

The social and gender context of HIV disclosure in sub-Saharan Africa: A review of policies and practices

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Abstract

This paper reviews the legal and policy context of HIV disclosure in sub-Saharan Africa, as well as what is known about rates, consequences and social context of disclosure, with special attention to gender issues and the role of health services. Persistent rates of nondisclosure by those diagnosed with HIV raise difficult ethical, public health and human rights questions about how to protect the medical confidentiality, health and well-being of people living with HIV on the one hand, and how to protect partners and children from HIV transmission on the other. Both globally and within the sub-Saharan African region, a spate of recent laws, policies and programmes have tried to encourage or – in some cases – mandate HIV disclosure. These policies have generated ethical and policy debates. While there is consensus that the criminalization of transmission and nondisclosure undermines rights while serving little public health benefit, there is less clarity about the ethics of third party notification, especially in resource-constrained settings. Despite initiatives to encourage voluntary HIV disclosure and to increase partner testing in sub-Saharan Africa, health workers continue to grapple with difficult challenges in the face of nondisclosure, and often express a need for more guidance and support in this area. A large body of research indicates that gender issues are key to HIV disclosure in the region, and must be considered within policies and programmes. Taken as a whole, this evidence suggests a need for more attention to the challenges and dilemmas faced by both clients and providers in relation to HIV disclosure in this region and for continued efforts to consider the perspectives and rights of all those affected.

Keywords: HIV testing, disclosure, policies, health providers, gender

Résumé

Cet article fait une revue du contexte légal et politique de la révélation du statut VIH, ainsi que des données concernant ses niveaux, ses conséquences et son contexte social, avec une attention particulière aux questions de genre et au rôle des structures de santé. La persistance de bas niveaux de révélation du statut par ceux qui reçoivent un diagnostic positif soulève des questions difficiles dans les domaines de l'éthique, des droits humains et de la santé publique. Ces questions on trait aux moyens, d'une part, de protéger la confidentialité, la santé et le bien-être des personnes vivant avec le VIH, et d'autre part, d'éviter la transmission du virus à leurs partenaires et leurs enfants. Au niveau global et en Afrique sub-Saharienne, beaucoup de lois, politiques et programmes ont récemment essayé d'encourager – et dans certains cas d'obliger – la révélation du statut VIH, ce qui a donné lieu à des débats d'éthique. Alors qu'il y a un consensus sur le fait que la criminalisation de la transmission et de la non révélation du statut va à l'encontre des droits humains et n'est pas utile du point de vue de la santé publique, la notification des tiers est plus controversée, surtout dans les pays à ressources limitées. Malgré des initiatives visant à encourager la révélation volontaire du statut VIH et l'augmentation du dépistage des partenaires en Afrique sub-Saharienne, les professionnels de la santé continuent à rencontrer des difficultés vis-à-vis de la révélation du statut et auraient besoin d'être mieux guidés et soutenus pour faire face à ces difficultés. Les recherches montrent que les questions de genre sont capitales pour la révélation du statut et doivent être incluses dans les politiques et programmes. En général, les données disponibles suggèrent qu'il faudrait donner plus d'importance aux défis et dilemmes auxquels font face les clients et le personnel de santé concernant la révélation du statut VIH dans la région et qu'il faudrait continuer à faire des efforts pour considérer les perspectives et les droits des personnes impliquées.

Mots clés: dépistage du VIH, révélation du statut VIH, politiques, personnel de santé, genre

1. Introduction

In sub-Saharan Africa, utilization of HIV testing and counseling and access to treatment have expanded greatly in recent

years, though coverage is still limited. Global estimates suggest that only about 34% of women and 17% of men in

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low- and middle-income countries have been tested and have received their results, and that the median percentage of people living with HIV who know their status is below 40% (WHO, UNAIDS & UNICEF 2010). Despite increasing numbers of people tested, research indicates that substantial proportions of individuals diagnosed with HIV do not reveal their serostatus to those around them, including sexual partners (Obermeyer, Baijal & Pegurri 2011).

Increasingly, researchers, policy-makers and programme planners have recognized the implications of HIV disclosure for prevention, treatment and stigma reduction. When people who test positive for HIV disclose their status they may encourage partners to be tested, obtain emotional support and caregiving from family and friends, and gain partners' cooperation in preventive behaviours such as safer sex, replacement feeding for infants and adherence to treatment. In contrast, nondisclosure may have negative consequences for preventing HIV transmission to partners and children, for continuity of care and for persistent levels of HIV stigma (Loubiere, Peretti-Watel, Boyer, Blanche, Abega & Spire 2009; Medley, Garcia-Moreno, McGill & Maman 2004). Nondisclosure to partners is particularly concerning in light of evidence that large proportions of new HIV infections occur within HIV-sero-discordant couples (Eyawo, de Walque, Ford, Gakii, Lester & Mills 2010).

Evidence suggests that individual disclosure behaviour and health-care practices with regard to confidentiality are heavily influenced by gender norms and power imbalances. In sub-Saharan Africa, women are not only more likely than men to be HIV+, but also more likely to be tested for HIV because of scaled up routine testing within antenatal care (ANC). A substantial body of evidence suggests that due to women's subordinate social and economic status relative to men in the region, fear of stigma, abandonment and violence are particularly important barriers to both testing and disclosure for women in many parts of the region (Maman & Medley 2004).

Low rates of HIV disclosure raise difficult ethical and human rights concerns about how to balance the medical confidentiality, safety and well-being of people living with HIV with the rights of partners and children to be protected from HIV transmission. Both globally and within the sub-Saharan African region, a spate of recent laws, policies and programmes have tried to encourage, or in some cases, mandate HIV disclosure. These policies have generated ethical and policy debates within legal and public health circles (Masiye & Ssekubugu 2008; UNAIDS & UNDP 2008). Meanwhile, the health sector has launched initiatives to encourage voluntary HIV disclosure and to increase partner testing in the context of ANC (Conkling, Shutes, Karita, Chomba, Tichacek, Sinkala, *et al.* 2010; Kululanga, Sundby, Malata & Chirwa 2011).

This paper provides an overview of the legal and policy context of HIV disclosure in sub-Saharan Africa, and a summary of the evidence about the rates, consequences and social context of HIV disclosure, with special attention to gender issues and the role of health services.

2. Methods

The literature searches for this paper were conducted among two sets of sources, the first pertaining to ethics, policies, law and human rights and the second, within the public health and social science literature. Search engines and databases such as PubMed, POPLINE and Google Scholar were scanned for key terms such as: HIV disclosure, confidentiality, partner notification, mandatory testing, HIV policies and legislation and criminalization of transmission. In addition, this review drew from papers and guidelines published by United Nations (UN) agencies such as the Joint UN Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), and by non-governmental organizations.

The second part of the search focused on HIV disclosure within the public health and social science literature. Databases such as PubMed, PsychINFO, Social Sciences Citation Index, and regional WHO databases were searched for articles with key words such as disclos(ure), notif(ication) and HIV. Some sources were identified during an earlier search on HIV disclosure around the world (Obermeyer *et al.* 2011). We identified 39 studies published between 2000 and 2012 that presented disclosure rates by adults living with HIV in sub-Saharan Africa, including 20 studies among women and men, 19 studies among women (mostly but not exclusively within ANC), and one review paper. Studies were included if they had more than 35 respondents and measured disclosure to at least one person or to partners. Studies on disclosure of children's and adolescents' HIV status were not included. In addition, this paper reviewed key findings from studies that explored determinants, reasons for and consequences of disclosure.

3. Results: The legal and policy context in sub-Saharan Africa

3.1 Legislation criminalizing HIV transmission and nondisclosure

Many governments in the sub-Saharan region have laws or policies that emphasize respect for informed consent and medical confidentiality. Nonetheless, a growing number of governments in the region have considered or enacted laws that criminalize HIV transmission by HIV+ individuals, mandate disclosure to partners, or authorize third party, involuntary partner notification by health workers.

In September 2004, West African parliamentarians developed the AWARE-HIV/AIDS 'model' legislation at a workshop in N'djamena, Chad, with the expressed aim of protecting the rights of individuals living with or exposed to HIV (Sanon, Kabore, Wilen, Smith & Galvao 2009). Critics have argued, however, that some provisions of the model law threaten the human rights of individuals living with HIV (Pearshouse 2007; Sanon *et al.* 2009). In particular, they cite concerns about a requirement that individuals disclose their HIV+ status to sexual partners within 6 weeks of diagnosis; that health workers notify sexual partners if the HIV+ patient does not; that mandatory testing be carried out during various circumstances, including pregnancy; and that HIV transmission by someone who previously tested positive should be considered a criminal act

under certain circumstances – including transmission from mother to child. Since 2004, provisions similar to this model legislation have been passed into law in countries throughout the region, including Benin, Burkina Faso, Burundi, Cape Verde, the Central African Republic, Chad, the Democratic Republic of the Congo (DRC), Djibouti, Equatorial Guinea, Guinea, Mali, Niger, Sierra Leone, Senegal and Togo (Kazatchkine 2010; Pears-house 2008a). Similar legislation has been considered in other countries, including: Cote d'Ivoire, Mozambique, Mali, Senegal and Uganda (Garmaise 2009; GNP+ n.d.; Pearshouse 2008a, 2008b).

In some African settings, including Zimbabwe, policy-makers and women's groups have supported criminalizing transmission as a way to protect women, change male behaviour and punish men who transmit HIV to female partners (UNAIDS & UNDP 2008). However, some researchers argue that, in practice, women may be more likely than men to be prosecuted for nondisclosure or criminal transmission, because they are more likely to be HIV+, to be tested before their partner in ANC, and to have limited access to the legal system (Clayton, Schleifer & Gerntoltz 2008; Pearshouse 2007).

After analysing the evidence, the UNAIDS Reference Group on HIV and Human Rights concluded that, 'in the overwhelming majority of cases, applying criminal law to HIV transmission or exposure does more harm than good' (UNAIDS Reference Group on HIV and Human Rights 2008). Instead, it called for, 'promoting a social and legal environment that is supportive of and safe for voluntary disclosure of HIV status' as well as for expanding evidence-informed programmes that prevent HIV transmission while, 'protecting the human rights both of those living with HIV and those who are not infected'. These arguments have persuaded parliamentarians in some parts of the region to reject criminalization, but such provisions remain on the books or under consideration in many countries.

3.2 Policies and guidelines related to ANC

In addition to legislation, governments in the region have developed policies, strategic plans and guidelines to influence health-care providers' behaviour with regard to confidentiality, disclosure and partner notification. Special attention has been directed to ANC, as one of the main settings in which testing has been scaled up in sub-Saharan Africa. Maman Groves, King, Pierce and Wyckoff (2008) examined government policies regarding HIV testing in ANC in 19 low- and middle-income countries, including Kenya, South Africa, Swaziland, Tanzania, Zambia and Zimbabwe (Maman *et al.* 2008). They assessed whether policies addressed consent, confidentiality and partner notification. They found that while policies in all these countries mentioned respect for confidentiality, some did so within limits. For example, in at least four countries, South Africa, Swaziland, Zambia and Zimbabwe, policies referred to 'shared confidentiality' – the notion that patients' HIV status should be shared with health workers or family members involved in care and support.¹ In South Africa, Swaziland, Zambia and Zimbabwe, policies allowed patients' HIV status to be shared among health-care workers; and in some countries, including Kenya, Tanzania and Zimbabwe, policies authorized health workers to disclose a

pregnant woman's HIV status to her spouse or sexual partner without her consent, if she refused to tell her partner herself.

According to UN High Commissioner for Human Rights and UNAIDS guidelines, laws and policies may authorize but not require health professionals to inform sexual partners about their clients' HIV+ status, if they meet eight conditions (Office of the UN High Commissioner for Human Rights & UNAIDS 2006). Maman and colleagues note that at the time of their study, policies in Kenya, Tanzania and Zimbabwe mentioned four of these conditions, including:

- the HIV+ person has been thoroughly counselled;
- counselling failed to achieve appropriate behavioural changes;
- the HIV+ person refused to notify or consent to notification of partner(s); and
- a real risk of HIV transmission to the partner(s) exists.

However, policies in these three countries did not mention the other criteria that the UN considers important for protecting the rights and safety of people living with HIV, namely: that the HIV+ person is given reasonable advance notice; that the identity of the HIV+ person is concealed from the partner(s), if possible; and that follow-up is provided to ensure support to those involved as necessary. Kenya's policy mentioned that counselling should include a discussion of potential violence that might result from disclosure, but other policies did not mention giving particular consideration or support to HIV+ women who may not want to disclose for fear of violence or other negative consequences – the final condition for ethical third party notification in UN guidelines.

3.3 Mandatory premarital testing policies

Another type of policy related to HIV confidentiality and disclosure are mandatory premarital HIV-testing policies, required by religious institutions or occasionally local governments in some sub-Saharan settings. For example, national or municipal governments have considered or implemented mandatory premarital HIV testing in parts of the DRC, Ethiopia, Guinea, Senegal and Uganda, while churches have adopted mandatory (or *de facto* mandatory) premarital HIV-testing policies in parts of Burundi, the DRC, Ghana, Kenya, Nigeria, Tanzania and Uganda (Burns 2010; Luginaah, Yiridoe & Taabazuung 2005; Pearshouse 2007; Uneke, Alo & Ogbu 2007).

Apart from questions about consent, evidence suggests that test results are sometimes shared with church leaders, local authorities or prospective spouses without the consent or even, in some cases, before they are given to the individuals tested (Luginaah *et al.* 2005; Uneke *et al.* 2007). A case study of mandatory premarital testing in the DRC found that local churches in Goma arranged for test results to be sent directly from the laboratory or clinic to the church pastors who would then disclose the results to the couple (Rennie & Mupenda 2008).

In some settings, such as Senegal and Zimbabwe, proponents of mandatory premarital HIV testing have argued that such policies are needed to protect girls and women, particularly when they

have little control over whom they marry (Burns 2010; Rennie & Mupenda 2008). However, researchers such as Rennie and Mupenda (2008) point out that – apart from evidence that such policies have questionable public health value – the consequences for young women who test positive during premarital testing may be more severe than for young men.

3.4 The context in which policies are put into practice

While the legal and ethical aspects of laws and policies related to disclosure have received a fair amount of attention, less is known about how they influence individual or provider behaviour in practice (Kazatchkine 2010; Maman *et al.* 2008). What is clear is that in many parts of the region, HIV services are delivered in a context of severe resource constraints, including staff shortages, a lack of private counselling spaces, and inadequate referral services (Evans & Ndirangu 2009). Health workers often report heavy workloads and high levels of stress and burnout (Mkhabela, Mavundla & Sukati 2008; Turan, Bukusi, Cohen, Sande & Miller 2008a). In some countries, to address resource constraints, programmes have shifted counselling tasks to lower level health workers or lay counsellors (Zachariah, Ford, Philips, Lynch, Massaquoi, Janssens, *et al.* 2009). Generally, research highlights a need for more support and guidance for HIV counsellors in settings such as Burkina Faso (Sarker, Papy, Traore & Neuhaus 2009), Kenya (Turan, Miller, Bukusi, Sande & Cohen 2008b), Swaziland (Mkhabela *et al.* 2008) and Uganda (Medley 2009; Medley & Kennedy 2010).

4. Results: HIV disclosure practices in sub-Saharan Africa

4.1 Definitions, measures and rates of disclosure

Reported disclosure rates can be difficult to compare across studies when researchers use different categories of people to whom individuals disclose (e.g. to anyone, family, friends, partners, etc.); if they do not report how much time has elapsed between diagnosis and the moment when disclosure was measured; or – as tended to happen in earlier studies – when rates of disclosure are presented without disaggregating respondents by HIV status. In addition, disclosure rates are usually based on self-reports, which may not always be reliable. For example, a study from Kenya found that a substantial percentage (27%) of men who said they had disclosed to their partner were contradicted by their female partners who said they did not know their partner's status (Katz, Kiarie, John-Stewart, Richardson, John & Farquhar 2009). Smaller but still substantial levels of conflicting reports were found in Malawi (Anglewicz & Chintsanya 2011).

Research suggests that HIV disclosure is not a one-time event, but a process that occurs over time as HIV+ individuals disclose to different people in their network (Obermeyer *et al.* 2011). For example, a study from South Africa found that while nearly all (92%) respondents disclosed to at least one person, a substantial percentage (15%) waited more than a year to tell their partners (Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, *et al.* 2006). In Tanzania, only 22% of pregnant women interviewed

disclosed to partners within 2 months of diagnosis, and 40% had done so after 4 years (Antelman, Smith Fawzi, Kaaya, Mbawambo, Msamanga, Hunter, *et al.* 2001). Disclosure often varies by HIV status, and those who test negative generally report higher disclosure rates than those who test positive (Brou, Djohan, Becquet, Allou, Ekouevi, Viho, *et al.* 2007; Medley 2009; Rutenberg 2003), with some exceptions (Kiene, Bateganya, Wanyenze, Lule, Nantaba & Stein 2010).

Table 1 presents disclosure rates reported in a selection of studies from sub-Saharan Africa published between 2000 and 2012. About half of these studies examined disclosure by women only, while the rest explored disclosure by both female and male respondents. Most studies (particularly those published more recently) focused on disclosure by HIV+ individuals, but some examined disclosure by both positive and negative respondents.

Of the 15 studies that reported disclosure to at least one person by HIV+ respondents, most reported rates over 74%. These moderate to high levels of disclosure are consistent with the global literature, though variations in sub-Saharan Africa appear to be greater than in other regions (Obermeyer *et al.* 2011). Studies of disclosure to partners suggest even wider variation, ranging from less than 25% in studies from Burkina Faso (Guio, Traore, Somda & Huang 2011; Nebie, Meda, Leroy, Mandelbrot, Yaro, Sombie, *et al.* 2001), Nigeria (Akani & Erhabor 2006), South Africa (Oley, Seedat & Stein 2004) and Tanzania (Kilewo, Massawe, Lyamuya, Semali, Kalokola, Urassa, *et al.* 2001), to over 90% in studies from Ethiopia (Deribe, Woldemichael, Wondafrash, Haile & Amberbir 2008), Malawi (Bobrow, Chasela, Kamanga, Adair, Bentley, Bloom, *et al.* 2008), Nigeria (Ezegwui, Nwogu-Ikojo, Enwereji & Dim 2009) and Uganda (Kiene *et al.* 2010).

While all studies in Table 1 explored voluntary disclosure, evidence suggests that involuntary disclosure may also be a problem in many settings. For example, a study from South Africa found that 32% of HIV+ respondents reported that their status was revealed to family members without their consent, often by someone to whom they had voluntarily disclosed (Varga, Sherman & Jones 2006). Breaches of confidentiality in health-care facilities may occur as well, as discussed later in this paper.

4.2 The influence of socio-economic factors and gender on disclosure

Variations in disclosure rates (particularly partner disclosure) probably reflect multiple factors. For example, in South Africa, studies have found higher disclosure rates in urban sites with more institutional services available compared with rural areas (Norman, Chopra & Kadiyala 2007), and among individuals with higher socio-economic status (Wong, Rooyen, Modiba, Richter, Gray, McIntyre, *et al.* 2009). Similarly, in Nigeria, researchers found that more-educated respondents disclosed more often than less-educated counterparts (Akani & Erhabor 2006). The association between disclosure and economic status is not simple, however, and may be influenced by gender. Research from Kenya found that women were significantly

Table 1. Percentage of respondents who reported having disclosed their serostatus to partners, family or friends, selected studies from sub-Saharan Africa, 2000–2012.

Country	First author	Year of publication	Sample	Disclosed to at least one person	Disclosed to sexual partner
Burkina Faso	Issiaka	2001	79 HIV+ pregnant women		31.6%
Burkina Faso	Nebie	2001	306 HIV+ post-partum women		18%
Burkina Faso	Ouedraogo	2005	122 HIV+ women, 66 HIV+ men	74.5%	
Burkina Faso	Guiro	2011	412 HIV+ women and men		22.3%
Burkina Faso	Kouanda	2012	740 HIV+ women and men	81.4%	67.7% ^a
Cameroon	Loubiere	2009	1014 HIV+ women		86.3%
Cameroon	Suzan-Monti	2011	1673 HIV+ women and men with a stable partner		85.4% ^a
Côte d'Ivoire	Brou	2007	546 HIV+ women in PMTCT		46.2% HIV+
			393 HIV- women in PMTCT		96.7% HIV-
Côte d'Ivoire	Tonwe-Gold	2009	568 HIV+ married women		53%
Ethiopia	Deribe	2008	353 HIV+ women, 352 HIV+ men	94.5	90.8
Ethiopia	Gari	2010	384 HIV+ women	92.2%	87.3% ^a
Kenya	Farquhar	2001	172 HIV+ women		67%
Kenya	Gaillard	2002	329 HIV+ women		31%
Kenya	Rutenberg	2003	HIV+ and HIV- pregnant women: 1300 in Karatina site	53% by HIV+, 70% by HIV-	58% ^b (HIV+ and HIV- combined)
			800 in Homa Bay site	35% by HIV+, 83% by HIV-	64% ^b (HIV+ and HIV- combined)
Malawi	Bobrow	2008	300 HIV+ pregnant women		90%
Malawi	Anglewicz	2011	916 HIV+ and HIV- currently married women	95.6% ^b	66.7% by HIV+, 85.8% by HIV-
			636 HIV+ and HIV- currently married men	99.0% ^b	90.0% by HIV+, 92.1% by HIV-
Nigeria	Akani	2006	187 HIV+ women and men	77%	23.6%
Nigeria	Ezegwui	2009	92 HIV+ pregnant women		94.4%
Nigeria	Iliyasu	2011	289 HIV+ women		67.1%
Nigeria	Olagbuji	2011	166 HIV+ pregnant women on ART		87.9%
Nigeria	Titilope	2011	499 HIV+ women and men		61.5%
South Africa	Olley	2004	69 HIV+ women and men		22%
South Africa	Sethosa	2005	41 HIV+ women, 14 HIV+ men	36%	
South Africa	Skogmar	2006	144 HIV+ women and men	92%	79%
South Africa	Visser	2008	293 HIV+ pregnant women	59%	80%
South Africa	Wong	2009	192 women and 23 men, all HIV+	87%	64% to any sex partner; 59% to spouse
South Africa	Vu	2012	630 HIV+ women and men with recent sexual contact		81.4% by whole sample; 87.4% by those with steady partner; 57.2% by those with casual partner
Tanzania	Antelman	2001	1078 HIV+ pregnant women		22% by 2 months and 40% by 4 years after diagnosis

(Continued)

Table 1. Continued.

Country	First author	Year of publication	Sample	Disclosed to at least one person	Disclosed to sexual partner
Tanzania	Kilewo	2001	288 HIV+ pregnant women	22%	16.7%
Tanzania	Maman	2003	245 HIV+ and HIV- women, VCT clients		69% by HIV+; 83% by HIV-
Uganda	King	2008	1092 HIV+ women and men		69%
Uganda	Kairania	2010	293 HIV- sero-discordant couples		81%
Uganda	Kiene	2010	28 HIV+ women and men, 187 HIV- women and men		91.7% (22) by HIV+, 86.9% by HIV-
Uganda	Ssali	2010	40 HIV+ women and men	95%	54% ^a
Uganda	Osinde	2011	256 HIV+ women and men (mostly women) receiving ART		61.5%
Uganda	Osinde	2012	403 HIV+ women and men		49.1%
Zimbabwe	Patel	2012	200 HIV+ women on ART or wait list	96.5%	78% ^a (by currently married)
Zambia	Rutenberg	2003	1002 HIV+ and HIV- pregnant women	49% by HIV+, 86% by HIV-	72% ^b (by HIV+ and HIV-)
Kenya, Tanzania, Trinidad	Grinstead	2001	1463 HIV+ and HIV- women and men		76% ^b (by HIV+ and HIV-)
Review: 15 studies sub-Saharan Africa and 2 from Asia					
	Medley	2004	HIV+ (and in some studies HIV-) women		16.7-86% ^b

Notes: Italics indicate that disclosure rates either included or were limited to HIV- respondents (as noted). PMTCT refers to prevention of mother-to-child transmission (programs). ART refers to antiretroviral therapy.

^aTo a stable partner, among respondents with a stable partner or spouse.

^bIncluded HIV- as well as HIV+ respondents.

more likely to notify their partner if they had limited resources or relied on their husband for economic support (Farquhar, Mbori-Ngacha, Bosire, Nduati, Kreiss & John 2001), suggesting that women may feel compelled to disclose to partners to ensure continuing economic support. Researchers have also found lower partner disclosure rates by women living in polygamous marriages (Brou *et al.* 2007).

The association between gender and disclosure is clearly important, as women tend to test more often than men because of the scale up in testing within ANC, and some evidence suggests that they may be more vulnerable to negative consequences after a positive diagnosis. But the evidence comparing *levels* of disclosure by women and men is mixed. Studies from Kenya (Katz *et al.* 2009) and South Africa (Olley *et al.* 2004) found higher rates of disclosure by women, while other studies have found no significant differences, as in Ethiopia (Deribe, Woldemichael, Bernard & Yakob 2009; Deribe *et al.* 2008). Nonetheless, substantial gender differences in *reasons for* nondisclosure have been documented (Anglewicz & Chintsanya 2011; Ssali, Atuyambe, Tumwine, Segujja, Nekesa, Nannungi, *et al.* 2010). For example, in Ethiopia, Deribe *et al.* (2009) and Deribe, Woldemichael, Njau, Yakob, Biadgilign and Amberbir (2010) found that men

were more likely than women to report that they did not disclose to their partner(s) because they did not want to reveal infidelity or cause their partner concern about contracting HIV, while women were more likely than men to cite fear of physical violence or abandonment. Indeed, a large body of evidence indicates that because of women's economic and social vulnerability relative to men, fear of rejection, abandonment or violence by partners remains a major barrier to both testing and disclosure for women in many parts of sub-Saharan Africa (Maman & Medley 2004; Mucheto, Chadambuka, Shambira, Tshimanga, Gombe & Nyamayaro 2011; Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo 2007; Visser, Neufeld, de Villiers, Makin & Forsyth 2008).

Disclosure may also be influenced by the context of testing, which varies by gender. Some evidence suggests that partner disclosure tends to be lower among women tested in ANC compared with women tested in other settings, such as free-standing voluntary testing and counselling (VCT) clinics (Maman & Medley 2004). Researchers suggest this may be because women do not come to ANC expressly for testing, and because pregnant women may have particular concerns about the negative consequences of disclosure (Kadowa & Nuwaha 2009; Medley *et al.* 2004).

4.3 The influence of treatment availability on disclosure

Much evidence suggests that nondisclosure poses a barrier to treatment initiation and adherence. Less well understood is how increased access to treatment will influence disclosure over time. Service available in a community can influence disclosure rates, as documented in a study from South Africa that explored why two culturally similar communities had such different disclosure rates – 30% compared with 70% (Norman *et al.* 2007). In Tanzania, researchers found that while unwillingness to disclose HIV status was a barrier to entering programmes that required a ‘treatment buddy’, they also found evidence that treatment availability had begun to change attitudes and reduce some barriers to disclosure in the community (Mshana, Wamoyi, Busza, Zaba, Changalucha, Kaluvya, *et al.* 2006). Other studies suggest that stigma may remain an important barrier to disclosure despite increased access to treatment. One study from South Africa noted that while clinicians had come to regard HIV as a chronic condition, HIV+ respondents continued to report intense stigma from those around them, with implications for both treatment adherence and disclosure (Gilbert & Walker 2009). Thus, while increased access to treatment may eventually reduce stigma and thereby increase disclosure, these changes may not happen quickly or consistently across settings.

4.4 Consequences of disclosure

Substantial research from the region has examined the social, physical and economic consequences of HIV disclosure – both positive and negative. Evidence suggests that HIV disclosure may positively influence behaviours that protect the health of people living with HIV, their partners and their children. For example, research from Cameroon (Loubiere *et al.* 2009), South Africa (Wong *et al.* 2009) and Uganda (King, Katuntu, Lifshay, Packel, Batamwita, Nakayiwa, *et al.* 2008) found that people who disclosed their HIV status to sexual partners were significantly more likely to report safer sex behaviours, including using condoms, reducing the number of sexual partners, and/or becoming monogamous (Wong *et al.* 2009). In addition, HIV+ women diagnosed within ANC who disclosed their status to partners were more likely to convince their partner to test than women who did not disclose (Brou *et al.* 2007). Finally, HIV disclosure has been linked to better adherence to treatment and to replacement feeding as a means of preventing HIV transmission to infants (Betancourt, Abrams, McBain & Fawzi 2010).

Researchers have documented negative consequences of disclosure for both sexes as well, such as isolation, criticism and ostracism by family members (Obi & Ifebunandu 2006; Ouedraogo, Ouedraogo, Kyelem & Soubeiga 2005), divorce, separation or violence from partners, and rejection by friends (Deribe *et al.* 2008; Gaillard, Melis, Mwanyumba, Claeys, Muigai, Mandaliya, *et al.* 2002; Gari, Habte & Markos 2010; Iliyasu, Abubakar, Babashani & Galadanci 2011; Semrau, Kuhn, Vwalika, Kasonde, Sinkala, Kankasa, *et al.* 2005). Some consequences are particularly commonly reported by women, as reported in the review by Medley and colleagues where 3.5–14.6% of HIV+ women experienced a violent reaction from their partners when they disclosed their status (Medley *et al.* 2004).

Rates of adverse consequences following disclosure have sometimes been hard to compare across studies, because of the wide range of what are considered to be negative reactions, from relatively mild examples of lack of emotional support to more severe cases of abandonment or physical violence. Some studies have had difficulty determining whether or not adverse events resulted from HIV disclosure itself. Nonetheless, it is clear that fears about negative reactions from partners, family members and communities are a major barrier to both testing and disclosure throughout the region, particularly among women (Maman, King, Amin, Garcia-Moreno, Higgins & Okero 2006).

Many studies have documented high levels of supportive reactions from families and friends, as in studies from Burkina Faso (Kouanda, Yameogo, Berthe, Bila, Bocoum Yaya, Somda, *et al.* 2012), South Africa (Skogmar *et al.* 2006), Kenya and Tanzania (Grinstead, Gregorich, Choi & Coates 2001). In fact, some studies report that negative consequences are relatively rare, as did one from Tanzania where only 5% of women reported a negative reaction following disclosure (Maman, Mbwambo, Hogan, Weiss, Kilonzo & Sweat 2003). However, low rates of negative consequences should be considered in light of the fact that individuals may not disclose if they expect serious negative reactions (Kilewo *et al.* 2001). Moreover, not all studies have found such low rates. One study from Ethiopia found that a majority of 385 HIV+ women who disclosed to their partner experienced negative reactions ranging from anger and blame to the end of the relationship, abandonment, and violence, including 59.3% of women with a regular partner and 66.7% of women with non-regular partner. Another study among 289 HIV+ women from Nigeria found that women who disclosed to their partner were significantly more likely to have experienced physical and emotional domestic violence than HIV+ women who had not – 28.4% vs. 9.5%, respectively (Iliyasu *et al.* 2011).

4.5 Medical confidentiality, involuntary disclosure and third party partner notification

Fears about lack of confidentiality and involuntary HIV disclosure represent barriers to health care in many parts of sub-Saharan Africa, particularly for women, as suggested by studies of HIV door-to-door testing in Malawi (Angotti, Bula, Gaydosh, Kimchi, Thornton & Yeatman 2009); labour and delivery services in Kenya (Turan *et al.* 2008b); prevention of mother-to-child transmission (PMTCT) programmes in Malawi and Uganda (Chinkonde, Sundby & Martinson 2009; Donahue, Dube, Dow, Umar & Van Rie 2012; Medley & Kennedy 2010) and HIV treatment services in Kenya (Otieno, Kohler, Bosire, Brown, Macharia & Stewart 2010).

There is relatively little published information on breaches of HIV medical confidentiality within health facilities in the region. One of the few studies on this topic was carried out among 1021 health-care providers (including 324 physicians, 541 nurses, 133 midwives, and 23 others) in 111 health-care facilities in four Nigerian states (Reis, Heisler, Amowitz, Moreland, Mafeni, Anyamele, *et al.* 2005). The study found that 38% of professionals reported giving confidential information about an HIV+ patient to family members without the patient’s consent; 53% had observed this behaviour by colleagues. A population-based study in

Botswana found that 5% of respondents tested for HIV reported a breach of confidentiality by a health-care worker (Weiser, Heisler, Leiter, Percy-de Korte, Tlou, DeMonner, *et al.* 2006).

Involuntary disclosure of patients' HIV status by health workers is observed in diverse settings, and may occur for many reasons, some having to do with the physical environment, others related to social and cultural factors (Obermeyer *et al.* 2011). Lack of privacy at health facilities is a serious challenge to medical confidentiality in many parts of sub-Saharan Africa. Patients are often accompanied by family members to overcrowded facilities that lack separate spaces for counselling (Gruskin, Ahmed & Ferguson 2008; Obermeyer & Osborn 2007; Turan *et al.* 2008a).

Cultural views about the need to involve husbands and other family members in medical decision-making, as well as concerns about ensuring continuity of care for patients may also influence provider behaviour. Turan *et al.* (2008a) found that maternity care providers in Kenya found it inconceivable that a husband would not be informed of his wife's HIV status. Similarly, in the previously mentioned study from Nigeria, a majority (57%) of providers believed that relatives and sexual partners of patients with HIV should be notified of their status even if the patient did not consent (Reis *et al.* 2005).

In addition, health workers may feel pressure to disclose patients' status without their consent in order to prevent transmission to a child or partner. In studies throughout the region, health workers often describe stress and uncertainty about how to respond when patients' refusal to disclose their status put partners or children at risk (Evans & Ndirangu 2009). For example, in Uganda, HIV counsellors described wanting more guidance about what to do when members of discordant couples refused to reveal their HIV status to each other (Medley & Kennedy 2010). In Cameroon, researchers concluded that counsellors regularly encountered 'ethical, legal and moral dilemmas' related to balancing confidentiality with a duty to protect others at risk (Njozing, Edin, Sebastian & Hurtig 2011), as did Angotti (2010, 2012), who described a tension between the social and ethical norms of rural communities in Malawi and the testing norms based on Western concepts of individual rights.

Such evidence suggests that policy debates about confidentiality and how health workers can facilitate disclosure of a patient's serostatus are highly relevant to difficult challenges that HIV counsellors face in their daily work, and that if common ground can be found between the values of patient privacy and protection of public health, then this should be translated into better guidance to health workers.

4.6 Programmatic strategies to increase disclosure and testing of partners

There have been numerous efforts to increase disclosure in sub-Saharan Africa including by offering 'facilitated disclosure' (whereby health workers help patients disclose) (Kairania, Gray, Kiwanuka, Makumbi, Sewankambo, Serwadda, *et al.* 2010); individual testing of male partners of women in ANC; couples testing

and counselling (Conkling *et al.* 2010); 'family focused' HIV care and treatment (Tonwe-Gold, Ekouevi, Bosse, Toure, Kone, Becquet, *et al.* 2009); and community support initiatives (Wouters, van Loon, van Rensburg & Meulemans 2009). These efforts have produced mixed results, and programmes are working to determine the benefits, risks and effectiveness of different strategies. Betancourt *et al.* (2010) reviewed programmes that aimed to increase family participation in PMTCT programmes, and they highlight the important role of gender norms and power imbalances – including fear of intimate partner violence – in influencing the success of these approaches.

More than a decade ago, researchers in Kenya, Tanzania and Trinidad found evidence that couples counselling was associated with higher levels of preventive behaviour compared with individual testing (The Voluntary HIV-1 Counseling and Testing Efficacy Study Group 2000). Since then, many programmes have tried to promote couples counselling and testing as a way to help women find safer ways to disclose to their partners and improve health outcomes (Katz *et al.* 2009; Maman *et al.* 2006). Evidence about couples counselling has been mixed. In Rwanda and Zambia, couples counselling reduced loss to follow-up in PMTCT programmes (Conkling *et al.* 2010). In Kenya, partner participation in VCT and couples counselling increased uptake of nevirapine and formula feeding (Farquhar, Kiarie, Richardson, Kabura, John, Nduati, *et al.* 2004). Other studies have found that it does not always produce better adherence to treatment or lower rates of violence and discrimination, however. For example, research from Kenya found that while couples counselling increased acceptance of HIV testing, it did not significantly increase uptake of nevirapine or decrease levels of adverse social events compared with individual HIV counselling (Semrau *et al.* 2005). In fact, at 6 months post-partum, that study found substantial levels of adverse events (including verbal abuse, separation, divorce and physical violence) among women in both couples and individual counselling groups.

It is also important to clarify what is meant by couples counselling. The approach evaluated in Rwanda and Zambia involved joint pre- and post-sessions, but after reviewing the evidence about risks of adverse consequences (especially for women), Maman *et al.* (2006) recommended the approach used by the AIDS Information Centre in Uganda, which provided separate, individual, but simultaneous pre- and post-test counselling sessions for each member of the couple, followed by an optional, mediated joint post-test counselling at the end.

Many health programmes in the region have tried to increase HIV testing among male partners of women tested in ANC, but have generally faced great difficulty (Auvinen, Suominen & Valimaki 2010; Brou *et al.* 2007). In Uganda, a study found that women who tested positive for HIV were often afraid to disclose to their partners for fear of abandonment or violence (Medley & Kennedy 2010). Counsellors encouraged women to bring their partners to the clinic for testing, counselling and in some cases 'facilitated disclosure', but few women were able to convince their partners to come. Evidence suggests that increasing testing, counselling and disclosure among male partners of ANC patients will require community education, mobilization

and outreach (Allen, Karita, Chomba, Roth, Telfair, Zulu, *et al.* 2007; Becker, Mlay, Schwandt & Lyamuya 2009; Conkling *et al.* 2010).

Some community-based approaches to increasing disclosure among clients of HIV services have also shown promise. For example, researchers found that community support initiatives that used community health workers and treatment-support groups increased HIV disclosure to family members by patients of public-sector antiretroviral therapy (ART) services in South Africa (Wouters *et al.* 2009). Other research from South Africa found that integrated community/home-based care increased disclosure by people living with HIV who participated in the programme compared with those who did not (Ncama 2007).

5. Discussion

Studies reviewed in this paper indicate that while rates of HIV disclosure vary widely, substantial proportions of women and men who test positive for HIV do not share that information with those close to them, including sexual partners. Nondisclosure may raise the risk of HIV transmission to partners and to children. It may also pose a barrier to treatment and represents a missed opportunity to test and treat partners.

Many recent laws, policies and programmes have tried to encourage, or in some cases, mandate HIV disclosure, both globally and within sub-Saharan Africa, often generating heated debates within legal, human rights and public health circles. There is a broad consensus that laws criminalizing transmission, mandating HIV disclosure by people living with HIV or requiring premarital HIV testing are difficult to enforce, undermine rights and offer no real public health benefit (Burns 2010; Pearshouse 2007; UNAIDS & UNDP 2008). There is less clarity about the ethics of involuntary, third party partner notification, especially in low resource settings. Some argue that routine partner notification may undermine patient privacy and confidentiality, but is the 'lesser of two evils' or is entirely outweighed by partners' right to be informed of the risks they face (Dixon-Mueller 2007; Masiye & Ssekubugu 2008). Others highlight the need for a cautious approach in which third party disclosure is accompanied by counselling and consideration for the risks for HIV+ individuals (Muula & Mfutso-Bengo 2005).

The UN Human Rights Commission and UNAIDS have developed guidelines for third party partner notification (Office of the UN High Commissioner for Human Rights & UNAIDS 2006), but policies in sub-Saharan Africa do not always follow these guidelines (Maman *et al.* 2008). Whether ethical third party partner notification is feasible in resource-constrained settings with limited post-test counselling and follow-up services is an important question that poses challenges for policy-makers and programmes in the region.

As highlighted throughout this review, gender issues are intimately linked with challenges and debates related to HIV disclosure in sub-Saharan Africa. Women are more likely than men to be HIV+, to know their status and to cite fear of abandonment or violence as the reason for nondisclosure (Deribe *et al.* 2009; Obermeyer *et al.* 2011). While protecting women from HIV

transmission is often cited as the rationale for policies mandating disclosure or criminalizing transmission in sub-Saharan Africa, such laws and policies do not address the underlying fear of stigma and discrimination (including violence) that contributes to low disclosure rates, particularly among women (UNAIDS & UNDP 2008).

Various programmatic efforts to facilitate voluntary disclosure, encourage partner testing, and mitigate risks of disclosure are promising. Efforts to increase partner participation in routine testing of women within ANC seem to have potential for positive outcomes, despite challenges, as do community support initiatives for people living with HIV. Nonetheless, HIV counsellors continue to face important ethical dilemmas about how to balance confidentiality with a duty to prevent transmission to others and to ensure that HIV+ patients receive the support they need. A key finding from this review is that health-care providers in many settings need more guidance about how to balance competing values and interests of different individuals.

6. Conclusion

Persistent rates of nondisclosure of HIV status by those who test positive pose difficult legal and ethical challenges for policy-makers, health workers, people living with HIV, their families and their communities. There is a need for more consideration of the perspectives and rights of all those affected as well as the gender power imbalances that are widespread in the region. In particular, more clarity is needed about the ethics of third party notification in resource-constrained settings, with attention to differences between international human rights guidelines, national and institutional policies, what health workers are actually doing, and what is feasible within the health service context in the region.

This review highlights various gaps in the evidence. While substantial theoretical scholarship has explored the ethics of policies and laws, and a fair number of studies have examined reasons for and rates of disclosure, less empirical research has investigated how policies in the region influence behaviour in practice, although it is clear that laws and policies are not always enforced or implemented. Another question is how increased treatment availability will influence disclosure over time. Ideally, as Norman *et al.* (2007) describe, there would be a 'virtuous circle' whereby increased access to treatment would lower fear and stigma associated with testing positive, thereby increasing disclosure and further destigmatizing HIV, but some evidence suggests that levels of HIV stigma may change slowly (Gilbert & Walker 2009).

There is clearly a need for more investment in health sector initiatives to encourage voluntary HIV disclosure and partner testing in sub-Saharan Africa, including those that provide guidance and training to HIV counsellors and those that support individuals diagnosed with HIV. More evidence is needed about the effectiveness of interventions to promote voluntary disclosure, including couples counselling, specifically about the extent to which they reduce adverse events, encourage male participation, increase utilization of services, and improve health outcomes. It is clear, however, that increasing disclosure and

mitigating negative consequences for women will require attention to gender norms and power differentials. Taken as a whole, the evidence presented in this review suggests a need for more attention to the challenges and dilemmas faced by both clients and providers in relation to HIV disclosure in the region, and for continued efforts to consider the perspectives and rights of all those affected.

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Note

1. Within sub-Saharan African policy documents, 'shared confidentiality' has generally referred to the concept that sensitive information about patients shall be shared with those involved in care and support, such as health workers or family members. 'Shared confidentiality' does not necessarily require or even allow forced disclosure, but it tends to de-emphasize individual rights to strict confidentiality (Seidel 1996; AIDS and Human Rights Research Unit 2007).

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