Following this, he defaulted treatment until an admission in 2008 when he was restarted on his treatment. This lasted but a fleeting moment and he would continue to default treatment until in 2011, when he was admitted with progressive limb weakness secondary to progressive multifocal leucoencephalopathy. During his transit between healthcare institutions, the diagnosis of HIV had been leaked to his family and without a moment's hesitation, he was cast out and at the mercy of the hospital. Thankfully, he found other family members who were willing to accept him and look after him. Sadly, not all patients have such happy endings. There are many patients today, who have been disowned by their families just because they had HIV. In fact, findings of a survey published in 2008 among the public in Singapore found just over half the respondents said that they would care for an infected family member, while less than 20% of respondents would buy food from a person infected with HIV.³

There have also been patients who have taken to committing suicide because the stigma was too great a burden. A cohort study conducted in Switzerland showed that although suicide rates have decreased significantly since the initiation of antiretroviral therapy, they are still higher compared to the general population.⁴ Another study conducted in the United Kingdom found that nearly one-third of patients living with HIV/AIDS experienced suicidal ideation.⁵ In fact, a literature review conducted on suicidal behaviour in HIV patients found that while suicide rates in HIV-infected persons were higher than the general population, they were not dissimilar to rates found in groups suffering from other chronic illnesses.⁶ Unfortunately, little data is available on the suicide rates in Singapore and other countries in Asia which show an increasing prevalence of HIV. Nonetheless, such statistics are an indication for the need to support such patients both emotionally and psychologically.

However, the stigma society creates not only affects the individuals but others as well. A study done among men

having sex with men (MSM) in Asia found that disclosure rates were as low as 33%, compared to those in Western countries where disclosure rates were higher at 75%.⁷ While Western culture may differ greatly from that of our own, encouraging disclosure may also reduce rates of HIV transmission. In fact, findings of the study also reveal that countries with the highest reported non-disclosure rates were also those which had enforced laws to criminalise HIV transmission and exposure. This is a perfect example of how societal stigma has created a negative pressure environment, whereby HIV transmission is increased not deterred.

A recent study conducted in Tan Tock Seng Hospital revealed that 79% of patients opted out of HIV testing, either because they perceived little or no risk of contracting HIV or fear of receiving a positive HIV result; the consequences of which would include the loss of life, the financial worries of treatment, the loss of livelihood and alienation from their loved ones.⁸ The study also found that among those who defaulted treatment, reasons included refusal to start treatment or the inability to accept their diagnosis. Andrew* was only 19 years old when he was diagnosed with HIV after his first sexual encounter. Unable to face the diagnosis and the shame he felt it would bring his family, he swept it under the carpet. Five years later, he presented with severe *Pneumocystis jirovecii* pneumonia. With treatment, he made a good recovery but still refused to start antiretroviral therapy and focused on one thought alone—suicide. But through the efforts of the various healthcare professionals looking after him, he found comfort and friendship in a support group and is now on the road to recovering his health, and his life.

Sadly, the stigma of HIV is not limited to the confines of the general public. In fact, a study conducted among doctors and dentists in Singapore in 2000 found that although respondents had accurate beliefs concerning HIV transmission, nearly 70% of doctors and dentists agreed that healthcare professionals seemed unwilling to treat persons with AIDS or infected with HIV.⁹ The study also showed that as many as 84% of doctors and 66% of dentists were not prepared to care for such patients. While further surveys are required to evaluate if there has been a change in the attitudes of healthcare professionals towards people living with HIV/AIDS, it is hoped that by reducing the stigma through education, the healthcare industry will become a place of solace for those who face the fear of abandonment from their friends and family.

Thankfully, the scenery is beginning to change. In Singapore, antiretroviral therapy can cost anywhere from S\$300 to nearly S\$1000 a month, a hefty cost for most Singaporeans, let alone those who are socially disadvantaged. In 2010, Singapore became the last developed Asian country

to provide free or subsidised treatment for HIV infection.¹⁰ As HIV was said to be acquired through a person's lifestyle, society had perceived such patients to be unworthy of financial aid. Today, Medifund assistance has helped many patients acquire their medications, enabling them to live healthy lives. In an effort to protect people with HIV/AIDS from stigma in the workplace, the Singapore National Employers Federation also formed a committee in 1992 to identify issues in the workplace. The first guidelines for employers regarding HIV/AIDS was published in 1993 and more recently updated in 2011.¹¹

The World AIDS Day theme for 2011 was selected as 'Getting to Zero', to fall in line with the UNAIDS vision of 'zero new HIV infections, zero discrimination, zero AIDS-related deaths'.¹² In Singapore, eliminating discrimination may be the most pertinent goal. Eliminating stigma will take years to accomplish but it is hardly an impossible one. Stigma stems from a lack of awareness, which some Western societies have overcome as a result of appropriate education about HIV/AIDS. This article aims to demonstrate how stigma can easily infiltrate every level of society—individuals, families, friends, industries, policy-makers, governments. However, through education, we can eliminate stigma. In fact, awareness campaigns have shown encouraging results. A survey recently conducted by the Health Promotion Board showed that about 41% of respondents would share a meal with a person infected with HIV/AIDS, compared to only 22% in 2007.¹³

Diabetes is a lifestyle-related disease, requiring lifelong monitoring and treatment. Other diseases which fit the bill also include chronic obstructive pulmonary disease, hypertension, so why not HIV? While patients with HIV need to be more socially conscious in order to prevent HIV transmission, our role as healthcare professionals is simple. We need to make a conscious effort to see them as any other person, to treat them as any other patient and to actively educate those around us about HIV.

*The patient's names have been changed to protect them.

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