

Exploring the well-being of people affected by skin NTDs in Kaduna and Kwara States, Nigeria: a photovoice and scoping review study

Oluwatosin Adekeye^{a,*}, Shahreen Chowdhury^b, Ayuba McRae^a, Temitope Olorunfemi^a, Edward Ozokede^a, Linda Dubukumah^a, Oluwabanmi Makinde^a, Jude Ewemade^a, Shuaibu Abdulkadir^c, Rebecca Ayuba^c, Suleiman Habib^d, Matthew Gurma^d, Rachael Thomson^{ib}, Sunday Isiyaku^a and Laura Dean^b

^aSightsavers, Nigeria, No 1 Golf Course Road 800283, Nigeria; ^bDepartment of International Public Health, Liverpool School of Tropical Medicine, L3 5QA, Liverpool, UK; ^cLere Local Government No 6 Ungwan Yango Nassarawa Saminaka, Saminaka, Lere, 811104, Kaduna, Nigeria; ^dBaruten Local Government No 3 Local Government Secretariat, Kosubosu, 242102, Kwara, Nigeria

*Corresponding author: Present address: Department of Psychiatry Ahmadu Bello University Teaching Hospital Shika, Zaria, Kaduna State, Nigeria; Tel: +2348035771016; E-mail: tosin.adekeye@gmail.com

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People affected by skin neglected tropical diseases (NTDs) grapple with both physical and emotional reactions that compromise their health and well-being. Multiple studies with people affected by skin NTDs have shown high levels of poor mental well-being using self-report questionnaires or psychological measures. However, few have provided in-depth documentation of lived experiences from the perspective of affected persons and there is limited consideration of how their viewpoints can be used to shape intervention design. This article draws together findings from an international scoping review and a photovoice study conducted in Kaduna and Kwara States, Nigeria. Our combined analysis, which situates the lived realities of people affected by skin NTDs within the existing evidence base, was used to inform the design of a subsequent well-being intervention. Using Meyer's (2003) minority stress model, we have illustrated that there is a synergistic relationship between mental health, chronic morbidity and disability from skin NTDs. This relationship results from a complex interplay of factors including pain and discomfort and a reduced ability to function and participate in areas such as livelihoods, food provision and education. Stigma and discrimination act as a catalyst for these functional limitations and participation restrictions, resulting in feelings of being useless, broken, shame and sadness. The critical role of participatory methods in our study emphasises how people affected by skin NTDs have multiple coping mechanisms that can be galvanised in the provision of holistic NTD care. We recommend that NTD programmes should strengthen relationships with affected persons to identify pre-existing support platforms that can be used to support the emotional and physical health and well-being of affected persons. Working with affected persons and community actors to strengthen necessary intersectoral approaches is a first step in designing and delivering such holistic care.

Keywords: emotional reactions, health, persons affected, psychosocial, skin neglected tropical diseases, well-being.

Introduction

People affected by skin neglected tropical diseases (NTDs) grapple with both physical and emotional reactions that tend to compromise their health and well-being.¹ These emotional reactions (anxiety and depression) are sometimes the result of stigma, discrimination and social exclusion, which in turn affect overall functioning in areas such as initiating or keeping livelihoods, bonding with family and limitations to participating in social activities within the community.^{1,2} Individuals and families affected by skin NTDs tend to have worse socio-economic status compared

with the general population, especially where the affected person is the major income earner.³ Loss of livelihoods tends to increase anxiety, further worsening social and economic well-being, especially in situations where, to avoid rejection in the community, persons affected have to sell their goods in secret or relocate to other communities where they are not known.⁴ The experience of stigma for people affected by skin NTDs can be both internal and external and can have significant impacts on physical health and mental well-being. External stigma frequently manifest as apprehension exhibited by people who come into contact with people affected by skin NTDs,⁵ while internal stigma manifest as

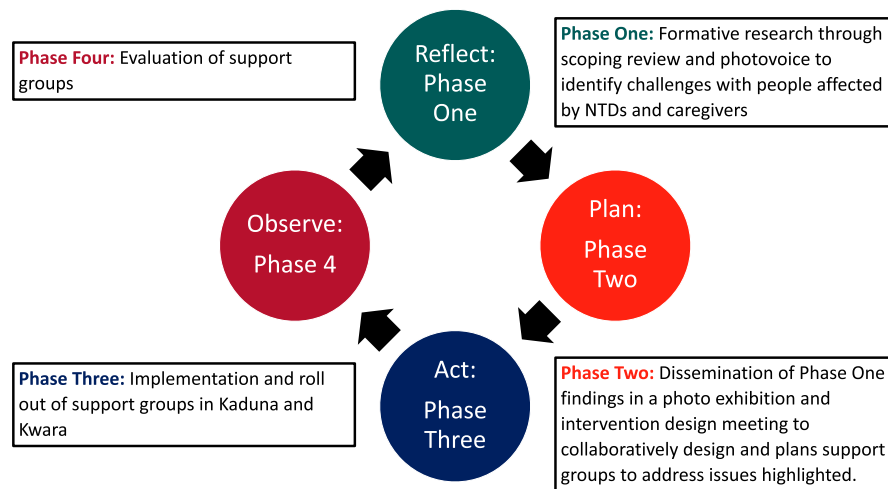


Figure 1. Overview of the CBPR cycle utilised to inform intervention design.

a withdrawal of affected persons from community life as a result of feeling ashamed or embarrassed by their health condition.⁶

Chronic morbidity coupled with physical impairment often results in physical pain (66.7%), anxiety (66.7%) and depression in up to 20% in people affected by skin NTDs.^{7,8} Gender analysis of data collected from people affected also identifies that women who are abandoned as a result of skin NTDs experience considerable psychological distress, frequently reported as anger, bitterness and sadness. Loneliness and the fear of being abandoned by family members are also key reasons cited that some persons affected preferred not to disclose their ailment at health centres and seek treatment from home rather than being hospitalized.⁸

Despite emerging evidence highlighting the complex links between mental and physical well-being that shape the everyday lives of people affected by NTDs, the evidence base is disparate and the voices and experiences of people affected frequently falls secondary to quantitative measurement. Thus, in this article, we aim to synthesise the existing evidence base through the use of a scoping review and illuminate the lived experiences of affected persons in relation to this evidence base using photovoice with affected persons in Kaduna and Kwara States, Nigeria.

This study was the first phase of a larger study that draws on community-based participatory research (CBPR) principles to inform the design of an intervention to support the physical and mental well-being of persons affected by NTDs. Figure 1 provides an overview of the CBPR study cycle. We have included co-researchers throughout the process, who are people affected by NTDs as well as their caregivers. Phase 1 (Reflect) of this study, which sought to understand the current evidence base around NTDs, disability and mental health, is presented here. Latter study phases are presented in Chowdhury et al. (forthcoming).

Conceptual framing

Drawing on Meyer's 'minority stress model',⁹ we have used Dean et al.'s¹⁰ adapted framework for NTDs (Figure 1). The minority

stress model is based on the idea that levels of stress faced by members of stigmatised minority groups may be caused by a number of factors.

The argument presented is that people affected by NTDs are a minority identity. Therefore we have used this theory to look at stress as a result of their minority identity, which can shape their overall well-being. General stress can affect everyone (e.g. poverty), but this can be worsened by minority status. The external stressors include enacted stigma from people facing discrimination and violence, while internal stressors include internalised stigma, pain and concealment—e.g. people hiding due to fear of being stigmatised. All of the aforementioned factors can have negative impacts on physical and mental well-being. The minority stress model illustrates that all of these factors interact to shape this syndemic outcome between chronic morbidity and disability from NTDs and mental ill health; when the NTD has greater physical impact, mental health is often more severely impacted.

Methods

In this study, we used various methods to capture the relationship between skin NTDs, mental health, stigma and disability. We also sought to identify existing and possible support structures for people living with skin NTDs that could be leveraged in future health interventions. A scoping review was carried out initially to synthesise the evidence base regarding the relationship between skin NTDs and mental health. We then used photovoice with people affected by skin NTDs to document their experience of daily living and to begin to establish a group that could support collective action within our latter study phases [see Chowdhury et al. (forthcoming)]. Utilizing a combination of both methods of scoping review and photovoice allowed for a comprehensive synthesis of knowledge on health and well-being among people affected by skin NTDs.

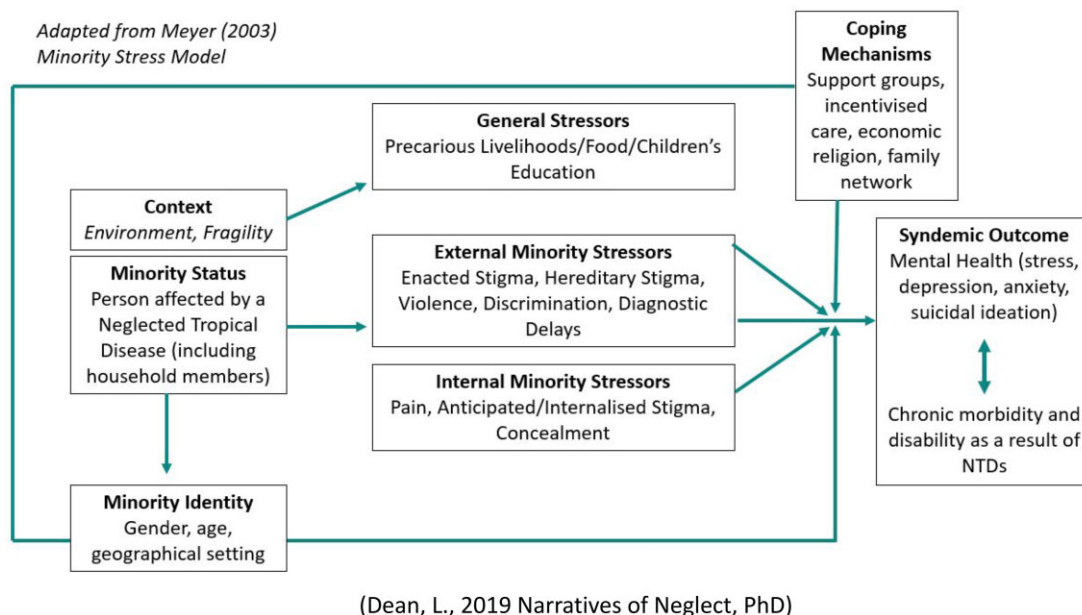


Figure 2. Minority stress model, adapted from Meyer.⁹

Scoping review

The aim of the scoping review was to consider relationships between NTDs, mental health, stigma and disability in sub-Saharan Africa and to understand existing/possible support structures in sub-Saharan Africa in integrated case management for skin NTDs from the perspective of affected persons. Our search strategy is summarised in Figure 2. We searched the MEDLINE, CINAHL, Global Health and Web of Science databases using pre-determined search terms (see Figure 2). Title and abstract screening was completed before full-text review of selected articles. All screening was completed against inclusion criteria: peer-reviewed publication between 2009 and 2019 (10 y of literature at the time of the search), available in English and focused on the health and well-being of people affected by skin NTDs from their own perspective. All articles were screened by at least two members of the research team to enhance quality. The 67 articles that were finally included in the review were then charted and summarised based on the minority stress model domains: general stressors, external minority stressors, internal minority stressors, coping mechanisms and syndemic outcome.

Photovoice

Photovoice is a creative participatory methodology that aims to empower participants to document their stories through photography.¹¹ The photovoice process involves participants taking photographs within their communities to capture their experiences and daily realities.^{12,13} The photos are followed up with a discussion to capture verbal accounts of what the photographs represent. Images are then selected to be presented and discussed within group discussions. Some photos are further selected to share in dissemination workshops, designed to develop

solutions to the challenges identified and/or to raise awareness of issues described in the photographs. Photovoice participants were given the option of whether they would like their data to be anonymised when presented. All photovoice participants requested that their names, photographs and quotes be expressly linked in the data so that anyone reading the data understood their story and could link the experience to them directly.

Study setting

Kaduna and Kwara States were purposively selected for the study because they are endemic for at least two of the stigmatising skin diseases (Buruli ulcer, clinical manifestations of lymphatic filariasis [hydrocele and lymphoedema] and leprosy), have an established stigmatising skin disease case detection programme in place and have both geographical and sociocultural diversity. Within each state, one focus local government area (LGA) was purposively selected: Lere LGA in Kaduna and Baruten LGA in Kwara. LGAs were selected in collaboration with the state and LGA Ministry of Health NTD Programmes based on programmatic need (available number of skin NTD cases per disease in the LGAs) using the same sampling criteria as the study states.

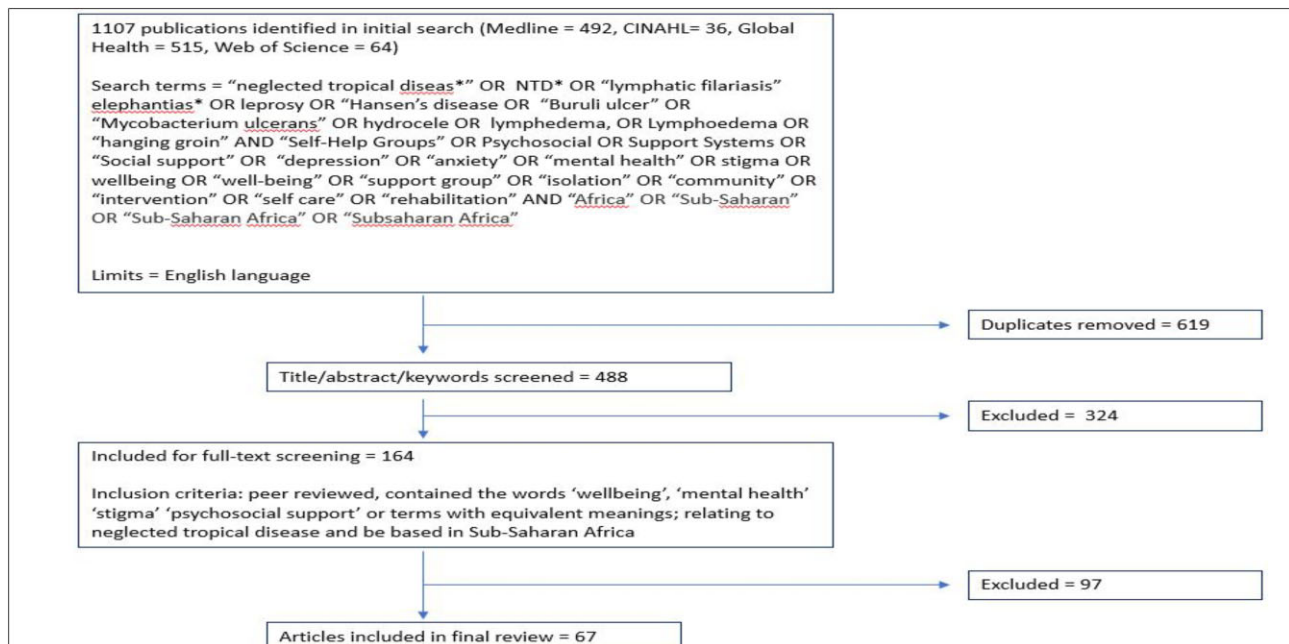
Selection and training of co-researchers and participants

Co-researchers included people affected by skin NTDs and caregivers, recruited as part of the research team to support the duration of the research from data collection to analysis. A total of seven co-researchers were selected in the study—three in Kaduna and four in Kwara—considering maximum variation in roles, age, disease condition and gender (see Table 1). Photovoice participants were purposively selected to ensure

Table 1. Participant selection of people affected by NTDs and caregivers

Persons affected	Buruli ulcer		Lymphoedema		Hydrocele		Leprosy		Total
	Male	Female	Male	Female	Male	Female	Male	Female	
Younger (18–49 y), n	1	1	1	1	1	N/A	1	1	7
Older (>49 y), n	1	1	1	1	1	N/A	1	1	7
Total per state, n	2	2	2	2	2	N/A	2	2	14
Study total, n	4	4	4	4	4	N/A	4		28
Caregiver, n	1	1	1	1	1	N/A	1	1	7
Total per state, n	1	1	1	1	1	N/A	1	1	7
Study total, n	2	2	2	2	2	N/A	2	2	14

N/A: not applicable.

**Figure 3.** Search strategy and screening summary.

maximum variation in age, gender and disease across the whole sample. Fourteen affected persons and 7 caregivers per state (across the LGAs) were selected, with a total of 28 participants across the study. Participants were identified in collaboration with the state NTD program, using the health facility registers and working closely with the health facility staff to identify affected persons. Caregivers were selected through asking participants to identify individuals who have been most involved in their illness or with whom they have a close relationship or regular interaction.

All participants were initially provided with a 1-d photovoice training facilitated by the research team and led by co-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, well-being and health. The photovoice process was adapted

from Ronzi et al.¹⁴ in a five-step process that is described in Figure 3.

Analysis

Findings from photovoice were analysed into key themes within focus group discussions with co-researchers and photovoice participants. Descriptions of themes were validated and key photos were collectively chosen, with captions checked by co-researchers. Key photos were developed into photo booklets per state. These booklets showcase the photos, showing the realities of people affected by NTDs through their lens, focusing on multiple themes including stigma, psychosocial well-being and support. These booklets can be accessed through the COUNTDOWN website (<https://countdown.lstmed.ac.uk/>).

Results and Discussion

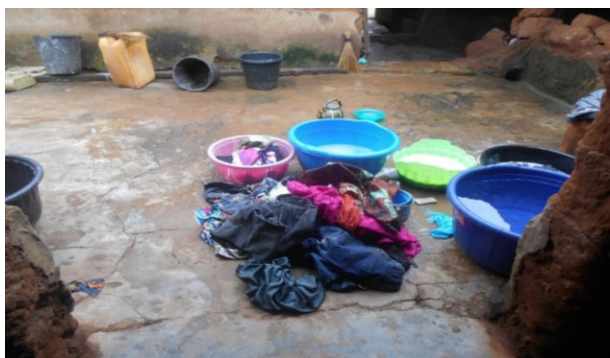
The results are presented from the literature review and the photovoice using the minority stress domains.¹⁰

General stressors (precarious livelihoods/food/children's education)

Thirty-eight articles cited general stressors such as precarious livelihoods. Many people and families affected by NTDs live in poverty, often living hand to mouth, working in livelihoods including fishing, subsistence farming and petty trades. Irrespective of disease condition or context, these factors were described as causing day-to-day stress. The literature reviewed indicated that most people affected by skin NTDs faced challenges in sustaining their means of livelihood, particularly when they were engaged in farming, as physical limitations affected their ability to farm as a result of pain and mobility restrictions. This creates additional financial barriers and can result in an inability to provide food for their families and in some cases finance to sustain the education of their children. Social discrimination and exclusion from participating in their jobs was also identified as a problem.

There were also requests for more support for the victims of Buruli ulcer because people of this village called victims by the names 'bankruptcy wound'. (Velink A et al. 2016)

This impact of the disease often resulted in economic strain as a result of lost livelihoods, limited or non-access to employment and increased dependency on primary caregivers. The photovoice data indicate that some of the people affected by skin NTDs reported in some cases having to sell off livestock to pay hospital bills or had their livelihood disrupted due to physical impairment.



When I was healthy I used to help people to do their laundry and I get paid for my services, now because of the way my fingers are I cannot again. I feel very sad I really wish and pray to God I get the help to get well again. (Modinat Tone, young female affected by leprosy)

The literature review and the report from photovoice also demonstrated the economic burden faced by caregivers such

that some caregivers had to leave their farmlands or stop their education to care for their dependants. Persons affected by skin NTDs described having to stop work as a result of sores, often leading to them resorting to begging.



My daughters help me on my farm, I can't work on my farm because of my condition...my sores cause serious pain whenever I try to farm...this is our only source of income—if they stop helping on my farm, that means we will have no food and resort to become beggars to earn a living. (Adamu Sabi, younger male affected by leprosy)

External minority stressors

Because of their minority status, people with NTDs are exposed to both internal and external stressors, largely driven by stigma. These stressors become additive to those general stressors such as poverty and precarious livelihoods that are often experienced by rural communities. Throughout the literature (42 studies) and photovoice data, external stressors were widely mentioned in relation to enacted stigma and hereditary stigma. Enacted stigma refers to stigma that are actually experienced; this includes discrimination and often violence. The experience of stigma documented in the photovoice data included being shunned, ridiculed in public, insults, being viewed as inferior on account of disability and strained relationships between affected persons and other members of the community. Enacted stigma were more pronounced, with greater severity of the disease and obvious physical morbidity. Enacted stigma were mentioned in relation to abandonment or isolation, negative attitudes and limitations in education and employment opportunities, often affecting poverty levels. Many people affected by NTDs, irrespective of their health condition, experienced stigma from their families, friends and members of their communities, often due to misconceptions about the cause of illness and the fear of exposure and association with the disease.^{15,16}



This shoe if I keep it at my door, because of my ailment no one will wear it and that hurts me...Before someone will pick it like when you keep a shoe at the door, someone will admire it and want to wear it to the toilet or so, but no one does that now because people are afraid to contract the disease...that hurts me. (Aliyu Yusuf, female affected by lymphoedema)

Internal minority stressors (pain, anticipated/internalised stigma, concealment)

Across diseases, the severity of the swellings from lymphoedema or hydrocele and associated pain led to concealment, internalised stigma and isolation. These findings from the photovoice data were supported by 33 articles within the literature review. The belief that affected persons were being punished by God for their wrong doings or by their enemies also contributed to negative feelings about oneself, or ‘internalised stigma’. This resulted in delayed treatment seeking, as this internalised stigma prevented patients from revealing their status. The shame felt from having contracted leprosy often resulted in some patients not wanting to return to their communities for fear of bringing shame to the community. Men and women with skin NTDs also described preventing themselves from pursuing relationships for fear of rejection and ridicule. Those with large hydroceles or lymphoedema were unable to find wives and husbands and were also not permitted to become chiefs, as chiefs were supposed to be without deformity. Challenging interpersonal relationships were particularly described by women, many articulating a fear that husbands would leave them to take another wife.

Data from the photovoice indicate that stigma was often deeply felt and experienced by participants across gender and disease. Some participants, especially young men affected by leprosy, lymphoedema and Buruli ulcer, reported feeling useless, broken, shame and sadness because of enlarged legs or obvious wounds.



...I feel bad because I can't do what children of my age can do, I can't play football, I can't go to farm, no support, no help from anybody; Yes, I do go out, I suffer stigma, people don't want to associate with me. It is very depressing, all my friends, we grew up together are no longer my friends. They are scared of my condition, I have wounds on my leg, my hand. People feel irritated with the wounds. (Mohamed Saliu, younger male affected with leprosy)

The literature indicated that although many were allowed to attend and contribute at community gatherings, persons affected by lymphatic filariasis hardly attended those meetings because they felt ashamed of themselves. In some literature, stigma was reported to increase with the severity of the disease, as those with more severe disability sometimes hid their swelling by covering it. Buruli ulcer patients were reported in some studies to hide scars even after being healed of the disease. Self-stigma and lack of confidence was reported in one study to limit the opportunities of leprosy patients as a result of low community awareness.

Participants in the photovoice described physical impacts that affected their day-to-day functioning and ability to take part in work or activities in the community, sometimes leading to feelings of sadness.



This photo of this table represents how I had felt when I start suffering with one of my leg, looking at it reminded me of the pain and how I felt incomplete, I feel a better part of me is missing that can never be replaced, this makes me feel sad and depressed seeing how my body is infected with this ailment. (Tanko Mohammed, younger male affected with lymphoedema)

Outcome

The physical impacts of disease expose patients to psychological stress, including low self-esteem and a loss of hope, which are symptoms of depression. Emotional and psychological reactions to living with disease was reflected across the photovoice data. Additionally, of the 63 articles reviewed, there was a total of 36 that related to emotional outcomes as a result of stressors according to Meyer's model.⁹ The literature reviewed reported emotional reactions in people affected by skin NTDs, such as anxiety, depression, suicidal ideation and asking God to take their lives.^{2,17,18} In one study in Nigeria, patients with grade 3 lymphoedema describe the degree of pain as so severe that they wish to 'die in order to avoid going through it in the next episode'.¹⁹ Some respondents report expression of anger, shame, crying, sadness and frustration. Another study reported psychosocial effects of being rejected and snubbed by family members, friends and community members. One study that focussed on women found that women abandoned as a result of their illness displayed considerable psychological distress related to failed expectations of support.⁸ Widows in particular experienced despair, as some of them had to place their children in foster care with distant kin in order to take care of themselves. Younger men and women affected by lymphatic filariasis described isolation, worries and the negative psychosocial impacts of being unable to join in activities with their peers or to work due to their condition. According to many studies, patients affected by skin NTDs were more prone to social isolation due to stigma, anxiety, relationship and marital problems and disruption of education and livelihoods, all of which have been reported as potential predictors of depression and mental ill health.^{18,20,21} It was demonstrated that these predictors of mental health problems and depression were more severe in the advanced stages of disease and with higher grades of disability.^{21,22}

Negative impacts on psychosocial well-being identified in the literature were corroborated within the photovoice study. The psychosocial impact on caregivers was also highlighted by Aliyu Yusuf, a young man affected by Buruli ulcer, who described his mother's distress and concern about how to treat his condition. The invisibility of psychosocial well-being was shown by a person affected who emphasised how his mind feels locked.



I am not fine as a result of this ailment, I always feel as if my head is under a lock and I think a lot but if am fine I will not be feeling like that and my head will feel open and I will understand things...even though I look healthy on the outside, I am really not healthy. (Aliyu Yusuf, younger male affected by Buruli ulcer)

Coping mechanisms

Key coping and support mechanisms were reported across 21 studies reviewed. The photovoice data also identified similar and additional coping strategies. Coping mechanisms included personal strategies such as social withdrawal to avoid awkward encounters, resignation to fate and seeking solace in their faith in God. Peer and family networks were widely mentioned as a source of encouragement and physical and emotional support, particularly self-care or peer support groups. Microcredit loans and vocational training were used as socio-economic rehabilitation mechanisms to reduce stigma by empowering people affected by leprosy in order to protect individuals against the loss of perceived social value. On the benefits of this microcredit program, a respondent is quoted as saying it has resulted in more acceptance in society.¹⁵

People used to say we were unfit for marriage because we were children of people affected by leprosy. We could only marry children of other leprosy-affected people. But now, we are uplifted, there are marriages between our families and those of people not affected by leprosy. (Female respondent, focus group discussion Ebenso and Ayuba, 2010)

Within the photovoice data, personalised, family and community-based support were available to participants. These were manifested in different areas, such as help with daily tasks,

resulting in positive feelings, but it also created a dependence on caregivers.



This is the photo of our mosque where we worship where my brother often goes to beg for alms so that he can afford to buy his drugs. I feel disturbed, because I am not always happy when he has to go and beg people for money to get his drugs because they are expensive. He does not work anymore because of his illness. (Issa Mohammed Sabi, caregiver to Ibrahim Saidu, an older person affected by lymphoedema)

Ways of positively impacting psychosocial well-being included safe spaces and seeking shade under trees. Another person affected by skin NTDs described how sitting under a tree and being among people improves his mood and helps take his mind off his thoughts and worries.



Whenever I feel downcast or sad, I go here and sit amongst people. Being with people and listening to them speak helps in getting me out of my moody state. This is the reason I took this photo. I only go there when I feel downcast. I feel better because being there takes my mind off so many thoughts

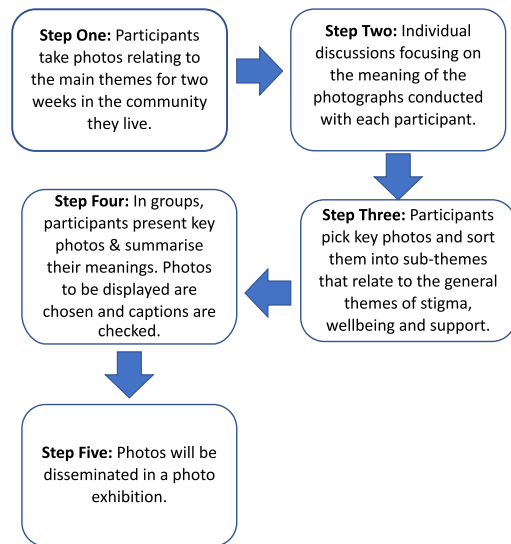


Figure 4. Phases of the photovoice process adapted from Ronzi et al.

and worries. Various thoughts especially of the past because I was not always this idle. (Istifanus Aidu, older male affected by leprosy)

Concluding thoughts

This article draws together findings from a scoping review and a photovoice study to situate and illuminate the lived realities of people affected by skin NTDs within the existing evidence base. We were able to highlight key challenges in relation to mental well-being and skin NTDs through this approach to inform the design of a responsive intervention outlined in Chowdhury et al. (forthcoming). Photovoice allowed people affected by skin NTDs and community members to describe the everyday impact of their conditions and their impact on their well-being. By synthesising the literature and photovoice findings within the domains of Meyer’s minority stress model⁹ (see Figure 4), we have identified social and structural factors that can trigger an emotional response among people affected by skin NTDs, negatively affecting their mental well-being.

General stressors can affect all members within any given society, particularly where events in their environments are considered demanding, challenging or threatening. Our study has shown that in the case of skin NTDs, general stressors such as precarious livelihoods or food provision are often exacerbated. As has been documented elsewhere, such exacerbations result from participants’ inability to work or having to forego their livelihoods due to their health condition.^{3,10,18} This often results in a heightened sense of anxiety or worry among affected populations, particularly when they are unable to pay to access healthcare or provide food for their families. Our study adds further clarity regarding the impact of these stressors on caregivers who are close to the people affected and are required to provide support. The well-being of families and caregivers is often underconsidered within the skin NTD literature, and is

something that our study has shown clearly requires greater exploration. Further, our findings in relation to general stressors emphasise the need for skin NTD responses to consider the broader socio-economic context that is influencing the lives of affected populations. Thus, in designing effective responses to support affected persons, inter- and intrasectoral collaboration is essential.

Coupled with general stressors, our study confirms that people affected by skin NTDs also face numerous additional stressors, many of which are driven by social and structural forms of stigma.¹⁰ These stigmas tend to be driven by the visible physical impairment and subsequent disability resultant from skin NTDs. As in other studies, we found that for people affected by skin NTDs, stigmatization is frequently embodied through different forms of discrimination in various social contexts, such as the home, market or community gatherings.²³ Our photovoice activities highlighted how experiences of stigma and discrimination can lead to periods of social isolation, which has further negative impacts on individual mental well-being as a critical coping mechanism of social connection is lost. Despair and sadness became a regular experience among our study participants, as has been shown in other studies,¹⁸ particularly as disease progresses and impairment worsens. Thus, providing support to affected populations through the strengthening of social connection coupled with stigma reduction activities has the potential to have a significant impact on individual mental well-being. Support to strengthen case detection and treatment platforms is also essential to minimise disease progression and subsequent impairment.

Our study also supports the literature that indicates the impact of skin NTDs on well-being is not the same for everyone and other socio-economic factors critically influence disease experience. For example, in general, gendered expectations mean that disease experience is nuanced for men and women.

Patriarchal norms often mean that men feel embarrassed when they cannot provide for their family. Women often feel unable to fulfil their gendered ideal as caregivers and thus placed their children in the care of kin. Women also feared abandonment from their spouse. All of these gendered dynamics reflect those documented within the literature and further emphasise the need for gender mainstreaming within support strategies for affected populations.

Despite the negative impacts on well-being articulated within our study, we have also shown that people with skin NTDs make a conscious choice to adapt to the stress within their environment and this brings them some form of psychological comfort. For example, some have resorted to avoidance as a form of emotional protection. Rather than engaging in social spaces they used to previously occupy, they now rely on faith as a sanctuary or safe space. In seeking peer help, others utilised a problem-focused coping approach where they resort to family to support them with daily tasks that prove difficult. Others have used forms of appraisal focused coping (e.g. adjusting their expectations of achieving their own financial goals) to enable them to access resources (financial and social) that helped to improve their well-being. This they have done by 'seeking solace in their faith in God' while others were simply resigned to fate or to 'begging' as a means of coping.²

Strengths and limitations

A key strength of this study was its ability to visually and metaphorically present experiences of psychological distress from the lens of affected persons alongside existing literature in this area to emphasise the reality of peoples' lived experience. Our use of evidence and photos together allowed us to have open discussions with affected persons, encouraging them to reflect upon and explore the reasons, emotions and experiences that were behind their chosen images. Discussing solutions to individual challenges also supported us to inform intervention design in latter study phases, as described in Chowdhury et al. (forthcoming). Nevertheless, there were some gaps and challenges experienced in both the scoping review and photovoice element. For example, inclusion of grey literature in the scoping review may have strengthened the breadth of resources reviewed, providing more information on coping mechanisms and intervention ideas often articulated in program documents. Within the photovoice study, the management of expectations was a limitation, as many participants thought the study would provide material/financial gains. This was mitigated in part through the initiation of collective action among photovoice participants themselves to establish peer support groups in latter study phases (see Chowdhury et al. [forthcoming]).

Using the minority stress model, we have illustrated that there is a synergistic relationship between mental health, chronic morbidity and disability from skin NTDs. This relationship results from a complex interplay of factors linked to the context and general environment and external and internal stressors. Looking to the future, we recommend that NTD programs should strengthen relationships with affected persons to identify pre-existing platforms that can be used to support the emotional and physical health of people affected by skin NTDs. Bringing affected persons together to share their experiences and support one another is a key strategy that should be given greater priority within national NTD policy and program design. Group activities should be holistic in nature, encouraging affected persons to work together with health systems to address physical, economic and emotional impacts of skin NTDs within one forum to improve the overall health and well-being of affected persons. Working with affected persons and community actors to strengthen necessary intersectoral approaches is a first key step in designing and delivering such holistic care.

Authors' contributions: OA, LD, RT, SC and SI conceptualised the study. OA, LD, RT, SC, SI and AM designed the study protocol. AM, TO, EO, LD, OM, JE and OA conducted the data collection. OA, AM and TO led the implementation. OA, SC, LD, AM and TO conducted the analysis. OA, SC and LD drafted the first manuscript. All authors read and approved the final manuscript.

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Competing interests: All authors declare that there are no competing interests.

Ethical approval: The study was approved by the Ethics Boards of the Liverpool School of Tropical Medicine (reference 19-091) and the Nigerian Federal Ministry of Health (reference NHREC/01/01/2007). Prior to participant selection, the study was explained to all participants with an information sheet and verbally. Once participants confirmed they were willing to participate, we arranged a convenient time to return to conduct the training on photovoice once informed consent was obtained and documented. The training included the ethics of photography, ensuring consent was obtained with a clear explanation of how their images would be used, before photographing any identifiable individuals and avoiding photographs of any recognisable images of minors.

Data availability: All data used in this study will be made available upon request.

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