

Illness experiences and mental health challenges associated with female genital schistosomiasis in Cameroon: a gender analysis

Makia Christine Masong ^{a,b,*}, Marie-Therese Mengué ^{a,b}, Nstinda Tchoffo Marlene ^{b,c}, Laura Dean ^d,
Rachael Thomson ^e, Russell Stothard ^f and Sally Theobald ^d

^aCatholic University of Central Africa, Department of Social Sciences and Management, Yaoundé, Cameroon; ^bInstitut des Politiques et Initiatives Sociales (IPIS); ^cCatholic University of Louvain, Faculty of Public Health, Belgium; ^dLiverpool School of Tropical Medicine, Department of International Public Health, Liverpool, United Kingdom; ^eLiverpool School of Tropical Medicine, Department of Clinical Sciences, Liverpool, United Kingdom; ^fLiverpool School of Tropical Medicine, Department of Tropical Disease Biology, Liverpool, United Kingdom

*Corresponding author: Tel: +237 680406147; E-mail: masongbye@yahoo.com

Received 3 June 2023; revised 29 September 2023; editorial decision 29 November 2023; accepted 10 January 2024

Background: This paper highlights the role of cultural and structural gaps that shape illness experiences of women with manifestations of female genital schistosomiasis (FGS) and their impacts upon mental well-being.

Methods: Using ethnography, case study narrative accounts of women manifesting symptoms of FGS, as well as interviews with health workers within FGS-endemic rural fishing communities in Cameroon, we present experiences of women affected by FGS, alongside information on FGS health service provision.

Results: Our results show how gendered power dynamics in decision making, gendered experiences around menstrual health and structural gaps in service provision, combine and lead to poor mental well-being. Subfertility brings a heavy psychosocial toll from external blame and rejection, exacerbated by internalised stigma and the challenge of not being able to fulfil cultural and gendered social norms.

Conclusions: Gender analysis is key to developing context-embedded understanding and addressing FGS-related challenges. With context-specific experiences demonstrating FGS comorbidity with mental ill health, there is a need to prioritise mental health integration at policy level through a person-centred approach. Furthermore, to address stigma and discrimination, campaigns to raise awareness in Cameroon, and beyond, are needed.

Contexte: Cet article met en évidence le rôle des lacunes culturelles et structurelles qui façonnent les expériences des femmes atteintes de schistosomiase génitale féminine (SGF) et leur impact sur le bien-être mental.

La méthode: À l'aide de l'ethnographie, de récits d'études de cas de femmes présentant des symptômes de schistosomiase génitale féminine, et d'entretiens avec des agents de santé au sein de communautés de pêcheurs ruraux endémiques de la schistosomiase génitale féminine au Cameroun, nous présentons les expériences des femmes touchées par le SGF, ainsi que des informations sur les services de santé liés au SGF.

Résultats: Nos résultats montrent comment la dynamique du pouvoir dans la prise de décision, les expériences de la santé menstruelle et les lacunes structurelles dans la fourniture de services, interagissent et conduisent à un manque de bien-être psychologique. La sous-fécondité entraîne un lourd fardeau psychosocial du fait du blâme et de rejet externes auxquelles sont assujetties les personnes souffrant de la maladie, ce qui est exacerbé par la stigmatisation intériorisée et le défi que représente leur incapacité à respecter les normes sociales culturelles et sexospécifiques.

Conclusion: L'analyse de genre est essentielle pour développer une compréhension intégrée au contexte et pour relever les défis liés aux SGF. les défis liés à l'ESF. Avec des expériences spécifiques au contexte démontrant la comorbidité de la FGS avec la mauvaise santé mentale, il est nécessaire de donner la priorité à l'intégration

de la santé mentale au niveau politique par le biais d'une approche centrée sur la personne. l'intégration de la santé mentale au niveau politique par une approche centrée sur la personne. En outre, pour lutter contre la stigmatisation et la discrimination, des campagnes de sensibilisation sont nécessaires au Cameroun et au-delà.

Antecedentes: En este documento se pone de relieve el papel de las brechas culturales y estructurales que dan forma a las experiencias de enfermedad de las mujeres con manifestaciones de Esquistosomiasis Genital Femenina (EGF), y sus impactos en el bienestar mental.

Método: Utilizando la etnografía, estudios de caso mediante relatos narrativos de mujeres que manifiestan síntomas de EGF y entrevistas con trabajadores sanitarios de comunidades pesqueras rurales endémicas en Camerún, presentamos las experiencias de las mujeres afectadas por la EGF, junto con información sobre la prestación de servicios sanitarios para la EGF.

Resultados: Nuestros resultados muestran cómo la dinámica de poder de género en la toma de decisiones, las experiencias de género en torno a la salud menstrual y las deficiencias estructurales en la prestación de servicios se combinan y conducen a un bienestar mental deficiente. La subfertilidad conlleva un alto coste psicosocial debido a la culpa y el rechazo externos, exacerbados por el estigma interiorizado y el reto de no poder cumplir las normas culturales y de género.

Conclusión: El análisis de género es clave para desarrollar una comprensión integrada en el contexto y abordar los retos relacionados con la EGF. Dado que las experiencias específicas de cada contexto demuestran la comorbilidad de las EGF con la enfermedad mental, es necesario priorizar la integración de la salud mental en las políticas a través de un enfoque centrado en la persona. Además, para hacer frente al estigma y la discriminación, son necesarias campañas de sensibilización en Camerún y en otros lugares.

Keywords: female genital schistosomiasis, gender dynamics, mental health, narrative discourse, structural violence.

Introduction

With historical contexts of social and political destabilisation dating from colonialism, most sub-Saharan African countries face similar structural challenges¹ and lack adequate social care and healthcare. Collectively, these challenges amplify negative illness experiences.² Health challenges and illness experiences are magnified by gender inequities,³ with several social and economic implications and mental health consequences. Gender analysis in health research is increasingly being used to understand neglected tropical diseases⁴ to address holistic needs, and is adding momentum to the growing understanding and application of person-centred approaches.⁵ Through gender analysis, it is possible to identify structural gaps⁶ that sustain and encourage inequity and neglect, thereby resulting in negative constructions of disease,⁷ typically encouraging stigma and negative impacts upon mental health.⁸

To date, research and action on stigma has mainly focused on visible skin-affecting conditions such as leprosy, cutaneous leishmaniasis and lymphatic filariasis.⁸ Diseases that do not cause such direct/obvious physical impacts or effects often do not consider mental healthcare within their control or management plans; this represents a missed opportunity for creating awareness of comorbid health conditions and building a more person-centred approach. This is the case with female genital schistosomiasis (FGS),⁹ a neglected and mostly undiagnosed¹⁰ gynaecological condition affecting an estimated 56 million¹¹ young girls and women. Although primarily caused by infection with *Schistosoma haematobium*,¹² FGS has several sexual

and reproductive health implications,¹² with symptoms including genital itching, abnormal vaginal discharge, pelvic pain or pain during or after intercourse, contact bleeding, subfertility and infertility.⁹ Of note, FGS has been shown to have adverse mental health and social consequences.¹⁰ In Cameroon, where it is endemic,¹³ it is still largely underexplored and misunderstood. Little awareness around the condition and its management exists within both schistosomiasis and sexual and reproductive health programmes,¹³ with gendered implications for stigma and mental ill health from missed prevention and treatment opportunities.

Through exploring illness narratives and local perceptions, this paper explores challenges that emerge as a result of cultural constructions around gender and structural gaps in the provision of care, stemming from individual perceptions and community views of a person affected as a result of their manifestation of FGS symptoms. Understanding the intersection of mental health, social stigma and exclusion,¹⁴ and how these are shaped by far-reaching social and structural drivers,⁷ is important in order to develop an integrated policy for the holistic management of FGS. This, inclusive of diagnostics and treatment as a central element of sexual and reproductive health, and also, the support for the management of related social and mental illhealth. In this paper, we highlight the impact that social stigma and cultural restrictions have on the social lives and mental health of women and girls manifesting FGS symptoms to advocate for an integrated, mental health inclusive and contextualised approach to the management of FGS within primary healthcare.

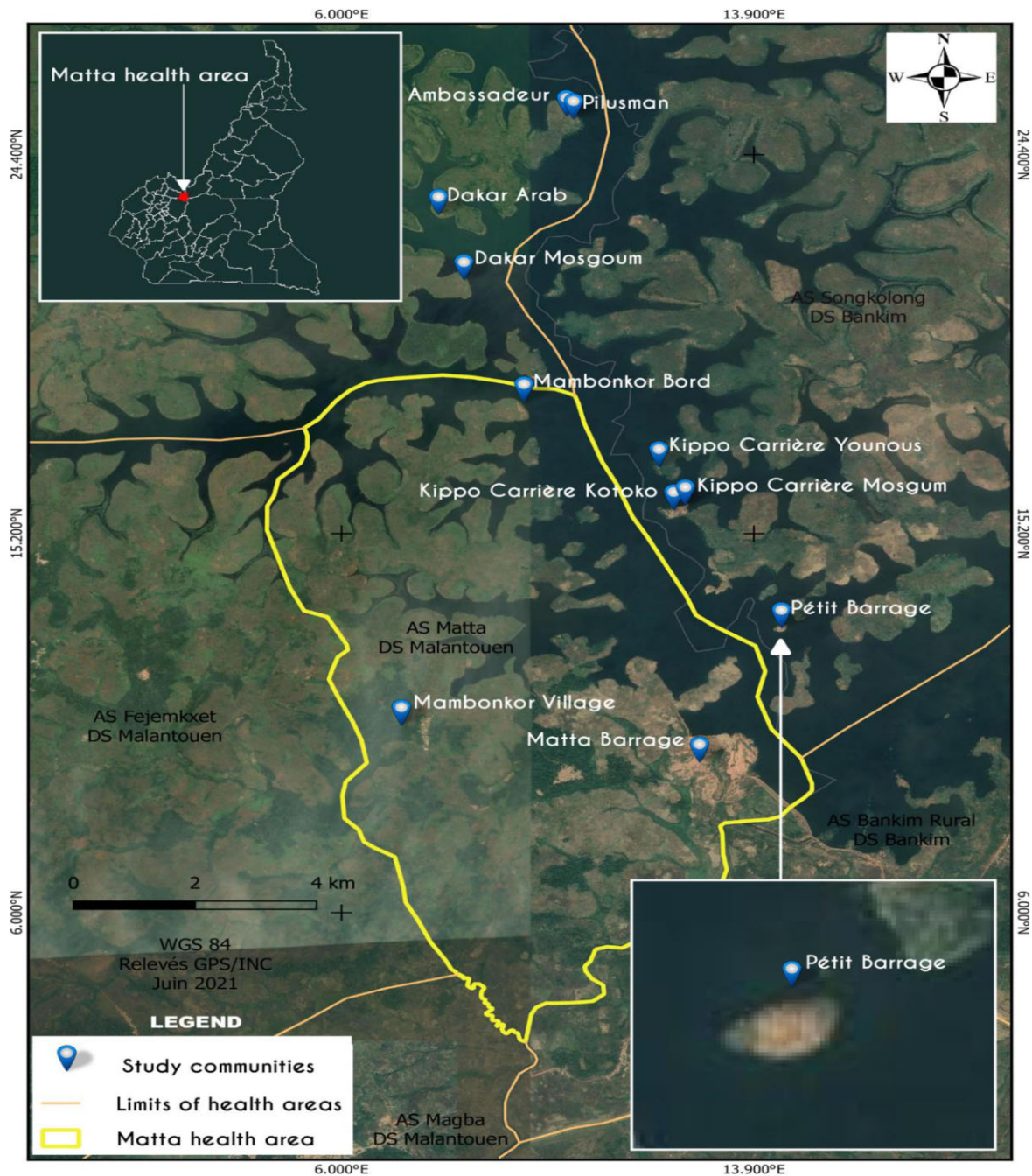


Figure 1. Matta Heath Area with study communities. Excerpt from Cameroon map showing the Matta Health Area with Island communities. Source data: Map base layer includes data from Google Earth, ©Maxar Technologies, CNES/Airbus, Landsat/Copernicus imagery from the dates 11/21/2012. Health boundaries are from the Ministry of Public Health Cameroon; National system of health information (<https://www.dhis-minsante-cm.org/portal/>); GPS coordinates collected during field survey.

Methods

Study setting

This study was conducted from June 2020 until February 2022 in 11 fishing communities in the Matta Health Area in Cameroon (Figure 1), where ethnographic activities were ongoing during

this period with field presence of the research team for 5 to 12 wk every 6 mo. The Matta Health Area is a urogenital schistosomiasis (UGS)-endemic community¹⁵ found within the Malantouen Health District in the western region of Cameroon. The population consists of rural communities grouped on several islands or ‘fishing camps’, residing around a man-made barrage.¹⁵

Table 1. Study site communities and ethnic groups

Community	Ethnic groups present
Mambonkor Bord	Massa, Arab, Mosgum, Bamum, Njorku, Mambilla
Kippo Carriere	Kotoko, Mosgum
Dakar	Arab, Mosgum
Petit Barrage	Njorku, Akum
Ambassadeur	Malian, Bamum, Arab
Pilusman	Njorku
Mambonkor Village	Bamum
Matta Barrage Village, (Hausa)	Bamum, Kotoko, Mosgum, Arab

Extensive fishing is the main activity in these fishing camps, and in these communities as in most others in Cameroon, Africa and the world at large, gender roles have been maintained and transmitted mainly through families and communities,¹⁶ with household and livelihood tasks divided according to gender. Informal education supports the process of learning and sustaining gender roles, with importance placed on early female initiation into marriage and childbearing, and sexual relationships with husbands being prioritised. With a culture of polygamy, gender, social and cultural norms mean strong childbirth expectations for women. Social stigma, blame, rejection and debasement are thus potential consequences for not adhering to the defined roles, norms and expectations for married women, among other context-specific implications for the different ethnic groups (Arab, Hausa, Massa, Kotoko, Mosgum, Bamum, Njorku, Mambilla and Malian) within the communities in the Matta Health Area (Table 1).

With a focus on protecting dignity and privacy, participants were informed about the research objectives, methods and how information provided will be communicated and used to inform health research and policy. Informed consent was received based on this freedom to analyse and make judgements about participation.¹⁷

Study design

This is a cross-sectional qualitative study.

Sampling and participant selection

The key informants (women found positive for FGS and health workers) (Table 2) were identified after a preliminary stakeholder identification¹⁸ within the case study communities. Participants were selected from an initial sample of 67 girls and women (34 FGS+) who had participated in a biomedical diagnosis of UGS and FGS in a related study.¹⁹ In summary, girls and women (n=304) aged 5–69 y submitted 10 ml of urine for the diagnosis of UGS through urine filtration and microscopy. Sixty-seven consenting (or assenting) girls and women aged ≥ 14 y from this group, who were married or who had sexual intercourse, were examined for the presence of FGS by a gynaecological examination with colposcopy. From this earlier study, females were purposively selected¹⁸ for participation in our qualitative study with the help of traditional birth attendants and contacted within communities (at their homes or 'safe houses'). This selection was based on their manifestation of FGS symptoms or having had a positive result after an FGS diagnosis (n=15). Health workers (n=5) functioning within the Matta Health Area were also included and were met at their place of work at a time of their convenience.

Methods and process

After informed consent was given, in-depth interviews (IDIs) (with interview guides)²⁰ and informal discussions were carried out with 20 informants (women with FGS and health workers), to probe existing gender dynamics, illness perceptions and lived experiences related to FGS; these were recorded then transcribed. Focus group discussions (two) were held with women from two dominant ethnic groups (the Mosgum and the Kotoko), to ensure that information was elicited from different cultural contexts. In addition to interviews, as part of the process of ethnography, participant observation, with an onsite presence of at least 3 mo over a period of 3 y, was carried out to support an emic understanding of cultures and people then recorded in field journals.

Table 2. Demographic description of study participants

Participants	Categories			
	Age (y)	Education level	Economic activity	Marital status
Young girls manifesting FGS symptoms	>14 and <18 (n=8)	-At least primary level (n=3) -No formal education (n=5)	-Fishing (n=5) -Farming (n=8)	-Married (n=3) -Single (n=5)
Adult women manifesting FGS symptoms	>18 (n=7)	-At least primary level (n=1) -No formal education (n=6)	-Fishing (n=5) -Farming (n=3) -Other (n=0)	-Married (n=6) -Single (n=1)
Health workers	>18 (n=5)	-At least primary level (n=5)	-Midwife (n=1) -Nurse aid (n=3) -Doctor (n=1)	Married (n=5)

Analysis

Based on an initial gender framework²¹ for data collection and analysis, lived experiences of the gender division of labour and everyday practices, decision making and value definition²² were captured and presented within their context, through a narrative analysis to understand the experience and discourse surrounding FGS.²³ These narrative discourses, presented as stand-alone stories and illustrative quotes, were analysed to elicit and illustrate the main themes around disease experience enabling an understanding of relevant social constructs and systemic gaps in policy and practice.

During data collection, an inductive approach was used, where at the end of each day, interview guides and interviews from recorded audios (translated into English from Fulbe and Arabic) were reviewed and reconsidered and the main themes adapted against an initial coding theme. This allowed for emerging themes not initially included to be identified and incorporated into the interview guide for subsequent interviews to ensure rich textured data and an iterative analytical process. At the end of data collection, a thematic framework²⁴ was developed and used to manually code the transcripts and all materials, including field notes. The final main themes were selected, with some cross-checking for consensus and quality, with similarities and differences among researchers' codes discussed, and a consensus achieved, concluding with a final thematic chart. Once the chart was completed, data were discussed at length by the research team to interpret descriptive and explanatory accounts of each emergent theme.²⁴

Results

Case study: narrative discourse from participant observation and an IDI on illness experience

We present here a case study (Box 1) of an adult woman (from the 25–35-y age group) manifesting symptoms of FGS (codename 'Lela'). Lela's case, constructed from participant observation and IDIs, illustrates how gendered power dynamics affect decision making around and access to healthcare, and how the experience of infertility/subfertility brings psychosocial stress from social stigma and rejection, as a result of her manifesting symptoms of FGS.

Gendered experiences of pain, distress and how these are experienced at a personal level:

Personal or self-directed shame and abuse emerged as a key challenge, with several women describing their symptoms of subfertility/infertility and pain, with feelings of guilt/self-blame and intense distress. Illustrative quotes include:

... I am a woman, but I cannot be as a woman to my husband. I do not even want to be again...I am tired, everybody knows my problem here, the baby cannot stay inside me... I just want to rest. He has his new wife...I cannot blame him...if I cannot be a woman for him, I cannot stop him from looking for a woman (adult female, informal discussion, Mosgum community).

It really pains me when he even just touches me there... He said it is me who does not want it and that time the blood came out even...so he left me... that I know what I have done behind his back... it is better for me, than the insults (adolescent, IDI, Kotoko community).

Also, other biological (menstruation) and culturally defined activities were also noted to enhance women's vulnerability to infection, causing distress. Inevitable biological processes, such as menstrual cycles, were an added challenge. Most adolescent girls attributed menstrual pain and vaginal itches to the fact that they wash their (menstrual) cloth in the lake during their periods, as they had no other alternative.

We wash our [menstrual] cloth in the lake...so we have to go down there always to wash when the blood comes...I think this is what makes us have pain (adolescent, focus group discussion, Njoirku community).

Lastly, as seen in Box 1, gender dynamics around power showed autonomous decision making for health to be a challenge faced by most women. Personal decisions related to health were taken by the husband, and most times the woman or girl had no say. An example is seen with Lela and her young co-wife (Box 1), where the husband decides if and when they can take treatment and makes the decision for gynaecological examination for both of them. Thus, formal treatment seeking was a decision not made by the women themselves, which brings an additional layer of complication as illness and healthcare seeking for the management of symptoms for FGS is either decided externally (solely by the husband) or needs to be negotiated within patriarchal family and community norms.

Experiences of gendered social stigma and exclusion within families and communities:

Interpersonal/societal challenges and abuse were evident, with cultural and gendered norms deeply shaping the different illness experiences of individuals. For example, as seen in Box 1 with Lela's experience, women with infertility like Lela faced several challenges:

Lela's husband has taken a younger wife and she is considered 'spoiled', and she is now the wife of the men in the family [left for any man of the family to share freely] (female health worker, informal discussion, Matta Health Centre).

Lela's is a particular case based on cultural or societal norms, but challenging, alienating and abusive and gendered experiences linked to manifestation of FGS (subfertility) were identified in several other cases too and emerged as a key theme:

It is a curse, she cannot have children...other villagers are saying she is a witch...her husband died, she cannot stay here as nobody wants her. They will drive her away from [the] village...this is not her village, it is her husband's own, she should go back to her place with her problems (adult female, informal discussion, Mambonkor Bord [Bamum quarter]).

Box 1

I met 'Lela' over a year ago (early June 2020); this is my second meeting with her. When we first met, it was in the 'meeting room', where women came in to meet us (directed by the traditional birth attendant, or by the chief, or their husbands/fathers). She was among a group of four young women who came in, all chatting and laughing freely amongst themselves in Fulbe. Our room was 'hidden' at the back of the market, so all the women who came in felt free, even taking off their facial covering in our presence. I noticed her especially because she was a bit different from the others. She looked healthier and wore cleaner clothes. She was a bit shy in responding to questions and opted out of the gynaecological examination, but gave her urine for analysis. There were two social scientists in the hall. Both females, our hair covered the same as them, but wearing trousers. They discussed our clothing, laughed at some things, but generally were kind. Our environment was relaxed and interactive. At this time, Lela said her husband did not want her to do any exam...

Presently (February 2022), I am standing in Lela's room, invited by her husband. He is the village Chief. It is a beautiful room, made of brown earth, clean, a bed (uncommon), a white curtain and a few lovely colourful handmade arts (bowls and clothes) pinned on the wall. Obviously, she is a favourite wife, and obviously a notable's (a chief or a leader in the community) wife.

I am with a female birth attendant/midwife from the health centre, trained in the use of our handheld colposcope for verifying sandy patches and abnormal blood vessels (i.e. FGS pathologies) on the cervix and surrounding vagina area. Lela's husband had met me on our arrival in the village, at the village square, and asked me (us) to come and 'check' his wife for the 'worms'. Last year (as mentioned earlier) he had refused for his wife to participate in the gynaecological examination, but he is willing now. I reflect on this (his) change of mind. He had told me, as well as other men we had come across, about the many pregnancies and babies that had arrived after we came last year 'with the medicines and machine'. They said the women (and their men) we had met were very lucky.

It had been 'difficult' with this chief. On my previous visits, he kept telling me to come 'after' before I could meet the women. This 'after' had taken two whole years, before gaining his trust enough for him to call out the women, or tell the men to let their women meet us...

Presently the chief is talking... He says the 'worms' disturb Lela... that she cannot have a baby, she has pain around her abdomen a lot too...

I listen to him talk; his French is not very comprehensive, but it is understandable. We communicate with some difficulty, but we understand each other. While he is talking, I am looking at Lela (and surprised too). She is seated on her bed facing us but looking at the floor while her husband is talking. I wonder if this is the girl I met last year? Everything about her is different. She has lost a lot of weight; she looks pale and sad. She looks up with a little smile and nods at me (in recognition and greeting). Her eyes are sad, her face is sad. You cannot help but notice. She looks 'tired', 'worn', 'faded'. I wonder what happened to the pretty lively girl I met last year.

Presently, while the gynaecological examination is taking place, I talk with Lela and try to calm her: I know this procedure is a bit uncomfortable. After a little chatting, around her previous menstrual experiences, parity, etc., she relaxes enough and starts telling me about her experience... *'it is difficult' ... 'it is sad' ...*

'enfant[baby]' ... (she shakes her head to say no baby)

she says...

'the worms disturb... the baby comes out when it enters [conceive] ...'

Her sorrow is obvious. She cannot express herself very much in French but uses a few words that are clear enough and express what she wants to say, in addition to her sighs and expressions. It is now obvious that this is her sorrow. This is what is taking out the joy and liveliness I had seen previously in her eyes. She cries softly as she speaks. I realise this clarity/awareness of her condition comes as a result of last year, with the other women participating in the FGS diagnosis, receiving treatment after medical examinations, and not her. I remember (and confirm this later in the evening) that her urine examination had tested negative for the presence of *Schistosoma* eggs, although she complained of some symptoms. She had been bypassed for FGS diagnosis because of her husband's refusal, and neither had she received any treatment for UGS because she was egg-negative. She had been missed (as are most other girls and women), without a clear diagnosis or treatment plan for FGS within such endemic communities.

After we are done, her husband comes back in. The midwife says we need to give her the praziquantel. She shows us all the pictures as well with the areas of yellow sandy patches and other lesions. She instructs him on how she is to take the praziquantel. He thanks us, requests we accompany him to see somebody else...

I say goodbye to Lela, tell her not to worry, if it is the worms, the medicine will help her, and that the others will run some other tests at the lab to confirm this, and also for a few other sexually transmitted infections. She only nods...

We follow the chief now. He asks us to come into a room just after Lela's, a bit further on. In the room is a very young girl, with a baby whom she says is 'tati' (Fulbe for 3) months. The Chief says she is his new wife; she has given him a baby. He insists he would like us to 'look' at her too, so she does not 'develop' the worm problem as the 'other'...

She speaks no French; the chief insists as well to stay on as she is examined... I ask her a few questions, which the midwife translates for her; she nods her head to some only, but the chief replies on her behalf...

After the visit, we thank the chief and leave. The midwife tells me sadly 'it means Lela is the "wife" of the men in the family since she cannot have a baby and has all those "woman" problems', the chief has the new wife...'. I understand this means the other men in the family can have access to her.

She has much trouble [her neighbour], he [husband] beats her most times. That problem for children is a serious one. At times, I pity her a lot and even wish he should drive her to go back to her people than stay here and suffer like that. For our tribe it is a shame when the girl comes back [is driven], but it is better than suffering like that... (adolescent, IDI, Mambonkor Bord [Massa quarter]).

Challenges in accessing care and treatment

Structural challenges, health system constraints and service delivery limitations related to diagnosis, treatment and drug availability emerged. The non-availability of drugs, and decision-making policies, for the treatment of schistosomiasis at health centres, were highlighted as a reason for continued infection:

Honestly, if we even had the expired drugs, I will be tempted to give... they may help...they [people] ask and ask, and you see they need it... but you can't help...the decision to give is not at our level, far above the health area/district, and we do not even have the drugs... (health worker, key informant interview, Integrated Health Centre).

Last year, we had the drugs here about to expire, but we received no permission to distribute.... they finally expired... here are more but expired... (health worker, key informant interview, Health District).

Routine diagnosis of schistosomiasis is also not provided at local health centres within endemic communities. This was evident with the limited access to diagnosis (lack of skills and material) for schistosomiasis (or FGS) at the main health centre in the Matta Health Area and its surrounding areas, also leading to increased costs for treatment:

The last lab technician left for studies two years ago...even the microscope doesn't work. But since before the technician left, we do not diagnose schistosomiasis, we send them to the lab in Magba [about 8 km further]. Even if we did, what will we treat you with?... Mostly, we just wait for when the deworming campaign begins [once or twice a year] then they test them and give it [treatment]... (health worker, key informant interview, Matta Health Area).

It is far [health centre] ...transport to go is much, then you make venereal disease tests and buy medicine. And then it does not work...the problem still comes back...my husband says he will not waste money again (adult female, IDI, Pilusman community).

Although in need, many women are also unable to access drugs from the treatment campaigns (where praziquantel to treat schistosomiasis is given out), due to distance, gender power dynamics in decision making and treatment strategies being mostly based on school-based mass drug administration for children aged 5–14 y.

Discussion

Gender analysis²² enables an understanding of the differences and dynamics in the conditions, needs and access to resources between (different groups of) women and men in their assigned gender roles as a result of culture and the effects thereof.²⁵ Gender roles and relations are shaped by and part of contextualised inequitable social structures.¹ Gender inequities linked to 'social conditions' and their 'discriminatory effects'² are clearly shown in the experiences of women with symptoms of FGS. The results outlined here show instances of how biological and sociocultural experiences (at an individual and societal level) combine with structural constraints (challenges in accessing drugs, healthcare and treatment) to create a pathway to illness, stigma and mental health challenges (exacerbated by pain and subfertility). These factors all encourage internalised and externalised stigma, placing a heavy toll on the psychosocial state of the affected woman. Figure 2 illustrates internalised or self-directed, interpersonal and collective challenges women manifesting symptoms of FGS face as a result of the structural policy and practice gaps and cultural or societal norms which shape their experiences.

Structural violence and stigma from within the health system can be seen as well as health system gaps in service delivery for schistosomiasis, which lead to a high prevalence of UGS,²⁶ as well as increasing the risk of chronic infection with FGS.²⁷ This highlights the need to incorporate the management of FGS within primary healthcare.^{28,29} Supporting healthcare workers at the primary level with the tools, skills and drugs to address UGS and FGS should assist in addressing the mental trauma from the manifestations of FGS that women and girls like 'Lela' face within *Schistosoma haematobium*-endemic communities. Within such contexts, such as our case study communities, gender roles and relations and embedded cultural constraints³⁰ limit women from sharing experiences, especially ones as intimate as sexual health, and experiencing sexual and reproductive health challenges opens the woman to challenges in managing her social life (private, sexual relations with her husband), risking interpersonal (intimate partner violence) and collective violence (Figure 2). This is especially seen in connection with infertility, which is known to cause social stigma and exclusion, with feelings of low confidence, low self-esteem and depression,¹³ complicating an already complex situation that women have to navigate on a daily basis.

Our results also show how women's biological challenges (menstruation and the need to wash menstrual cloths), as well as household and livelihood tasks (e.g. washing, cooking and childcare), mean that they are in regular contact with water and hence face a condition beyond their control. This strongly highlights the need to advocate for promoting the social and economic rights of people in the context of disease management,² and FGS in particular.³¹ Raising awareness from lived experience and illness representations³² from FGS has an important role to play in the understanding and management of internalised and externalised stigma related to this condition, highlighting better the social inequity and structural violence that surround it. Better understanding and health systems and community action here could alleviate (for the affected person) external blame (from the husband and society) and self-shame, which have a huge impact on mental health.

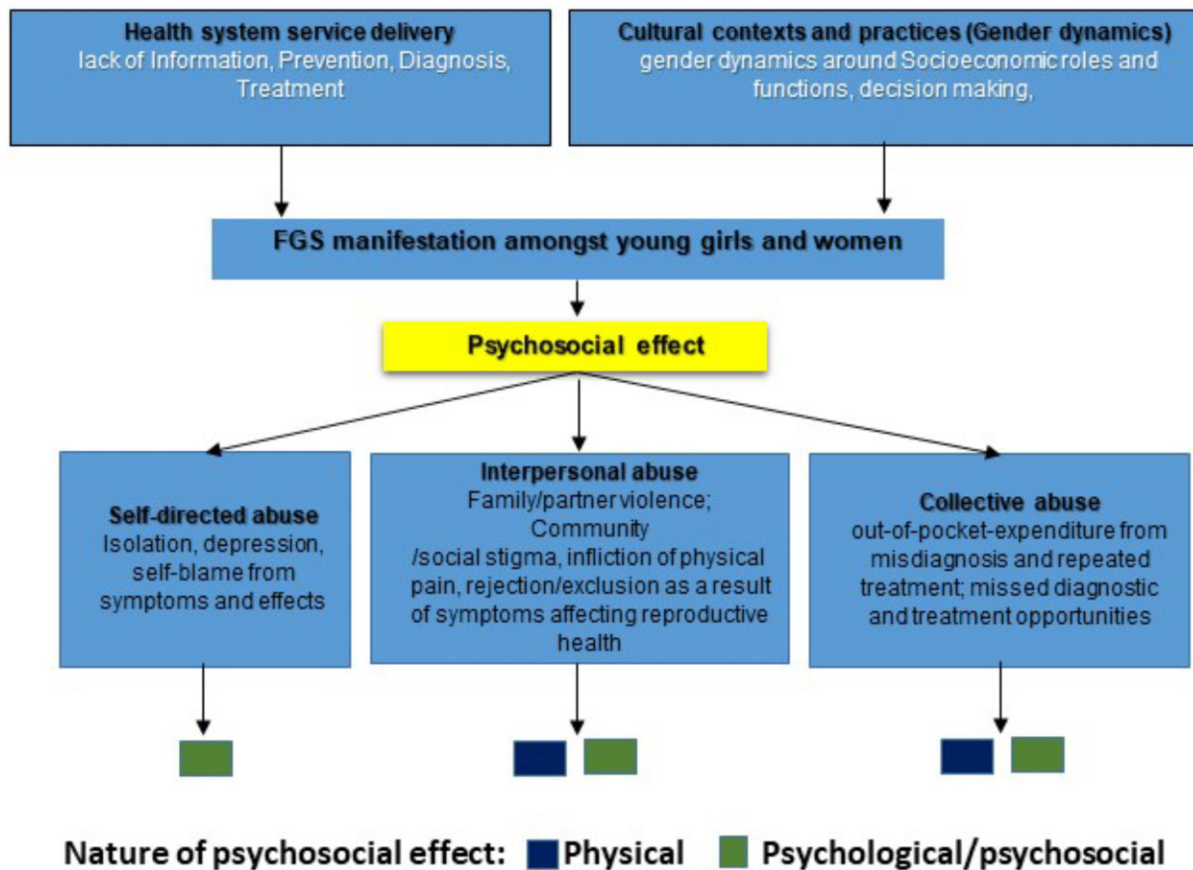


Figure 2. Pathway of dynamics causing illness and impacting illness experience from FGS as a neglected gynaecological disease. Figure adapted from WHO World Report on Violence and Health https://www.researchgate.net/publication/282096365_World_Report_on_Violence_Health; Saferspaces: working together for a safer South Africa, initiated by the Inclusive Violence and Crime Prevention for Safe Public Spaces programme <https://www.saferspaces.org.za/understand/entry/what-is-violence>

The need to readdress the unfortunate oversight of mental ill health from FGS manifestation is important if health and gender equity-related goals laid out in the Sustainable Development Goals are to be met. The gap in routine detection of FGS within current primary healthcare settings means that most endemic communities are still unaware of the existence or diagnosis of this important gender-specific manifestation of UGS, exposing the affected group to continued gendered physical and psychological violence as a result of the multiple and complex sexual and reproductive challenges that come with the condition.

With respect to its limitations, it is important to note the current study based its sample selection on an established participant base used in a previous study,¹³ which limited both geographical context and the selection of participants. However, we believe that the in-depth qualitative methods deployed through time means that the experience and themes identified have a wider resonance within rural Cameroon. We encourage further research and action in this neglected area in Cameroon and beyond to further build the evidence base for action on mental health,

gender and health needs of women and girls in UGS-endemic communities.

Conclusions

Biological, social and culturally defined gender roles shape the manifestation of FGS in the Matta Health Area in Cameroon, challenging the daily lives of women³¹ and redefining sickness experiences. These include elevated distress and psychosocial trauma. Structural and policy gaps and an inequitably structured health system exacerbate the situation. This means that many women and girls already facing sociocultural and biological challenges (menstruation/subfertility) are exposed to infection and psychosocial and mental health stress. Action is necessary to meet health and gender equity goals and support healthcare workers at the primary level with the tools, skills and drugs to address UGS and FGS as an urgent priority. Beyond this we also argue for the need for ongoing awareness raising among endemic

communities, health practitioners, policymakers and programme heads, for more equitable, accessible, integrated and context-specific FGS management.

Authors' contributions: MCM conceptualised the study and MCM and MTM planned the methodology. NTM and MCM carried out field investigation and analysed the data. MCM, MTM, NTM, ST and RT interpreted the results for this manuscript. MCM acquired funding for the study. MCM, ST and RT planned and wrote the original draft of the manuscript with support from LD. RS and MTM supervised the study and contributed to the methodology and analysis of the data. All authors reviewed and edited the manuscript. All authors approved the final version of the paper before submission.

Acknowledgements: The authors acknowledge here the warm and welcoming girls and women, and health workers of the Matta Barrage community and surrounding fishing camps, who trusted us to highlight this significant challenge they face as individuals and as a group, by sharing their experiences and private fears around the symptoms of FGS. We acknowledge the significant and continued support of the COUNTDOWN Programme, a UK Aid-sponsored multidisciplinary research consortium in capacity building and limitless work on FGS. We also acknowledge the REDRESS consortium National Institute for Health Research (NIHR), Research for Innovation for Global Health Transformation REDRESS Programme (NIHR2001129). Also, we acknowledge the coordination team of the MTN-OCEAC Fellowship project for their support in this research.

Funding: This study is funded through a fellowship offered by 'l'Organisation de Coordination pour la lutte contre les Endermies en Afrique Centrale', financed by the Ministry for Economic Cooperation and Development (BMZ) of the Federal Republic of Germany, through the KfW (German Development Bank). 'Projet Lutte Contre Les Maladies Tropicales Négligées en Afrique Centrale' (MTN) [grant numbers BMZ-Nr 2015.69.227, BMZ 2016.68.797]. The funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

Competing interests: LD is a Guest Editor of this supplement but had no role in the review of this manuscript.

Ethical approval: The Cameroon National Ethics committee on Human Health Research (ref no. 2020/07/1266/CE/CNERSH/SP) approved this study. After receiving information on the research objectives, activities and plan of action, all research participants gave written and verbal informed consent or assent, for their participation within the study. Apart from procedural ethics, with reflexivity (for equilibrium) and consideration of context-specific power relations, processual ethics was carried out through comprehensive, relational and positional understanding of the specifics of our case study site.

Data availability: The authors confirm that data supporting the findings of this study are available within the article.

References

- Farmer P. An anthropology of structural violence. *Curr Anthropol*. 2004;3:305–25.
- Farmer P. *Pathologies of Power*. University of California Press; 2004.
- Vlassoff C. Gender differences in determinants and consequences of health and illness. *J Health Popul Nutr*. 2007;25:47–61.
- Theobald S, MacPherson EE, Dean L, et al. 20 years of gender mainstreaming in health: Lessons and reflections for the neglected tropical diseases community. *BMJ Global Health*. 2017;2:e000512.
- WHO. *Mental Health of People with Neglected Tropical Diseases: towards a Person-centered Approach*. Geneva, Switzerland: WHO; 2020.
- Galtung J. Violence, peace and peace research. *J Peace Res*. 1969;6:25.
- Weiss M. Cultural epidemiology: Conceptual framework and current directions of an interdisciplinary field. *Glasnik Etnografskog Instituta*. 2018;66:245–53.
- Koschorke M, Al-Haboubi YH, Tseng P-C, et al. Mental health, stigma, and neglected tropical diseases: A review and systematic mapping of the evidence. *Front Trop Dis*. 2022;3:37.
- WHO. *Female Genital Schistosomiasis: a Pocket Atlas for Clinical Health-care Professionals*. Geneva, Switzerland; WHO; 2015.
- Hotez P, Engels D, Gyapong M, et al. Female genital schistosomiasis. *N Engl J Med*. 2019;381:2493–5.
- UNAIDS JUNP on H. *No More Neglect: Female Genital Schistosomiasis and HIV : Integrating Sexual and Reproductive Health Interventions to Improve Women's Lives*. Geneva, Switzerland: WHO; 2019.
- Kjetland EF, Leutscher PDC, Ndhlovu PD. A review of female genital schistosomiasis. *Trends Parasitol*. 2012;28:58–65.
- Masong MC, Wepnje GB, Marlene NT, et al. Female Genital Schistosomiasis (FGS) in Cameroon: A formative epidemiological and socio-economic investigation in eleven rural fishing communities. *PLOS Global Public Health*. 2021;1:e0000007.
- Litt E, Baker MC, Molyneux D. Neglected tropical diseases and mental health: A perspective on comorbidity. *Trends Parasitol*. 2012;28:195–201.
- Mewabo AP, Moyou RS, Kouemini LE, et al. Assessing the prevalence of urogenital schistosomiasis and transmission risk factors amongst school-aged children around Mapé dam ecological suburbs in Malantouen district, Cameroon. *Infect Dis Poverty*. 2017;6:40.
- Farré L, Vella F. The intergenerational transmission of gender role attitudes and its implications for female labour force participation. *Economica*. 2013;80:219–47.
- Massé R. *Anthropologie De la Morale et De L'éthique*. Quebec: PUL Diffusion; 2015.
- Pope C, Mays N. *Qualitative methods in health research*. In: *Qualitative Research in Health Care*, 3rd ed. Williston, VT, USA: BMJ Books, 2006; 1–11.
- Makia CM, Fesuh NB, Amabo EN, et al. Urogenital schistosomiasis (UGS) and female genital schistosomiasis (FGS) in Cameroon: An observational assessment of key reproductive health determinants of girls and women in the Matta Health Area. *BMJ Open*. 2023;13:e063392.
- Hinton L, Ryan S. *Interviews*. In: *Qualitative Research in Health Care*. Newark: Wiley, 2020; 43–55.
- Moser C. *Gender Planning and Development: Theory, Practice and Training*. 1th ed. London, UK: Routledge; 1993.
- Morgan R, George A, Ssali S, et al. How to do (or not to do)... gender analysis in health systems research. *Health Policy Plan*. 2016;31:1069–78.
- Greenhalgh T. *Cultural Contexts of Health: the Use of Narrative Research in the Health Sector*. Copenhagen, Denmark: World Health Organization. Regional Office for Europe; 2016.
- Pope C, Ziebland S, Mays N, et al. In: *Qualitative Research in Health Care*. Newark: Wiley, 2020; 111–33.

- 25 Garrison-Desany HM, Wilson E, Munos M, et al. The role of gender power relations on women's health outcomes: Evidence from a maternal health coverage survey in Simiyu region, Tanzania. *BMC Public Health*. 2021;21:909.
- 26 Faust CL, Osakunor DNM, Downs JA, et al. Schistosomiasis control: Leave no age group behind. *Trends Parasitol*. 2020;36:582–91.
- 27 Engels D, Hotez P, Ducker C. Integration of prevention and control measures for female genital schistosomiasis, HIV and cervical cancer. *Bull World Health Organ*. 2020;98:615–24.
- 28 Nganda M, Bettee AK, Kollie K, et al. Incorporating the diagnosis and management of female genital schistosomiasis in primary health-care in Liberia: A mixed methods pilot study. *Int Health*. 2023;15: i43–51.
- 29 Nemungadi TG, Furumele TE, Gugerty MK, et al. Establishing and integrating a female genital schistosomiasis control programme into the existing health care system. *Trop Med Infect Dis*. 2022;7:382.
- 30 Kampete F. Gender-based violence (GBV): Its effectson development and the society, initiatives in place. Focus on the women and young girls in the Far North Region Cameroon. Online Thesis, Hacettepe University, Turkey, 2019. <https://avesis.hacettepe.edu.tr> [accessed February 2023].
- 31 Williams CR, Seunik M, Meier BM. Human rights as a framework for eliminating female genital schistosomiasis. *PLoS Negl Trop Dis*. 2022;16:e0010165.
- 32 Weiss MG. Cultural epidemiology: An introduction and overview. *Anthropology & Medicine*. 2001;8:5–29.