

EXPERIENCES OF STIGMATIZATION AND DISCRIMINATION: INSIGHTS AND PERSPECTIVES OF CURED LEPERS

Presenter: Dr. Mavis Dako-Gyeke

Department of Social Work

University of Ghana

17th September, 2015

INTRODUCTION

- ❖ Leprosy is a public health concern due to the fact that permanent disabilities could develop if intervention is delayed or not properly implemented.
- ❖ The effects of leprosy could linger on for an indefinite period as a result of the residual permanent impairments and progressive physical disabilities caused by the disease.
- ❖ Consequently, the condition is associated with many challenges which affect the social, economic and psychological wellbeing of affected persons.
- ❖ For instance, cured lepers are likely to be stigmatized and discriminated against.

- ❖ While significant efforts have been made to reduce the development of disability in leprosy patients, there are still large numbers of cured lepers with residual deformities (Bello et al., 2013), which make them vulnerable.
- ❖ Stigma and its resulting discrimination could deepen the pain and suffering of both cured lepers and their families.
- ❖ Though previous studies have focused on persons affected by leprosy, there is paucity of studies that capture the voices of cured lepers.
- ❖ Hence, there are very little qualitative data on the nature and types of problems faced by people with leprosy-related disabilities, as well as their needs for services.
- ❖ This study therefore explored how stigma and discrimination affect the lives of persons affected by leprosy.

OBJECTIVES OF THE STUDY

The study aimed to find out:

- ❖ cured lepers' perceptions about stigmatization and discrimination.
- ❖ stigmatizing and discriminatory factors that serve as barriers to accessing health care facilities by cured lepers.
- ❖ stigmatizing and discriminatory factors that limit cured lepers' access to employment and other social services.
- ❖ stigmatizing and discriminatory factors that affect reintegration of cured lepers into their communities.

THEORETICAL DISCOURSES

- Contemporary understanding of disease stigma owes much to Goffman (1963), who argued that people who possess a characteristic defined as socially undesirable (leprosy in this case) acquire a spoiled identity which then results in social devaluation and discrimination (Deacon et al., 2010).
- Stigma is not a single phenomenon; consists of numerous possible facets.
- It may be conceptualized in terms of self-stigma (shame and lowered self-esteem) or public stigma (public prejudice) that is linked with social participation limitations and discrimination (Brakel et al., 2012; Weiss, 2008).

THEORETICAL DISCOURSES

- While stigma relies existing prejudice and social stereotypes, it does not always have to result in discrimination to have a negative impact as people may internalize stigma or anticipate to be stigmatized or discriminated against and as a result, may not avail themselves for treatment (Deacon et al., 2010.)
- Even though discrimination can result from stigma it could also stem from fear of infection or resource concerns (Deacon et al., 2010).
- Stigma is experienced through, at least, three stigma mechanisms: enacted, anticipated and internalized (Dako-Gyeke, Dako-Gyeke & Asampong, 2015; Earnshaw & Chaudoir, 2009).

METHODOLOGY

Research Design

- A qualitative research design was employed for this study because it provides complex descriptions of how people experience and perceive a given phenomenon.

Study Participants

- Twenty-six cured lepers at the Weija Leprosarium comprising of 16 males and 10 females were recruited for the study.

Data Collection Procedures

- Data were collected from cured lepers through observations and in-depth interviews after approval was given by the Ethics Committee for the Humanities (ECH) at the University of Ghana.

FINDINGS OF THE STUDY

Demographic Characteristics of Participants

<i>Age Range</i>	1(40-50), 7(51-60), 7(61-70), 6(71-80) and 5(90+) years.
<i>Sex</i>	10 Females and 16 Males.
<i>Employment Status</i>	Yes - 1 No - 25
<i>Country of Origin</i>	Ghana (13), Benin (2), Burkina-Faso (1) and Nigeria (10).
<i>Educational Background</i>	No Formal Education (17), Primary Education (5). JHS (2), SHS (1) and Post Secondary (1).

FINDINGS OF THE STUDY

Demographic Characteristics of Participants

Marital Status Married (13), Single (8), Widowed (2), and Divorced (3).

Number of Children 14 (1-4), 6 (5-8) and 6 (None).

Employment Status Yes - 1
No - 25

Years Lived with the Disease 1(1-10 years), 2 (11-20 years), 4(21-30 years), 5 (31- 40 years), 5 (41-50 years) and 9 (51+ years).

Cured Lepers' Perceptions about Stigma and Discrimination

🌺 The cured lepers' had knowledge of stigma and discrimination (enacted, internalized and anticipated). Many of them experienced stigma and discrimination through interactions with people:

They say the sickness is contagious . . . not want you close to them . . . I normally tell them sickness is infectious at the early stages but now there are medicines that when you take within two years you will be healed . . . many people do not believe this . . .

People need to be considerate; we all humans . . . I tell my friends at the Leprosarium to be patient . . . we can't change people who stigmatize discriminate against us.

Cured Lepers Access to Health-Care Services

- It was found that health-care facilities were available and accessible to cured lepers.
- The Leprosarium is close to a Municipal Hospital and also through the support of a philanthropist, a well-resourced clinic has been built mainly for the cured lepers at the Leprosarium.



Cured Lepers Access to Health-Care Services

- It is important to note however that there were health-related issues that affected the general health and well-being of the cured lepers.
- These included health-care financing; stigmatization and discrimination experiences when they accessed health services outside the Leprosarium and the Municipal Hospital.

Financing Health-Care

- Although at the time of the data collection, all the cured lepers included in this study were enrolled onto NHIS, there were additional health costs the participants had to bear.

Financing Health-Care

It was found that when cured lepers were transferred to the Korle-Bu teaching hospital and other hospitals, they were required to pay some money and commenting on this issue, a participant remarked:

All of us at the Leprosarium have NHIS cards, but there are times that when we are transferred to the Korle-Bu hospital, the NHIS does not cover all expenses so Father Campbell with the support of other philanthropists, pay the bills. This normally delays health-care treatment especially when Father is not around . . .

Health Practitioners-Cured Lepers Relationship

Another issue that limited cured lepers' access to health-care services were the stigmatizing and discriminatory attitudes and of some health practitioners.

While the participants revealed that some of practitioners were nice and patient with them, others were rude and neglected them:

. . . when we go to other hospitals, it is very difficult for us because many doctors and nurses there are scared of the sickness. . . they don't believe we are cured and so when we go to the hospital, they do not want treat us.

. . . there were times some doctors and nurses refused to treat us had it not been the intervention of Father Campbell . . .

Cured Lepers' Access to Employment

- Participants mentioned that many employers were unwilling to employ them because of their negative perceptions and beliefs about the disease:

Sometimes when employers get to know you are sick, it becomes difficult for them to employ you. . . . they think it is contagious . . . they employ other people even if you can do the job better . . .

- With regard to employment, participants recounted the challenges and experiences they faced during their youthful years since many of them were elderly.

- The age range of participants was between 40 and 90 years but majority of them were between the ages of 51 to 80. years.

Cured Lepers' Access to Employment

Participants major challenge related to their physical disabilities as a participant said:

Let say you want a security man job, if you do not have hands and legs how can you do it?



Access to other Social Interventions and Services

The LEAP Cash Transfer Program

It was found that the participants were beneficiaries of the LEAP.

We receive LEAP cash payments every two months . . . we are given GHC 48 . . . although the money helps, it is not enough. . . we are a bit relieved when we receive the money.

Formal Psychosocial Support Services

The study found that there were no formal psychosocial support services available; the leprosarium had no counselors or social workers.

Some churches do come around to preach and pray with us , but we do not have counselors in this Leprosarium. When I am worried I only pray to God . . .

Access to Informal Support and Donations

- Evidence showed that informal social support was available at the Leprosarium.
- Many benevolent persons provided the cured lepers with donations, including food, clothing and other essential items:

There are women groups and other faith-based associations who donate items to us, especially during Easter celebrations.

Most often, we receive food items, clothes, as well as money from the churches . . . as for the church people , they do help us a lot . . .

Access to Informal Support and Donations

■ In addition to the support they received from groups, the participants indicated they received enormous support from philanthropists like Dr. Stanley Owusu and Alhaji who give them monthly stipends and food donations:

There is one man, Dr. Stanley, every month he gives us 10 Cedis, initially it was 5 cedis. It helps us a lot , , ,

We all have a friend called Alhaji, he is very good . . . every month, he brings money and at times food items . . . everybody here gets 10 Cedis

Stigmatization and Discrimination and Reintegration

- The findings indicated that participants were stigmatized and discriminated against in by family:

My family members do not treat me well because of the disease . . . my father is dead and my family members are scarce to find. I come from the Northern part of Ghana and I don't remember the last time I saw any family member . . . They do not care about me ...

- Another factor that inhibit reintegration of cured lepers into their communities is the belief associated with the disease.
- It is often attributed to supernatural causes or curse from God. As a result, families and communities do not want persons affected with the disease to be close to them.

❖ The participants also indicated that it is often difficult when a leper decides to rent a room from landlords since many of them believe the cured lepers will bring bad luck to their houses due to the disability.

When they see the way we look, they do not want us around them . . . , especially staying in their houses even if we have money to pay the rent. or advance . . .



CONCLUSIONS

- ❖ Evidently, the cured lepers included in the study had knowledge about stigma and discrimination based on their experiences.
- ❖ The participants were stigmatized and discriminated in areas such as employment, health seeking, as well as family and community relations, and these were experiences both overtly and clandestinely.
- ❖ We thus assert that many cured lepers would remain on the fringes of society due to stigma and discrimination.
- ❖ Accordingly, argue that efforts aimed at reintegrating cured lepers into their families and communities would be inhibited given that stigma functions at the intersection of culture, power, and difference and exists at the structural, social and self levels in society.

**THANK YOU FOR YOUR TIME
AND ATTENTION**

Acknowledgement

The researchers are most grateful to the Office of Research, Innovation and Development (ORID) at the University of Ghana, for funding this Research Project.