

# Stigma measurement among people with TB accessing TB care services in three African countries

*Rachel Mukora, Jeniffer Nagudi, Lindiwe Tsope, Lonze Ndelwa, Thobani Ntshiqqa, Manthomeng Matete, Issa Sabi, Knut Lönnroth, Kavindhran Velen, Molebogeng Rangaka, Salome Charalambous*



## Background

---

- Accessing tuberculosis (TB) care services remains challenging in low and middle-income countries for various reasons, including stigma.
- TB is a highly stigmatized disease where the stigma is a significant barrier in the control and prevention of the disease.
- TB related stigma is commonly linked with lack of knowledge about the cause, transmission, or treatment of the disease.
- Additionally, the disease is perceived as synonymous with an HIV diagnosis as the symptoms are commonly misidentified.
- The stigma attached to the disease affects health seeking behaviour, adherence to treatment, and use of healthcare services for prevention and control.
- In order to improve health outcomes in people with TB , it is critical to understand the prevalence of stigma that may prevent people with TB from accessing TB care services.

## Study Aim

---

- ◆ The aim of the study was to describe stigma prevalence as reported by People With TB (PWTB) during the CUT-TB pilot study evaluating TB contact tracing strategies in South Africa, Lesotho and Tanzania.
- ◆ CUT-TB Pilot Study (Phase 1) was a pragmatic cluster randomized trial identifying drug-sensitive or drug-resistant TB index cases from health facilities and performing TB screening and latent TB Infection Testing LTBI testing among their close contacts.
- ◆ The CUT-TB Pilot Study took place between July 2021 and September 2022 in South Africa, Lesotho and Tanzania.

## Methods

---



### Study design

We conducted a cross-sectional survey at enrolment of PWTB into the CUT-TB trial



### Study Period

The survey took place between July 2021 – September 2022



### Target population

- People with TB who were adults  $\geq 18$  years with microbiologically confirmed TB disease accessing study clinics.
- Diagnosed with active TB  $\leq 6$  weeks at time of enrolment



### Study setting

Peri-urban communities of South Africa, Tanzania and Lesotho



### Study outcome

Prevalence of TB stigma

## Data Collection

---

Using a validated questionnaire, we covered five domains;

1. Social exclusion
2. Being made fun of
3. Health setting stigma
4. Internalised stigma
5. Disclosure

## Data collection

---

Domain	Question – Since you have fallen ill have you...
1. Social Exclusion	<ul style="list-style-type: none"><li>• Been excluded from social gathering?</li><li>• Abandoned by spouse/partner?</li><li>• Isolated by your household?</li><li>• Your children or family have been isolated/shunned?</li></ul>
2. Being made fun of	<ul style="list-style-type: none"><li>• Lost respect or standing in the community?</li><li>• Been teased, insulted or sworn at?</li><li>• Been gossiped about?</li></ul>

## Data Collection

---

Domain	Question – Since you have fallen ill have you...
3. Health setting stigma	<ul style="list-style-type: none"><li>• Been treated worse than patients with other diseases by health staff?</li></ul>
4. Internalised stigma	<ul style="list-style-type: none"><li>• Unclean or dirty because of your TB?</li></ul>
5. Disclosure	<ul style="list-style-type: none"><li>• Have you told anyone outside of your household about your TB diagnosis?</li></ul>

## Data Collection

---



### Descriptive analysis

Used to measure the prevalence of TB stigma which was calculated as a proportion of those who answered “yes” to any question out of the total participants surveyed by country.

The proportion was converted into a stigma score ranging from 0-4.



### Logistic regression

Used to measure association between stigma and the following variables of interest:  
**disclosure of TB diagnosis outside the household, age, gender**



## Findings - Demographics

Country	All		South Africa		Lesotho		Tanzania	
	#	%	#	%	#	%	#	%
<b>N</b>	<b>342</b>		<b>152</b>	<b>44%</b>	<b>100</b>	<b>29%</b>	<b>90</b>	<b>26%</b>
<b>Gender</b>								
Male	230	<b>67%</b>	98	64%	66	66%	66	73%
Female	112	33%	54	36%	34	34%	24	27%
<b>Age</b>								
18-29	67	20%	29	19%	23	23%	15	17%
30-39	108	32%	54	36%	23	23%	31	0%
40-49	74	22%	32	21%	21	21%	21	17%
50-59	55	16%	26	17%	12	12%	17	34%
60+	38	11%	11	7%	21	21%	6	23%
Mean (sd)	41.6 (13,8)		40.6 (12,3)		43.6 (16,9)		41.3 (12,3)	
Median (IQR)	<b>39 (31-51)</b>		39 (31-49)		41 (30-58)		39 (33-50)	

## Findings – prevalence of any form of stigma

	South Africa		Lesotho		Tanzania	
	#	%	#	%	#	%
Scores	152		100		90	
0	145	95.4%	87	87.0%	74	82.2%
1	3	2.0%	10	10.0%	9	10.0%
2	1	0.7%	3	3.0%	4	4.4%
3	0	0.0%	0	0.0%	1	1.1%
4	3	2.0%	0	0.0%	2	2.2%
Total	7	<b>4.6%</b>	13	<b>13.0%</b>	16	<b>17.8%</b>

## Findings- logistic regression

	Univariable Analysis		Multivariable Analysis	
	OR (95% CI)	P-Value	AOR (95% CI)	P-Value
<b>Disclosure outside the household</b>				
No	1		1	
Yes	1,88 (0,86 - 4,14)	0.12	1,31 (0,57 - 3,02)	0.52
<b>Gender</b>				
Female	1		1	
Male	2,65 (1,07 - 6,57)	<b>0.04</b>	2,42 (0,96 - 6,09)	0.06
<b>Age</b>				
	1,01 (0,99 - 1,04)	0.35	1,01 (0,98 - 1,03)	0.56

## Limitations

---

- ◆ The cross-sectional survey was conducted at enrolment into the CUT-TB trial which was less than 6 weeks after the participants were diagnosed with TB. Little is known about how the stigma may have changed over time.
- ◆ Household contacts of PWTB were not included in the survey which may have given further insights on social exclusion or any associative stigma that may have prevented contacts from accessing TB care services upon clinic referral.

## Conclusion

---

- ◆ Across the three countries, TB stigma was reported by almost 11% of PWTB, creating the need for a stigma reduction intervention.
- ◆ Being male was correlated to experiencing stigma and may have an influence on accessing TB care services.
- ◆ Stigma reduction interventions should be intentional on targeting males who are more likely to experience stigma due to their TB diagnosis. Stigma may affect men's health seeking behaviour, adherence to treatment, and use of healthcare services for prevention and control.
- ◆ In-depth interviews being conducted in Phase 2 of CUT-TB study will help gain further insight on experiences of stigma for both PWTB and their household contacts.

## Acknowledgments

- Study Participants
- National and Provincial Department of Health
- Data Collection Team
- Investigator Team
- Consortium Partners
- Trial Steering Committee
- Funder – EDCTP



This project is part of the EDCTP2 programme supported by the European Union



health

Department:  
Health  
REPUBLIC OF SOUTH AFRICA

E D C T P

# THANK YOU