

# Perceived Stigma of Leprosy Patients in Rural Tanzania



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### Abstract:

Background: Leprosy, a debilitating chronic infectious disease, continues to be a major public health problem in Tanzania. The most visible long-term complication of leprosy is physical deformity, which can lead to severe social stigma.

Objective: To measure the perceived stigma of leprosy patients in rural Tanzania and determine its impact on several different aspects of their lives.

Methods: Data were collected from face-to-face interviews with 28 patients obtaining care at a leprosy clinic in rural Tanzania. Patients were read questions from a 40-item questionnaire, which were translated by a native Luo speaker.

Results: Leprosy patients seeking care at a leprosy clinic reported stigma across a range of family, vocational, and social contexts.

Conclusions: Because leprosy affects multiple aspects of a patient's life, public health interventions are needed to address the negative impact of stigma in Tanzania.

## Background:

#### What is Leprosy?

- Leprosy is a chronic disease caused by a bacillus, Mycobacterium leprae.
- M. leprae multiplies very slowly and the incubation period of the disease is about 5 years. Symptoms can take as long as 20 years to appear.
- Leprosy is not highly infectious. It is transmitted via droplets, from the nose and mouth, during close and frequent contacts with untreated cases.
- Untreated, leprosy can cause progressive and permanent damage to the skin, nerves, limbs, and eye (Ref: WHO, 2010).

### Prevalence of Leprosy

- The global registered prevalence of leprosy at the beginning of 2009 stood at 213,036 cases, while the number of new cases detected during 2008 was 249,007.
- Pockets of high endemicity still remain in some areas of Angola, Brazil, Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania (Ref: WHO, 2010).

### Stigma & Leprosy

- Leprosy draws forth stigma due to visible physical deformities, which can cause sufferers to become beggars and can delay treatment leading to increased risk of disability (Ref: Tsutsumi, 2004).
- Public stigma has a negative impact on patients' mental health and social engagement and can lead to suicidal thoughts and attempts (Ref: Tsutsumi, 2004).
- It is important to understand how socio-cultural beliefs influence stigma towards leprosy patients and how stigma affects health care seeking behavior (Ref: Mull, 1989).
- · By increasing our understanding of the dynamics and causes of stigma, more effective interventions for rehabilitation and integration can be developed to enhance these patient's quality of life (Ref: Van Brakel, 2003).

### Methods:

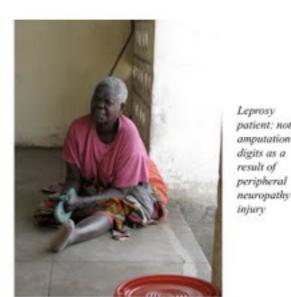
Within a leprosy ward in hospital in Shirati, Tanzania, 28 patients were recruited to participate in a face-to-face structured interview, which was based on a 40-item questionnaire. A native speaker of Luo assisted in translating each question. The questionnaire was divided into six areas: (1) Demographics, (2) Family Relationships, (3) Vocational Condition, (4) Social Interaction, (5) Self-Esteem, (6) Treatment & Health Care. Our measure of perceived stigma due to leprosy was based on a validated scale that has been used internationally (Anandaraj, 1995). No personal identifying information was collected. Data were analyzed using SAS software. The survey instrument and study procedures were approved by the University of Southern California Institutional Review Board (IRB).

## Results:

Table 1: Demographic Characteristics of Tanzanian Sample

Variable	% (N=28)	Mean (SD)
Age [26-87]		62.6(13.2)
Gender (male)	57.0	
Education [1-4]		2.3(1.2)
Literate (read and/or write)	62.7	
Marriage status		
Married	39.3	
Separated	3.8	
Divorced	17.9	
Widowed	25.0	
Unmarried	14.3	
Work Status		
Working	46.3	
Not working	53.6	
Family member w/ leprosy	50.0	
Seen a traditional healer	46.4	





Leprosy patient: note

result of

amputation of

neuropathy &



Leprosy patient: Note loss of digits and collapse of the



Patients who lived in the leprosy camp were not allowed to return to their communities because of stigma



A patient exhibiting hypo-pigmented leprosy skin



Leprosy patients playing mancala in the hospital ward

Table 2: Family Relationships Data (Because of my leprosy, ...)

Variable	% (N=28
Important family members in my family know I have an illness	100
I am an accepted part of my family	60.7
I have been thrown out of my house	35.7
My spouse had divorced me	35.3
My spouse avoids all physical contact with me	25.0
My spouse behaves disrespectfully	12.5
My family members do not touch me	32.1
I used a separate plate and cup	35.7
I personally avoid all physical contact with others	46.4
My family takes special care for me	64.3
I do not touch my children purposely	6.7
My children have been separated from me	9.1
My family considers me as a burden	42.9
My relative's/children's future will be affected	23.5

Table 3: Vocational Condition Data (Because of my leprosy, ...)

Variable	% (N=28)
I have no occupation	33.3
I have lost my job	75.0
I am worried about losing my job	69.6
Others at my work place know I have a disease	89.3
Others at work avoid touching me	42.9
Others at work speak disrespectfully	28.6
At work, I avoid making friends	32.1
I have been refused jobs	32.1
I might have to end up begging	53.6

### Table 4: Social Interaction Data (Because of my leprosy, ...)

Variable	
My friends don't invite me to their homes	35.7
I avoid my friends	32.1
I have no one to share my feelings with	17.9
People are afraid of touching me	53.6
I feel society has discarded me	28.6
I have not been able to get married	27.8
I have been physically attacked by people	25.9
I have been refused the purchase of something by a shopkeeper	17.9

Table 5: Self-Esteem Data (Because of my leprosy, ...)

Variable	% (N=28)
There is no use in living	7.1
I have felt like ending my life	21.4
I feel I cannot do anything useful	42.7
I sit idle most of the time	42.9
I think of my problem most of the time	39.3
I feel guilty and ashamed	14.3
Begging is the only way to make a living	32.1
I feel I am personally responsible for my misfortune	0.0

### Conclusions:

Because leprosy appears to affect so many aspects of a patient's life due to its resulting stigma, program interventions are needed to address the negative impact of stigma. Efforts should be made to educate the public on leprosy and address false myths in order to eradicate stigma. Public health education should also emphasize the importance of being treated at the hospital as early as possible to prevent consequential disabilities.

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# Machine Learning Identifies Key Risk Factors of

# Linear Growth Faltering and Death in Young Children With and Without Diarrhea

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# Introduction

- Stunting: height-for-age (HAZ) z-score >2 standard deviations below population mean (1).
- ~140 million children stunted globally (2).
- Short-term: Stunting leads to worse health, delayed cognitive development, and increased expenses (medical care, lost work) (3).
- Long-term: Stunting contributes to adult comorbidities, including obesity, reproductive issues, reduced school performance, decreased work ability (3).
- The causes of stunting are multifaceted, including national, neighborhood, household, individual factors (4).
- 13.5% of all stunting is attributable to diarrheal disease (4).
- Seeking care for any cause (i.e. diarrhea) is an opportunity to identify children at risk for negative outcomes (e.g. growth faltering, death).
- Aim: Use machine learning methods to identify key risk factors predictive of growth faltering and death for children with and without diarrhea in low and middle income countries (LMICs).

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# **Predictive Models of Growth Faltering and Death**

	0-11 months		12-23 months		24-59 months		
	Cases	Control	Cases	Control	Cases	Control	
Growth Faltering							
	n=3068	n=4414	n=2494	n=3967	n=1773	n=3582	
Number of outcome (%)	1027 (33%)	1299 (29%)	540 (22%)	549 (15%)	83 (5%)	31 (1%)	
AUC (95% CI)	0.63 (0.62, 0.64)	0.71 (0.69, 0.73)	0.61 (0.60, 0.63)	0.67 (0.66, 0.69)	0.59 (0.58, 0.61)	[failed to converge]	
<b>Top 10 Predictors</b>	HAZ	HAZ	HAZ	HAZ	Respiratory rate	HAZ	
	MUAC	Height	MUAC	Height	Temperature	MUAC	
	Temperature	MUAC	Respiratory rate	MUAC	HAZ	Height	
	Respiratory Rate	Wealth	Temperature	Respiratory rate	Age	Wealth	
	Wealth	Respiratory rate	Wealth	Wealth	MUAC	Temperature	
	Age	Temperature	Age	Age	Wealth	Age	
	# ppl house	# ppl house	# ppl house	Temperature	# ppl house	# ppl house	
	# share latrine	Age	Recomnd. ORS	# ppl house	# share latrine	# sleeping rms	
	# diarrhea days	# sleeping rms	# sleeping rms	# sleeping rms	# sleeping rms	Respiratory rate	
	# sleeping rms	# <5yr	Water source	# <5yr	Feces disposal	# <5yr	
			 Death				
	n=3369	n=4556	n=2792	n=4110	n=1895	n=3665	
Number of outcome (%)	98 (3%)	22 (<1%)	51/2792 (2%)	12 (<1%)	17 (1%)	3 (<1%)	
AUC (95% CI)	0.79 (0.75, 0.83)	0.64 (0.55, 073)	0.82 (0.78, 0.88)	0.56 (0.45, 0.67)	0.84 (0.80, 0.87)	[failed to converge]	
<b>Top 10 Predictors</b>	MUAC	HAZ	MUAC	Height	MUAC	MUAC	
	HAZ	Temperature	HAZ	HAZ	Arthritis	Arthritis	
	Respiratory rate	Height	# ppl house	Temperature	HAZ	HAZ	
	Convulsions	Respiratory rate	Temperature	Wealth	Flaky skin	Wealth	
	Temperature	MUAC	Wealth	MUAC	Abn. Hair	Height	
	Wealth	Wealth	Respiratory rate	Respiratory rate	Convulsions	Edema	
	Age	Convulsions	Convulsions	Memory	Temperature	Previous diarr care	
	# ppl house	Memory	# diarrhea days	# ppl house	Respiratory rate	Water	
	Water source	# ppl house	Age	Convulsions	Family relationship	Temperature	
	(enrollment & f-up)	Age	Feces disposal	# sleeping rms	Age	Feces disposal	

## Results

- The youngest children (0-11 mo) experienced the most growth faltering and death.
- There were few deaths in controls, but growth faltering was prevalent in the youngest controls.
- Top predictors were similar for growth faltering and death across cases, controls, and age categories, and included child descriptors, individual symptoms, and household socioeconomic status markers.
- Using this data, we had moderate discriminative ability to predict growth faltering in cases across all age groups (AUC ~ 0.6).
- Our models had lightly higher ability to predict growth faltering in controls (AUC ~ 0.7).
- There was good discriminative ability to predict death in cases (AUC ~ 0.8), but poor ability in controls.

# Conclusions

- We were able to predict with moderate discriminative ability which children experienced growth faltering, especially in the youngest children.
- Risk factors and predictive ability were the same for cases and controls.
- Any healthcare contact represents an opportunity to identify children most at risk of growth faltering.
- We had good ability to predict child mortality when children sought care for acute diarrheal disease.
- When children present for acute diarrhea care, we can identify children most likely to die at the hospital and after discharge.

# Global Enteric Multicenter Study (GEMS)



Gates Foundation funded study of children's diarrhea conducted in 7 different countries (5) Data collected 2007-2011 in children <5 years

Case-control study of children <60months seeking care for acute moderate or severe diarrhea

Acute diarrhea: 3+ looser than normal stools within 24 hours

Each case matched with 1-3 community controls without diarrhea

Clinical & epidemiological info collected from cases and controls at enrollment and ~60 days later 150+ possible predictors explored

# Methods

## Outcomes

- Growth faltering: decrease ≥0.5 height-for-age z-score (HAZ) over 60 days
- Mortality: any death between enrollment and 60 day follow-up

## **Predictive Model Building**

- variable screening via random forest
   rank variables based on reduction in variance
- 5-fold cross-validation
- Fit regression models using:Random forest regression
- Logistic regression
   C-statistic (AUC) to assess predictive ability

 $\Delta HAZ(Y/N) = age + income + HH size + etc.$ death(Y/N) = age + income + HH size + etc.

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