

COR-NTD 2020

Virtual Meeting, November 12 – 14

Integrating for Impact

Lessons from ongoing NTD research on disability, stigma and mental health

Session Date: 11/14/20

Session Time: 9:00 AM - 12:00 PM EST

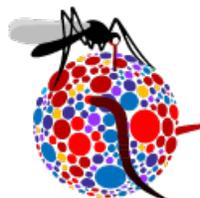
Session Description: A research agenda related to disability, stigma and mental health was identified at a previous COR-NTD meeting and was subsequently published. A range of COR-NTD-funded projects is now underway addressing different aspects. This provides a unique opportunity for researchers to meet and learn from each other, exchanging methods and tools developed, experiences in their use and preliminary findings. This breakout session will facilitate this learning while these projects are still in progress. It fits very well with the COR-NTD theme of 'Integrating for Impact' since it combines an integration perspective from two different angles that are both grounded in the new WHO NTD Roadmap. The first is the integration across NTDs. The workshop aims to highlight lessons on how research methods and tools can be integrated and used across a range of NTDs and in different cultural settings. The second is the integration across crucial disciplines in the health services. The projects in this workshop will share lessons on how to integrate NTD control, disability and mental health services at the peripheral level and how tools and approaches can be adapted to make them suitable for non-specialist use in primary health care.

This discussion on the tools and methods used and preliminary findings is likely to raise further research gaps and questions, some of which may be addressed as part of the ongoing projects or otherwise in future research.

Session Rapporteur: Anna Wickenden

Agenda

Welcome and Introductions	Dr Wim van Brakel
Presentation of ongoing research (5 mins per presentation; 2 mins changeover and introduction next speaker) – the presentations will be pre-recorded, but announced live	Chair: Dr Neerja Chowdhary
Improved delivery of / access to Morbidity Management and Disability Prevention (MMDP) / Disease Management, Disability and Inclusion (DMDI) for persons affected by LF, leprosy, and/or konzo in Nampula, Mozambique	Mr. Litos Raimundo
Trachomatous Trichiasis and Mental Health: a comparative impact study	Dr Esmael Habtamu
The influence of stigma on social participation and mental well-being amongst men and women affected/disabled by lymphatic filariasis and leprosy in Jaunpur and Bokaro, India	Mr Sushil Kumar
Developing an appropriate model of care for lymphatic filariasis and leprosy patients who need MMDP services in Bihar State, India	Mr Rajni Kant Singh



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IMPRESS – Improving access to integrated Morbidity management and disability PREvention Services through Stigma reduction for people with lower limb lymphoedema in Ethiopia: Feasibility and quasi-experimental study	Dr Maya Semrau
Addressing the Mental Health of Persons Living with Lymphatic Filariasis in Léogâne, Haiti: Effectiveness of a Chronic Disease Self-Management Program	Ms. Sadie Bazur-Leidy
The Neglected Mind-Skin Link: Promoting mental health and wellbeing of people affected by skin NTDs: Formative piloting of the WHO Guide on Mental Health and NTD Integration	Dr Julian Eaton

KEY DISCUSSION POINTS

What key findings and data did the group identify via presentations? What issues were raised in discussions?

Multi-sectoral coordination and collaboration

- Importance of learning from other chronic illnesses, such as the stigma associated with HIV
- How can we strengthen collaborations between sectors including the Ministry of Health and Ministry of Social Action (to improve focus on livelihoods)?
- Livelihoods are a critical area of intervention for people with mental ill health – it increases sense of confidence in the community, there are examples of people trained to be experts on organic farming who found as a result people listened to them as they were integral to the economy. (Agricultural rehabilitation).

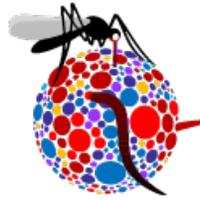
Importance of participation of people affected by leprosy and their communities

- Working with people affected has value including through self-support groups, especially in relation to increasing community knowledge
- Increased participation of people affected in design interventions is critical
- Community conversations are vital, there is an important role of community and other actors in delivering stigma reduction interventions

Effective strategies for addressing stigma and improving mental wellbeing

- Community sensitisation can build understanding of disease in communities (as seen in leprosy) – a range of interventions may be necessary for different population groups
- Self-support groups are helpful in addressing internalised stigma
- We need the interventions to move forward from the assessments and pilots to actually demonstrate how these can be implemented at scale and linked to other programs.

Tools and their application in other settings



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- Request for further information on how tools were validated, translated and adapted for NTDs and where they can be accessed. (Tools including PHQ-9, GAD 7, SBQ-R, Psychological First Aid, 5-QSI-AP, EnDPoINT Care Package). Note: most of these are available on InfoNTD.org

Post-Traumatic Stress Disorder (PTSD) and NTDs

- What is the state of research and data in terms of NTDs and PTSD? Has any research been conducted into the use of the Impact of Events Scale for trauma?
- CouNTDown in Liberia has used intersectional analysis and explored intersection of NTDs and trauma

Intersectional and person-centered approaches to mental health and NTDs

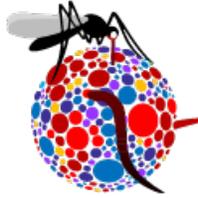
- Intersectionality is something important that should be considered – we need to take into account multiple factors related to mental health. Stigma can be a driver, but so can gender, age etc. There was a study into the perception of leprosy and leprosy related stigma study in India – role of religion was not considered, and this was seen as an omission.
- Intersectional framework: CouNTDown in Liberia has used intersectional analysis and explored intersection of NTDs and trauma.
- Disaggregated data for gender is typically available but there has been a strong argument to include measures related to function, but also other identities. If we think something is important, we need to measure it. This is true in much wider work and data should be disaggregated at least by age, gender and disability.
- Along with specific measures and reporting related to stigma and mental health, we should also report on things that relate to people's daily life. This will also facilitate the understanding and relevance of the issues to donors

Pain and mental health

- An additional factor that should be considered is pain and pain management and its impact on mental health

Intersection between stigma, mental health and other consequences of NTD treatment and morbidity

- There needs to be research to better understand the link between depression and internalised stigma
- There are links between treatment efficacy and depression. We need to demonstrate more the connections between good and effective treatment for mental health and treatment compliance and health outcomes.
- We should also consider that long term treatment can in itself have a mental health impact as shown in HIV
- The process of concealment and information management in itself causes a psychological burden on persons affected



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KNOWLEDGE GAPS IDENTIFIED

What follow-up research questions were identified, if any, in your group discussion?

Group 1: Study Design

- No gaps were identified

Group 2: Instruments to assess stigma and mental wellbeing

- How can we strengthen the quantitative data that we have in this area?
- Could instruments such as EQ-5D and DALYs be useful in this area?

Group 3: Interventions to reduce stigma and improve mental wellbeing

- Impact of increased communication/bringing groups together between stigmatised persons and people who may drive stigma?
- How can we provide longer term psychosocial support once physical symptoms have been treated? (Including consideration of impact of chronic and episodic pain)
- How can we effectively engage with teachers, religious leaders and explore the role of traditional healers – all of these are actors within a health system?
- Different interventions to address stigma at different levels – internal and within the community?
Note: see www.stigma-guides.org
- Intervention strategies involving and integrating community – how can we best involve community in delivering stigma reduction (considering cultural settings)? Note: see www.stigma-guides.org
- Sustainability of services – how to strengthen referral pathways?
- What are the drivers around stigma (cultural beliefs vs disease specific, fears of contagion vs stigma of mental health – circular/double burden of stigma)? Note: see www.stigma-guides.org

RECOMMENDATIONS AND NEXT STEPS

What recommendation(s) would your group like to make for implementation of research on NTD-related disability, stigma and mental health?

What further operational research or other actions need to be taken to address the knowledge gaps identified by the group?

Group 1: Study Design

- Support wider validation of tools
- Assess feasibility/uptake of guides (many seem complex to academics, so must seem daunting in affected communities)
- Continue to support a cross-project experience-sharing forum such as today's workshop.

Group 2: Instruments to assess stigma and mental wellbeing

- How can we assess prevalence/incidence of PTSD, especially in conflict and fragile state?
- How can we adapt tools we are using among younger populations, children and adolescents?



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- How can we calculate DALYs in relation to mental health?
- There are a lot of tools, we need to work out how we can make these available more widely and how we can help people choose the most appropriate tool

Group 3: Interventions to reduce stigma and improve mental wellbeing

- How can we strengthen multi-sectoral collaboration?
 - How can we integrate livelihoods into NTDs programs and vice versa and linking these?
Learning from tools already developed
 - Working within schools
- Learning from other sectors (disability) – how can we increase participation and inclusion of people affected in design interventions to highlight their priorities and needs?
- How to strengthen referral pathways? 2-way pathway, training community level staff/people affected linking with community and primary health system (reduce burden on PHC) working with people affected – particularly in low-income settings.
- Learning from cognitive behavioural therapy as an intervention in other settings
- What role can the community and other informal actors play in delivering stigma reduction interventions?
- How can we consider tools for children affected by NTDs?

Summary:

It is critical that persons affected by NTDs are involved in the design and implementation of research and interventions, and that their lived experience of NTD research and interventions is considered as paramount. This reflects a recognition of the need for a person centered and intersectional approach that acknowledges that mental ill- health has multiple determinants and manifestations. The cultural context needs to be integrated into research design and validation studies should be conducted both locally and in different cultural contexts, related to this is the need for a comparison of tools and the relative benefit of tools, including an openness to improve on existing tools if necessary. Tools are also predominantly focused on adults, but not children, despite many children being affected by NTDs directly or through their parent's disease, and are short term in their application, which does not necessarily address the long-term consequences of NTDs and mental ill-health and the need for long term support. There is further work needed on the link between tools, measurement and DALYs and how we can work together on getting a better assessment of the burden posed by NTDs that takes stigma and mental health into account. Finally, we need an approach that is multi-sectoral and recognizes the potential benefit of interventions beyond the health sector and support groups.