“It is not an easy decision on HIV, especially in Zambia”: opting for silence, limited disclosure and implicit understanding to retain a wider identity
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“It is not an easy decision on HIV, especially in Zambia”: opting for silence, limited disclosure and implicit understanding to retain a wider identity

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As universal testing moves onto the HIV agenda, there is a need for more understanding of the relatively low uptake of HIV testing and the dynamics of disclosure in Sub-Saharan Africa. Despite the expanding provision of anti-retroviral therapy in Zambia since 2004, disclosure of HIV status – beyond a closed network – remains limited. Drawing on 20 years of living and working in a high HIV prevalence country, research on HIV-related stigma and existing literature on disclosure, this paper explores the reasons that lie behind limited disclosure. Unravelling why HIV disclosure remains “a navigation in a moral field”, the pattern of silence around HIV and the routine and often subtle presence of HIV in daily life reveals two key dynamics. The first dynamic is shifting public/private boundaries and retaining a wider identity. People living with HIV juggle the pragmatic advantages of disclosing to a limited circle with the importance of maintaining not only their moral integrity, status and (for some) professional and group identity but also of maintaining their privacy. A more public disclosure (“speaking it” more widely) shifts private–public boundaries and can be threatening, dangerous and can fix identity. Furthermore, disclosure carries obligations which, given high levels of poverty, can be hard to meet. The second dynamic is a pattern of implicit understanding. It can be easier in a context of high HIV prevalence to opt for silence, in its various forms, with the presence of HIV implicitly understood but not often explicitly spoken about. Although this gives more room for manoeuvre and for respect, silence too can be dangerous and certain situations dictate that it is better to breach the silence. More aggressive promotion of HIV testing needs to both respect and consider how to work within these existing dynamics to facilitate safe disclosure.

Keywords: TB; HIV; disclosure; stigma; Africa

Introduction

Why do most people living with HIV (PLWH) remain reluctant to disclose their status more widely now that HIV treatment is more accessible? As the recent intense debate on the possibility of universal HIV testing (see Garnett & Baggaley, 2009; Granich, Gilks, Dye, De Cock, & Williams, 2009a, 2009b) tips into wider deliberations on human rights (see Johannesburg Civil Society Consultation on ART for Prevention, 29 April, 2009), more understanding is needed of the relatively low uptake of HIV testing and the experience of disclosure in Sub-Saharan Africa. Currently the literature on disclosure is “extremely fragmented” (Greeff et al., 2008, p. 322). This paper argues that in Zambia, HIV disclosure remains a “navigation in a moral field” (Twehaze, 2009, p. 5) and aims to make the point that the vulnerability, even danger, of shifting public/private boundaries contributes to a pattern of silence (in different forms) around the continued presence of HIV in many situations which is less about denial and more about implicit understanding. Although this prevailing silence, often respectful and avoiding invidious conceptions of shame and explicit stigma, can be dangerous and even tragically fatal, it also allows individuals living with HIV room for manoeuvre and the possibility of defining their identity separate from their disease. Implicit understanding – as opposed to widespread disclosure – allows PLWH to retain wider identities.

The paper draws on my own experiences and research in Zambia, including an interview with a woman living with HIV in January 2003 conducted whilst developing a HIV toolkit (see Kidd & Clay, 2003), a community randomised trial (Zambia and South Africa TB and AIDS Reduction Study – ZAMSTAR, see Ayles, Sismanidis, Beyers, Hayes, & Godfrey-Faussett, 2008) and a collaborative study carried out amongst health workers in Lusaka District

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in 2007 looking at burnout, attrition and access to HIV services (Kruse et al., 2009).

Extraordinarily high HIV prevalence

Currently in Zambia, HIV prevalence remains high – nationally 14.3% of the adult population are estimated to be living with HIV (Central Statistics Office (CSO), 2007). At the peak of the epidemic, in the late 1990s, national prevalence was around 22% with much higher prevalence in urban areas. Therefore, for many years, roughly one in four adults in Zambia have been living with HIV. This is an abnormal situation to live and work in but one which has also become the norm. Peters, Walker, and Kambewa (2008, p. 660) argue that aiming for normality in abnormal times is less about denial and more about not giving into “pervasive defeatism or fatalism” and attempting to control abnormal circumstances. Pragmatically one just has to get on with life despite the shadow of HIV.

Reluctance to test

In Zambia it is estimated that around 35% of women and 20% of men have been tested and received their HIV results (CSO, 2007). Therefore despite the roll out of free ART to 320 government health facilities across nine provinces by the end of 2007 (Ministry of Health (MoH) and National AIDS Council, 2008), most sexually active Zambians still do not know their HIV status. The low uptake of HIV testing amongst most TB patient household members in a counselling intervention (2006–2009) reflects a general trend in Zambia that only people who are sick come forward for testing (ZAMSTAR, unpublished data). As a nurse in the health worker study in 2007 commented, “normally one would go for HIV testing if you see two or more signs on yourself. That is when you can go for a HIV test... as long as there is nothing wrong, that is the last thing you would want to do”. Other ethnographic works in Zambia confirm this trend. Colson (2005, p. 18) documents that in the Gwembe Valley in Southern Zambia, despite people’s knowledge about HIV by 2000, “few know their HIV status or the status of others whom they are on familiar terms with until AIDS becomes apparent”. And amongst a cohort of 30 Zambian men that Simpson (2009b) followed from secondary school to their early 40s, uptake of testing has remained low with the men only testing when “their bodies fail them”. The relatively low uptake of HIV testing is also evident in South African communities; for example, amongst 1077 adult respondents in two communities in Tshwane, South Africa, 69% reported they had not yet tested for HIV (Visser, Makin, Vandormad, Sikkema, & Forsyth, 2009). In Sub-Saharan Africa, WHO (2009) estimates that the majority of those living with HIV are not aware of their status and another study of data in Rwanda and Zambia estimates that 90% are not aware of their partners’ status (Dunkle et al., 2008).

In the health worker study in 2007, 370 of 456 health workers (81%) reported having tested in a self-administered questionnaire; 240 (50%) said they had tested in the last year but discussion groups with health workers perceived lower testing rates amongst colleagues of between 25% and 50% (Kruse et al., 2009). Another similar study of health care workers in Malawi in 2008 found the same discrepancy (Namakhoma et al., 2009). The “truth” is probably somewhere in-between, but the point is that even health workers in Lusaka, where ART access is relatively optimal, are not all aware of their HIV status. As one doctor commented, “the big step is to actually get tested; it is easier to start on ART”. One option, and evident pattern, is to self-test – Zambian nurses said that indeed some health care workers “do their own self-test and find out their results, then start ART”.

Reluctance to disclose

The 149,199 PLWH who are now on ART in Zambia represent roughly half of those who are currently in need of treatment (MoH and National AIDS Council, 2008). Out of 1045 PLWH across 16 communities (situated in five provinces), most (72%) said they had disclosed their HIV status to their main sexual partner and most (65%) said they had disclosed to other household members, but the majority (57%) said they had not disclosed to anyone outside of their household (ZAMSTAR, unpublished data). This reflects that disclosure is very often limited to a closed network. Other anthropological data on disclosure in Zambia (Simpson, 2009b) and Uganda (Daniel, Apila, Bjorjo, & Lie, 2007; Twehaze, 2009) reflects a similar pattern.

The era of ART – an era of “telling”?

As more PLWH start ART in Zambia, and as popular discourse rapidly picks up on the availability of HIV treatment, one might anticipate that there would be surge in the number of people wanting to know their status and that this would ripple out slowly to a pattern of wider disclosure (Fitzgerald, 2008). My own experience is that ART has made it easier to discuss the presence of HIV within one’s family and for people to disclose in certain spheres. For example, when recruiting new personnel, sometimes candidates will now disclose to the interview
Why is it hard to test for HIV?

In the health worker study, reasons for not testing revolved around denial and a range of anticipated fears. The nurses commented about the power of denial, “sometimes you would even ignore even if you saw the signs. If they test and you are not seeing it’s you, and if it’s not you, then it somebody else”. The act of testing was alone anticipated to instigate gossip. If one tested HIV-positive, health workers feared breaches of confidentiality, lack of support from family, lack of support from the state, depression and loss of status. Doctors in particular anticipated a loss of professional identity, status and privacy if they tested HIV-positive – “They all want to start dipping into your private life ... You are like the overall boss and they all look up to you. They respect you and suddenly you are known as positive”. The fear of gossip is pronounced and a major form of HIV-related stigma throughout Sub-Saharan Africa (see Ogden & Nyblade, 2005; Tanzania Stigma Indicators Field Test Group, 2005). Gossip is one way of talking about things which “cannot be spoken about openly” (McNeill, 2009, p. 12) and is bound up with concepts of morality and decency. Simpson (2009a, p. 7) argues that when considering HIV testing, “the fear of being stigmatised was uppermost in many minds”; one of his respondents who does not wish to test explains “maybe the time is not yet ripe to have that stuff exposed” (Simpson, 2009a, p. 10). Simpson sees this issue of a “discredited status” (Goffman, 1963) at the heart of a reluctance to test; in his cohort of well-educated Zambian men and their wives, most supported the idea of testing, many suspected they were HIV-positive but did not plan to discover their own status because a positive diagnosis could hasten their deaths, “they felt ill prepared to deal with the consequences that such knowledge could bring”; and “the cost of acknowledgement of an HIV-positive status still appears too high” (Simpson, 2009a, pp. 7–13).

In the health worker study, the midwives said “we are not very comfortable” with having a HIV test and that “It is not an easy decision on HIV especially in Zambia”. I can recall very few direct conversations about HIV testing in my years in Zambia. The conversations I have had have been with friends in discordant relationships (often some time after the relationships have broken up), with close girlfriends and relatives at thresholds in relationships, in a few moments of crisis in my own life, after a colleague was released from prison, on a few occasions when colleagues or friends were extremely sick and in my work when interviewing PLWH. I know that none of these conversations have been easy and that the outcome has not always been that people do test for HIV.

Deciding to test is often a protracted, courageous and painful decision. I interviewed “E” in 2003. She traces her HIV infection back to her first sexual relationship as a schoolgirl when she first suffered from herpes zoster. It took her 15 years to pluck up the courage to test – in that time E had experienced a marriage fractured by illness and accusations, a chain of miscarriages and her husband’s death. She remembers three experiences of being tested for HIV. She was first tested without her consent at hospital and then subsequently visited by “nurses in uniform” at home who just asked her to come for reviews. After her husband died, it took her two visits to the VCT centre to actually test and find out she was living with HIV.

Why is it hard to disclose that one is living with HIV?

If testing for HIV carries a degree of moral exposure, disclosing that one living with HIV can carry an extraordinary degree of exposure. This emanates from the association between HIV and sex – and (more especially prior to ART) between HIV and death. At every public testimony about living with HIV that I have attended in Zambia, someone will ask the person living with HIV, “How did you get infected with HIV?” E says that she finds it painful that the community assumes that she must have had many sexual partners to get infected with HIV and that her husband used to accuse her of “giving him the disease”.

E’s own experience of disclosure is of gradual and limited disclosure. She first told her father’s sister’s daughter who was a “close and understanding relative” and whose response was to compliment her on her courage and remark how most people do not know their status. E felt her “load lighten” after telling her cousin. Later, concerned by her two brother’s casual sexual behaviour and acting in her role as their elder sister, she arranged to meet them at their workplace and explained, “You are seeing me ill most of the time and can appreciate why I decided to go for a HIV test. I am HIV-positive’. My brothers were completely quiet and said nothing, changing the
They have continued to support me. My burden was lifted out of me since they received my burden”. When she is sick, her brothers care for her and have never shunned her; she feels that their understanding has deepened since sharing her results with them. She was never to talk directly to her brothers again but knows through her cousin that they do not wish her to go public, in an effort to protect the family name. She had avoided telling her stepmother (whom she does not trust) and her father (whom she resents) but had told her teenage nieces since they were beginning to “experiment” with boys. She assumes her cousin must be a bit talkative because other family members on her father's side have come to her seeking her practical advice about HIV symptoms and treatment.

E’s story demonstrates not only the careful process of limited disclosure but also different types of disclosure and different motives for disclosure. Managed disclosure, concealment, voluntary disclosure, disclosure without consent (Greeff et al., 2008) as well as partial disclosure (Twehaze, 2009) and breaching cultural silence at a private level (Daniel et al., 2007), are all evident in her story. The importance of situations and contexts and her desire to not reveal the information about her status indiscriminately and to “test the water” are manifest. Her own control over disclosure also begins to breakdown when her cousin shares her status with others; this is called mismanaged disclosure (Greeff et al., 2008) or “third party leakage” (Greene, Derlega, Yep, & Petronio, 2003). Motives for E’s disclosure include wanting someone to talk to, needing understanding, needing material and practical support and wanting to protect others that she cares about. Her motives for not disclosing including protecting the identity and respect of herself and her family, avoiding rejection and a lack of trust in certain individuals. The stress surrounding E’s decisions to disclose, the care she takes over these decisions and her courage are also evident.

There are two other threads that run through E’s story. One is whether people actually want to know if someone is living with HIV; disclosure entails shifting the burden to others who then become locked into another’s private boundary and are thereafter confidants, co-owners of the information (Greene et al., 2003) and obliged to certain responsibilities – as kinsmen, E’s brothers are required to look after their elder sister and, if she were to die, their responsibility over certain rites, property and any children would continue. Mogensen (2002) writes about this in relation to relatives feeling obliged to provide ART in Uganda, prior to the provision of free treatment, when they could not afford to do so.

The second thread in E’s story is of the navigation of disclosure. Once she has told her cousin or brothers, she doesn’t tell them again; they don’t talk directly to her about it and neither do other relatives. This very familiar pattern of circumlocution has also been observed by Simpson amongst his cohort of Zambian men; in his terms, as “discretion and compassion” (Simpson, 2009a, p. 5).

Private/public boundaries and “boundary turbulence”

Because HIV is about sex and about death, it is intrinsically private (Greene et al., 2003). Because the manifestations of AIDS are so obvious and so frightening and the consequences so big, it is intrinsically public. It is hard to make HIV a “manageable” chronic illness because it is weighted by such extraordinary baggage. HIV has to be both clinically and socially managed. HIV pushes public/private boundaries, particularly in settings of high prevalence. HIV disclosure also carries with it higher levels of risk and vulnerability (Greene et al., 2003), particularly in a society like Zambia where the Christian notion of “respectability” is central (Simpson, 2009a).

Private information belongs to individuals (Greene et al., 2003) and the right to disclose is the right to “personal privacy and dignity” (Greeff et al., 2008, p. 312). Any breaking of privacy rules can be referred to as “boundary turbulence” (Greeff et al., 2008). There is something about HIV that seems to demand that we lay our private life on the table for others to see. The onus put on public testimony in HIV education has Christian and North American zeal; such openness is sometimes regarded as “Western” and “modern” in Sub-Saharan Africa. A Zimbabwean doctor who was living with HIV and moved into exile in the USA in the late 1990s was disturbed by the pressure on her to speak publically about her status; “In Zimbabwe people just publically about her status; “In Zimbabwe people just knew about it but didn’t ask me to speak about it” she lamented (Peter McDermott, personal communication, July 2002). To disclose in Africa can be dangerous as evident in the now extensive literature on HIV stigma and discrimination (Bond et al., 2003; Clay, Bond, & Nyblade, 2003; Mahajan et al., 2008; Ogden & Nyblade, 2005) and a recent Human Rights Watch report (2007) which documents issues around violence and ART in Zambia. There is “some normalcy in the experience of people not talking about their illness” (Greeff et al., 2008, p. 314) if PLWH commonly anticipate and experience stigma and discrimination.

Malinowski (1959) writes about a publicised yet prohibited affair between a young Trobiand man and his mother’s sister’s daughter that “public opinion is lenient though decidedly hypocritical...the public will gossip but not demand harsh punishment”
Different forms; it can be acknowledging, conspiratorial, just as there are many ways to disclose, silence can take different forms; it can be acknowledging, conspiratorial, judgemental, respectful and colluding; and it can differ across cultures. Cultural silences are often around the taboo subjects – including sex – and “silence . . . can often be pregnant with ‘eloquent assumptions’ about local knowledge” (McNeill, 2009, p. 12). Setel (1999) refers to a “sexual culture of silence”, coined more recently by Simpson (2009a) and Twehaze (2009) as poor communication between sexual partners about intimate matters and “the prevailing gender order” (Simpson 2009a). Nagler et al. (cited in Daniel et al., 2007), writing about the consequences of cultural silence for children affected by HIV/AIDS in Uganda, says that the issue of secrecy is more about naming than about knowing. In a BBC report (13 April 2009) on child carers in Zimbabwe, the boy carer told the journalist that he did not know what was wrong with his frail mother whilst the mother openly shared with the journalist that she was HIV-positive. “Your son said he does not know what is wrong with you”, Mike Thomson (2009) stated; “Oh he knows”, she replied, “But he does not tell”.

There are dangers in silence. In the case of children affected by HIV, Daniel et al. (2007, p.15) argue that both relationships and children’s competence are undermined by cultural silence and their self-worth, confidence, self-esteem and capacity to grieve are diminished whilst their anxieties increase. Silence can be expensive – forcing one to travel far or to a less convenient place to access ART. Keeping quiet can be a burden inciting duplicity, driving people to lead a double life, increasing stress and blocking relations, better health and care (Greeff et al., 2008; Greene et al., 2003). Silence can reinforce stigma by not challenging it. Gossip and blame can be fuelled by silence; as McNeill writes about the patterns of obfuscation around HIV/AIDS in South Africa that “for every moment of public silence, there was private speculation and blame” (McNeill, 2009, p. 12). And tragically, as I have witnessed often in Zambia, silence can lead to death and to continued transmission.

Breaking the silence

If silence is often safer but can be dangerous, when is silence broken? Ilse Mwanza was the research affiliation officer at UNZA. In the early 1990s, her eldest daughter Julie and her grandson were extremely sick with AIDS; her grandson died first and, in 1993, Julie died. When her daughter died, the death notice in a national paper carried her daughter’s photo and a statement that her daughter wished people to know she had died of AIDS (Mwanza, 1994). The family’s open disclosure was and is extremely unusual, despite the early precedence set by first republic President

A pattern of silence

As anthropologists we know all too well it is “hard to draw an appropriate line between private dialogue and public relevance or revelation” (Wallman, 2002, p. 100). There are some who have the courage and make the decision to be public about living with HIV and/or being on ART and who make this their fixed identity. But in my experience most would rather have their identity defined otherwise – as an anthropologist, as a doctor, as a mother, as a father, as a child. Two nurses living with HIV (one Zambian, one Kenyan interviewed in November 2009 whilst developing a health care worker anti-stigma module) are both stigma activists but continue to be careful about when and to who they disclose particularly in the hospitals where they work and the churches they attend. This is partly due to fears that patients, other health care workers and church members will shun them and call them “prostitutes”, but also due to their wider identities as midwives or as church members and not needing to necessarily disclose more widely. Retaining a wider identity involves being silent about their HIV status at certain times and in some spheres of their lives. Disclosure is thus mirrored by silence.
Kenneth Kaunda who in 1988 told an International AIDS Conference in Vancouver that his own son had died of AIDS.

There are some initiatives that build social skills for disclosure. Greene et al. (2003) provide exercises and resources to empower individuals living with HIV to explore the benefits and costs of disclosing their HIV status. Social support external to the family, counseling, information, education, advice, faith and contact with others in the same situation have been shown to constructively facilitate safe disclosure to significant others (for example, from mothers living with HIV to their children; Daniel et al., 2007; Greeff et al., 2008). Being able to disclose safely within one space or sphere has been shown to enable people to manage HIV and stigma (Daniel et al., 2007, Fitzgerald, 2008; Greeff et al., 2008). Anti-stigma education tools and initiatives are available to enhance the ability of PLWH and their families to challenge and cope with stigma (see Kidd & Clay, 2003). Wider initiatives to challenge the prevailing gender order and transform the performance of masculinity (Simpson, 2009a, p. 12) and improve intimate dialogues between sexual partners also have potential to aid disclosure between couples. Conversion experiences in Pentecostal churches (Simpson, 2009a) and marriage encounter sessions in the Catholic Church are examples of the latter in Zambia.

Implicit understanding

Unpicking the difference between an implicit “knowing” that someone else has HIV and being told explicitly by someone that they have HIV reveals that more often than not people are not directly informed about someone’s HIV status – but they assume that someone is living with HIV – usually from signs and symptoms and more lately from body changes and other indications that people are on ART. Akin to community diagnosis (as opposed to an actual diagnosis), actual disclosure is far less common than an implicit understanding that is reached between both “actors” – with HIV and/or ART only made explicit either if absolutely necessary or if initiated by the person living with HIV. Assumptions play out into gossip particularly in the absence of a respectful or close relationship or if people do not understand the damage stigma can inflict.

Conclusion

In a sense the starting point of this paper – limited HIV disclosure despite the increasingly availability of ART to treat PLWH in Zambia – is the end point. This paper has attempted to unravel reluctance in Zambia to disclose HIV status and to talk more widely and openly about PLWH even when ART is available. There are many issues in the pot and no single explanatory model seems to fit. Perhaps it is partly an attempt at normalcy, a reflection of the inability to live life continually in crisis mode, and, a need for “time out” (Colson, 2005; Peters et al., 2008). It is to some extent about distancing, “separation” (McNeill, 2009), anticipated stigma and the real danger of enacted stigma and discrimination. And to a degree it allows relatives, particularly in the context of poverty, to duck obligations. But it is also about respect, privacy and a need for a wider identity. Nuanced and rarely absolute, disclosure of HIV and silence about HIV are embedded in social reality. Most people implicitly understand that to shift private/public boundaries too far through indiscriminate disclosure can not only be unsafe but also fix one’s identity as a “PLWH”. As the pressure mounts in Southern Africa to both promote HIV testing more aggressively and to articulate human rights, there is a need to revisit how disclosure is conceptualised and justify more carefully why and when we promote HIV disclosure. Social skills for deliberating about disclosure need to be further developed.

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