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DALYs, Socioeconomic Consequences, Stigma

The burden of suffering from TB

Christian Auer, 21 March 2023

Overview

The “TB journey” as gross simplification

DALY

Cured!? Post-Tuberculosis Lung Disease

The context – often poverty

TB and stigma

Consequences, final thoughts

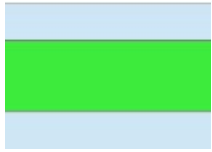


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The “TB journey”
(from coughing to cure)

The TB journey (gross simplification)



> Clin Infect Dis. 2022 Aug 25;75(2):314-322. doi: 10.1093/cid/ciab970.

Prevalence of Mycobacterium tuberculosis in Sputum and Reported Symptoms Among Clinic Attendees Compared With a Community Survey in Rural South Africa



Indira Govender ^{1 2}, Aaron S Karat ¹, Stephen Olivier ², Kathy Baisley ³, Peter Beckwith ^{1 4},

Clinic setting: 20/2055 (1.0%) were CU+
14 of the 20 (70%) reported **no** symptoms

Community setting: 58/10'320 were CU+
45 of the 58 (78%) reported **no** symptoms

Symptoms



TB but no symptoms: findings from TB prevalence surveys

Clinical Infectious Diseases

1 August 2021

REVIEW ARTICLE

Subclinical Tuberculosis Disease—A Review and Analysis of Prevalence Surveys to Inform Definitions, Burden, Associations, and Screening Methodology

Beatrice Frascella,¹ Alexandra S. Richards,^{2,3} Bianca Sossen,^{4,5,6} Jon C. Emery,² Anna Odone,¹ Irwin Law,⁷ Ikushi Onozaki,⁸ Hanif Esmail,^{4,5,9} and Rein M. G. J. Houben^{2,3}

Findings from 23 national and 5 subnational surveys (conducted in 23 countries across Africa and Asia):

Between 36.1% and 79.7% of prevalent bacteriologically confirmed TB was **subclinical. Median: 50.4%**



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DALY (some numbers)

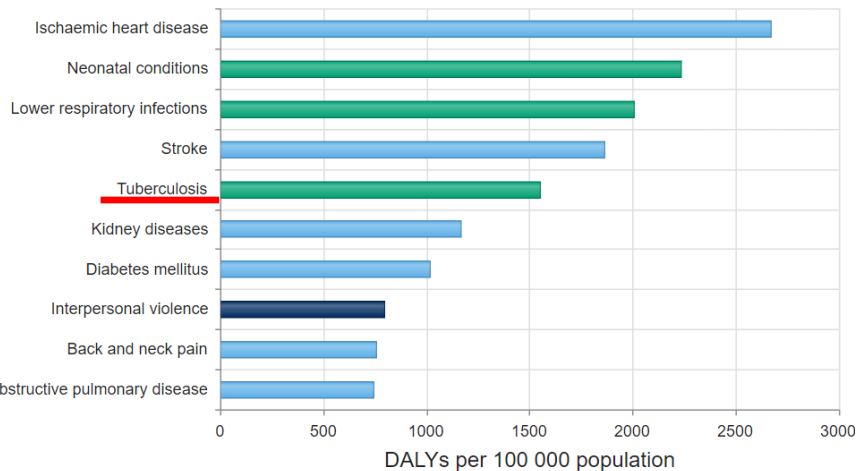
The top ten global causes of disability-adjusted life years (DALYs) in 2019

1. Neonatal conditions
2. Ischaemic heart disease
3. Stroke
4. Lower respiratory infections
5. Diarrhoeal diseases
6. Road injury
7. Chronic obstructive pulmonary disease
8. Diabetes mellitus
9. Tuberculosis **Post-tuberculosis not considered!!**
10. Congenital anomalies

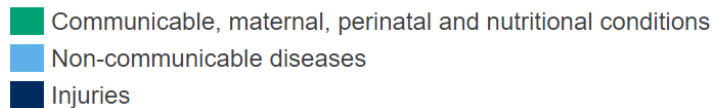
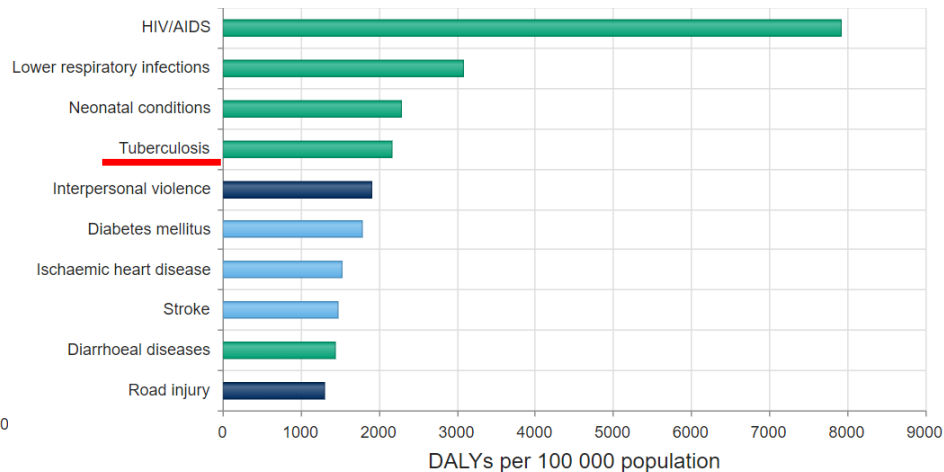
Source:

The top ten causes of DALY, 2019

A) The Philippines



B) South Africa



Source:



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“Cured”! Cured?

Post-Tuberculosis Lung Disease

The First International Post-Tuberculosis Symposium (Stellenbosch, South Africa), July 2019

INT J TUBERC LUNG DIS 24(8):820–828

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<http://dx.doi.org/10.5588/ijtld.20.0067>

VIEWPOINT

Post-tuberculosis lung health: perspectives from the First International Symposium

B. W. Allwood,¹ M. M. van der Zalm,² A. F. S. Amaral,³ A. Byrne,⁴ S. Datta,^{5,6,7} U. Egere,⁸
C. A. Evans,^{5,6,7} D. Evans,⁹ D. M Gray,¹⁰ G. Hoddinott,² O. Ivanova,¹¹ R. Jones,¹² G. Makanda,¹³
F. M. Marx,^{2,14} J. Meghji,¹⁵ S. Mpagama,¹⁶ J. G. Pasipanodya,¹⁷ A. Rachow,^{11,18} I. Schoeman,¹³
J. Shaw,¹ C. Stek,^{19,20} S. van Kampen,²¹ D. von Delft,¹³ N. F. Walker,^{15,22} R. S. Wallis,²³
K. Mortimer^{24,25}

Main findings of the meeting

The importance of extra-pulmonary consequences and **progressive impairment** throughout the life-course was identified, including **TB recurrence** and **increased mortality**.

Patient advocates emphasised the need to address the **psychological and social impacts** post-TB.

“When we started tuberculosis treatment, no-one told us that it would never leave us”.

Long-term all-cause mortality in people treated for tuberculosis: a systematic review and meta-analysis

Kamila Romanowski, Brett Baumann, C Andrew Basham, Faiz Ahmad Khan, Greg J Fox, James C Johnston

*Lancet Infect Dis 2019;
19: 1129–37*

Published Online
July 16, 2019
[http://dx.doi.org/10.1016/
S1473-3099\(19\)30309-3](http://dx.doi.org/10.1016/S1473-3099(19)30309-3)

Data from ten studies, reporting on 40'781 individuals and 6922 deaths.

The pooled standardised mortality ratio for all-cause mortality among people with TB, compared with the control group, was 2·91 (95% CI 2·21–3·84).

When restricted to people with confirmed treatment completion or cure, the pooled standardised mortality ratio was 3·76 (95% CI 3·04–4·66).

These findings (almost triple mortality) remained consistent when the data was stratified by tuberculosis type, country income category, patient demographic factors, and co-infection of HIV.

People treated for TB are at high risk of premature death after treatment. These individuals frequently have negative health effects after treatment, in addition to lower socioeconomic status and more comorbidities than the general population.

Tuberculosis related disability: a systematic review and meta-analysis

- Systematic review of TB-related disabilities.
- Proportions of common types of disabilities by country income level created.

Main findings, overall and by income level (I)

	Mental health disorders		Respiratory impairment	
	Number of studies	Prevalence (%)	Number of studies	Prevalence of disabilities
Overall	41	23.1	43	20.7
Countries income level				
High-income	3	4.3	9	14.9
Upper middle-income	14	30.6	12	15.3
Lower middle-income	18	31.3	19	56.1
Low-income	6	42.0	3	61.2
Type of TB				
Drug susceptible	24	21.9	24	33.1
Drug resistant	7	26.0	7	58.7

Re-visiting DALY calculations

Lifetime burden of disease due to incident tuberculosis: a global reappraisal including post-tuberculosis sequelae

Nicolas A Menzies, Matthew Quaipe, Brian W Allwood, Anthony L Byrne, Anna K Coussens, Anthony D Harries, Florian M Marx, Jamilah Meghji, Debora Pedrazzoli, Joshua A Salomon, Sedona Sweeney, Sanne C van Kampen, Robert S Wallis, Rein M G J Houben, Ted Cohen

*Lancet Glob Health 2021;
9: e1679-87*

- Globally, we estimated 122 million DALYs due to incident TB disease in 2019, with 58 million DALYs attributed to post-tuberculosis sequelae, **47% of the total burden** estimate.
- The burden of post-tuberculosis was spread over the remaining lifetime of TB survivors, with almost a third of total DALYs (28%) accruing 15 or more years after incident tuberculosis.



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The context for many people
with TB

Let's face it

Visit to a TB survivor in an urban poor area of Manila







CHARLES JOHN BARRA BONNYS
ALWAYS
NATED
ALIPAYO
ALIPAYO ASSOCIATION

NGC
PREDENT







Here a video of the paths in the slum going to the TB survivor would come.





The following slides contained videos,
presenting an interview with the TB survivor.

Question 1:

We met a long time ago, in 2008. You did not feel well then. What were your symptoms?



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Stigma and TB

TB - a severe «emotional challenge»

Stigma – what is it?

Often connected to the severe emotional distress.

Self-perceived stigma *“My life is collapsed completely. I am the only earning member in our family. I have been forced to send my wife to work in the rice mill. I feel bad for that.”* Bangladeshi male

Enacted stigma *“When I became sick, my mother-in-law and husband told me that they would not keep me there. They said I had to go to my father’s home. They told me that I had a dangerous disease.”* Bangladeshi female

The quotes are from the TB gender study Swiss TPH did for TDR/WHO.

Weiss, MG, Auer C, Somma DB, Abouihia A. Gender and tuberculosis: Cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi, and Colombia (2006). WHO/TDR SEB Report Series, Number 3.

(See also the special section in *Int J Tuberc Lung Dis* of July 2008 on TB and gender.)

Stigma – what is it?

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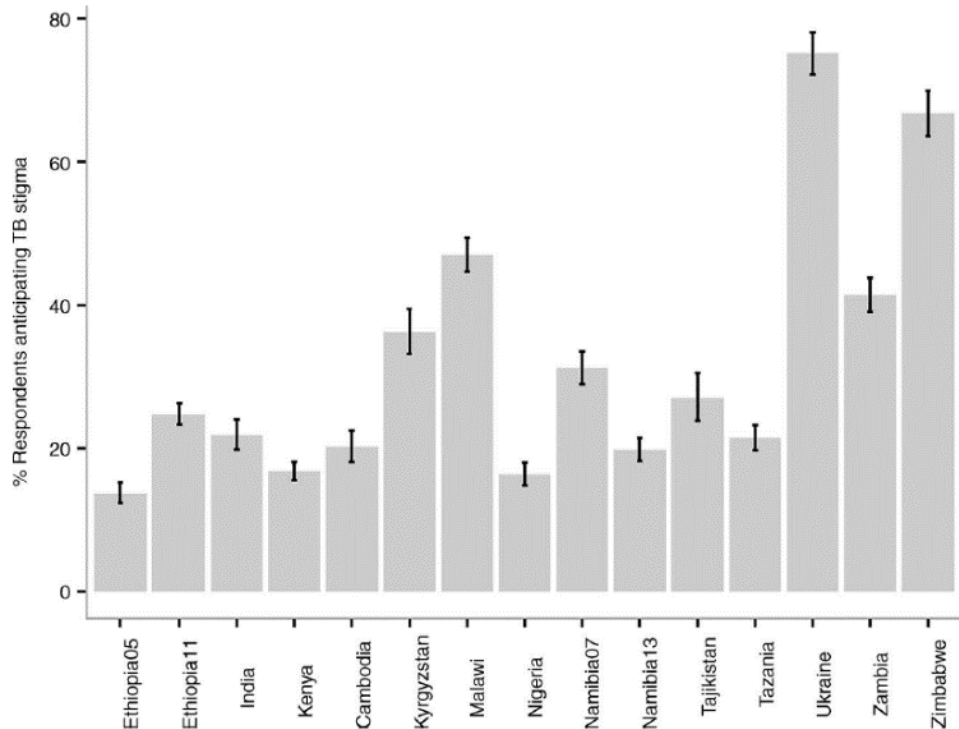
Courtesy stigma

Carry-over stigma experienced due to connection (e.g. familial ties) with a stigmatised person.

% of respondents' indication to keep it a secret if a family member has TB (approx. 17% to 75%)

Findings from 13 countries

Rood et al, Int J Tuberc Lung Dis Suppl. 11-2017





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Part 6: Consequences, final thoughts

TARGETS: postponed, postponed, postponed again!

70% case detection rate and 85% treatment success rate: 2000 → 2005

Reduce by 2015 the TB prevalence and death rates by 50% relative to 1990
42% 47%

0% households with catastrophic cost: 2020 → 2025

TARGETS: postponed, postponed, postponed again! (II)

Our 2022 targets: mostly not reached

The UN Political Declaration on TB's targets for UN member states to achieve by 2022:

- 1 SUCCESSFULLY TREAT 40 MILLION PEOPLE WITH TB**, including 3.5 million children (under 15 years of age).
- 2 SUCCESSFULLY TREAT 1.5 MILLION PEOPLE WITH DR-TB**, including 115,000 children.
- 3 PROVIDE TB PREVENTIVE THERAPY FOR AT LEAST 30 MILLION PEOPLE**
- 4 INCREASE GLOBAL INVESTMENT** for TB prevention, diagnosis, treatment and care to US\$ 13 billion annually.
- 5 INCREASE GLOBAL INVESTMENT FOR TB R&D** to US\$ 2 billion annually.

Why have we failed for the last 25 years?

Benatar & Upshur (2010) suggest that is a «failure of how human society is structured and functions rather than failures of medical practice»

«We can either begin to gear ourselves now towards the mind-set required to face the challenge of alleviating poverty and improving health, or we can ‘continue with business as usual’»

International J Tuberc Lung Dis 14(10), 2010

«One reason that millions of people affected by tuberculosis are left behind is an absence of coordinated, international action to combat poverty and inequality.»

Wingfield and colleagues in The Lancet, 24 March 2018

After more than two decades of work with urban poor communities of Callao, Peru, to generate evidence on the feasibility, acceptability, and impact of socio-economic support for people affected by tuberculosis.



We know the importance of poverty; but are we acting accordingly?

Engage world-leading experts on poverty and poverty alleviation in the TB community!

Abhijit Banerjee and Esther Duflo
Nobel prize laureates in 2019



Fight for a more equitable world, a more just world!

Ultimately a spiritual issue. «The undoubted pains were offset by increases in the extent to which respondents had been able to discover and share the capacity to *care for each other* in difficult times », the 10th World Happiness Report found.

The Guardian, 20 March 2023

Let's get realistic: people with TB need more than 6 months of pills!

Medical care and comprehensive support for at least two years.
(People with HIV get lifelong support!)



Thank you for your attention

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With thanks to:

Xavier Bosch-Capblanch (discussions, inspiration, sounding board, feedback to an earlier version of these slides)

Davide Cirrincione (preparing the videos)