Published in final edited form as:

Glob Public Health. 2014 ; 9(6): 723–739. doi:10.1080/17441692.2014.920039.

Quality, not just quantity: Lessons learned from HIV testing in Salvador, Brazil

Sarah MacCarthy^{a,*}, Jennifer J. K. Rasanathan^b, Ines Dourado^c, and Sofia Gruskin^d

^aAlpert Medical School of Brown University and Miriam Hospital, Providence, RI, USA

^bDepartment of Family and Social Medicine, Montefiore Medical Center, Bronx, New York, USA

^cInstitute of Collective Health, Campus Universitario Canela, Salvador – BA, Brazil

^dProgram on Global Health and Human Rights, Institute for Global Health, University of Southern California, Los Angeles, CA, USA

Abstract

Studies have demonstrated that an early HIV diagnosis is a critical first step toward continued engagement in care. We examined HIV testing experiences in Salvador, Brazil, to understand how a focus on quality services can inform service provision more generally in the post-2015 global health agenda.

Seventeen semi-structured interviews were conducted with HIV-positive pregnant women in Salvador, a large urban centre of northeast Brazil. Interviews were transcribed, translated, and coded for analysis. Deductive codes confirmed factors identified in the literature review. Inductive codes highlighted new factors emerging from the initial coding. ‘Quality’ was defined according to global and national guidelines as HIV testing with informed and voluntary consent, counselling, and confidentiality (3Cs).

No pregnant woman experienced all elements of the 3Cs. Three women did not experience any informed and voluntary consent, counselling, or confidentiality. Few women provided consent overall and none received pre-test counselling. Post-test counselling and confidentiality of services were more consistently provided.

This study suggests that testing in Salvador—the third-largest city in the country—is not of the quality called for by global and national guidelines, despite the fact that HIV testing is being routinely provided for HIV-positive pregnant women in Brazil. Going forward, additional clarity around the 3Cs is necessary to improve how the quality, not just the quantity, of HIV services is measured.

Keywords

HIV/AIDS; HIV testing and counselling; human rights; Brazil; linkage to care

*Corresponding author. sarah_maccarthy@brown.edu.

Institutional Review Board Approval: The study was approved by an Ethics Committee at the State Secretary of Health in Salvador, Brazil, and by the Harvard School of Public Health in Boston, USA.

Introduction

The Programme of Action (PoA) for the International Conference on Population and Development (ICPD) made substantial gains in clarifying the reproductive and sexual health and human rights for women and men globally (United Nations, 1994, annex). Despite its unprecedented recognition of reproductive and sexual health rights, HIV and human rights activists have critiqued the minimal attention paid to HIV in the initial PoA and called for a greater emphasis on the integration of HIV/AIDS prevention, treatment, and continued care with comprehensive sexual and reproductive health services. Indeed, its initial recommendation for ‘responsible sexual behaviour, including voluntary [sexual] abstinence’ (United Nations, 1994, para. 8.31) for the prevention of HIV infection proved insufficient: the impact of HIV on the ability of individuals to realise their reproductive and sexual health and human rights could not go unnoticed, and subsequent efforts addressed HIV more comprehensively.

Today, 35.3 million women and men are living with HIV globally, although less than half know their HIV status (UNAIDS, 2013). In low- and middle-income countries, an average of 34% of HIV-positive women and men who know their status are receiving lifesaving antiretroviral medications (ARVs) (UNAIDS, 2013). Hence, while considering ICPD beyond 2014, it is clear that further advances in the discussion around HIV are needed to effectively address the HIV epidemic. At the same time, the political and economic landscape of global health is shifting to a post-2015 agenda focused on improving health systems as well as working to meet the demands of non-communicable diseases and redoubling efforts toward unmet Millennium Development Goals (MDGs), including ‘the provision of universal access to sexual and reproductive health services’ (Task Team for the Global Thematic Consultation on Health in the Post-2015 Development Agenda, 2013). The health of women and men is unlikely to improve, however, if the health services provided are not also of sufficient quality.

To consider the additional health benefits that might be gained by considering *quality* in addition to the availability of a particular health service, we examine HIV testing in Brazil, where ARVs are universally available. Specifically, we explore the evolution of HIV testing policies globally and in Brazil, discuss the essential components of quality HIV testing as defined by global and national guidelines, and evaluate the combined implementation of all 3Cs during HIV testing from women’s perspectives in Salvador, Brazil. In so doing, we aim to further the conversation on HIV testing while also encouraging the current focus on the universal provision of services to also monitor the *quality* of health services provided.

Background

Studies have demonstrated the importance of early HIV diagnosis, treatment, and retention in care to successfully suppress HIV viral load (Cohen et al., 2011). HIV testing is also the first crucial step in enabling HIV-positive women to take antiretroviral prophylaxis in order to substantially reduce the risk of vertical transmission from mother to child if they become pregnant (Jamieson et al., 2012). Despite international, national, and community-led efforts,

an estimated 50% of individuals who may have been exposed to HIV have actually been tested (UNAIDS, 2012).

Low testing rates, in part, reflect ongoing HIV-related stigma and discrimination. Since HIV testing kits first became available in 1985, individuals discovering their HIV-positive status—including pregnant women—have been subject to social abandonment, violence (Maman et al., 2002), and loss of economic support (Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, 1996). UNAIDS subsequently worked with the Office of the High Commissioner for Human Rights to develop the International Guidelines on HIV/AIDS and Human Rights in 1996 to inform governments and others how best to respect, protect, and fulfill the human rights of women and men discovering their positive HIV status (Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, 1996). In the interest of protecting women and men newly diagnosed with HIV, UNAIDS advocates for quality HIV testing conducted with ‘the 3Cs’: *consent* that is informed and voluntary, accompanied by pre- and post-test *counselling*, all of which—including test result disclosure—are to be *confidential* (Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, 1996). The 3Cs are recognised as the key components comprising quality HIV testing, reaffirmed in guidance from global organisations such as UNAIDS and WHO in 2004 (UNAIDS & World Health Organization, 2004), 2006 (Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, 2006), and again in 2007 (World Health Organization & UNAIDS, 2007).

In 2013, testing guidelines were expanded to include two additional components: going forward, quality HIV testing services must also ensure that individuals receive the ‘correct test result’ and are ‘[connected] to care, treatment, and prevention services’ (World Health Organization, 2013). These additional components make explicit the crucial follow-up after post-test counselling: women and men who are linked to care have significantly better health outcomes and substantially reduced risk of transmission to their sexual partners (or infants) than those who are not linked to treatment and care (Cohen et al., 2011). While these additions further emphasise the importance of quality HIV testing, this article focuses only on the provision of the original 3Cs.

In Brazil, voluntary counselling and testing centres were established in 1987 to provide free, confidential, and anonymous testing. By 1997, the same year that treatment was made free and universally available in the country, the Ministry of Health released HIV testing guidelines that emphasised consent, counselling, and confidentiality in response to reported consequences for individuals discovering their HIV-positive status. In 2006, guidelines specific to pregnant women were published, similarly reinforcing the 3Cs (Ministério da Saúde, Secretaria de Políticas de Saúde, & Coordenacao Nacional de DST e Aids, 2006). Most recently, a training manual was developed in 2008 for health care professionals to improve the likelihood of the 3Cs being provided to patients undergoing HIV testing (Ministério da Saúde, Secretaria de Políticas de Saúde, & Coordenacao Nacional de DST e Aids, 2008).

National surveillance reports estimate that 77,066 pregnant women were HIV-positive between 2000 and 2013, with a 26.3% increase in the rate of HIV detection among pregnant women in the same time period. Most of these women lived in the southeast (41.7%) and south (31.3%). Unfortunately, HIV incidence appears to have increased from 2011 to 2012 in most states (Ministério da Saúde, Secretaria de Vigilância em Saúde, & Departamento de DST, Aids e Hepatites Virais 2013).

Given universal access to ARVs and the associated opportunity to improve pregnancy outcomes when HIV-positive women know their status and are linked to HIV treatment and care, we sought to examine pregnant women's experiences with the receipt of quality HIV testing services in Salvador, the third-largest city in Brazil.

Data and Methods

Qualitative data were collected in semi-structured interviews. Employing a convenience sampling strategy, women with scheduled appointments at the State Reference Centre for HIV (SRC) were approached by interviewers. In total, 30 women were interviewed. However, the data analysed for this article was restricted to women who learned of their HIV-positive status during a pregnancy within the past 5 years and who were receiving HIV/AIDS treatment and care at the only SRC for HIV/AIDS in Salvador, Brazil. Therefore, the data from 17 HIV-positive women were considered in this analysis.

All interviewers received training related to HIV/AIDS, and interview scripts were extensively field-tested. One researcher (SM) met weekly with study staff to review pilot interviews, ensuring the clarity of questions asked and the quality of information collected. The interviews were conducted between November 2010 and March 2011.

All women who gave informed consent to participate were interviewed in a private room. All interviews were conducted individually and recorded. They were later transcribed and professionally translated from Portuguese into English for analysis.

Transcripts and related field notes were reviewed and researchers identified deductive codes following a review of the literature. Next, NVivo software (QSR International) was used to deductively code key themes identified in field notes, transcripts, and the literature review. Inductive codes were also created to include factors that were not previously identified in the literature. As categories emerged, data was pulled from relevant categories and compared. The relationships among categories were specified and outliers were explored. Finally, exemplars were identified to further illuminate the key themes emerging from each interview. Data was reviewed and discussed by two authors (SM and JR), and conclusions were reviewed by an additional author (ID) to ensure cohesion with the cultural context of Brazil.

The primary outcome of interest is the experience of all 3Cs in combination by pregnant women, with secondary interest in the receipt of each 'C' individually. Recognising that there is a vast body of literature on each 'C' in the context of other diseases, for the purpose of this analysis, the definitions of each 'C' stem from an assessment of global and national guidelines on HIV testing in particular. Where definitions of the 3Cs lack sufficient

specificity, we developed interpretations of the 3Cs that are based on the guidelines; the synthesised definitions for each ‘C’ are briefly reviewed below.

For each ‘C’ we opted to assess whether or not it occurred. Women were considered to have given ‘informed and voluntary consent’ if they reported agreeing to test for HIV or requesting an HIV test. Women who only learned that they had been tested for HIV when they were told they were HIV-positive were reasoned to have not provided informed and voluntary consent. Pre- and post-test counselling were assessed as having occurred or not: women were considered to have received pre-test counselling if they reported having had either individual or group counselling prior to an HIV test, and post-test counselling was considered to have occurred if a woman reported speaking with a provider individually about her test results once the test result was known. Comprehensive counselling included receipt of both pre- and post-test counselling. Finally, a woman was considered to have experienced full confidentiality if she trusted that her test results would not be shared with other non-health care providers and received her HIV status in a private physical space. In the absence of a standardised set of minimum criteria for confidentiality, we prioritised participant perceptions of confidentiality (rather than confidentiality as reported by providers) because of their greater impact on patient willingness to participate in continued treatment and care.

Results

Table 1 summarises the demographic characteristics of participants, and Table 2 summarises women’s experiences receiving the 3Cs. No woman interviewed experienced all of the 3Cs in combination, and three women did not receive any of the 3Cs as they are defined here. As depicted in Table 2, 13 women did not provide consent, no women received comprehensive counselling (received pre- and post-test counselling), and 12 experienced full confidentiality (reported trust in their provider and received their results in a private space). Quotes representing women’s experiences of receiving—or not receiving—the 3Cs are included below to further illustrate key findings.

Key findings: combined consent, counselling, and confidentiality

None of the women interviewed experienced all of the 3Cs in combination when undergoing HIV testing. Further, three women did not receive any of the 3Cs during HIV testing.

Two of the three women who did not receive any of the 3Cs underwent ambulatory prenatal HIV testing but were informed of their HIV-positive status in the absence of confidentiality at a maternity hospital while in labour.

One woman who was informed of her HIV status in labour had a negative HIV test during prenatal care. When she presented to the maternity hospital in labour, she neither consented to testing or received counselling when she underwent repeat testing:

Interviewer ‘But, did the doctor tell you [about being tested]? ... Did he advise you in any way? Did he say that you could refuse ... testing?’

Woman ‘No ... It was already done. They came and said, “Look mother, I have a request here to run some tests” ... I didn’t even know what the tests were. Then, done, they did it. Next thing that I heard was [the result]’.

When she was told she was HIV-positive, the only information she was given by the doctor was that she could not breastfeed, and she reported fearing that people from the health centre would learn of her HIV status on those grounds.

The other woman who received her results during labour similarly underwent prenatal HIV testing (without consent or pre-test counselling) and did not receive her test results at that time (no post-test counselling). When she arrived at the maternity hospital in labour, one of her health care providers said,

‘We did the HIV test and [you] tested positive... . And our concern is not with [you]. Not even with [your husband]... . It is with the child’.

She noted that the health care professional made few provisions to keep her HIV status private at the maternity hospital.

Another woman who underwent prenatal care reported that she ‘asked [what the test was for and was told] “It’s for prenatal”. That’s it’. She did not give informed consent, did not receive pre-test counselling prior to learning that she was HIV-positive, and she stated, ‘I do not trust [the health providers]... . Not there [where I was tested.]’ Although she later received post-test counselling and support at the SRC, she did not give consent, experience confidentiality, or receive pre-test counselling (and therefore did not receive comprehensive counselling).

This woman’s experience most closely resembles the majority of the study participants, in that most women did receive one or two—but not all—of the 3Cs during HIV testing.

Key findings: 3Cs individually

When each ‘C’ is considered individually, additional gaps in their implementation appear. As depicted in Table 2, 13 women did not provide informed and voluntary consent, no women received comprehensive counselling (both pre- and post-test counselling), and 12 experienced full confidentiality (reporting trust in their provider and receipt of their results in a private space). Supplementary quotes regarding consent are included in Table 3 and Table 4 regarding counselling, and in Table 5 regarding confidentiality.

Informed and voluntary consent—Overall, only four pregnant women gave informed and voluntary consent to undergo HIV testing, two of whom had HIV-positive partners. Among those who did provide consent, two women requested an HIV test and two women did not opt out of testing when it was offered to them. All of these women were tested in different locations during prenatal care.

Thirteen women did not provide informed and voluntary consent to testing, and only discovered they had been tested for HIV when a health professional told them they were

HIV-positive. Like the woman who was retested while in labour, one participant's experience is presented as follows:

Interviewer 'And then, didn't [the health care professional] also ask you if you [agreed to an HIV test] ... that it wasn't mandatory, that if you wanted you could refuse?'

Woman 'No'.

Interviewer 'Didn't he explain anything?'

Woman 'No'.

When asked specifically about her HIV testing circumstances, one woman said, '[The health professional] gave me the paper, I signed it, all very well. But I didn't know what had happened'. As such, there are varying degrees of consent, and concrete definitions of 'informed' and 'voluntary' remain elusive in practice.

Comprehensive counselling: pre- and post-test counselling—Although 12 women received post-test counselling, no one received pre-test counselling. Because both pre- and post-test counselling are essential for comprehensive counselling, it was determined that no pregnant woman in this study experienced comprehensive counselling.

Almost all women described the moment they discovered their HIV status as devastating to their sense of self, and women who received post-test counselling expressed the importance of the support they received from their post-test counsellor. For example, one respondent recalls:

'[The doctor] talked to me, [saying] "No. This is not the end of the world". Then he started telling me of people ... that already had [HIV], that ... "they have a normal life, they take care of themselves". Then he explained that I had to be extra careful'.

Five women did not receive post-test counselling. Three of these women were tested in maternity hospitals at the time of labour, and two underwent testing during prenatal care in a hospital setting.

Full confidentiality: receiving HIV status in a private space by a trusted provider—Overall, 13 women reported trusting their provider to keep test results private and 14 women received their HIV test results in a private space, but only 12 women reported both elements essential for full confidentiality.

Some women reported clear examples of breached confidentiality. One participant, for example, recalled the lack of privacy due to the actions of the health professional and the limits of the physical space:

Woman '[There were] two women next door and [my husband] by the table. [One woman said] ... "You will be admitted as HIV-positive, you know?" [The doctor] and a lot of trainees [were there]... Everyone still and listening ... I don't know if I'm wrong thinking

this... I just think ... the right thing was for [her] to call me in a [private room for this interview] ... Just me and my husband ... [not in a full room]’.

Having been told her HIV status in a room full of people (not all of whom were health care providers), this woman’s experience demonstrates a loss of provider trust, the limitations of physical space, and an example of how confidentiality might have been maintained in practice.

Discussion

Despite global and national guidelines calling for the combined implementation of the 3Cs during HIV testing, none of the pregnant women in this study experienced the combined 3Cs, and three women did not experience any of the 3Cs at all. Considering each ‘C’ individually, few women provided informed and voluntary consent and no one received pre-test counselling. In contrast, post-test counselling and confidentiality for HIV testing were provided more often than not, although they were still provided inconsistently. The hospital environment in particular may pose challenges to providing counselling and full confidentiality, but it continues to be a common place for learning the result of an HIV test. The qualitative data presented here suggest that HIV testing among pregnant women in Salvador occurs with insufficient and inconsistent attention to the 3Cs and cannot be characterised as quality testing, even when assessing for the occurrence—rather than the specific components—of pre- and post-testing counselling.

To our knowledge, six studies have previously evaluated receipt of the 3Cs during HIV testing (individually, not combined), only one of which considered pregnant women specifically (Angotti, 2010, 2012; Angotti, Dionne, & Gaydosh, 2011; Evans & Ndirangu, 2011; Hardon et al., 2011; Hardon, Vernooij, Bongololo-Mbera, Cherutich, & Desclaux, 2012; King, 2014).

Despite the unique challenges of providing informed consent during labour and the reduced implementation of the 3Cs in maternity hospitals (documented elsewhere and suggested here) (Angotti et al., 2011; Njeru, Blystad, Shayo, Nyamongo, & Fylkesnes, 2011; Ujiji et al., 2011), advocates of neonatal health increasingly promote HIV testing during labour and delivery (Armstrong, 2008). Two women in this study described their HIV testing experiences during labour, noting the lack of informed consent, pre- or post-test counselling, or full confidentiality at the time of status disclosure. It is possible that the quality or extent of services provided is routinely compromised by the competing urgency to begin ARV treatment for a HIV-positive woman in labour in order to prevent vertical transmission. More research is required to understand the ways in which, under these circumstances, HIV testing can balance the health needs of pregnant women both during and after pregnancy with the wish to prevent vertical HIV transmission.

Similarly, where ARVs to prevent vertical transmission are available, voluntary consent to testing has been limited (Bell, Mthembu, O’Sullivan, & Moody, 2007; Groves, Maman, Msomi, Makhanya, & Moodley, 2010; Rennie & Behets, 2006) in both high- (Guenter et al., 2008; Halpern et al., 2007; Sherr, Bergenstrom, & Hudson, 2000) and low-resource settings

(Abdool Karim, Abdool Karim, Coovadia, & Susser, 1998; Siziya, Muula, Rudatsikira, & Mataya, 2008; Ujiji et al., 2011), with the consequence that women feel obligated to accept HIV testing regardless of their wishes, out of fear that refusing testing will compromise the care they receive. Most recently, however, Obermeyer, Verhulst, & Asmar (2014) published an elegant mixed-methods analysis of consent to HIV testing in four African countries. The authors reported challenges in defining what constitutes informed and voluntary consent and found substantial differences between quantitative and qualitative assessments of consent, nonetheless concluding that study participants in fact had a considerable degree of agency in deciding whether or not to test for HIV (2014). Shifting to Brazil, a population-based cross-sectional study of postpartum women in 12 cities found that 92.5% of women agreed to HIV testing but that 37.5% were not informed that they could refuse the test (Veloso et al., 2008). In our study, however, informed consent for HIV testing was obtained by less than a quarter of study participants, two of whom voluntarily opted into testing (and as both of them had HIV-positive partners, they may have been aware of their increased risk). Taken together, these studies show that globally there are variable rates of consent and challenges in articulating what is 'informed' and 'voluntary' in the context of HIV testing.

Even when consent to testing is not fully informed or voluntary, pre- and post-test counselling play an important role in connecting HIV-positive women with treatment and care during and after pregnancy (Hanh, Rasch, Chi, & Gammeltoft, 2009). Despite some progress in providing counselling, research in Brazil and elsewhere has documented insufficient or altogether absent counselling (Njeru et al., 2011; Omuemu, Akemokwe, & Ahanmisi, 2008). In Brazil, the percentage of women thought to have received pre-test HIV counselling during prenatal care varied regionally from 40-48%, while estimates of post-test counselling (sometimes received during labour) ranged widely from 10% to 62.5% (Paiva et al., 2002; Veloso et al., 2008), though neither of these studies detail the way in which pre- and post-test counselling were defined or measured. In contrast, no women received pre-test counselling in our study, while the majority of pregnant women diagnosed with HIV did receive post-test counselling. Post-test counselling was almost uniformly positive and essential for women in this study, perhaps even more crucial in the absence of pre-test counselling.

As with consent and counselling, challenges persist in providing and maintaining confidentiality in practice, again in both high- (Napravnik, Royce, Walter, & Lim, 2000) and low-resource settings (Ekanem & Gbadegesin, 2004; Johnson et al., 2004; Oosterhoff, Hardon, Nguyen, Pham, & Wright, 2008; Pool, Nyanzi, & Whitworth, 2001; Rogers et al., 2006; Turan, Bukusi, Cohen, Sande, & Miller, 2008; Turan et al., 2011). Here, confidentiality was more consistently provided when compared to consent and counselling, but it was still limited by physical space constraints and broken by providers, particularly in hospital settings. The degree of confidentiality possible in labour and maternity wards may not only be limited by physical space, but by provider practices, perceived prior knowledge of HIV status, and the fact that women are often accompanied by partners or family members while in labour (Gruskin, Ahmed, & Ferguson, 2008).

Several steps were taken to heighten the validity of results. The data were comprehensive, and interviews provided ample opportunity for the interviewer to capture relevant

information at multiple points in the interview. Furthermore, results were discussed with researchers in Salvador to ensure that the language and metaphors used were correctly interpreted by the individuals analysing the data and writing the results and conclusions. Finally, discrepant cases were examined, looking both at women who did and did not experience each of the 3Cs, and descriptive statistics (as summarised in Table 2) were used to further ensure the validity of the analysis.

There are, however, limitations to this study. In setting out to assess the quality of HIV testing services provided to previously pregnant women in Salvador, we were surprised not to find specific criteria available in global and national guidelines regarding quality HIV testing, even when guidelines identify the 3Cs as quality standards. We addressed these uncertainties by adapting guideline-based definitions and measured whether or not each ‘C’ occurred. For example, because it was not possible to observe any pre- or post-test counselling that had taken place for participants, assessing whether specific components of counselling had occurred would have permitted greater recall bias. Therefore we opted to only assess whether pre- or post-test counselling occurred at all. Further, the small sample size limits the generalisability of results, although the lessons learned may be applicable to other areas in Salvador or other states in Brazil since participants were tested for HIV in various health care settings. Finally, the study design also limited our ability to triangulate women’s experiences of the 3Cs with provider and health-care setting reports of the 3Cs, so women’s reports of HIV testing were not confirmed with additional data. However, we believe that women’s perceptions of the 3Cs are more likely to affect later care than provider perceptions of the 3Cs.

In addition, 2013 global guidelines call for the 5Cs, while at the time of data collection the focus of global guidelines were the 3Cs. As such, no data on ‘correct test result’ and ‘connections to care, treatment and prevention services’ were collected. Finally, there is some potential for recall bias because all women underwent more than one HIV test prior to study enrolment and were asked to recall the circumstances of the testing that occurred during a prior pregnancy. We have attempted to minimize recall bias by limiting study participants to those women who were pregnant in the past five years. Since a single researcher coded the interview transcripts, it may be more susceptible to individual bias.

Moving forward—clarifying the 3Cs

This analysis identifies gaps in the implementation of the 3Cs during HIV testing in Salvador and, to the best of our knowledge, is the first study to have evaluated the combined implementation of all the 3Cs during HIV testing from women’s perspectives. Further, this study suggests that evaluating whether a health service exists (e.g., HIV testing, received by all participants) must be accompanied by an assessment of its quality (e.g., no woman received quality testing) to determine whether the women’s health needs are being met. This study provides one example of health service quality assessment while more broadly suggesting that access to services alone may not meet the targets set out in ICPD.

As alluded to above, global and national guidelines lack concrete definitions and parameters for implementing the 3Cs in practice and may be contributing to their uneven

implementation. For example, it is challenging to identify and describe the context-specific features that manifest in truly informed and voluntary consent. Existing evaluations of consent for HIV testing have largely focused on the voluntary nature of testing rather than on the criteria that must be satisfied for consent to be well informed. Furthermore, pregnant women, and particularly those in socially or economically marginalised populations, may feel constrained into accepting or undergoing HIV testing in light of power structures between patients and health care providers. Unfortunately, the data are not available in this analysis to determine if this was a concern among women in this sample. Thus, as described by Groves et al. (2010) and more recently by Obermeyer et al. (2014), there are varying degrees of consent, and concrete definitions of ‘informed’ and ‘voluntary’ remain elusive in practice.

There is also little information available to help distinguish between the perceived overlap of informed and voluntary consent and pre-test counselling or between post-test counseling and confidentiality. In the first case, informed and voluntary consent is necessary but not sufficient to fulfill pre-test counselling. For example, even if a woman was informed and has agency in deciding to test for HIV, it is still critical that she receive pre-test information to prepare her for the implications of a positive test result, in addition to education on HIV transmission regardless of the test result. Finally, while the 3Cs are widely recognised as being critical to providing quality HIV testing, additional research is needed to determine if the implementation of the 3Cs should be expanded to the 5Cs, or perhaps if a different constellation of quality indicators altogether may better improve the time interval between HIV diagnosis and further engagement in continued treatment and care.

This analysis reveals the discrepancy between simply counting the number of HIV tests provided and considering the overall quality of HIV testing services. This study suggests that testing in Salvador—the third-largest city in the country—is not of the quality called for by national guidelines or by international standards, despite the fact that HIV testing is being routinely provided for HIV-positive pregnant women in Brazil. As the post-2015 agenda continues to develop, those concerned with improving services should address the quality, not just the quantity, of HIV services going forward.

Acknowledgements

We are grateful for the support of UNAIDS, UNIFEM, Brazilian National Department of STD/AIDS and Viral Hepatitis/Ministry of Health, the Foundation for Research Support of the State of Bahia (FAPESB), The HIV/AIDS Reference Center of the Bahia Department of Health (CEDAP/SESAB), and the Pathfinder Foundation. This article was made possible with the support of ‘HIV and Other Infectious Consequences of Substance Abuse’ (T32DA13911-12), the Lifespan/Tufts/Brown Center for AIDS Research (P30AI042853), and the National Institute Of Allergy And Infectious Diseases. Finally, we appreciate the careful assistance of Ashley Batson in finalising this article for submission.

References

- Abdool Karim Q, Abdool Karim SS, Coovadia HM, Susser M. Informed consent for HIV testing in a South African hospital: is it truly informed and truly voluntary? *American Journal of Public Health*. 1998; 88(4):637–640. [PubMed: 9551007]
- Angotti N. Working outside of the box: how HIV counselors in Sub-Saharan Africa adapt Western HIV testing norms. *Social Science & Medicine*. 2010; 71(5):986–993. [PubMed: 20619944]

- Angotti N. Testing differences: the implementation of Western HIV testing norms in sub-Saharan Africa. *Culture Health & Sexuality*. 2012
- Angotti N, Dionne KY, Gaydos L. An offer you can't refuse? provider-initiated HIV testing in antenatal clinics in rural Malawi. *Health Policy and Planning*. 2011; 26(4):307–315. [PubMed: 21047809]
- Armstrong R. Mandatory HIV testing in pregnancy: is there ever a time? *Developing World Bioethics*. 2008; 8(1):1–10. [PubMed: 18315721]
- Bell E, Mthembu P, O'Sullivan S, Moody K. Sexual and reproductive health services and HIV testing: perspectives and experiences of women and men living with HIV and AIDS. *Reproductive Health Matters*. 2007; 15(29 Suppl):113–135. [PubMed: 17531751]
- Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *The New England Journal of Medicine*. 2011; 365(6):493–505. [PubMed: 21767103]
- Ekanem EE, Gbadegesin A. Voluntary counselling and testing (VCT) for Human Immunodeficiency Virus: a study on acceptability by Nigerian women attending antenatal clinics. *African Journal of Reproductive Health*. 2004; 8(2):91–100. [PubMed: 15623124]
- Evans C, Ndirangu E. Implementing routine provider-initiated HIV testing in public health care facilities in Kenya: a qualitative descriptive study of nurses' experiences. *AIDS Care*. 2011; 23(10):1291–1297. [PubMed: 21939406]
- Groves AK, Maman S, Msomi S, Makhanya N, Moodley D. The complexity of consent: women's experiences testing for HIV at an antenatal clinic in Durban, South Africa. *AIDS Care*. 2010; 22(5):538–544. [PubMed: 20229376]
- Gruskin S, Ahmed S, Ferguson L. Provider-initiated HIV testing and counseling in health facilities—what does this mean for the health and human rights of pregnant women? *Developing World Bioethics*. 2008; 8(1):23–32. [PubMed: 18315722]
- Guenter D, Barbara AM, Shaul RZ, Yudin MH, Remis RS, King SM. Prenatal HIV testing: women's experiences of informed consent in Toronto, Ontario. *Journal of Obstetrics & Gynaecology Canada*. 2008; 30(1):17–22. [PubMed: 18198063]
- Halpern SD, Metkus TS, Fuchs BD, Ward NS, Siegel MD, Luce JM, et al. Nonconsented human immunodeficiency virus testing among critically ill patients: intensivists' practices and the influence of state laws. *Archives of Internal Medicine*. 2007; 167(21):2323–2328. [PubMed: 18039991]
- Hanh NT, Rasch V, Chi BK, Gammeltoft T. Posttest counseling and social support from health staff caring for HIV-infected pregnant women in Vietnam. *Journal of the Association of Nurses in AIDS Care*. 2009; 20(3):193–202. [PubMed: 19427597]
- Hardon A, Kageha E, Kinsman J, Kyaddondo D, Wanyenze R, Obermeyer CM. Dynamics of care, situations of choice: HIV tests in times of ART. *Medical Anthropology*. 2011; 30(2):183–201. [PubMed: 21400352]
- Hardon A, Vernooij E, Bongololo-Mbera G, Cherutich P, Desclaux A. Women's views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries. *BMC Public Health*. 2012; 12(26):1–30. [PubMed: 22214479]
- Jamieson DJ, Chasela CS, Hudgens MG, King CC, Kourtis AP, Kayira D, et al. Maternal and infant antiretroviral regimens to prevent postnatal HIV-1 transmission: 48- week follow-up of the BAN randomised controlled trial. *Lancet*. 2012; 379(9835):2449–2458. [PubMed: 22541418]
- Johnson N, Mullings AA, Harvey KM, Alexander G, McDonald D, Smikle MF, et al. HIV seroprevalence, uptake of interventions to reduce mother-to-child transmission and birth outcomes in greater Kingston, Jamaica. *West Indian Medical Journal*. 2004; 53(5):297–302. [PubMed: 15675494]
- Joint United Nations Programme on HIV/AIDS, & World Health Organization. UNAIDS/WHO policy statement on HIV testing. Geneva: 2004.
- King EJ, Maman S, Wyckoff SC, Pierce MW, Groves AK. HIV testing for pregnant women: a rights-based analysis of national policies. *Global Public Health*. 2013; 8(3):326–341. [PubMed: 23181608]

- Maman S, Mbwapbo JK, Hogan NM, Kilonzo GP, Campbell JC, Weiss E, et al. HIV-positive women report more lifetime partner violence: findings from a voluntary counseling and testing clinic in Dar es Salaam, Tanzania. *American Journal of Public Health*. 2002; 92:1331–1337. [PubMed: 12144993]
- Ministério da Saúde, Secretaria de Políticas de Saúde, & Coordenacao Nacional de DST e Aids. Aconselhamento em DST, HIV e Aids: diretrizes e procedimentos básicos. O Ministério; Brasília-DF: 1997.
- Ministério da Saúde, Secretaria de Políticas de Saúde, & Coordenacao Nacional de DST e Aids. Protocolo para a prevenção de transmissão vertical de HIV e sífilis. O Ministério; Brasília-DF: 2006.
- Ministério da Saúde, Secretaria de Políticas de Saúde, & Coordenacao Nacional de DST e Aids. Centros de Testagem e Aconselhamento do Brasil: Desafios para a Equidade e o Acesso. O Ministério; Brasília-DF: 2008.
- Ministério da Saúde, Secretaria de Vigilancia em Saúde, & Departamento de DST, Aids e Hepatites Virais. Boletim Epidemiológico: HIV/AIDS. O Ministério; Brasília-DF: 2013.
- Napravnik S, Royce R, Walter E, Lim W. HIV-1 infected women and prenatal care utilization: barriers and facilitators. *AIDS Patient Care and STDS*. 2000; 14(8):411–420. [PubMed: 10977970]
- Njeru MK, Blystad A, Shayo EH, Nyamongo IK, Fylkesnes K. Practicing provider-initiated HIV testing in high prevalence settings: consent concerns and missed preventive opportunities. *BMC Health Services Research*. 2011; 11:87. [PubMed: 21507273]
- Obermeyer CA, Verhulst C, Asmar K. Could you have said no? a mixed-methods investigation of consent to HIV tests in four African countries. *Journal of the International AIDS Society*. 2014; 17(1)
- Office of the United Nations High Commissioner for Human Rights, & Joint United Nations Programme on HIV/AIDS. International guidelines on HIV/AIDS and human rights. Geneva: 2006. Available from: http://data.unaids.org/publications/irc-pub03/3797_en.html#top
- Omuemu VO, Akemokwe FM, Ahanmisi IE. Attitude and practice of antenatal HIV screening among pregnant women attending a secondary health facility in Benin-city. *Nigerian Journal of Clinical Practice*. 2008; 11(4):324–329. [PubMed: 19320404]
- Oosterhoff P, Hardon AP, Nguyen TA, Pham NY, Wright P. Dealing with a positive result: routine HIV testing of pregnant women in Vietnam. *AIDS Care*. 2008; 20(6):654–659. [PubMed: 18576166]
- Paiva V, Latorre R, Gravato N, Lacerda R, Ayres JR, Segurado A, et al. Sexuality of women living with HIV/AIDS in Sao Paulo. *Cad Saude Publica*. 2002; 18(6):1609–1620. [PubMed: 12488888]
- Pool R, Nyanzi S, Whitworth JA. Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda. *AIDS Care*. 2001; 13(5):605–615. [PubMed: 11571007]
- Rennie S, Behets F. Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bulletin of the World Health Organization*. 2006; 84(1):52–57. [PubMed: 16501715]
- Rogers A, Meundi A, Amma A, Rao A, Shetty P, Antony J, et al. HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural Southern India. *AIDS Patient Care and STDS*. 2006; 20(11):803–811. [PubMed: 17134354]
- Sherr L, Bergenstrom A, Hudson CN. Consent and antenatal HIV testing: the limits of choice and issues of consent in HIV and AIDS. *AIDS Care*. 2000; 12(3):307–312. [PubMed: 10928208]
- Siziya S, Muula AS, Rudatsikira E, Mataya RH. Correlates of HIV testing among women in Malawi: results from the 2006 Multiple Indicator Cluster Survey. *Tropical Medicine & International Health*. 2008; 13(11):1351–1356. [PubMed: 18803613]
- Task Team for the Global Thematic Consultation on Health in the Post-2015 Development Agenda. What do people want for health in the post-2015 agenda? *Lancet*. 2013; 381(9876):1441–1443. [PubMed: 23602316]
- Turan JM, Bukusi EA, Cohen CR, Sande J, Miller S. Effects of HIV/AIDS on maternity care providers in Kenya. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2008; 37(5):588–595.

- Turan JM, Bukusi EA, Onono M, Holzemer WL, Miller S, Cohen CR. HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS Study. *AIDS and Behavior*. 2011; 15(6):1111–1120. [PubMed: 20827573]
- Ujiji OA, Rubenson B, Ilako F, Marrone G, Wamalwa D, Wangalwa G, et al. Is 'Opt-Out HIV Testing' a real option among pregnant women in rural districts in Kenya? *BMC Public Health*. 2011; 11:151. [PubMed: 21385423]
- UNAIDS. Handbook for legislators on HIV/AIDS, law and human rights. UNAIDS; Geneva: 1999.
- UNAIDS, & World Health Organization. UNAIDS/WHO policy statement on HIV testing. 2004
- UNAIDS. UNAIDS world AIDS day report. Geneva: 2012. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/jc2434_worldaidsday_results_en.pdf
- UNAIDS. Global report. 2013. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf
- United Nations. Report of the international conference on population and development. 1994 UN Doc. A/Conf.171/13.
- Veloso VG, Portela MC, Vasconcellos MT, Matzenbacher LA, Vasconcelos AL, Grinsztejn B, et al. HIV testing among pregnant women in Brazil: rates and predictors. *Revista de Saúde Pública*. 2008; 42(5):859–867. [PubMed: 18833385]
- World Health Organization, & UNAIDS. HIV/AIDS Programme: guidance on provider-initiated HIV testing and counselling in health facilities. 2007
- World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach. World Health Organization; Geneva: 2013.

Table 1

Demographic characteristics among women (n=17) receiving HIV/AIDS care at the State Reference Centre in Salvador, Brazil, in 2011.

VARIABLES	n
<i>Location of HIV test</i>	
Maternity ward during labour	5
Hospital during prenatal care	12
<i>Age</i>	
Less than 24 years old	3
25–34 years old	11
35–44 years old	3
<i>Color/race</i>	
Brown	7
Black	8
Other	2
<i>Civil status</i>	
Married or live with someone	10
Single, divorced, or widowed	7
<i>Residence</i>	
Outside of Salvador	5
Salvador	12
<i>Employment status</i>	
Unemployed	12
Employed (formally or informally)	5
<i>Monthly income of those working</i>	
Minimum wage or below	4
Above minimum wage	1

Table 2

Experience of consent, counselling, and confidentiality among women (n=17) receiving HIV/AIDS care at the State Reference Centre in Salvador, Brazil, in 2011.

VARIABLES	n
<i>Experienced all 3Cs in combination</i>	0
<i>Experienced none of the 3Cs</i>	3
<i>Informed and voluntary consent</i>	
Yes	4
No	13
<i>Counselling</i>	
Pre-test	0
Post-test	12
Comprehensive counselling	0
<i>Confidentiality</i>	
Health care worker trust	13
Private space	14
Full confidentiality	12

Table 3

Supplementary quotes regarding consent.

Consented	Context	Location	Quote
no	labour	maternity	I: Did someone ask if you wanted to do it and told you it was not mandatory? W: No.
no	prenatal	hospital	W: She then gave me the paper, I signed it, all very well. But I didn't know what had happened.
no	prenatal	hospital	I: And then, didn't he also ask you if you were interested nor even ... that it wasn't mandatory, that if you wanted you could refuse? W: No. I: Didn't he explain anything? W: No ... I: The first moment when they did not tell you anything. Do you think they should ask you if you want or not want? W: I think ... I think that it should be asked, right then, right? But they did not ask me anything. But I think they should.
no	prenatal	hospital	I: So no one ever asked if you agreed or not. W: No.
no	prenatal	hospital	I: Did you know that you could refuse it? W: No.
no	prenatal	hospital	I: Before taking your blood, did they tell you that you could refuse to take the test? W: No.
no	prenatal	primary facility	I: Did you talk about something like that you could refuse to take the test, which was not required, that you had to give permission to do it... Did she say that if you did not want to, you could refuse? W: No.
presumed yes	woman requested	hospital	I: Do you remember when the doctor asked [you to take the HIV test]? If it was in April or was it before? W: The doctor asked me in March. Only that he asked for many tests. Then I did the first [HIV test], I did this one first, then I did the rest....
presumed yes	woman requested	laboratory	I: Why did you do this test for HIV? W: Because of pregnancy, when they ask for everything. W: The doctor asked? W: The doctor asked for everything.
explicit yes	partner sick	primary facility	W: They asked me why I had to do [the HIV test] so I told them that the doctor there from prenatal had a suspicion that I was [HIV positive] but was not sure I was supposed to come to take the exam.
explicit yes	partner sick	specialised service	I: So, when you did the HIV test: what were the reasons for you taking it? ... W: I was pregnant, and then I came here. Because my husband already had the problem of HIV. So I came here.

Table 4

Supplementary quotes regarding counselling.

Counselled	Context	Location	Quote
no	labour	maternity	<p>I: Did they talk to you? Did they tell you why they were doing it? Did they give you some sort of advice, guidance, something? W: No.</p> <p>W: They just gave me the result. I: And did she prepare you? Talked [about] anything before so she could give you the news? W: No, just asked how many partners I've ever had, if I was married, if my husband had other women ...</p>
no	prenatal	hospital	<p>I: Did they ask you if you wanted to do it? How was that? W: No. They didn't ask me if I wanted to do it, nor did they give me any instruction.</p> <p>W: But, like, [the doctor] talked to me [saying] 'No. This is not the end of the world...'. Then he started telling me of people that already had it, that it had happened to other people. But they have a normal life, they take care of themselves...'. Then he explained that I had to be extra careful.</p>
no	prenatal	primary facility	<p>I: Did you have counselling... Did someone come up to you to say what HIV was? W: No.</p> <p>I: And how do you think this conversation with the assistant was? For you was it something that helped you better accept [the test result]? W: It was a conversation... It calmed me down, made me calmer....</p>
no	woman requested	hospital	<p>I: [Did you have] some kind of guidance before taking the HIV test? W: No.</p> <p>W: Then the other day I went to get the result, I got there.... So I ended up asking for a social worker, she talked to me ... she grabbed me and explained all things, the treatment . . .</p>
no	woman requested	laboratory	<p>I: And did you have counselling there in the health centre? ... Any health care professional, before taking your blood, did they talk to you? W: No. I: About HIV? Say anything? W: No. Not at all.</p> <p>I: And when they gave you the result, what did they say? W: Nothing. Just gave me the result and that was all.</p>
no	partner sick	primary facility	<p>I: There was not any kind of advice or guidance before? W: No, no, no.</p> <p>I: Can you talk a little bit about the time you found out you had HIV, when he spoke, confirmed to you that you had HIV? W: Listen, it was really normal, you know he told me, he explained everything right.</p>

Table 5

Supplementary quotes regarding confidentiality.

Confidential	Context	Location	Quote
yes	labour	maternity	I: Do you trust them [the health care workers] with the fact they know that you have HIV? W: I trust that they know they can't go out telling people out there, and between themselves I know you know, everybody knows what they talk among themselves.
yes	labour	maternity	I: ... about the people at the health service - do you think they keep your test result a secret? The fact that you have HIV? W: I think so.
yes	prenatal	hospital	I: Did it meet your expectations of what should be done when they have to deliver the results? That it was done in a proper way? W: My mom and her friend were in the room. He asked them to leave for a moment. Then he talked to me... When my husband was in the room, he didn't say anything. He was very discrete.
yes	prenatal	hospital	I: And do you think that the health professionals, people you have contact [with] here [at the SRC] or in any other health unit, that know you have HIV, do you trust these people or think they can comment with others? W: I don't think so. I: Do you trust them? W: I do.
yes	prenatal	hospital	I: And do you think people of health, the health professionals who do their follow-up do you think they keep your information confidential? W: Yes. I: About HIV? W: Yes, I think so.
yes	prenatal	primary facility	I: Right. Do you think ... Trust in health care professionals, people who know you have HIV here or anywhere else you go to, do you trust, or do you think these people can tell someone? W: I think here [at the SRC] I have a little bit of trust. But there ... Down at the health centre, in the Secretary of Health ... Always... Changing employees ... I: And do you trust these people? W: I trust with suspicion ...
yes	prenatal	primary facility	I: And you think these health professionals who know you have HIV, these people keep [that] secret or you don't trust them? W: I do not trust, do not. Not there [where I was tested].
yes	prenatal	primary facility	I: She called you to a more reserved area to talk to you? W: It was a room. Locked!
yes	woman requested	hospital	W: [They told me when I wanted my daughter to pick up the exam] 'Listen dear, we're not giving the exam, no. We just give the exam to you'.
no	woman requested	laboratory	I: And with regards to health professionals, do you trust the fact that they know you have HIV or [do] you have a bit of suspicion? W: I trust them. I: Do you think they can tell someone? W: I trust them.