Participatory Research Can Influence Policy: Using the Strategic Assessment of HIV/AIDS Transmission in Brazil's Border Communities for Policy Development

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Summary

This study demonstrates how incorporating stakeholders in planning and implementing a strategic assessment of HIV/AIDS afforded greater access to a variety of perspectives, facilitated consensus building, and allowed for greater impact on policy. The assessment was undertaken in border municipalities between Brazil and six of its neighboring countries. We found severe deficiencies in access to and quality of services, particularly in prevention, magnified by socio-economic contexts unique to the borders that increase residents' vulnerability to disease, such as proximity to and involvement with drug traffic, contraband, and sex commerce. Involving stakeholders throughout the research led to more inclusive results and better acceptance of the results by authorities, facilitating rapid incorporation of assessment recommendations into policy and program activities.

Introduction

Brazil was one of the first countries to attempt to mitigate the impact of the AIDS epidemic by implementing an innovative public health policy guaranteeing universal access to antiretroviral drugs for residents. This policy, along with aggressive prevention campaigns and the structuring of an STI/AIDS health service network, has resulted in a reduction of new

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cases and AIDS-related mortality since 1998.[1] Because case reporting is concentrated in the major metropolitan areas, there is no documented evidence regarding similar downward trends in smaller towns, rural areas, and the border communities.

Brazil shares 11473 km of borders with nine countries plus the Ultramarine French Department of Guiana. Most of the municipalities along the border present social, economic, and legal conditions that affect the transmission of HIV/AIDS. Most borders are open, with intense legal and illegal trade, including contraband, commercial sex and drug traffic. Significant proportions of people living in these areas are not legal residents, and therefore have limited access to educational and/or medical services (such as diagnosis or treatment). In addition, the border areas are the sites from which many Brazilians and foreigners travel to other regions of Brazil, increasing the possibilities of movement and dissemination of the disease throughout the country.

Because the National AIDS Program had incomplete and insufficient data on the situation of HIV/AIDS around the borders, they requested a diagnostic assessment be undertaken in six municipalities representing the diversity of the border regions before defining new policies and programs for these areas. The Strategic Assessment, the first stage in a three-stage strategy developed by the WHO[2] was deemed the most appropriate method to inform programmatic and policy decisions.

Materials and Methods

The Strategic Assessment is a participatory, multidisciplinary, and rapid research tool that is implemented on the basis of collective decisions with stakeholders and executed to inform policy makers. The participatory process in a Strategic Assessment begins with the stakeholders' meeting, which provides the forum for developing priority strategic questions that will direct the fieldwork and define problem-solving strategies. The Stakeholders meeting in Brazil gathered an interdisciplinary group of professionals from the governmental and private sectors. Among the stakeholders were professors of medicine and public health, experts in gender studies, reproductive health, geography, epidemiology, economics, indigenous health, HIV/AIDS program managers, organizations working in HIV prevention with commercial sex workers (CSW), MSM, and adolescents, members of the National AIDS Program, donor and advocacy agencies (UNAIDS, USAID), and researchers participating in the fieldwork.

During the meeting, the Stakeholders defined the following strategic questions to guide the research: 1) Is there a need to improve the quality of or implement new actions in prevention, diagnosis, and treatment of STI/HIV/AIDS at the borders? 2) Is there a need to create or implement specific programs to combat STI/HIV/AIDS for mobile or vulnerable populations at the borders? 3) Is it necessary to improve collaborative

efforts in the area of STI/HIV/AIDS with neighboring countries?

The data collection and analysis process combines a review of published literature and quantitative data (National AIDS Program's data bank, DHS surveys, and municipal data on reportable conditions), with collection and analysis of qualitative data compiled during the fieldwork (principally individual and group interviews and service observations). Multidisciplinary teams, trained by experts in the methodology, implemented the fieldwork in Foz do Iguaçu (bordering Argentina, Paraguay), Uruguaiana (Argentina), Corumbá (Bolivia), Guajará-Mirim (Bolivia), Tabatinga (Colombia, Peru), and Oiapoque (French Guiana), through a collaborative process involving stakeholders from each location. STI/AIDS program staff, community leaders, and secretaries of health participated in the preparation of the fieldwork agenda, in coordination of the fieldwork, and as interviewees.

The fieldwork teams spent a minimum of five days in each municipality, visiting health and social service locations, areas where vulnerable and mobile populations congregate, and interviewing community members, service providers, civil, religious and political leaders. Each research team completed a summary of the findings based on analysis variables, including quality of care, access to HIV/AIDS services, availability of reproductive health services, human and materials resources, environmental factors shaping vulnerability to HIV/AIDS, social mobilization, and international collaboration. Population Council representatives wrote the municipal reports, which were reviewed by all fieldworkers, and prepared a summary project report for discussion at the second stakeholders meeting.

Results

Results were presented at the second stakeholders meeting, or the dissemination seminar, which took place in Brasilia in May 2002. Among principal findings, the study documented severe deficiencies in quality and access to health services, with a concentration of HIV/AIDS related activities in HIV/AIDS specific service centers. This centralization has translated into a paucity of outreach to vulnerable groups, low prioritization of prevention, and is aggravated by a complete lack of integration of thematic content (such as dual protection) within services. Insufficiencies in HIV programs are magnified by the social and economic contexts at the borders, which increase residents' vulnerability to disease, such as proximity to and involvement with drug traffic, contraband, intense commercial sex trade, and a number of populations without legal residence. In addition, analyses of local data indicate that the epidemic in the border areas does not match the parallel national decrease in new AIDS cases; instead, data from the border municipalities evidence an epidemic that is still on the rise.

The dissemination seminar included the participation of the stakeholders from the first meeting in addition to state HIV/AIDS program representatives,

HIV/AIDS program and NGO representatives from study municipalities, and an expanded number of national and international NGO representatives, including representatives from WHO, PAHO, and UN agencies. After discussing the study findings and considering parallel efforts to combat the AIDS epidemic around border areas, the participants proposed a series of recommendations. Recommendations include: the prioritization of prevention efforts, especially with CSW, truck drivers, adolescents, and other marginalized populations; the need to implement and operationalize a national policy for HIV/AIDS actions at the borders; integration of HIV prevention efforts into the health system, including incorporation into the reproductive and family health programs; increased support for CBOs and NGOs; the creation of a task force on HIV/AIDS activities at the borders; and support for further research with border populations.

Conclusions

The assessment succeeded in identifying the major factors influencing HIV/AIDS transmission at the borders and in prioritizing programmatic, policy, and research recommendations built on consensus. It was clear that the participation of a wide range of stakeholders from the beginning of the process was critical for successful execution of the project. First, stakeholders were of invaluable importance in identification of key themes for investigation in the field, and for facilitating entry into the varied communities affected by HIV/AIDS in the heterogeneous border areas.

Second, working intimately with local stakeholders ensured municipal ownership and serious contemplation of the findings. Researchers were viewed as partners in the search for solutions to community-identified problems. Once the reports were distributed to the participating municipalities, program coordinators and secretaries of health felt that the documents accurately described their situation, provided a critical and useful examination of their programs, and most importantly, the stakeholders felt that the research offered a vehicle for change, with executable recommendations for programs and policy. Immediately following the fieldwork, the Coordinator of the AIDS Program in one municipality implemented an itinerant HIV/AIDS service to provide attention to incarcerated men and women, as a number of HIV positive inmates were not receiving services prior to the assessment. Simply identifying this problem in conjunction with the authorities was enough stimulus to bring about a new program.

Third, the vital and consistent participation of the National AIDS Program and the involvement of other international agencies such as USAID, PAHO and UNAIDS member agencies, validated the findings and increased the possibility of promoting international collaboration, further facilitating an immediate response to the recommendations. A number of actions were implemented even before the second stakeholders meeting took place. For example, continued participation of the USAID Mission resulted in

an agreement to finance two major prevention campaigns with truck drivers and CSW before publication of the findings. The Ministry of Health has pledged to provide necessary resources for increased STI/HIV testing and treatment linked to the USAID projects. Additionally, the National AIDS Program is now awarding increased project funds for preventative efforts in border municipalities and discussion is currently underway with UNFPA to support parallel activities in Bolivia.

Overall, the Strategic Assessment has proven an invaluable tool in bringing together key decision makers, donors, community members, and researchers in defining priorities for HIV/AIDS related programs and policies. The participatory process rapidly led to an understanding of the multiplicity of contexts, situations, populations, and resources available around the borders and to the prioritization of efforts, which have already begun. The assessment report will be published and disseminated nationally and internationally and will serve as a guide for policy development for HIV/AIDS prevention and services at the borders in coming years.

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