

IMPACT OF SOCIO-ECONOMIC REHABILITATION ON LEPROSY STIGMA IN NORTHERN NIGERIA: FINDINGS OF A RETROSPECTIVE STUDY

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ABSTRACT

This study explored the perceptions of people affected by leprosy regarding impact of socio-economic rehabilitation (SER) on stigma-reduction. The study combined a quantitative questionnaire (the P-scale) with semi-structured interviews of 20 individual SER participants, five focus group discussions and 10 key informant interviews. The P-scale results showed four men suffered significant participation restrictions (scores of >12 points) in finding work and in social integration. The narratives of SER participants, focus groups and key informants showed that SER improved self-esteem, financial independence, acquisition of new skills, and access to public institutions. The authors speculate that through the pathway of improvements in economic and living conditions, SER is beginning to influence the process of social interaction, resulting in positive attitudinal change towards SER participants. The subjective opinions of interviewees suggest that improved self-esteem, positive family and community support for SER participants and increasing participation in community activities are indications of stigma-reduction.

INTRODUCTION

Until recently, leprosy affected persons abandoned by their families received lifelong treatment or care in institutions, because for them, the institution was considered a point of no return. They were engaged in different occupations like agriculture, animal husbandry, weaving and tailoring. Such institutional approach was considered as “rehabilitation”. Yet in that system, individuals became totally dependent on the institution for survival (1). With advances in treatment procedures and surgery, institutional-based “rehabilitation” has become outdated.

Through socio-economic rehabilitation (SER), people cured of leprosy are helped to regain their place in the community. Opportunities are developed to help them to find productive employment, to contribute to the economy of their family and live with dignity as useful self-supporting members of the community (1).

For almost a decade now, SER in northern Nigeria has been conceived and implemented primarily to alleviate social and economic problems and not as a stigma-reduction intervention. SER in northern Nigeria is categorised into community and individual interventions. Community interventions include provision of water boreholes and electricity; and construction of markets and schools. Individual interventions include housing projects; scholarship schemes for education; micro-credit loans schemes; and vocational training. In spite of implementation for almost a decade, an impact evaluation of SER on changes in living conditions of SER participants or on stigma-reduction is yet to be conducted. This study is a first step to understanding the impact of SER on stigma-reduction with a view to improving service delivery. The scope of the study is restricted to individual SER interventions only.

The objectives of the study were to i) explore the perceptions of people affected by leprosy to understand adjustments made by SER participants in their experience of stigma; and ii) utilise the statements of SER participants, to evaluate the impact of SER for improving self-esteem, participation in community activities and community support for participants.

Study Area

The study was conducted in five leprosy communities of five northern states of Nigeria, namely Kebbi, Kogi, Niger, Sokoto and Zamfara. The five states have a combined 2005 population of 16 million people. Approximately 5,000 people live in the leprosy communities with about 1,500 (36.3%) of them suffering visible deformities (2). Compared to the average national socio-economic conditions (3, 4), inhabitants of study communities are more likely to be unemployed (>34% vs. 30%), uneducated (56% vs. 73%), more likely to be Muslim (80% vs. 50%), and rural farmers (80% vs. 70%) with a lower household income (GDP per capita US\$ 300 vs. US\$ 1000).

METHOD

The research adopted a combined retrospective-prospective approach and concurrent quantitative and qualitative methods. Only the retrospective phase is described here. Although

concurrent quantitative and qualitative methods were utilised in this study, the qualitative method predominates, as this is the first study exploring the impact of SER on leprosy stigma in the region. The quantitative data were collected to shed light on the context in which qualitative data were collected and to aid interpretation of qualitative findings (5). Five rehabilitation workers (one of whom is affected by leprosy) assisted in the organisation of the research.

Data Collection

Over a two-week period in September 2006, a set of quantitative questionnaire surveys and semi-structured interviews were conducted with 20 randomly selected SER participants. Five focus group discussions and ten key informant interviews were also conducted to complement individual participant interviews. Hausa and Yoruba languages are spoken in the study area. Rehabilitation workers fluent in the two languages conducted the interviews. Rehabilitation workers received a one week training in qualitative interview skills and administration of the P-scale prior to the interviews.

Inclusion criteria required that individual SER participants be: i) adults over 15 years of age; ii) leprosy affected persons, iii) resident in the study area; and iv) beneficiaries of SER. The 20 participants [10 men and 10 women] were drawn from a list of 131 volunteers among 538 SER participants of year 2004 and 2005.

Focus group discussants were required to be: i) family members or neighbours of SER participants, and ii) resident in the study area. To facilitate optimal exchange of ideas and experiences by women, there were separate focus groups for men and women. Three of the five focus groups were women groups. The average group size was seven members.

Key informants were required to be: i) health or development workers, ii) village leaders, iii) religious leaders, iv) teachers, and v) unrelated to SER participants. Key informants comprised eight men and two women. Two key informants were affected by deformities, one by poliomyelitis and the other by leprosy.

Quantitative data

In the absence of a stigma scale, an internationally validated questionnaire called participation scale (or P scale) was used as a proxy measure for stigma. The P Scale is an interview-

based instrument for quantifying perceived participation restriction (psycho-social and economic problems) experienced by people affected by leprosy, disability or other stigmatised conditions. The scale is based on the terminology and structure of the International Classification of Functioning, Disability and Health (ICF), published by the WHO in 2001 (6). The P scale covers eight ICF domains and consists of 18 items with a Likert response scale of 0, 1, 2, 3 or 5. The maximum score is 90. Higher scores signify worsening severity of participation restriction as follows: no significant restriction [0-12], mild [13-22], moderate [23-32], severe restriction [33-52], and extreme restriction [53-90]. It was established that 95% of the general population is likely to score between 0 and 12 on the P scale (7). For the purpose of this evaluation, only scores of >12 indicated significant levels of participation restriction. To use the P scale in the study, it was first translated into Hausa and Yoruba languages and then translated back into English to verify the accuracy of translation of questions on the P scale.

Qualitative data

The semi-structured interview generated narratives of participant experiences of SER and its effect on their living conditions. The interviews covered: a) relationships of participants with family members, b) economic and social interactions, c) access to local services, and d) involvement in community activities.

Focus groups were conducted among family members of SER participants covering the following areas: a) facts about leprosy, b) people's attitude towards leprosy, c) level of independence or integration of SER participants, d) the impact of SER on public attitude toward leprosy.

Key informant interviews covered: a) people's attitude towards leprosy, b) SER interventions implemented in the study area, c) impact of SER on local attitudes or stigma-reduction.

All interviews were recorded for reasons of accuracy, after the consent of the interviewees. The transcription and translation of interview recordings were done by three members of the research team.

Data Analysis

Quantitative data (frequencies of participation restriction) of the 20 SER participants were analysed using SPSS 10.0 software for windows. For analysis of qualitative interviews, a

general inductive approach aided the emergence of research findings from the frequent, dominant or significant themes in the content of the interview transcripts. Qualitative analysis involved repeated reading of the transcripts, to articulate an overall sense of each account, and to identify the pattern in multiple participants' perspectives, as specified in their words. The authors reviewed line, sentence and paragraph segments of interview transcripts with a view to deciding what codes fit the concepts suggested by the data. Codes were constantly compared to identify similarities and general patterns. Themes gradually emerged as a result of becoming intimate with the data, making logical linkages with interview questions, and considering lessons learned from initial review of the literature. They also looked for contradictions to the thread of thought developed from the data and considered what these tensions highlighted. The analysis was structured by the key themes identified from the data and used material from the interviews to support the discussion.

RESULTS

The age range of the 20 individual participants was 18-80 years (mean age, 54 years). Fifty percent of them were women. The majority (16 or 80%) of the sample were married, and illiterate, while 15 of them (or 75%) were Hausa, Moslems with visible deformities. Seventeen persons (or 85%) had participated in single SER interventions i.e. loans or housing only while the remaining 3 persons participated in various combinations of loans, housing, vocational training and adult education.

P-Scale Results

a) Domains of ICF where participants reported experiencing participation restriction

Fourteen (or 70%) of 20 SER participants reported experiencing participation problems in five domains of ICF, with some of the 14 suffering restrictions in more than one domain. The most common reports of participation restriction were in areas related to work, domestic life and interpersonal relations. Nine persons (or 45%) reported restrictions in finding work, ability to work hard and financial contribution to the household. Five persons reported problems in domestic life e.g. assisting friends or relatives with collecting water; and five persons reported having problems with meeting new people.

b) Grades of participation restriction

Only four men out of the 14 persons who reported participation problems had P-Scale grades of >12. Table 1 reveals that their participation restriction is due either to severe deformities or advanced age. P4 had bilateral fixed claws of fingers and toes; P11 was 80 years of age (though without deformity); and P12 was blind with fixed clawing of fingers and toes and ulcers. P16 suffered facial deformity causing self-stigma, difficulty with meeting new people and looking for paid employment. He (P16) therefore relied on self-employment (animal trading) financed through SER loan.

Table 1. Characteristics of individuals with significant grades of participation restriction

| ID.No. | Sex | Age (Yrs) | Occupation | Type of deformity | Grade of restriction |
|---------------|------------|------------------|--------------------------|--|-----------------------------|
| P4 | M | 60 | Farming | Bilateral fixed clawing-fingers & toes | 17 (mild) |
| P11 | M | 80 | Begging | Nil | 17 (mild) |
| P12 | M | 77 | Begging | Blind; Bilateral fixed clawing- fingers and toes; ulcers of feet | 27 (moderate) |
| P16 | M | 60 | Animal trader and Beggar | Collapsed nose; Bilateral absorption of 5 th fingers | 23 (moderate) |

Qualitative Findings

The concepts of dignity, independence, supportive relationships, and social interaction were used as sensitising concepts to set the context and direction for qualitative inquiry. The key themes to emerge from the qualitative data were:

- i) Stigma: knowledge, beliefs and attitudes.
- ii) Overall changes in participants' lives following their experience of SER.
- iii) Impact of SER on participation in life situations.
- iv) Changing community attitude toward SER participants.
- v) Suggestions for improving SER service delivery.

The interview excerpts are referenced in the following manner:

- (P11 Male) indicates a quote is taken from interviewee number 11 who was male.
- (R8-FG3 Female) indicates a quote is taken from respondent 8 in focus group 3 who was female.
- (KI 6 Female) indicates a quote is taken from Key informant 6 who was female.

Stigma: Knowledge, Beliefs and Attitudes

Knowledge and Beliefs about leprosy

Focus groups displayed fairly accurate knowledge of the signs of leprosy, its treatment with modern drugs and the need for referral of suspects to the hospital for treatment. However, their belief regarding the cause of leprosy is flawed as described by respondents:

“What I know about leprosy is that it affects the skin, joints, nerves and eyes. Its’ signs are rashes and nodules on the body...hands and feet can be damaged” (R7-FG4 Female).

“It causes body damage or shows as rashes and nodules, some weep and some don’t. If you see somebody with these signs, you can take him to Amanawa hospital to seek help...there he will get drugs free of charge” (R5-FG4 Female).

“As a child, I can remember noticing a small patch which started expanding. They gave me different traditional remedies...it did not work until I was brought to Zuru settlement...that is how the modern medicines given to me worked and I was cured” (R3-FG3 Female).

“What we know about leprosy is that we are destined by God to have it, and He also made provision for its treatment. Now there is modern medicine that when given to somebody with the disease, with God’s help he will be alright” (R1-FG5 Male).

The erroneous belief that leprosy is caused by God is also held by one key informant. Such beliefs may in part contribute to the misconception that leprosy is incurable and the reported negative public attitudes towards people affected by leprosy.

Attitudes towards leprosy

The most common attitudes revealed by the study are: devaluation, distancing, hatred, rejection by family, exclusion, and labelling. Similar to work by Calcraft, fear was often found to be the root of these negative attitudes e.g. fear of exposure to the disease, fear of being infected, fear of association with a person affected by leprosy (8). These negative attitudes were more prevalent in two (Kogi and Niger) states as highlighted by focus group discussants and key informants below:

“They look down on people affected by leprosy. Even in my father’s family, they did not want to see me. My mother’s people separated themselves from me, so that they will not contract the disease” (KI 3 Female).

“Some people think that if they sit beside a person affected by leprosy, the disease will jump on them. They will not want to sit closer to you. If you stop a vehicle and you enter it, they will withdraw from you” (R6-FG 1 Male).

“You could be discriminated against whether you have disability or not...you could also be discriminated against if you are poor. Some people shun you because they think leprosy is contagious...some others have no real reason for shunning people affected by leprosy” (KI 10 Male).

“They are treated as dirty irritable and repulsive...so people do not want to associate with them” (KI 6 Female).

These negative attitudes were reported to be changing in three states (Kebbi, Sokoto and Zamfara). Focus groups and key informants suggested that public enlightenment, self-care, and drug treatment were necessary for changing public attitudes. A few key descriptions were:

“In time past if you were called “a leper” nobody would want to come close to you except when necessary. Any where you went no one cared about you. But with enlightenment, we are happy people are now interacting with us. We have female children who are being taken into marriage without discrimination any where you go. We now sell food without difficulty” (R3-FG 3 Female).

“To change public attitude, we should take good care of our wounds, wear clean clothes, and bath regularly” (R8-FG1 Male).

“In time past, when leprosy patients were sighted, they were so ill; they did not look good at all...they were looked down upon. But now, God has brought a change to the situation because of the medicines they are now receiving, no one dislikes them anymore...we have become one” (R1-FG3 Female).

Overall changes in the lives of SER participants following SER

The study revealed both positive and negative changes. However, a majority of SER participants (9 males and 9 females) reported that SER resulted in a range of improvements including:

- Personal and family happiness and joy.
- Ability to meet family needs (e.g. freedom eat what they like, support children’s education).
- Ability to sustain or manage a business.
- Acceptance and integration (participation in social functions).
- Improved standard of living.

Typical statements to support improvements are:

“The change it has brought is great. I eat what I like and am doing my business. I also send some things to my relatives” (P2 Female).

“It was from the loans I was able to send my children to school and we eat out of it” (P4 Male).

“Before receiving the loan, I had nothing in my hands [no source of income]. But with that loan I am happy...at least I am getting something to do [trading] now and I have made some profit, thank God” (P7 Female).

“I can see improvement because I have finished re-paying the loan I collected and I am left with two goats as part of my profit. I even used the rest money to go into farming” (P8 Male).

Compared with those who participated in single SER interventions, participants in multiple SER interventions reported more improvements as shown by the following descriptions:

“When my house was in a state of disrepair, the house flooded when it rained. But now, since it was renovated, I am happy and my life was at peace and rest due to the changes. From the loans I received, I am now buying and selling... up till now, am still continuing to trade [sustaining my business]. I am able to meet basic family needs...it has changed my life. Yes, the adult literacy class has helped me to be enlightened. Any time I’m on my way to the class, people around will say ‘Lets see your books’. My status is high...I feel important”(P13 Female – participated in loans, housing renovation and adult literacy).

While a majority of SER participants reported improvements linked to SER, one woman did not have such good news to share. She related how her business had failed because she used part of the loans meant for trading, for family survival and to meet emergencies in the family:

“The issues of life are numerous...everybody knows there are problems. After receiving this loan, there was some progress e.g. attending ceremonies and dressings. But you see I had to travel four times to the village because my father was so ill and has now died...What about my business? Well, it is poor; it has collapsed because of family issues I mentioned” (P17 Female).

Impact of SER on participation in life situations

To assess the impact of SER on participation in life situations, interview questions were structured to cover both personal and social interaction issues. The personal issues covered by interview questions were:

- dignity.
- independence and income generation.
- acquisition of new skills and capabilities.

Social interaction issues covered by the inquiry were:

- location of participant’s house in the community.
- accessibility to local services.
- participation in family and community functions.
- attitude of family and community toward SER participants.

Dignity

For this study, dignity means a sense of self-importance or worth. A majority of participants (17 persons) claimed that SER improved their dignity. Participants felt dignified by: a) acceptance in society, b) ability to meet family needs [e.g. feeding or children's education], c) ability to work like others in society, d) when they stopped begging, and e) being sought after by the community. Descriptions of dignity included:

“It has increased my dignity in every area because I am now able to send my children to school and I am able to work like other women in the society” (P1 Female).

“In fact, it has improved my self worth...before benefiting from the loans, I used to go to people to beg for something [money] but now I no more go to beg, but my neighbours now come to ask me for cooking items like salt, cooking oil etc. because I am selling essential items now and sometimes they buy on credit” (P6 Female).

“Yes it changed my status; there is progress and peace. I don't think about where I will sleep now. I'm comfortable...my room is the only one with a tin roof in our family compound. Yes it has raised my status and I am happy with this renovation” (P12 Male).

Only one lady whose business had collapsed (see section on “overall changes to participants' lives”) said SER had not improved her self-importance. [She appeared shy during the interviews]:

“Well, as for me ...nothing has really changed concerning dignity or status due to the loan” (P17 Female).

Independence and income generation

This study defines independence as ‘not relying on the support [especially financial] of others for survival’. Independence is closely linked to income generation. A majority of participants (7 men and 7 women) claimed they became independent following SER interventions. Data revealed that a) ability to meet family needs, and b) stoppage of begging engendered a sense of independence and improved dignity. A few key statements describing independence were:

“In terms of begging, I thank God and TLM, I don't beg again. I am now giving money to people, I used the loan for farming and from the harvest of farm produce, I eat, sell

and give some to my relatives. I used to lack foodstuffs but now I am eating in plenty” (P3 Male).

“The loan increased my independence. In the past, I had to wait for my husband before I can buy something, but now because of the loan that I use in buying and selling, I can do some things on my own, I don’t have to wait for my husband to do all the things again and it has also brought wealth for enjoyment” (P7 Female).

“I am independent in my trade and family issues as I do them on my own. For example feeding the family, buying dresses, are the signs of self-reliance. I had difficulty doing these things in the past. I no longer wait on others. I just know I am independent. In fact I don’t want to be associated with the word begging anymore. I love to hear people say she has a business” (P16 Female).

The state of independence of SER participants was corroborated by focus groups, who interpreted independence to mean: ability to help family and community members financially; or repair one’s house without financial assistance from neighbours. Typical statements of focus groups were:

“Yes she’s really self-reliant now because the way things are... she is able to assist not just we [her children] or relations, she do assist others out of will and joy since she got loan” (R3-FGD 3 Female).

“Yes she is now trading, she makes profit and she is now useful to neighbours and assists others financially and we are grateful” (R1-FGD 2 Female).

However, while most participants became independent, four persons (2 men and 2 women) were still dependent on others in spite of participation in SER. The two men [who are beggars by profession and beneficiaries of housing renovation] continued to beg, perhaps because housing schemes per se do not translate to financial independence. The women continued to depend on others, because their businesses had collapsed after using their loans to solve family problems.

Acquisition of new skills

This denotes the acquisition of skills and capabilities that help participants to lead productive lives as self-supporting members of the community. A majority of people (8 women and 3 men) reported gaining the following new skills as a result of SER:

- business skills.
- ability to manage money or save money.
- making profit from their trade [income generation].
- ability to balance business and family needs.
- ability to keep the business running.
- diversifying into multiple trades.

Key descriptions of skills gained by SER participants are:

“I am able to handle money. I have improved my trading ability, whatever I buy; I can retail and make profit. We have learnt to save some money. Be informed that [from the profit of my business] I and my son are able to build a house for him and in the process of getting him married. The engagement box is almost complete. As every one meets his family needs, so we do too. We are happy [expressed with obvious tones of joy]” (P13 Female).

“Of course, it increased my skills. This trade is continuing [has not collapsed]. When it [my wares] is finishing I go to market to buy again...I still have the ability to meet some family needs daily. It's like that. I cannot just be spending money uselessly or that will not contribute to the business. As one tries to meet family needs, one should not forget the trade so, as not spend it all. I am able to save some money...and if there are family issues, I will use money from the savings to solve them with peace of mind” (P18 Female).

Four participants whose houses were renovated (all men) reported that though participation in housing schemes had brought great relief, it did not lead to acquisition of skills.

Accessibility to local services

Improved accessibility to local services is an indication of social interaction. A majority of participants (8 women and 5 men) reported increased accessibility to hospitals, schools, places of worship and ceremonies following their participation in micro-credit loans. An unexpected finding was the indigenous perspective that money facilitates access, as described in the words of participants below:

“It has improved my access to places. Where I can't go before, I can now go; you know 'money is the vehicle of interaction'. I am now going to places like church and contribute my own share” (P3 Male).

“Yes I now enter to many places in the community, but in the time past I was not allowed into some places because of lack of money to contribute to the activities” (R5 Male).

“In fact, we do visit market and hospitals. Every where the ‘healthy’ go, we do go too. We have increased access after the loans. At hospitals, whether it is the leprosy clinic or general clinics, if they prescribed drugs we are being given too” (P17 Female).

“Oh yes the loan has helped me to gain entrance to other places, before I had no clothes to wear to any gathering, not to talk of clinics, mosque, but now because of the loan, I can take care of myself and family and even bought clothes to wear to occasions. I thank God for that” (P6 Female).

Three housing beneficiaries reported that housing schemes did not influence access to public places, as shown by this quote from a participant: “Yes, with the loan came wisdom, but access to people and places, well the house renovation raised more of satisfaction [not access] (P20 Male).

Participation in family and community functions

A majority of people (nine women and six men) reported increased participation in family activities as a result of SER. They interpreted increased participation mainly as a financial contribution that facilitates both decision making and solving family problems. The statements of SER participants were often confirmed by focus groups:

“In fact yes, before, I used to be dependent on the children for everything but now even when I have visitors I can easily take care of them without asking my children for help. It has given me opportunity to take up more family issues, for instance when my son’s shop collapsed last year, I took over the care of his family without people really knowing the true family problems” (P20 Female).

“First, the food is much better now. Second, I am more enlightened and the children too. Dressing mode has improved following what I have [profit] after selling my wares. Now, we do go to hospital, the children attend school. Since we now have these privileges...we are uplifted” (P16 Male).

“She has helped the family, husband and even her neighbours. There’s improvement for the family. She does everything for the family” (R3, R4 and R5-FGD 2 Females).

Similar to participation in family functions, most people interpreted increased participation in community functions to mean financial contribution to community development activities; increased opportunity to attend ceremonies; and ability to help community members. However, unlike participants in family functions, most of those who reported increased participation in community functions were men (10 men and 6 women).

Following are the words of SER participants involved in community activities and confirming statements of focus groups:

“Yes, initially I could not contribute to community development, but now I am involved in the community development, where it involves contributing money, I will contribute my own share of the money” (P3 Male).

“Yes, if somebody has a ceremony, we have a women’s group that I belong to... we are invited, and we’ll get set and attend and participate in the activity” (P10 Female).

“In time past, he was an object of pity. But now through the loans, he is able to support us in the community. Look at me, I am not deformed but when I’m in lack [financially], I will call on him, and borrow about N200 till I’m blessed to repay... is that not a benefit to us all? He got help and God has blessed it” (R4-FG 5 Male).

Changing community attitudes toward SER participants

Attitude refers to how the family and community deal with, react to or regard SER participants. A majority of SER participants reported improved family (9 men and 6 women) and community (8 men and 5 women) attitude. Improvements in attitude were classified as honour, respect, dignity, recognition, reduced verbal abuse, inclusion in activities and increased access to information. Typical descriptions of changing attitudes were:

“Before they will separate my plate, but now we are eating together. Since I don’t have to beg from them [any longer], they are now recognising me as a member of the family” (P3 Male).

“Yes I am now treated well and with respect because I have something doing or I have my trade that I am doing which brings income. Before this intervention I do not travel home because I will not be welcome” (P5 Male).

“In fact the way I am treated by the community has changed, before people don’t allow me in their houses... not because of leprosy but because I had nothing to offer [contribute to the community]. But now that I am trading and I don’t go to beg again, so they now come to me and I am treated with respect” (P6 Female).

The changing community attitude was confirmed by focus groups and key informants:

“Through the SER programme...they have stopped begging...every one [of them] has started farming. Though some can’t work the farms themselves because of their disability, but they are able to hire other people to work for them from the loan they receive from TLM. These have caused people to interact with them more” (KI 6 Female).

“In my opinion, no other intervention has reduced discrimination like giving people something [loans] to trade with. As many people are aware...if someone is poor, and is ill and unable to do anything [no livelihood] to care for himself...then people may run away from him. But if he has money that he can do something [livelihood]...whether he has a disease or not, people would interact with or approach him as long as he is not dirty or clumsy. Lacking [deprivation] can be responsible for being disliked” (KI 9 Male).

“It has reduced stigma. The medicines they have received, together with houses they live in and the money to eat now make their bodies look fresh. The interventions have attracted people to be living with them...in time past people usually avoid them” (KI 2 Male).

It is clear from these statements that triggers for positive community attitudes are a source of income, improved self-care and drug treatment. This affirms the response of focus groups that self-care, and drug treatment were necessary for changing public attitudes (see section on knowledge and attitudes).

Suggestions for improving SER service

Five recommendations were advanced by SER participants, focus groups and key informants for improving SER.

1. Increase amount and frequency of loans

Generally, SER participants perceived improvements in SER to mean more loans, so a majority of them (16/20) suggested increasing the amount or frequency of loans. Reasons advanced by SER participants, focus groups and key informants for recommending loan increases were:

- i) increasing the capital base for starting a business or sustaining/expanding present trades.
- ii) increasing farm yields.
- iii) enhancing participants' ability to render more assistance to relatives.
- iv) enhancing interaction in the community.

“Those you give N20,000 could be given N50,000 to trade because the cost of living now is expensive. Starting a trade with a small capital will not give good profit and help us to solve family problems...we will need a bigger capital” (KI 10 Male).

“While we enjoyed the previous loans, but more loans will increase our recognition and interaction with people...so that when they talk, we can talk too...we can be like other people. You know a little more money like N20,000 or N30,000 will uplift us. Yes, I am grateful for your coming and care” (P10 Female).

“Yes we have even started asking the SER workers to give us more loan so that we can continue with our business [are unsustainable without more loans]. We will like if the loan could also be increased to between N20,000 to N30,000 that will even help me to expand my trade” (P9 Female).

2. Involve Village Heads in loan repayment

“The advice I will give is...see that you involve the village heads and district heads [to help you supervise loan repayments], because community leaders are closer to people affected by leprosy and they know them better” (KI 5 male).

3. Advocate for collaboration with governments and general public

“We should meet with local government authorities periodically to make them aware of what assistance to render to the people...this will make “the local authority” increase their care to this group of people” (KI 9 male).

“Expand your services to include more beneficiaries...this will challenge the public and state governments to start doing something too. Yes, the government and general public have important roles to play towards the less privileged or destitute suffering from leprosy” (KI 9 male).

4. Include people with general disability in SER

“If possible, other disability groups should be included in your SER programme. By this gradually it [SER] could become a natural programme [for everyone in need]” (KI 10 male).

5. Continue drug treatment alongside SER; it facilitates acceptance and interaction

“They should supply more drugs to people with active leprosy, so that the disease will not affect their children. Before medicines were available we could not eat with them but now we can eat together” (KI 1 male).

DISCUSSION

There were two points of convergence in the findings of the P-scale and the qualitative inquiry. First, the P-Scale and semi-structured interviews agree that majority of SER participants did not suffer significant participation restriction in the domains of self-care, communication, and community life. Second, three of the four men adjudged by the P-scale as suffering significant participation restrictions were confirmed by the qualitative inquiry to have problems with financial independence and social integration. It is understandable that the advanced age of participants P11 and P12 (80 and 77 years respectively), and the deformity status of P12 (blindness with severe clawing of hands and feet) causes them to be dependent on others for their survival. The self-stigma of the third man (P16) due to his facial deformity, affects his ability to interact with people including during his trade. He too continues to beg, in spite of the fact that he is a trader.

There was one point of departure between the P-Scale and semi-structured interviews. Whereas the cross-sectional data generated by the P-Scale showed that nine SER participants suffered significant restrictions in finding employment, working hard and contributing financially to family life; the qualitative interviews provided additional information to show that SER

facilitated self-employment for 17 of the 20 participants who received loans. Through self-employment in trading and farming, loan participants contributed financially to their family/community and enjoyed blossoming interpersonal relations.

In analysing the qualitative data, the statements of SER participants were used as evidence for drawing conclusions regarding the impact of SER on stigma-reduction. When statements from focus groups and key informants elicited the same evidence as SER participants, a conclusion was drawn regarding the effect(s) of SER on a given domain of life. Four of such inferences are presented.

1. The people's knowledge regarding signs of leprosy, its treatment and referral of suspected cases to hospital was adequate, while their belief about the cause of leprosy was wrong. The finding from focus groups that the practice of segregation is being replaced by acceptance and social integration, is confirmed by SER participants in the paragraphs that follow.
2. While the accounts of interviewees highlighted many positive effects of the SER programme such as happiness, improved self-esteem, financial independence, acquisition of new skills and improved access to public institutions, and social integration, they also expressed concerns about: i) inadequacy of loans provided by the programme; ii) a tendency for using loans for family survival when things go wrong; and iii) the relative ease of sliding back into poverty after participants have repaid loans. Most of the positive effects associated with SER were reported by participants in micro-credit loans, adult literacy and vocational training. Participants claimed housing schemes did not influence financial independence, skills acquisition or accessibility to public institutions.
3. The subjective opinions of SER participants and their communities suggest that the SER programme seems to have initiated change processes in the norms and values of social interaction of the study population. Positive attitudinal change towards SER participants is a possible indicator of changes in social interaction. A significant finding was the widespread association of financial contribution with improved social interaction. This association in part clarifies the perceptions that SER has influenced stigma-reduction in their communities. While the authors suspected financial contribution could influence a person's status in families, they were unaware of its central role in everyday interaction in the world view of the people.

4. The association of financial contribution with social interaction may also explain why a majority of interviewees favour increasing the amount and/or frequency of the loans. While there is merit in recommending an upward review of the micro-credit loans, caution should be exercised in granting repeated cycles of micro-credit loans to avoid dependency on the SER programme. An alternative solution would be increasing the finite amount of loans and the loan repayment period.

CONCLUSION

This study has shed some light on the question of the impact of SER on stigma-reduction in northern Nigeria. Although the findings highlighted some concerns, there is sufficient evidence in the narratives of service-users, families and community members to show that SER resulted in happiness, improved self-esteem, and skills acquisition, and financial independence for most SER participants. It is speculated that through the pathway of improvements in economic and living conditions, SER is beginning to influence social interaction in the study population, resulting in positive attitudinal change towards SER participants. From the perspectives of the people, improved self-esteem, positive family and community support for SER participants and increasing inclusion in community activities are indications of stigma-reduction. This conclusion supports evidence from Ethiopia, that small loans schemes facilitate improvements in living standards of participants and positive attitudinal changes in communities (9). Furthermore, the speculation that SER enhances stigma-reduction affirms the work of Heijnders from Nepal, that leprosy stigma does not have to be permanent (10). The findings of this study in northern Nigeria will form a basis for tracking further changes resulting from programme interventions and for improving service delivery in the region.

Limitations

The findings of this study are limited in three main ways. First, generalisability of results may be limited, as the study's five communities were not selected to be nationally representative. Nevertheless, apart from under-representing Christians in the sample, socio-demographic and economic characteristics of these communities are similar to other communities affected by leprosy in Nigeria. In spite of cultural diversity of the study region, there were remarkable similarities in the experiences of participants to SER and the community's response to SER participants. Thus, the findings from these five multi-

lingual and multi-cultural communities should still stimulate interest in understanding the impact of SER on stigma within the country.

Second, the reliance of the study on the participants' memory to generate research data is a limitation because pre-SER information had not been collected when participants entered the programme. Participant selection was thus limited to SER participants of 2004 and 2005 to optimise participants' recall. While the memories of 2005 SER participants (12/20) who repaid their loans in 2006 is speculated to be fairly recent, future research will collect pre and post SER information to aid evaluation of the effects of SER on leprosy stigma.

Third, the cross-sectional nature of the study suggests that interpretation of the results of the data is limited to association and not causation as other circumstances [not discussed in this paper] could contribute to attitudinal changes in the study population. While this cross-sectional study renders it difficult to disentangle association from causation, follow-up data in future studies will provide a prospective dataset more conducive to making causal inferences. The prospective study design will compare changes in SER participants with non-SER participants.

These limitations notwithstanding, this study provides a base on which future investigations on the effect of SER on leprosy stigma in the Nigerian context can be built.

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