II. STUDY METHODS

Purpose

he goal of the Botswana/Swaziland study was to understand the effects of women's social, economic and legal status on HIV/AIDS; assess current attitudes, policies, and practices; and propose pragmatic solutions to protect and promote the health and human rights of women and men in Botswana and Swaziland.

To this end, qualitative and quantitative fieldwork was designed to: 1) identify and understand the barriers and facilitators to HIV prevention, testing and treatment in Botswana and Swaziland and how these may differ for women and men; 2) assess the attitudes of the general population towards PLWA in Botswana and Swaziland and describe how stigmatizing attitudes may relate to prevention and access to care; 3) describe the relationship between rights and prevention, testing and treatment; in particular, the ways that women's legal status and traditional customary practices relate to HIV risk for women and men: 4) formulate recommendations based on these findings and based on the opinions of Batswana and Swazi study participants who assessed the strengths and weaknesses of leadership in addressing the HIV/AIDS epidemic in each country.

Subjects

Participants in the surveys and qualitative interviews were women and men, ages 18-49. Participants were excluded if they did not meet the age criteria for the study, had cognitive disabilities, did not speak either English or Setswana (in Botswana) or siSwati (in Swaziland), were not residents of the country or if there was inadequate privacy to conduct the survey or qualitative interview. Participants in the community surveys were not asked to disclose their HIV status; participants in the PLWA interviews self-identified as HIV-positive.

Key informants were individuals and representatives from a range of organizations including local NGOs, international agencies and government offices. Agencies included those that provide health services related to HIV/AIDS or support for PLWA, devise policies and programs for the prevention and treatment of

HIV/AIDS, engage in community mobilization or human rights advocacy, or work in women's empowerment, development or other relevant areas.

Sampling

Botswana Community Survey

The Botswana community survey sample was a probability sample of 1,268 adults selected from the five districts of Botswana with the highest numbers of HIV-positive individuals. The Botswana Central Statistics Office at the Ministry of Finance and Development Planning assisted with the design of the sampling frame and the provision of maps. The five districts were Gaborone, Kweneng East, Francistown, Serowe/Palapye and Tutume; they represent a population of 725,000 in the eastern corridor of the country, out of a total population of 1.64 million.

A stratified two-stage probability sample design was used. In the first stage of sampling, 89 enumeration areas were selected with probability proportional to measures of size, where measures of size were the number of households in the enumeration area as defined by the 2001 Botswana Population and Housing Census. Out of 89 randomly selected enumeration areas, 69 were from large urban settlements and small urban villages, and 20 were from rural villages, agricultural lands and cattle posts.

At the second stage of sampling, households were systematically selected in each enumeration area by trained field researchers under the guidance of field supervisors. With a target sample of 1,200 households and 15 percent oversampling (for an anticipated 85 percent response rate), 1,433 households were selected. Within each household, random number tables were used to select one adult resident from a list of residents meeting the study criteria for subjects. Up to two repeat visits were made to the household to survey that person.

Swaziland Community Survey

The Swaziland community survey sample was a probability sample of 788 adults selected from all four regions of Swaziland (Hhohho, Lubombo, Shiselweni

and Manzini), with a combined population of less than 1.2 million people. The Swaziland Central Statistical Office assisted with the design of the sampling frame and the provision of maps; a stratified two-stage probability sample design was used. In the first stage of sampling, 54 enumeration areas were selected with probability proportional to measures of size, where measures of size were the number of households in the enumeration area as defined by the 1997 Swaziland Population and Housing Census. Out of 54 randomly selected enumeration areas, 31 were from urban and peri-urban areas and 23 were from rural villages. 109

At the second stage of sampling, households were systematically selected in each enumeration area by trained field researchers under the guidance of field supervisors. With a target sample of 800 households and a 10 percent oversampling (for an expected 90 percent response rate), 876 households were selected to participate. Within each household, random number tables were used to select one adult resident from a list of residents meeting the study criteria for subjects. Up to two repeat visits were made to the household to survey that person.

Botswana and Swaziland PLWA Interviews

A purposeful approach was used to identify HIV-positive women and men in Botswana and Swaziland for qualitative interviews regarding their experiences and perspectives. The 24 Batswana respondents were HIV-positive members, leaders, volunteers or counselors from support groups for people infected or affected by HIV/AIDS from Gaborone, Serowe and the surrounding villages and rural areas. The 58 Swazi participants were drawn from patients visiting the Mbabane VCT center, those attending support groups in the Mbabane and Manzini areas, and referrals from health care workers and NGO representatives providing HIV-related services, including PMTCT. This sample included people from diverse geographical areas in Swaziland.

Botswana and Swaziland Key Informant Interviews

Thirty-eight key informants from Botswana and Swaziland were identified for their expertise in HIV/AIDS, human rights, gender, health services and other fields relevant to the subject of the study.

Survey Questionnaires and Interview Instruments

All surveys and semi-structured interview instruments are included in the Appendix to this report.

Domains of inquiry for the study included: a) demographics; b) food insufficiency; c) knowledge of HIV transmission and prevention; d) availability of HIV testing and treatment and experiences with testing; e) gender-specific barriers to prevention, testing and treatment; f) HIV/AIDS-related stigma, including participants' attitudes towards PLWA and (for PLWA only) experiences with poor treatment; g) depression symptoms; h) HIV-related risk behaviors and sexual practices; i) attitudes towards women and beliefs about gender roles and norms; j) participants' recommendations regarding decreasing women's and men's risk of HIV and eliminating barriers to prevention, testing and treatment; and l) participants' assessment of leaders' efforts to address the HIV/AIDS crisis.

Community Surveys

The surveys consisted primarily of close-ended questions. The questionnaires were written in English, one of two official languages in each country, translated into Setswana (in Botswana) and siSwati (in Swaziland), and back-translated into English. The community surveys were piloted with 20 individuals from Gaborone, Botswana and 29 in Mbabane, Swaziland and surrounding areas. Revisions were made for clarity and cultural appropriateness based on the pilot testing. Researchers administered the survey in the language chosen by the participant. All answers were recorded on English language surveys and reviewed in the field for completeness by the researchers and checked daily by supervisors. Researchers returned to households to complete incomplete interviews when feasible. Surveys took approximately 45-60 minutes.

PLWA Interviews

For the qualitative interviews in both countries, semistructured surveys consisting primarily of open-ended questions were used. In Swaziland certain close-ended questions adapted from the community survey were added to the instrument. The interview instruments were written in English and administered by PHR staff or consultants, working with one of the trained local field researchers as a translator when needed. Interviews lasted 45-60 minutes. The exact words (translated if necessary) of participants are used as testimony in the findings wherever possible to give full expression to participants' ideas and narratives.

Key Informant Interviews

Key informants were interviewed with a semi-structured instrument consisting of open-ended questions.

All key informant interviews were conducted by PHR staff or consultants in English, lasted approximately 45-90 minutes and took place in the workplace or another private setting chosen by the participant. In the results, where possible, the exact words of participants are used in quotations.

Interviewer Training

The Botswana community surveys were conducted by 26 Batswana women and men trained by the PHR/University of Botswana field team in Gaborone, Botswana. The Swaziland community surveys were conducted by 21 Swazi women and men trained by the PHR/WLSA field team in Mbabane, Swaziland. All local field researchers had prior survey experience and many had expertise in HIV/AIDS. The training, which included detailed instruction in the study protocols and research ethics, consisted of classroom teaching and role play for 4 days in Botswana and 2 days in Swaziland, followed by field practice in interviewing and continuous field supervision throughout the study. Additional training was given to field researchers interpreting or administering PLWA interviews in Swaziland. Three to 5 members of the field team served as field supervisors in each country. The supervisory team had extensive expertise in applied research, human rights, gender, mental health and HIV/AIDS.

Data Collection

In Botswana, the community surveys and PLWA interviews were administered in November and December 2004. In Swaziland, the community survey and the PLWA interviews were conducted in May 2005. Key informant interviews were conducted in September 2004 in Botswana and in March and May 2005 in Swaziland.

Human Subjects Protections

This research was conducted in accordance with the Declaration of Helsinki (as revised in 2000). The Botswana research protocol was reviewed and approved by the Human Subjects Committee at the University of California, San Francisco and the Botswana Ministry of Health Research and Development Committee. The Swaziland research protocol was reviewed and approved by an Ethics Review Board convened by PHR consisting of individuals with expertise in public health, clinical medicine, bioethics, gender, HIV/AIDS and international human rights research, including the cofounder of a Swazi PLWA support group, faculty from

the University of Swaziland and UN country representatives. The research protocol and instruments were additionally approved by the chair of the newly reconstituted Ethics Committee of the Swaziland Ministry of Health.

Written consent was obtained from participants in the Botswana community surveys and the Botswana PLWA interviews in either English or Setswana, depending on the preference of the participant. Oral consent was obtained from Swaziland community survey and PLWA interview respondents and from key informants in both countries. Participants were informed of the purpose of the surveys and interviews in general terms and how the data would be collected and used. Participants in the community surveys were informed that they would not be asked to disclose their HIV status. Participants in the PLWA interviews who were referred by treatment clinics or other organizations were assured that any services that they were receiving would not be affected in any way by participating or refusing to participate in the study.

All interviews (except key informant interviews) were anonymous and all were conducted in a private setting. At the conclusion of the survey or interview, participants (except key informants) were offered literature regarding HIV/AIDS testing, prevention and treatment, and information concerning domestic violence victims' assistance. Respondents who self-identified in the depression symptoms screen as having suicidal thoughts were referred by field interviewers to one of the clinician field supervisors.

Study subjects were not compensated. Participants in the surveys received a token gift of a value equal to or less than US\$1-2 after the completion of the interview and were not informed of this beforehand. Participants in the PLWA interviews were given money for transport, and a snack and beverage were made available during the interview and while waiting.

Statistical Analysis

The survey data were analyzed using STATA statistical software. 110 Descriptive statistics were used to characterize the study populations and distribution of responses. Multivariate logistic regression analyses were employed to examine factors associated with testing, holding gender discriminatory beliefs and sexual risk. Pearson chisquare tests of association were used to determine differences in responses based on gender or other respondent characteristics (testing/not-testing, for example) and two-sample t-tests were run for comparison of means. Based on literature reviews and consultations with colleagues, a conceptual model was developed to guide the selection of variables for the multivariate models. Relevant variables are explained in the findings sections. For all statistical determinations, significance levels were established at p \leftarrow 0.05. Regression diagnostic procedures yielded no evidence of multi-collinearity or overly influential outliers in any of the models.

Limitations

Given the cross-sectional nature of the study, the direction of causality cannot be established from the findings. The prevalence of sexual and other gender-based violence and risk-taking sexual practices or circumstances were likely under-reported due to the intimate and/or stigmatized nature of these experiences and the likelihood that participants in a brief survey would be reluctant reveal such matters to field researchers. In addition, given widespread awareness of the existence of the HIV/AIDS epidemic in both countries, participants' responses may have been biased by a desire to give socially "correct" answers or please interviewers on matters related to testing, prevention and attitudes towards those living with HIV/AIDS. They may therefore have overreported their engagement in safe sex practices, willingness to test, support for PLWA and related matters. To minimize self-report bias, measures to safeguard the privacy of the interview and assurances of anonymity and confidentiality were incorporated into the study protocol.

Generalizability of Study Results

A random sample design was used in order that the community survey results would be generalizable to the five districts with the highest prevalence of HIVpositive individuals in Botswana and to a nationally representative sample in Swaziland. Because individuals from the most remote areas in Botswana and the company town communities in Swaziland were excluded, the results may not be generalizable to the entire Motswana and Swazi populations.

Testimony from the Botswana and Swaziland PLWA interviews, each a convenience sample, only represent the views and experiences of those who participated in the study. HIV-positive individuals who have ascertained their status and made some disclosure to others, and who have joined support groups or accessed services, are likely to be different from those who have not. Moreover, those who agree to be interviewed and desire to share their stories may have a different perspective and distinct experiences from those who did not make themselves available or were not presented with the opportunity to speak with researchers in the limited time period for data collection.

While the results of the Botswana and Swaziland PLWA interviews were not intended to represent larger populations of PLWA, comparison of these assessments along consistent domains of inquiry with the responses in the community surveys allowed PHR to consider converging and diverging lines of evidence. These interviews assisted in the interpretation of the findings of the community inquiries by providing insight into the patterns of experiences of those infected and affected by HIV/AIDS. Likewise, the key informant interviews, while not an exhaustive survey of expertise on gender and HIV/AIDS in Botswana and Swaziland, comprise a credible contribution, framed by background research, to assist in understanding the data collected. These interviews also assisted with the formulation of a range of recommendations to address the health and human rights concerns documented in this report.

Notes

¹⁰⁹ The Swazi population is classified at the household level, into regular and irregular households; the latter, which comprise compounds like teachers' quarters, boarding schools and military barracks, are generally excluded from household-based sampling frames. Company towns, where laborers for a particular corporation live, with or without their families, may be classified as either regular or irregular households, depending on whether they comprise individual houses or compounds. All irregular households and company towns were excluded from the PHR study sample, the latter given difficulties in obtaining access and the consideration that residents may differ from the general population in ways that could bias study responses.

 $^{\rm 110}$ STATA 9.2 (Intercooled) for Windows. STATA Corporation, College Station, TX, 1984-2006.