

# **EXPERIENCES OF STIGMATIZATION AND DISCRIMINATION: INSIGHTS AND PERSPECTIVES OF CAREGIVERS**

DISSEMINATION WORKSHOP

*Presentation by:*

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# Introduction

- Care giving is at the heart of family life.
- Parents care for children.
- Spouses care for each other.
- When illness or disability occurs, family members care for each other.

# Introduction

- Leprosy is an illness that results in some disabilities after cure.
- Families affected by a disability experience a host of relational opportunities and challenges.
- **INSIGHTS AND PERSPECTIVES OF CAREGIVERS**
- Institutional and Family Caregivers

# Findings

## Demographic Characteristics of Participants

<b>Variable</b>	<b>Frequency</b>	<b>Percentage</b>
Institutional caregivers	9	45
Family caregivers	11	55
<b>Total</b>	<b>20</b>	<b>100</b>
<b><u>Age of Respondents</u></b>		
18-28	8	40.0
30-40	3	15.0
41-50	6	30.0
51-60	1	5.0
61-70	2	10.0
<b>Total</b>	<b>20</b>	<b>100</b>
<b><u>Sex of Respondents</u></b>		
Male	8	40.0
Female	12	60.0
<b>Total</b>	<b>20</b>	<b>100</b>

# Caregivers' Initial Perception of the Leprosarium

*"...the first time I went to Weija (Leprosarium) I did not eat there".*

*"Initially people couldn't even eat, they were scared to eat here but now people come and they eat here".*

*"...when I came, it was difficult for me. Now, when she eats and some remains, I am able to eat it. Me it does not do anything to me".*

# Caregivers' perception of Stigma among cured Lepers themselves

- *“Not among themselves they are okay because all of them at Weija are cured”.*

# Social Acceptability of Cured Lepers

- *“Yes there is this question mark about it in the sense that people are not forth – coming when they hear of lepers”.*
- *“They were even producing soap but it collapsed in the sense that people had the mentality that how can somebody with this disease at the end of the day do soap for you to buy”.*
- *“...I remember one time some big people came to Weija, it’s over a year ago, I said follow me and shake hands with the Lepers and they said “next time father next time”.*

# Relationship with Health Personnel

- *“I took somebody to the hospital and the doctor just refused to take care of him, he didn’t tell me to my face but he left the patient....the next day, he was dead”.*



# Possible Antecedent of the Stigma

- “...when you go back to the old testament, Leviticus and the rest, they have got awful descriptions in the old testament...and that is the stigma we still have today”.
- *“Deformity that comes later on, that is what happens. Because if I am walking and I have HIV, you will want to speak to me normally like any other person until you realize that maybe my body is deteriorating or you notice something about my condition then you wouldn’t want to be associated with me”.*

# Extension of Stigma(Courtesy Stigma)

- *“...if I heeded to what people said about the marriage, I don’t think I would have been able to stay with him. People kept on telling me there were a lot of healthy men out there wanting to marry me and that why would I want to marry this one”.*

# Access to Health Services

- *“Yes they get access to health services. We take them to the hospital”.*

# Healthcare Financing

- *“...all of them are on the free NHIS so they are able to get all those things for free so that is not really a problem”.*
- *“NHIS is good but it doesn’t tackle the detailed issues that it is supposed to”.*
- *“They are on NHIS but the NHIS does not cover everything like operations so the Lepers Aid Committee through donors and benefactors find monies and pay”.*

# Co morbidities among cured lepers

- *“...they often get eye problems and others get ulcers so these ones we have always got to be careful”.*

# Financial Support

## LEAP

- *“...they receive 80pesewas a day for an adult to live on, what can you buy with 80pesewas a day when the normal wage every day is seven cedis and you expect them to live on 80 pessewas”.*
- *“...because he is married he receives 60 cedis every two months but when he doesn't receive it in two months then it comes in four months and he takes 120 cedis”.*

## LEPERS AID COMMITTEE

- *“...it is father who adds 20 cedis every month when they give us food”.*

# Weija as the hub for External Support

- *“A lot of things are given to us and this is where we start from so we go round the whole country, we go to Kokofu, Nkankyena, Ahotokrom and all that, we go to Ho and then everything is carried from here to them so Accra has become the main centre from where we carry the food to them”.*

# Employment Opportunities

- *“...at their age nobody will give them employment”.*
- *“...Err no! Who would want to employ a leper”?*
- *“...people wouldn't accept so, who wants to say that I am working with a leper”.*



# Relationship with Family members

- *“... family members only come around when the person is dead”.*
- *“The last time some relative came here, it was because of funeral that they came here if not so ....”.*

# Conclusion

- Stigma can lead to psychological stress, depression and fear, all of which restrict the progress towards health
- One leprosy sufferer explained it as *“We can endure losing fingers and toes, eyes and nose, but what we cannot endure is to be rejected by those nearest and dearest”* (Rafferty, 2005, p. 120).