

## Social stigma as an epidemiological determinant for leprosy elimination in Cameroon

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### Abstract

Leprosy has been eliminated as a public health problem in most countries of the world according to the WHO, but the social stigma to the disease is still very high. The present study was performed to investigate the role of social stigma as a determinant for leprosy elimination in a leprosy endemic region of Cameroon. Focus group discussions, in-depth interviews and structured questionnaires were used to investigate leprosy social stigma among lepers, their contacts and a control group consisting of patients attending a health facility for reasons other than leprosy. Informed consent was sought and gained prior to starting the study. Focus group discussions and in-depth interviews identified three types of stigma:

lack of self-esteem, tribal stigma and complete rejection by society. From the 480 structured questionnaires administered, there were overall positive attitudes to lepers among the study population and within the divisions ( $P=0.0$ ). The proportion of participants that felt sympathetic with deformed lepers was 78.1% [95% confidence interval (CI): 74.4-81.8%] from a total of 480. Three hundred and ninety nine (83.1%) respondents indicated that they could share a meal or drink at the same table with a deformed leper (95% CI: 79.7-86.5%). Four hundred and three (83.9%) participants indicated that they could have a handshake and embrace a deformed leper (95% CI: 80.7-87.3%). A total of 85.2% (95.0% CI: 81.9-88.4%) participants affirmed that they could move with a deformed leper to the market or church. A high proportion of 71.5% (95.0% CI: 67.5%-75.5%) participants stated that they could offer a job to a deformed leper. The results indicate that Menchum division had the lowest mean score of 3.3 on positive attitudes to leprosy compared with Mezam (4.1) and Boyo (4.8) divisions.

The high proportion of positive attitudes among the participants and in different divisions is a positive indicator that the elimination of leprosy social stigma is progressing in the right direction. Quantification of stigma to assess the elimination struggle is a new research area in public health.

### Introduction

Leprosy has been described as a neglected tropical disease and *social killer* because it causes disability, has economic implications and results in social exclusion compared with other diseases like malaria that are *serial killers*.<sup>1</sup> Goffman<sup>2</sup> has provided the most widely accepted definition and description of stigma referring to bodily signs designed to expose something unusual or bad about the moral status of the signifier. Stigma itself is a complex issue, with the capacity to affect all facets of a leprosy-affected person's life.<sup>3</sup> Many examples of social exclusion are available in the literature.<sup>4-7</sup>

Today, leprosy is clinically cured relatively easily, yet, the effects that it has on a patient's life can carry on indefinitely.<sup>3</sup> The stigmatising condition can lead to the person affected being rejected and excluded from society.<sup>8</sup> In the past two decades effective treatment has reduced leprosy prevalence in the world.<sup>9,10</sup> However, the number of people living with its effects is counted in millions and prejudice still remains a burden to those affected which directly or indirectly affect its elimination. Leprosy social stigma has been described as worse than the

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disease itself by leprosy patients.<sup>11</sup> Leprosy is still a public health problem in Essimbiland of Cameroon even though the country has attained the elimination threshold set by the WHO.<sup>12</sup> In this study we investigated the role of social stigma as a determinant for leprosy elimination in this endemic focus in Cameroon.

### Materials and Methods

#### Study area

The study area and methods have been described elsewhere in detail.<sup>12</sup> Briefly, the participants were drawn from Boyo and Menchum divisions of north-western Cameroon because they had the highest prevalence of leprosy (3.4/10,000 and 4.5/10,000, respectively).<sup>13-15</sup> These divisions still have the highest leprosy prevalence (1.7/10,000 for Menchum and 2/10,000 for Boyo) in the North West Region of Cameroon.<sup>16</sup> In Boyo division, the study was concentrated in the Mbingo leprosarium and surrounding villages and in Menchum division, it was concentrated in Benakuma and surrounding villages of Essimbiland. This study was conducted from June 1998 to October 2002.

## Design and setting

The study was a descriptive observational case-control study that was community-based in one low (Mezam division) and two high (Menchum and Boyo divisions) leprosy-prevalent areas. Leprosy patients constituted the cases and the contacts were a high-risk group for developing leprosy. The control group consisted of patients attending a health facility for reasons other than leprosy. Leprosy patients, their contacts and controls were matched for geographical location, age and sex.

## Inclusion and exclusion criteria for leprosy patients, contacts and controls

All intra-familial contacts (wife, children and other relatives) and extra-familial contacts (friends, peers, colleagues and villagers) were involved in the study. Controls were those who attended the Bamenda Hospital in Mezam division for reasons other than leprosy who were selected based on a well-structured, guided questionnaire; those who either live or lived with a leper in the same household or quarter were eliminated from the study.

## Selection techniques for focus group discussions, in-depth interviews and structured questionnaire

Nine focus group discussions (FGDs) [5 with contacts and 4 with cases] and 6 in-depth interviews (IDIs) [3 with contacts and 3 with cases] were conducted using a guide to gather information on leprosy social stigma and to fine-tune the structured questionnaire. The participants in the FGDs were purposively chosen in which minigroups of 4 to 8<sup>17-19</sup> from the target population discussed topics on leprosy social stigma. The groupings were based on the profession, literacy, and social status of participants. Direct interviews were conducted in Pidgin English, English language and the Bikom dialect with the help of a trained interpreter. In all FGDs, the lead author acted as the moderator and trained internship students acted as note-takers. All the FGDs and IDIs were recorded on audiocassette tapes. The purpose of taping the interviews was explained to the participants and their consent obtained before this was done. The notes and replayed cassettes were transcribed after the interviews. The list of patients was obtained from health facilities. The patients in different villages assisted in the identification of other patients whose names were not in the registers. In the leprosarium, all available leprosy patients on treatment, those discharged and living within the neighbouring villages, including those rehabilitated, were involved. After identifying 138 leprosy patients, 180 contacts and 162 controls were recruited for the study. A partly open and closed pre-tested structured questionnaire

was administered to all 480 respondents. Those who could read or write the English language filled the questionnaire and those who could not were communicated to through an interpreter in Bikom and Essimbi dialects. The questionnaire contained socio-demographic variables on age, sex, marital status, religion, geographical location and profession. Attitudinal questions on social stigma of leprosy constituted the dependent variables.

## Ethical approval and clearance

The authorization to carry out the work was obtained from the Cameroonian Ministry of Public Health (N° D76/A/MSP/SESP/SG/DRH/SDGP/SFS). Informed consent was obtained from all respondents before discussions/interviews were conducted, questionnaires administered and from the patient whose picture is presented.

## Data management and analysis

The audiotapes from FGDs and IDIs were replayed and transcribed, and the different responses to the questions on social stigma were analysed manually using a code tree. Content and construct validity were checked to ensure the validity of transcribed FGDs by comparing the transcribed notes with written notes taken during FGDs. Relevant comments on social stigma were analysed. Similar views on each discussion item were grouped separately from dissimilar ideas. Discussions on topics with many dissecting views were presented in the form of graphic comments.

Each time the questionnaires were brought from the field, they were checked for unanswered questions and edited for the use of correct codes and completeness, including range and consistency errors. The structured questionnaire data were analyzed using Epi-Info after a double entry by two data clerks. Data summary such as proportions and percentages and testing of the working hypothesis were also carried out using the chi-square and Fisher exact tests for tests of significance of association between categorical variables. The working hypothesis was that attitudinal questions on social stigma were not going to vary among the study and the control groups and within the divisions.

## Results

### Focus group discussions among leprosy patients, contacts and controls

It was gathered from FGDs that there were three types of social stigma, which vary from lack of self-esteem (self stigma) among the leprosy patients, tribal stigma, and complete

rejection by society. Majority of contacts shunned interactions that could entail person-to-person contact especially with deformed patients. Most contacts said they could tolerate handshake with a leper. Only few contacts accepted the idea of marrying a leper. The FGD views of the participants on the social stigma of leprosy are presented in Table 1. Among the graphic comments made on the social stigma to leprosy by contacts, the following was pertinent and frequently mentioned.

“There is rejection and people despise them because they cannot contribute to the development of the society; they lack proper lodging”.

All community-based rehabilitation workers (contacts of patients) commented that social stigma was a stumbling block to leprosy elimination as expressed in the following comments.

“The leprosy patient rejects his/herself first by shying away from people and sitting at corners in gatherings, followed by the family and the community”.

“There are 13 villages in my area. These villages have their traditional taboos. In some, the patients are rejected in “Manjong” houses (Manjong is a social gathering), they don’t drink from the same pot with others. This happens to treated and untreated patients. They cannot play the drum and dance well”.

All participants expressed the views that social stigma to leprosy was high in their places of origin. Among the leprosy patients involved in FGDs, it was unanimously accepted that society had positive attitudes towards them compared with the past years of the 50s and 60s when social stigma was very high.

### In-depth interviews among leprosy patients, contacts and controls

#### Social stigma among lepers

During IDIs, it emerged that social stigma was deeply rooted in the study area among non-lepers. However, the lepers expressed the views that society was having positive attitudes towards them. Among the non-lepers the following pertinent comments were frequently mentioned:

“These patients are looked upon as second class citizens. Discrimination forces some patients to do certain activities just to look like normal people, which results in further deformities. Some, who came to the leprosy colony for treatment, had their property seized. Normal people cannot marry them. However, social stigma is decreasing now. If somebody is treated of malaria, there is no reason to continue calling him/her a malaria patient for life. Why then with leprosy? When a heavy wind blows down a plantation stem, after the wind the stem cannot stand up. We cannot say that the wind is still blowing. Why should we keep on calling these people leprosy patients?”

Deformities are like scars of any wound”.

“Social stigma used to be very high but now many patients who are discharged live, play and dance well in society”.

The lepers unanimously agreed that the attitude of society towards them was improving as expressed in the following comment: “All children born in NewHope village are married to government officials and none of them has leprosy; we interact with people freely”.

### Social stigma among non-lepers

It emerged from the study that social stigma to leprosy was high in the study area among non-lepers which can hinder the effective elimination of the disease. Three types of stigma were identified—first, the patient rejecting himself because of lack of self-esteem, and secondly, the repulsive attitude of the society to the patient.

### Leprosy determinants from structured questionnaire among leprosy patients, contacts and controls

The significant findings on attitudes to leprosy among lepers, contacts, and controls are shown in Table 2. The proportion of participants that indicated that they felt sympathetic with deformed lepers was 78.1% (95% CI: 74.4–81.8%). There was no statistically significant relationship between the feelings of intra-familial and extra-familial contacts towards deformed lepers ( $P=0.8$ ). Three hundred and ninety-nine (83.1%) respondents accepted that they could share a meal or drink at the same table with a deformed leper (95% CI: 79.7–86.5%). There was no statistically significant association in the attitude of sharing a meal or a drink at the same table with a treated but deformed-leper among intra-familial and extra-familial contacts ( $P=0.4$ ). Four hundred and

three (83.9%) participants accepted that they could have a handshake and embrace a deformed leper (95% CI: 80.7–87.3%). Four hundred and nine, corresponding to 85.2% of total participants [95.0% CI: 81.9–88.4%], accepted that they could move about with a treated but deformed leper to a public place (market or church). More intra-familial than extra-familial contacts (85.9% *vs.* 52.8% respectively) accepted that they could move with a treated but deformed leper to a public place ( $P=0.3$ ). Three hundred and forty three (71.5%) participants accepted that they could offer a job to a deformed leper [95.0% CI: 67.5–75.5%]. The summary statistics on attitudinal questions on feelings, sharing a meal or drink, movement to public places, handshake and job offer to treated but deformed lepers is shown in Table 3. Lepers and controls had higher mean scores than contacts for these determinants.

**Table 1. Interactions with respect to the social stigma of leprosy expressed by leprosy patients, contacts and controls during focus-group discussions.**

Interactions encouraging social stigma	Category of participants who expressed similar views	Examples of factors leading to similar behaviours
Lack of self-esteem (patients shy away by themselves)	Contacts	People despise lepers because they cannot contribute to development of society; leprosy patients are poor; lepers lack accommodation; patients sit at corners in gatherings
Cultural taboos	Contacts	Leprosy is caused by past bad behaviours, witchcraft, or gods of the land are angry with one; patients are rejected in some social gatherings like “Manjong” houses
Shunning physical and social contacts	Contacts	Scared by deformities of the patient; cannot tolerate handshake; insults and slants from society when lepers ask for help; cannot marry somebody treated of leprosy; cannot go to cinemas or stadiums with lepers; scared when lepers sleep with open eyelids.
Interactions discouraging social stigma	Category of participants who expressed such views	Examples of some factors that lead to such behaviours
Greetings	Contacts	Visit a leper in their village; eating with lepers; embrace lepers; play games like football and cards with lepers.
Other positive attitudes from society	Lepers	Greet lepers by handshaking and ask about their work and family. Lepers attend the same church with other villagers; male leprosy patients marry normal women and vice versa; lepers exchange gifts like pineapple, sugar cane, baskets, with normal people; people freely come to the leprosarium to visit lepers

**Table 2. Comparison of attitudes to lepers among leprosy patients, contacts and controls.**

Question	Attitudes to leprosy	Total n=480 (%)	Leprosy patients n=138 (%)	Contacts, n=180 (%)	Controls n=162 (%)	$\chi^2$	P
Feelings about deformed lepers	Sympathetic	375 (78.1)	123 (89.1)	118 (65.6)	134 (82.7)	38.4	0.0
	Not sympathetic	105 (21.9)	15 (10.9)	62 (34.4)	28 (7.3)		
Can you share a meal or drink with a treated but deformed leper at the same table?	Agreed	399 (83.1)	134 (97.1)	136 (75.6)	129 (79.6)	28.6	0.0
	Disagreed	49 (10.2)	3 (2.2)	25 (13.9)	21 (13.0)		
	Undecided	32 (6.7)	1 (0.7)	19 (10.6)	12 (7.4)		
Can you shake hands and embrace a treated but deformed leper?	Agreed	403 (83.9)	136 (98.6)	144 (80.0)	123 (75.9)	47.2	0.0
	Disagreed	55 (11.5)	0 (0.0)	20 (11.1)	35 (21.6)		
	Undecided	22 (4.6)	2 (1.4)	16 (8.9)	4 (2.5)		
Can you move about to a public place (e.g. market or church) with a treated but deformed leper?	Agreed	409 (85.2)	131 (94.9)	143 (79.4)	135 (83.3)	17.2	0.0
	Disagreed	41 (8.5)	6 (4.3)	19 (10.6)	16 (9.9)		
	Undecided	30 (6.3)	1 (0.7)	18 (10.0)	11 (6.8)		
Can you offer a job to a treated but deformed leper?	Agreed	343 (71.5)	114 (82.6)	112 (62.2)	117 (72.2)	37.2	0.0
	Disagreed	108 (22.5)	9 (6.5)	58 (32.2)	41 (25.3)		
	Undecided	29 (6.0)	15 (10.9)	10 (5.6)	4 (2.5)		

The significant findings on attitudes to leprosy in the three divisions are shown in Table 4. There was a statistically significant relationship between all the attitudinal questions in the three divisions ( $P=0.0$ ). The summary statistics of positive attitudes to leprosy shown in Table 5 indicate that Menchum division had the lowest mean score of 3.3. Despite the high positive attitudes to leprosy in Boyo and Mezam divisions, it was observed that leprosy social stigma is very high in Menchum ( $P<0.05$ ). Figure 1 shows a female leprosy patient without deformities sent away from the village with her children living in the bush.

### Variation of attitudes to leprosy with the demographic characteristics of the respondents

No relationship was established between the feelings of the respondents when they see deformed lepers with religion, educational and marital status ( $P>0.05$ ). However, older people were less sympathetic with lepers than younger ones [254 (96.6%) vs. 211(97.2%)] ( $P<0.05$ ). Seven (5.1%) leprosy patients indicated that their separation or divorce from their spouse was due to leprosy. Two hundred and forty seven (70.6%) educated people vs. 18 (13.9%) illiterate participants accepted that

they could share a meal with a treated but deformed leper ( $P<0.05$ ). No relationship was established between the attitude of sharing a meal with a deformed leper with religion and marital status of the respondents in this study ( $P>0.05$ ).

Two hundred and forty seven (70.6%) educated participants compared with 22 (16.9%) illiterate participants stated that they could offer a handshake to a deformed leper ( $P<0.05$ ). One hundred and twelve (68.7%) farmers, 43 (36.4%) students and 13 (14.8%) unemployed participants indicated that they could offer a handshake to a deformed leper. No relationship was established between the attitude of having a handshake with a deformed leper and gender, religion, or marital status of the subjects in this study ( $P>0.05$ ).

More Christians than participants of other religions accepted they could move to the market or church with a deformed leper [393 (87.5%) Christians vs. 10 (47.6%) other religions] ( $P=0.0$ ). Three hundred and eighteen (90.9%) educated people and 91 (70.0%) illiterate participants accepted that they could move with a treated but deformed leper to a public place ( $P<0.05$ ). More singles than married couples [168 (85.3%) vs. 107 (68%)] affirmed that they could move with a deformed leper to a public place ( $P<0.05$ ). No statistical-

ly significant relationship was established between the attitude of moving about with a treated but deformed leper with age, marital status and gender of the respondents in this study ( $P>0.05$ ).

There was no statistically significant rela-



Figure 1. An active female multi-bacillary leprosy patient sent away from home and living with her children on a hill in Benahudu village of Essimbiland.

Table 3. Summary statistics of positive attitudes to lepers (feelings, sharing a meal or drink, movement, handshake and job offer to treated but deformed leprosy patients) among lepers, contacts, and controls.

Summary statistics of positive attitudes to treated but deformed lepers					
Category of subject	Number of subjects	Total scores	Mean score	Variance	Standard deviation
Lepers	138	638	4.6	0.9	0.9
Contacts	180	715	3.9	1.7	1.3
Controls	162	666	4.1	1.1	1.1
Analysis of variance for positive attitudes to treated but deformed lepers					
Variation	Sum of squares	Degree of freedom	Mean square	F-statistic	P
Among groups	35.3	2	17.7		
Within groups	613.3	477	1.3	13.7	0.0
Total	648.6	479			

Table 4. Comparison of attitudes to lepers in the divisions of the study area.

Question	Attitudes to leprosy	Total n=480 (%)	Boyo n=213 (%)	Menchum n=105 (%)	Mezam n=162 (%)	$\chi^2$	P
Feelings about deformed lepers	Sympathetic	375 (78.1)	163 (76.5)	78 (74.3)	134 (82.7)	53.3	0.0
	Not sympathetic	105 (21.9)	50 (23.5)	27 (25.7)	28 (7.3)		
Can you share a meal or drink with a treated but deformed leper at the same table?	Agreed	399 (83.1)	202 (94.8)	68 (64.8)	129 (79.6)	50.8	0.0
	Disagreed	49 (10.2)	3 (1.4)	25 (23.8)	21 (13.0)		
	Undecided	32 (6.7)	8 (3.8)	12 (11.4)	12 (7.4)		
Can you shake hands and embrace a treated but deformed leper?	Agreed	403 (83.9)	201 (94.4)	79 (75.2)	123 (75.9)	43.6	0.0
	Disagreed	55 (11.5)	3 (1.4)	19 (18.9)	35 (21.6)		
	Undecided	22 (4.6)	9 (4.2)	7 (6.7)	4 (2.5)		
Can you move about to a public place (e.g. market or church) with a treated but deformed leper?	Agreed	409 (85.2)	206 (96.7)	68 (64.8)	135 (83.3)	63.3	0.0
	Disagreed	41 (8.5)	0 (0.0)	25 (23.8)	16 (9.9)		
	Undecided	30 (6.3)	7 (3.3)	12 (11.4)	11 (6.8)		
Can you offer a job to a treated but deformed leper?	Agreed	343 (71.5)	191 (89.7)	35 (33.3)	117 (72.2)	117.2	0.0
	Disagreed	108 (22.5)	16 (7.5)	51 (48.6)	41 (25.3)		
	Undecided	29 (6.0)	6 (2.8)	19 (18.1)	4 (2.5)		

tionship between the attitude of offering a job to a deformed leper and age, religion, or marital status of the subjects in this study ( $P>0.05$ ). Fewer males than females [157 (70.7%) vs. 186 (72.4%)] stated that they could offer a job to a deformed leper ( $P>0.05$ ). More educated subjects than illiterate participants [208 (59.4%) vs. 21 (16.2%)] stated that they could offer a job to a deformed leper ( $P>0.05$ ). Most of the subjects who could offer a job to deformed lepers were farmers [126 (77.3%)] and students [85 (72.0%)] rather than other occupations ( $P<0.05$ ).

## Discussion

This study has very important implications for the control and elimination of leprosy in Cameroon because social stigma is a major determinant for the rehabilitation of leprosy patients. Leprosy has been eliminated in Cameroon<sup>12</sup> according to the WHO standard, but there are still endemic foci such as that in Essimbiland. Leprosy has been integrated into primary health care in Cameroon but during FGDs and IDIs, leprosy social stigma among health personnel was very high which can lead leprosy patients doubt the effectiveness of treatment, which has negative effects on elimination. By drawing attention to stigma, this study can help fine-tune public health messages and sharpen awareness campaigns because stigma has proven to be tremendously useful in neglected tropical disease control.<sup>20</sup>

Stigma is an important disincentive to treatment<sup>21</sup> and this has been proven for leprosy.<sup>22</sup> The harm of stigma is that it inhibits treatment of the stigmatising disease, and therefore both illness and stigma persist,<sup>20</sup> which may affect leprosy elimination in Essimbiland. Social stigma is manifested in several ways - verbal abuse, ostracism from social functions, enforced isolation and separation from the family. If stigma is carried through to its conclusion, the person may be forced into destitution. In many cases, going forward for treat-

ment is left too late to avoid deformity. This is due very often to lack of knowledge of the symptoms of leprosy.<sup>23</sup> Stigma is related to the fact that leprosy is one of the diseases with physical imperfections that leads to disabilities but seldom kills so the patient lives and continues to suffer. These deformities worsen with age<sup>24</sup> and since deformed lepers are poor because of physical disabilities, there is no will power, they cannot feed and accommodate their families nor educate their children. This leads to hopelessness and lack of self-esteem.<sup>23</sup>

Every society considers disease in different ways and this influences the attitude of the community to leprosy patients.<sup>25</sup> In the study area, the use of traditional medicine to explain life activities is commonly practiced which encourages superstition. This may explain why the respondents associated leprosy to witchcraft, bad behaviour or sin. These cultural taboos can hinder leprosy control in the study area.<sup>23</sup>

Social contact with leprosy patients was generally shunned by majority of participants. A community-based rehabilitation worker commented that "sleeping with eyelids open, make children to run away from lepers that they are not normal people. People don't want to sit with them on the same bench in the church, or eat with them." These findings are in agreement with the work of Touko *et al.*<sup>26</sup> in Yaounde, Cameroon who found that social relationships with lepers were shunned because of physical imperfections. Most non-leprosy participants believed that patients with clawed hands and feet and other deformities were still infectious and as such many refuse body contact with them. The misunderstanding of a society that treated leprosy, its victims and those working against it, with fear and prejudice has been reported from the Cross River State of Nigeria.<sup>27</sup> Such misconceptions still exist in Essimbiland.<sup>23</sup> All these are associated to the high social stigma of leprosy, which is a stumbling block to leprosy elimination in the study area.

This study has revealed that lepers, contacts

and controls feel sympathetic when they see deformed lepers. Contacts could be so used to deformed leprosy patients that they don't see them as a problem contrary to controls who are not used to leprosy and a deformed leper to them looks so strange that they show a lot of sympathy towards the patient.<sup>23</sup> Lepers may want to associate with non-lepers, hence the high proportion of this category of respondents who expressed such views.

## Overall variation of attitudinal questions on social stigma among the study participants

Results showed that lepers had the highest mean score of positive attitudes towards themselves followed by controls and contacts ( $P=0.00$ ). This highlights the fact that lepers are interested in socializing with society but society on the contrary has a hostile attitude towards them because of their physical imperfections and fear of contagion.<sup>28</sup>

In a community-based study on attitudes to leprosy in Yaounde, Cameroon, Touko *et al.*<sup>26</sup> found that interactions that did not involve physical contact with lepers were generally welcomed by 94% of the respondents, whereas physical contact was shunned by all, except 4.5%. In this study, social contacts like handshaking and embracing each other, movement to public places and sharing a meal with lepers was accepted by more than 50% of the respondents. Leprosy is more a public health problem in Boyo and Menchum divisions than Yaounde.<sup>23</sup> In these divisions, inhabitants may not see leprosy as a problem; hence they tolerate a lot of physical contact with lepers compared with inhabitants of Yaounde. These findings are positive indicators of leprosy elimination. Because of the high social stigma, many leprosy patients may opt not to attend health facilities since their presence may reveal their condition.<sup>23</sup> Contacts are so used to lepers that leprosy is no more a problem for them so many may not sympathise with deformed lepers contrary to controls that see leprosy as a strange disease and may feel more sympathetic with deformed lepers.

**Table 5. Summary statistics of positive attitudes to leprosy patients (personal feelings by seeing a leper, sharing a meal or drink, handshake and job offer to treated but deformed leprosy patients) in the divisions.**

Summary statistics of positive attitudes to treated but deformed lepers					
Study area	Sample size	Total scores	Mean score	Variance	Standard deviation
Boyo	213	1013	4.8	0.4	0.7
Menchum	105	340	3.3	2.0	1.4
Mezam	162	666	4.1	1.1	1.1
Analysis of variance for positive attitudes to treated but deformed lepers					
Variation	Sum of squares	Degree of freedom	Mean square	F-statistic	P
Among groups	164.2	2	82.1		
Within groups	484.4	477	1.0	80.9	0.00
Total	648.6	479			

## Types of leprosy social stigma

In this study, three types of stigma were discovered-the social stigma which leprosy patients suffer because of the presence of the disease and the physical imperfections resulting in disabilities. As Bainson and Borne<sup>28</sup> reported from Nepal: "Some people seem ugly to most observers. A leprosy patient with numerous large nodules on the face or one who has lost all her fingers would hardly be described by most people as beautiful." This makes the leprosy sufferer to lose social status and become progressively isolated from society, family and friends. Frustration with unemployment and crippling deformities finally force him into alcoholism, begging and adaptation of a hostile attitude towards society leading to debilitation. Contrary to the belief in the study area, the leprosy patient becomes hostile to society not because of the cruel way society treats him/her but because some components of multi-drug therapy affect him/her mentally.<sup>23</sup> There was also the *tribal stigma* which most health personnel of the Mbungu leprosarium and Regional Delegation of Public Health in the North West Region have towards the people of Essimbi in Menchum division.<sup>23</sup> The bulk of leprosy in this region comes from Essimbi so much so that health staff associate leprosy with Essimbi people.

Thirdly, in other areas of the North West Region including Essimbi land, people believe that leprosy is caused by ones' enemies or a curse from the ancestors; it is generally believed that lepers are witches and wizards or have some very wicked characters. Anybody associating with lepers including the health personnel is believed to have some supernatural powers that prevent them from having leprosy. This may explain why close relations and sometimes health workers attending to leprosy patients also suffer some stigma. Goffman<sup>2</sup> recognised this phenomenon and called it *courtesy stigma*. The different types of stigmas were not mentioned by any of the survey respondents because it was not specifically raised as such since the aim of the qualitative data was to fine-tune ambiguous structured questions for the survey.

## Marriage and divorce or separation due to leprosy

In this study, 5.1% lepers indicated that their divorce or separation from their spouse was due to leprosy. The patients who reported that they were married were not necessarily with their original spouses. On further re-examination, many debilitated patients admitted that they were previously married and left their first spouses when they were diagnosed with leprosy. Some female patients admitted that they were convinced their first spouse had abandoned them when they did not

attend the discharge ceremony (a festive occasion when treated patients are formally discharged from the colony and given certificates to go and live normal life in society).<sup>23</sup> In neighbouring villages around the leprosarium, cured leprosy patients as well as the deformed discharged inmates make new alliances with other ex-patients. Some leprosy patients even rear children. Leprosy patients marrying non-patients was observed among hospital staff and the local community, but it was not a common occurrence.

## Overall variation of attitudes to leprosy in the three divisions

On positive attitudes to leprosy, it was observed that social stigma to leprosy was very high in Menchum division. Menchum division is a remote area of the North West Region with a high rate of illiteracy and has many other social problems that can contribute to high stigma, for example, poverty and superstition. In this locality, disease causation is always linked to witchcraft and leprosy is believed either to be due to witchcraft or some past bad behaviour. Social stigma in leprosy results from the deformity the disease causes.<sup>23</sup> The high social stigma to leprosy in this environment can affect leprosy elimination. The degree of stigma against leprosy in a given community influences many aspects of leprosy control; some people may conceal their illness, discontinue chemotherapy, and present themselves late for treatment.<sup>28</sup> Misconceptions like leprosy is hereditary<sup>29</sup> or leprosy is due to past bad behaviour<sup>30</sup> can encourage high social stigma.

As Van Brakel<sup>31</sup> argues in his literature review on leprosy and stigma, with conditions like leprosy, HIV/AIDS, epilepsy, schizophrenia, etc., stigma may be worse than the disease. For this reason stigmas are often labelled as *social killers* since the rejection can lead to loss of social networks, loss of work, difficulty in finding marriage partners, divorce, loss of reputation, discrimination and ostracism, etc and ultimately to isolation.<sup>20</sup> All these tally with views expressed by participants in this study.

Because of the high social stigma, many leprosy patients may opt not to attend health facilities since they presence may reveal their condition. This may explain why many people prefer attending health facilities far away from their home in order to remain anonymous- a coping strategy described by Barret<sup>32</sup> for leprosy patients, which can slow down the elimination of the disease.

## Conclusions

A characteristic type of stigma described as

*tribal stigma* associated with the Essimbi people of Menchum division for contributing to the bulk of leprosy in the study area was discovered. Behavioural studies should be carried out in the study area to overcome the socio-cultural aspects of leprosy stigma. Quantification of stigma to assess the elimination struggle is a new research area in public health. Stigma-related factors should be researched into and analysed to develop appropriate health education strategies and define specific messages.

This work is vital to the long-term goal of leprosy elimination, as, until stigma is dealt with, the disease cannot be fully cured. "The fight is not over yet. But it is winnable and leprosy sufferers need not - must not - be shunned... Unless the message reaches every continent, every country, every village, every patient, the disease will prevail in dangerous pockets".<sup>33</sup>

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