PROGRAM FOR PREVENTION OF Mother-to-Child Transmission of Syphilis and HIV in Brazil: missed opportunities

Programa de prevenção da transmissão materno-infantil de sífilis e HIV no Brasil: oportunidades perdidas

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ABSTRACT

While antenatal screening for HIV and syphilis is part of the national policy in Brazil, screening and treatment coverage remain inadequate in many parts of the country. This study aimed to describe missed opportunities concerning mother-to-child transmission (MTCT) from the point-of-view of pregnant women, health professionals, and health care managers. A semi-structured interview was conducted in six Brazilian states. Pregnant women, health professionals, and health care managers were interviewed to identify failures in the process of care for pregnant women and MTCT of syphilis or HIV. The project had a quantitative approach but included open-ended questions to capture the views of participants regarding the feasibility of strategies adopted for controlling MTCT. The sample consisted of 109 women, 62 health professionals, and 34 health care managers. The median age of women was 24 (range: 15–46) years, and the median schooling was 8 years. Eighty percent of those interviewed received prenatal care. Among those who attended antenatal visits, the median was 6.43 (range: 1–20) visits. Managers and health professionals had a median of 10 (range: 4–25) working years. In the interviews, the managers declared that they had provided tests and treatment for these infections, but health professionals stated that they did not have tests or treatment available to offer, and most women complained about the difficulties of receiving treatment. Organizing the logistics and breaking down barriers related to care in Brazil is challenging. An adequate health care system and policy factors that address this situation can help to eliminate MTCT by implementing strategies adopted to control these infections in the country.

Keywords: Mother-to-child transmission; HIV; syphilis; health system; health policy.

RESUMO

Embora o rastreamento para HIV e sífilis no pré-natal faça parte da política nacional no Brasil, a cobertura do rastreamento e tratamento permanece inadequada em muitas partes do país. O objetivo deste estudo foi descrever as oportunidades perdidas de transmissão materno-infantil (TMI) do ponto de vista de gestantes, profissionais de saúde e gestores de saúde. Uma entrevista semiestruturada foi realizada em seis estados brasileiros. Foram entrevistadas gestantes, profissionais de saúde e gestores dos serviços de saúde, com o objetivo de identificar falhas no processo de atendimento às gestantes e à TMI de sífilis ou HIV. A abordagem do projeto foi quantitativa, mas perguntas abertas foram incluídas para capturar as opiniões dos participantes sobre a viabilidade das estratégias adotadas para o controle da TMI. Participaram do estudo 109 mulheres, 62 profissionais de saúde e 34 gestores. A mediana de idade das mulheres foi de 24 (intervalo:15-46) anos e a mediana de escolaridade foi de 8 anos. Oitenta por cento dos entrevistados fizeram consultas de pré-natal. Entre as que participam de consultas pré-natais, a mediana foi de 6,43 (intervalo: 1 a 20). Gestores e profissionais de saúde tiveram uma mediana de 10 anos de trabalho (intervalo: 4-25). Nas entrevistas, os gestores disseram que haviam fornecido testes e tratamento para essas infecções, mas os profissionais de saúde disseram que nem sempre tinham testes ou tratamentos disponíveis para oferecer às pacientes e a maioria das parturientes reclamou das dificuldades em receber tratamento. Organizar a logística e derrubar barreiras de cuidado ainda representam um desafio no Brasil. O sistema de saúde com funcionamento adequado e uma ação política de enfrentamento da situação podem ajudar a eliminar a TMI, quando atuam na aplicação das estratégias adotadas pelo país no controle dessas infecções.

Palavras-chave: Transmissão da mãe para o filho; HIV; Sífilis; Sistema de saúde; Política de saúde

INTRODUCTION

Brazil is a multifaceted country experiencing complex economic, social, and environmental changes. Social, economic, and regional inequalities are still extreme and rampant; basic living conditions must be dramatically improved for a large part of the population. Health problems are often a result of social and environmental changes and remain unabated⁽¹⁾.

Sexually transmitted infections (STIs), including HIV infection and syphilis, are important public health issues that lead to perinatal morbidity and mortality^(2,3). Neonates who survive with HIV or congenital syphilis are at a greater risk of low birth weight, premature delivery, congenital anomalies, and long-term sequelae — such as deafness

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and neurological impairment, for example^(3,4). These consequences are preventable if health clinics are prepared to provide adequate care, and if infected mothers are identified earlier during pregnancy and receive proper treatment^(5,6). In this process, antenatal HIV and syphilis testings are essential to prevent the mother-to-child-transmission (MTCT) of these infections and offer an opportunity for women and other family members to find out their status and access treatment^(7,8).

Prevention of MTCT of HIV and syphilis are significant and recognized steps towards achieving the United Nations Sustainable Development Goals, particularly the health-related goals of decreasing pregnancy complications and child and maternal mortality⁽⁹⁾. In 2010, the Pan American Health Organization (PAHO) countries agreed to implement strategies for eliminating MTCT of syphilis and HIV by 2015. HIV elimination goals consisted of a reduction in the incidence of HIV cases in children to 0.3 cases/1,000 live births and an MTCT rate $\leq 2\%$; syphilis elimination goals included prevalence of 0.5 cases/1,000 live births. In 2016, these goals were changed and extended upon by the Plan of Action for the Prevention and Control of HIV and Sexually Transmitted Infections 2016–2021⁽¹⁰⁾.

While antenatal screening for HIV and syphilis are part of Brazil's national policy, both screening and treatment coverage remain inadequate in many parts of the country, mainly due to technical and logistical problems. Together, the health care system and new policies are capable of eliminating MTCT while overcoming barriers and integrating surveillance, as well as strengthening service delivery and community leadership⁽¹¹⁾.

In Brazil, an estimated 0.38% of all pregnant women are infected with HIV, corresponding to almost 11,000 pregnant women infected with HIV per year. A total of 108,134 cases of pregnant women with HIV were notified from 2000 to June 2017. Over ten years, the detection of HIV in pregnant women increased 23.8%⁽¹²⁾. In 2016, Brazil had 87,593 cases of acquired syphilis, 37,436 cases of syphilis in pregnant women, and 20,474 cases of congenital syphilis, with 185 deaths among them. The detection rate of syphilis in pregnant women and the incidence rate of congenital syphilis were 12.4/1,000 live births and 6.8/1,000 live births, respectively⁽¹³⁾.

A previous study in Brazil evaluated the cascade of HIV care in pregnant women and identified flaws in all stages of care. It showed a lack of connection between primary care and referral centers for HIV/AIDS, which could organize the care delivery for families and promote better outcomes for children⁽¹⁴⁾. Another study described increased detection rates of syphilis in pregnancy and revealed that better organization of health services and professional awareness could improve the care offered to these patients⁽¹⁵⁾.

In Brazil, both prenatal care and childbirth coverage are close to 100%; syphilis and HIV tests and drugs are available for free to prevent MTCT. Formula for HIV-exposed children is also available. It is crucial to identify the gaps that could help eliminate these infections in Brazil.

OBJECTIVE

This study aimed to describe the missed opportunities in preventing MTCT in Brazil based on the perspective of women in the maternal ward who delivered babies with HIV and/or syphilis, health professionals, and health care managers working in the same institutions.

METHODS

In 2015, a sample consisting of cases of pregnant women notified for syphilis and/or HIV with a positive newborn was chosen in the state capital and one city in six Brazilian states: Amazonas, Ceará, Espírito Santo, Rio de Janeiro, Rio Grande do Sul, and the Federal District. Participants were equally chosen among states. The selection was based on the availability of complete data in the Notifiable Diseases Information System (Sistema de Informação de Agravos de Notificação - SINAN) form from the mother and her child. The maternity hospitals involved presented different characteristics, according to the states where they belonged, but all of them were part of Brazil's public health care system (Sistema Unico de Saúde - SUS). MTCT cases were chosen from the SINAN database, and women were invited to participate in the interview. Physicians, nurses, and managers working in the same institution where these cases happened were also invited to participate in the interview and share their views on MTCT of HIV and syphilis in their health care center and city.

A semi-structured interview, including demographical (age, gender, education, occupation, time working in the field, etc.) and health care access data (prenatal care, access to HIV/syphilis diagnosis and treatment, follow-up, professional years of experience, training opportunities for professionals, etc.), was conducted with 20 women aged 15 years or over, who delivered their babies at the chosen health center, 10 health professionals, and five health care center managers in each Brazilian state. The data collected were entered in an Excel worksheet (Microsoft[®]) and analyzed in SPSS 19.0. We used measures of central tendency and dispersion for continuous variables and measures of frequency for categorical variables to build the participants' profile.

A smaller number of women in the maternal ward who delivered babies with HIV and/or syphilis, health professionals, and health care managers working in the same institutions were invited for an in-depth interview focusing on why they thought the transmission had occurred and what were the failures. We opted for the individual interview because it is a faster method for obtaining qualitative data, and also more suitable for this project, since participants had little free time to answer the questions. Moreover, interviews allow people to talk on their own terms. Interviews took place at private venues chosen by participants and lasted 30-40 minutes; they were recorded and later transcribed and de-identified for analysis. We included open-ended questions to understand better how HIV and syphilis counseling and diagnosis were carried out at health care centers and grasp the opinions of women, health professionals, and managers about health care access and approach, including laboratory and medical supplies and professional training. These answers would offer better knowledge and the possibility of reassessing the relevance of current strategies or the control of MTCT of HIV and syphilis.

From the in-depth interviews, we extracted and included quotes to complement the descriptive approach and provide a better understanding of the missed opportunities to prevent MTCT of HIV and syphilis. Interviews focused on the participants' perceptions of existing workflows between diagnosis and care delivered to each case, and how they reacted to them. With this technique, we were able to find more about the words they use, their priorities and concerns⁽¹⁶⁾ regarding MTCT, and its implications for health care units. It could offer answers on how to improve services and professional approach.

Interviews were conducted after the participants invited signed an informed consent form. We assigned names to the participants to preserve their anonymity and confidentiality. The Research Ethics Committee from the Universidade Federal do Espírito Santo approved the project (#640,580/2014). Privacy and confidentiality were protected in all phases of the project using data codification.

RESULTS

A total of 109 parturient women, 62 health professionals, and 34 health care managers were interviewed. The median age of parturient women was 24 years, ranging from 15 to 46, and the median schooling was 8 years. Among those who attended antenatal visits, the median was 6.4 (range: 1–20) visits. Managers and health professionals had a median of 10 (range: 4–25) working years in the field.

 Table 1 describes the perception of care by parturient women infected with HIV and syphilis. We highlight that 62.4% of them

Table 1 – Perception of the health care system reported by women who delivered babies with HIV and/or syphilis in Brazil, 2014.

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Variables	N (%)
Considered health professionals prepared to counsel the	nem about HIV
and syphilis during antenatal care	
No	26 (23.8)
Yes	68 (62.4)
Did not attend antenatal care	15 (13.8)
Quality care in the maternity hospital	
Excellent/very good	31 (28.4)
Good	63 (57.9)
Bad	15 (13.7)
Received counseling about diagnosis in the hospital	
No	23 (21.1)
Yes	86 (78.9)
Who counseled you about the infections in the hospital	?
Health team (physician and nurse)	28 (25.7)
Physician alone	42 (38.5)
Nurse alone	31 (28.4)
No one	8 (7.3)
Did you receive treatment for the infection?	
No	9 (8.2)
Yes	100 (91.8)
Did the baby receive care for PMTCT?	
No	7 (6.4)
Yes	102 (93.6)
Did health professionals advise you to talk to your partr	ner?
No	14 (12.8)
Yes	95 (87.2)
How did you talk to your partner about the diagnosis?	
He already knew it	25 (22.9)
We were together in the center when the health professional disclosed the diagnosis	51 (50.8)
I decided not to talk about it with my partner	23 (21.1)
I do not have any contact with my partner anymore	10 (9 2)

HIV: human immunodeficiency virus; PMTCT: prevention of mother-tochild transmission. considered health professionals prepared to counsel them about HIV and syphilis during antenatal care. A total of 21.1% decided against talking about their diagnosed infections with their partners.

 Table 2 presents the characteristics and perspectives of health

 professionals involved in HIV and syphilis cases. Interestingly,

Table 2 – Profile and perspectives of health professionals involved in the care of cases of mother-to-child transmission of HIV and syphilis in Brazil, 2014.

Variables	N (%)
Professional age	
<30	11 (17.7)
30–35	8 (12.9)
>35	43 (69.4)
Profession	
Physician	28 (45.2)
Nurse	31 (50.0)
Social worker	2 (3.2)
Psychologist	1 (1.6)
Years in professional practice	
<5	12 (19.4)
5–9	12 (19.3)
10–15	11 (17.7)
>15	27 (43.5)
Received training for PMTCT of HIV and syphilis	
No	32 (51.6)
Yes	30 (48.4)
Would like to be trained for PMTCT of HIV and syphilis	()
No	13 (21.0)
Yes	49 (79.0)
Syphilis diagnosis available in your health center	()
Point-of-care test	25 (40.3)
VDRL	34 (54.8)
Both tests	3 (4.8)
HIV diagnosis available in your health center	()
Point-of-care test	57 (91.9)
Elisa	5 (8.1)
How long it takes to receive the HIV test results?	()
Less than 1 hour	40 (64.5)
1–24 hours	17 (27.4)
2–7 days	1 (1.6)
8 or more days	4 (6.4)
How long it takes to receive the syphilis test results?	()
Less than 1 hour	19 (30.6)
1–24 hours	27 (43.5)
2–7 days	7 (11.3)
8 or more days	9 (14.6)
Have access to confirmatory tests for HIV and syphilis	· · · ·
No	11 (17.7)
Yes	51 (82.3)
Have regular access to diagnostic tests for HIV and syph	ilis
No	5 (8.1)
Yes for both infections	52 (83.9)
Yes for HIV but not for syphilis	5 (8.0)
Medicines available to prevent MTCT of HIV and syphilis	x - /
Yes for both infections	57 (91.9)
Yes for HIV but not always for syphilis	5 (8.1)

HIV: human immunodeficiency virus; MTCT: mother-to-child transmission; PMTCT: prevention of MTCT; VDRL: venereal disease research laboratory; Elisa: enzyme-linked immunosorbent assay.

despite almost 50% of them having declared being trained in MTCT of HIV and syphilis, 79% reported that they would like to receive training in the prevention of MTCT. **Table 3** shows the characteristics and perspectives of health care managers involved in the HIV and syphilis cases included in this study; 61.8% reported that they had been in their current management position for less than five years, and less than 50% had received any kind of management training.

In the in-depth interviews, we tried to understand the offer of diagnosis and treatment in the units as a way to measure how the managers and health professionals perceive the availability of supplies, training, clinical support, and supervision. The managers declared that they had provided tests and treatment for these infections in their health centers. Some answers are quoted below:

> I cannot explain this! We buy tests and antibiotics. We also provide training for health professionals. What more we can do? (Ana, 36)

> I know there are problems! It is a complicated situation. We try to do our best, but sometimes things do not work out the way they should! (Jorge, 42)

However, health professionals stated that they did not always have tests or treatment available to offer to their patients. They also complained that they did not feel confident enough to perform rapid tests and that they would like to receive more training. Training and supplies sometimes were missing.

> Sometimes there are no rapid tests at the center, and I need to recommend regular tests, but Elisa (HIV) or VDRL (Syphilis) results can take at least a week. (Miguel, 28)

> I would like to receive more training to feel more confident in carrying out rapid tests. I am still doubtful about how to use it. They are treponemal tests, how can I know if it is not just a scar? (Elisa, 33)

> When the pregnant woman tests positive, I offer counseling and send her on to treatment. I cannot administer penicillin in my center because conditions are not safe, and pregnant women must seek out another health center. (Paulo, 45)

In the interviews with the women, the main goal was to discuss access and barriers to receive appropriate and comprehensive care. Most parturient women complained about how hard it was to understand the disease and receive treatment. It is hard to have effective care if you do not understand the problem you have to handle.

> The doctor was nice to me. He told me I needed to receive treatment for syphilis to try to protect my baby, but he did not explain anything about the disease to me. What is syphilis? I was wondering what it means. (Maria, 22)

> The health center did not have penicillin, and they sent me to the hospital, but I did not go because I did not have

Table 3 – Profile and perspectives of health care managers in centers that treated cases of mother-to-child transmission of HIV and syphilis in Brazil, 2014.

and syphilis in Diazi, 2011.	
Variables	N (%)
Professional age	
<30	3 (8.8)
30–35	8 (23.5)
>35	23 (67.6)
Professional background	
Physician	13 (38.2)
Nurse	16 (47.1)
Other professions	5 (14.6)
Years working as a manager	
<5	21 (61.8)
5–9	6 (17.6)
10–15	4 (11.8)
>15	3 (8.8)
Received management training for health care service	es
No	19 (55.8)
	15 (44.2)
Received management training for PMICI of HIV and	d syphilis
No	17 (50.0)
Yes	17 (50.0)
Thinks that management training for PMTCT of HIV a	nd syphilis is
Ne	45 (44 4)
No	10 (44.1)
Tes	19 (55.9)
Doint of core for both infections	10 (25.2)
VDPL for symbilis and Elica for HIV	12 (33.3) 5 (14 7)
Point of care for HIV and VDRI for synhilis	3(14.7) 17(500)
How long it takes to receive the HIV test results?	17 (30.0)
Less than 1 hour	23 (67 6)
1-24 hours	<i>A</i> (11 8)
2-7 days	3 (8 8)
8 or more days	4 (11 8)
How long it takes to receive the syphilis test results?	4 (11.0)
Less than 1 hour	14 (41 2)
1–24 hours	10 (29 4)
2-7 days	4 (11.8)
8 or more days	6 (17.6)
Have access to confirmatory tests for HIV and syphilis	3
No	8 (23.5)
Yes	26 (76.5)
Have regular access to diagnostic tests for HIV and s	vphilis
Yes for both infections	30 (88.2)
Yes for HIV but not for syphilis	4 (11.8)
Medicines available to prevent MTCT of HIV and syph	nilis
Yes for both infections	31 (91.2)
Yes for HIV but not always for syphilis	3 (8.8)
Penicillin available in antenatal clinic and hospital	
No	4 (11.8)
Yes	30 (88.2)
Antiretroviral drugs available in antenatal clinic and ho	ospital
No	2 (5.9)
Yes	32 (94.1)
The unit has a program to follow patients with positive	tests
No	21 (61.8)
Yes	13 (38.2)

HIV: human immunodeficiency virus; MTCT: mother-to-child transmission; PMTCT: prevention of MTCT; VDRL: venereal disease research laboratory; Elisa: enzyme-linked immunosorbent assay.

money to pay for the bus fare, and I could not lose another day of work. (Helena, 26)

I did not tell my partner about the diagnosis because I was afraid he would beat me. I thought it was enough to do the treatment alone. (Marta, 31)

It was important to listen to the different health care actors and observe the importance of a better linkage among managers, health professionals, and the client's needs to offer an effective health care access for pregnant women. As important as access to a health unit is to receive the right diagnosis, treatment, and counseling.

DISCUSSION

The findings suggest problems in the communication of all parties involved in antenatal care and maternal wards, with different information obtained depending on who is answering the questions. They may also indicate inadequate approaches to training and supervision, as per the answers from both managers and health professionals. Although prenatal care is available for almost all pregnant women in Brazil and the public health system offers universal screening for HIV and syphilis, our data showed that broken communication between health care providers and the women admitted for care leads to technical and logistical challenges, as expressed during the in-depth interviews. Women's needs may be better fulfilled with more comprehensive care. The Brazilian Ministry of Health distributes more than 12 million HIV rapid tests and more than 9 million syphilis rapid tests per year to the 27 states^(12,13). The states are responsible for the logistics to reach all their cities. Cities, in turn, have health centers to deliver care to the population, including prenatal care. Knowledge and communication in the health system are important tools for organizing services and adequate care⁽¹⁷⁾.

In 2014, the World Health Organization (WHO) presented a guide that included joined processes and criteria for validation of EMTCT (elimination of MTCT) of HIV and syphilis(18); one year later, Cuba became the first country to achieve EMTCT of both HIV and syphilis⁽¹⁹⁾. Other countries have followed Cuba and, in 2016, Thailand and Belarus were validated for EMTCT of HIV and syphilis, Moldova for EMTCT of syphilis, and Armenia for EMTCT of HIV⁽²⁰⁾. Several countries have EMTCT plans in place, including Brazil, and others are set for EMTCT validation by a target date^(6,18). The countries that have achieved EMTCT have similar strategies established to ensure universal and equitable antenatal care services, which include HIV and syphilis testing and treatment at no cost to pregnant women⁽²¹⁾. Brazil has the same strategies of these countries, but being a vast country with a large population and huge regional inequalities has hampered the efforts to reach EMTCT. Policy makers and stakeholders must develop strategies according to the characteristics of each region. All regions have shown a combination of strategies referring to social, economic, and regional policies to promote development in a more widespread way over the last few years; however, limitations to policies implemented for the universalization of the health system remain⁽²²⁾.

The study was carried out during a period when the penicillin was not available in most Brazilian health centers, due to the global shortage of the drug. Nevertheless, even when the drug is available, resistance to the intramuscular administration of penicillin at primary care level is still present in health centers across Brazil and should be addressed as a priority to eliminate MTCT of syphilis. The literature has good evidence that penicillin is safe to use in health facilities⁽²³⁾. Regarding HIV infection, no one complained about drug availability or problems with antiretroviral adherence. Prevention of MTCT has been an important step in inhibiting HIV infection in children. However, improving the uptake of and adherence to care continues to be a significant challenge in resource-poor settings⁽²⁴⁾.

We also found that, at times, pregnant women did not receive appropriate counseling. A significant factor that prevents Brazil from achieving EMTCT of HIV and syphilis is the quality of prenatal care. Despite efforts to improve obstetric and neonatal quality of care, this topic remains a challenge in the Brazilian public health system, both in terms of enhancing its quality as such, and of introducing changes to the principles of care⁽²⁵⁾. Studies that have evaluated prenatal work processes demonstrated that not all recommended practices are followed, and some are far below the desired, including the time of prenatal care initiation⁽²⁶⁻²⁸⁾. Moreover, there are social and economic problems influencing the provision of care. Although health care is considered universal in Brazil through SUS, some women lack funds to reach the health centers, do not have help to leave their older children while away, or cannot miss work^(1,26). We highlight that providing free and easy access to health units for prenatal care is not enough if the clinics do not offer adequate diagnosis and treatment. Public health in Brazil needs to improve the dialog among the different care actors. Managers, health professionals, and pregnant women need to be included in the decisions and solutions because it is the only way to have effective control of MTCT cases in Brazil.

In addition, the inadequacy of national registries has also been pointed out as one of the obstacles to improving the quality of prenatal care, as missing and partial information will mislead policy makers and managers in health planning. The government needs to know the number of cases to be able to buy the necessary test and drug supplies. There is also a long way to go to incorporate evaluation as a systematic activity, allowing managers to intervene and redirect actions⁽²⁰⁾. Therefore, improving training in both care and surveillance, as well as monitoring health professionals in charge of prenatal care through medical record review is paramount to reach EMTCT goals. Domingues et al.²⁹ assessed knowledge, practices, and attitudes of health professionals delivering prenatal care in the city of Rio de Janeiro, and found that lack of knowledge about protocols and limitations regarding management of patients with STI were among the main barriers to dealing with the burden of syphilis. The present study showed that less than 50% of health professionals considered themselves well trained in MTCT of HIV and syphilis, and almost 80% would like to be trained again.

One of the limitations of our study was the small sample size for the descriptive analyses. However, our intention was not to reach statistical power but rather to understand who the professionals in the states are, and what their perceptions regarding the MTCT program are. Face-to-face and audio-recorded interviews are always complicated, and we cannot rule out the possibility of response bias due to the general tendency to give socially acceptable answers. Nevertheless, these limitations do not diminish the importance of the study in increasing visibility to a relevant problem and the urgency in scaling up actions toward EMTCT in Brazil.

Primary care units and maternity hospitals need to provide easy and effective access to health services to offer quality prenatal and labor care for their clients. It is also important to prepare managers and health professionals to answer clients' needs because only a flexible and personal agenda can improve the services. The way the health care system and certain policy factors are set up can serve as barriers to successful engagement in HIV and syphilis care activities in our fragmented health service. Nonetheless, with robust governmental will and leadership in local communities, opportunities can arise to increase emphasis and improve efforts in this field⁽¹⁹⁾. The success of such efforts depends on overcoming obstacles between actors and integrating surveillance and care, which influence the spectrum of engagement.

CONCLUSION

The key message from our study is the need to improve communication — among policy makers, managers, health professionals, and the general population. New guidelines have to reach their public — physicians and nurses — in order to be read, accepted, and implemented. Managers have to follow the availability of tests and drugs closely, avoiding shortages that could hamper efforts already in place to tackle syphilis and HIV. Moreover, the general population should be better informed about STIs and their impacts on their lives and the lives of others — and also to be heard by their caregivers, who must be able to answer their questions and help them to find their own answers.

Participation of each author

All authors were active and had equal participation in the study.

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Conflict of interests

The authors declare no conflict of interests.

Ethics Committee Approval for Human Research

The Research Ethics Committee from the Universidade Federal do Espírito Santo approved the project (#640,580/2014).

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