

Improving the HIV Response for Women in Latin America: Barriers to Integrated Advocacy for Sexual and Reproductive Health and Rights

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Civil society plays an important health governance role by influencing international sexual, reproductive health and HIV agendas as expressed in international conferences; monitoring and evaluating implementation; and holding governments accountable for their commitments. Integration of sexual and reproductive health (SRH) and HIV services to achieve the health-related MDGs would seem to be a strategic joint advocacy agenda for the women's sexual and reproductive health movement and HIV activists, particularly women living with HIV. However we found that the self-perpetuating invisibility of women and children in concentrated HIV epidemics and divisive issue-framing which pits women's rights against infant health and SRH against HIV are barriers to joint advocacy in Latin America. Based on their lived experience, women with HIV articulate a rights-based argument for SRH/HIV integration which could discursively organize a cohesive policy community, but face gender, class and HIV-related discrimination in coalition building. Poor progress on SRH/HIV integration in the Latin American countries studied exemplifies the need for greater involvement of people living with HIV and AIDS, especially women, to generate relevant and effective programming, policy, and civil society advocacy at the country level.

INTRODUCTION

The synergistic benefits of linking sexual and reproductive health (SRH) and HIV have been recognized and promoted by the United Nations system for over a decade.^{1,2} Yet global monitoring demonstrates insufficient progress. In 2008, a mere 21% of pregnant women giving birth in low- and middle-income countries were tested for HIV and only 45% of pregnant women living with HIV received antiretroviral treatment to prevent vertical HIV transmission.³ Significant numbers of women with HIV continue to report unmet need for family planning and high rates of unintended pregnancies, as well as other sexual and reproductive rights violations.^{4,5}

In Latin America, most countries have the necessary healthcare infrastructure to implement two crucial pillars of SRH/HIV integration—prevention of parent-to-child HIV transmission (PTCT) and provision of sexual and reproductive health services to women with HIV—but have lagged behind countries and regions with weaker health systems in terms of implementation.⁶ To analyze lack of progress towards meeting country commitments for PTCT and the context for SRH/HIV integration over the past decade in eight Latin American countries, we apply Shiffman and Smith's framework for analyzing the priority accorded to health issues which considers: 1) political context and opportunities; 2) issue characteristics; 3) the power of the ideas used to portray the issue; and 4) the strength of the actors involved.⁷

We are particularly interested in how the epidemiological context of HIV in Latin America and the position of women living with HIV within networks of people living with HIV and vis-à-vis the broader women's health movement have impacted on the priority accorded to PTCT and SRH/HIV integration. Civil society is increasingly influential in setting global and national health policy.⁸ Two areas of global health where civil society actors have been especially active and successful at generating both international and domestic awareness and political will have been HIV and sexual and reproductive health and rights.^{9,10} In Latin America, activism for access to treatment by networks of people living with HIV and in favour of reproductive rights by the women's movement is ongoing, as these aspects of the right to health are not effectively guaranteed despite international agreements.¹¹ The prevention of PTCT and the sexual and reproductive health and rights of people with HIV would seem to be a strategic issue for joint advocacy and collaborative action between these two influential civil society movements. Why haven't HIV and women's health movements in Latin America developed a coherent and persuasive discourse and a joint advocacy agenda focused on achieving the United Nations Declaration of Commitment on HIV and AIDS and the health-focused Millennium Development Goals: reducing child mortality (MDG4); reducing maternal mortality and achieving universal access to reproductive health (MDG5); and halting and beginning to reverse the spread of HIV and AIDS (MDG6)?¹²

METHODOLOGY

We reviewed reporting on the United Nations General Assembly Special Session on HIV and AIDS (UNGASS) and the Millennium Development Goals to assess operational progress towards meeting country commitments to prevent PTCT of HIV and to provide reproductive and HIV health care services in eight Latin American countries. To explore reasons for poor progress towards PTCT in 2007, given high levels of prenatal care coverage and relatively widespread access to antiretrovirals, we undertook a content analysis of the current National HIV and Reproductive Health plans and in-depth, semi-structured interviews with women living with HIV, feminists working in sexual and reproductive health, and national bureaucrats and United Nations functionaries between September 2009 and June 2010 (n=72). The interviews were divided roughly between the three sub-regions: North America (Mexico, n= 26); Central America (Guatemala, Honduras, and Nicaragua, n=19); South America (Bolivia, Colombia, Paraguay, and Peru, n=27). We validated our findings about preventing PTCT and availability of sexual and reproductive health services with 81 activists in national meetings with women leaders with HIV in Guatemala (n=12), Nicaragua (n=18), and Mexico (n=42) and at a forum with activists from all sub-regions (n=19).¹³

The content analysis and interview guides were constructed around the four prongs of the WHO/UNFPA Glion consultation on strengthening linkages between reproductive health and HIV to respond to HIV among women and children: primary prevention of HIV infection in women; prevention of unintended pregnancies in women living with HIV; prevention of transmission from women living with HIV to their infants; and provision of care, treatment and support for women living with HIV and their families.¹⁴ Interviews also explored the political context for SRH/HIV integration, identified institutions and individuals that had promoted or impeded PTCT

implementation and SRH/HIV integration, and documented the relationships between women with HIV and HIV and feminist reproductive health organizations.

NORMATIVE AND OPERATIONAL INTEGRATION OF REPRODUCTIVE HEALTH AND HIV SERVICES IN 8 LATIN AMERICAN COUNTRIES

In 2001, the member states of the United Nations committed to reaching 80% of pregnant women with interventions to reduce PTCT of HIV by 2010.¹⁵ Table 1 shows that while countries have included preventing PTCT in national HIV and reproductive health plans, operational progress has been insufficient. In 2007, only two countries (Nicaragua and Peru) were halfway towards meeting the target and most countries reported less than 10% coverage. This failure cannot be explained by the absence of needed healthcare infrastructure. All of the countries report antenatal care coverage and access to antiretrovirals disproportionately higher than the estimated number of pregnant women living with HIV who actually received treatment. Our qualitative research confirms that once diagnosed the vast majority of women with HIV receive antiretroviral treatment to prevent PTCT. This suggests that a key stumbling block for implementation of PTCT in Latin America is the failure to integrate HIV into maternal-child health by offering HIV testing during antenatal care. The reproductive health needs of people living with HIV remain invisible in national HIV plans. Less than half of the eight countries studied mention reproductive health in their national HIV plans and only one country explicitly includes family planning. The 81 HIV activists (mostly women leaders with HIV) consulted during the validation process corroborated that even when family planning for women living with HIV is mentioned in the National Reproductive Health or HIV plan, the sexual and reproductive health care counselling in HIV care is generally limited to promotion of the male condom; in no settings were other contraceptives routinely provided in HIV clinics.¹⁶

The integration agenda is far from being realized in the countries studied. However, the capacity of these healthcare systems to deliver antenatal care, family planning services, and antiretroviral treatment means that advocacy which increases the priority given to SRH/HIV integration can pay huge dividends towards achieving MDGs 4, 5, and 6. What barriers must be overcome for this to occur?

THE POLITICAL CONTEXT: INTERNATIONAL IMPETUS AND LOCAL INERTIA

At the supranational level, the impetus to link HIV and SRH to achieve the Millennium Development Goals is gaining momentum. Major HIV funding mechanisms such as the Global Fund for AIDS, Tuberculosis and Malaria and the US Global Health Initiative with PEPFAR2 are explicitly soliciting investments in HIV/SRH integrated service delivery, as are some bilateral donors.¹⁷ Since his appointment in 2009, the Executive Director of UNAIDS Michel Sidibé has made SRH/HIV integration a policy priority.¹⁸ HIV was explicitly recognized as a driver of maternal mortality during the 54th Commission on the Status of Women.¹⁹ Despite tensions provoked by donors not meeting or scaling back prior commitments for HIV treatment, there appears to be an international consensus among the UN system, donors, and global civil society on the need to integrate SRH and HIV to achieve the MDGs.²⁰ In Latin America, country

members of the Pan-American Health Organization have committed to a plan for eliminating mother-to-child transmission of HIV and syphilis by 2015.²¹ The end of 2010 appears to provide an excellent window of political opportunity to promote integration of HIV and SRH services to achieve MDGs 4, 5 and 6.

Does the political impetus exist at the country level where implementation will take place? While it seems curmudgeonly, we must consider that when the original targets for preventing PTCT and providing HIV and reproductive health services were established in the MDGs and UNGASS a decade ago the political context also seemed promising. To generate strategies for moving forward in Latin America we must identify some of the political barriers to progress.

ISSUE CHARACTERISTICS: WOMEN AND CHILDREN IN CONCENTRATED HIV EPIDEMICS

Shiffman and Smith identify the importance of a series of issue characteristics which facilitate a health issue attracting political priority. These include the existence of effective interventions — the extent to which avenues for addressing the problem are clearly explained, cost-effective, backed by scientific evidence, simple to implement and inexpensive; the availability of credible evidence and indicators to measure the problem; and perceived severity.²² Preventing PTCT has a strong evidence base for clinical efficacy and the cost-benefit of universal voluntary screening is clear for countries with high HIV prevalence but also in low prevalence HIV epidemics where highly active antiretroviral therapy is provided as the standard of care, as in these Latin American countries.²³ Evidence is accumulating, showing that the provision of reproductive health services to women with HIV (especially family planning) and SRH/HIV integration improves coverage, quality of service delivery, and can be cost-beneficial in generalized HIV epidemics.²⁴ Since 2004, multilateral organizations have recognized that in addition to being necessary for preventing PTCT, prenatal HIV-testing has multiple benefits. The offering of HIV-testing during prenatal care is a unique opportunity for HIV education for HIV-negative women and permits timely access to healthcare for women with HIV. Testing may also allow early diagnosis for the women's partner(s) and other children. Yet, only 19 of 72 of our informants identified one or more of these additional benefits of prenatal HIV testing. Likewise, in response to questions about optimal family planning methods and priority SRH issues, most informants reduced the SRH needs of women with HIV to condom access. These responses suggest that while the United Nations system has articulated the benefits of strengthened linkages between HIV and SRH and the integration of services, these arguments are not necessarily known or accepted by government and civil society actors in the countries studied.

According to Shiffman and Smith, the second group of issue characteristics which impact political priority involve measurement: does credible evidence exist to show the problem is serious?²⁵ We found that insufficient epidemiological data on HIV prevalence and incidence among women and children and related maternal and infant mortality negatively impacts the priority given to PTCT and SRH/HIV integration:

We are part of the working group on safe birth and motherhood, and HIV isn't part of the agenda. Because we don't have sufficient data, and it doesn't seem that the incidence is significant. [...] For those working on HIV, the issue of pregnant

women living with HIV is supposedly miniscule. That it is a part of the agenda that is trying to take funds away, or diminish the importance of HIV in risk groups. So, for neither of the two sides is this issue relevant.²⁶

In the countries studied, estimated HIV prevalence in the general population is low (<1%) but UNAIDS estimated that in 2007 there were 194,500 women with HIV in the eight countries studied, representing 35% of the total population of people with HIV in the eight countries studied. However, only a minority of both men and women in these countries know their HIV status or are on treatment.²⁷ The lag in recognizing HIV infection in the absence of widespread access to testing contributes to perpetuating the idea that HIV is not a women's issue. A decision-maker from the United Nations system told us:

Concretely in HIV there is a cultural barrier: in this country they still think that it is a problem of men who have sex with men; and that there is a low incidence in women; and while the contrary is not demonstrated, public policy is going to prioritize men who have sex with men.²⁸

The failure to implement HIV testing during prenatal care because women are perceived as "low risk" creates a feedback loop in which heterosexual women of reproductive age from the "general population" living with HIV are not diagnosed. The failure to capitalize on the opportunity offered by prenatal care to allow women to access a timely diagnosis means that in the short-term, existing infections among women remain invisible to healthcare providers and national decision-makers. This undermines arguments for prevention and care programmes for women in the decision-making mechanisms of funding bodies, such as the Country Coordinating Mechanisms of the Global Fund for AIDS, Malaria and Tuberculosis.²⁹ The failure to diagnose women is also an impediment to involving the broader women's movement: "*In our own feminist organizations, we have not effectively incorporated the issue of HIV in the agenda—because of our assumption that it is an issue for gay groups.*"³⁰

A second and related issue characteristic is the underreporting of AIDS-related maternal and infant deaths in the region. A feminist ally of women living with HIV stated that: "*Maternal mortality is just that. If it is with HIV or without, no one is interested—they don't record it, they don't measure it.*"³¹ AIDS-related morbidity and mortality among infants and children are also under reported:

In 2007, the doctor told me right to my face: I am the one who buys the medications, and I can tell you whether we have [HIV] medicines for girls and boys and what we have. Because we don't have any, there are no HIV-positive children [in the state medical system].³²

Not implementing PTCT prevention creates a vicious cycle where failure to diagnose HIV among women and children perpetuates the perception that the issue is unimportant and justifies the omission. On the other hand, scale-up of prenatal HIV testing makes the impact of HIV on women and children visible:

With rapid testing available in most, not all, of the maternal-child hospitals, a large number of pregnant women with HIV have been diagnosed. Based on this activity, you can see the feminization of HIV.³³

Several government decision-makers reported that nationally generated epidemiological reports showing increased numbers of HIV diagnoses among women spurred them to develop policies and implement programmes.

According to Shiffman and Smith's framework PTCT and the integration of SRH and HIV services have characteristics such as clinical efficacy and cost-benefit that could motivate political priority.³⁴ However, the synergistic benefits of SRH/HIV integration were not readily articulated by the majority of our informants. Further, failure to identify HIV cases among women and children contributes to the perception that PTCT and SRH/HIV integration are relatively unimportant health issues for the countries studied.

THE POWER OF IDEAS

The power of ideas refers to the importance of framing a resonant and coherent argument for both internal and external audiences. To be most convincing, the argument or "collective action frame" should build consensus about what the problem is and then mobilize for action.³⁵

SRH/HIV integration to achieve the health-related MDGs comes up against two divisive frames: the perception that the implementation of PTCT privileges infant health over women's rights and an issue at the core of the vertical vs. horizontal health care delivery debate—funding.

PTCT AND CONSTRUCTING "WOMEN AS VECTORS"

Some feminists and women living with HIV in Latin America objected to focusing on PTCT as an advocacy priority in the field of women and HIV on the grounds that the intervention is implemented in a way that treats women as vectors of HIV transmission: "*One of the advantages is reducing mother-child transmission, but a disadvantage is that only the child is considered important, they keep conceiving of and treating women like machines*".³⁶ The understanding of PTCT prioritizing the baby's health over the woman's rights excludes the intervention as an advocacy rallying point for feminists: "*They don't think about the woman's life, or her health, but about the child. [...] Personally, as a feminist, I would focus on other areas, not that one.*"³⁷

FUNDING: HIV VS. REPRODUCTIVE HEALTH

Competition for funding was cited by some members of women's groups as a reason for not becoming involved in HIV:

There is a network of organizations that work on HIV, and they have asked us to join. But we, no, no, no. Because it is a world of men, where people are frequently fighting over money."³⁸

Feminists reported being accused by gay colleagues of being interested in women and HIV for mercenary motives. Some women with HIV expressed caution about collaborating with other movements out of fear that they would "*use HIV for their own benefit*".³⁹ With specific reference to SRH/HIV integration to achieve the Millennium Development Goals, the perennial argument that HIV captures the lion's share of available resources was articulated as a barrier:

Conceptually, I agree with it [integration]. Since Cairo in 94 we have talked about a focus on reproductive health, and that is the way it should be. That should be the

model, which hasn't happened and I don't know if it is going to happen. But there is another issue—there is a worldwide struggle for resources. Maternal mortality is the MDG with the fewest resources internationally. And if now you want to include HIV, HIV will take away more of the already scarce resources for maternal mortality. And HIV has its own MDG, isn't that right? And its own resources, and its own actions.”⁴⁰

FRAMING AN INTEGRATING DISCOURSE: WOMEN'S RIGHTS AND THE RIGHT TO HEALTH

A promising avenue for overcoming divisive framing was identified in the rights-based discourse articulated by women with HIV based on their lived experience. Increasing the capacity of women with HIV to link their experiences to the content and objectives of the international conferences would support them to enunciate a “frame bridge” between the master narratives of the HIV movement—the rights to health and non-discrimination, and the master narrative of the women's movement—women's rights and combating gender oppression.⁴¹

Women living with HIV have experienced the consequences of fragmented HIV and reproductive healthcare delivery. Some of these consequences include: losing a child to AIDS (MDG4); raising children with HIV (MDG 6); not finding out about their HIV diagnosis until they or their partner became ill because of AIDS (MDG 6); or experiencing unintended or unwanted pregnancies because dual protection (condom plus another contraceptive method) is not promoted in HIV care (MDG 5). Women living with HIV asserted their right to health services independent of their HIV status:

Part of the right to health is comprehensive care—from availability of services like the HIV test, exams, ultrasounds, all of that and prenatal care that should be evaluated by health professions—all of this has to be a human right of every woman, independent of her [HIV] status.”⁴²

Others reflected on how gender power differentials had negatively affected their sexual and reproductive health, and emphasized the importance of skills-building and access to services which would allow them to take “*autonomous decisions about our bodies*.”⁴³ However, minimal or no participation in sexual and reproductive health advocacy or exposure to the women's movement prior to their HIV diagnosis also means that many women living with HIV don't speak the language of the Cairo and Beijing conferences or frame their demands and priorities within the language of the MDGs.⁴⁴ Emblematically, a new woman leader with HIV said:

I haven't worked [with the feminist movement] but now that I am coordinating the network [of women with HIV], I am just starting a process of information gathering, education, absorbing everything that's related to gender and HIV, women, AIDS, to have a discourse on these issues; right now, my discourse on these issues is poor.⁴⁵

The discourse enunciated by women with HIV based on their felt needs and lived experiences echoes framing used by the broader HIV movement in their struggle for the right to health and non-discrimination and also resonates with the discourse of the feminist women's health movement on women's right to autonomy and the ill-health caused by gender oppression. Currently the limited ability of many women leaders living

with HIV to speak the language of the international conferences and frame their demands in these terms makes it difficult for them to communicate the need for integration of SRH and HIV services as a common agenda and be recognized as champions for women's health and rights.

STRENGTH OF ACTORS: WOMEN WITH HIV FACE BARRIERS WITHIN THE BROADER HIV AND WOMEN'S HEALTH MOVEMENTS

Shiffman and Smith identify four components of "actor strength" that contribute to the priority accorded to a health issue: the existence of guiding institutions; leadership; cohesion of the policy community; and civil society mobilization.⁴⁶ While the United Nations system has provided policy guidance, PTCT and SRH among women living with HIV is not the remit of a single United Nations agency and joint responsibility can lead to inaction.⁴⁷ Commenting on lack of action on PTCT and the integration of SRH and HIV services driven by the UNAIDS Theme Group, one United Nations official commented: *I don't think we are taking sufficient advantage of our differentiated capacities. And at times, despite striving for inter-agency collaboration, we are falling into vertical execution.*⁴⁸ A feminist noted that:

There is a monopoly of the LGBT population that has received a lot of support from the international agencies. UNAIDS has indicated that this is the population that you have to work with, as has UNFPA. The only voice that has spoken up for the issue of pregnant women and the importance of vertical HIV transmission has been, notoriously, UNICEF.⁴⁹

While the United Nations had pronounced itself in favour of SRH/HIV integration and the implementation of PTCT at the global level, this has not translated into strong and cohesive leadership at the national level in the countries studied.

Another aspect identified by Shiffman and Smith as important for generating political priority is civil society mobilization. Again, mobilization has been stronger and more effective at the global level than nationally or locally. At the supranational level, advocacy by the International Community of Women with HIV and AIDS (ICW) for the sexual and reproductive rights of women with HIV has garnered recognition from the United Nations and support from feminist, reproductive rights organizations.⁵⁰ However, at the country and community level, most Latin American women leaders with HIV continue to be fairly isolated and lack institutional support from either the broader HIV movement or the women's health movement. In the words of one woman leader with HIV who has worked as a "trainer of trainers" with her peers:

It doesn't work to do ten trainings in the capital, bringing a woman from each state, if you leave her all alone, shitting bricks [pariendo chayotes] in her state, or in her community.⁵¹

The most common organizational alternative for women with HIV is to participate in local mixed gender HIV organizations, which tend to be led by gay men. In these spaces, women living with HIV struggle to get their issues on the agenda. In one woman's words "*...discrimination is present there too. It is as if they say "this group is different, they are not like us", and they push us aside.*"⁵² Reflecting on the absence of reproductive rights from a manifesto on the rights of people living with HIV, which proclaims sexual rights, an allied HIV activist noted:⁵³

...the vision is clearly macho, from a masculine perspective, and furthermore a gay perspective. So, you see how we can eliminate certain issues or agendas or things, just because they aren't inside you. They aren't internalized.⁵⁴

While mutual support between people living with HIV exists, *“solidarity has limits. Everyone has their own agenda, and they have to fight for their agenda.”*⁵⁵

With respect to the broader women's movement, the continued perception that HIV is not a women's issue, HIV-related stigma and discrimination and class differences are barriers to coalition building. When feminists express surprise, shock, distaste or fear when HIV is mentioned, as in this account by a woman leader living with HIV, the idea that HIV is not a women's issue is perpetuated:

I once went to a training with feminists, with lesbians, and when I started talking speaking about HIV, they were terrified: “Omigod, we never thought HIV could happen to us”—it really surprised me.”⁵⁶

HIV-related stigma was identified as a barrier to collaboration, as in this comment by a feminist about why collaborations between women with HIV and feminists haven't prospered:

*When we share and dialogue as peers, I think that is when there will be better results. Because there are still people in the feminist movement that if they know the women [compañeras] have HIV, they put up a big wall. And they don't want to work with them, and they stay away from them.*⁵⁷

Both feminists and women living with HIV reported instances when members of the women's movement avoided physical contact and spatial proximity with women with HIV and feminist colleagues working with HIV-positive women. For example, a member of the women's movement asked a woman leader with HIV to co-present with her on the sexual and reproductive rights of women with HIV at a meeting of a feminist, professional organization. For the first time, her feminist peers “... never sat at the table with me [sic]. I felt discriminated against, I felt stigmatized—just for working on the issue.”⁵⁸

Class differences also make coalition building between women with HIV and feminists difficult. Latin American feminism is a heterogeneous movement but most leaders are educated professionals with excellent contacts inside governments and multilateral organizations.⁵⁹ In contrast, most women living with HIV in the region come from situations of social disadvantage.⁶⁰ Discussing a meeting with government officials and feminist leaders, women living with HIV spoke about struggling to gain respect for their proposals because they lack university degrees, but also disparaged feminists as “chalinitas” [little shawls] because they appropriate the shawls traditionally worn by indigenous women as adornment.⁶¹ Perhaps as a consequence of these social hierarchies, the leadership of women living with HIV tends not to be recognized by the broader women's movement: none of the international and regional champions for the integration agenda identified by feminist informants were HIV-positive women.

We also identified feminist organizations that were working “on HIV” without working with women living with HIV:

FEM: The idea of [the NGO] is precisely to train new leaders, so that new voices are heard. We have indigenous voices, we have union leaders, we have a bit of everything. [...]

INT: And has the organization ever considered women with HIV as a possible public for inclusion in your networks?

FEM: We work on HIV. These leaders have a menu of ten key issues that they have to discuss with civil servants, or health promoters, or in workshops, etc. And one of the issues is HIV and STIs.⁶²

The Greater Involvement of People with HIV (GIPA) principle is important because it can improve the relevance, acceptability and effectiveness of programs, in this case by bringing the need for and benefits of multiple linkages between SRH and HIV to the forefront. GIPA also destroys the stigmatizing assumption that the “experts” or “service providers” are HIV negative, while the “beneficiaries” are people with HIV.⁶³ The inclusion of HIV in the agenda of feminist SRH organizations without the corresponding inclusion of women with HIV and their perspectives is one reason that feminists who are engaging with HIV-positive women told us that there “*is no articulated response yet*” between the two movements.⁶⁴

In general, the level of collaboration reported by feminists and women living with HIV did not go beyond attending public marches or rallies to support the other movement. There are, however, some promising trends. In 2009, women living with HIV were included for the first time in the monitoring and evaluation of ICPD carried out by regional feminist networks. In the same year, an organized contingent of women living with HIV attended the regional *Encuentro* (an important event for feminist organizing) for the first time. Our research also identified instances of initially superficial involvement, such as attending the same marches, developing into more committed relationships. In one country, marches progressed to joint lobbying of legislators and then to women living with HIV challenging feminists to include them in their SRH agenda, by saying: “*If you, as feminists, as a women’s movement, are proclaiming the sexual and reproductive rights of women, where are we?*”⁶⁵ A coalition of women’s groups rose to the challenge which opened the door to provide technical support in gender analysis to women living with HIV. This support was perceived as valuable by women leaders with HIV and contributed to them developing a feminist analysis:

I think it has been years of women [with HIV] without any training. It is only now that we are learning that it is because we are women that we live in these conditions, and that it is related to questions of patriarchal power. We are also recognizing how institutions have created violence against women, unemployment, stigma and discrimination.⁶⁶

Another avenue for coalition-building identified during our research is relationships between women with HIV and lesbian feminists “*because HIV is very close to LGBTI, [...] when we L [lesbians] are there, we are the ones from the feminist movement who get together with the women with HIV.*”⁶⁷

In summary, the leadership and a cohesive policy framework for SRH/HIV integration generated at the global level in the United Nations system has not translated into strong guiding institutions at the country level in the eight Latin American countries studied. Nor has the integration agenda been prioritized by civil society organizations led by gay men or feminists. Women with HIV interact with both movements, but at the national and local level are relatively weak actors.

DISCUSSION AND CONCLUSIONS

At the international level, there is a strong impetus and global consensus on the importance of integrating SRH and HIV services, including PTCT, to achieve the MDGs. Commitment by members of PAHO to eliminate vertical transmission of syphilis and HIV by 2015 at the end of October 2010 provides a regional advocacy opportunity. A window of political opportunity is open.

Issue characteristics identified as barriers to the emergence of a cohesive policy community must be addressed in order to move forward. These include the perception that HIV among women and children is an insignificant public health issue, lack of awareness among stakeholders of the multiple benefits of implementing PTCT, and reductive conceptions of the SRH needs of women living with HIV. Greater awareness of existing evidence for the value of SRH/HIV integration in concentrated HIV epidemics and the current public health costs of inaction could lower some of these barriers. Findings that show the cost-benefit of universal voluntary HIV screening for pregnant women even in very low-prevalence HIV epidemics in high- and middle-income countries where highly active antiretroviral therapy is the standard of care need to be widely shared.⁶⁸ Also, stakeholders need to be sensitized to the fact that HIV and AIDS related maternal mortality made a significant contribution to overall maternal mortality rates in Guatemala, Nicaragua and Paraguay between 1990 and 2008.⁶⁹ And, a slow but steady rise in AIDS-related maternal deaths while other causes of maternal mortality have decreased has also been documented in other countries, such as Mexico.⁷⁰ Further, our research suggests that implementation of PTCT prevention can transform perceptions of the HIV epidemic among national decision-makers, inciting a virtuous cycle of action for women and children to replace the vicious cycle of omission.

We found that the multiple benefits of implementing PTCT and a comprehensive conception of the sexual and reproductive health needs and rights of women with HIV are marginalized discourses. The narrow and divisive framing of PTCT as infant health vs. women's rights rather than promoting the health of women, children and the community, and tensions over funding between SRH and HIV civil society, government programmes and UN agencies are significant impediments to the SRH/HIV integration agenda. International reviews have vindicated the generally positive effects of investments in HIV for health systems and demonstrated positive results of strengthening linkages between SRH and HIV for the quality of service delivery and some initial cost-benefit analyses.⁷¹ To generate a cohesive policy community for SRH/HIV integration in Latin America, these findings must be widely disseminated and more operational research on SRH/HIV integration must be conducted in concentrated HIV epidemics. Research and evidence-based dialogue may be a particularly effective platform for coalition-building. In other highly politicized settings, researchers have successfully brought together fragmented actors and provided technical support for coalition-building around women's health without being seen as competitors for scarce resources.⁷²

Based on their lived experience, women living with HIV perceive SRH/HIV integration as a priority but have faced challenges in attracting institutional support and political priority from the HIV and women's health movements. Within networks of people living with HIV, different perceived needs and priorities from the predominantly

gay male membership are barriers to prioritizing PTCT prevention and SRH/HIV integration. While feminists, including the authors, are working with women living with HIV at the country and regional level, generally speaking these are recent collaborations that haven't yet generated an articulated advocacy agenda between national networks of women living with HIV and the women's movement. Identified barriers to collaboration include the continued perception that HIV is not an important women's issue among feminists, HIV-related stigma, class differences, and lack of knowledge about the international conferences that form the backbone for the feminist SRH agenda among women with HIV. One of the key problems identified was that when feminists did work on HIV, they frequently did so without the meaningful involvement of HIV-positive women. GIPA can be an effective antidote to feminist perceptions of women with HIV as "other" and broaden understandings of the benefits of PTCT prevention and SRH/HIV integration.

In conclusion, we contend that demands for SRH/HIV integration articulated by women with HIV resonate with the stated objectives and master narratives of feminist women's health and HIV civil society. As such, this discourse could provide the "collective action frame" for the integration agenda in the region. In order to be ambassadors of the integration agenda and to dialogue with the feminist women's health movement and HIV civil society as colleagues and peers, women with HIV require specific training on the evidence-base for SRH/HIV integration and capacity building to frame their demands within the terms of the international conferences, including the MDGs.

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Table 1

Table 1	Bolivia ^a	Colombia ^b	Guatemala ^c	Honduras ^d	Mexico ^e	Nicaragua ^f	Paraguay ^g	Peru ^h	
Epidemiology of HIV among women¹									
HIV prevalence adults 15-49 (2008)	0.20%	0.60%	0.80%	0.70%	0.30%	0.20%	0.60%	0.50%	All <1%
Women with HIV	2,200	47,000	52,000 o	7,400	57,000	2,100	5,800	21,000	Total 194,500
Policy: Integration of HIV and reproductive health services									
Preventing parent-to-child transmission in the HIV Plan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Reproductive health of women with HIV mentioned in HIV Plan	No	Yes	Yes	No	No	Yes	No	No	37.5%
Family planning for women with HIV in HIV Plan	No	No	No	No	No	Yes	No	No	12.5%
Preventing PTCT in Reproductive Health Plan	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	87.5%
Reproductive health of women with HIV (including family planning) mentioned in Reproductive Health Plan	No	No	No	No	No	Yes	No	Yes	25.0%
Healthcare system capacity: Access to prenatal care, safe delivery, and antiretrovirals^l									
1 prenatal visit	77.2% (2008)	93.5% (2005)	84.3% (2002)	91.7% (2007)	86.1% (1995)	90.2% (2007)	94.2% (2004)	91.0% (2006)	88.5%
4 prenatal visits	57.9% (2003)	83.1% (2005)	No data	80.8% (2006)	No data	77.8% (2006)	78.8% (2004)	87.4% (2006)	77.63%
Skilled birth attendant	65.8% (2008)	96.4% (2005)	41.4% (2002)	66.9% (2006)	93.4% (2006)	73.7% (2006)	77.1% (2004)	71.0% (2006)	73.2%
% of people who with advanced HIV disease who require antiretrovirals and receive them	22%	38%	37%	47%	57%	30%	22%	48%	
Progress towards preventing vertical HIV transmission^k									
% of pregnant women with HIV who received antiretrovirals to prevent PTCT (2007)	No data	6%	7%	34%	5%	No data	No data	39%	18%

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