Problems and Recommendations to Improve the Quality of Health Care Services for Women Living with HIV/AIDS

Background

In Mexico, women and AIDS have little social visibility, which hinders timely and appropriate responses for women living with HIV or AIDS. Nevertheless, the epidemic’s growth in women is real, and it questions the response capacity of the different actors involved in treating HIV-positive individuals.

To mobilize and improve responses to problems that have arisen from the epidemic, there needs to be an assessment to identify the gaps and needs for prevention, treatment, and follow-up for women who are infected by the virus or who have AIDS. The assessment must take into account elements such as informed consent, confidentiality, non-discrimination, and the right to receive quality care for those who are HIV positive.

Other critical elements include resources to confront the experience of living with HIV/AIDS, services, and women’s access to these services. This study, undertaken with HIV-positive women, aims to understand the current situation and identify action to improve it by offering various recommendations to improve quality of care.
Study Objective

The study’s central objective was to document experiences of women living with HIV/AIDS, analyzing the underlying causes and related factors such as availability, access, effectiveness, and gaps related to health services for these women. This information was used to develop recommendations for appropriate and sensitive responses to these women’s needs related to health services and HIV prevention.

Methodology

The steps undertaken include:

1) A review of available literature on women and HIV/AIDS, treatment and support services, and Mexican norms for health service provision.

2) A review of interviews and findings from a previous situational assessment with 30 Mexican women living with HIV/AIDS.

3) Completion of seven in-depth interviews with HIV-positive women from Aguascalientes, Hidalgo, Guerrero, Mexico City, and State of Mexico.

4) Organization of a focus group with six women in Hidalgo. The interviews explored women’s views, perceptions, experiences, needs for health services, and access to these services. Organizations and activists who work in the field of HIV/AIDS contacted the women who participated in the study. The interviewees reflected the diversity of women affected by HIV. Although they were all HIV positive, they varied according to age, marital status, economic status, and the time elapsed since diagnosis.

5) Codification and analysis of interviews, including the focus group. After reviewing the transcripts, categories of analysis were defined to identify similarities and differences in service provision and use patterns.

6) Development of a series of recommendations to improve health services offered to women with HIV/AIDS, based on the situations most frequently reported, and the most pressing questions identified by the interviewees.

Findings

The governmental sector (health treatment, medical support) and civil society (education, emotional support, assistance) primarily offer services to Mexican women with HIV/AIDS.

Despite notable efforts of the government, civil society, and other sectors to respond appropriately to the problems stemming from the HIV/AIDS epidemic, documented experiences show that the current challenges in Mexico continue to be numerous and urgent.

One of the most valuable and needed efforts has been the establishment and distribution of health service guidelines for quality and respectful care for people with HIV/AIDS. Despite these guidelines, service provision and daily care practices fall below the established norm. Women participating in the study revealed the following as some of the most serious problems:
• Absence of prevention strategies that include women’s needs, context, and capacities.

• Tendency to delay diagnosis and relaying results, medical negligence, and a lack of sensitivity during the process, which represents an extremely painful experience for women.

• Health service providers have different care criteria and lack knowledge of quality standards.

• Poor quality health services that infringe upon women’s dignity.

• Lack of adequate emotional support and few safe, reliable arenas to discuss the experience of living with HIV/AIDS.

• Frequent resistance to drugs and adherence problems in environments with poor prescription capacity and little sensitive counseling.

• Stigma, discrimination, and mistreatment in health services particularly critical for women, such as gynecological and prenatal services. There are also contradictory practices within the medical system, which violate women’s reproductive and sexual rights.

All of the problems listed above are shadowed by unequal power relationships between health service providers and women living with HIV/AIDS. Many of the problems and obstacles reported by women relate to availability, use, and access to services. Other individuals living with HIV/AIDS commonly face these problems as well. Medical bureaucracy and the stigma associated with HIV/AIDS are among the underlying causes, revealing the widespread need to not only expand access, but also to improve the quality of available services and coordination between institutions to enhance, complement, and increase the services.

Women face bureaucracy, low-service quality, and the stigma associated with HIV/AIDS. These elements, combined with the poor visibility of HIV/AIDS in women and gender inequality, make their situation more serious, as they affect their health and life in an important manner. Some specific manifestations of this combination of factors include: a perception that women face low risks for HIV infection; a lack of power during sexual relations to demand the use of protection from their partner; a tendency toward delayed diagnosis in women; and the strong emotional weight generated by their health condition and poor quality services. Other factors include their weak economic power; the great social and familial responsibility that hinders women’s treatment of their own health; discrimination and mistreatment in reproductive health care, particularly in gynecology and prenatal care; and finally, the unequal power relationship between women and service providers.

After reviewing women’s common experiences, we can say that their needs are not being considered in the provision of and access to HIV/AIDS services. A gender perspective should be included immediately in discussions and activities for prevention and care services. In this vein, the following recommendations were derived from the study’s findings:

**Recommendations**

After reviewing women’s common experiences, we can say that their needs are not being considered in the provision of and access to HIV/AIDS services. A gender perspective should be included immediately in discussions and activities for prevention and care services. In this vein, the following recommendations were derived from the study’s findings:
Prevention

• Continue prevention programs to promote consistent condom use, along with the adoption of safe or protected sex practices.

• Overcome economic and cultural barriers that hinder access to family planning methods by guaranteeing the supply and distribution of high-quality male and female condoms. Prioritize the development of microbicides and other methods controlled by women.

• Intensify prevention campaigns to increase the perception of women’s risk of acquiring HIV/AIDS.

• Prevention campaigns should take into account cultural factors that impede women’s full knowledge of the risks they face with respect to HIV/AIDS and other sexually transmitted infections (STIs).

• Prevention programs should consider women’s obstacles to negotiating safe sex practices, including ways in which women can make these negotiations with their partners.

• Design prevention programs with a gender perspective, specifically geared toward overcoming the power differential between men and women. This difference has previously been ignored. One way to do so is to develop messages that directly discuss sexual inequality, with examples from women’s daily experiences.

• Design and publicize campaigns to ensure that women understand that love, marriage, or a stable partner does not guarantee that they are free from HIV/AIDS.

• Prevention programs should be directed toward increasing women’s self-esteem and confidence, recognizing the valuable role they play in society, and overcoming traditions that exclude them. For example, programs should emphasize that health care does not refer only to caring for others, but also caring for themselves.

• HIV-prevention programs should include education on other STIs and the need for treatment, given that a STI presence can be a risk factor for acquiring HIV.

• Public education and prevention campaigns should address exercising reproductive and sexual rights and the painful effects (often fatal, in the case of HIV) of unequal gender relationships.

Health Services Provision

• Guarantee that health services are offered within a framework of absolute respect for human dignity through humane, efficient, effective, confidential, dignified, and specialized treatment that responds to the women’s needs.

• Review the organizational factors—availability and administration of human and material resources, clear information, and policies—in health services with the aim of improving the effectiveness of existing resources, strengthening collaborations inside and outside institutions, and including a gender perspective in the design and supply of services.

• Develop and evaluate comprehensive service models with accessible prices for HIV-positive women and those with AIDS. HIV-positive women require diagnostic and specialized services such as: external consultations, pathology, odontology, psychology, gynecology, social work, and laboratory services. In addition, a variety of services should be accessible throughout the day, in order to overcome scheduling difficulties.
• Guarantee women’s voluntary and unconstrained access to HIV/AIDS testing services, which includes trained personnel to offer pre and post-test counseling.

• Establish mechanisms to improve pre- and post-test counseling. Improve the quality of information on HIV/AIDS that is offered on the individual and family level.

• Implement projects to integrate HIV/STI prevention, family planning, and maternal child care services.

• Ensure that medical systems offer support to women with HIV in their reproductive decisions, implying:

  a) respectful and effective prenatal supervision that includes access to prenatal prevention if the woman wishes to become pregnant;

  b) information and access to temporary or permanent birth control methods if an HIV-positive woman decides to prevent pregnancy;

  c) and respect and access to guidelines for interrupting pregnancy if the woman decides not to have a child.

• Improve counseling that is offered before medical intervention on issues such as pregnancy, breastfeeding, and birth control.

• Ensure the provision of family planning services for HIV-positive women, as well as information on alternative nourishment for their babies.

• Develop mechanisms that ensure users’ rights to share opinions on the way in which services are offered. Ensure that these opinions are respected and taken into account.

• Recognize quality indicators, such as respect for the users’ bodily privacy, service provision that accommodates women’s schedules, and users’ opinions on received services.

• Integrate prevention and treatment of HIV/AIDS and reproductive health care so that family planning, prenatal care, gynecology, and STI treatment includes information on HIV/AIDS. Ensure that these services are offered in a sensitive, non-discriminatory, high-quality manner.

• Guarantee women’s participation in all decisions related to the development, implementation, supervision, and evaluation of HIV/AIDS and other STI policies and programs.
Problems and Recommendations to Improve the Quality of Health Care Services

Health Personnel

- Identify reasons why health personnel have negative attitudes toward individuals infected with AIDS. Create educational interventions directed toward motivating health personnel to prevent HIV/AIDS and promote quality care of these patients.

- Establish and publicize mechanisms that define discrimination indicators between health providers and users.

- Sensitize and train health service providers. The most urgent skills needed include: clear criteria for the detection of HIV/AIDS in women, pre and post-test counseling, objective and encouraging diagnosis, prescriptions for HIV medication, and counseling on medication. The training should provide professional and economic incentives for those who attend, including a selection of personnel who show interest and willingness.

- Health personnel should be trained on reproductive and sexual rights, informed consent and informed choice, stigma and discrimination against people with HIV, and transformation of hierarchical relationships between providers and users.

- Create mechanisms to ensure respectful and egalitarian relationships between providers and users.

- Establish effective and independent mechanisms to ensure that users can complain when mistreated or offered poor service in health institutions.

- Develop models to measure the quality and friendliness of medical treatment. Offer incentives to health personnel that considerably improves their service.

- Based on Mexican guidelines for comprehensive and quality care, design and apply monitoring programs to ensure friendly treatment, along with giving service providers feedback to improve their performance.

- Include the following issues within health service providers’ training: men and women’s social construction of identity, the different values placed on men and women’s socially assigned roles and activities, the consequences of this inequality in sexual decision making (particularly for women), the overvaluing of maternity and marriage for women, and the legitimacy of experiencing pleasure within sexuality.
Investigation

- Carry out research to develop comprehensive health care models and evaluate the impact of these programs.
- Support research for the creation of accessible, women-controlled methods to prevent HIV and other STIs.
- Complete research on strategies that allow women to protect themselves from STIs, and on care, support, and treatment methods for women, guaranteeing their participation in all aspects of research.
- Support and begin research that details women's needs and situations that isolate them, along with male and female attitudes and high-risk practices.

Health Service Users and their Partners

- Support actions that guarantee women's rights to safe sexuality and autonomy in all related decisions.
- Conduct outreach with HIV-positive women on empowering strategies to confront and improve their relationship with service providers. Women can learn to play a more proactive role and improve health care and access to services if they understand the care standards; are conscious of their rights, including the right to decide over their own body and health; agree to processes that help them strengthen their self-esteem; increase their communication skills; and form allies inside and outside the medical system to overcome barriers and discrimination.
- Create practical, easy tools for women to help them monitor the care process. Using a framework of comprehensive care with a gender perspective, a simple health guide, notebook, or pamphlet should be distributed. This health guide should systematize the type of services, the time required, and the manner in which services should be offered.
- Catalyze men's participation as caretakers of women through workshops, informational materials, and direct interventions with men who accompany their partners to appointments.
- Increase consciousness among heterosexual and bisexual men on their risks for HIV.
- Develop strategies to encourage men's shared responsibility in reproductive and sexual health, including prevention of HIV.
- Support actions toward modifying men's behavior and attitudes to encourage the adoption of HIV-prevention methods.
- Foster exploration of men and women's perceptions of gender roles in order to recognize that male and female stereotypes can be oppressive and provoke irreversible damage, such as HIV infection.

Human Rights

- Guarantee that the human rights framework is the framework of reference for health service provision, thus securing respect for individual rights and confidentiality for those infected with HIV.
- Offer basic information on health services users' rights, the human rights of persons living with HIV/AIDS, and reproductive and sexual rights to both health service providers and users.
- Assure that HIV-infected individuals receive adequate medical care and are not subjects of discrimination.
• Support the development of compassionate, supportive, and non-discriminatory polices and practices on HIV/AIDS. These policies should protect the rights of infected individuals within all sectors of society, including the public sector as well as international organizations.

• Research human rights violations committed against women with HIV/AIDS and their family members.

• Create networks that document, support, and offer follow-up to promote legal and social resolutions for HIV-positive women who have suffered human rights violations.

Informed Consent

• Promote a culture of informed consent and choice within health care. Informed choice should not be limited to obtaining the user’s informed consent, but implies that providers and users have access to adequate information on problems, needs, and alternatives, which enables them to make effective and appropriate decisions together. Informed choice can offer great benefits toward improving treatment and overcoming adherence problems.

• Create mechanisms to ensure that individuals undergo HIV tests voluntarily, with full knowledge of the implications of positive results.

• Guarantee respect for the decisions made by HIV-positive women related to termination or continuation of pregnancy, and ensure that they have sufficient information to make these decisions.

• Guarantee respect for the decisions made by HIV-positive women related to treatment, and ensure that they have sufficient information to make these decisions.

Research and text: Hilda Pérez Vázquez and Rosario Taracena
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