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Version: Published Version

Article:

Pedeboy, Delphine (2023) Female genital schistosomiasis: my personal account and key recommendations to the global health community. *International Health*, 15 (Supplement_3). iii12 - iii13. ISSN 1876-3413

<https://doi.org/10.1093/inthealth/ihad097>

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Female genital schistosomiasis: my personal account and key recommendations to the global health community

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Received 3 July 2023; editorial decision 8 September 2023; accepted 1 October 2023

One woman's personal account of contracting female genital schistosomiasis, a neglected tropical disease that currently affects 56 million women worldwide. This account includes recommendations to the public health community to improve outcomes for women living with or having had the illness.

Le récit personnel d'une femme ayant contracté la schistosomiase génitale féminine, une maladie tropicale négligée qui touche actuellement 56 millions de femmes dans le monde. Ce récit comprend des recommandations à l'attention de la communauté de la santé publique afin d'améliorer la qualité de vie des femmes vivant avec ou ayant souffert de la maladie.

Relato personal de una mujer que contrajo esquistosomiasis genital femenina, una enfermedad tropical desatendida que afecta actualmente a 56 millones de mujeres en todo el mundo. Este relato incluye recomendaciones a la comunidad de salud pública para mejorar los resultados de las personas que padecen o han padecido la enfermedad.

This is a personal account of my experience with female genital schistosomiasis (FGS), a lesser known form of schistosomiasis which affects an estimated 56 million women and girls worldwide. Schistosomiasis is a Neglected Tropical Disease (NTD) for which the WHO estimated in 2021 that over 250 million people required treatment.¹ It moves from a host (typically a freshwater snail) to humans who have to use and/or enter water for everyday activities. If left untreated, it can cause a host of symptoms (bloody urine, fatigue, and eventually, organ damage). For female patients, it can affect the reproductive organs, causing symptoms such as pruritus, discharge, and pain in the abdominal and pelvic area.² This is what experts refer to as FGS. Left untreated, it can eventually lead to infertility, and increases a woman's chance of contracting HIV and HPV.³

I hope that sharing my experience publicly will help shed light on this poorly known, highly stigmatised disease, and help those still suffering.

I contracted schistosomiasis during a work trip to Malawi in 2017. In February 2018 I started experiencing gynaecological symptoms that went undiagnosed for almost 4 months. The doctors determined a diagnosis by elimination, screening for the most common gynaecological ailments before concluding it would be necessary to carry out a skin biopsy. I was only then formally diagnosed with schistosomiasis in June of that year. During those 5 months, I realized that the doctor did not know what was wrong, and was misdiagnosed a few times. I

knew that I did not have a Sexually Transmitted Infection (STI), but was made to doubt the negative results I received. The doctor I saw never once considered the possibility of a tropical health issue, despite my extensive travel history in sub-Saharan Africa.

I was prescribed and took a dose of praziquantel (PZQ), the internationally recognised standard treatment for schistosomiasis. I experienced a painful parasite die-off phase of a few hours, as well as feeling unwell due to the high potency of the drug. The most obvious symptoms went away very quickly, which was a huge relief, but I shortly thereafter started experiencing chronic urinary and pelvic health issues that I am still actively managing 5 years later. This has been the single most challenging thing I have experienced, due to the lack of knowledge and research around the disease's chronic effects and the confusion this causes. This was made worse by the surrounding stigma, shame and resulting isolation of having not only a neglected tropical disease, but moreover, one that affects women's health, which is still in large part taboo and underresearched. FGS is indeed doubly neglected. Doctors are still unable to tell me what the long-term impacts of FGS could be. My ongoing symptoms are not something that the handful of clinicians I have seen over the years are familiar with in the context of FGS, and to this day I am unable to get clear answers from the medical community. I only know of one other woman who experienced FGS and was willing to talk with me about it, but her symptoms were different. I haven't met any other FGS patients who have the same chronic

symptoms as me, which is very isolating. I am from a privileged socio-economic background, and have had the ability to navigate both the medical system and find (sparse) information online. I cannot imagine what FGS means for women who are navigating their symptoms alone, due to lack of proper medical care and access to information.

My experience is an opportunity for me to share two key messages that I believe, if acted on, could significantly reduce the pain and suffering of millions of FGS patients.

First, make it a priority to train doctors on the lesser known NTDs. This includes NTDs that adversely impact women's health and other marginalized communities in particular, like FGS. My case alone illustrates how a lack of knowledge by health practitioners on FGS can lead to devastating consequences for their female patients. It is not acceptable that many doctors and women's health professionals do not know how to diagnose this very serious reproductive health issue, experienced by almost 60 million women worldwide, often leading to completely impaired quality of life. I know of an adolescent girl in Malawi who was given an (unnecessary) full hysterectomy following misdiagnosis, when what she needed before anything else was a dose of praziquantel. This kind of medical neglect could very well happen again, unless doctors are properly educated about FGS.

Second, help patients experiencing isolation to connect with other survivors and patients. A health issue that affects the genital area is often experienced as shameful because sexuality and reproductive health is often taboo, and this can lead to isolation. Creating peer support groups at health centres, or through professionally mediated groups online (using WhatsApp or other platforms, and leveraging the power of digital health products), for example, could help bring together women who have had similar experiences and share worries as well as coping strategies with one another, and together build resilience and help prevent isolation.

My story is far from being an isolated case. Hopefully the medical community is receptive to the messages I have shared and will help bridge the knowledge gap for FGS, and find new ways of reducing patient isolation.

Author's contributions: DP drafted and wrote the manuscript.

Acknowledgements: Useful resources include World Health Organization, 2015, Female genital schistosomiasis: a pocket atlas for clinical health-care professionals (<https://www.who.int/publications/item/9789241509299>) and Unlimit Health website, 2023 (<https://unlimithealth.org/ntds/female-genital-schistosomiasis/>).

Funding: None.

Competing interests: DAP is a guest editor of this supplement but had no role in the review of this manuscript.

Ethical approval: Not required.

Data availability: All data are provided in the article.

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