



## Case study: NTD-related stigma and mental health- putting wellbeing at the heart of NTD elimination

Globally, neglected tropical diseases (NTDs) affect the lives of millions of marginalised and impoverished populations. Many NTDs cause chronic lifelong disabling conditions. However, the focus of NTD interventions has not been on these individuals. Currently, NTD programmes are working to change this with the introduction of strategies around disease management, disability and inclusion (DMDI) for affected individuals. Liberia is one of the first countries in the world to co-implement such a strategy across numerous NTDs as well as consider how these services should be integrated within the broader health system. Although this presents progress for affected individuals, their experiences and opinions about such strategies and health interventions are often absent.

Stigma and discrimination have an impact on many aspects of life, including economic status and social participation. Its impact on mental health is very significant and has recently been highlighted as a major contributor to the global burden of mental ill-health (1, 2). People with NTDs such as LF have been shown to have significantly higher levels of mental distress or disorder than others in the same communities. In fact, the burden of disease associated with LF may be around twice as high if comorbid depressive illness is taken into account. In addition, the mental health burden which caregivers suffer in the care of chronic NTD patients has only been assessed in filariasis (3).

The mental health community must not overlook the impact NTDs has on global mental health morbidity, and the need to address the patient and caregiver needs, bringing together opportunities for communities to work together. Mental health is already projected to be the largest cause of Global Disease Burden by 2030, without consideration of the contribution of NTDs. Including NTDs within these mental health projections are important and will further elevate the serious comparative lack of recognition for both sets of diseases.

As approaches to health systems strengthening that emphasise the control or containment of NTDs have dominated policy and programming. This has led to weak, fragile and fragmented systems in many LMIC contexts which have also been designed and shaped by donor priorities. This leaves significant gaps in health systems to be able to deliver a solid continuum of care that allows for; prevention, detection, referral, management (including both pharmacological and psychosocial), surveillance and monitoring, and quality of care assessment, in response to the management of disease and associated debility and disability. Furthermore, person centred approaches that prioritise the beliefs and values of patients are frequently ignored or ill-considered. To be able to respond to debility and disability effectively within health systems, there is therefore a need to re-orientate approaches to health systems strengthening towards a focus on multistakeholder and multi-sectoral partnerships that put the needs of patients and persons affected by disability at the centre of services.

COUNTDOWN research has provided a platform to discuss moving beyond the dichotomies of physical and mental health and disease and disability with health systems researchers and practitioners to emphasise the importance of these issues using findings from research conducted in Liberia. Health systems need to be able to respond to provide both preventive interventions and those which focus on the case management of disease, all of which requires advances in health service delivery mechanisms and collaboration with other sectors. .



## Research Aim

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This COUNTDOWN study explored experiences of people living with NTDs and their families in Liberia. Specifically, people affected by lymphatic filariasis, Buruli ulcer, leprosy and onchocerciasis. It looked for variation in experience and how it is shaped by different social axes such as gender, age, geographic location and level of disease progression and disability. Policy analysis was conducted as well as talking to key informants to understand the health system and NTD programme responses to these diseases. Combined analysis of various data collection methods allowed us to reflect on the extent the health system and NTD programme are currently meeting the needs of people living with these diseases and helped us to make recommendations for change at the community, county and district level to make health systems interventions more inclusive of the needs and experiences of affected individuals.

This study used qualitative research methods. Specifically: key informant interviews; illness narrative and indepth interviews with people living with one or more of the focus NTDs and in-depth interviews with affected family members of people living with NTDs.

## Research Findings

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NTD-related stigma and its impact on mental health is cross-cutting. A recent review showed published evidence of stigma affecting as many as 10 NTDs (4). Stigma can affect all aspects of NTD control, including health-seeking behaviour, case detection, treatment, including uptake and adherence, prevention of disabilities and social inclusion. Thus a significant negative effect on NTD control is evident. While the causes of stigma may differ between NTDs, the manifestations and consequences are remarkably similar across cultures and diseases. This is especially true for the impact on mental health.

High levels of pain associated with specific diseases such as BU and Leprosy, often led people to describe a loss of hope and a resolution that they were going to die. This was often linked to not knowing what the cause of the illness was or where participants believed they were sick because of witchcraft.

Feelings of helplessness and or worry were similar across diseases and often shaped by participant gender and generation as well as their pre-illness identify as a 'parent' or 'household provider'. For example, for younger participants, being unable to go to school or interact socially with their peers created a huge sense of loss; however, for older participants who had got sick later in life, worry was linked less explicitly to current illness experience and more associated to ageing and no longer being able to do the things they used to do. For participants who constructed their identity prior to illness around being a parent or household provider, transition to the role of a 'dependent' and limitations to their ability to provide for their family had implications for psycho-social wellbeing and contributed toward a general sense of worry or anxiety about how to fulfil the needs of their families and households. Some male participants also found this challenged their gendered identity or masculinity as it was their role to be able to support their family's needs. This was often explicitly linked to challenges in providing food based on an inability to farm or being unable to work hard or far from communities to generate economic support for the household.

*"Even my children who I supposed to help them...no other means for me to help them is also bad feeling..."*

(CS012)

Extreme experiences of social isolation coupled with feelings of helplessness, worry and anxiety often resulted in description of suicidal attempts or thoughts within patient narratives. These were either related to their own direct experiences or 'others like them' who they had known within their community. For some participants, particularly those currently receiving treatment or those who were unclear about their future disease outcome, these thoughts were still present.

This was particularly true for participants who were receiving in-patient treatment at Ganta Rehab, the prospect of future negative treatment from family members based on a lack of interaction since arrival often made the future seem unmanageable. Whereas, for others the description of these thoughts and events was historic and something which they had worked through, usually linked to the role of faith within their experience or based on a renewed sense of purpose or belonging within the community. This transition in mental ill-health was most common amongst leprosy patients who lived in communities in and around Ganta Rehab. For many participants living with LF, not knowing their diagnosis or the irreversibility of their condition, presented a sense of hope for a 'cure', however, many described that if this 'state' was permanent then they would not want to go on living.

Suicidal attempts or thoughts described within patient narratives, were often described by household members as causing them worry or anxiety and in extreme circumstances caused them to refuse to leave affected persons on their own for fear they may harm themselves.

Descriptions of mental ill-health were often separated from the biomedical treatment of disease. Participants frequently described that although they had been told they were 'free' from disease their physical condition, perception of 'self' and mental wellbeing remained as it was when they weren't 'free' from disease. For persons affected by Buruli Ulcer, this was particularly the case even in the absence of physical morbidity, the social isolation and stigma associated with the illness experience had long lasting impacts on mental-ill health, with one participant describing that 'her friends not coming around her anymore still made her want to kill herself'.

*"Because they say, you free but then the other area there, it still hampering you. I am moving without limbs, I went with all limbs on me, all my feet, but now the sickness has caused it to be amputated. So that's it."*

(CS018)

*"I know within myself that all hope is lost that I won't be able to do anything for myself. Life is so hard for me to the extent that all hope is lost from me"*

(CS014)

*"I feel within myself that I am sick and my walking, strange change, all the way the body, all change, then the feeling there is, whether you look at me, I will accept. If you look at me, I say well, I was not born like this, that sickness"*

## Patient Narratives

Patient narrative is particularly important when considering management and rehabilitation linked to chronic ill-health, debility and disability. Chronic disease and disability can often dominate the experience of everyday life, so unless we understand how individuals conceptualise and navigate these experiences, we are unlikely to be able to respond in appropriate ways. Interventions should consider how to enhance collaboration with the primary health care system as well as the disability community to ensure that the needs of individuals are not forgotten.

**Hannah's story** highlights the impact that disability, because of onchocerciasis, can have on an individual but also on other members of the household, in ways that are influenced by gendered roles and poverty. The impact on Hannah, her mother and children, presents a need for holistic support interventions for people who are living with the clinical manifestations of onchocerciasis, such as skin disease and blindness, to ensure their psychological, social and physical support needs are met. It is only if these things are provided that we will ensure that no-one is left behind in managing the impacts of onchocerciasis.

### Hannah's Story: Adolescent Disability and Household Impacts

In 1989, Hannah was happily attending school and her family were told 'to take care of her because she was clever'. Hannah wanted to be a doctor. In 1991, as a teenager, Hannah started to experience severe itching on her skin and 'tears were coming from her eyes' when she looked at the light. Liberia was in conflict and health seeking was difficult. Hannah's mother sought care for her daughter in Guinea and the Ivory Coast where she accessed traditional medicines, before finally reaching a hospital in Liberia where she was given Filaria medicine. She was told to return to the facility when the medicine ran out, but healthcare seeking was expensive. The family asked for support from the community to return to the hospital, but people didn't have money; it was the end of the war, and they were frequently told 'the way we come from war that who got money, our money then we are keeping it oh.' In 1994, Hannah described that she woke up 'noticed that she couldn't see her parents again, she started telling them I can't see, I can't see, [I] was looking all around for things from beside [me], [I] was looking for something to just finish [my] life.'

Since 1994, Hannah described that 'men will come and tell me they will help me, but after a period of time, they leave', she explained that she has given birth to four children but she has sent them to her sister as she and her mother struggle for food and 'when they [her children] be here [and] she gets food, [then] she gets nothing, so that the reason why she asked her sister so at least she can take some [food] for them.' Contribution to the household is difficult for Hannah, and her siblings often exclude her and tell her that they have their own children to look after, 'they don't want to be close [to her], they just distance themselves [from her].' As a result, Hannah's mother has become her primary carer. Hannah felt herself to be a liability or burden on her mother and was worried 'who will take care of me, when my mother dies'. Hannah described that the recent medicine they brought for Filaria she took, and this helped her skin to stop itching, however, she still struggles to move around in the community due to her eyes as she feels 'afraid' and 'ashamed' and 'people might laugh at her'

## Hannah's Story ctd

Her toilet is outside and far from the house, so she must defecate just behind the house so as not to move too far. The place where she can retrieve clean water is also too far for her to access. Despite facing numerous challenges, Hannah described listening to the 'radio to find comfort' and a desire to be able to 'make and sell clothes at the market' to support her and her mother. Hannah's mother described that since her daughter had got sick she had given up farm work and her job as a trained traditional midwife to 'just sit down and look after her daughter'. As a practising Catholic since her daughter's sickness 'decided to be praying in the house with her. [I] can't go there [to church] to leave her... [I] can't go nowhere to leave her...for that reason she just decided to be glue to her.' When asked why, she explained: 'because Hannah always saying she will kill herself. So, [I am] afraid maybe if [I] go out, she may come and take something to harm herself. So, for that reason [I] don't want to go far from her.' She described that they have been living like that for a long time now and have received no help.

She worries about what will happen to her daughter when she is not around. She also described conversations with her daughter where her daughter considers killing herself to reduce the burden on her mother. She described that because of the situation, her and her daughter often struggle for food, and they are reliant on donations from people in the community. She described that sometimes people will give them money which they use to buy some cups of rice that they save for when they are hungry. She described a division in the household between her children, stating that on good days her other children would share with her and her daughter but on bad days they do not.

**Jon's story** highlights weaknesses in health systems during periods of conflict that can lead to inability to access care for NTDs, resulting in debility, disability and unmet health and social care needs for individuals, households and communities.

## Jon's Story: Conflict, Fragility, NTDs and Disability

Jon is 46 years old and lives in a peri-urban village in Liberia. Since 1991 Jon had been running a Methodist school in his community. Jon established the school during Liberia's conflict so that the children of the community could be educated as there was no government school at that time. On a wall in Jon's house, he had documented his story in chalk. Each marking means something to him as a step on his pathway to his today. The below gives a brief overview of Jon's story, cumulating in how he currently feels because of being blind due to onchocerciasis.

In 1985, Jon had experienced severe itching and sought treatment at the hospital, where he was given Banocide. He describes 'They 'cut my skin' at that time and told me it was filaria, 'they said it was inside plenty, [the medicine] worked my skin could not itch again'. However, in 1990, the itching started again. This was during Liberia's conflict, so accessing medicines for Jon was challenging. Despite believing that he had been 'infected' by someone in his community following a disagreement, in 2005 Jon began healthcare seeking for his illness.

Firstly, he went to the hospital, where they told him there was nothing they could do. Jon then went to see an old lady in the community who gave him bitter root to manage the itching. In 2012, he went to a larger hospital where he was told he had glaucoma and then cataract needing surgery. He was given medicines to reduce his blood pressure, however, the medicines didn't work, so the surgery never took place. The costs of healthcare seeking, and medicines were very high so Jon returned to his community. When the mectizan distribution programme then came to his community, some of the distributors were charging for the medicine, but Jon went to the distributors house and demanded the medicine. He still couldn't see 'the wall' right, so he decided to go back to the hospital. He was told it was filaria and given some more medicines. Despite describing that 'even when I took that medicine now my whole body [am] starting scratching' and consistent care seeking, Jon's sight was deteriorating. He described that word had spread in the community that he was going blind until the last entry on the wall where he told us:

*'I feel hurt when I open it [his eyes] I can see no writing. Hmm I can see no writing'*

Since this last entry, Jon described how his wife had left him and taken their children to live in another community due to criticism and pressure she had faced in that community due to his blindness. Jon described how challenging he found it being alone in the house as he couldn't fix the leaking roof and often slept on the wet ground; he also described challenges in finding food. When asked what he does each day, he described 'I just sit down the whole day. You alone and you know what it means'.

Jon described his last chalk marking and going blind as the end of his journey as he now felt isolated and alone. Jon no longer teaches in the school, which he described affects him and the community. As we move toward onchocerciasis elimination in many contexts, it is vital that people like Jon are not left behind and that this isn't the end of their story. Identifying ways to support people living with visual impairment and their families is a critical part of achieving health for all, equitable onchocerciasis elimination and should not be forgotten. Furthermore, in contexts such as Liberia that have faced challenges in implementing continuous mass drug administration campaigns due to periods of instability and conflict, additional efforts should be made to strengthen health systems so that when people like Jon seek help, it is readily available to them.

## Impact

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Addressing NTD-related stigma and mental health consequences as part of holistic NTD programmes can improve health outcomes of millions of persons affected. It will also contribute to improved NTD control through early detection and treatment of cases, improved treatment adherence and a reduced cost to health services due to a lessening of the psychosocial burden. The research challenge is how interventions to reduce NTD-related stigma and mental health consequences can best be integrated into NTD programmes and how the benefits of these can be best demonstrated. Prioritising the needs and experiences of persons affected by NTDs, their families and communities is also essential in ensuring the acceptability of NTD related support services.

The integration of case management has been informed and guided by COUNTDOWN experts and research and the team are working with the NTD Programme in Liberia to build a mental health pillar into integrated service responses.

## Key Recommendations

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- ✓ Debility and disability due to chronic conditions arising from NTDs requires a complex health systems response that focuses on a continuum of care.
- ✓ Debility and disability can shape vulnerabilities in relation to NTDs in various ways and health systems need to be able to adapt to address these vulnerabilities.
- ✓ Patient experience of NTDs and their associated debility and disability is unique to the individual, shaped by broader social and structural factors and frequently includes health needs that are broader than medical interventions.
- ✓ Early access to preventive, curative, medical management and psychosocial services is critical.
- ✓ Attention to the practical and psycho-social support needs of carers is required, including family, community and frontline health workers.
- ✓ The importance of linkages between different service providers, even within physical or mental health services moving from acute/crisis to chronic phases of illness is often ill-defined with insufficient service linkages.
- ✓ Peer support approaches through self-organised groups may be a helpful approach to enable shared problem solving, practical and psycho-social support

## References and Further Reading

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