

Gender Inequalities in Access to Information about Ebola as Gender-Based Violence

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The current Ebola virus disease outbreak in West Africa has infected 27,237 people—almost exclusively in Guinea, Liberia, and Sierra Leone—of whom 11,158 died.² This public health emergency has significantly impacted the right to health and the right to freedom of expression in these three countries. Early in the outbreak, the governments of Guinea, Liberia, and Sierra Leone cracked down on freedom of expression, particularly press freedom, in order to protect their reputations on crisis management and corruption.³ Since journalists are often key providers of public health education in West Africa, these government restrictions compromised people's access to timely, accurate information about Ebola, leading to ignorance and consequent fear about the disease.⁴

Due to significant gender inequality⁵ and the traditional gender roles played by West African women in caretaking, performing funeral rites, and cross-border trading, the Ebola epidemic has rendered women more vulnerable to infection. In a fight in which information remains a powerful weapon, the susceptibility of women to Ebola has been compounded by socioculturally driven barriers to women's access to acceptable health information. The deadly effects of traditional roles and gender discrepancies in information access can be seen in what little sex-disaggregated data exist from the first year of the outbreak. By August 2014, approximately 55–60% of Ebola fatalities collectively in Guinea, Liberia, and Sierra Leone were women; health ministries in Guinea and Liberia reported, respectively, that 54% and 75% of cases were

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² *Ebola Situation Report – 10 June 2015*, WORLD HEALTH ORGANIZATION [WHO] (June 10, 2015), <http://apps.who.int/ebola/en/current-situation/ebola-situation-report-10-june-2015>.

³ See *Freedom of Information Hit by Ebola Virus*, REPORTERS WITHOUT BORDERS (Oct. 8, 2014), <http://en.rsf.org/africa-freedom-of-information-hit-by-08-10-2014,47071.html>; *Special Report: Ebola and Freedom of Expression in West Africa*, MEDIA FOUND. FOR W. AFR. 2, 5 (Oct. 15, 2014), http://www.mfwa.org/media/documents/document1415906014_0.pdf.

⁴ *Special Report: Ebola and Freedom of Expression in West Africa* at 3, 10–11.

⁵ *Table 4: Gender Inequality Index*, U.N. DEV. PROGRAMME, <http://hdr.undp.org/en/content/table-4-gender-inequality-index> (last visited June 15, 2015).

women.⁶ The gender imbalance in infections may have decreased since then, but this conclusion is tenuous given the unavailability of sex-disaggregated data before December 2014.⁷

I. The Right to Health and Access to Information

The provision and consumption of health information can significantly prevent communicable diseases from quickly escalating into epidemics and can therefore inform future prevention, treatment, and control strategies. The Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression recognized this potential in 2002, emphasizing the importance of the enjoyment of the right to freedom of expression—specifically the right to seek, receive, and impart information—as a precondition for the implementation of effective health information campaigns to combat epidemics.⁸ In fact, the realization of the right to health as codified in the International Covenant on Economic, Social and Cultural Rights (ICESCR) depends on access to health information, which is an underlying determinant of health.⁹ Under the ICESCR, States Parties must take steps necessary for “[t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases,” which attaches a minimum core obligation to provide access to information on preventing and controlling the main health problems in the community.¹⁰

II. Inequalities in Access to Gender-Sensitive Information about Ebola

Health information campaigns by intergovernmental organizations, states, and civil society have made major contributions to preventing and controlling the spread of

⁶ *West Africa: Respect Rights in Ebola Response*, HUM. RTS. WATCH (Sept. 15, 2014), <http://www.hrw.org/news/2014/09/15/west-africa-respect-rights-ebola-response>.

⁷ Recent data from the World Health Organization (WHO) indicates that, to date, Ebola has infected 51.9% of women in Guinea, 49% in Liberia, and 51.6% in Sierra Leone. However, the WHO explicitly notes that these figures exclude cases for which data on sex is unavailable. *Ebola Situation Report – 10 June 2015*; Sophie Harman, *Gender-Blind Global Health Institutions Ignore Misery for Women in Ebola-Affected Regions*, OPENDEMOCRACY (Mar. 21, 2015), <https://www.opendemocracy.net/sophie-harman/genderblind-global-health-institutions-ignore-misery-for-women-in-ebolaaffected-region>.

⁸ Special Rapporteur on the Right to Freedom of Opinion and Expression, Comm’n on Human Rights, ¶ 41, U.N. Doc. E/CN.4/2003/67 (Dec. 30, 2002) (by Ambeyi Ligabo).

⁹ Committee on Economic, Social and Cultural Rights, CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12), ¶¶ 3, 11, U.N. Doc. E/C.12/2000/4 (2000) [hereinafter CESCR General Comment No. 14].

¹⁰ International Covenant on Economic, Social and Cultural Rights art. 12, para. 2(c), Dec. 16, 1966, 993 U.N.T.S. 3, available at <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>; see CESCR General Comment No. 14 at ¶ 44(d).

Ebola. Unfortunately, both discrepancies in the ability of men and women to access information—which stem partly from gender inequalities in literacy and secondary education—and inadequate provision of gender-sensitive information continue to pose threats to ending the proliferation of disease.¹¹ As seen in the decades-old HIV/AIDS epidemic, inadequate access to health information can further increase the risk of contraction and exacerbate the gender gap in infections.¹²

Given analyses of previous Ebola outbreaks in central and eastern Africa, which indicated the role of gender-related factors as key determinants of exposure and infection, stakeholders today should have better targeted women and mainstreamed gender into their health information campaigns.¹³ Instead, there remains a dearth of discussion concerning the gender dimension of information accessibility in the fight against Ebola. The grave ramifications of this are illustrated by the estimated gender asymmetries in Ebola infections and fatalities. Moreover, in a panel on lessons learned and next steps regarding Ebola, the Executive Director of U.N. Women emphasized the importance of engaging and providing information to women and noted that such measures could have reduced the number of deaths.¹⁴

However, the fulfillment of women's right to health requires more than mere access to health information; such health information must be acceptable, which necessitates gender sensitivity.¹⁵ While West Africa continues to make strides toward eliminating Ebola, the deaths of two women with no known factors besides male

¹¹ Table 4: *Gender Inequality Index*; Mégane Ghorbani, *A Gendered Lens on the Current Ebola Epidemic in West Africa*, THOMSON REUTERS FOUND. (Feb. 20, 2015), <http://www.trust.org/item/20150220102611-ym3vo/>; see *Presentation on UN-Women's Response to the Ebola Crisis in Liberia and Sierra Leone*, U.N. WOMEN (Feb. 9, 2015), available at <http://www.unwomen.org/en/executive-board/documents/special-briefing-on-the-operational-response-of-un-women-at-country-level>.

¹² See generally Michel Carael et al., *Is There a Gender Gap in the HIV Response? Evaluating National HIV Responses from the United Nations General Assembly Special Session on HIV/AIDS Country Reports*, 52 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES 111 (Supp. 2 2009), available at https://gcwa.unaids.org/sites/womenandaids.net/files/JAIDS-Dec09-Is_There_a_Gender_Gap_in_the_HIV_Response_6-1-.pdf.

¹³ CESCR General Comment No. 14 at ¶ 20; WORLD HEALTH ORGANIZATION [WHO], ADDRESSING SEX AND GENDER IN EPIDEMIC-PRONE INFECTIOUS DISEASES 24, 29 (2007), available at <http://www.who.int/csr/resources/publications/SexGenderInfectDis.pdf>; see Ndana Bofu-Tawamba, *African Women Face Ebola Triple Jeopardy*, AL JAZEERA AM. (Nov. 7, 2014), <http://america.aljazeera.com/opinions/2014/11/ebola-response-africanfemalehealthworkersculturecaringroles.html>.

¹⁴ "The number of deaths could have been avoided. Better engagement of women at the grassroots level who are midwives, who are death attendants, who are traditional healers, who were not aware of all the details. Just respecting their leadership and engagement could have decreased the number of people who died." Phumzile Mlambo-Ngcuka, Exec. Dir., U.N. Women, Remarks at the BBC World Debate in Accra, Ghana: Ebola – What Next? (Mar. 25, 2015), available at <http://www.bbc.co.uk/programmes/p02mcz5g>.

¹⁵ CESCR General Comment No. 14 at ¶ 12(c).

partners who survived Ebola highlight the ongoing need for targeted gender-sensitive information campaigns to prevent resurgences of the disease. Although a country is declared Ebola-free 42 days after the last patient dies or tests negative twice, the semen of male survivors may be infectious for up to three or more months after the onset of symptoms, increasing the vulnerability of their sexual partners. For example, in March 2015, a pregnant woman in Sierra Leone and a food seller in Liberia died of Ebola. Neither woman had any known risk factors, so scientists began investigating the possibility of contraction during sex with their respective partners, both Ebola survivors.¹⁶

The likelihood of sexual transmission of Ebola presents a hurdle to quashing the outbreak in still-infected Guinea and Sierra Leone, but this can be overcome through the dissemination of gender-sensitive information that considers biological and sociocultural factors affecting women's health. In spite of this and recommendations to counsel survivors and their partners on safe sex, typically, only survivors have been informed about their potential to spread the virus.¹⁷ Furthermore, neither intergovernmental organizations nor affected states have recognized the role of sexual violence in increasing exposure to Ebola. This is extremely problematic in light of a rise in sexual violence and exploitation, ranging from sex work to stranger and partner rape, since the outbreak began.¹⁸ Since only men—not women—can sexually transmit the Ebola virus, stakeholders should continue to increase their efforts in targeting women¹⁹ when disseminating information about the risks of contracting the disease during sex.²⁰ Unless both men and women receive gender-sensitive health information, including sensitization on sexual violence as a disease vector, more sexually transmitted Ebola

¹⁶ Sheri Fink, *Ebola Researchers Take New Look at Risk of Sexual Transmission*, N.Y. TIMES, Apr. 17, 2015, at A6, available at <http://www.nytimes.com/2015/04/17/world/africa/ebola-researchers-take-new-look-at-risk-of-sexual-transmission.html>; Sheri Fink, *Exposure Concerns Grow in Liberia After Diagnosis of First Ebola Case in Weeks*, N.Y. TIMES, Mar. 25, 2015, at A12, available at <http://www.nytimes.com/2015/03/25/world/africa/exposure-concerns-grow-in-liberia-after-diagnosis-of-first-ebola-case-in-weeks.html>.

¹⁷ *Interim Advice on the Sexual Transmission of the Ebola Virus Disease*, WORLD HEALTH ORGANIZATION [WHO] (May 8, 2015), <http://www.who.int/reproductivehealth/topics/rtis/ebola-virus-semen/en/>.

¹⁸ In Sierra Leone, for example, the number of sexual assaults reported to the police increased by 48% from 2013 to 2014. Mardia Stone, *Ebola: The Overlooked Sexually Transmitted Disease*, THE WORLD POST (May 26, 2015), http://www.huffingtonpost.com/mardia-stone/ebola-the-overlooked-sexu_b_7428342.html; see, e.g., Nina Devries, *Ebola Drives Increase in Sexual Violence in Sierra Leone, Experts Say*, AL JAZEERA AM. (Feb. 20, 2015), <http://america.aljazeera.com/articles/2015/2/20/sex-assault-on-the-rise-in-sierra-leone.html>.

¹⁹ Women are likely at highest risk for contracting Ebola through sex, but men who have sex with men must also be targeted as they may be similarly at risk of contracting the virus through semen.

²⁰ Evidence of persisting Ebola in vaginal secretions is significantly weaker than evidence of the virus in semen. There have been no conclusive reports of live Ebola virus in the vaginal fluids of survivors, although traces of the virus have been detected in convalescent females. *Interim Advice on the Sexual Transmission of the Ebola Virus Disease*.

infections may spread and endanger the significant progress made in containing the disease.²¹

Although Guinea, Liberia, and Sierra Leone all have domestic right to information legislation, with Liberia's and Sierra Leone's being among the best in the world,²² economic, social, or cultural barriers may prevent women from seeking information. Obstacles to information access faced by women include a lack of education and literacy, awareness of how to access public information, confidence to seek information, and time due to gender roles in childrearing and housework.²³ Therefore, it is incumbent on the state to proactively provide information and respect freedom of expression by fostering an enabling environment for health workers, journalists, and other stakeholders to impart information about Ebola. Unfortunately, early government tactics of censoring and deliberately withholding information by preventing journalists from reporting on Ebola denied the public access to invaluable health information and contravened states' obligation to respect the right to health.²⁴ In addition to violating the right to health in general, such acts violate women's right to health in particular, which cannot be realized without the removal of all barriers to access to information.²⁵

III. Conceptualizing the Denial of Access to Information about Ebola as Gender-Based Violence

Due to the discriminatory impact of Ebola on women, violations of the right to health hurt women more than men, conforming to characterizations of gender-based violence in international instruments and interpretations. While the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) does not explicitly reference gender-based violence, the CEDAW Committee clarifies that discrimination includes gender-based violence.²⁶ The CEDAW Committee defines gender-based violence as "a form of discrimination that seriously inhibits women's

²¹ Matthew Mpoke Bigg, *Liberia's Sole Remaining Known Ebola Patient Dies*, REUTERS AFR. (Mar. 29, 2015), <http://af.reuters.com/article/idAFKBN0MO0IM20150329>.

²² *Country Rating Results*, GLOBAL RIGHT TO INFO. RATING, <http://www.rti-rating.org/> (last visited Mar. 27, 2015).

²³ See generally THE CARTER CENTER, WOMEN AND THE RIGHT OF ACCESS TO INFORMATION IN LIBERIA (2014), <http://www.cartercenter.org/resources/pdfs/peace/ati/women-and-ati-prepub-07172014.pdf>.

²⁴ CESCR General Comment No. 14 at ¶¶ 34, 50.

²⁵ See CESCR General Comment No. 14 at ¶ 21.

²⁶ Convention on the Elimination of All Forms of Discrimination Against Women art. 1, Dec. 18, 1979, 1249 U.N.T.S. 13, available at <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>; Committee on the Elimination of Discrimination Against Women, General Recommendation No. 19: Violence Against Women, ¶ 6, U.N. Doc. A/47/38 (1993) [hereinafter CEDAW Committee General Recommendation No. 19].

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ability to enjoy rights and freedoms on a basis of equality with men” or “violence that . . . affects women disproportionately.”²⁷ As identified by the Special Rapporteur on Violence Against Women in 2011, both discrimination and violence against women can be interpersonal and/or structural. Structural violence is any form of physical or ideological structural inequality or discrimination that maintains the subordination of women, and it can include laws, policies, and beliefs that disadvantage women.²⁸

Together, the barriers to accessing health information faced by West African women, including government censorship, can be understood as embodying structural discrimination—structural gender-based violence—that has greatly disadvantaged women.²⁹ The de facto denial of women’s access to information about Ebola shares consequences of gender-based violence by violating, impairing, or nullifying women’s enjoyment of their human rights and fundamental freedoms, including their right to health.³⁰ Due to the structural gender-based inequality perpetuated by a lack of information access, which also impairs the enjoyment of the fundamental right to health by women more than by men, the denial of access to information during epidemics constitutes gender-based violence.

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IV. Concluding Remarks

Ending gender-based violence seems to have greater normative status as an aspiration of international human rights and development agencies than the aim of advancing access to information.³¹ Conceptualizing violations of women’s access to information during epidemics as gender-based violence—an already omnipresent issue on human rights and development agendas—would mainstream gender into issues of information accessibility and also bolster advocacy efforts in promoting access to

²⁷ CEDAW Committee General Recommendation No. 19 at ¶¶ 1, 6.

²⁸ Special Rapporteur on Violence Against Women, *Multiple and Intersecting Forms of Discrimination and Violence Against Women*, Hum. Rts. Council, ¶¶ 24, 26-28, U.N. Doc. A/HRC/17/26 (May 2, 2011).

²⁹ See *id.* at ¶ 35.

³⁰ CEDAW Committee General Recommendation No. 19 at ¶¶ 7, 7(g); Fourth World Conference on Women, Sept. 4-15, 1995, *Beijing Declaration and Platform for Action*, ¶ 112 (Sept. 15, 1995), available at <http://www.un.org/womenwatch/daw/beijing/pdf/BDPfA%20E.pdf>; see Declaration on the Elimination of Violence Against Women, G.A. Res. 48/104, arts. 3, 3(f), U.N. Doc. A/RES/48/104 (Dec. 20, 1993), available at <http://www.un.org/documents/ga/res/48/a48r104.htm>.

³¹ Both the U.N. Millennium Development Goals (MDGs) and proposed Sustainable Development Goals (SDGs) related to gender equality note the necessity of eliminating gender-based violence. Access to information is neither a goal nor a target of the MDGs and is only a target of the proposed SDGs, having just recently emerged in the rhetoric of international priorities. See *Goal 3: Promote Gender Equality and Empower Women*, U.N., <http://www.un.org/millenniumgoals/gender.shtml>; Report of the Open Working Group of the General Assembly on Sustainable Development Goals, 68th Sess., at 14, 22, U.N. Doc. A/68/970 (Aug. 12, 2014), available at <http://undocs.org/A/68/970>.

information. This in turn may provide greater impetus to prioritize gender in health information campaigns at the onset of a viral outbreak. Ultimately, such a targeted approach could reinforce the significance of access to information and, more importantly, save the lives of thousands—even millions—of men and women during public health crises such as the HIV/AIDS epidemic or West Africa’s now-dwindling, yet still threatening, Ebola outbreak.