




Participatory development of a community mental wellbeing support package for people affected by skin neglected tropical diseases in the Kasai province, Democratic Republic of Congo

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Background: Skin neglected tropical diseases (NTDs) produce signs and symptoms that are often physically challenging, stigmatizing and have a negative impact on the mental wellbeing of people affected. In the Democratic Republic of Congo (DRC), little is known about the mental wellbeing experiences of people affected by skin NTDs and support is lacking. We collaborated with ongoing NTD programs, the Ministry of Health and people affected to evidence experiences and opportunities for change and co-developed a mental wellbeing support package for people affected and local health system actors.

Methods: This implementation research study used the photovoice method alongside key-informant interviews to evidence mental wellbeing challenges in people affected by skin NTDs and explore opportunities for change. These were used to co-develop a skin NTD mental wellbeing support package with people affected, community members and local health system actors through a participatory workshop.

Results: Stigma, discrimination, decreased livelihoods and mental wellbeing challenges were evidenced by people affected by skin NTDs, their communities and health system actors. Participants identified and co-established community-led peer support groups, strengthened with basic knowledge on psychosocial support, and income-generating or recreational initiatives to support mental wellbeing of people affected by skin NTDs.

Conclusions: Co-developing a support package with persons affected, community members and health system actors is a step towards holistic care for people affected by skin NTDs and promotes uptake and ownership of intervention components.

Contexte: Les maladies tropicales négligées (MTN) cutanées produisent des signes et des symptômes qui sont souvent difficiles à supporter physiquement, ils sont également stigmatisants et ont un impact négatif sur le bien-être mental des personnes touchées. En République Démocratique du Congo (RDC), on sait peu de choses sur le bien-être mental des personnes atteintes de MTN cutanées, et le soutien fait défaut. Nous avons collaboré avec les programmes de lutte contre les MTN en cours, le ministère de la santé et les personnes touchées pour mettre en évidence les expériences et les possibilités de changement, et nous avons élaboré un programme de soutien au bien-être mental pour les personnes touchées et les acteurs du système de santé local.

Méthodes utilisées: Cette étude de recherche sur la mise en œuvre a utilisé la méthode photovoix, ainsi que des entretiens avec des informateurs clés, afin de mettre en évidence les problèmes de bien-être mental des personnes touchées par les MNT cutanées. Ces éléments ont été utilisés pour élaborer un programme de soutien au bien-être mental des MNT cutanées avec les personnes concernées, les membres de la communauté et les acteurs du système de santé local dans le cadre d'un atelier participatif.

Résultats: La stigmatisation, la discrimination, la diminution des moyens de subsistance et les problèmes de bien-être mental ont été mis en évidence par les personnes atteintes de MTN cutanées, leurs communautés et les acteurs du système de santé. Les participants ont identifié et mis en place des groupes communautaires de soutien par les pairs, renforcés par des connaissances de base en matière de soutien psychosocial, et des initiatives génératrices de revenus/récréatives pour soutenir le bien-être mental des personnes touchées par les MTN cutanées.

Conclusions: L'élaboration d'un ensemble de mesures de soutien en collaboration avec les personnes concernées, les membres de la communauté et les acteurs du système de santé, constitue une étape vers une prise en charge holistique des personnes atteintes de MNT cutanées et favorise l'adoption et l'appropriation des composantes de l'intervention.

Antecedentes: Las enfermedades tropicales desatendidas (ETDs) cutáneas producen signos y síntomas que a menudo suponen un reto físico, estigmatizan y tienen un impacto negativo en el bienestar mental de las personas afectadas. En la República Democrática del Congo (RDC), se sabe poco sobre las experiencias de bienestar mental de las personas afectadas por ETDs cutáneas, y falta apoyo. Colaboramos con los programas en curso sobre las ETDs, el Ministerio de Sanidad y las personas afectadas para poner de manifiesto las experiencias y las oportunidades de cambio, y desarrollamos de manera conjunta un paquete de apoyo al bienestar mental para las personas afectadas y los agentes del sistema sanitario local.

Métodos: Este estudio de investigación utilizó el método fotovoz, junto con entrevistas a informantes clave, para poner de manifiesto los desafíos de bienestar mental de las personas afectadas por ETDs cutáneas y explorar las oportunidades de cambio. Estos datos se utilizaron para desarrollar un paquete de apoyo al bienestar mental de manera conjunta con las personas afectadas por las ETDs cutáneas, los miembros de la comunidad y los actores del sistema sanitario local a través de un taller participativo.

Resultados: El estigma, la discriminación, la disminución de los medios de subsistencia y los problemas de bienestar mental fueron evidenciados por las personas afectadas por ETD cutáneas, sus comunidades y los agentes del sistema sanitario. Los participantes identificaron y establecieron conjuntamente grupos de apoyo entre pares dirigidos por la comunidad, fortalecidos con conocimientos básicos sobre apoyo psicosocial e iniciativas recreativas y generadoras de ingresos para apoyar el bienestar mental de las personas afectadas por las ETD cutáneas.

Conclusiones: El desarrollo conjunto de un paquete de medidas de apoyo con las personas afectadas, los miembros de la comunidad y los actores del sistema sanitario es un paso hacia la atención holística de las personas afectadas por las NTDs a y promueve la adopción y apropiación de los componentes de la intervención.

Keywords: co-development, mental wellbeing, neglected tropical diseases, stigma.

Introduction

People affected by neglected tropical diseases (NTDs) frequently struggle with mental health conditions and psychological distress due to disease burden, stigma and discrimination.¹⁻³ NTDs are a group of 20 diseases endemic to poor regions deprived of basic facilities and public health initiatives. Skin NTDs, such as lymphatic filariasis (LF) and leprosy, are a subgroup of NTDs that show signs and symptoms on the skin, which are often painful, debilitating and stigmatizing.¹ According to the World Health Organization (WHO), >1 billion people are affected by or at risk of skin NTDs.^{4,5} Skin NTDs can cause disability, chronic sequelae and precarious disease outcomes. These can lead to loss of livelihood/reduced income, catastrophic health expenditures, reduced societal status,

loss of relationships and family, decrease in quality of life and, consequently, mental distress.^{1,4} Mental distress influences behaviour, including reduced health-seeking attitudes, with the consequence of disease stagnation or aggravation, excessive alcohol and substance use, self-harm or suicidal ideation. Mental wellbeing should be integral to the person-centred approach to services and universal health coverage.³ An integrated approach to manage skin NTDs that includes mental wellbeing will reduce stigma and discrimination and increase quality of life.

For more than 2 decades, the Democratic Republic of Congo (DRC) has had a history of war and socio-economic instability, particularly felt in the province of Kasai. This protracted conflict has led to fragility within the health system, including limited

accessibility to basic services for NTDs.⁶ Conflicts, political instability and weakened health and social systems often augment mental distress, which is compounded by stigma and discrimination among people affected by skin NTDs.⁷ The DRC carries one of the highest burdens of leprosy within sub-Saharan Africa, with limited detailed information available regarding the prevalence of other endemic NTDs.^{8,9} In 2022, 3032 new cases of leprosy were detected, of which 317 were already disabled at diagnosis.¹⁰ The DRC also has one of the highest burdens of onchocerciasis and LF in sub-Saharan Africa (about 36 000 000 and 39 000 000 cases treated by mass drug administration every year, respectively).¹¹

Despite growing evidence of stigma, discrimination and mental distress among people affected by skin NTDs,¹² little is known in the DRC and other post-conflict settings. In Kasai, the Leprosy Mission DRC is working to develop and expand their program of work to provide a holistic package of support for people affected by skin NTDs, which includes a focus on mental wellbeing. To date, anecdotal evidence from ongoing NTD program implementation in this area suggests that there is a significant program gap in responding to the mental health and wellbeing needs of people affected by skin NTDs. Partnerships and interactions between ongoing program implementers, persons affected and the health system is a critical pathway towards addressing this gap and developing a person-centred approach to care. Thus this article documents the current mental health and wellbeing impacts of skin NTDs among affected persons in Kasai province, DRC, documented through photovoice. We also describe the process of utilising photovoice activities to harness political support and co-develop a mental wellbeing support package with and for people affected and local health systems actors.

Methods

This study was an implementation research study to develop an intervention aimed at supporting the mental wellbeing of people affected by skin NTDs in Kasai province, DRC. To evidence the experiences of people living with skin NTDs and its impact on their mental health and wellbeing, we applied photovoice as a visual creative participatory research method,¹³ that can harness social action, alongside a quantitative survey to emphasise the scale of the challenge. Results of the survey are presented elsewhere in this supplement (Seekles et al.,¹⁴). We also used qualitative key informant interviews (KIIs) with community and health-related stakeholders to discuss existing mental health interventions and explore opportunities and platforms for community and health system engagement in supporting the mental wellbeing of people affected by skin NTDs. Preliminary findings from surveys, photovoice and KIIs were shared with community and local, provincial and ministerial health system stakeholders in a participatory workshop. This workshop was used to develop a community mental health and wellbeing support package for people living with skin NTDs in Kasai province.

Study setting

This study was conducted in the Ngombe and Tshisele health areas in Kasai province, DRC, endemic for leprosy, LF and onchocerciasis. Ngombe and Tshisele are primary health units in the

Table 1. Distribution of photovoice participants

Participants	Area		n
	Ngombe	Tshisele	
Women	6	4	10
Men	6	4	10
Total	12	8	20

Tshikapa health zone, Kasai province. The main activities in these areas are agriculture and petty trading and the dominant languages spoken are Tshokwe and Tshiluba.^{15,16}

Data collection

Photovoice

Sampling and recruitment. The photovoice activity was conducted with 20 people affected by either leprosy, clinical manifestations of LF including lymphoedema and/or hydrocele or onchocerciasis. We purposively selected 20 participants (10 men, 10 women) to take part in photovoice activities to ensure maximum variation (age, disease type) within the sample while also maintaining a practical and feasible approach to photovoice that was supported by study resources (Table 1). Participants were selected from the known NTD-affected population registered at local health facilities. The minimum age of participation was 18 years, as this is the age of majority in DRC, where participants are legally able to give consent.

Participants were contacted via the use of community relay agents (community health workers) and, where possible, by phone, and asked to participate in the study by explaining the participant information sheet. Community relay agents are community members who have received basic training on health promotion or preventive care administration and are assigned to work in collaboration with primary health facilities.¹⁷

Training. All participants were provided with a 1-day training, facilitated by the researchers, to provide an overview of the research, the ethics of taking photos and how to use the cameras. This included discussion of the three main study areas: stigma, mental wellbeing and coping strategies. Participants were given guidance that photographs should only focus on the inclusion of objects/environments essential to their experience of illness and to avoid photographing people where possible. Should a participant wish to take a photo of people, then participants were advised to seek verbal consent. Training was conducted in French and translated into Tshokwe and Tshiluba. A group of 20 community relay agents were also trained to support participants during data collection.

The photovoice process. As described in Figure 1, we adapted the photovoice process from Ronzi et al.¹³ Steps 1–3 were conducted individually with each participant, while step 4 was conducted in a group.

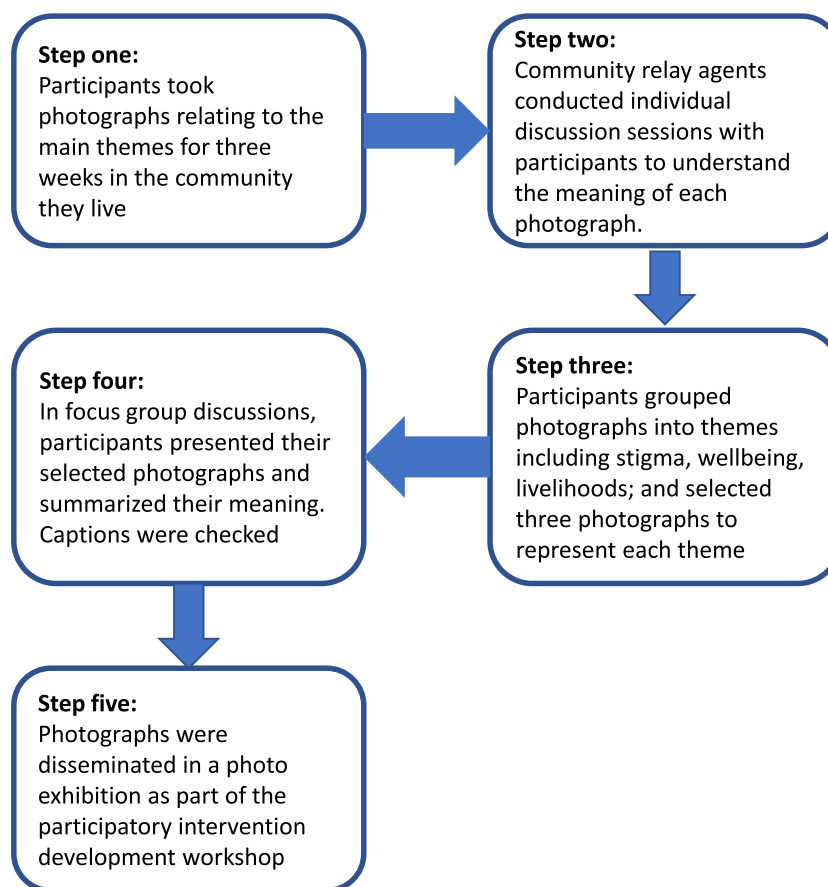


Figure 1. The photovoice process as adapted from Ronzi et al.¹³

KIIs

Semi-structured interviews were conducted with 23 key informants purposively selected to represent all levels of the health system and a wide range of (potential) actors relating to the mental wellbeing of people affected by skin NTDs. Informants included representatives of the NTD and leprosy programs of the Ministry of Health in Kinshasa (n=2), health system stakeholders at the provincial (Kasai) and zonal (Tchikapa) levels including medical practitioners (n=7), registered nurses (n=3), schoolteachers (n=2), community leaders (n=3), religious leaders (n=4) and traditional healers (n=2). We estimated that a sample of 23 purposively selected participants would obtain maximum variation within our study based on the diversity of job roles related to the provision of skin NTD services or community-based mental healthcare. During data collection we also identified a point of saturation where similar ideas and thoughts were being identified by multiple participants and minimal new information was emerging. The purpose of the KIIs was to elucidate participants' reflection on current policy and program context in relation to NTDs and mental health in Kasai province. Some participants were asked to provide their own viewpoint (e.g. community leaders), while others were asked to provide the perspective of policy and program guidance in their organisation pertaining to skin NTDs (e.g. provincial and zonal health officials). Participants

were contacted through phone, letter or e-mail. Interviews were conducted in French or in Tshokwe/Tshiluba with simultaneous translations to French.

Data management and analysis

Interviews and group discussions were audio recorded and transcribed verbatim. Notes taken during workshop and photovoice training were used to produce reports. Topic guides, transcripts, reports and intervention components were translated from French to English and back-translated for quality assurance by researchers who understood both languages (PL, JKukola and MN). A thematic framework analysis was conducted using NVivo 12 (Lumivero, Denver, CO, USA) for all data. Codes were developed using pre-tested topic guides and they were added/modified as the team gained familiarity with the data. Coding, charting and mapping of emerging themes were independently carried out by MN, PL, JKukola, YD, JKadima and LD and reviewed by MN and YD.

Dissemination and intervention development workshop

A 2-day workshop was conducted with photovoice participants, community relay agents, community representatives and health system actors from Ngombe/Tshisele, Tshikapa and Kasai

provinces. Preliminary research findings were shared with workshop attendees by the core research team and photovoice participants for validation and appreciation. Workshop participants together with the core research team identified/prioritized the needs of persons affected by skin NTDs, designed a framework of activities that responds to those needs and developed a plan of action. A steering committee was established to support the core research team in formalizing intervention components and pilot within study communities.

Results

In this section we present participants' lived experiences of skin NTDs, specifically, how physical challenges, stigma, impacts on livelihoods and the social environment all converge together to have a negative impact on mental wellbeing. Using photographs, participants expressed lived experiences and directly or indirectly linked them to their mental wellbeing. We also present available platforms for mental wellbeing support, opportunities for engaging community and health system actors and intervention components that were identified as harnessing these opportunities for change.

Experiences of people affected by skin NTDs and impact on their mental wellbeing

Pain, disfigurement and mobility restrictions

Pain, disfigurement and mobility restrictions limited daily life, including access to basic services (e.g. toilets were not adapted to support physical accessibility). Many participants reported dependence on pain medications such as ibuprofen. These further strained existing financial difficulties to buy medications. Photovoice participants reported being distressed about the physical changes to their bodies, often comparing themselves with objects like rotten fruit and wasted tree trunks (Figure 2).

Nevertheless, some participants were positive about their wellbeing and quality of life if their conditions were cared for. Using the example of a corn farm that produces when weeded, one participant stated:

“If the fields are weeded, there will be good production. Otherwise, there will be no good performance. Comparable to me, if I am taken care of, I will produce well.” (Photovoice, male with LF, Tshisele [Supplementary Figure S1])

Stigma

Using Weiss' model of stigma,² we categorized experiences of stigma described into felt (the feeling that discrimination and exclusion will happen among people affected or their family members) and enacted stigma (actually experiencing discrimination and exclusion, e.g. through acts of violence or unallowable involvement in community activities). Most people were ashamed of their skin NTD, especially leprosy. Stigma, irrespective of its form, resulted in isolation from family, friends and community for fear of discrimination. Participants were often excluded from society, as people assumed they were infectious and called them derogatory names such as 'sorcerer' and 'useless to society'.



Figure 2. “It is the image of a palm tree trunk with cracks, cut and left on the ground. This represents my swollen legs with sores”. (Photovoice, female with LF, Tshisele)

These derogatory terms were often accepted by health professionals, putting further strain on the mental wellbeing of people affected, who felt uncomfortable seeking care from these health professionals even though they had nowhere else to go (Table 2).

Poverty, depression, self-harm and suicidal ideation

Experiences of depression and loss of hope among people affected by skin NTDs were linked with poverty, uncertainty around disease outcome, irrespective of whether they practice self-care or not, and lack of support from family, community and the health system. From workshop reports, some people affected by skin NTDs reported episodes of excessive alcohol intake and smoking, neglect of body hygiene and thoughts of self-harm or suicide. According to one health professional, the formal health system perceives people affected by chronic NTDs as 'dying', with little motivation for supportive interventions.

“Often, these people are depressed, these chronic patients are poor people who have lost hope,...some of the people with the illness decide to harm themselves, they try to suicide themselves...They are dying people, I don't think there are any other ways that the state thinks of them.” (KII, health professional, Kasai)

Increased dependency due to illness was common, and often linked to loss of physical abilities/capabilities and self-worth. The resulting poverty risks persisting over generations as people affected were often cared for by children who miss out on school and other opportunities.

Table 2. Types of stigma experienced by people living with NTDs in Tchikapa, Kasai province, DRC

Type of stigma	Experiences of people living with NTDs		Supporting quotes
Felt stigma	Internalized stigma	Felt ashamed, associated disease to spells, isolated from the public. Compared skin to rotten fruits	<p><i>“They are worried to have developed leprosy in their body, some think that it is due to the fact that people have cast on them the spells, and others think that is sorcery. Most of those people are ashamed of suffering from leprosy”.</i> (KII, health professional, Kasai)</p> <p><i>“This is a picture of a lemon and two mangoes, A healthy mango and a rotten mango. These 3 fruits represent my life, before the disease, my organism was like a good mango. With the disease, my skin had become like the skin of a lemon. Currently my organism is comparable to this rotten mango”.</i> (Photovoice, male with LF, Ngombe) (Supplementary Figure S2)</p>
	Anticipated stigma	Internalized stigma was endorsed by health professionals Fear of being discriminated upon	<p><i>“Well, these people have to accept their condition, very often, they consider themselves as destitute people. I think that the challenge is to accept their condition and to make them become autonomous in order to be useful in society”.</i> (KII, health professional, Tchikapa)</p> <p><i>“It is the image of a road. When I was in good health, I went everywhere without any problem. Today I am no longer able to move freely because of the mockery due to my disease”.</i> (Photovoice, male with LF, Tshisele) (Supplementary Figure S3)</p>
Enacted stigma	Excluded for fear of being infectious		<p><i>“They are excluded because they are contagious, people don’t want to get the diseases when they come to them”.</i> (KII, community member, Ngombe)</p> <p><i>“With my illness, the few times I’ve exhibited an item for sale, no one comes close to buy for fear of being contaminated”.</i> (Photovoice, female with leprosy, Ngombe) (Supplementary Figure S4)</p>
	Termed ‘sorcerers’ who do not deserve care		<i>“Our communities incriminate them to be sorcerers, they do not care about saving you, they put you aside, you are not useful for the society, you are unproductive”.</i> (KII, health professional, Tchikapa)
	Rejected from work		<i>“Right now, I can’t do it (work in diamond extraction site) anymore because of rejection from others. They don’t want to work with me anymore because of my (ill) health”.</i> (Photovoice, male with leprosy, Tshisele) (Supplementary Figure S5)
	Being useless to society was accepted by health professionals		<i>“The experiences are that an illness makes the person crippled, hence poverty, blindness, filth and dependency follow. In short, he becomes useless to society”.</i> (KII, health professional, Tchikapa)
	Intergenerational stigma		<i>“They are ducks. These ducks belong to me. When they go to the neighbouring premises, they are chased. Similarly, my children are chased away by my neighbours saying that they have leprosy like me, their father”.</i> (Photovoice, male with leprosy, Ngombe) (Supplementary Figure S6)



Figure 3. “This pot and plates gives the image of the culinary work of any woman. This reminds me of what I am no longer able to do as a woman and a mother because of my state of health”. (Photovoice, female with LF, Tshisele)

“In addition, the person not being able to produce any more, the child who was to go to study does not study any more, he is with him on the road, to beg here and there, he is quite simply destined to remain in poverty. The whole life becomes precarious and there is a risk for the generation of the children.” (Key-informant interview, health professional, Kasai)

Gender and family

In general, men and women described the overall impact of NTDs in similar ways. However, when discussing family and changes in this sphere of their life, gendered norms and responsibilities were apparent. For example, while men were worried about not being able to work and provide for their families, women were worried about not being able to carry out their roles as a wife and mother (Figures 3 and 4).

Furthermore, the impact of skin NTDs on relationships and marriage are different for men and women and sometimes perceived to be more severe for women than men. Single men with skin NTDs were described as having a higher chance of finding a wife than a single women had of finding a husband, and married men with skin NTDs were generally abandoned by their wives, who took their children with them, while married women were abandoned with the children to look after.

“For married people we had a case here; a man abandoned his wife because of lymphatic filariasis, he went to look for another wife. That woman was really affected (shocked, hurt). She was supposed to stay alone, taking care of children and of herself, on economic plan she cannot do anything, no farming, no moving.” (KII, health professional, Tchikapa)

Available support services for people with skin NTDs in the Kasai region

Medical services

Interventions for people with skin NTDs have predominantly been medical, including free case management (wound care,



Figure 4. “They are calabashes with palm wine in them. To make this wine, sell it and make money, you must have physical strength. I no longer have the strength to work. I can no longer produce”. (Photovoice, male with LF, Ngombe)

medications and self-care) and mass drug administration provided within the frame of the formal health system and with non-governmental organizations. However, the supply of case management kits is often underfunded and irregular.

“The support that we bring to those people is very small, the financing that does not cover what we have to do. For the kits, we give for leg washing. We present cases during training on what to do concerning lymphatic filariasis, but we have never organized distribution of kits at the level of the community because what we receive is not sufficient.” (KII, health professional, Tchikapa)

Mental health services

Services to support mental health are rare in Kasai and notably absent in the communities. Mental health units with psychologists who provide mental health support are not decentralized. Health professionals and community members had no recollection of any mental health intervention in Kasai and attributed this to a lack of resources.

“There is no support service reserved for these people because resources are limited. There has never been a mental health intervention.” (KII, health professional, Kasai)

Support from community members and health workers

Community members and some health workers expressed sympathy and compassion for people affected by skin NTDs, advising them on health-seeking attitudes. Community members sometimes accompany affected people to health facilities to get help, while some health workers provide counselling in addition to medical care.

“I feel very bad in my heart, they live in miserable conditions, without value, without merit. When this disease affects people, we accompany them to the health centre, though I have never accompanied a person who has leprosy.” (KII, community representative, Ngombe)

Opportunities for community and health system engagement on mental health support platforms in Kasai

Opportunities for mental health support were centred around increasing awareness of the hidden burden of mental distress among people affected by skin NTDs and establishing a locally driven and sustainable approach to supporting their mental wellbeing. Participants suggested the establishment of support platforms and mechanism to explore/support the potential of people living with skin NTDs to be self-sufficient. These opportunities are summarized in Table 3.

Intervention components

During the 2-day workshop on intervention development, participants used research findings presented by the core research team and photovoice participants to identify needs and develop a framework of activities that respond to the needs and priorities of people affected by skin NTDs. Drawing on sample projects from Nigeria¹⁸ and India,¹⁹ participants decided to es-

tablish community-led peer support groups with six key areas of intervention (Figure 5).

Peer support groups were designed to be led by a selection of people affected by skin NTDs and supported by community relay agents, all trained on basic psychological support for NTDs, that was first created and piloted in India by Norwegian Leprosy Relief (NLR).¹⁹ The training focused on supporting group leaders to identify peers struggling with mental wellbeing and to provide basic support and use look, listen and link processes to refer those who need it. Support groups will also engage in health-related, recreational and income-generating activities to aid the functioning of the groups and individual members and share information between the groups.

Participant feedback on the intervention development process

Workshop participants described the intervention development as inclusive, participatory and targeted. People affected by skin NTDs were impressed with being included in developing an intervention that concerns them. Their expectations were high, as many wished for a curative treatment to see their conditions disappear. However, they were counselled that while medications for some NTDs are available and free, management must be holistic to include mental wellbeing, which is often a quiet burden. Stakeholders found the experiences of people affected by skin NTDs concerning. They were keen on supporting the sustainability of this mental wellbeing intervention.

Discussion

This study developed a community-led mental wellbeing support package of people affected by skin NTDs in Kasai based on their experiences and available local resources and opportunities. In this discussion we support the increasing evidence that people affected by skin NTDs experience stigma and psychosocial distress with a negative impact on their mental wellbeing. We also discussed how we harnessed local opportunities, including the will of people affected and health-related actors, to co-develop activities/interventions tailored to the needs of people affected by skin NTDs.

As evidenced in our study, stigma, discrimination and mental wellbeing are growing concerns among people affected by chronic NTDs.^{3,7,20} Comorbidity of mental health and skin NTDs, including LF, leprosy and onchocerciasis, is significant.¹ According to the WHO's guidance document Mental Health of People with Neglected Tropical Diseases: Towards a Person-centred Approach 2020, the high risk of mental wellbeing issues among people affected by skin NTDs is bidirectional.³ This increases the burden of both conditions with immediate and long-term impacts on the lives of the individuals and their families, often with intergenerational impacts, as evidenced in our study. This is worsened by additional stressors such as the post-conflict context, which includes the chronic effects of NTDs, ongoing infrastructure challenges and limited social cohesion.⁷ We also showed that societal gender roles and norms shape the impact that skin NTDs have on people's environment and psychosocial wellbeing. For example, our study found that the impact of skin NTDs on relationships and marriage were perceived to be more severe for women than

Table 3. Opportunities for community and health system engagement on mental health support systems in Tchikapa

Opportunity	Activity	Supporting statement
Increase awareness in primary healthcare and the community	Train health workers and community relay agents on mental health and NTDs	<i>“What I can give as recommendations, the first one is to train people, health providers, since they go to communities, they can also teach the notion of mental health in the community level and assist those people with mental health, not to stigmatize them”. (KII, health professional, Kasai)</i>
	Cascade awareness to communities using community relay agents	<i>“Continue sensitization and active search for cases in the community, use community intermediate person (community relay agents). When some persons will present any sign for mental health, the community intermediate persons, will explain to the community, train someone established here that will be helping us, not to stigmatize them”. (KII, community representative, Ngombe)</i>
	Engage people affected by skin NTDs	<i>“What works well is the inclusion of people affected by chronic diseases in activities to talk about what they think. All of these will be well reasoned by the sick person and his or her mental health will no doubt have an impact”. (KII, health professional, Kasai)</i>
Improve on health system organizational challenges	Provide medications, improve logistics and motivate health personnel	<i>“It is necessary to make available to the nurses the inputs such as drugs, and transport. Motivate the people who take care of these people who are affected by chronic NTDs”. (KII, health professional, Kasai)</i>
Establish a community-driven mental health support platform	Establish community-led mental health support groups	<i>“At the community level, it is necessary to accompany the patients who are in the community, it is also necessary to create support groups, mentors, people who are already sick, who become autonomous and who can support the people who are weak. It is necessary to create this group of self-help or self-support at the community level that will be accompanied or will be under the coordination of the technicians”. (KII, health professional, Tchikapa)</i>
	Accompany people with chronic skin NTDs with psychological support using established examples	<i>“Often these patients are depressed, it is a question of accompanying them and supporting them psychologically which I do in my experience with people living with HIV. So to include them in society easily it is necessary to support them psychologically”. (KII, health professional, Kasai)</i>
	Establish a formal mental health coordination bureau	<i>“Apart from that, having a mental health coordination office here is also a recommendation, to train someone that can stay here for help in case of any need”. (KII, health professional, Kasai)</i>
Explore/support potentials of people living with skin NTDs to be self-sufficient	Promote income generating activities	<i>“Give an activity adapted to the people affected which can provide them with money so that they do not beg”. (KII, community member, Ngombe)</i>
	Support the needs of people with chronic skin NTDs	<i>“The only solution I find is to ask the authorities to take care of these patients, that is to say the right treatment, accommodation and food, that’s my experience”. (KII, community representative, Tshisele)</i>

men. This is consistent with other studies that found women and girls experience a greater share of the NTD burden.²¹ Researchers have also reported worse psychological and social consequences among women with NTDs, particularly with diseases such as LF that lead to disfigurement.²²⁻²⁴

We uncovered little motivation from the formal health system to engage in interventions for people with skin NTDs. In some

cases, health workers accepted the societal stigma of affected people and joined in calling them derogatory names. Health workers perceived that the system considers chronic skin NTDs as an end-of-life pathway, a demotivation for any supportive intervention. This leads to distrust of the entire formal health system, hindering health seeking and access to healthcare and treatment when available.²⁵ Stigma and discrimination against people

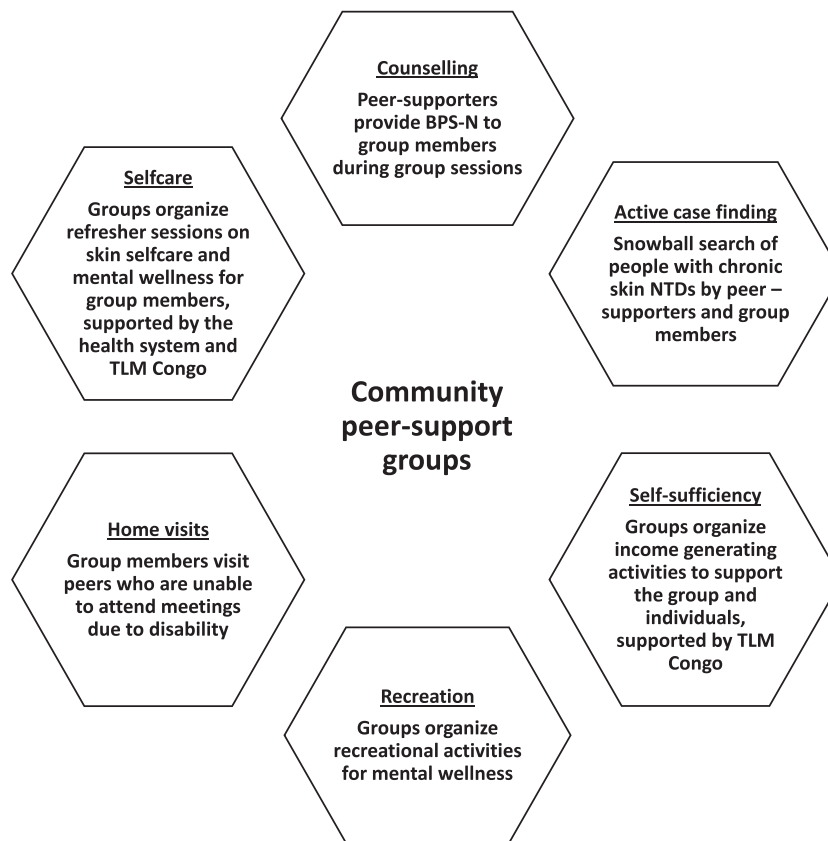


Figure 5. Key activities of community-led peer support groups for people with chronic skin NTDs.

affected by skin NTDs is common in healthcare settings, often leading to denial of care, poor quality care and abuse.²⁶ In many cases, healthcare providers do not have the training to provide care for people affected, including their mental wellbeing.²⁷ To achieve the objectives of the WHO road map 2030,²⁸ such as to reduce by 90% the number of people requiring treatment for NTDs and to advance towards universal health coverage, a more comprehensive and person-centred approach to management of NTDs needs to be established in NTD-endemic areas like Kasai. According to the WHO, mental health and psychosocial wellbeing are important in NTD programs and should incorporate mental health programs through training of the health workforce and support for affected people.³ In our study, affected people had hope for better wellbeing if they are supported, with the community and health system supporting a feasible and sustainable mechanism that caters to people affected by skin NTDs. Developing such an intervention through a participatory process was imperative to look after the mental wellbeing of people affected by skin NTDs and to enhance political commitment.

We applied an all-inclusive approach to the development of the intervention, including persons affected, the community and all levels of the health system, with the aim of promoting embedment within the community and health system by galvanising local ownership. Co-creating interventions with affected persons, communities and the health system often boosts uptake of intervention components and local ownership.^{18,29,30}

Community-led support groups for people affected by skin NTDs has often led to improved self-esteem, improved overall health and health outcomes and a sense of reduced stigma in the community.¹⁸

Collaborating with and harnessing the opportunities and platforms presented by people affected by skin NTDs, community representatives and health-related stakeholders to develop a mental wellbeing support package led by affected people themselves was a strength of our study. However, impact and sustainability will only be known after evaluation of the intervention process and outcomes, which is forthcoming. Intervention implementation began immediately after establishment of peer support groups. Peer support group members and leaders have started providing/receiving peer support using the basic psychological support for NTD resources, particularly the look, listen and link approach for referral. Peer support group members and leaders were trained on these resources by community relay agents, who are also supporting peer support groups to make plans to engage in self-care and recreational and income-generating activities.

Conclusions

People affected by skin NTDs in the Kasai region experience physical challenges and stigma that negatively affect their livelihoods

and social environment, with a consequent negative impact on their mental wellbeing. Access to mental wellbeing support is minimal or non-existent, however, there are opportunities to engage the communities and the health system to establish a mental wellbeing support package for people affected by skin NTDs. Co-developing a support package with affected persons, community members and health system actors is a step towards holistic care for people affected by skin NTDs and promotes uptake and ownership of intervention components.

Supplementary data

Supplementary data are available at *International Health* online (<http://inthehealth.oxfordjournals.org>).

Authors' contributions: The authors wish it to be known that, in their opinion, the first two authors (MN and PL) should be regarded as joint first authors. LD and LS conceived the study. LD, LS, MN, PL, JKukola, YD, CB, JKadima, SM, RM and FN designed the study protocol. MN, PL, JKukola, YD, CB, JKadima, JKim, SM, RM, SN and LS coordinated the data collection. MN, PL, JKukola, YD, JKadima and MS completed the analysis and interpretation of these data. MN and JKukola drafted the manuscript. LD critically revised the manuscript for intellectual content. All authors commented on and contributed to draft revisions and read and approved the final manuscript. MN, PL, JKukola and LD are guarantors of the paper.

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Ethical approval: This study was approved by the Liverpool School of Tropical Medicine Research Ethics Committee (ref: 21-053) and the National Health Ethics Committee of the Ministry of Health of the Democratic Republic of Congo (MS/PNEL/CN/MD/067/2021). Participation in this study was voluntary and all participants provided written informed consent for all sections of the study. For participants unable to read and write or visually impaired, informed consent was read out loud in the presence of a witness (family member or community relay agent) and thumb prints were taken place of signatures. Researchers were trained on the skills to recognize any distress that people affected by skin NTDs might have due to discussing their disease condition and the skills to link them with available support services should they be required, including local health facilities.

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

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