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Published in:
SAHARA-J

DOI:
[10.1080/02664763.2012.755317](https://doi.org/10.1080/02664763.2012.755317)

[Link to publication](#)

Citation for published version (APA):

Hardon, A., Desclaux, A., & Lugalla, J. (2013). Editorial: Disclosure in times of ART: A relational analysis of social practices. *SAHARA-J*, 10(S1), S1-S4. <https://doi.org/10.1080/02664763.2012.755317>

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EDITORIAL

Disclosure in times of ART: A relational analysis of social practices

Anita Hardon, Alice Desclaux, Joe Lugalla

Abstract

The reach of HIV counseling and testing has grown rapidly since the 2000s, particularly since 2007 when provider-initiated counseling and testing was implemented alongside voluntary counseling and testing and testing for the prevention of mother-to-child transmission. Nevertheless, we still know little about the attendant practices of disclosing HIV-positive status. Persistently high rates of non-disclosure raise difficult ethical, public health and human rights issues. The articles in this special issue show that disclosure practices in Africa not only follow the public health rationality but are shaped by fears of stigma that favor secrecy. They show how practices of disclosure are embedded in social relationships. More specifically, they present disclosure practices at the intersection of five social spaces: international norms, national legislation and public health recommendations; household and family settings; couples' relationships; parental relationships; and relationships between health workers and PLWHA. The authors describe how people pursue strategies of disclosure in one or more of these social spaces, which sometimes allows them to avoid barriers (for instance when they choose to disclose only partially to certain 'significant others' in the household). One important finding is that counselors often do not support PLWHA to disclose their HIV status. Counselors themselves may be influenced by divergent logics and experience conflicts in values; they may also lack sufficient knowledge and skills to discuss sensitive issues based on rapidly changing medical data and public health recommendations.

Keywords: disclosure, counseling, testing, stigma, secrecy

Résumé

Le Conseil et le test VIH ont été développés de manière considérable depuis les années 2000, en particulier depuis 2007, lorsque le Conseil et Test à l'Initiative du Soignant a été mis en œuvre en complément du Conseil et Dépistage Volontaire et des tests dans le cadre de la Prévention de la transmission du VIH de la Mère à l'Enfant. Dans ce contexte évolutif, l'expansion des pratiques en matière de partage du statut VIH n'a pas encore été évaluée et la persistance de taux élevés de non-divulgaration du statut VIH soulève des questions difficiles relevant de l'éthique, de la santé publique et des droits humains. Les articles de ce numéro spécial montrent que les pratiques ne relèvent pas seulement d'une logique de santé publique favorisant la communication, ni de la seule crainte de la stigmatisation favorisant le maintien du secret. Elles sont aussi façonnées par des cadres sociaux et intégrées dans les relations sociales. Deux articles montrent comment ces relations permettent ou empêchent le partage dans un pays d'Afrique de l'Ouest et un pays d'Afrique australe aux modèles matrimoniaux différents. D'autres articles montrent aussi les difficultés rencontrées au sein des familles où les parents et les enfants - que ce soit les jeunes adultes ou les moins âgés - sont pris dans la culpabilité et la honte qui sous-tendent la communication entre générations et l'exercice de la parentalité, et peuvent retarder le partage du statut VIH. Un point de vue théorique mettant l'accent sur ses dimensions sociales permet de comprendre le partage du statut VIH à l'intersection de cinq espaces sociaux : ceux des normes internationales et des législations nationales ainsi que des recommandations de santé publique ; des foyers et les familles ; des couples ; des relations entre parents et enfants ; des relations entre les agents de santé et les PVVIH. Les articles présentés dans ce numéro spécial montrent comment les gens construisent leurs stratégies de communication en utilisant un ou plusieurs de ces espaces sociaux,

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ce qui permet parfois d'éviter certains obstacles (par exemple quand ils choisissent de ne partager que partiellement à certains membres de l'entourage). Cette interprétation du processus de partage comme une négociation entre les espaces sociaux avec leurs normes variées peut être heuristique pour d'autres études sur ce sujet. Une importante observation empirique de ce numéro est que les conseillers n'apportent qu'un appui insuffisant au partage du statut par les PvVIH, comme le rapportent des patients. Ils sont souvent préoccupés par des logiques divergentes et des conflits de valeurs, mais leurs connaissances et leurs compétences pourraient être insuffisantes pour aborder des questions sensibles dans un contexte d'évolution rapide des données médicales et des recommandations de santé publique. Ainsi ce numéro apporte des réponses contextualisées aux questions complexes que posent les pratiques de partage du statut, met au jour des propositions pour l'amélioration des services et ouvre quelques pistes théoriques pour des études ultérieures.

Mots clés: *partage du statut, conseil, test, stigmatisation, secret*

As HIV testing is being scaled-up throughout Africa alongside the implementation of large-scale antiretroviral treatment (ART) programs, it is assumed that health workers will convey results to tested persons. HIV-positive persons are then expected to disclose their HIV status to significant others. But in fact, neither can be taken for granted. Three aspects must be underlined: (1) the health worker's communication of test results to a patient (i.e. announcement) and the subsequent transmission of this information by the concerned person to others (i.e. disclosure) are not independent processes; (2) disclosure practices can be understood only when considering the broad meaning of HIV testing; and (3) the social effects of disclosure are related to meanings of HIV infection in private and public spaces where stigma toward people living with HIV/AIDS (PLWHA) still often prevails. These considerations may explain why empirical data show that disclosure practices are heterogeneous and largely depend on the social profile of the concerned individuals and on the social context. We need to know more about the social processes that underlie this variety in disclosure practice, particularly in the era of increasing use of antiretrovirals (ARVs) for treatment and prevention.

Before considering these issues, a rapid assessment of the dynamics of disclosure practices and rationalities since the beginning of the epidemic in Africa may be useful to understand the present situation. During the 1980s, HIV tests were promoted primarily for AIDS diagnosis. Later, during the 1990s and early 2000s, when testing expanded through voluntary counseling and testing (VCT) programs, the emphasis was mainly on prevention. Over the past decade, testing has been further scaled-up to allow more people to benefit from ART, particularly through provider-initiated testing and counseling programs.

Besides these changes in the aims of HIV testing, public health recommendations and health workers' practices have also evolved. During the 1980s, people diagnosed with HIV were not always informed by health workers, who instead preferred to inform influential family members or persons who could meet the patient's health costs (Collignon, Gruénais & Vidal 1994). When ethical recommendations were progressively defined and implemented along with recommendations on counseling in the 1990s, health practitioners began informing test-takers of their HIV status, recommending that they disclose to their partners – sometimes in an authoritarian way (Desclaux & Raynaut 1997). Cases of social rejection were often reported, particularly by women who tested before their

partners, who were then accused of introducing the virus into the family. At that time, many counselors and health workers encouraged PLWHA to conceal their status in order to avoid social stigma.

A different perspective arose when prevention of mother-to-child transmission programs were implemented in the early 2000s: disclosure by HIV-positive mothers to their partners was now presented as a way to protect infants from mother-to-child transmission (Desclaux, Msellati & Sow 2011). More generally during the 2000s, people who tested negative in VCT were counseled on the practice of safe sex; those who tested positive were encouraged to disclose to their sexual partners to prevent further transmission of the virus as well as to access care. AIDS activists were in favor of disclosure: 'living positively' – with its emphasis on openness about one's status – was considered crucial for breaking the stigma surrounding HIV/AIDS. Although informing the HIV-positive individual about his or her status is now unquestioned and widely practiced by health teams – and concealing this information is considered an ethical breach – attitudes toward disclosure by PLWHA remain more nuanced. While health professionals, activists and PLWHA generally believe that HIV-positive persons should disclose to at least their sexual partners, individually they understand reasons for not doing so and tend to defend the right to secrecy.

HIV tests today have become increasingly routine when people request care for various HIV-related symptoms or when they present themselves in clinics for other ailments. Motivations for testing have also changed as the chance to benefit from early treatment has transformed HIV into a chronic but manageable disease. Stigma has been slightly reduced, though this largely depends on the social context as well as regional HIV prevalence levels (Winskell, Hill & Obyerodhyambo 2011). People who disclose may more easily receive support from PLWHA organizations and support groups when facing adverse reactions from their families, since such organizations now operate all over Africa. However, this in no way means that disclosure has become easy.

While quantitative studies on disclosure rates tell us something about practices among PLWHA (see, for instance: Akani & Erhabor 2006; Varga, Sherman & Jones 2006; Wong, Rooyen, Modiba, Richter, Gray, McIntyre, *et al.* 2009), they face two main methodological challenges: (1) disclosure rates strongly depend on the duration of the recall/study period; (2) though

disclosure is considered as a yes/no variable, communication about HIV status may be much more complex, including several forms of partial or indirect disclosure.

Past studies on disclosure have shown that practices vary across cultures, age groups, genders, types of social relationships, income and educational levels, situations and contexts (Cusick & Rhodes 1999; Nsabagasani & Yoder 2006). Social relations and family dynamics play a key role in determining patterns of disclosure. While in some settings friends of similar ages may disclose to each other more often and be perceived as more supportive than family members, in other settings mothers and sisters are disclosed to more often than fathers and brothers, and perceived as more supportive than other family members (Kalichman, DiMarco, Austin, Luke & DiFonzo 2003; Lugalla, Yoder, Sigalla & Madihi 2012). Disclosure to sexual partners is reported to be more likely in longer-term, romantic relationships than in casual relationships such as one-night stands, anonymous partners, group scenes, etc. (Duru *et al.* 2006). These studies in various contexts (low-income and developed countries, varied cultural areas, countries with different laws on confidentiality and varied levels of scaling-up in testing facilities) show a heterogeneous landscape where general trends and local specificities are not precisely understood.

Alongside the rational motivations for disclosure emphasized by public health recommendations, the choice of disclosing – and to whom – often reflects power differentials within social relationships. Disclosing one's HIV status has been described as particularly risky for women, as (fear of) accusations of infidelity, rejection, abandonment, discrimination and violence may follow (Medley & Garcia-Moreno 2004; Parsons, Van Ora, Missildine, Purcell & Gomez 2004; Skogmar, Shakely, Lans, Danell, Anderson, Tshandu, *et al.* 2006; Makhoulf Obermeyer, Sankara, Bastien & Parsons 2011).

The situations presented and analyzed in this special issue add to our empirical knowledge of disclosure, helping to document the wide range of social contexts that influence practice and the ethical issues involved. The literature review by Sarah Bott and Carla Obermeyer gives an overview of disclosure policies and practices in Africa. The literature review shows that generally around two-thirds of HIV-positive individuals disclose, but that those who disclose do so very selectively.

According to international recommendations, when informing their patients about their HIV test results during post-test counseling, health workers are supposed to encourage them to disclose their status to 'significant others'. Since ART is available, politicians and parliamentarians in some countries have been promoting mandatory disclosure to partners in renewed 'HIV laws'. This raises many issues: Why are such proposals emerging now, when VCT programs in the past preached confidentiality? Is the importance of confidentiality losing its meaning? Does mandatory partner notification make sense to PLWHA, given that their marital partners are not necessarily their (only) sexual partners? At field level, how do doctors who adhere to the Hippocratic Oath view the mandatory disclosure laws and regulations recently adopted or reviewed? Bott and Obermeyer argue that these ethical and rights

issues are related to gender issues, which may be a feature of the African context where more women than men are HIV positive.

Two other articles explore how PLWHA select the 'significant others' to whom they disclose. In Cape Town, South Africa, Pride Linda shows that people disclose mainly to family members, then partners and then to friends and other persons. Their tactics for selection include weighing other people's reactions, anticipating the effects of disclosure on their 'targets', and concealing one's status to evade negative reactions. Pride Linda shows that negotiating disclosure means finding good opportunities to disclose or ways of hiding one's status and/or medication in order to enhance access and adherence to ARV treatment. However, some informants were unable to negotiate disclosure in the way they would have liked. In Dakar, Senegal, Khoudia Sow shows that similar strategies may face different constraints. Most people interviewed over a 10-year period had disclosed to someone, many to their mothers rather than partners. In polygamous households, many women agreed to disclose to their husband but wanted to be sure that their co-spouses would not find out. In such cases, secrecy may be limited to the couple. In other cases, women may divulge information according to the household hierarchy. Khoudia Sow also describes cases where co-spouses were informed and maintained secrecy.

The articles by Georges Tiendrebeogo and colleagues (on Burkina Faso), and David Kyaddondo and Rhoda Wanyenze (on Uganda) focus on the dynamics of disclosure between parents and children. Do parents on ARV therapy disclose their HIV status to their children? How do children respond? Georges Tiendrebeogo shows that in his study sites in Burkina Faso children usually already suspected their parents' HIV status, while most parents believed that children lacked the emotional skills to understand or that they would be unable to keep the secret. However, parents who disclosed to their children did not experience blame; nor was their secret revealed. Rather, children became their treatment supporters. In Uganda, David Kyaddondo and Rhoda Wanyenze show that both parents and adult children face dilemmas of disclosure, whether it was parents disclosing their own status to their children, talking to perinatally infected children, or young adults telling their parents. For both groups, there is fear of blame, stigma, shame and guilt related to unsafe sex, while young people also fear loss of privileges. Both studies agree that HIV-positive individuals and their families require professional counseling to help them work through their emotional challenges and to identify mechanisms of support and coping.

The articles by Eileen Moyer and colleagues (for Kenya), Odette Ky-Zerbo and colleagues (for Burkina Faso) and Alice Desclaux and Chiara Alfieri (also for Burkina Faso) consider the role of health workers in supporting disclosure. In everyday practice in Kenya, health workers face three models of disclosure: voluntary-consensual disclosure (in line with international guidelines); involuntary, non-consensual disclosure (which may be intentional or accidental); and obligatory disclosure (which occurs when PLWHA are forced to disclose to access services at health facilities). Health-care workers are often caught between the three and struggle with the competing demands of promoting prevention, adherence and confidentiality. In Burkina Faso,

Odette Ky-Zerbo and colleagues reveal that less than one-third of those tested state that disclosure to partners or family members was discussed with them during post-test counseling. They relate this finding to the uncertainties and concerns of health-care workers on how to disclose, and on risks related to disclosure. Alice Desclaux in her contribution on the complexity of HIV diagnosis in infants of HIV-positive mothers, describes the interactions between health workers and parents over time. She reveals the ambiguities of disclosure: information that doctors keep secret, reciprocal expectations in communication between doctors and mothers, and mothers' interpretation of so-called evidence regarding their children's health.

Findings from previous studies inform the theoretical perspective of this special issue on disclosure in the times of ART. Alongside their sensitivity to changing rationalities underlying disclosure, the articles share an understanding of disclosure as embedded in existing and evolving social relationships. Five social spaces are considered to shape disclosure practices:

- International recommendations and their translation into national norms: legal and normative frameworks for sub-Saharan African countries are addressed by Sarah Bott and Carla Obermeyer.
- Household and family settings, including partners and 'significant others' to whom HIV status should be disclosed: this choice may be influenced by their social organization such as in nuclear/extended families in South Africa, studied by Pride Linda.
- Couple relationships: as defined by local interpretations of gender relationships and marital relationships, overviewed by Sarah Bott *et al.* and studied in polygamous households in Senegal by Khoudia Sow.
- Parental relationships influence disclosure in various ways according to children's age and to local norms regarding parenthood, as examined by David Kaddyondo and Wanyenze in Uganda and by Georges Tiendrébéogo *et al.* in Burkina Faso.
- Patient–health worker relationships: disclosure is shaped by counseling and support provided by health teams, as studied in Kenya by Eileen Moyer, and in Burkina Faso by Odette Ky-Zerbo *et al.* (regarding disclosure by adults) and by Alice Desclaux *et al.* (for infants' HIV test results).

These social spaces are not mutually exclusive. They can overlap (such as the social spaces of couple and household), be partially separate (such as the social spaces of patient–health worker relationships and parental relationships), or completely independent (international recommendations and households). The articles in this special issue show how people tend to use these various social spaces to their advantage.

Finally, the articles assembled in this special issue address how disclosure or non-disclosure is related to local moral words, family dynamics, socio-economic relations and local understandings about intimacy and secrecy. All of them (except the literature

review) involve ethnographic fieldwork, providing in-depth and contextual understanding of disclosure patterns and processes. Findings come from both Anglophone and Francophone Africa, and cover both West and East Africa with their different prevalence rates. Several articles provide operational insights, especially when showing how health-care workers struggle between the imperatives of furthering HIV prevention and ARV adherence on the one hand and maintaining confidentiality on the other. Maintaining confidentiality in fact contradicts new laws and regulations requiring partner notification by health-care workers in situations where the patient is unwilling to self-disclose. Since past studies have rarely addressed this contradiction, the articles in this special issue provide new insights for how processes of HIV testing and disclosure should be implemented in the future.

Acknowledgment

To Rosalijn Both for her editorial work.

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