

Sero-silence and sero-sharing: Managing HIV in serodiscordant heterosexual relationships

Dr Asha Persson
National Centre in HIV Social Research
University of New South Wales, Sydney, Australia

Paper presented at the 8th *International AIDS Impact Conference*, Marseilles (July 2007).

“A chronic disorder can become a powerful third member in any dyadic family relationship”, John Rolland (1994) suggests in his much-cited study on couples and illness. This is a significant point to consider in couples where only one partners has an illness, as in HIV serodiscordant couples. Yet, in the HIV literature, only a handful of studies explore how such couples experience and manage HIV.

The word itself – discordant – suggests disharmony and tension. Indeed, the available literature focuses on such tensions, showing how serodiscordant couples face a number of social, sexual and relationship challenges.¹ Most studies emphasise communication as the key to couples’ ability to cope with these challenges,² often in reference to Rolland’s (1994) argument that “Sensitive, open, direct communication about a range of issues is essential to living well with chronic disorders”.

Communication tends to be positioned as functional and ‘healthy’, as an imperative that should be encouraged. Silence by implication becomes positioned as inherently negative, even dysfunctional. I hasten to add that my intention here is not to argue against the importance of communication. The point I want to make is that the privileging of communication as proper therapeutic adjustment to illness forecloses consideration of the complexities of managing HIV as a serodiscordant couple, let alone any enabling aspects of silence.

My paper examines the usefulness of this polarisation between communication and silence and explores alternative ways of understanding silence that might offer useful tools for HIV health workers and researchers.

My discussion draws on findings from the Straightpoz study, a qualitative longitudinal cohort study and the first Australian study to explore the experiences of heterosexual men and women who live with HIV, including HIV-negative partners.³ The study commenced in 2004 and is now in its second phase of data collection. The cohort consists of 46 participants, including 19 serodiscordant couples from a diverse range of ages, socioeconomic and cultural backgrounds (see Persson *et al*, 2006).⁴

In this study, we identified two main modes of managing HIV among serodiscordant couples. We conceptualised these, firstly, as ‘sero-sharing’, in which HIV was a shared and central experience and, secondly, as ‘sero-silence’ in which HIV was bounded by silence in different ways. These two modes are not understood as representing functional or dysfunctional modes of managing HIV, nor are they seen as discrete or exclusive. Although most couples tended more towards one mode or the other, all relationships had overlapping and complex shades of both, as I will discuss.

In the sero-sharing mode, both partners engaged in the emotional and practical management of HIV. There was a sense of shared experience, of a shared identity as an ‘HIV couple’. HIV was often described as a bond: ‘It’s something that locks us together ... We understand each other’. (Claire, HIV-negative) Negative partners were typically well-informed about HIV and invested in developing strategies around HIV inside and outside of the relationship. These couples were often close and devoted, but often isolated and reliant on each other for companionship and support. Gavin said about his partner Katya: ‘She’s lost a lot of friends. I’ve lost a lot of friends. Basically we care about each other a lot. We look after each other.’ Maria elaborated:

Our life together is a very particular life; it’s a consciously nurturing life and it’s full of rituals ... around the fact that we are still together, that we love each other, that we’ve survived, that every day is a precious time ... He survived the plague of the twenty-first century and I don’t ask life anything more.

Many of these couples had been through a lot. Often the positive partner had been extremely ill or near death, shaping the lives of both partners in profound ways. Grief and suffering forced HIV into focus, making it 'real' as a shared concern. Likewise, ongoing uncertainty affected the identities and life ambitions of both—their choices around work, career, friendships, children—and changes in the epidemic forced them to reinvent themselves and their relationship together.

In the sero-silent mode, HIV was very much in the background and was seen by either or both partners as the domain of the positive partner, rather than as a shared experience. Negative partners were rarely involved in the medical or emotional management of HIV. They tended not to be well-informed and HIV was hardly ever talked about. However, in this mode, silence worked in more ways than one. For some, silence meant they were forced to carry the responsibility alone, or it was seen as a sign of their partner's denial, their refusal to engage with HIV:

My last partner ... didn't want to know anything. Never once came with me to a doctor's appointment; he was not supportive in that respect. He was very happy to stay with me, to live with me, providing the virus didn't raise its ugly head and wasn't in his face. So he was accepting—but didn't want to know about it. If I got sick, *he* went to bed. He didn't react very well at all to it, which was a burden for me (Donna).

Conversely, some negative partners felt excluded from any engagement with HIV: 'It's like we're two different people, not a couple,' Hazel said. Thus, for some couples, silence was a source of tension, raising difficult issues around trust, intimacy and acceptance. At times, it had a troubling effect on sexual practice as silence negated the possibility of mutual decision-making around safe sex. This kind of silence around HIV in relationships can be seen to partly reflect a broader silence in Australian society; the absence of HIV from mainstream awareness and culture due to a common perception that it is a gay disease, which makes most heterosexuals utterly unprepared for HIV. In addition, they often lack access to peers and communal resources essential to the production of a language around HIV (see Persson *et al*, 2006).

Yet, for some couples, silence was seen as a positive force in that it enabled a comforting sense of normalcy. They expressly refused to allow HIV to dominate their lives and explained that *not* talking about HIV was a way to deflect feelings of ‘otherness’ and to claim their place in an ordinary, everyday world. Jason described how HIV figured in his relationship with Audrey who was currently well and on treatments:

We go on with life like there’s nothing wrong. I never bring it up ... It’s never an issue at all. We just live our life ... We never talk about it ... because this is like minor ... I don’t know about Audrey. It might be a big thing for her. But for me, because I love her, I don’t really give a damn ... I don’t want to talk about it. I mean, like as in making it an issue.

Some participants, including Audrey, welcomed the fact that their partner did not make an issue of HIV or treat them differently from anyone else. They spoke of this as liberating and supportive, as a sign of unconditional acceptance. Shifting the focus away from HIV was perceived as conducive to emotional health and allowed them to get on with their lives.⁵

Here, we can begin to understand silence as having multiple capacities; enabling *and* constraining. This helps us to consider how silence may operate in serodiscordant couples, why certain aspects of HIV may be encased in silence and not others. I’d like to give one example of this:

Maria and Adam’s relationship could be said to be defined by sero-sharing. They were very close, mutually supportive and emotionally engaged. HIV was a highly thematised and central aspect of their lives, and they had spent years developing a considered and structured way of living with HIV. HIV was clearly positioned as a shared and jointly managed experience. But there were also elements of sero-silence. Maria did not get involved in medical issues, nor did she keep up with the latest information, or accompany Adam to his doctor. She said she left that part to him, because the way Adam managed his health and medication was working so well, having narrowly escaped

death in the mid-90s just as combination therapy arrived. And *silence* played an important part in maintaining this balance:

That's his space and I don't get in there with him ... I don't want to get in his way and I know he's doing it really well. I have a lot of respect for him ... This is how he's stayed alive. And he's only alive so long as he can do this. So I watch him do it and I think, "God, you're *amazing*, your strength and focus, and your ability to take this on" ... It never fails to amaze me ... So I don't do anything to disturb him. I don't do anything that would make it harder for him. I don't badger or bother him ... I don't do anything emotionally unnecessary around him ... Because our lives and happiness depend upon his ability to do that ... This tip of our life is sitting on this mass of chemicals, and his ability to take them in ... Peace and quiet has become the holy grail of how to live with the virus ... because it's in that peace and quiet that his relationship with those drugs can be a good one.

In this example, we can understand silence not as a dysfunctional absence of communication, but as a medium of equilibrium and survival. It is an active silence that gives space to the other partner, while remaining aware and engaged. It also illustrates how silence may be very specific, rather than absolute. If anything, communication about HIV was vital to this couple. At the same time, for Maria, their health and happiness rested on a conscious decision to seal *certain* aspects of HIV in silence.

The examples provided in this paper destabilise the common distinction between communication and silence as proper and dysfunctional ways of managing HIV among couples. As an alternative to this dichotomy, the concepts of sero-sharing and sero-silence describe ways of living with HIV that either foreground or background HIV in different ways. They are an attempt to capture the layers and trajectories of communication and silence, and what they achieve in a relationship. Sero-silence allows us to consider silence as a potential medium of both support *and* denial, as both a skilled and

unskilled practice, and as having both positive and troubling effects on couples' health, happiness and sexual decisions. We could unpack communication in a similar way.

These concepts have broader applications among people living with HIV. For example, we can consider what we *mean* by serodiscordant relationships, perhaps opening it out to include not only couples, but also families of differing serostatus. We could also explore how these modes operate more broadly in the lives of people who live with HIV; how sero-silence and sero-sharing shape contact and relationships with other people, engagement with the world, and social identity.

While time has not permitted me to explore this in detail, in the Straightpoz study, sero-silence and sero-sharing intersected with gender, length of relationships, illness, treatments, and the invisibility of HIV in Australian mainstream society. Understanding what shapes patterns of communication and silence, and how they in turn shape well-being and sexual practice among serodiscordant couples, is imperative for effective HIV education and health promotion. If silence is understood simply as a deficiency, as a lack of ability to manage HIV as a couple, it may hamper our attentiveness to the complexities and specificities of people's lives.

NOTES

¹ VanDevanter *et al*, 1999; van der Straten *et al*, 1998; Jarman *et al*, 2005; Pomeroy *et al*, 2002; Knight *et al* (1997).

² Palmer and Bor 2001: 430; Pomeroy *et al*, 2002; Bunnell *et al*, 2005: 1007.

³ The Straightpoz study is conducted by the National Centre in HIV Social Research (UNSW) in collaboration with the Heterosexual HIV/AIDS Service, NSW.

⁴ In the case of nine couples, both partners were interviewed. Among the remaining nine couples, only one partner was interviewed. In ten of the couples the male partner was positive, in seven of the couples the female partner was positive, and in one couple both partners were positive.

⁵ Studies have shown that positive people in relationships report less distress than those who are single. A common explanation is that a relationship provides tangible and emotional support (for example, Kalichman 2000). However, others have suggested that relationships may provide a sense of 'normality' and thus 'psychological protection' from feelings of 'otherness' (Jarman *et al*, 2005: 542-543).

REFERENCES

Bunnell, R.E., Nassozi, J., Marum, E., Mubangizi, J., Malamba, S., Dillon, B., Kalule, J., Bahizi, J., Musoke, N. and Mermin, J.H. (2005) Living with discordance: Knowledge, challenges, and prevention strategies of HIV-discordant couples in Uganda. *AIDS Care*, 17 (8): 999-1012.

Jarman, M., Walsh, S. and De Lacey, G. (2005) Keeping safe, keeping connected: A qualitative study of HIV-positive women's experiences of partner relationships. *Psychology and Health*, 20 (4): 533-551.

Kalichman, S.C. (2000) Couples with HIV/AIDS. In Schmalings, K.B. and Sher, T.G. (Eds.) *The psychology of couples and illness: Theory, research and practice*. Washington, DC: American Psychological Association

Knight, K.R., Van der Straten, A., Vernon, K.A., Gomez, C.A. and Padian, N. (1997) The management of HIV, sex, and risk among HIV serodiscordant heterosexual couples [poster]. *National Conference on Women and HIV*, May 4-7, Los Angeles.
<http://www.caps.ucsf.edu/projects/CApartners/CPSLApaper.php> [accessed 17 April 2007]

Palmer, R. and Bor, R. (2001) The challenges to intimacy and sexual relationships for gay men in HIV serodiscordant relationships: A pilot study. *Journal of Marital and Family Therapy*, 27 (4): 419-431.

Persson, A., Barton, D. and Richards, W. (2006) *Men and women living heterosexually with HIV: The straightpoz study Volume 1*. Monograph 2/2006 Sydney: National Centre in HIV Social Research, the University of New South Wales.
<http://nchsr.arts.unsw.edu.au/pdf%20reports/Straightpoz.pdf>

Pomeroy, E.C., Green, D.L and Van Laningham, L. (2002) Couples who care: The effectiveness of a psychoeducational group intervention for HIV serodiscordant couples. *Research on Social Work Practice*, 12 (2): 238-252.

Rolland, J.S. (1994) In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy*, 20 (4): 327

Van der Straten, A., Vernon, K.A., Knight, K.R., Gómez, C.A. and Padian, N.S. (1998) Managing HIV among serodiscordant heterosexual couples: Serostatus, stigma and sex. *AIDS Care*, 10 (5): 533-548.

VanDevanter, N., Stuart Thacker, A., Bass, G. and Arnold, M. (1999) Heterosexual couples confronting the challenges of HIV infection. *AIDS Care*, 11 (2): 181-193.