

## The duty to disclose in Kenyan health facilities: a qualitative investigation of HIV disclosure in everyday practice

Eileen Moyer, Emmy Kageha Igonya, Rosalijn Both, Peter Cherutich, Anita Hardon

### Abstract

Disclosure of HIV status is routinely promoted as a public health measure to prevent transmission and enhance treatment adherence support. While studies show a range of positive and negative outcomes associated with disclosure, it has also been documented that disclosing is a challenging and ongoing process. This article aims to describe the role of health-care workers in Central and Nairobi provinces in Kenya in facilitating disclosure in the contexts of voluntary counselling and testing and provider-initiated testing and counselling and includes a discussion on how participants perceive and experience disclosure as a result. We draw on in-depth qualitative research carried out in 2008–2009 among people living with HIV (PLHIV) and the health workers who provide care to them. Our findings suggest that in everyday practice, there are three models of disclosure at work: (1) voluntary-consented disclosure, in alignment with international guidelines; (2) involuntary, non-consensual disclosure, which may be either intentional or accidental; and (3) obligatory disclosure, which occurs when PLHIV are forced to disclose to access services at health facilities. Health-care workers were often caught between the three models and struggled with the competing demands of promoting prevention, adherence, and confidentiality. Findings indicate that as national and global policies shift to normalize HIV testing as routine in a range of clinical settings, greater effort must be made to define suitable best practices that balance the human rights and the public health perspectives in relation to disclosure.

**Keywords:** HIV/AIDS, Kenya, disclosure, consent, confidentiality, HIV support groups

### Résumé

Le partage du statut VIH+ est systématiquement présenté comme une mesure de santé publique visant à prévenir la transmission du VIH et à améliorer l'appui à l'observance du traitement. Des études ont mis au jour une variété d'effets positifs et négatifs du partage; il a aussi été montré que l'annonce du statut VIH est un processus difficile et étalé dans le temps. Cet article vise à décrire le rôle joué par le personnel de santé pour faciliter le partage par les personnes atteintes, dans le cadre du conseil et dépistage volontaire et du dépistage et conseil à l'initiative du soignant, dans les provinces du Centre et de Nairobi au Kenya. Il discute aussi la manière dont les participants perçoivent et vivent le partage. Nous nous appuyons sur une recherche qualitative approfondie réalisée en 2008–2009 auprès de personnes vivant avec le VIH et des professionnels de santé qui leur fournissent des soins. Nos résultats suggèrent que, dans la pratique quotidienne, il existe trois modèles de partage du statut VIH : 1) la divulgation volontaire et consentie, suivant les directives internationales, 2) le partage involontaire, non-consensuel, qui peut être intentionnel ou accidentel, et 3) le partage obligatoire, lorsque les PVVIH sont tenues de divulguer leur statut pour accéder à des services dans les établissements de santé. Les agents de santé ont souvent été pris entre ces trois modèles et ont dû gérer des conflits entre les exigences contradictoires de la prévention, de l'appui à l'observance et du respect de la confidentialité. Les résultats indiquent qu'alors que les politiques nationales et internationales vont dans le sens de la normalisation du dépistage du

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VIH en routine dans une variété de contextes cliniques, davantage d'efforts doivent être faits pour définir des « bonnes pratiques » afin de prendre en compte de manière équilibrée les droits de l'homme et les perspectives de santé publique en matière de partage.

**Mots clé:** VIH/sida, Kenya, partage, consentement, confidentialité, groupes d'appui aux personnes vivant avec le VIH

## Introduction

The role of health-care workers in facilitating HIV disclosure is seldom a topic of study. In this article, which examines everyday practices of disclosure in health-care settings in Kenya, we demonstrate that health-care workers play a key role in facilitating disclosure. We found that health-care workers frame HIV disclosure in different ways depending on the particularities of their training and experience; existing guidelines and norms in the locations where disclosure is encouraged (or discouraged); and various factors relating to the individual who is being advised on disclosure. Whereas disclosure is often referred to as an ongoing process rather than a specific event in the literature (Maman, Mwambo, Hogan, Weiss, Kilonzo & Sweat 2003; Norman, Chopra & Kadiyala 2007), little attention has been given to the roles played by health-care workers in facilitating or hindering the process of disclosure. In this article, we examine the way these advice-givers shape the process of disclosure in different contexts. Disclosure in our perspective is both situated and relational. To understand disclosure processes, we need to investigate what goes on in practice in a variety of health facilities. Who is involved in the disclosure process, how does disclosure take place?

Those who test positive for HIV are routinely encouraged by health-care workers to disclose their status. Disclosure is considered an important step in HIV prevention, for treatment adherence, and for gaining access to psychosocial support. The World Health Organization (WHO) and the United Nations Programme on HIV/AIDS encourage voluntary and confidential disclosure to promote openness about HIV/AIDS in the community and to reduce stigma; they also advise providers in post-test counselling situations to encourage disclosure (UNAIDS/WHO 2000; WHO/UNAIDS 2007). Disclosure is considered critical because (1) it allows individuals to garner social support for preventive actions; (2) disclosing to sexual partners helps prevent HIV transmission; and (3) it facilitates access social or medical services (i.e. Lugalla, Madihi, Sigalla, Mrutu & Yoder 2008). Disclosure may also help counter HIV stigma and allows individuals and couples to make informed reproductive health choices (Medley, Garcia-Moreno, McGill & Maman 2004; Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, *et al.* 2006).

While most guidelines on HIV disclosure stress that it should always be voluntary and consensual, some advocate for routine third-party notification by health-care workers or other public health employees to identifiable sexual partners of those testing HIV positive in sub-Saharan Africa (Masiye & Ssekubugu 2008). Disclosure in settings where people with HIV still suffer severe stigma and discrimination comes with risks. Indeed, tensions exist between the ethical obligation to respect the privacy and confidentiality of people living with HIV (PLHIV) and the 'moral obligation' to partners and caregivers.

Several studies on HIV self-disclosure have been conducted in Kenya (Miller & Rubin 2007a, 2007b). One from Nairobi and Thika Districts, carried out in 1999–2001 (before antiretroviral treatments (ARTs) became widely available), reported that 55% of HIV-positive male and female clients had disclosed within 6 months of receiving test results, one-third to a primary partner (Arthur, Nduba, Forsythe, Mutemi, Odhiambo & Gilks 2007). A more recent study on the characteristics of adults receiving care in two public HIV clinics in Western Kenya, North Rift Valley Province, found that 16% of women knew the HIV status of their spouse compared to 32% of men. Men and urban clinic patients were more likely to know the HIV status of their spouse (Diero, Shaffer, Kimaiyo, Siika, Rotich, Smith, *et al.* 2006). Another study conducted in Western Kenya reached a similar conclusion, finding that women less often disclosed their status to significant others (Shacham, Reece, Ong'or, Omollo, Monahan & Ojwang 2008). In Nairobi, it was found that HIV-positive individuals commonly use intermediation to ease the process of disclosing, especially to partners. HIV-positive women more often reported informing their partners directly, while men more often utilized third parties and other indirect approaches to disclose to their partner, including initiating couples counselling, dropping hints, and gradually leading up to disclosure (Shacham *et al.* 2008). Most participants who told their spouses about their diagnosis found them supportive, although in several cases the spouse left after learning that the partner was HIV positive.

Although there are few studies of the roles played by health-care workers in disclosure practices, one study conducted at an HIV counselling clinic in India found two main patterns of disclosure: voluntary disclosure and disclosure without consent (Chandra, Deepthivarma & Manjula 2003). Within the category 'disclosure without consent', people reported that information regarding their HIV status was disclosed to their friends or family members without consulting them. In most cases, it was health-care workers who disclosed on behalf of patients. Another study conducted in five African countries showed that although people rely on clinics and medical staff to protect information about their sero-status, in some situations medical staff breached that trust and informed others whom they believed needed to be aware of the HIV infections of their clients without asking them for consent (Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, *et al.* 2008). In health-care settings, then, disclosure often turned out to be the choice of health-care workers. Not surprisingly many of the HIV-positive people interviewed for the study reported that they did not like health workers to know their status because they expected them to inform others or to change their attitude towards them (Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, *et al.* 2008).

## Background

At the time of the study, HIV prevalence in Kenya was estimated to be 6.3%, with approximately one and a half million PLHIV (WHO/UNAIDS/UNICEF 2010). Of these about 337,000 were receiving ART and about 700,000 were still in need of treatment (WHO/UNAIDS/UNICEF 2010). In terms of absolute numbers, Kenya was providing more people with ART in 2009 than any other country in Africa except South Africa, having rapidly scaled up access in a short number of years. Access to HIV testing has expanded quickly in Kenya since 2000 when HIV national prevalence rates were at the highest. In 2000, there were only three voluntary counselling and testing (VCT) sites in Kenya, but by 2007 there were nearly 1000 (National AIDS Control Council, Office of the President, Kenya 2008). Kenya has set a national target to test 2 million people annually through various initiatives, including the scale-up of provider-initiated testing strategies and door-to-door testing. In the year 2009, when this study was carried out, more than 4.4 million Kenyans were tested for HIV (one in four of the adult population). The 2008 Demographic and Health Survey (DHS) survey reports that 73.5% and 58.6% of HIV-infected women and men, respectively, have been tested in Kenya at least once in their lives (Kenya National Bureau of Statistics (KNBS) & ICF Macro 2010). This monumental testing and counselling scale-up effort has presented challenges to the existing health structures including, as we demonstrate in this article, the ability of health-care workers to guarantee client confidentiality, leading to instances of non-consensual disclosure.

As part of its massive national effort to scale up HIV testing in Kenya, in 2008, the Kenya National AIDS & STI Control Programme (NASCOP) revamped its national HIV testing and counselling (HTC) guidelines as well as initiated accelerated training programmes for test providers. HIV trainings consisted of a 2-week residential training programme that was offered to a few health-care workers in each health-care facility, who were then expected to pass on the knowledge to their colleagues on the job. Such training appeared to be sufficient for teaching the new guidelines to experienced HIV counsellors, but seemed to fall short when offered to health workers without such experience. The new guideline outlined protocols for the two most common modes of testing in Kenya: VCT and provider-initiated testing and counselling (PITC). While the first mode relies on an individual taking the initiative to test for HIV, the second mode requires a health provider to offer an HIV test. Historically, HIV tests would only have been offered to patients who presented with symptoms associated with HIV, but as the Kenyan government now wants every citizen to know their status, HIV tests are meant to be offered to all patients presenting at public health-care facilities, regardless of reason. As will become evident in the discussion below, the scaling-up of PITC has had specific consequences for disclosure.

All public health-care facilities that provide HTC services in Kenya are ideally meant to follow the national guidelines and the HIV Prevention and Control Act 2006. These require medical personnel to disclose to sexual partners if the HIV-infected client does not disclose after a reasonable time and to

maintain shared confidentiality regarding a patient's HIV status. These guidelines are in accordance with international standards, which reflect a concern for the right of individual privacy as a measure of protection from stigma and discrimination.

Our findings show, however, that health providers at different health facilities interpret national guidelines differently. Concepts such as 'a reasonable time' and 'shared confidentiality' could easily be interpreted differently depending on the contexts. We also found that many health facilities and departments did not even have HIV guidelines available for staff. Despite this oversight, hospital administrators and supervisors rather optimistically assumed that test providers and counsellors routinely observed the confidentiality practices they were meant to have learned during their HIV trainings. As one VCT/PITC supervisor put it:

*You see confidentiality is a must whether for HIV or any other condition and is part of health care providers' training right from college ... they are supposed to maintain confidentiality ... So naturally we are supposed to maintain confidentiality whether it is HIV, Hepatitis ... patients' information must be kept confidential... a patient's file must be kept confidential.*

The findings presented in this article are based on primary qualitative data collected from April 2008 to March 2009 in Kenya's Central and Nairobi provinces to investigate the advantages and disadvantages of emergent forms of testing and counselling, including VCT and PITC.<sup>1</sup> Our main objective was to identify and compare counselling and testing practices in routine settings, paying particular attention to shifts in counselling practices, as well as confidentiality and counselling procedures in non-VCT settings. Our secondary objective was to provide insight to the development of evolving HTC policies and guidelines at international, national, and health facility level. The majority of our research team consisted of anthropologists; we employed a range of ethnographic methods to access multiple viewpoints (policy-makers, hospital administrators, health-care providers, and PLHIV clients) and analysed the data carefully to reach our conclusions. However, this research was also carried out in partnership with clinical doctors and the National AIDS Control Program (NASCOP) and WHO, which meant that our objectives remained largely applied, with a focus on producing results to inform the policy-making process.

## Study participants and methods

A range of ethnographic methods, including participant observation, key informant interviews, in-depth interviews (IDIs), and focus group discussions (FGDs) were used to collect data for this study. The main field researchers in this study had extensive experience conducting qualitative research on HIV in Kenya at the time of the study. In most cases, research was conducted by native Kenyans; none of the interviews were conducted by people who were employed by or in any other way formally connected to a Kenyan health facility. While this was stressed to participants, the fact that research was conducted in the facilities and with

the approval of hospital administration, study participants likely associated researchers with health facility management, which may have influenced their responses. We attempted to counter this by recruiting some HIV-positive participants from community-based support groups. Additionally, since research was carried out in multiple sites (12), we believe were able to overcome biases that might be associated with single site research.

Our sampling strategy was motivated from two perspectives. In terms of facilities visited, the sampling was meant to be representative for provinces where research was carried out. Within the facilities, sampling of participants continued until saturation of knowledge was complete. This approach, which is common in ethnographic studies, continues interviewing people until no new knowledge is being gained or when all possible subjects have been interviewed. In some of the smaller facilities where we conducted research, we were indeed able to interview all health workers involved in providing HIV care.

Six of the 12 health facilities where research was conducted were purposefully sampled. Kenyatta National Hospital and Nyeri General Provincial Hospital were chosen because they are the main public referral health facilities in Nairobi and Central provinces, respectively; Mbagathi is the main district hospital in Nairobi and the main referral hospital for tuberculosis, and Rhodes Chest Clinic is the main tuberculosis health centre in Nairobi; Casino Health Centre is the only public clinic providing specialized care for sexually transmitted infections clinic in Nairobi; and NASCOP VCT offers state of the art care as dictated by national guidelines. The other sites, which were systematically randomly selected, included Embakasi and Njiru health centres in Nairobi Province, and PCEA Kikuyu, Lusighetti Health Centre, Most Precious Blood VCT, and WEMIS in Central Province.

Key informants were purposefully and conveniently selected. In each health facility, one health manager who was also the health facility/programme manager was included in the study. Administrators included station in-charges or Medical Officers of Health. In health centres and VCT centres, the health manager and administrator or in-charge was always the same one person. Staff members were selected from those providing hands-on HIV services who were present at the time of the study.

Hospital managers/health centre in-charges or their deputies present during the study period were recruited into the study. However, at Kenyatta National Hospital, Mbagathi Hospital, and PCEA Hospital, the hospital management chose a suitable representative – normally the head of HIV or HIV Comprehensive Care Centre (CCC). The health facility manager usually served as the entry point to health facilities. At Kenyatta National Hospital, letters were sent out to various departments and clinics; in other health facilities, health management introduced the research team to different clinics and department heads through one of the staff members.

Recruitment of HIV-positive participants for IDIs and FGDs was done with assistance of CCC and Prevention of Mother to Child Transmission (PMTCT) staff. During morning health talks,

health providers introduced the researchers to patients in the waiting areas. The researcher introduced the study and explained the sampling procedures. Based on the total number of patients in the queue during health talks, patients were given successive repetitive numbers; researchers selected one of the numbers and all patients responding to the number were prospective study participants. Selected numbers were different on different. The researcher approached those who were selected and took them through the consent procedure; those who consented participated. Appointments for a later date were made with those who were selected but were in a hurry. Researchers used the same method to select FGD participants, who were always asked to return on a later, set date when a separate interview venue would be made available. Ten PLHIV from the communities around the study health facilities also participated in the study. These were identified with the help of peer educators and health-care providers, and support.

Key informant interviews were conducted among health-care providers engaged in providing counselling and testing services, and leading PLHIV representatives, including support group leaders and coordinators. Additionally, IDIs and FGDs were carried out with PLHIV. We conducted key informant interviews with 31 health-care providers, including nurses, counsellors, administrators, and managers, who were selected from 12 public health facilities (six in Nairobi and six in Central Province) providing VCT and PITC. A total of 27 PLHIV (11 men and 16 women) were interviewed in Central Province and 23 in Nairobi (8 men and 15 women). A total of 48 PLHIV participated in five FGDs – three with men and two with women. These FGDs were conducted with PLHIV selected from HIV support groups. Semi-structured topic guidelines were used to facilitate FGDs and IDIs where participants' perspectives, practices, and experiences with disclosure were explored.

Ethical approval was obtained from Kenyatta National Hospital/University of Nairobi Research and Ethics Committee. No cash or other incentives were provided to key informants. PLHIV IDI and FGD participants were offered 200 Kenyan shillings as compensation for time and transport. In addition, FGD participants were provided with a snack during the sessions.

All interviews with staff, administrators, and health facility management were conducted in English, while most of those with PLHIV were conducted in Kiswahili. FGDs lasted 90–130 min and in-depth and key informant interview sessions lasted 30–60 min. With the permission of the participants, all interviews were recorded. The recorded interviews were transcribed verbatim. All authors attended an analysis workshop and worked together to explore and discuss vertical and horizontal analysis and interpretations to inform the development of a codebook that was used to code the data thematically in tree nodes using NVIVO computer-assisted software. Findings from FGD, IDIs, and key informant interviews from different sources was triangulated and considered for analysis. The study collected data on experiences with counselling, consent, and confidentiality in HIV testing; motivations for uptake of HTC; experiences and practices of disclosure; and social support. For this paper, we limited our analysis on experiences

and practices of disclosure by PLHIV in IDI and FGD and from health-care providers.

## Results

### Three models of HIV/AIDS disclosure

Our findings indicate that despite the difficulties imagined and faced in disclosure, a majority of study participants reported that they believed that disclosure was important at some point in the lives of PLHIV either for preventive or for adherence purposes, or to get psychosocial, moral, or economic support. In this article, we use the word 'duty' because disclosure is often associated with obligation. We argue that in the context of current public health, activist, and clinical medicine, disclosure is couched in normative discourses that indicate a social and moral duty to disclose ones HIV-positive status to sexual partners and caretakers. Although our model demonstrates a sliding scale of disclosure practices from voluntary to obligatory, in fact, we would argue that this normative stance towards disclosure shrouds all acts of disclosure in moral obligation.

As the quotes below taken from PLHIV key informants in Nairobi suggest, people often disclose for pragmatic reasons, when they need help from family members, or when they fear being found out:

*Disclosure comes in stages. If I have wounds, I would not want my children or husband to clean them without gloves; I will have to tell them that I have HIV, since I might infect them also. Nobody with HIV dies without having disclosed to at least one person.*

*Being HIV positive means that you might have to start on ARVs... This is an important time to disclose because ARVs are taken daily and your partner will be suspicious when they see you taking drugs daily.*

In short, few would argue against disclosure as an important step for those diagnosed with HIV. Simply put, if no one knows you are infected, no one can help you. Most PLHIV we interviewed wanted to disclose, but there were deep ambivalences about it, due to feared consequences. There were, however, strong feelings that when done right, disclosing can bring relief to PLHIV as they are no longer left alone to deal with their illness. However, doing it right, that is, disclosing in a manner likely to result in positive benefits for the infected individual is rarely straightforward. This is why we argue the roles played by advice-givers in the context of testing and treatment is so important when it comes to disclosure. While bad advice can lead to isolation and extreme psychological distress, good advice can have a very positive outcome for the PLHIV and his or her loved ones. In what ways do advice-givers engage in the disclosure process? We observed three dominant patterns.

*Voluntary-consented disclosure* occurs when PLHIV inform other people of their HIV status or when they request others to disclose their status on their behalf to other people. Voluntary-consented disclosure also includes the 'test together' tactic commonly used by people in relationships, as well as the use of non-verbal or

silent hints such as taking drugs openly in presence of other people, and by joining, and openly participating in HIV support groups. In this model, PLHIV should only disclose when ready. Health workers and others support PLHIV in deciding when they are ready.

*Involuntary non-consensual disclosure* is revealing someone's HIV-positive status without the person's consent to other people known or unknown to them. It can occur intentionally or accidentally by health-care workers, family, fellow support group members, or anyone else privileged to the information. Most often, it takes place without the PLHIV being aware, and those receiving the information are rarely counselled, even in situations of spousal disclosure, when disclosure may carry implications of infection for them as well. This type of disclosure often leads to undue psychological stress for PLHIV, as well as those receiving the information.

*Obligatory disclosure* occurs when PLHIV are pressured, forced, obliged, or manipulated to disclose their HIV-positive status by a health provider, most often in exchange for enrolment in an ART programme or before being discharged from hospital.

In Nairobi, where VCT has the longest history, consented disclosure appeared to be the norm; in Central Province, obligatory disclosure was a common pattern. In both areas, accidental and intentional non-consensual disclosure occurred. The situations in which these three modes of disclosure occurred are described in more detail below.

### Voluntary-consented disclosure: practices, perspectives, and experiences

In Nairobi's public health facilities, voluntary-consented disclosure was considered to be the standard of practice. Most of the public health providers we interviewed purported to follow the national HTC guidelines. In our analysis, voluntary-consented disclosure comes closest to those guidelines. Patients testing positive at the hospital were expected to disclose when they felt ready to do so and to the person of their choice. As a health-care provider at Nairobi's Mbagathi hospital put it, 'once I know about the patient's HIV positive status, I do not tell their relatives unless the patient wants to disclose'. Further, a majority of the PLHIV we interviewed who received services from Vets and public health facilities in Nairobi reported that, in fact, counsellors and health providers who conducted HTC often encouraged patients to keep their status a secret, and only to disclose to someone who would be expected to keep the secret and give them support. Voluntary-consented disclosure does not pressure people to disclose, but rather encourages them to take time to psychologically prepare themselves for the possible consequences of disclosure.

Generally, PLHIV agreed with this approach, and most reported that, amidst fear and uncertainty, they often took some time to evaluate the best person to tell, carefully choosing the right time and how best to disclose. In an effort to determine how a person would react, PLHIV reported they would listen to what people said when the subject of HIV or PLHIV came up, often

introducing the subject in a round about way or engaging people in generalized discussion about HIV/AIDS.

Overall, it was clear that PLHIV in Nairobi were encouraged to weigh the consequences of disclosure carefully before acting, and evidence suggests that is exactly what they did. When a man in an FGD commented, 'you never know how people react until you disclose', the others in the group nodded in agreement as if this were deep insight. In another example, a still hospitalized woman, weighing the possible consequences of her husband's reaction, said, 'I would like to disclose to him, but let him pay the bills (hospital) first then you (health provider) disclose to him.'

At the same time, some PLHIV felt that health providers often reinforced secrecy around HIV status, which sometimes had a negative impact on disclosure. Perhaps lacking more subtle counselling skills to explain consent, it was common for HIV testers in Nairobi's public hospitals to tell those testing positive that their status was 'their secret', and that it should remain so. One PLHIV from the city reported:

*there is a problem with confidentiality because people gossip about it. It is good to keep it a secret. Within a family they do not disclose yet they are partners. This is because you are told it is a secret when you test.*

Delaying disclosure and living with the secret does allow PLHIV to avoid negative consequences, but many of those interviewed acknowledged that living with the secret was psychologically stressful, leading to isolation and often unwarranted fear, as people tended to imagine the worst-case scenario. Others pointed out that fear of disclosure could interfere with treatment adherence, since people who were hiding their status were also likely to hide their medicines. For example, a young college student from Nairobi explained the stress he felt as keeping the secret from his roommate. Whenever he left the room he worried that his roommate would find clues or ARVs and figure out that he was HIV positive. Finally, many PLHIV were also concerned that delayed disclosure also put sexual partners and caregivers at unnecessary risk. Some we interviewed reported having lived with the secret for a long time, and nearly all felt this had been a mistake, resulting in their living in fear and agony and forgoing any possibility of support from friends and relatives. For both test providers and PLHIV, the act of disclosure was couched in moral obligation – a duty that must eventually be faced. When that duty had been fulfilled, people on both sides of the counselling table felt relieved.

Another area where test providers and PLHIV seemed to agree was that it was always difficult for spouses to inform one another of HIV status. This was especially the case when both were not actively involved in the decision to test together. Perhaps this is why one of the most common ways employed by men wishing to disclose to their wives is inviting them to take a test together. In such cases, men who already know their status re-take the test in the presence of their wife, acting as if it is the first time. This approach allows them to make use of the

skills of the couples counsellor in hopes of negotiating a positive outcome. The test together approach seems to be most commonly initiated by men, as many of those we interviewed suggested that gender norms made it more difficult for women to suggest testing in the context of marriage as it would be interpreted as either a confession or accusation of infidelity. However, it was normally test providers who suggested to men (and women) who were struggling with the fear of disclosure to sexual partners that they could return with those partners and test again as a couple. This disclosure strategy allowed sexual partners to be counselled and tested separately, but the assumption was that each would disclose their results to the other in front of the counsellor. In this way, a form of disclosure that appeared voluntary was so shrouded in accepted norms regarding partner disclosure that, for some, it seemed rather obligatory.

What is evident from our data is that disclosing is difficult for both men and women, even if for different reasons. The following interview excerpt is from a man from Central Province. Both he and his wife were HIV positive and taking ARVs, but for a long time they meticulously kept the secret from each other, fearing the other's reaction. As he told the story, his relief at having been found out was palpable.

*Interviewer: How did you disclose to your wife?*

*Respondent: We accidentally met here (Nyeri Provincial Hospital Comprehensive Care Centre) when we had come for ARVs. In 2000, my wife and I met here; we both had come for ARVs. You know when I tested I never disclosed to my wife, she also tested and never disclosed to me, whereas both of us were on ARVs. So, when ARVs were introduced in this facility and I came here for the drugs, one day I came to the clinic for ARVs and I met my wife.*

*Interviewer: How did you react to each other?*

*Respondent: We just laughed (laughs). Now what could we do? You know both of us left home at different times and no one told the other they were going to hospital. So when I came I saw my wife on the queue. She was surprised to see me . . . I went and greeted her and went back on the queue.*

It seems that the stakes were higher when disclosing to one's spouse for both men and women, largely because of fears of blame and abandonment. In this sense, the fear of disclosure was in fact a fear of the social consequences of doing so. Disclosure to sexual partners calls the morality of the disclosing partner to question, which perhaps also helps to explain why such strong moralistic norms have evolved to encourage disclosure in these contexts and even, in some cases, to justify obligatory disclosure.

Given gendered income inequalities in Kenya, it seemed the big fear for women was the possibility of losing the family breadwinner or being put out of the house. Such fears were intensified when the woman could not claim absolute fidelity and shift the blame to the man. In instances of discordance, when a woman is positive and a man is negative, it is commonly assumed that

the man will abandon his wife. As a female PLHIV in an FGD noted, 'it is women whose lives are on the line . . . my children on the line and my marriage is on the line'. Another woman added:

*I think my husband now wants to leave me and go away . . . he was telling me to leave my daughter with him and then pack my things and go. I think that my husband is also going to run away . . . he is negative.*

And another:

*Men are the ones who are stressing us. I was even telling my husband that we should separate. I told him that if he decides to leave me, my life would still continue. I told him to get a woman who is HIV negative like he is.*

Men also have their fears, however, and also find it difficult disclosing their status to their wives. Though they are more likely to inform their wives than the other way around, it is clear that it is rarely easy for them to do so. The main fear from men was that they would be accused of infidelity and blamed for bringing HIV into the family. As a support group leader put it, 'men fear to disclose to their wives because they know they have been unfaithful'. As one man shared during an FGD in Central Province:

*I was told if I have a wife I should tell her to come for HIV test. On reaching home, it was very difficult for me; I didn't know how to start telling her. How to start telling her was a very big problem because, you know, when you tell your partner they will blame you for being promiscuous. I just didn't know what to do.*

Neither are men exempt from abandonment, especially in the context of discordance. A man in Nairobi reported during an FGD:

*I was admitted in Nazareth hospital. I disclosed to my wife. She was shocked and I have never seen her again since that time . . . while I was at the hospital she packed all her belongings and removed them from my house.*

In fact, women can be quite confrontational when it comes to disclosing. Because their honour is at stake, they are often heavily invested in shifting the blame to men, accusing them of unfaithfulness. Many of the women we interviewed made a point of their own innocence in regard to infidelity. For example, one from Nairobi stated, 'I knew he was the one who brought this because he keeps disappearing to live with other women. I have never had sex with other men.' Another added 'he is the only man that I had ever had sex with, but he was notorious with women . . . even when he was with me he would still stare at other women . . . he has refused to go for HIV test'. In one example, a woman who had tested HIV positive went so far as to incite family members against her husband, declaring that he

had been unfaithful and infected her, a stance that was difficult to maintain when the man tested negative. Not surprisingly, such a confrontational approach rarely yields positive responses from husbands, many of whom simply refuse to test, perhaps less from outright denial than from not wanting to confirm their wife's accusations. This is not to suggest that some men do not suffer extreme shock when hearing of their wife's infection. In fact, in one case, we learned that a man committed suicide upon hearing the news.

Because women fear the consequences of disclosing to their husbands, many never do. Instead they look for an alternative confidant like a friend or a fellow support group member. This seemed to be even more the case in Central Province, where most women reported disclosing to sisters, brothers, parents rather than risk disclosing to their husbands.

### Involuntary non-consensual disclosure

Involuntary non-consensual disclosure can be either intentional or accidental. When it is intentional, it is usually carried out by well-meaning health-care providers or by relatives of the PLHIV without the consent of the patient, and often without their knowledge. While both health-care providers and PLHIV reported examples of this type of disclosure in health facilities in both provinces, it was least likely to occur in Nairobi's public hospitals where most health-care providers tried to adhere to the national guidelines, which do not recommend involuntary disclosure. Health-care providers in Nairobi public hospitals who disclosed to the relatives of a patient without the patient's consent were generally not trained counsellors. Instead, it was either hospital administrators or registrars who did so – often when concerned with securing payment – or medical doctors, who tended to discuss diagnostic tests with the patient with little regard for who else might be present. Doctors were also known to refer the spouses of HIV-positive patients to the VCT centre without telling them why. One VCT/PITC supervisor, dismayed at the behaviour of her MD colleagues, reported:

*Even some doctors have done that. They tell the wife . . . 'Go to the VCT.' If someone tells you go to the VCT, what does that mean? Even our manager and counsellors will tell you . . . people come here crying.*

Health workers also reported that they were often asked by a patient's relatives about the HIV status of the patient, or asked to run HIV tests without the patient's consent. Neither was hospital staff above such behaviour, as it was also reported that staff members were known to approach HIV counsellors to gain privileged information about the HIV status of their own relatives. Health workers who disclosed on behalf of patients in this way often did so rather ambiguously, disclosing 'accidentally on purpose'. This ambiguity gave a degree of power to health workers who believed it was their duty to disclose despite the guidelines. It also, however, gave power to patients, who sometimes reported using similar indirect tactics to disclose to their loved ones, for example, leaving clinic cards or medicines in the open.

Perhaps this is why the PLHIV we interviewed who had direct experience with health professionals disclosing on their behalf without prior consent expressed different opinions towards the practice. While some reported very negative consequences resulting from involuntary disclosure, others maintained that, while it was far from ideal, sometimes it did make their lives easier, relieving them of the burden of disclosing. One 33-year-old man from Central was still quite bitter when we interviewed him, several months after a positive HIV test that was discussed with his mother rather than him. Because the mother knew the health provider they discussed the patient's condition and the mother was the first to receive the test results. When asked whether he received counselling before his test, he replied:

*At the TB clinic they (health provider) counselled my mother instead of me yet I am an adult, I can read, so I heard what they talked about then I was told they have to do the HIV test ... What could I do and the nurse was talking with my mother instead of me. I just left them to talk. I was sort of forced to take HIV test. I didn't like it. They are supposed to give patients options but not to be forced.*

Similarly, an elderly woman reported: 'Now, I am not the one who disclosed. My daughter who took me to hospital was told about my status by the matron.'

The practice of intentional involuntary non-consensual was common in Nairobi's private health facilities, which rarely adhered to the national HTC guidelines. In some instances, this could be explained by the fact that often there were no designated test providers in private facilities, or because those who did exist had very little experience and/or training specific to HTC. In these situations, it was usually left to doctors, who justified such behaviour by saying they were overworked and did not have the time to counsel patients. As a result, they sometimes informed family members or others in the patient's entourage who were then expected to inform the patient. In these situations, it was rare for doctors to establish the patient's relationship with those accompanying him or her, at times leading to disastrous consequences. Several participants in an FGD in Nairobi discussed this practice. One woman explained:

*if you are admitted in the hospital your husband or wife will be called in. The nurse will tell the partner of the patient that you are HIV positive without doing any couple's counselling. The nurse or the doctor does not have any time to talk to you about disclosure. The nurses talk about your status openly ... so everybody around will know your status.*

Another explanation given for health providers disclosing to a patient's entourage was that sometimes the patient was very sick at the time of the test. While this may be understandable, in a setting where health-care workers are overworked they may neglect to counsel the patient once they regain their health. One example offered to us from a VCT/PITC counsellor in at Kenyatta National Hospital reported an extreme case where 2 weeks after the patient regained consciousness no health provider talked to

her about her HIV status. She came to know she was HIV positive by reading her own medical summary sheet, which had been left near her bed. This led to the patient's collapse and a rapid response from the hospital's experienced counsellors, who were left to mend the damage.

Another problem stemming from medical personnel disclosing on behalf of a patient without the patient's consent is that it was impossible for the health-care provider to know if the person disclosed to could be trusted with the secret. Often they told other relatives, leading to both positive and negative consequences. One woman we interviewed disagreed with the practices, but observed:

*my daughter who took me to hospital was told about my status by the matron. My daughter then told my other children and grandchildren my status and told them to accept and support me ... they accepted me, they were supportive. They still support me.*

Not everyone was so lucky, however, as another woman reported that her mother had disclosed her status to her children, instigating and reinforcing stigma.

Overall, little is gained from the practice of intentional non-consensual disclosure, other than perhaps allowing medical personnel to save time and hospital administrators to secure payment for services rendered. In the best case, doctors inform sympathetic family members who are able to provide support to the patient. But even these family members complain as they are expected to provide counselling services to the patient, even in circumstances where the patient's HIV status might point to the likelihood of one's own positive status, as might be the case with a spouse or child. In the worse case, doctors inform family members who are not close with the patient and either abandon them, or actively spread knowledge to the patient's HIV status to others. Neither could be considered a best or even preferable practice.

Involuntary non-consensual disclosure also occurs accidentally. Even in health-care facilities that purport to follow the national HTC guideline, maintaining confidentiality can be a challenge. It is particularly a problem in the context of PITC, where all patients should ideally be offered an HIV test. How is it possible to maintain confidentiality in a crowded health facility, where patients' beds are often very close to each other, screens are rarely available, and family members are expected to carry out nursing duties, such as feeding and bathing the patient, and changing the linens? The problem of confidentiality is exacerbated in teaching hospitals, where students may be expected to present a patient's case during rounds, when he or she is likely to be overheard by other patients. During ward rounds, it is a normal practice for students or registrars to present the medical conditions and treatment of their patients to consultants for review. The students must be loud enough in their presentations to be heard by the consulting physician, but in the process they end up disclosing patients' HIV status to other patients in the ward. Problems also arise due to the sloppy handling of records or during shift changes

when information about patients must be passed on quickly to those reporting for duty. Though medical personnel try to maintain confidentiality by using coded language, it rarely takes long for patients in the ward, especially in wards where in-patients may not be discharged for a while, to decipher the codes. A VCT/PITC supervisor at Kenyatta National Hospital (a teaching hospital) described the problem as follows:

*For example it is very common when we are having ward rounds . . . the doctors go bed to bed to review patients and if they know this is a patient with HIV maybe they feel there is nothing much so they just look at the file and say 'CT' (continued treatment). So after some time patients realize that if the doctor just passes your bed and writes CT you should know that you are HIV positive. (KNH VCT/ PITC supervisor)*

A nurse working in the surgical wards in Central Province indicated a similar problem:

*Confidentiality can also be broken when reading the patients' diagnosis while handing over the report to the next nurse in the shift. You may use a code to say the status but since people are learned nowadays, the other patients will know what you are talking about.*

When confidentiality is broken and a patient's status becomes known on the ward, it is not uncommon for patients to experience discrimination and/or stigmatization from their ward mates. A woman receiving treatment for PMTCT at Kenyatta described her experience:

*I was admitted in the ward, the doctors come in to see me with 25 students surrounding me. The doctor has to give a report to the students and yet the other patients in the ward can hear them. The doctor asks for a report and one of them opens your file and reads, 'This is Mary. She is positive and she is on PMTCT'*

Another woman added, 'When I was in the ward, the doctor asked me whether I had been given some nevirapine.<sup>2</sup> The mother next to me told me that she understands my situation because she is also positive.' When a woman is told not to breastfeed on the wards, other patients and visitors quickly assume the woman must be HIV positive. One woman who had recently given birth told us, 'a nurse shouted, "why are you breastfeeding", and one mother who was HIV positive started talking to me'.

Across the board, lack of privacy was reported in medical and surgical wards where most testing and counselling was done at the bedside. In some cases, two patients shared the same bed and one could not prevent such patients from listening to what was going on. HIV counsellors are aware of the problem and do their best to compensate, speaking in low tones, asking patient's to move to the nursing desk for purposes of counselling, even asking patients to interpret their own test results so that the

result does not have to read out loud. Despite these measures, sometimes there is no choice. As one counsellor explained: 'Sometimes patients may not be able to move so we are forced to do counselling and testing at the bedside and you cannot hinder the patient from the next bed from hearing about the discussion.' Although counsellors do their best to find ways around the lack of privacy, it remains a problem. Privacy is needed to give patients test results, but also to allow patients to ask questions, receive advice, and psychologically process the life-altering reality that comes with a positive diagnosis.

Protocols for keeping client information confidential differ in PITC and VCT. While VCT protocols require that testing results not be linked to a client's name, in PITC, HIV test results are kept in patient files for better health management. This means that anyone with access to a patient's file will have access to his or her HIV status. In most hospitals, patient files are kept in medical wards and outpatient clinics from 8:00 to 17:00. At 17:00 all patient files are collected and taken to a central medical record office. When in the wards and clinics, patient files are only meant to be handled by doctors and nurses on duty, but in practice anyone in a white coat can access the files. While the health providers we interviewed reported being careful in keeping patients files confidential, the PLHIV with experience being treated in hospital to whom we spoke, reported laxity in keeping files confidential in Nairobi, especially during visiting hours. This was a problem because some visitors, eager to know what was wrong with the patient, would try to read his or her file. Others would remove files from nurses' trolleys when they were in the corridors. To protect their privacy, some PLHIV patients reported hiding their files under their mattresses during visiting hours. Similarly, it was observed that some visitors paid keen attention to the treatments administered and, if familiar with treatments for HIV, would be able to guess the patient's status. In many hospitals, it is routine to leave patients treatment on a clipboard that is placed on the bed, making it easy for visitors to access the information. To prevent such inadvertent violations of patient privacy, public hospitals in Central Province now keep patient records and prescriptions at the nurses' station following ward rounds. However, if a patient's visitors are present during ward rounds, which is quite common given that so many nursing tasks fall to a patient's family, they are in a perfect position to overhear the patient's HIV status.

Another practice that may lead to accidental disclosure occurs when patients are discharged from health facilities. It is common to provide a discharge summary sheet to whoever is paying the medical costs at the time of patient discharge. These summaries often indicate the patient's HIV status and advice on follow-up medical care, including ART. One PLHIV in the PMTCT programme at Kenyatta National Hospital shared her experiences with this practice:

*My brother-in-law had meningitis when he was admitted here; he was discharged and given a case summary. My husband read that case summary, even before my brother-in-law had read it. And that is how my husband knew that my brother-in-law was HIV positive. When I was discharged here myself, my husband was given the case summary and*

my sister-in-law also wanted to look at it . . . when you are being discharged from hospital, the person who has come to pick you is the one who is given your documents.

### Obligatory disclosure: no disclosure? No ART and no discharge!

Contrary to Kenya's HTC guidelines, which do not encourage forced or obligatory disclosure, in the context of scaling-up ART to public facilities around the country, it has become quite common for those facilities to develop their own treatment protocols, requiring those testing positive to disclose to someone before being put on ARV treatment. As the objective behind this is to encourage adherence to treatment, PLHIV are also expected to bring this person, known as a treatment supporter or treatment buddy, to the adherence counselling sessions they are required to attend prior to starting ARVs. Even those not yet requiring treatment often find they will not be discharged from hospital until they have disclosed to caregivers. This is because many of the health workers we interviewed believed that caretakers had the right to know a patient's HIV status so they could protect themselves by wearing gloves.

A health provider in charge on an ART programme in Central Province explained the protocol in place for disclosure to us:

*But the first thing, when one tests HIV positive, you encourage them to disclose to their next of kin or to their friends or relatives because of the issue of long term ART. And of course if they have disclosed you enrol them in the ART program. It must (stressed) be after disclosing that we enrol them on ART program. If you do not disclose, no enrolment unless is emergency like PMTCT. You see for mothers who are pregnant and they turn HIV positive, you cannot tell them it is a must they disclose to their husbands or to the next of kin to get ARVs because you want to prevent infection to the child.*

Here, the nurse points to an important exception to obligatory disclosure. In the context of PMTCT, women are encouraged to disclose, but not required to do so before treatment can be initiated. This is because the sooner the woman is started on treatment the less likely she is to pass on the infection to the foetus in the womb. Although the nurse spoke about obligatory disclosure as routine procedure, it was also clear from the interview that it was not uncommon for people to resist, to take their time disclosing, or try to find a way around the system. She continued:

*If a person has not disclosed . . . we continue counselling them and showing them the importance of disclosure. We wait for them to disclose . . . it does not matter how long they are going to take even if it takes two weeks or more then they come back when they have disclosed . . . But sometimes we tell them to disclose and they come tell us they have disclosed while they have not, so, on the day of enrolment, we normally demand they come with the next of kin they have disclosed to together. And we ask the next of kin what the client told him or her. From the next of kin's response then you are able to know whether they properly disclosed and we enrol them.*

Although obligatory disclosure is meant to enhance treatment adherence, in practice, both health workers and PLHIV talk about it as if it is a barrier to accessing ARVs. Basically the message is: 'no disclosure, no ARVs'. We found that in Central Province it is mandatory that PLHIV produce a treatment buddy before being enrolled in an ART programme. This was in contrast to what we found in Nairobi, where both health providers and support groups oppose obligatory disclosure. The interviews and FGDs we held with PLHIV in Central Province provided abundant evidence that requiring a treatment buddy was common practice. One reported 'he (the doctor) conducted the test, I tested positive again and he referred me to another doctor, who told me I have to go with someone to be initiated on ARVs. The following day, I came with my wife'. Another added that as he had served as treatment buddy for someone else, the experience seemed quite normal.

For some, however, the experience proved traumatic and did not always lead to the support imagined by those who put the requirement in place. The quote below from a Central Province woman demonstrates some of the problems that arise from obligatory disclosure:

*First, I didn't want people to know I am HIV positive. But what I really did not like was being told to disclose to someone before being started on ARVs. I was told I have to tell someone I am HIV positive. It was a painful decision, but I ended up telling my aunt . . . she was very shocked. I went to her house and told her I wanted to see her on some private issue. We went to her bedroom and I told her I was tested HIV positive and they needed someone who knows about my status as a guarantor at the clinic before I am started on treatment. She was shocked and was quiet for some time. I told her that I was not going to disclose to her but the clinic required that I disclose to someone and go with the person to the clinic before I was started on ARVs. She still kept quiet, and then I asked her if she would agree to come with me to the clinic. She did not talk and I left. But a few minutes after arriving at my home, my aunt came to my house and told me she had accepted to come with me to the clinic.*

Another woman summarized her experience when a doctor forced her to disclose to her sister who had brought her to the hospital:

*I decided to disclose because there was a time I had kept my HIV status a secret then I got very sick . . . I was bedridden, so, one of my sisters came to take me to another hospital. When we reached that hospital, my sister was asked if she didn't know where such people are taken for treatment. My sister asked the doctor, 'Where are they taken?' And the doctor told me, 'Why don't you tell your sister where you should be taken for treatment?' I told my sister and she really cried. Not even my mother knew about it.*

As was the case with voluntary-consented disclosure, problems also arise when people are obliged to disclose to their spouses.

While there is no requirement that one discloses to a spouse specifically, for some, there is no other choice. For others, the problem arises when they seek treatment far from home, something common among people who choose to conceal their status from people in their community.

### Disclosure for protection of caregivers and sexual partners

In addition to being obliged to disclose one's HIV status to access ART, PLHIV are also often required to disclose to those who will care for them upon discharge from hospital. If a patient is unable to disclose, then health providers feel obliged to disclose to their caregivers on the patient's behalf, regardless of whether the patient agrees. According to health providers, caregivers should be protected from being infected while caring for a patient and encouraged to wear gloves. While admitted in the ward, HIV-positive patients are given time to disclose to their caregivers. If by the time of discharge patients have not yet disclosed, however, the health provider will. When asked in what circumstances a health provider might disclose on behalf of a patient against the patient's wishes, a nurse in charge of a medical ward in Central Province gave the following example:

*The challenge is that many patients do not want their relatives to know their HIV positive status, and maybe that patient is very sick and needs to be taken care of by the relatives. So, it is a problem because we have a patient who is very sick, cannot take care of herself and doesn't want her relatives to know. So, you wonder how she will be taken care of and you cannot just risk discharging her when the relatives have not been told. So, finally we tell close relatives.*

While health providers often maintained that disclosing to the family also helped the patient, as they would be able to get the support they required, they also recognized that, in practice, disclosing often led to problems. One health-care worker observed that sometimes once disclosure is done, those who are disclosed to do not like to wash the utensils of their patients after feeding them. In another example, once a mother was told the status of her 10-year-old son she abandoned him at the hospital.

In addition to PMTCT, the only other area where health providers routinely made exceptions to the obligatory disclosure rule was when the only available person to disclose to was a spouse or sexual partner. In such cases, the health-care provider would suggest that the couple test together, so they could go through couple's counselling, but where the partner declined the HIV test, then no disclosure was done. The reason for this sensitivity was that health providers feared that disclosing to partners could lead to the break-up of marriages and domestic violence, actions for which they might be held accountable. According to a health-care provider from Central Province:

*For the couple it is very difficult because of the sensitivity, and sometimes we just let them go home without disclosing, because sometimes you try to counsel the husband but the*

*husband will decline ... so, if the husband refuses to take the HIV test, you do not disclose the wife's status.*

The issue is so sensitive that it seems that even the test together approach does not always work, especially in cases of discordance. The same health provider continued:

*Recently we had a case of a woman in her fifties who came with a stroke but the doctor decided we offer her an HIV test and it turned positive. So, the husband came, we counselled him and he accepted to take the HIV test. He was negative and the wife was positive. And the man said, 'this is the end, I know myself ... I have never moved out and I have really taken care of this woman, I have even employed house help to help her ... where did she get it from?' The man was very annoyed and just went away. He later came to pay for the wife but we don't know what happened thereafter.*

Although obligatory disclosure helped some PLHIV to disclose and thus get some form of support outside of the medical arena, overall, the PLHIV we interviewed felt the system was far from ideal and that it would have been helpful had they received more advice on how to disclose. Those who had been obliged to disclose before they were ready reported feeling forced or manipulated into disclosing. Some also said that the experience made them hesitant to disclose to others. Others said they felt short-changed when health providers disclosed on their behalf without first seeking consent. In fact, many of the married people we interviewed who had disclosed to their spouses had found them to be supportive, while those who had been encouraged to disclose to another relative or friend to serve as treatment buddies, often found they had very little to do with treatment adherence. Overall, PLHIV agreed that they should be given time to negotiate disclosure to minimize psychological stress and other negative consequences, as well as to improve the likelihood of disclosing to those most likely to lend the desired support, be it for adherence, economic reasons, or simply an understanding ear.

### Discussion

Our findings indicate that in Kenya disclosure remains a challenge for HIV-positive people and the health workers who take care of them. Further, these challenges are only intensified in the context of treatment and PITC scale-up. Although national guidelines are in place to promote voluntary-consented disclosure, in practice, health workers routinely disclose on behalf of patients without their consent, whether intentionally or accidentally. In the defence of the health workers, this was often done only after patients failed to disclose after the patient had been given time to disclose on their own. In addition, we observed the practice of obliging PLHIV to disclose before being enrolled in ART programmes or being discharged from hospital is considered acceptable protocol in health facilities in Central Province. Further, such obligation, or duty, to disclose, while framed as a strategy to improve care and adherence support in the home, is

also often couched in moral terms about protecting caregivers and sexual partners.

In the context of the everyday provision of HIV services, health-care workers struggle with dilemmas around disclosure, often arguing that, as experienced practitioners, they should be permitted to disclose an individual's HIV status in certain circumstances. While very few health-care workers argued for an either-or approach, those working in major referral hospitals, where monitoring by management was routine and where training was regularly offered, most often followed the national guidelines despite any misgivings they might have had. This was not because they agreed completely with the guidelines, but rather because they feared reprisals from management. In smaller hospitals, however, especially those in more rural areas, there was less monitoring and less training, which in practice allowed those providing HTC services a certain degree of latitude when interpreting the national guidelines. In these settings, health-care workers freely and without consequence usually followed what they saw as their own duty to disclose on behalf of patients in certain circumstances.

While there is no clear solution to the disclosure dilemma faced by health-care workers when PLHIV refuse to disclose to those who will take care of them once they are discharged, it seems that most often, little is gained when health workers disclose on behalf of PLHIV without their consent and, in fact, the result can be negative for the patient as well as his or her family. Delivering an HIV-positive test result, whether it be to the person taking the test or their loved ones, is an emotionally fraught event that should take place in a private setting, where people feel free to discuss the diagnosis. An experienced counsellor can often make the process easier for everyone involved, especially if adequate time is taken.

Given the context of rapid treatment and testing scale-up, however, it is rare for those testing in health facilities to be afforded this standard of care. Many test providers have very limited experience delivering positive test results and the 2-week training offered by the Ministry of Health, while a step in the right direction, does not provide trainees with such practical experience. Health facilities that employ experienced counsellors are able to call on them to deliver positive results, but the fact is there are far too few experienced counsellors to meet the demands of so many positive test results. To address this gap, greater attention should be given to the training and ongoing supervision of HIV testing counsellors. In addition to classroom training, counsellors would benefit greatly from completing practical training under the guidance of more experienced counsellors.

Kenya's national HTC guidelines follow the international standard in regard to requiring consent, counselling, and confidentiality in the context of HIV testing. This approach ensures that PLHIV have the power to decide about disclosure. Unfortunately, the existence of guidelines does not ensure they will be followed. This is especially the case when health facilities do not have the resources to adhere to the guidelines or when competing hospital policies encourage a contradiction of the guidelines, as is often the case with PITC and unintentional disclosure on the wards where

confidentiality remains a major challenge. One means of addressing this problem would be establishing confidential counselling rooms in each ward. These spaces could be used for discussing HIV diagnoses, as well as other sensitive issues that patients may wish to keep private. Counselling done at bedside should be done with the utmost care.

Obliging PLHIV to disclose their status before enrolment in treatment programmes is both unethical and unproductive, as there is little if any evidence to suggest that the treatment buddies actually lead to improved adherence rates. Requiring a patient to undergo forced trauma at the moment when they are clinically most in need seems difficult to justify. The practice of obliged disclosure reflects a lack of training of the front-line workers and the hospital administrators who participate in testing and treatment scale-up. It occurs in facilities where testing has been recently introduced. Although there is nothing in the national guidelines to encourage forced disclosure, it is commonly practised in health facilities. Greater effort must be made to address the gap between policy and practice, especially outside of Nairobi, where the supervision of counsellors and others providing HIV testing services is minimal at best.

Solutions to disclosure-related challenges might include health facilities and HIV support groups working together. This might include allowing HIV-positive people with counselling experience to work in health facilities as peer counsellors, delivering HIV-positive test results, and follow-up counselling.<sup>3</sup> At the very least, health facilities should have a referral system in place to provide information about support groups to those testing positive. Another practice, which seems to alleviate the strain of disclosure, is testing together – for couples and whole families. This may take place in health facilities, where the family members of an inpatient are offered testing and counselling services together with the patient, or through home-based testing. Given the ample evidence in our data of the difficulties people have disclosing to their spouses, it would seem wise to promote practices that make the process easier. However, facilitating disclosure in such situations can be tricky business and it should not be assumed that counsellors are able to do this without sufficient and appropriate training and experience.

The findings of this study may have broader application beyond Kenya as countries increasingly undertake massive efforts to scale up access to ARV treatment and, consequently, HIV testing. Even the strongest public health proponents of policies and practices to normalize HIV testing as a key first step to fighting HIV in Africa have cautioned about challenges related to disclosure and confidentiality (i.e. De Cock, Bunnell & Mermin 2006). As global policies shift towards the promotion of provider-initiated testing, whether in health facilities, mobile outreach clinics, or door-to-door campaigns, efforts must be made to define suitable best practices that balance human rights and public health perspectives in relation to disclosure.

## Notes

1. Data presented are part of a larger study on HIV testing in counselling in Kenya, Uganda, Malawi, and Burkina Faso

(The Multi-Country African Study on Testing and Counseling for HIV) and funded by the National Institutes of Health (2007–2012). International research partners include the University of Amsterdam, University Paul Cezanne-Aix-en-Provence, and the WHO. Key partners in Kenya included NASCOP and Kenyatta National Hospital.

2. A medication given for PMTCT.
3. At the time of writing, a programme using PLHIV peer mentors on the wards in PITC settings was being trialed at Kenyatta National Hospital in hopes of developing a framework for scaling up to national level. While many similar programmes have been utilized to employ trained PLHIV to provide services to other PLHIV, this is the first time such an initiative has been led by the Kenyan government.

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