Changes in stigma and discrimination of onchocerciasis in Africa

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A B S T R A C T

Forms of onchocerciasis-related stigmatisation, following over 10 years of implementation of community directed treatment with ivermectin (CDTI), were documented through a survey conducted between September and November 2009 to look at perceived changes in stigma over the past 7–10 years. We documented people’s perceptions towards stigma before and after the introduction of CDTI from 1600 structured interviews with households selected from the community treatment registers; in-depth interviews with 57 community leaders, community directed distributors and health personnel; 33 focus group discussions with male and female community members in different age groups; and 13 case studies. People with onchocercal skin disease (OSD) with rough skin, swellings and rashes were the most stigmatised. People still fear sexual intimacy with infected persons. In the past, people with OSD were considered unclean and stigmatised because of fear of OSD transmission and embarrassment. People who had lived in the community less than 5 years tended to stigmatise OSD patients more than those people who had lived in the community for longer than 5 years. The youth stigmatised the most. Although stigmatisation persists, avoidance of people with OSD decreased from 32.7% to 4.3%. It is notable that treatment availability has improved relationships between healthy people and those with OSD symptoms in endemic communities and this can be attributed to CDTI. Health education should be emphasised in the communities during distribution.

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1. Introduction

Stigmatisation of people suffering from certain diseases is not a new phenomenon. Historically, smallpox, leprosy and epilepsy led to the isolation of affected people by members of their societies. Currently, onchocerciasis and HIV/AIDS are conditions that are still stigmatised. Stigma can hinder the treatment and prevention of new infections. Patients who feel stigmatised have more symptoms of depression and can default in treatment. Stigmatisation is a silent epidemic of different contexts and levels.

Stigma is a physical, mental or social attribute of an individual or a group that elicits discriminatory response from others. Skin diseases have been a major source of social stigma and discrimination, whether infectious or not. People who stigmatise are engaged in the process of exclusion, using their power to discriminate unfairly, ostracising or troubling someone they regard as unacceptable because of his or her condition. Stigma can reduce infected
individuals’ social networks and their chance of finding work.\textsuperscript{10} Non-stigmatised people often treat stigmatised people as invisible, non-existent or dead.\textsuperscript{11}

Onchocerciasis can have severe social consequences, including social ostracism and rejection.\textsuperscript{9,12} Several studies indicate that onchocercal skin disease (OSD) is associated with problems in productivity, breastfeeding and school attendance.\textsuperscript{13–18} It can affect marriage prospects of young women where beauty and healthy skin are critical assets.\textsuperscript{15} In general terms, onchocerciasis affects all members of society and social integration.

The annual mass treatment of endemic communities with ivermectin under the African Programme for Onchocerciasis Control (APOC) community directed treatment with ivermectin (CDTI) strategy has reduced the rate of OSD in endemic communities.\textsuperscript{19–21} Most of the clinical benefits of CDTI are well documented.\textsuperscript{22} Its impacts on social relationships and stigmatisation are yet to become clear.

APOC supported a study in Cameroon, Democratic Republic of Congo (DRC), Nigeria and Uganda to document CDTI social benefits and the current status of OSD-related stigma after several years of CDTI.\textsuperscript{23} This paper reports on the forms and changes in OSD-related stigma in the study communities.

2. Methods

2.1. Study design and area

The study, which involved four research teams based in Cameroon, Democratic Republic of Congo (DRC), Nigeria and Uganda, was conducted between September and November 2009 in one state/health district in each of the four countries: Bangangte health district (Cameroon), Kasai district (DRC), Imo State (Nigeria) and Hoima District (Uganda). These were randomly selected from a pool of CDTI projects with ≥7 years of distribution.

A cross-sectional design was used in the study, which focused on households as the unit of analysis. The research teams followed a standard research protocol. An interviewer-based questionnaire was used to obtain information from household members. In-depth interviews and focus group discussions were used to collect data from community leaders and community members, respectively. Data from these two methods were triangulated to understand community OSD-related stigmatisation.

2.2. Sampling

A multi-stage sampling technique was used in the study. First, we randomly selected two districts/local government areas (LGAs) from a list of districts/LGAs within the study region/state in each country. There were lists of communities under treatment that served as a sampling frame. These lists were obtained from the district/LGA departments for primary health care. The communities were stratified into large (≥250 households) and small (<250 households). Only communities with ≥250 households were included in the study to allow for standard application of the systematic sampling techniques in all the sites. This is necessary because of the multi-site nature of the study. Two communities were randomly chosen from each selected district/LGA. All the communities included in the study also had 7–10 years exposure to the programme. The communities developed and maintained treatment registers with a page for each household. The household listings in these registers served as a sampling frame for the selection of households in the selected communities. From each community, 100 households were systematically chosen using the community treatment registers; however, the first household was randomly selected. We conducted 1600 household interviews, 33 focus group discussions, 57 in-depth interviews and 13 case studies.

2.3. Data collection and analysis

Quantitative and qualitative methods were used to capture the perceptions of people towards onchocercial and stigma. In addition, the quantitative method captured the sociodemographic characteristics of the respondents in the survey.

The questionnaire was administered to household members aged 18 years and over. Focus group discussion participants were male and female community members categorised as youth (18–24 years), adults (25–54 years) and the elderly (>55 years).

In-depth interviews were administered to community leaders, heads of households, health workers, community members and community directed distributors (CDDs). The case studies were constructed with people who had relevant experience with onchocerciasis. The study materials were gathered through some in-depth interviews. This method differed from others because it sought information that was specific to the case and could help in the analysis of individual cases, while the focus group discussions and in-depth interviews sought information for the analysis of community experiences.

Qualitative data consisted of textual data, including transcripts of in-depth interviews and focus group discussions, and field notes. Interviews were transcribed and translated into English using standardised transcription and annotation guidelines. All qualitative data were processed using AtlasTI version 5.0 (GmbH, Berlin, Germany). Coding of textual data was performed on the basis of a cross-site code list. Data checks were conducted by the code and code families to elicit emerging themes. The qualitative data were written up initially by site, using a uniform report structure adopted by all sites. Focused discussion on emerging single and cross-site themes allowed the development and refinement of the entire process. Quantitative data were processed in EPI Info 6.0 (CDC, Atlanta, GA, USA) and analysed with SPSS 18.0 (IBM, Germany). Data on perceived stigma were transformed to develop an index of stigma perception. The respondents mentioned a range of stigma perception items. The index was constructed by scoring ‘1’ against every stigma indicated by each respondent and later summed for each respondent. The mean, median and SDs for the stigma tendencies were taken.
3. Results

Illustrative quotes from the qualitative data are presented alongside the quantitative data. These qualitative data are drawn from the focus group discussions and in-depth interviews. The goal in terms of number and type of qualitative data was achieved in all sites. The quantitative data consisted of 1600 respondents: 400 per site.

The gender distribution of the respondents follows a trend in most African countries where there are slightly more women than men in the population. However, the gender distribution in Cameroon is biased in favour of men (58.8% of the 400 respondents), which could be due to migrant farm labourers in Bangantse, the study site. This finally gave a gender distribution of 50.9% men and 49.1% women for the entire study.

Most of the 1600 people interviewed were engaged in income generating activities (79.7%), mainly in the form of farming (63.7%) followed by trading (16.1%). The study sites in Uganda (89.8% of the 400 respondents) and Cameroon (67% of the 400 respondents) were mainly engaged in farming, which was associated to the fertility of the land. This was confirmed through the qualitative data:

*I think that the population of the village has increased because before the arrival of the ivermectin people avoided the village because of this disease (onchocerciasis). Since the distribution of ivermectin started people are returning to the village to be treated and they are becoming strong to work (focus group discussions, male youth, Cameroon).*

*Of course, there are places like Mbaraara that were not inhabited by people but they are now occupied. People were scared of oncho but now they have moved there (in-depth interview, male community leader, Uganda).*

Two-thirds of the 1600 respondents were married, with a slightly higher proportion of the respondents in Nigeria (20.5%) reporting widowhood. This could be due to the fact that the sample had a relatively higher proportion of older persons (n = 400; 30.5% aged ≥55 years) compared with the other three sites.

The ages of the respondents ranged from 18 years to ≥80 years, with a mean age of 39.5 years (39.5 ± 16.52 SD) and a median age of 37 years. This is largely the same across the sites and shows that the respondents were old enough to discuss the problem of onchocerciasis in the communities.

Over two-thirds (1152/1600; 72%) of all the respondents had been resident in the specific sites for 10 years or more. Therefore, most of them were able to relate to community events and activities around CDTI events with confidence.

3.1. Forms of stigma and its impression

Almost two-thirds of the respondents (58.2%; 931/1600) said they would not marry a person with onchocerciasis while 42.7% (683/1600) would avoid a person with onchocerciasis. About half (46.9%; 751/1600) would not share a bed with someone suspected to be infected with the disease (Table 1).

Stigma was higher in Uganda where 87.8% (351/400) and 87.5% (350/400) would neither have sexual relations nor marry someone with OSD, respectively. The qualitative study highlighted aspects of stigma:

... some people had different attitudes towards persons who had that disease. Looking at someone itching and scratching is scary because the government had not come out clearly to check people’s blood to know. ... when people get this skin rash others may think they have AIDS (focus group discussions, teacher, Uganda).

We constructed an OSD-related-stigmatisation index using the respondents’ agreement/disagreement with certain statements about persons with onchocerciasis. There were a total of 10 items, including whether the respondent will ‘not marry a person with OSD’; ‘avoid a person with OSD’; ‘will not eat with OSD person’; ‘will not drink with OSD person’; ‘will not share bed with OSD person’; ‘will not have sex with OSD person’; ‘consider OSD person dirty’; ‘OSD is manageable’. We constructed the index by using the percentage of respondents who agreed with each item. We calculated the index by summing the percentage of respondents who agreed with each of the 10 items.

Over two-thirds (1152/1600; 72%) of all the respondents had been resident in the specific sites for 10 years or more. Therefore, most of them were able to relate to community events and activities around CDTI events with confidence.
The scores for individual items ranged from 0 to 1, with a mean score of 0.421 (0.494 SD) for refusal to marry; 0.576 (0.494 SD) for avoidance of OSD person; 0.553 (0.497 SD) for refusal to eat with OSD person; 0.551 (0.498 SD) for refusal to share drinks with OSD person; 0.532 (0.499 SD) for refusal to share bed with OSD person; 0.465 (0.483 SD) for refusal to shake hands with OSD person; and 0.569 (0.495 SD) for regarding an OSD person as dirty. Furthermore, the respondents recorded mean score of 0.883 (0.321 SD) for recognising that onchocerciasis can be managed now and 0.637 (0.481 SD) for refusing to avoid an OSD person. Overall, the scores ranged from 0 to 10 points. The mean and median scores were 5.95 and 6.0 points, respectively (5.95 ± 3.22 SD).

The individual item test against the overall stigma score revealed significant association between each item and the overall stigma score (p < 0.001). The overall multiple regression coefficient was also significant at p < 0.001 levels.

Figure 1 shows that the tendency to discriminate against people with OSD was more among the youth across the four study sites. Stigmatisation was more in Uganda with a median score of 7 and 6 for the youths and older persons, respectively. The Cameroonian youths followed with a median score of 4 points. The tendency to stigmatise was lowest among the Cameroonian older respondents. Young girls with OSD were reported to experience more stigmatisation in Uganda because the boys ridiculed them, lowering their self-esteem and life prospects. A study participant observed that:

In 1992 we heard of incidences of couples having marital problems simply because a spouse had OSD-related skin infections. Sometimes they would separate beds if they could not divorce but as we moved on these problems are no longer there (in-depth interviews, adult man, Uganda).

From the focus group discussions with youth it was learnt that the youth feared older community members with OSD due to ignorance of what happened to the older person in their past. They feared the severe leopard skin appearance on the elderly persons with OSD. Community members seem to know those with OSD symptoms, which enhanced discrimination. Children who had grown up hearing these people being called discriminatory names picked these up and used them as a given.

3.2. Perceptions of onchocerciasis in the past

The questions on perceptions assessed ways in which community members related with persons infected with onchocerciasis in the past. The results show that before the introduction of ivermectin (772/1600) of people related normally and 32.4% (519/1600) avoided somebody with onchocerciasis manifestation (Table 2). Box 1 presents some statements from the four countries on perceptions towards people with symptoms of onchocerciasis.

3.3. People’s explanations of why they perceive stigma

The reason given for avoiding people infected with onchocerciasis was mainly the fear of transmission of the disease to the healthy members of the community (67.2%; 646/961). People with severe symptoms of onchocerciasis, such as deformed skin ‘like that of a frog’, were reportedly often discriminated against. Other people would not want even to look at them while eating. They were considered dirty: 11.8% (113/961) of the respondents agreed with the statement that people who suffer from onchocerciasis are dirty (Table 3).
Table 2
Relationship with people with onchocerciasis symptoms in the past

<table>
<thead>
<tr>
<th>Nature of relationship</th>
<th>Cameroon (n = 400)</th>
<th>DRC (n = 400)</th>
<th>Nigeria (n = 400)</th>
<th>Uganda (n = 400)</th>
<th>Total (n = 1600)</th>
</tr>
</thead>
<tbody>
<tr>
<td>They related normally</td>
<td>148 (37.0%)</td>
<td>204 (51.0%)</td>
<td>277 (69.3%)</td>
<td>143 (35.8%)</td>
<td>772 (48.3%)</td>
</tr>
<tr>
<td>They avoided the person</td>
<td>199 (48.9%)</td>
<td>129 (32.3%)</td>
<td>87 (21.8%)</td>
<td>104 (26.0%)</td>
<td>519 (32.4%)</td>
</tr>
<tr>
<td>They chased them away</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>2 (0.5%)</td>
<td>0 (0.0%)</td>
<td>2 (0.1%)</td>
</tr>
<tr>
<td>Pry</td>
<td>2 (5.0%)</td>
<td>6 (1.5%)</td>
<td>32 (8.0%)</td>
<td>5 (1.3%)</td>
<td>45 (2.8%)</td>
</tr>
<tr>
<td>Do not know</td>
<td>50 (12.5%)</td>
<td>61 (15.3%)</td>
<td>2 (0.5%)</td>
<td>135 (33.8%)</td>
<td>248 (15.5%)</td>
</tr>
</tbody>
</table>

DRC, Democratic Republic of Congo.

Table 3
Why people avoided people with symptoms of onchocerciasis

<table>
<thead>
<tr>
<th>Reasons of avoidance</th>
<th>Cameroon (n = 215)</th>
<th>DRC (n = 344)</th>
<th>Nigeria (n = 335)</th>
<th>Uganda (n = 67)</th>
<th>Total (n = 961)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considered infectious</td>
<td>106 (55.8%)</td>
<td>125 (36.3%)</td>
<td>334 (99.7%)</td>
<td>67 (100.0%)</td>
<td>646 (67.2%)</td>
</tr>
<tr>
<td>Looked ugly</td>
<td>62 (28.8%)</td>
<td>48 (14.0%)</td>
<td>12 (3.6%)</td>
<td>26 (18.8%)</td>
<td>148 (15.4%)</td>
</tr>
<tr>
<td>Were irritating</td>
<td>15 (7.0%)</td>
<td>29 (8.4%)</td>
<td>23 (6.8%)</td>
<td>13 (19.4%)</td>
<td>80 (8.3%)</td>
</tr>
<tr>
<td>Were dirty</td>
<td>30 (14.0%)</td>
<td>63 (18.3%)</td>
<td>8 (2.4%)</td>
<td>12 (17.9%)</td>
<td>113 (11.8%)</td>
</tr>
<tr>
<td>Were scary</td>
<td>43 (20.0%)</td>
<td>41 (11.9%)</td>
<td>7 (1.8%)</td>
<td>12 (17.9%)</td>
<td>103 (10.7%)</td>
</tr>
<tr>
<td>Were embarrassing</td>
<td>45 (20.9%)</td>
<td>20 (5.8%)</td>
<td>5 (1.5%)</td>
<td>1 (0.3%)</td>
<td>71 (7.4%)</td>
</tr>
</tbody>
</table>

DRC, Democratic Republic of Congo.

Table 4
Demographic factors and stigma against people with onchocerciasis

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number</th>
<th>% Stigmatised</th>
<th>$\chi^2$ value</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>399</td>
<td>52.1</td>
<td>$\chi^2 = 1.81$</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>412</td>
<td>55.7</td>
<td>$\chi^2 = 3.11$</td>
</tr>
<tr>
<td>Age</td>
<td>Youth (&lt;25 y)</td>
<td>215</td>
<td>58.0</td>
<td>$\chi^2 = 3.03$</td>
</tr>
<tr>
<td></td>
<td>Adult (≥25 y)</td>
<td>596</td>
<td>52.5</td>
<td>$\chi^2 = 0.06$</td>
</tr>
<tr>
<td>Ever married</td>
<td>Yes</td>
<td>142</td>
<td>49.1</td>
<td>$\chi^2 = 1.33$</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>668</td>
<td>55.0</td>
<td>$\chi^2 = 1.93$</td>
</tr>
<tr>
<td>Religion</td>
<td>Christian</td>
<td>643</td>
<td>53.4</td>
<td>$\chi^2 = 10.51$</td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td>131</td>
<td>54.6</td>
<td>$\chi^2 = 4.33$</td>
</tr>
<tr>
<td>Education</td>
<td>Yes</td>
<td>643</td>
<td>52.0</td>
<td>$\chi^2 = 2.43$</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>168</td>
<td>62.5</td>
<td>$\chi^2 = 10.51$</td>
</tr>
<tr>
<td>Occupation</td>
<td>Yes</td>
<td>675</td>
<td>56.0</td>
<td>$\chi^2 = 2.43$</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>136</td>
<td>45.3</td>
<td>$\chi^2 = 2.43$</td>
</tr>
<tr>
<td>Length of stay</td>
<td>&lt;5 y</td>
<td>142</td>
<td>58.7</td>
<td>$\chi^2 = 2.43$</td>
</tr>
<tr>
<td></td>
<td>≥5 y</td>
<td>668</td>
<td>53.0</td>
<td>$\chi^2 = 2.43$</td>
</tr>
</tbody>
</table>

Table 3 reveals frequencies of the people's perception of risk of transmission of disease. Shame was another important factor. Further analysis was performed on demographic factors that might influence stigma and discrimination against people with OSD (Table 4).

The results show that the critical demographic factors that influence stigma and discrimination against people with OSD are education and employment status of the respondents. The less educated members (n = 168, 62.5%, $\chi^2 = 9.33$) of the communities were found to discriminate more than the more educated members (n = 643, 52%, $\chi^2 = 9.33$) (p = 0.002). This highlights the effect of education and awareness on onchocerciasis-related issues. The respondents did not differ significantly on other demographic characteristics such as religion, length of stay in the community, age and gender. However, people who had stayed <5 years in the community tended to stigmatise more than those who had stayed for longer periods. In addition, as far as the marital status was concerned, unmarried people seemed to stigmatise more than married ones. This is the same situation with youths who tended to stigmatise more than adults.

3.4. Current perceptions of onchocerciasis

Respondents reported that they perceive today is different from what they perceived in the past, especially before the implementation of CDTI. There is a considerable improvement in the relationship between healthy people and those with symptoms. Almost all respondents (81.8%; 961/1120) said that people have normal relationships with only 4.3% (48/1120) reporting that they avoided those with signs and symptoms (Table 5).

The results show that before CDTI, the level of stigma and discrimination was relatively high. It is clear that there is a perception of changed relationships at the community level. The proportion of people who viewed relationships as normal in the past (48.3%; 772/1600) was much lower than those who perceived them as normal currently (81.8%; 961/1120). Avoidance of people with onchocerciasis has also reduced from 32.4% (519/1600) in the past to 4.3% (48/1120) currently. However, it is notable that respondents in Uganda recorded lower levels of ‘relate normally’, which was highest in Cameroon. Box 2 presents some of the sentiments...
used to express views on changes in perceptions toward onchocerciasis.

4. Discussion

This study assessed the issue of stigma associated with onchocerciasis, which has been reported in earlier studies.14,15 In the past, people with onchocerciasis were discriminated against for various reasons; findings that compare favourably with the results from other studies.14,15 Stigmatisation was mainly due to ignorance about the disease, fear of transmission and misconceptions about the aetiology of the disease. This study has shown that the people with onchocerciasis were excluded from society and given nicknames like ‘skin of toad’ in reference to the complexion of their skins. Such attitudes were influenced by the perception of onchocerciasis as a curse or fate in the communities. Those having signs and symptoms of onchocerciasis were considered pariahs and ugly people. It is notable that the stigma and discrimination were not just a ‘one way relation’, that is, people with no onchocerciasis rejecting people with onchocerciasis, but a ‘bilateral relation’ meaning that people with the disease were forced to adopt a certain perception towards other members of the society as a coping strategy.

Stigma and discrimination against people suffering from onchocerciasis and the magnitude of this problem varied with the gender of the patient and other characteristics. Women have been found to be more concerned than men about the consequences of onchocerciasis.14–19 Thus, the communities had a tendency to isolate or avoid people that present visible signs of the infection. In the case of patients suffering from AIDS, stigmatisations were severe at home compared with those reporting discrimination from community members.24

The manifestations of the disease also determine the level of stigmatisation. It has been found that people suffering from skin rashes or lizard skin are more stigmatised than people with hanging groin or blindness. This could be due to the fear that close association can lead to contamination. In addition, outward appearance is important to many people; therefore, those who look ‘ugly’ are easily identified and isolated. This was clearly illustrated by the high proportions of people who could not be sexually intimate with those with signs and symptoms of the disease.

The complexion of the skin (colour, texture) being part of beauty norms, and even a factor of belonging to an ethnic group, explains why a skin difference can lead to rejection of an individual inside his or her social group. Thus, as far as onchocerciasis is concerned, people with lizard skin or severe skin rashes are easily set apart from the group. However, in Cameroon the leopard skin presents a particular status. In fact, people suffering from this kind of manifestation of onchocerciasis instead of being rejected are accepted. To understand this dissymmetry (two people showing skin problems but not treated in the same way) we have to consider the culture and the world view of the people. For example, in Cameroon the leopard skin phenomenon has a cultural explanation that is integrated in people’s way of thinking. The fact that this manifestation is seen more in elderly people than in youths is socioculturally related to the length of time someone spends close to a fire. Therefore, the outcome on the skin would be considered a sign of long life rather than that of an infection. Everything that is visible attracts attention and judgment from others, and if the culture where the person with skin problems due to onchocerciasis lives does not have a socially approved explanation of the phenomenon it sets it apart as a stigmatised condition. As for hanging groin, because it is hidden, particularly if it is a small swelling, it helps the person suffering from this symptom to escape the stigmatisation.

The qualitative data revealed that, previously, people held several theories of the cause of the disease; hence, they avoided people infected with it. In Uganda, a family with a person suffering from epilepsy was seen as cursed and the other members of the community would not associate

Table 5

<table>
<thead>
<tr>
<th>Nature of relationship</th>
<th>Cameroon (n = 119)</th>
<th>DRC (n = 126)</th>
<th>Nigeria (n = 313)</th>
<th>Uganda (n = 282)</th>
<th>Total (n = 1120)</th>
</tr>
</thead>
<tbody>
<tr>
<td>They relate normally</td>
<td>184 (92.5%)</td>
<td>257 (78.8%)</td>
<td>283 (90.4%)</td>
<td>192 (21.0%)</td>
<td>916 (81.8%)</td>
</tr>
<tr>
<td>They avoid the person</td>
<td>3 (1.5%)</td>
<td>13 (4.0%)</td>
<td>27 (8.6%)</td>
<td>5 (1.8%)</td>
<td>48 (4.3%)</td>
</tr>
<tr>
<td>They chase them away</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>1 (0.3%)</td>
<td>0 (0.0%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Pity</td>
<td>0 (0.0%)</td>
<td>7 (2.1%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>7 (0.6%)</td>
</tr>
<tr>
<td>Do not know</td>
<td>12 (6.0%)</td>
<td>49 (15.0%)</td>
<td>2 (0.6%)</td>
<td>85 (30.1%)</td>
<td>147 (13.1%)</td>
</tr>
</tbody>
</table>

DRC, Democratic Republic of Congo.

Box 2. Stigma against people with onchocerciasis (after community directed treatment with ivermectin).

‘Thanks to ivermectin, those we pushed away from the community meetings because they had skin eruptions are accepted.’ (In-depth interviews: stakeholder, Cameroon).

‘Today people feel free to shake hands. They can also hug each other freely because everyone is healthy.’ (Focus group discussions: youth, Uganda).

‘In the past people would not come together like we have done now for fear that if a fly bites me and assuming I have the disease, it will go and bite another person immediately and in the process it will transmit the disease from one person to another. But these days we meet and there is no problem.’ (Focus group discussions: youth, Uganda).

‘Although we know better now, there is still that fear that something like hanging groin is hereditary. Really, people no longer avoid sufferers so much but I know that here we think that if it gets to the stage where one’s groin is hanging, then it will be hereditary. Before, no-one would go into marriage with a girl whose mother had leopard skin because it was believed that she would develop it and no female would ordinarily marry a man whose father had hanging groin. But now these things are changing because we know better.’ (Focus group discussions: young man, Nigeria).
with such a family. People would never marry from such families and young girls from such households ended up staying at home. Young children who had onchocerciasis-related problems, especially skin rashes, were feared and could not associate with their peers both at home and school. This social discrimination denied them the chance to relate, play and grow normally as other children. Consequently, this affected their psychological growth and ability to relate well with others. The results indicate that older members of the community who had OSD were feared by the younger generation who sometimes did not know what had happened to these people.

Discussions in the four sites show that stigma in the past had a gender dimension. OSD limited the range of social involvement and affected the sexual life of affected individuals. Young women with OSD suffered stigmatisation more than young men. This affected their prospects of marriage and the kind of partners they got. Women in Uganda were reported to have encountered most types of stigma. For example, when a married woman showed signs of the disease, the man would either abandon her or let her stay but marry another wife. It was noted that men were very conscious about their wives’ skins and if any rashes were seen the women would be abandoned. This is confirmed through the assertion by 46.9% (n = 751/1600) of the respondents that they would never share a bed with a person suffering from OSD. Women expressed more concern about physical appearance and life chances, especially marriage. Some girls missed out on marriage or some members of an association missed out on posts of responsibility because of OSD.

Although social stigmatisation was prevalent in the past, we note that the degree of stigmatisation has reduced in all study communities. This is mainly due to the fact that stigma is largely a coping strategy by communities for situations that are beyond their management. Moreover, the qualitative data revealed that the level of stigmatisation has decreased for several reasons: people are aware of how onchocerciasis can be transmitted and the reduction of severe OSD cases in the communities thanks to the CDTI programme.

Although all the participants noted that the levels of stigma have gone down it is also clear that there are still areas where people are reluctant to associate with those with visible signs of the disease. The fact that the youth stigmatised more than the older age groups is indicative of a need to target interventions and active engagement of the youth in CDTI activities. There is also a need to target those with lower levels of education and in gainful employment who were found to be more stigmatising; the less educated discriminated more against people with OSD (p < 0.001). This highlights the effect of education and awareness on onchocerciasis-related issues.

Through CDTI, the communities have access to health education and other critical information about onchocerciasis and the people have a better understanding of the disease aetiology. They also know that it is preventable. The stigmatisation of those infected has transformed largely to sympathy and care. The health education provided by CDDs has helped the communities to know more about onchocerciasis and its consequence. Moreover, ivermectin has drastically reduced the manifestation of the infection in the communities. That is why a mass treatment programme like CDTI is necessary to reduce the impact of social, physical and economical discrimination due to stigmatisation. Desclaux presented the same perspective when he talked of epidemics, ‘social diseases’ and reduction of stigma.26

The cross-sectional design used to study stigma and discrimination encountered one major limitation in that respondents were required to retrospectively discuss their experiences with OSD. It was envisaged that most of the respondents may not have been born when the control programmes were initiated and implemented. In view of this apparent limitation associated with the younger population, the analysis of onchocerciasis-related stigmatisation used only data from the older populations. The larger study collected data from all spectrums of the population ranging from children in primary schools and high schools to those ≥ 18 years. Among the primary school children, the participants were required to draw their impression of onchocerciasis based on what they see in their environment. This segment was not used in looking at the issues of stigma and discrimination. Similarly, the high school students aged 13–17 years were made to write essays on what they know of onchocerciasis in their communities. This again was not considered suitable for exploring the element of change in stigma and discrimination due to onchocerciasis. However, the segment of stigma and discrimination was restricted to those aged ≥ 18 years who on average were aged 40 years.

Another limitation is the presence of other skin diseases in the communities. It is feared that people may be discussing other diseases instead of onchocerciasis. The team made conscious effort to focus on onchocerciasis, which is quite distinctive due to the CDTI structure in the communities. The inclusion of the respondents was based on the village ivermectin treatment registers. The respondents were also reminded that the discussions were about the disease for which the CDD distributes drugs, the dosage of which is determined with the ‘dose pole’. This helped to mitigate the impact of these limitations on the data quality.

5. Conclusions and recommendations

This study reveals that there is a reduction of stigma in most communities, which is a positive indicator for increased social integration for those with the symptoms. However, there are aspects of stigma in the study communities, especially among the youth, which should be addressed through integrating these specific aspects into health education. Some people still have fears and mixed feelings about the disease and the patients. The persistent bias against young girls and women with OSD is a problem, although it is notable that this has reduced in most communities. Socially, there has been marked reduction in stigma and discrimination against individuals with severe symptoms of onchocerciasis who previously would hide the symptoms for fear that they would be laughed at or segregated. This reduction can be attributed to CDTI although more efforts need to be targeted to the categories of people prone to stigmatisation.
CDTI projects need to address the stigmatizing points identified in this paper, especially stigmatization in intimate relations. Further, there is a need for innovative mechanisms to involve the youth in CDTI activities as it was notable that they had higher levels of stigmatizing compared with the older groups. Health education should continue with a focus on the identified stigmatizing statements/factors.

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References