

Epidemic of Inequality

Women's Rights and HIV/AIDS in Botswana & Swaziland

An Evidence-Based Report on the Effects of Gender Inequity, Stigma and Discrimination

Epidemic of Inequality

Women's Rights and HIV/AIDS in Botswana & Swaziland

An Evidence-Based Report on the Effects of Gender Inequity, Stigma and Discrimination

© 2007, Physicians for Human Rights Cambridge, Massachusetts All rights reserved. Printed in the United States of America

ISBN: 1-879707-51-9

Library of Congress Control Number: 2007928206 Design: Glenn Ruga/Visual Communications

PHYSICIANS FOR HUMAN RIGHTS

hysicians for Human Rights (PHR) mobilizes health professionals to advance health, dignity, and justice and promotes the right to health for all.

Since 1986, PHR members have worked to stop torture, disappearances, and political killings by governments and opposition groups and to investigate and expose violations, including: deaths, injuries, and trauma inflicted on civilians during conflicts; suffering and deprivation, including denial of access to health care caused by ethnic and racial discrimination; mental and physical anguish inflicted on women by abuse; exploitation of children in labor practices; loss of life or limb from landmines and other indiscriminate weapons; harsh methods of incarceration in prisons and detention centers; and poor health stemming from vast inequalities in societies.

PHR's Health Action AIDS campaign works to engage the US health professional community in international advocacy and education to stop the global AIDS pandemic. The project's objectives include: organizing a large-scale education initiative to raise awareness in the health professions and mobilize support for a comprehensive AIDS strategy; urging the US

government to increase its financial commitments to the Global Fund to Fight AIDS, Tuberculosis and Malaria; providing up-to-date research on the connection between human rights and AIDS; and developing opportunities for health professionals in the US to support AIDS activists around the world.

As one of the original steering committee members of the International Campaign to Ban Landmines, PHR shared the 1997 Nobel Peace Prize.

Physicians for Human Rights 2 Arrow Street, Suite 301 Cambridge, MA 02138 Tel. (617) 301.4200 Fax. (617) 301.4250 www.physiciansforhumanrights.org

Washington, DC Office: 1156 15th Street, NW, Suite 1001 Washington, DC 20005 Tel. (202) 728.5335 Fax. (202) 728.3053 www.physiciansforhumanrights.org

CONTENTS

Acknowledgementsix		V. Botswana Recommendations	
		To the Government of Botswana	63
_	-	To the US Government	64
I.	Executive Summary1	To All Donors	65
II.	Study Methods	W.C. ''. IO. I. D. I.	/8
	Purpose	VI. Swaziland Country Background	
	Subjects19	Map of Swaziland	
	Sampling	Geography and Population	
	Survey Questionnaires and Interview	History and Politics	
	Instruments	Health Care System	
	Interviewer Training	HIV/AIDS Epidemic	
	Data Collection	Swaziland HIV/AIDS Policy	
	Human Subjects Protections21	Women's Status	
	Statistical Analysis	VII. Swaziland PHR Study Findings	87
	Limitations	Characteristics of Study Participants	
	Potowana Country Packground 22	HIV Knowledge	
••••	Botswana Country Background 23	HIV Testing	
	Map of Botswana	HIV-Related Stigma and Discrimination	
	History and Politics	Sexual Practices: Risk-taking and	75
	Economy	Risky Circumstances	99
	Health Care System	Gender Norms and Beliefs and Perceived	, ,
	HIV/AIDS Epidemic	Vulnerability to HIV/AIDS	10%
	Botswana HIV/AIDS Policy25	Leadership on HIV/AIDS in Swaziland	
	Women's Status	Conclusion	
IV.	Botswana PHR Study Findings 39		
	Characteristics of Study Participants 40	VIII. Swaziland Recommendations	
	Access to ARV Treatment41	To the Government of Swaziland	
	HIV Knowledge	To the US Government	
	HIV Testing43	To All Donors	121
	HIV-Related Stigma and Discrimination49	IX. The Human Rights Framework and	its
	Sexual Practices: Risk-taking and	Application to the Findings	
	Risky Circumstances53	Relevant Treaties	
	Gender Norms and Beliefs and Perceived	Additional Human Rights Obligations	124
	Vulnerability to HIV/AIDS56	Key Rights and Application to the	
	Leadership on HIV/AIDS in Botswana60	Study Findings	125
	Conclusion61	Equality and Non-Discrimination Based on Sex	125
		Non-Discrimination and Rights to Equal	IZJ
		Protection Based on HIV/AIDS Status .	127

Relevant UN Guidelines	
International Organizations 131	
Conclusion	
Appendix135	
Botswana Community Survey	
Botswana PLWA Interview151	
Botswana Key Informant Interview	
Swaziland Community Survey	
Swaziland PLWA Interview	
Swaziland Key Informant Interview 191	

GLOSSARY

Definitions

Agency: Having the empowerment and authority to make decisions and act on one's own behalf.

Batswana: Persons from Botswana (plural of Motswana).

Discrimination: Unfair or bad treatment directed at those who belong to, or are perceived as belonging to, a marginalized group, such as women or people living with HIV or AIDS. Discrimination reinforces social stereotypes and inequities and, for populations marginalized on more than one basis (for example, women living with HIV/AIDS), it has a harmful multiplicative effect.¹ Discrimination based on "race, color, sex, language, religion, political or other opinion, natural or social origin, property birth or other status" is prohibited under international human rights law.²

Food Insufficiency: The condition of not having a quantity of food available to meet the hunger or nutritional needs of an individual at any time in the past 12 months.

Gender: A social and cultural construct; the widely shared expectations and norms within a society about appropriate male and female behavior, characteristics, roles and relationships.³

Hunger: The uneasy or painful sensation caused by the lack of food.

Routine Testing: In general, HIV testing in the context of a health services visit for primary care or other routine clinical care, such as antenatal appointments. Routine testing can be "opt-out" (health worker-initiated testing which is done unless the patient refuses) or "opt-in" (testing to which the patient affirmatively consents). This is a broad policy category encompassing many definitional variables, including the existence or types of symptoms presented by the patient, the national context (HIV prevalence and treatment availability, for example) and standards for counseling and informed consent. The chief distinction is with voluntary counseling and HIV testing (VCT), which takes place in a stand-alone facility created exclusively for the purpose of HIV testing, and in some contexts, follow-up AIDS treatment or other HIV-related care.

Sex: A biological category, defined by characteristics related to reproduction (e.g., male or female).

Sexual Risk-Taking: Practices or circumstances that are likely to expose an individual to the risk of HIV transmission through sexual intercourse; markers or predictors for sexual intercourse without a condom with a person infected with HIV. These include having multiple sexual partners, having a relationship with an older and more experienced partner ("intergenerational relationships") where the younger partner is also likely to lack control over condom use and other aspects of the relationship, and other intimate relationships where the partner, and not the individual herself, makes decisions regarding sexual matters ("lack of control").

Stigma: A loss of status and the social sanctioning of prejudice, domination and inequity based on membership in a particular group. ^{4,5} Stigma arises when a community or authority links social differences to negative stereotypes and categorizes these "others" as different from and inferior to themselves. HIV-related stigma developed out of an early association of AIDS with already marginalized populations — the poor, ethnic minorities, women, men who have sex with men, sex workers and IV drug users — as well as the association of AIDS with death. ⁶

Southern Africa: This region includes Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe. Some lists also include Madagascar.⁷

Sub-Saharan Africa: This region encompasses fortyseven countries including the southern African countries.⁸

Vulnerability: The risk of being exposed to HIV infection, including due to social factors and determinants in the external environment which are beyond an individual's control. Women and girls are a population group with an elevated vulnerability to HIV infection as a result of unequal gender relations and entrenched gender inequity and sex discrimination.⁹

Acronyms

ACHPR: African "Banjul" Charter on Human and

Peoples' Rights

ACRWC: African Charter on the Rights and Welfare of

the Child

AIDS: Acquired Immune Deficiency Syndrome

AOR: Adjusted odds ratio

ARV: Anti-retroviral

CEDAW: Committee on the Elimination of Discrimina-

tion against Women

CHR: UN Commission on Human Rights

CI: Confidence interval

CRC: Committee on the Rights of the Child

CSO: Civil society organization

GDP: Gross domestic product

HIV: Human Immunodeficiency Virus, the cause of

AIDS

ICCPR: International Covenant on Civil and Political

Rights

ICESCR: International Covenant on Economic, Social

and Cultural Rights

NACA: National AIDS Coordinating Agency (Botswana)

NERCHA: National Emergency Response Council on

HIV/AIDS (Swaziland)

NGO: Non-governmental organization

PEPFAR: (United States) President's Emergency Plan

for AIDS Relief

PHR: Physicians for Human Rights

PLWA: People living with HIV or AIDS

PMTCT: Preventing mother-to-child transmission

PPACHPR: Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa

SADC: Southern African Development Community

TCM: Total Community Mobilization

UDHR: Universal Declaration of Human Rights

UNAIDS: The Joint United Nations Programme on

HIV/AIDS

UNDP: United Nations Development Programme

UNFPA: United Nations Population Fund

UNICEF: United Nations Children's Fund

VCT: Voluntary counseling and HIV testing

WFP: World Food Programme

WHO: World Health Organization

WLSA: Women and Law in Southern Africa Research

Trust

ACKNOWLEDGEMENTS

his report was written and edited by Karen Leiter, JD, MPH, Senior Research Associate, Physicians for Human Rights (PHR) with substantial contributions by Amy Senier, joint Masters/JD student at the Fletcher School of Law and Diplomacy and Northeastern University Law School (Botswana and Swaziland Backgrounds, Human Rights Framework); Lynley Rappaport, MPH, Consultant, PHR (Botswana and Swaziland Backgrounds and Study Findings); Leonard Rubenstein, JD, Executive Director, PHR (Executive Summary); Vincent Iacopino, MD, PhD, Senior Medical Advisor, PHR (Human Rights Framework); and Ingrid Tamm, MS, Consultant, PHR (Botswana Study Findings).

Contributions to the Botswana community survey analysis were drawn from draft manuscripts by Sheri Weiser, MD, MPH, Epidemiology and Prevention Interventions Center and Center for AIDS Prevention Studies (CAPS), University of California, San Francisco. The PLWA testimony was drawn from written analyses prepared by Fiona Percy-de Korte, MBA, DPh, Consultant, PHR (Botswana) and David Tuller, Consultant, PHR (Swaziland) and from PLWA data analysis contributed by William Wolfe, MD, Department of Psychiatry, University of California, San Francisco (Swaziland). Key informant interview analysis for Swaziland was contributed by Ms. Senier. The authors are grateful to the participants in the Gender and HIV Workshop, co-sponsored by PHR and the Centre for the Study of AIDS at the University of Pretoria, South Africa, 15-17 November, 2006, for their contributions to the report recommendations. The authors thank Kate Krauss, Health Action AIDS Media Relations Coordinator, PHR, for her contribution to the US recommendations. The authors also thank the Gender and PEPFAR Working Group of the Global Health Council for sharing their draft recommendations for PEPFAR reauthorization.

A background chapter on HIV/AIDS in Southern Africa [available on the PHR website, www.physiciansforhumanrights.org] was written and edited by Ms. Leiter with Ms. Senier, Ms. Rappaport, Mr. Tuller and Madhavi Dandu, MD, MPH, Division of General Medicine, Department of Internal Medicine, University of Michigan. Dr. Weiser reviewed the chapter.

The report is based on a study conducted by Ms. Leiter, Dr. Weiser, Dr. Percy-de Korte and (in Botswana) Nthabiseng Phaladze, PhD, RN, Department of Nursing Education, University of Botswana and (in Swaziland) Zakhe Hlanze, MA, Women and Law in Southern Africa Research Trust — Swaziland (WLSA), Mr. Tuller and Dr. Wolfe, and local field researchers. The authors are very grateful for the hard work and dedication of these local researchers. In Botswana: Tefo Atholang, Lillian Buzwani, Bettsally Chemutai, Diane, Elton Katlholo, Lesley Kentse, Bonolo Kgabaetsile, Sellah Lusweti, Onneetse Makhumalo, Victor Makwati, Mpho Masale, Jobela Masole, Kaone Matswiki, Khumo Mokane, Lebogeng Mokhure, Duduetsang Molephe, Obonye Monamati, Geoffrey Nkoro, Matshidiso Nthela, Kelebile Nthomiwa, Onkabetse Obe, Mpho Kennedy Okopeng, Frank Radebe, Kgalalelo Seanana, Rachel Taukobong and Kagiso Tlhalogang.

In Swaziland: Cebile Dlamini, Khangezile Dlamini, Lungile Dlamini, Sakhile Dlamini, S'bongile Dlamini, Sindi Dube, Gugu Gumedze, Nondumiso Hlanze, Thobile Khumalo, Lwati Manana, Cebile Manzini, Sikelela Mazibuko, Sibonelo Mdluli, Philile Mlotshwa, Sithembiso Nhlengethwa, Hlobsile Nkambule, Nomakhosi Nxumalo, Bonginkosi Sengwayo, Dumsani Sithole, Jabulile Tsabedze and Phumelele Thwala.

The authors also thank the drivers: Joe Ramhago, Paul Letshotelo and Enoch Ngwenga (Botswana), Mazoco Dlamini and Samuel Gama (Swaziland).

Many individuals assisted with the realization of the two investigations. The authors would like to thank the following individuals and organizations for their contributions to the study design and/or support for implementation of the fieldwork in Botswana: Sheila Tlou, PhD, former HIV/AIDS Coordinator, University of Botswana; Dr. David Bangsberg, CAPS, University of California, San Francisco; Christine Stegling, Executive Director, Botswana Network on Ethics and Law (BONELA); David Ngele, Executive Director and the staff of the Botswana Network of People Living with HIV/AIDS (BONEPWA); the Centre for Youth of Hope (CEYOHO); the Coping Centre for People Living with HIV/AIDS (COCEPWA); Dr. Ibou Thior, Project Director, Botswana Harvard AIDS Institute Partnership (HAI); Dr. Howard Moffat, Princess Marina Hospi-

tal; Dr. Banu Khan, former National Coordinator, National AIDS Coordinating Agency (NACA); Elaine Kabogo, NACA; Dr. Agathe Latre-Gato Lawson, United Nations Population Fund (UNFPA) Representative (Botswana); Dr. Peter Kilmarx, Todd Kopenhaver, Marion Carter and Dawn Smith, The BOTUSA Project; Deborah Stanford, African Comprehensive HIV/AIDS Partnership (ACHAP); and Dr. Diana Dickinson, the Independence Surgery. The authors are grateful to Shenaaz El-Halabi and the Health Research Unit at the Ministry of Health for granting permission to conduct the study in Botswana and to Dr. Thior for facilitating the ethics review process.

The authors are especially grateful to Minnehy Mukoma for acting as administrative assistant to the field study in Botswana. The authors are indebted to Dr. Vijai Dwivedi, Botswana Central Statistics Office, for the sampling frame for the Botswana community survey and to Mr. Mabaka and Tutu of the Cartography Section of the Census Office, Ministry of Finance and Development Planning, for providing maps.

In Swaziland, the authors thank Swaziland for Positive Living (SWAPOL); Swaziland AIDS Support Organisation (SASO); Swaziland Infant Nutrition Action Network (SINAN); Pilot Operational Research and Community Based Project (PORECO); Women Together; the International Community of Women Living with HIV/AIDS, and Swaziland Network of People Living with HIV/AIDS (SWANNEPHA) for assisting with recruitment for the PLWA interviews.

The authors especially thank Sibongile Maseko, MPH, formerly with the United Nations Development Programme (UNDP) Swaziland, for her contributions to the study design and implementation; Lomcebo Dlamini, Acting Coordinator, WLSA; Siphiwe Hlophes, Director, SWAPOL, and Tenele Dlamini, WLSA, for acting as administrative assistant to the field study. The authors thank Dr. Lawson, Non-Resident UNFPA Representative (Swaziland); Lynne Lackey, PhD, former Fulbright Lecturer at the University of Swaziland; Professor George Vukor-Quarshie, University of Swaziland, and Rudolph Maziya, National Coordinator of the Alliance of Mayors and Municipal Leaders on HIV/AIDS in Africa (AMICAALL), for early guidance and support.

The authors are grateful to Choice Ginindza, Statistician and Head of the Agriculture Statistics Unit, Swaziland Central Statistics Office (CSO), for his work creating the Swaziland community survey sampling frame, and to Gerald Dlamini of the CSO for providing census maps.

Drs. Nonhlanhla Sukati, Mildred Mkhabela and Murmly Mathunjwa of the Department of Community Health Nursing and the General Nursing Program, Faculty of Health Sciences, University of Swaziland, assisted with piloting and adaptation of the community survey in Swaziland.

The authors thank Dr. LT Kanya, Deputy Director, Health Services, Swaziland Ministry of Health and Social Welfare, for ethics review and Patricia Thuli Mngadi, National Programme Officer, United Nations Population Fund (UNFPA) Swaziland, for assisting with this process.

Chen Reis, JD, MPH, former PHR Senior Research Associate, Lynn Amowitz, MD, MSPH, MSc; former PHR Senior Medical Researcher, Claire Beiser, MD; Ms. Leiter; Dr. Weiser; Dr. Percy-de Korte; Dr. Phaladze; Dr. Tlou, and Dr. Iacopino were pivotal to the conception and development of the project. Michele Heisler, MD, MPA, Division of General Medicine, Department of Internal Medicine, University of Michigan contributed to the project design and community survey development, and Dr. Heisler and Sonya DeMonner, MPH, Consultant, PHR, analyzed the community survey data. The authors thank Mechelle LeFleur, Michelle Schaan, Jill Baker and Jodi Talley for data entry for the community surveys.

The authors thank the following PHR interns for contributing literature reviews, desk research and/or data analysis to the report: Jutta Bosch, Philip Kellmeyer, Megan Bremer, Tali Averbuch, MPP, and Jeremy Goldberg. Jessica Cole, PHR Research Assistant, provided research updates. The authors are grateful to Uyapo Ndadi of BONELA for updating the section on women's legal status in Botswana.

The report was reviewed (all or in part) by: Mr. Rubenstein; Susannah Sirkin, MEd, PHR Deputy Director; Gina Cummings, PHR Deputy Director for Operations; Alicia Ely Yamin, JD, MPH, PHR Director of Research and Investigations; Barbara Ayotte, PHR Director of Communications; Nancy Marks, PHR Director of Outreach; Gina Coplon-Newfield, PHR Health Action AIDS Campaign Director; Eric Friedman, JD, PHR Senior Global Health Policy Advisor; Frank Davidoff, MD, PHR Board Member; Justice Richard Goldstone, PHR Board Member; Ronald Waldman, MD, MPH, PHR Board Member; Dr. Weiser; Dr. Percy-de Korte; Ms. Hlanze; Dr. Phaladze; Mary Rayner, MD, International Secretariat of Amnesty International; and Farhana Zuberi, LLB, LLM, Centre for the Study of AIDS, University of Pretoria. Caitriona Palmer copyedited the report. Judith Brackley, PHR Marketing and Publications Director, prepared the manuscript for publication.

Support for this research was provided by the Foundation Open Society Institute (Zug), The Moriah Fund, The Overbrook Foundation, Tides Foundation and two anonymous donors.