

*AIDS Care* 14(4): 559-67 (2002)

## **THE PARADOX OF PUBLIC HIV DISCLOSURE**

***Susan Paxton, Ph.D.***

***Australian Research Centre in Sex, Health and Society, La Trobe University, Australia***

For over a decade, HIV-positive people have spoken out openly, presenting the reality of living with HIV, in order to carry out AIDS education. They play an essential role in challenging myths and misconceptions about who becomes infected and making people examine their risk of infection (Paxton, 1999). Contact with people living with HIV (PLWHA) results in significantly more tolerant attitudes towards HIV (Takai et al, 1998) and significantly changes young people's attitudes to HIV prevention (Paxton, 2000).

There is a dearth of research about the impact of public disclosure on the wellbeing of PLWHA and the skills, training and support needed to speak out publicly. Analysis of the role of PLWHA in the global response to AIDS is largely absent from peer-reviewed literature.

Parker (1996) traced a shift in approaches to AIDS education during the 1990s, from information-focussed prevention campaigns based on the health-belief model, to a focus on empowerment based on social changes in gender and power relationships. He describes a paradigm shift from individual risk to social vulnerability, due to increased awareness of the fundamental link between public health and human rights. This new model focuses on collective empowerment and community mobilisation as central to the response to AIDS but does not incorporate the role of people with HIV/AIDS. Stephens (1999) describes HIV-positive activists as an unrecognised and under-utilised epistemic community that operates beyond the constraints of established theoretical frameworks.

UNAIDS have adopted the principle of increasing the capacity and co-ordination of networks of PLWHA and ensuring their greater involvement in the formulation and implementation of AIDS policies and programs (UNAIDS, 1999). This is seen to be important for several reasons:

- a) publicly acknowledged involvement helps to reduce stigma and discrimination and can be a powerful tool in breaking the silence and helping individuals overcome fear and prejudice;
- b) PLWHA bring the unique perspective of their experience to organisations and can perform valuable functions as AIDS educators;
- c) involvement builds the morale of PLWHA.

The study described here was designed to evaluate the impact of public disclosure of HIV status, on HIV-positive people. The aim of the study was to determine how public HIV disclosure affects the speaker, including:

- Are there necessary conditions for positive people to disclose publicly?
- What are the disadvantages and/or benefits of public disclosure?
- Is the experience different for speakers from different regions and cultures?

## **Deciding to Disclose**

Because of the fear of AIDS-related stigma, very few people contemplate voluntarily disclosing their HIV status. However, it is widely accepted that holding back one's feelings results in stress, which negatively impacts on physical health. Pennebaker et al (1988) indicated, via controlled clinical studies, that inhibition affects the immune system. They demonstrated that immune functions are significantly heightened after expressing long-held secrets or traumatic experiences. This is the case even if doing so is painful. Although members of the study group experienced some initial negative feelings, they were significantly happier than control subjects were three months after the experiment. Pennebaker states that "*whereas inhibition is potentially harmful, confronting our deepest thoughts and feelings can have remarkable short- and long-term health benefits*". (Pennebaker, 1990, p.14)

Qualitative studies support these findings. According to Schatzow and Herman (1989), disclosure of a traumatic secret related to sexual abuse can be an important step in recovery. By unburdening the weight, the shame is lifted. The authors argue that disclosure can be empowering regardless of the response because the power of the act lies in the "truth-telling" itself.

*A successful disclosure is almost always followed by exhilaration... The patient feels surprised at her own courage and daring. She has broken the secret and survived, no great catastrophe has befallen her or her family.*  
(Schatzow & Herman, 1989: p.347-8)

Timewell (1992) states that AIDS-related stigma creates secrecy, which in turn creates psychological isolation and depression. Disclosure, on the other hand, produces an immediate and lasting end to the depression. Hays et al (1993) suggest that disclosure of one's HIV status to individuals who respond in a helpful manner contributes to improved psychological wellbeing.

Fear of rejection appears to be almost universal amongst PLWHA and often leads to self-imposed isolation (Laryea and Gien, 1993). Meursing (1997) examined the impact of living with HIV on 96 Zimbabweans. Most study participants found decisions to disclose their status extremely difficult. Despite Zimbabwe's high HIV-prevalence, participants' need for family support and counsellors' encouragement and assistance, only half of the sample disclosed their status to anybody.

Holt et al (1998), investigating the role of disclosure in British males, concluded that it has a dual role, as a stressor and as a mechanism for coping with the disease. Although individual accounts have been presented at international AIDS fora (Balasubramaniam, 1996; Mukasa, 1996; O'Connor, 1996), only one analytical study of the impact on the discloser of going public about HIV has been located in the peer-reviewed literature. Wiener et al (2000) interviewed 18 HIV-positive American children who had gone public in the media. Respondents said the decision to do so had been painstakingly difficult but cited many subsequent benefits, including the freedom to be open about the disease, doing new things, meeting celebrities and receiving praise and gifts. All said that relationships with family and friends were unchanged and, given the choice, they would do it again, although a little differently. One-third of respondents could identify no "worst thing" about going public.

## **METHODOLOGY**

In-depth interviews were conducted with people who disclose their HIV status in small group settings, such as school groups or health workers, and/or in the media. Research ethics approval for the study was obtained from The University of

Melbourne. Data was collected between May 1997 and January 1999. The author, who is herself HIV-positive, interviewed all respondents.

The 75 interviewees (43 females; 32 males) came from 20 countries in eastern and southern Africa and the Asia-Pacific region. (*Australia 14, Botswana 3, Guam 1, Hong Kong 1, India 1, Indonesia 1, Japan 1, Kenya 3, Malaysia 1, Singapore 1, South Africa 4, Swaziland 1, Taiwan 1, Tanzania 1, Thailand 9, The Philippines 12, Uganda 12, Vietnam 1, Zambia 4, Zimbabwe 3.*) All interviews with Thai, Japanese, and Vietnamese speakers were conducted using voluntary interpreters.

A cross-section of respondents from The Philippines and Australia were recruited in country in order to compare at least two disparate groups of HIV-positive educators. Most respondents from other countries were recruited at international AIDS conferences or PLWHA fora using the “snowballing” method, starting from the author’s wide network of openly HIV-positive people. Many respondents were the first person ever to come out openly as HIV-positive in their country or district. The sample is heavily biased towards people who are public in the media.

The speakers represent countries at many different stages of the epidemic, with vastly different infection rates, and with varying levels of public education about HIV. The breakdown of speakers by sex and region is given in Table 1.

---

**TABLE 1 Breakdown of number of interviewees by sex and region**

---

<b>Region</b>	<b>Males</b>	<b>Females</b>	<b>Total</b>
<b>Africa</b>	12	19	<b>31</b>
<b>Asia-Pacific</b>	12	18	<b>30</b>
<b>Australia</b>	8	6	<b>14</b>
<b>Total</b>	<b>32</b>	<b>43</b>	<b>75</b>

---

Interviewees came from a range of socio-cultural backgrounds – from widows barely able to feed their children one decent meal a day, to single males with the advantages of reliable incomes, secure housing and affordable access to optimal treatment and care. Women were less likely than men were to have a secure income source.

Some respondents, particularly women from Asia and Africa, had not completed primary education; others, both males and females from Africa to Australia, had university degrees. Age range of respondents was 11–52 years. Mean age was 31.6 years (*males, 34.5 years; females, 29.4 years*). The majority of respondents were parents; nevertheless approximately half of the sample had gone public in the media.

Respondents were not asked how they contracted HIV, yet most disclosed this during the interview. The vast majority (almost fifty respondents) had contracted the virus from unprotected heterosexual sex. Twelve males interviewed identified as gay men, nine interviewees volunteered that they had contracted HIV through sharing injecting equipment, three respondents had contracted it through a blood transfusion and the one child interviewed was born with HIV.

## RESULTS

Most respondents felt shame, loss and worthlessness after diagnosis. Most led a “double life” for some time, carefully guarding the secret of their HIV status for fear of negative repercussions. Several said they were constantly anxious that people would find out and in some instances this led to self-imposed social isolation.

*I couldn't talk to about it to anybody and it was very psychologically heavy for me. I began to isolate myself. I couldn't socialise with people because I was so suspicious of anything that anybody said... It was really draining me physically, psychologically and healthwise, and I was having a lot of physical problems.*

**(Zimbabwean Female, 28)**

Deciding to publicly disclose was rarely easy. It was frightening and confronting and required high motivation and great strength of character to face the unknown consequences of speaking out to strangers about such a taboo subject as AIDS.

*I was so afraid. I was afraid of what might happen to my family. I was not afraid of what could happen to me. I'm ready to die any time, but I was not yet ready for my child's future. At that time she did not know that I was HIV-positive.*

**(Philippine Female, 32)**

The reason people decide to carry out AIDS education is either to prevent further infections or to challenge AIDS-related stigma, or both. Many respondents were motivated to speak out after having personally experienced or witnessed particularly discriminatory behaviour. Young women whose husbands had died of AIDS were often determined to reach out and educate others. Some were encouraged to go public by peers or family. Decreasing discrimination and stopping new infections were equally strong motivators within the sample and across regions.

Some people went public immediately after diagnosis but this was rare. Most people needed time to come to terms with HIV. Usually it was necessary to talk through their fears with peers or with a counsellor. The average time between diagnosis and public disclosure was 2.6 years (*females, 2.0 years; males, 3.4 years*).

### **The Necessary Conditions to Disclose - Training and Support**

Although many respondents had some experience in public speaking before their diagnosis, the vast majority received no training before going public about HIV. Many were frustrated with the lack of available training and support. Several speakers said that too many demands were placed on them and some expressed feelings of exploitation by AIDS organisations.

Most, but not all interviewees had reasonably good social support. A person's ability to cope with adverse responses to public disclosure was often dependent on their level of support. For the majority, the greatest supports were other HIV-positive people and/or family members. Over half of respondents said peers were their major source. Women were more likely to seek peer support than men were. Peer support groups were lifelines for some speakers.

Family members play a very important role in the lives of many speakers, both male and female, whether the family was aware of their status or not. Disclosure to family was far more complex and frightening than disclosure to peers, yet the majority of speakers found that a close relative, usually their mother, a sibling or their partner, was one of their prime sources of support. African respondents were less likely to have strong support from family members than speakers from other regions were.

### **Disadvantages Faced**

Most speakers faced some level of social discrimination but usually this was not severe. For some, it was reduced after public disclosure. Women were more likely to experience discrimination than men were, from the community and/or their partner's family, yet more women speak out in public than men do, and at a younger age. African women, many who contracted the virus from their spouse, faced more discrimination than any other group, yet they were the most strongly motivated to speak out about HIV.

Most respondents who experienced discrimination had gone public in the media. Discrimination sometimes came from family members, though in most cases family became more supportive over time, once they saw the beneficial consequences of the speaker's work. Speakers faced various levels of harassment and hostility from the community. Some lost their jobs and some children of interviewees faced discrimination in school. Some women, from Thailand and Uganda, said community members had assumed they were HIV-positive before their public disclosure because their husband had died of an AIDS-related illness. Discrimination within the health sector was common both before and after going public.

### **Benefits Gained**

For the vast majority of interviewees, breaking through the barrier of silence and speaking out as community AIDS educators was an extremely rewarding experience. Despite various negative consequences, almost all had no regrets about going public. The gains, they said, outbalance any disadvantages they have faced. This was the strongest of all interview themes and cut across age, sex, culture and socio-economic class.

*There's nothing that I've ever regretted... I am proud I can come out and say I am HIV-positive, with the conviction that... it's not wrong for me to be positive.*  
**(Kenyan Male, 39)**

Speakers reported several benefits to their communities as a consequence of their greater visibility. In countries where large numbers of PLWHA have put a human face to AIDS, speakers perceive they have made their communities aware of who can become infected with HIV and dispelled many of the myths surrounding transmission. This has led to greater community acceptance and support of PLWHA, decreased stigma and more sensitive health care policies and services.

The feedback speakers usually receive from audiences is very rewarding. Many feel they get much more from speaking out than they give.

*You get love and you get support and you get caring coming back from who you're talking to, so it's really good for your self-esteem. It makes you feel very good about yourself. It makes you feel like you've done something worthwhile.*  
**(Australian Male, 28)**

Contributing to community AIDS education provides a sense of purpose. Respondents were no longer merely recipients of services. They hadn't lost their worth as a person. This was important in instilling self-respect and rebuilding self-confidence

*I feel I am doing something very active and positive for my family and my community... My self-esteem and pride have increased. Especially when I see in my own community that everybody knows so much more and is so active.*

**(Thai Female, 28)**

Some speakers said that articulating their experience rather than burying it deep in their subconscious was cathartic. One described the process as a stepping stone in dealing with the virus, others as psychologically healing.

*Today, I can talk to anybody. I can go to the President and say this is what the PLWA want. Before, I couldn't do that. I was so scared. But talking openly about my HIV status made me very, very strong... It has helped me a lot. How can I put it? Keeping quiet, it kills. It really kills.*

**(Botswanan Female, 43)**

Speaking out enables many to take back control over their lives and re-establish personal dignity and pride. Several speakers talked about the importance of high self-esteem in contributing to a positive mental and emotional outlook and to physical wellbeing. Many talked of improved health as a result of going public.

*Once I spoke about my situation I was very happy. Speaking out is good for my health. I am not taking medicine, only speaking out. When I speak to society about AIDS, I don't have stress. I feel good.*

**(Japanese Male, 29)**

### **Regional and Cultural Similarities**

There were great commonalities of experiences across the sample. Speakers of all ages and from all regions said they felt a sense of freedom since coming out publicly about living with HIV. This feeling was particularly strong amongst speakers who have gone public in the media. The majority felt they had been released from a torturous burden of secrecy.

*I don't want to live being ashamed of myself; denying myself; not telling people who I am. [Speaking out] makes me feel good. It enhances confidence in myself. It gives me a lot. It empowers me in many areas. I'm no longer scared or afraid. I no longer have to live in a shell, and live basically in a split personality. I can be myself whenever I want, wherever I want. I don't have to put on a mask when I leave. It gives me peace.*

**(Singaporean Male, 33)**

*The more I talk about it the more I feel the burden less and less... If you don't talk about it, it piles and piles and piles. You feel the burden heavy. But once you share it with other people you feel light.*

**(Ugandan Female, 27)**

Speakers emphatically stated that lifting the burden of secrecy was beneficial. There were no differences in responses between males and females or from speakers in different cultural contexts. Speaking out enriched the lives of all the speakers interviewed. Releasing the stress of a "double life" had a beneficial impact on their psychological and physical health and led to a happier, more productive life.

### **DISCUSSION**

Disclosure is stressful because it makes one vulnerable to perceived stigma of friends, family or the community. However, leading a double life is psychologically disturbing. The study findings contribute to the growing body of evidence indicating that disclosure of a stigmatising condition or experience is extremely difficult and frightening but leads to alleviation of stress and improved health. The findings support the theory that it is physically beneficial for people to disclose secrets, even

when the personal costs may be high. The paradox of public HIV disclosure is that the very thing that seems, the most dangerous thing to do, openly confronting stigma and facing possible discrimination, ultimately can be the most liberating. This finding is crucial in its importance not only in the sphere of preventive education, but also as a way to help the health and wellbeing of people diagnosed with HIV.

Because of the opportunistic nature of the sampling method, results cannot be taken as representative of the experiences of all HIV-positive speakers. Nevertheless, the similarities of respondent's experiences, which cut across sex, age, race, culture and religion, reflect some universal elements of human beings – the desire to have meaning and value. Despite there being seemingly nothing to be gained personally by confronting society's fear of contagion, by doing so people's sense of self was restored. Stigma hinders disclosure yet becoming AIDS educators helps people transcend externalised and internalised stigma. It is striking that virtually all speakers from every setting saw only the benefits of public disclosure. Despite huge cultural differences and geographical divides, experiences of HIV-positive speakers are echoed across continents.

In light of the benefits that accrue from disclosure, HIV-positive people should be encouraged to gain the confidence and support needed to come out and publicly discuss what it is like to live with a life threatening condition that carries with it so much stigma. In most populations very few positive people choose to take this brave step. In a British study by Chidwick and Borrill (1996) interviewees who expressed least difficulty in coping with their HIV diagnosis saw themselves in good health and were able to draw upon a social support network that could meet their needs. It can be argued that a prerequisite to public disclosure is addressing not only the fear of rejection but also facilitating the process of disclosure to family and the development of autonomous peer support groups. Counselling must also be available as it helps people to deal with the secrecy, stigma and loss related to an HIV-diagnosis (Gewirtz and Gossart-Walker, 2000). In Zimbabwe counselling has been shown to reduce fear and prevent suicides (Krabbendam et al, 1998).

Members of the Philly Lutaaya Initiative in Uganda state that before PLWHA can come out publicly they also need training (Amooti, 1996). A speaker's experience as an educator should be an enriching one, not one in which they feel overwhelmed, under-resourced or exploited. HIV-positive speakers are the experts in what it is like to live with HIV. They need appropriate training to be utilised most effectively.

There is a need to guard speakers' welfare against burnout (Katongole et al, 1996). Meursing (1997) believes that, in addition to strong practical and social-emotional support from colleagues, peers and counsellors, HIV-positive community AIDS educators need a reasonable wage. It is important that their value be recognised via payment for services. It gives people with fragile income security an opportunity for increased self-esteem. This, in crude economic rationalist terms, is beneficial to the wider community as it contributes significantly to keeping these educators alive and active longer. Positive speakers deserve a secure, sustainable income.

Extreme care needs to be taken with the timing of media exposure. Speakers need very good support, as well as a sustainable income. The death of Gugu Dlamini (McNeil Jr, 1998), who went public in the South African media on World AIDS Day, 1998, and was killed three weeks later at the hands of her neighbours, provides a solemn warning to those who dare to break down the wall of silence surrounding AIDS. No HIV-positive person should disclose in the media unless personal security in the home is ensured. Increasing the numbers of speakers who are "out" is only

possible in a conducive environment. Governments have a role to ensure that PLWHA can come out safely.

Providing PLWHA receive adequate support, disclosure of HIV status is beneficial to all concerned. It enriches the lives of speakers and helps the community. The paradox of coming out openly as an HIV-positive person is that in facing monumental fear and stigma, one is inevitably liberated from the overwhelming burden of secrecy and shame.

## **BIBLIOGRAPHY**

AMOOTI, N. (1996). Going Public Gives PLWAs Confidence: The Philly Lutaya Initiative. *SidAfrigue*. 8/9 34.

BALASUBRAMANIAM, S. (1996). Positive Attitude – Positive Living: An Introspection. Ab.PuD1485. XIth International Conference on AIDS, Vancouver.

CHIDWICK, A., BORRILL, J. (1996). Dealing with a Life-threatening Diagnosis: The Experience of People with the Human Immunodeficiency Virus. *AIDS Care*. 8 (3), 271-84.

GEWIRTZ, A., GOSSART-WALKER, S. (2000). Home-based Treatment for Children and Families Affected by HIV and AIDS: Dealing with Stigma, Secrecy, Disclosure and Loss. *Child & Adolescent Psychiatric Clinics of North America*, 9 (2), 313-30.

HAYS, R., MCKUSICK, L., POLLACK, L., HILLIARD, R., HOFF, C., COATES, T. (1993). Disclosing HIV Seropositivity to Significant Others. *AIDS*, 7 (3), 425-31.

HOLT, R., COURT, P., VEDHARA, K., NOTT, K. H., HOLMES, J., SNOW, M. H. (1998). The Role of Disclosure in Coping with HIV Infection. *AIDS Care*, 10 (1), 49-60.

KALEEBA, N., KALIBALA, S., KASEJE, M., SSEBBANJA, P., ANDERSON, S., VAN PRAAG, E., TEMBO, G., KATABIRA, E. (1997). Participatory Evaluation of Counselling, Medical and Social Services of The AIDS Support Organisation (TASO) in Uganda. *AIDS Care*, 9 (1), 13-26.

KATONGOLE, D., NAKAZIBWE, M., NDHOLOLWA, R., KAASIIMWE, D., NAMWEBYA, H. (1996). The Initiative of People with HIV/AIDS Utilising Life Experiences to Encourage Behaviour Change. Ab.WeD471. XIth International Conference on AIDS, Vancouver.

KRABBENDAM, A., KUIPER, B., WOLFFERS, I., DREW, R. (1998). The Impact of Counselling on HIV-Infected Women in Zimbabwe. *AIDS Care*. 10 (Suppl 1), S25-37.

LARYEA, M., GIEN, G. (1993). The Impact of HIV-Positive Diagnosis on the Individual, Part 1: Stigma, Rejection and Loneliness. *Clinical Nursing Research*. 2 (3), 245-266.

MCNEIL Jr., D., G. (1998). Neighbours Kill an HIV-Positive AIDS Activist in South Africa. *New York Times*. 28 December 1998.

MEURSING, K. (1997). *A World of Silence – Living with HIV in Matabeleland, Zimbabwe*. Royal Tropical Institute, The Netherlands.

MUKASA, D., WANGALWA, S., BWIRE, N. (1996). Feeling and Problems Affecting the Quality of Life of Youth living with HIV/AIDS Going Public in Uganda. Ab.TuB2342. XIth International Conference on AIDS, Vancouver.

O'CONNOR, L. (1996). Positive Women - Empowerment Through Advocacy. Ab.ThD5148. XIth International Conference on AIDS, Vancouver.

- PARKER, R. (1996). Empowerment, Community Mobilisation and Social Change in the Face of HIV/AIDS. *AIDS*. 10 (3): S27-31.
- PAXTON, S. (1999). Breaking the Silence - The Role of HIV-Positive Speakers in AIDS Education and Information *FID Review* 1 (6): 39-49.
- PAXTON, S. (2000). Longitudinal Impact of Using HIV-Positive Speakers. Ab.P85. 12<sup>th</sup> Australasian Society for HIV Medicine Annual Conference, Melbourne.
- PENNEBAKER, J., KIECOLT-GLASER J., GLASER R. (1988). Disclosure of Traumas and Immune Function Health Implications for Psychotherapy. *Journal of Consulting and Clinical Psychology*. 56 (2), 239-45.
- PENNEBAKER, J. (1990). *Opening Up - The Healing Power of Confiding in Others*. William Morrow & Co.
- SCHATZOW, E., HERMAN, J. L. (1989). Breaking Secrecy: Adult Survivors Disclose to Their Families. *Psychiatric Clinics of North America*. 12 (2), 337-49.
- STEPHENS, D. (1999). Two Decades of PLWHA Experience in Asia and the Pacific. Plenary Address. Vth International Congress on AIDS in Asia and the Pacific, Kuala Lumpur.
- TAKAI A., WONGKHOMTHONG, S., AKABAYASHI, A., KAI, I., OHI, G., NAKA, K. (1998). Correlation between History of Contact with People Living with HIV/AIDS (PWAs) and Tolerant Attitudes toward HIV/AIDS and PWAs in Rural Thailand. *International Journal of STD and AIDS*. 9 (8), 482-4.
- TIMEWELL, E. (1995). *AIDS in Australia*. Ed. Timewell E, Minichiello V, Plummer D. Prentice Hall.
- UNAIDS. (1999). *UNAIDS Best Practice Collection. From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*.
- WIENER, L. S., BATTLES. H. B., HEILMAN, N. (2000). Public Disclosure of a Child's HIV Infection: Impact on Children and Families. *AIDS Patient Care and STDs*, 14 (9), 485-97.