Stigmatisation and discrimination: Experiences of people affected by leprosy in Southern Ghana

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Summary

Introduction: Leprosy, a chronic infectious disease, poses a serious public health concern due to its impact on the wellbeing of affected people. This study, which was set in Ghana, explored stigmatisation and discrimination experiences of people affected by leprosy resident at the Weija Leprosarium in Accra.

Methodology: Using a qualitative research methodology, 26 participants were purposively selected and in-depth interviews conducted. The interviews were audio-recorded, transcribed, and categorised based on the objectives of the study.

Findings: The findings revealed that participants experienced stigma and discrimination from their families, friends, healthcare providers and community members. Evidence showed that whereas some participants anticipated stigma and discrimination from prospective employers, others internalised the negative beliefs associated with the disease and gave up searching for jobs. Moreover, the findings indicated that participants were not willing to reintegrate into their communities since they considered the Leprosarium a safe haven.

Conclusion: Based on the findings of the study, we conclude that people affected by leprosy included in this study experienced stigmatisation and discrimination. We therefore suggest that efforts aimed at reducing and in the long run curing the stigma of leprosy must be contextualised and scaled up. Also, implications are discussed for social work and public health practices.

Introduction

Leprosy, also known as Hansen’s disease, is a chronic infectious disease caused by Mycobacterium leprae. It is a serious public health concern due to the fact that permanent impairments can develop if interventions are not provided on time or are not implemented correctly.1 Although with regular care, the worsening of existing impairments and the appearance of new physical impairments due to leprosy can be prevented, the Innovative Care for Chronic Conditions (ICCC) programme promoted by the World Health Organization...
(WHO) observes that adherence to long-term treatments among people with chronic conditions, such as leprosy, is extremely low.\textsuperscript{2,3} The impact of leprosy on the wellbeing of those affected is so profound that the World Health Organization formulated three cardinal management strategies to curtail its incidence and lasting effects.\textsuperscript{4} The leprosy management strategies included (a) interrupting the transmission of the disease, (b) prompt treatment of patients and (c) preventing the development of deformities.\textsuperscript{1}

Also, the WHO classifies leprosy-related impairment into three grades: Grade 0 - no impairment, Grade 1 - loss of sensation in the hand or foot and Grade 2 - visible impairment.\textsuperscript{5,6} Even though with advancement in medical care and improved socioeconomic conditions in developed countries, the incidence of leprosy has reduced drastically, in developing countries, including Ghana, it continues unabated.\textsuperscript{1,7} The effects of leprosy linger on for an indefinite period due to the residual permanent and progressive physical impairments caused by the disease.\textsuperscript{1,8} As a result, the management of the condition requires lifestyle changes because the burden of the disease consists mainly of impairments of the feet and hands.\textsuperscript{3,5,9–11} These conditions could have major impacts on the social, economic and psychological wellbeing of affected people in view of the fact that leprosy is uniquely stigmatised.\textsuperscript{10,12,13} Consequently, it has long been seen as the epitome of stigmatisation and has become an allegory for humiliation since it has an extremely negative image.\textsuperscript{14,15}

The negative effects of stigmatisation and discrimination on people affected by leprosy may be so intense that it could prevent them from seeking treatment. Compounding the situation is the fact that some health providers do not often have appropriate attitudes or the sensitivity to assist those affected by leprosy.\textsuperscript{16} In a study on knowledge and attitudes towards leprosy disease among healthcare workers in Guyana, Briden and Maguire found that many healthcare workers were afraid of leprosy, and believed the disease was contagious and incurable.\textsuperscript{16} In addition, Scott reported that some doctors refused to treat people affected by leprosy in India.\textsuperscript{17} Moreover, due to stigma and discrimination, many people affected by leprosy may find it difficult to (a) involve themselves fully in society, (b) participate in educational activities, (c) engage in income-generation and employment ventures, and (d) exercise their civil and political rights.\textsuperscript{5,15}

The quality of life of people affected by leprosy may become compromised due to impairments, which could hamper their daily functioning in productive activities, and participation restrictions,\textsuperscript{10,15,17} thereby leading to social and economic losses. As argued by Harris, stigma remains an existent problem for people affected by the illness and a key challenge for implementation of effective and efficient public health interventions.\textsuperscript{14} Similar to other countries, people affected by leprosy are stigmatised and discriminated against in Ghana due to concerns about the risks posed to the wider community by the presence of their leprosy-related impairments. This is mainly attributable to (a) the limited availability of resources in developing countries and (b) the socio-economic impact resulting from the physical and psychological impairments of leprosy.\textsuperscript{1,13}

**Theoretical Underpinnings**

The definition and understanding of stigma has varied greatly over the centuries.\textsuperscript{18} However, both classical and contemporary explanations of disease stigma owe much to Goffman.\textsuperscript{19} In his landmark work on management of spoiled identity, Goffman asserted that people who possess a characteristic defined as socially undesirable (leprosy in this context) acquire a spoiled identity which then results in social devaluation and discrimination.\textsuperscript{20} While the
concept of stigma is ubiquitous in leprosy literature, it is not always apparent how the term is used given the number and diversity of theories of stigma. What many of these theories have in common is an inherent strain between the individual and the collective; while psychological models focus more on individual experience, sociological models tend to focus more on how stigma is used as a mechanism of social control.

Stigma has a serious effect on the incidence, experience, and management of life-threatening medical conditions, which in turn aggravate the effects of these diseases. Consequently, blame has derisively been placed on many people affected by chronic infectious diseases, such as leprosy. The blaming model of stigma suggests that negative meanings are linked with infectious diseases (e.g., leprosy), as well as people who become infected, in order to allay anxiety about the risk of infection. Stigma has an important impact on the wellbeing of many people affected by leprosy for the reason that it relies heavily on existing prejudices and social stereotypes. Nevertheless, it does not always have to result in discrimination to have a negative impact, as people may internalise stigma or anticipate being stigmatised or discriminated against and, as a result, may not avail themselves for treatment. Even though discrimination can result from stigma, it could also stem from fear of infection or resource concerns. Additionally, Earnshaw and Chaudoir argue that discrimination is one of the means through which stigma is manifested and refer to discriminatory behaviours perpetuated by non-stigmatised people toward people who are stigmatised.

People who belong to marginalised groups possess a position of subordination in society based on the knowledge that their status is socially devalued and therefore may experience negative treatment from people. This knowledge is experienced through, at least, three stigma routes: enacted, anticipated and internalised. Enacted stigma is when stigmatised people believe they have in reality experienced prejudice and discrimination from people. Anticipated stigma is the extent to which individuals expect that others will stigmatise them if their identity becomes known. Internalised stigma refers to the degree to which people who are stigmatised endorse the negative opinions and feelings linked with their status. Besides, stigma is not a single phenomenon, but consists of numerous possible facets; it may be conceptualised in terms of self-stigma (e.g., shame and lowered self-esteem) or public stigma (e.g., general public’s prejudice) that is also linked with social participation limitations and discrimination.

The relationship between disease stigma and other forms of prejudice has been referred to as multiple stigmatisations to reflect a trend in racism and gender studies in which it is argued that various kinds of prejudice intertwine. Disease stigmatisation, however, operates in a slightly different way since this type of stigma associates diseases with negative meanings by suggesting that an already-defined out-group (e.g., people affected by leprosy) are in some way responsible for the disease because of certain negatively valued traits or behaviours, rather than representing all people with a particular disease in the same way. Furthermore, Fife and Wright contend that the particular nature of stigma that is connected with serious illnesses depends on three features: (a) blaming the individual for the illness, (b) threat to the illness represents to others and (c) threat it poses to individual competence. These features are linked to the conventional concept of stigma as an individual attribute, which marks the difference between the stigmatised person and those regarded as normal in a particular environment.

Moreover, emotions, thoughts, behaviours and relationships have been identified as four key domains in which stigma impacts the lives of people affected by diseases, such as
leprosy. These domains are interrelated and exhibit themselves in diverse ways at different moments, degrees and contexts. The emotions domain consists of feelings (e.g. fear, grief, depression, shame, guilt, anxiety, low self-esteem, or inability to express such feelings). Negative and pessimistic thoughts and beliefs about self and the world, reflect the thoughts domain. As part of the behaviour domain, are emotions and thoughts that influence the way people act and react, and could lead to lack of confidence, avoidance, severance from social life, and self-isolation. Since social support networks and the attitudes of people in the network play a vital role in the experience of stigma, the depressing conditions of rejection, forced isolation and restricted social participation could negatively affect the individual and this describes the relationships domain. These theoretical perspectives are useful for this study, especially the sociological perspectives which guided analysis of the data. These perspectives provided explanations regarding why people affected by leprosy remain ensnared in disease-related stigma and discrimination. Drawing on these theoretical viewpoints, the researchers explored the roots and routes of stigma and discrimination from the perspectives of people affected by leprosy.

LEPROSY WORK IN GHANA

There has been tremendous progress in leprosy control in Ghana since the 1940’s. In 1948, there were over 40,000 registered cases in the country and this figure has reduced over the years. Ghana is among the medium burden countries with low risk of infection and has therefore reached the target for elimination, below 1 case per 10,000 population. This success has been achieved through the efforts of the Government, non-governmental organisations and officials of the Ghana Health Service. While in 2011, a total of 794 new cases were detected nationwide and the number of registered cases was 568, in 2014, registered cases were 345 and a total of 366 new cases were detected. The new cases reported in 2014 included seven children, which is a sign of active and recent transmission. In 2014, a total of 430 patients completed treatment and this brought the total cumulative number of patients who completed Multi Drug Therapy (MDT) to 43,435 since the introduction of MDT in the early 1980s. Management of complications of leprosy as early as they arise was done in districts where they had cases, and leprosy reactions were referred to health facilities for appropriate treatment. In endemic districts, leprosy days are organised to change the image of leprosy and ensure that those who are diagnosed complete their treatment. Also, the Leprosy Elimination Programme is promoting public awareness about the disease in communities, intensifying case searches in high prevalence areas, providing MDT services to all health facilities and ensuring that all existing and new cases are given appropriate MDT.

Even though Ghana has reached the elimination stage in the fight against leprosy, there are some districts (Akyemansa, Ho, Kpando, Lawra, and Tatale Sangule) in the country, which continue to report cases of leprosy every year. Furthermore, about 25% of leprosy patients in developing countries, including Ghana have some form of disability, which may affect their engagement in physical and socioeconomic activities, as well as predisposing them to an altered role in society. Stigma and discrimination against people with leprosy-related impairments cannot therefore be overlooked. In addition, although leprosy treatment is free on an out-patient basis and does not require isolation of patients, many people affected by leprosy in Ghana, especially the elderly, are confined in institutions.
Moreover, as previous studies on people affected by leprosy in Ghana\textsuperscript{1,7} have employed quantitative research methods, there is paucity of studies that capture the voices of people themselves on the nature and types of problems they face, as well as their needs. This study therefore aimed to explore (a) affected people’s perceptions about stigmatisation and discrimination, (b) stigmatising and discriminatory factors that serve as barriers to accessing health care and employment opportunities by people affected by leprosy and (c) stigmatising and discriminatory factors that affect the reintegration of people affected by leprosy into their respective communities.

This study is vital because people may refuse or delay accessing leprosy-related treatment and care due to stigmatising and discriminatory attitudes towards people affected by leprosy. Most often, some individuals may openly or secretly stigmatise and discriminate against people affected by leprosy in areas, such as access to health care, employment and social interaction, among many others. Information from this study would be useful to social workers, public health professionals, and policy actors in designing interventions that would help reduce the stigma and discrimination experienced by people affected by leprosy. This could help improve their wellbeing and aid their transition from confined institutional life to normal communal living.

**Methodology**

**RESEARCH DESIGN**

A qualitative research design was utilised for this study in view of the fact that it allowed the researchers to tackle sensitive issues and also understand the experiences of study participants.\textsuperscript{47,48} This approach was useful as participants in the study were allowed to share their perceptions and experiences regarding stigmatisation and discrimination. Thus, employing a qualitative research paradigm, it was possible for the researchers to obtain information about the values, opinions, behaviours, and social contexts of people affected by leprosy.

**PARTICIPANTS AND STUDY AREA**

The participants were people affected by leprosy resident at the Weija Leprosarium in the Greater Accra Region of Ghana, who were 18 years old and above. A total of 26 people affected by leprosy (10 females and 16 males) were purposively recruited for the study. The researchers initially contacted the manager at the Weija Leprosarium and sought permission to visit those affected. They were subsequently invited by the manager to visit the Leprosarium in order to interact and build rapport with them. Following an information sharing session by the researchers, people affected by leprosy who were willing to participate in the study provided their contact details. Appointments were then scheduled for the in-depth interviews (IDIs) with participants at their convenience.

The Weija Leprosarium is located in Accra, the capital city of Ghana. Over the years, the Weija community has become an urban settlement since it has seen an increase in population and has transformed into a lively, active community. The Leprosarium has many amenities, including a clinic, offices for workers, apartments for people affected by leprosy and their families and a community centre. It has nurses who take care of the people affected by leprosy...
and it is currently the largest among the other Leprosaria located across the country: Ankaful, Ho, Nkanchina, Kokofu, Anindado and Ahontokrom.

DATA COLLECTION AND ANALYSIS PROCEDURES

The study was approved by the Ethics Committee for the Humanities (ECH) at the University of Ghana and was conducted from December, 2014 to May, 2015. Data were collected through individual in-depth interviews using open-ended questions. The IDIs were used to explore the various ways participants dealt with stigma and discrimination in their daily lives and thus provided them the opportunity to speak privately with the researchers. Besides, the open-ended questions allowed participants to express themselves freely, permitted the researchers to probe participants’ responses for clarification and enabled the researchers and participants to discuss emerging issues in greater detail.29

The purpose of the study was explained to each participant before the data collection began and they were individually informed of their right to withdraw their participation at any point in time during the study. Participation in the study was voluntary and potential participants were assured of confidentiality regarding the information they provided. Verbal consent was sought from each participant and this was followed by a written informed consent. Participants completed a short demographic questionnaire prior to commencement of the interviews. The interviews were conducted in English and Ghanaian languages (Hausa, Twi and Ga). The language used for each participant was based on his/her preference. The researchers and research assistants spoke these Ghanaian languages.

Each interview was facilitated by a researcher and a research assistant who took notes. On average, an interview lasted between 45 and 60 minutes and all took place at the Leprosarium. An interview guide, based on the objectives of the study, was developed by the researchers and used for the data collection. The interview guide was first created in English and then translated into the three Ghanaian languages used for the interviews. With participants’ permission, the IDIs were audio-recorded. Questions asked included “Have you ever felt you were treated unfairly because of the disease?”, “How do you take care of your basic needs?”, “Do you experience challenges when accessing healthcare?” and “Do you have any plans of moving out of this Leprosarium?”

Subsequent to the data collection, the audio recorder was replayed several times for the purpose of transcribing the data. The interviews conducted in Ghanaian languages were translated into English and some quotes were edited grammatically, but the researchers ensured that the content was preserved. The data were coded in order to conceal the identities of participants and were stored in a secure location. All three researchers individually extracted and coded broad themes from the text. The themes considered statements of meaning that were present in most of the data. In order to ensure credibility of the findings, sets of codes and themes independently developed were interpreted and discussed, until a consensus was reached by the researchers. Emerging themes and categories were used to address the objectives of the study. The transcriptions were augmented with the research assistants’ field notes taken during data collection.

FINDINGS

This section presents the findings of the study. In addition to the demographic characteristics of the participants, the findings are presented under the following themes: (a) the link between
lack of knowledge/myths about leprosy and stigma, (b) affected people’s access to health services, (c) affected people’s access to employment, and (d) affected people’s contentment with the Leprosarium.

Demographic Characteristics of Participants

The participants (10 females and 16 males) were aged between 40 and 90 years with the majority of them being Muslims (14). The rest were Christians (nine), traditionalists (two) and other religion (one). The highest educational background of participants was post-secondary (one), senior high (one), junior high (two), primary (five), and no formal education (17). With regard to employment, 25 participants were unemployed while one was employed. In terms of marital status, 13 participants were married, eight never married, three divorced and two widowed. The number of children participants had was as follows: 14 (1–4), six (5–8) and six had none.

The number of years participants had lived with the disease were as follows: one (1–10), two (11–20), four (21–30), five (31–40), five (41–50), seven (51–60) and two (61–70). Thirteen participants were from Ghana, 10 from Nigeria, two from Benin and one from Burkina Faso. The ethnic background of participants was diverse: Hausa (10), Akan (six), Ga Adamgbe (two), Ewe (two), Dagomba (one), and other (five). The fact that the educational background of the majority of participants is low is not surprising because they had to drop out of school due to the negative beliefs associated with the disease. Also, given that many of the participants were elderly, finding jobs could be difficult.

Link between Lack of Knowledge/Myths about Leprosy and Stigma

The people affected by leprosy had knowledge of stigma and discrimination (enacted, internalised and anticipated). Many of them experienced stigma and discrimination through interactions with people. They indicated that several people, including their families, friends and members of their communities, neglected them since they did not believe they had been cured of the disease:

Many people, including my family members do not believe I am cured because of the deformities, especially the sores on my leg . . . people stigmatise and discriminate against people with disability . . . because of the disease, my wife divorced me and left with our children . . . I do not have contact with them. (Male with visible impairments)

According to a male participant who had visible impairments, he contemplated suicide because he was stigmatised and discriminated against by his family and friends. He indicated that he was neglected by his family due to the disease:
After I moved to the Leprosarium, sometimes I felt like killing myself because of this sickness. My family members did not believe I was cured. There were other family members who had one sickness or another, but they were treated well because their sickness was not leprosy. My family did not care about me, even getting a place to live and food to eat was a problem. I became very sad, bad thoughts came to my mind and I felt like ending my life. Luckily, someone directed me to this Leprosarium.

Illustrating self-stigma, a male participant with visible impairments indicated that although he had been neglected by his family, he felt it was not necessary to complain:

My own half-sister lives in Accra, her father is a rich man who owns houses, my sister and her father have never visited me at the Leprosarium, they always attend a church that is very close to this Leprosarium, but they have never stepped in here to visit me. I don’t hold any grudge against them because I would have done the same if I was in their shoes.

Other participants described how their status as sick people or people affected by leprosy, influenced how people related to them. They believed people did not understand their condition and as a result, did not treat them well as a female participant with visible impairments phrased it:

People need to be considerate; we are all humans. I tell my friends at the Leprosarium to be patient. We can’t change those who relate to us badly. They think we are not completely cured because of our deformities. They run away from us as if we are not human beings. I do not go anywhere, I am always here, why should I go to town or my country if people think I am sick or treat me as a sick person? My family members don’t know where I am now; I did not tell anyone when I was leaving my country. Even my mother is not aware that I am currently in Ghana.

A male participant who did not have much visible impairments provided a very good example of self-stigma:

When I tell people that I live at the Leprosarium, they do not believe it. Since I do not have much visible impairment, people tell me not to associate myself with the evil and contagious disease. Always ask, why would I marry a person with leprosy if I do not have the sickness myself? It is because I am sick that is why I am married to a sick person. People are afraid of this disease so we have to marry ourselves. If I did not have the condition, I would not have married her. We are married because we are both affected by leprosy.
Access to Health Services

Given their residual deformities and disabilities, people affected by leprosy are likely to interact with healthcare providers more often. Hence, factors that served as barriers to accessing health care facilities by participants were explored. At the time of the data collection, all participants had been enrolled on the National Health Insurance Scheme (NHIS) and had valid NHIS cards. It is important to emphasise that the NHIS does not cover some health conditions and medications.

Generally, the people affected by leprosy accessed health services at the Weija Leprosarium clinic, and a nearby Municipal Hospital. However, participants indicated that they encountered some challenges when they accessed health services outside the Leprosarium clinic and the Municipal Hospital. They had difficulties paying their medical bills, as well as being stigmatised and discriminated against by healthcare providers in outside health facilities. They emphasised, however, that the Chairman of the Lepers Aid Committee, a Roman Catholic Father, had been very supportive. A female participant with visible impairments remarked:

All of us have NHIS cards, but there were times we were referred to the Korle-Bu referral hospital, and because the NHIS did not cover all expenses . . . we were only able to pay our bills with the support of benefactors, especially Father . . . this delayed treatment, particularly, if we were unable to receive financial assistance on time . . . the situation worsened during periods that Father had travelled out of the country.

It was found that some people affected by leprosy who felt they could not afford their medical bills refused to access services when they were referred to larger health facilities. They resorted to herbal or non-prescription medicines:

Anytime we were sick, we first attended the clinic at the Leprosarium, but if the disease could not be treated there, we were referred to Korle-Bu Hospital or the 37 Military Hospital. I had asthma and was referred to Korle-Bu. After consultation, I was asked by the doctor to buy my medication from the Hospital’s pharmacy shop. I did not have money so the Leprosarium nurse who accompanied me to the hospital arranged for money and I was able to buy the medicines. Later, a lady gave me herbal medicine, which I took and now I feel better . . . I will not attend the big hospitals again when I am sick. (Male without visible impairments).

Anytime we were referred to Korle-Bu, we felt uncomfortable because we would be asked to buy our medication . . . with our condition, we cannot work and therefore cannot afford to buy medicines. We feel more comfortable with the doctors and nurses at the Leprosarium’s health facility, where services are free. If we fall sick and the health professionals here refer us to other hospitals, we would rather find money to buy non-prescribed medicines from pharmacy shops. (Female with visible impairments).

Besides the financial challenges, some participants reported of instances when they were treated unfairly by healthcare staff at hospitals outside the Leprosarium. Speaking about the negative attitudes of these health providers, a male participant without visible impairments had this to say:

When we go to the big hospitals, it is very difficult for us because many doctors and nurses there are scared of the sickness, they don’t believe we are fully cured because of our deformities . . . we expect them to understand our condition because they are
doctors and nurses like those at the Leprosarium, but when we go to these hospitals, they
do not want to attend to us . . . we would wait for a very long time before they even talk
to us. Sometimes we call on some influential people to intervene.

Also, some participants explained that they would not have been attended to by healthcare
providers outside the Leprosarium had it not been the intervention of an official at the
Leprosarium:

. . . there were times some doctors and nurses refused to attend to us; when I was sent to
another hospital by our nurse here, we sat there for a very long time and nobody was
willing to attend to us. The nurse who sent me to the hospital had to call our Manager at
the Leprosarium who had discussions with them before they agreed to attend to me . . .
because some influential people have spoken to the health providers on our behalf, their
relationship with us is getting better, it used to be very bad some years back. (Female,
with visible impairments).

Access to Employment

For people affected by leprosy in our study, finding jobs was a challenge due to the negative
perceptions and beliefs people had about the disease, as well as their deformities. For their
daily upkeep, they relied on the Livelihood Empowerment Against Poverty (LEAP) cash
transfer received from the government and support (cash, food, clothing and toiletries)
received from benefactors (individuals and groups). While they were discouraged by officials
at the Leprosarium from begging on the streets, some people affected by leprosy engaged in
this activity to support themselves financially since the various forms of assistance they
received were inadequate. Some of the participants indicated that prospective employers
were unwilling to employ them because of the disease and therefore they resorted to begging
in order to earn some money:

. . . I will not ask anybody for a job because employers are not willing to hire us . . . they
think we cannot work. I can make pastries and bake bread, but people will not buy from
me because they think I am sick. I beg for money although we have been told to stop
begging, we still do it as the money from the government is not enough. I go out three or
four days a week to beg for money. It is luck; sometimes you get enough money and other
times you don’t. I appreciate the money people give me: I have not argued with anyone
to complain about the amount they gave. (Female, with visible impairments).

The money we receive from government is not sufficient. This is a big problem because
I do not have anybody to support me financially . . . If I wake up in the morning and
I have no money on me, I borrow one Cedi to pay for my lorry fare to Lapaz or Nyamekye
(communities near the Leprosarium) to beg for alms for two or three hours and I get
some money . . . (Male, with visible impairments).

One participant, who was promised a job while begging for money on the street, shared his
experience:

A man saw me on the street begging for money and he asked if I could work . . . I replied
that if he had a job for me, I had the strength to do it. He promised to offer me a job but I did
not see him again. Potential employers are often reluctant to offer us jobs because of the
disease. Even though we are cured, they think the disease is contagious . . . they employ other people even if we can do the job better. (Male, without visible impairments).

This participant highlighted how the physical limitations of the disease had an impact on employment:

*I do not think anyone will employ a person with leprosy related impairments so for me, I will not even look for a job because of my visible impairments. If people who are healthy do not have jobs, how much more those of us who are not healthy? We made efforts to look for jobs, but we were advised not to waste our time. Let us assume you were offered a job and you do not have fingers and toes, how can you work?* (Female, with visible impairments).

A male participant who previously had a job, but had to quit due to health challenges explained:

*I used to sell newspapers on the streets of Accra. I stopped this job due to my poor eyesight, I could be knocked down by a vehicle . . . I stayed at home without a job and after a while, I started a small business, which did not last for long. Even if I am offered a job now, I cannot do it because my legs are weak.*

For another participant, his challenge regarding employment was two-fold; lack of formal education and sickness:

*The world is a difficult place for us . . . even people who have graduated from school are unable to find jobs . . . a person like me without formal education – how will I get a job? If healthy people search and do not get jobs, how much more those of us who are not healthy and do not have the strength to work? Nobody is willing to employ us even as watchmen or gatemen* (Male, with visible impairments).

**Contentment with the Leprosarium**

People affected by leprosy often experience rejection from society because of their impairments that are visible to members of their respective communities. In this regard, the findings indicated that participants had no intentions of leaving the Leprosarium to reintegrate into their communities. Their experiences of stigma and discrimination from families, friends, and community members made the Leprosarium a safe haven where they felt secure and comfortable. The Leprosarium was regarded as a place where they could trust and accept each other. Prior to their relocation to the Leprosarium, some participants were forced to live in isolation in forests since it was a taboo for people affected by leprosy, even if they were cured, to live in the same community with non-affected people.

A male participant with visible impairments narrated how he was assured of a cure by a traditional healer, only to have his condition worsened and this eventually led to his exit from his village:

*When the sickness worsened, I was directed to a Mossi (traditional healer) who asked me to boil the bark of a particular tree, drink the concoction and use some for bathing. When I used the concoction, I developed sores all over my body . . . I suffered a lot and people were scared of me. I found out later that it was a deliberate attempt to kill me*
since people in my community did not want me to live together with them in the village. They believed I was possessed by evil spirits so I had to leave the village quickly. I therefore migrated to Ghana for treatment. Currently, I am happy in this Leprosarium. I do not have anywhere to go; I will stay here till my time comes to exit this world.

Moreover, another male participant with visible impairments described how he was treated unfairly by members of my community before relocating to the Leprosarium:

People stigmatise and discriminate against us all the time so I do not plan to leave this place . . . before I moved in here, people in my community always said bad things about me because of my visible impairments. I felt compelled to move to this Leprosarium in order to live with people with a similar condition . . . I have no family outside this Leprosarium.

In addition, a female participant with visible impairments indicated that it was very difficult when individuals affected by leprosy tried to rent rooms since many house owners held the belief that those affected by leprosy would bring bad luck to their houses due to their visible impairments:

Because of our visible impairments, many people do not want us around them, especially living with them in the same house . . . even if we had money to pay rent, landlords were not willing to accept us since our own family members were unwilling to accept us. We will continue to reside in this Leprosarium because we are happy here.

Other factors that inhibited the reintegration of people affected by leprosy into their communities were the misconceptions and beliefs associated with the disease. Many people had the belief that the disease was caused by supernatural forces or was a curse from God:

I will not go back to my community or any other community . . . in my country, those affected by leprosy were sacked from their communities. Even if they were cured, they were not allowed to live with non-affected people . . . Many people believed we were cursed or that the sickness was spiritual so we were expelled from the community and kept in the forest to take care of ourselves . . . if we were unlucky, we could die in the forest. (Female with visible impairments).

In order to avoid family humiliation, some people affected by leprosy moved to the Leprosarium as revealed by this participant:

I had to move to this Leprosarium because my parents and siblings felt the disease made me a disgrace to the family. I don’t want to go back to my family or community; if I move out of this Leprosarium, I will not be happy and may die soon afterward . . . I am happy here as there is a saying that ‘comparison is what keeps prisoners strong’ . . . all of us here have the same sickness so we are happy and accept each other. (Male with visible impairments).

DISCUSSION

This study aimed to explore the experiences of stigma and discrimination among people affected by leprosy resident at Weija Leprosarium in Accra, Ghana. The findings revealed
that while participants differed in terms of gender, age, nationality, marital status, type and the duration of impairment, they all perceived leprosy as a socially undesirable disease which was associated with stigma and discrimination. This confirms assertions made by some scholars regarding negative connotations that are associated with chronic infectious diseases.\textsuperscript{14,18,19} In order to assuage the anxiety and risk of becoming infected, people normally link negative meanings with the disease, as well as those affected by the disease.\textsuperscript{26} This is mainly due to misconceptions people have about the causes of leprosy and the belief that the disease is incurable.

It was found that participants in this study experienced stigma mainly through enacted, anticipated and internalised mechanisms as proposed by Earnshaw and Chaudoir.\textsuperscript{28} Although they were cured of the disease, they were stigmatised and discriminated against by close associates like family and friends, as well as the general community. The social and harmful consequences of the disease on the life of people affected by leprosy are harsh and persist even after cure.\textsuperscript{16,49} Most often, people affected by leprosy experience insensitive reactions, insults, abhorrence and rejection from society.\textsuperscript{5,50} These are likely to affect their emotions, thoughts, behaviours and relationships, leading to a lower quality of life.\textsuperscript{40,51} In terms of emotions, participants expressed feelings of shame, sadness, and grief due to their visible impairments since they had lost contact with loved ones, such as children, spouses, siblings, parents and friends. It is extremely difficult to bear rejection in African and other societies where so much value is placed on family (both nuclear and extended) and communal living. In these places, people have a strong culture of belonging to their families and communities, given that people’s identities are bound up with their roles in their family and wider community.\textsuperscript{15}

Furthermore, participants in this study reported negative thoughts, such as self-loathing and suicide. This finding corroborates other studies that found relations between disease stigma and self-hatred or suicide.\textsuperscript{17,29} For instance, in a study on the psychosocial needs of people affected by leprosy in South Africa, it was found that one third of black patients included in the study, reported they had contemplated suicide when they learned about their diagnosis.\textsuperscript{17} Negative attitudes towards people affected by leprosy act to destroy their psychological and social health.\textsuperscript{15} The self-loathing that is connected with leprosy can be permanent, persisting even after the disease is cured.\textsuperscript{17} People affected by leprosy may become discomfited possibly because of their visible impairments and societal rejection. This could result in isolation and perpetuate the misconception that leprosy is shameful and must be hidden from society.\textsuperscript{15} These findings and assertions highlight the need for social support which is unavailable to many people affected by leprosy due to deeply held cultural and spiritual beliefs, as well as negative assumptions about the disease.

Another finding of this study is startling and relevant. Evidence showed that participants had challenges paying for their medical bills and some healthcare staff stigmatised and discriminated against them. In view of the fact that the participants did not earn income and the NHIS did not cover their medications, they had difficulties paying for their medical bills. In this regard, some participants resorted to the use of herbal and non-prescription medications, which unquestionably could have harmful consequences on their health. Besides, participants complained of healthcare professionals’ negative attitudes toward them, as well as delay in receiving treatment. As suggested by Bakirtzief, the healthcare seeking behaviour of people affected by leprosy is influenced by the availability, accessibility, acceptability and affordability of health services and quality of the healthcare provider-patient relationship.\textsuperscript{52} Participants in this study encountered challenges when they accessed medical services at larger health facilities outside the Leprosarium. Attitudes and behaviours
of healthcare providers influence how patients and communities perceive leprosy.\textsuperscript{15–17} This could further alienate healthcare providers from people affected by leprosy and strengthen society’s misconceptions about the transmission of leprosy and the effectiveness of medical treatment. Subsequently, it worsens the stigma associated with leprosy and would continue the cycle of stigmatisation.\textsuperscript{15}

Regarding employment, it was found that some participants lost their jobs due to the disease. For younger participants, while some indicated that employers were unwilling to hire them because of the stigma associated with the disease, others alluded to their lack of enthusiasm to look for jobs due to their visible impairments. Leprosy often afflicts individuals in their most productive stage of life and could prevent them from fulfilling normal roles in society since they are likely to lose their economic independence.\textsuperscript{51,53} Despite the fact that some people affected by leprosy anticipated that they would be stigmatised and discriminated against by prospective employers, others endorsed the negative beliefs and feelings associated with the disease and gave up searching for jobs. Individuals affected by leprosy may lose their employment or may not be employed because of the disease, visible impairments associated with it, as well as the negative attitudes of potential employers.

It is important to note that people affected by leprosy who were diagnosed with the disease at a younger age may be restricted in education; schools may be unwilling to admit them or place limitations on what they can do.\textsuperscript{15,54} Eventually, they would not have the means of supporting their families and would be denied the respect of their communities and this could result in loss of self-worth.\textsuperscript{15,27} While people affected by leprosy in this study were supported financially by the government and benefactors, the amount of money they received was not sufficient to cover their daily basic needs. As a result, some people affected by leprosy resorted to begging on the streets in order to get additional money. In Ghana, most often, people affected by leprosy with severe visible impairments beg on major streets in urban areas like Accra.

Given that usually, affected people’s social support networks did not function due to rejection by family and friends, taking care of their basic needs was a challenge. This made their reentry difficult, as people in their communities were likely to stigmatise and discriminate against them. People affected by leprosy in this study did not have plans of reintegrating into their respective communities or moving into new communities. They did not feel comfortable returning to their communities although they were cured, because in many developing countries including Ghana, it is the belief that leprosy is a spiritual disease that cannot be cured. Also, they were not encouraged to reintegrate into communities because of the contagious nature of the disease, which required segregation to protect others from becoming infected. Stigma that is linked with serious diseases like leprosy depends on threats the sickness represents to others.\textsuperscript{38} The shame linked with the disease could serve as a barrier to people seeking treatment until considerable visible impairments have occurred, while those who have been treated may never be cured in a really holistic way nor be received back into society.\textsuperscript{15}

Narratives from this study indicate that society did not recognise participants as having been cured of the disease and this skepticism is likely to continue for a long time if nothing is done to reduce society’s misconceptions about the disease. Even if people were cured of their mycobacterial disease, stigmatisation and discrimination could hinder the process of reintegration into their families, communities and wider society.\textsuperscript{15} As argued by Fife and Wright, those affected by leprosy were stigmatised because they were blamed for the illness and also the threat the disease posed to their competence.\textsuperscript{38} In spite of the fact that people
affected by leprosy in our sample were discouraged from returning to their communities, it is worth noting that they reported being happy at the Leprosarium. This was not surprising given that participants felt safe at the Leprosarium. The resumption of normal life outside their current residence could be difficult, particularly in a country like Ghana, where the government does not have much to offer its vulnerable citizens in terms of jobs, healthcare and housing.

A limitation of this study is that the participants did not include people affected by leprosy who were homeless or lived in isolation. Only people affected by leprosy who had stable housing and some form of support at the Leprosarium were considered. In addition, the participants did not include people affected by leprosy who did not perceive themselves as stigmatised. Moreover, given that the study was based on participants residing in one Leprosarium in Ghana, future research should consider people affected by leprosy in other Leprosaria in Ghana. The limitations notwithstanding, the findings provide evidence regarding experiences of stigmatisation and discrimination against people affected by leprosy at the Weija Leprosarium in Accra.

Conclusions and Implications

In conclusion, we note that the stigma of leprosy is a social problem in many societies, including Ghana. In this study, participants had knowledge about stigma and discrimination based on their personal experiences. They were stigmatised and discriminated against in areas, such as relations with their loved ones, employment, and health care. Stigma is a real problem for people affected by leprosy since it has devastating effects on their lives.\textsuperscript{14,15} We therefore argue that many people affected by leprosy would remain on the fringes of society due to stigma, discrimination and inadequate resources. Accordingly, we suggest that efforts aimed at reducing and ultimately curing the stigma and discrimination against people affected by leprosy, as well as promoting reintegration must be contextualised and scaled up.

For the reason that stigma operates at the nexus of culture, difference and power, and the fact that it exists at the individual, family, community and structural levels in society, the role of helping professionals, especially social workers and public health practitioners cannot be overemphasised. With the distressing effects of leprosy on the lives of affected people, it would be useful for social workers to provide counseling services for this population and also link them with social welfare services, to ensure their holistic cure and care. The absence of available services for people affected by leprosy is very challenging, especially for the elderly who are confined in the Leprosarium. There is a need for social workers to assist people affected by leprosy to improve upon their health and socio-economic status because their profession’s codes of ethics mandate the provision of services to vulnerable populations.

Furthermore, as healthcare workers directly and indirectly influence the way people perceive leprosy and how it is dealt with,\textsuperscript{16,55} public education aimed at decreasing the misconceptions about the disease and its associated stigma, should be championed by public health professionals. More importantly, the attention of healthcare providers should be drawn to the fact that people affected by leprosy are just like other people who visit health facilities for treatment and therefore should be treated with dignity. In order to enhance the acceptability of psychosocial interventions and public health education messages, the personal needs, as well as cultural and religious beliefs of targeted people, groups and communities must be considered.
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Details of Contributors

MD-G conceived the study. All authors (MD-G, EA, RO) were involved in the data collection and analysis. MD-G led the writing of the article and all authors agreed to the publication of the article.

References
