Gender and Disease Outbreaks- Time for action- Lessons from NTDs

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Kim Ozano, Laura Dean, Julie Irving, Rachael Thomson, Sally Theobald, Mariam Otmani, Olumide Ohundahunsi, Chandani Kharel and Mami Yoshimura

During the COVID-19 pandemic, policies and public health efforts need to address the gendered dimensions of disease outbreaks(Smith, 2019). Recognising the extent to which disease outbreaks affect women men, boys and girls differently is a fundamental step to understanding the effects of a health emergency on different individuals and communities, and for creating effective, equitable policies and interventions(Wenham et al., 2020). Environmental and structural factors, including substandard living conditions and a lack of safe water and sanitation, intersect with biological, social, economic and cultural factors to shape vulnerability to and experiences of health. Understanding how sex and gender intersect with other key social determinants, such as poverty, education and livelihoods, is essential to ensure no one is left behind. Here we share learnings from our webinar on the gendered dimensions of Neglected Tropical Diseases as a case study to stimulate discussion and consider implementation research strategies that have supported gender sensitive actions for addressing risk of transmission, prevention and treatment of NTDs .

Understanding and addressing gender inequities in NTDs is critical to meeting NTD targets. On the inaugural World NTD Day on 30 January 2020 ("#BeatNTDs. For good. For all"), 150 people from across the world logged on for the first gender and NTD webinar, signalling high levels of interest in this area. More have listened to the webinar online and downloaded the paper with key recommendations to address the gender dimensions of NTDs. The large online audience wanted to better understand how gender impacts NTD experiences and outcomes and what could be done to address the inequities they create. Three excellent presentations were followed by a series of questions from the audience which could not all be addressed due to time. These are discussed in this blog. The plethora of questions demonstrates that there is a thirst to better understand and take -action for gender justice.

Presentations

Sally Theobald

A presentation from Professor Sally Theobald highlighted the contents and recommendations within the **Discussion paper on the gender dimensions of NTDs**. *The five recommendations from the discussion paper are also synthesised in this fact sheet.* She linked these to the journey of a girl child who has no choice but to interact with schistosomiasis infected water sources for daily tasks which puts her at ongoing risk of Female Genital Schistosomiasis. A girl child who may not be able to access prevention and treatment because she may not be able to go to school where medicines are distributed or access health care because of her social position, roles and responsibilities. A girl child

who may be stigmatised because of health workers misunderstanding of FGS symptoms as a sexually transmitted disease. All of which translate to long term impacts on her economic stability and intergenerational health challenges for her future children. The overarching message delivered was clear: **Gender inequality and inequity in relation to NTDs is predominantly socially governed and therefore actionable.**

Photo 1 Children collecting water from a reservoir in Ogun state, Nigeria (Kim Ozano January 2020)

Chandani Kharel

Dr Chandani Kharel followed with a presentation that focused on a dengue outbreak in Nepal. She highlighted how the new policies developed are still lacking a focus on the gender dimensions of dengue. Interestingly, there is a unit within the Ministry of Health that focuses on gender - 'Gender equality and social inclusion unit', and could inform gender sensitive actions within NTD programmes but communication gaps limit opportunities for change. Chandani described how data is not disaggregated by sex or gender which leaves little scope to identify and address inequities, not only for gender but also for caste, ethnicity and other axes of marginalisation. Chandani concluded with a call for better integration and communication when implementing NTD programmes and for legal frameworks to be established that mainstream gender across health policies.

Olumide Ogundahunsi

The last presentation from Dr Olumide Ogundahunsi highlighted the need for implementation research that puts communities in the driving seat when addressing gender inequities in NTD

programme access and delivery. This means paying attention to multi-level power relations and the processes by which power and inequity are reproduced. He stressed the importance of applying an intersectional lens within infectious disease research and equity analysis to better understand how sex and gender intersect with other factors. Olumide demonstrated how the process of analysing gender power relations and their intersections with other social stratifiers can help to understand how NTDs affect people's lives, create differences in needs and experiences, and can provide information of how policies, services, and programs can help to address these differences. In conclusion, he ended the presentation with a call for multidisciplinary teams, including social scientists whom have expertise and experience in gender research to conduct detailed gender analysis.

Questions from the webinar participants: Let's keep the dialogue alive for gender justice

We followed up on the questions that were not answered during the session, and the panellists answered by drawing on their research teams and experience and sharing examples.

Question 1: Any recommendations on how to influence social norms related to gender without being rejected by the communities?

The COUNTDOWN consortium from LSTM uses participatory approaches with communities and health systems actors to explore social norms and their gendered impacts on NTDs (Dean et al., 2019a, Oluwole et al., 2019). In Liberia and Nigeria communities have collected, analysed and presented data to make changes to:

- the way information is communicated – using art for example in contexts where women in particular have low literacy levels
- the places treatment and prevention are delivered – treatment being delivered outside of farming or fishing times allows more men to access treatment and alternative distribution points such as clinics allows women to access treatment when attending facilities for other reasons
- how marginalised people living with NTDs can be identified and supported both in terms of psycho-social support and medical treatment(Dean et al., 2019b).

Participatory research methods are also used by TDR-supported social science research projects to generate dialogue and discussion from within communities. These methods aim to realize better ownership and sustained action to support communities in driving the changes that are possible. Communities frequently identify other development priorities that are important to them in addition to NTDs. Making sure we collaborate with other sectors for holistic community development is also of critical importance.

Question 2: Focusing implementation research on gender dimensions is definitely very important and a first step to demonstrate inequity. Could you please provide examples of how evidence around this has actually influenced policy making at country level?

Within COUNTDOWN, health systems actors are co-researchers in implementation research. This means they are involved in collecting data and co-developing outputs that can be actively communicated to other policy makers not directly involved in the research process. This requires establishing trust and demonstrating quality and validity of findings and solutions to gender inequities. The co-production of outputs and tools such as guides for planning, learning packs, visual

representation of findings, and policy briefs all served as useful mechanisms for policy change. Health systems actors have presented findings, openly discussed what they learnt during the research and suggested how findings can be embedded within policy. They can disseminate information to policy makers in terms that researchers may not. Having joint ownership of research process and outputs with health systems actors supports the integration of scientific findings in policy implementation.

In Nigeria, the research showed how male Community Drug Distributors (CDDs) were not always able to enter households due to purdah and other gendered cultural norms hence more women drug distributers were required to access households when men were away from the home. This change was taken up within the programme, and early results show that more women received preventive treatment for NTDs. This analysis was facilitated using WHO's guidance 'Towards Universal Health Coverage for preventive chemotherapy for NTDs: guidance for understanding who is left behind and why'. Using internationally recognised tools for equity analysis within NTD programmes that utilise action research approaches supported programme implementers to make policy change whilst also strengthening their capacity in gender and equity analysis.

In Liberia, COUNTDOWN was able to use research findings to support the development of the first NTD communications strategy that is gender sensitive. Policy makers and programme implementers were involved in community level data collection and analysis which enabled them to see and understand first-hand how gendered power hierarchies can shape medicine access and disease experience. The use of participatory visual methods enabled research data to be presented in a powerful way to stakeholders and emphasised the value of awareness generation in ensuring equitable access to MDA. Intra-sectoral collaboration between the NTD programme and the health promotion division supported the development of the communications strategy which includes gender specific communication techniques and adaptable communication methods to reach people with disability. The strategy is currently in roll-out phase.

TDR, as part of its effort to build sustainable implementation research (IR) capacity in low- and middle-income countries, has developed training tools on implementation research that have been disseminated in many countries. The outcomes of the subsequent research efforts can serve to inform policies at country level. The tools developed include a Massive Open Online Course on IR and Implementation Research Toolkit. TDR recognizes the importance of gender dimensions in research and so these tools are also being updated to incorporate and address gender-related aspects within research processes.

Question 3*: The local specific culture sometimes let women become more vulnerable to NTD such as LF, because they need to work in a risky environment… what do you say about this?*

Yes, there is research to show how gendered roles and responsibilities shape vulnerability to NTDs. The example of girls and women's ongoing exposure to schistosomiasis-infected water sources is given in the Discussion paper on the gender dimensions of NTDs. Women may face increased risk from contact with contaminated water via gendered household roles - collecting water, washing and cleaning. Men, too, may be at risk of male genital schistosomiasis through gendered livelihoods and occupations, e.g. fishing and swimming, involving contact with contaminated water.

In Nepal, TDR is supporting research that explores how social variables intersect with gender dimensions to influence vulnerability to illness, exposure to pathogens, response to illness, treatment received and discrimination in access to healthcare.

Gendered roles and responsibilities and livelihoods shape whether people of all genders are able to access Mass Drug Administration. In Ghana, for example, COUNTDOWN research showed that the timing of mass drug administration is an important factor for uptake of NTD treatment relating to mobility and migration for livelihood activities, socio-cultural activities and festivals, weather/seasonality and challenges with reaching whole population with current distribution strategy. Men and women's involvement in different livelihood activities shaped their mobility and migration into and out of the communities. Men were often absent for longer periods of time. This meant that they were often missed from the drug distribution programmes. Mass drug administration programmes need to be gender aware in their planning of distribution to ensure they meet the needs of men, women, girls and boys. This participatory process engaged different communities to understand their realities and different perspectives that fed into NTD control programme planning processes for more equitable treatment delivery in Ghana.

Question 4: Are we engaging those who face gender vulnerabilities to NTDs early on in the R&D process to eventually come out with gender-responsive solutions later on, in addition to addressing gender in the access and delivery process?

The REDRESS programme prioritises the engagement of people affected by stigmatising skin diseases including leprosy (Hansen's disease), Buruli ulcer, lymphoedema and hydrocele in the design and delivery of a multi-disciplinary action research cycle created to strengthen integrated health systems responses to these diseases. REDRESS includes a focus on the participatory development (with community members) of gender transformative strategies designed to tackle stigma and support people affected by mental health challenges as a consequence of NTDs. Including people affected by NTDs right from project inception has been essential to ensure adaptation of research and programme design to local need. The stories and testimonies of people affected by NTDs can also serve as powerful tools in shaping policy maker decisions.

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