The Socioeconomic Impact of Tuberculosis on Children and Adolescents
Main findings from a scoping review

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Review rationale

- Impact of poverty among adults is well established, little is known about impact of catastrophic costs and poverty on children
- Catastrophic costs affect the family unit or household, but we know little of how children fare in this equation
- No reason why this impact should be different from adults: need to go beyond the strictly ‘financial’ impact
- A largely under-investigated area of research
- We sought to map the quantity and type of evidence about the socioeconomic impact on children and adolescents
Beyond financial impact

- Childhood poverty is multidimensional
- Psychosocial domains as important as the material one
- Need for a long-term / life – course perspective
  - Physical and cognitive impairment
  - Trauma and loss

- Income loss/Unemployment
- Increased health expenditure
- Increased food insecurity
- Child/adolescent displacement
  - School withdrawn
  - Child labor

- Neglect/violence
- Attachment issues (anxiety, stress from separation)
- Orphanhood
- Stigma

- Caregiver income loss/Unemployment
- Growth deficit/malnourishment
  - School withdrawn

- Depression/anxiety
- Stigma/isolation
- Violence

Life Course

- Increased child poverty
  - Increased vulnerability and susceptibility to poor health
  - Reduced physical and emotional growth
  - Reduced mental health wellbeing
  - Reduced life opportunities
Review aim and objectives

To understand the socioeconomic impact of tuberculosis on children and adolescents

Specific objectives:

1. To explore how this socioeconomic impact has been conceptualized and operationalised in the literature (beyond financial impact)
2. To appraise the extent to which the evidence available support an a priori defined conceptual framework and what knowledge gaps emerge.
3. To understand whether the socioeconomic impact differs when the child is the primary TB patient (i.e. TB affects directly children and adolescents) and when the primary patient/s is one of the household member and possibly a caregiver (i.e. TB affects indirectly children and adolescents)
4. To investigate the potential life-course consequences of experiencing TB in childhood and adolescence

Review methods

Design          | Scoping review
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Inclusion criteria |  
- Children or adolescents from 0-19 years of age  
- Tuberculosis, including active and latent TB; drug susceptible and drug resistant TB; pulmonary and extra-pulmonary  
- Qualitative, quantitative or mixed methods  
- Social, economic, or cultural impact in short and long term
Exclusion criteria |  
- TB vaccines or medications development  
- Socioeconomic causes of TB without a focus on impacts  
- Clinical outcomes or case reviews of TB treatment  
- Letters or editorials without reporting research results
Search strategy |  
- Databases: Proquest, CINAHL, Medline(Pubmed), OpenGrey, Google Scholar  
- Articles between January 1st 1990 to April 7th, 2021 (GS: First 20 pages)  
- Studies in any language  
- Search terms in three blocks: (1) Tuberculosis; (2) Child or adolescents; (3) Socioeconomic impacts as defined by the conceptual framework
Evidence synthesis |  
- Narrative
Papers included: PRISMA flowchart

- Records identified from: Pubmed (n=10531); CINAHL (n=2029); Proquest (n=216); SCOPUS (n=161); Opengrey (n=504); Google Scholar (n=200); TOTAL (n=13,641)

- Records removed before screening: Duplicate records removed (n = 1546)

- Records screened (n = 12095)

- Records excluded (n = 11972)

- Reports sought for retrieval (n = 123)

- Reports not retrieved (n = 3)

- Reports excluded:
  - Clinical study (n = 3)
  - No child/adolescent focus (n = 35)
  - No socio-economic impact (n = 32)
  - No TB focus (n = 1)

- Reports assessed for eligibility (n = 120)

- Reports excluded:
  - Clinical study (n = 3)
  - No child/adolescent focus (n = 35)
  - No socio-economic impact (n = 32)
  - No TB focus (n = 1)

- Studies included in review (n = 49)

Studies description

- WHO Region
  - Africa (N. 18)
  - South East Asia (N. 9)
  - Americas (N. 7)
  - Western Pacific (N. 5)
  - Eastern Mediterranean (N. 3)

- Methods
  - Qualitative (N.30)
  - Quantitative (N.9)
  - Mixed-methods (N.3)
  - Reviews (N.7)

- Type of TB*
  - Not specified (N.36)
  - TB meningitis (N. 5)
  - PTB (N. 4)
  - MDR-TB (N. 6)
  - Any type of TB (N. 8)
  - TB contact (N. 1)
  - IPT management (N. 1)

- Study population
  - TB directly affecting children and/or adolescents (N.19)
  - TB indirectly affecting children and/or adolescents (N.30)

*Total > 49 as some studies reported more than one type of TB
### Socioeconomic impact assessment

**Type of impact**

<table>
<thead>
<tr>
<th>Impact Description</th>
<th>EDUCATION</th>
<th>FINANCIAL</th>
<th>PSYCHOSOCIAL</th>
<th>Grand Total</th>
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<tbody>
<tr>
<td>challenge in administering medication to children</td>
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<td>6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>challenge to accompanying child</td>
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<td>1</td>
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<tr>
<td>child separation from family</td>
<td></td>
<td></td>
<td>9</td>
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</tr>
<tr>
<td>child separation from friends</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>childcare arrangements</td>
<td>7</td>
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<tr>
<td>children contracting TB from family members</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>children financing TB treatment costs</td>
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</tr>
<tr>
<td>cognitive skills and behaviour</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>death or abandonment by parent</td>
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<td>2</td>
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<tr>
<td>dissolution of parental relationships</td>
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<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>employment impact</td>
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<td></td>
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<tr>
<td>exclusion</td>
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<td>financial impact</td>
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<tr>
<td>impact on mental health</td>
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<tr>
<td>impact on nutrition</td>
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<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>impact on parental mental health (stress)</td>
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<td></td>
<td>5</td>
<td></td>
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<tr>
<td>impact on schooling</td>
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<td>14</td>
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<tr>
<td>impact on social relations</td>
<td></td>
<td></td>
<td>5</td>
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<tr>
<td>self esteem</td>
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</tr>
<tr>
<td>stigma/discrimination</td>
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<td>20</td>
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<tr>
<td>TB patient as a burden to caregivers</td>
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<tr>
<td>Grand Total</td>
<td>14</td>
<td>30</td>
<td>66</td>
<td>115</td>
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</table>

**Socioeconomic impact assessment by study method**

<table>
<thead>
<tr>
<th>Study method/ type of impact</th>
<th>Direct TB</th>
<th>Indirect TB</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mixed methods</td>
<td>0</td>
<td>3</td>
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</tr>
<tr>
<td>Financial</td>
<td>0</td>
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<td>1</td>
</tr>
<tr>
<td>Psychosocial</td>
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<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Qualitative</td>
<td>14</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>Financial</td>
<td>3</td>
<td>0</td>
<td>3</td>
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<tr>
<td>Psychosocial</td>
<td>10</td>
<td>14</td>
<td>24</td>
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<tr>
<td>Quantitative</td>
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<td>6</td>
<td>10</td>
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<tr>
<td>Education</td>
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</tr>
<tr>
<td>Financial</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Psychosocial</td>
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<td>3</td>
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</tr>
<tr>
<td>Review</td>
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<td>Education</td>
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<tr>
<td>Financial</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Grand Total</td>
<td>19</td>
<td>30</td>
<td>49</td>
</tr>
</tbody>
</table>
SA(1) review the slide for table accuracy and circle thingy
Salla Atkins (TAU); 28.5.2021

SA(2) done already? Cannot see.
Salla Atkins (TAU); 28.5.2021
### Financial impact and education: Closely related

<table>
<thead>
<tr>
<th>Education and child development</th>
<th>6 qualitative studies</th>
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</thead>
<tbody>
<tr>
<td>Impact on treatment on cognitive skills and behaviour</td>
<td>South Africa</td>
</tr>
<tr>
<td>Scholastic attainment following treatment</td>
<td>South Africa, India, Brazil, China</td>
</tr>
<tr>
<td>Impact of financial situation on education</td>
<td>India</td>
</tr>
<tr>
<td>Conflict between clinic appointments and school attendance</td>
<td>South Africa, Brazil, India, China</td>
</tr>
<tr>
<td>Anxiety and stress regarding falling behind</td>
<td>South Africa, China</td>
</tr>
</tbody>
</table>

- Conflict between a need to earn a living and a child’s treatment
  - Peru, South Africa, China

- Prohibitive cost of travel to visit children
  - South Africa, Botswana

- Overall impact on family finances
  - Peru, South Africa, India, China, Botswana

- Nutrition
  - India

> “I stopped everything, I stopped my life to take care of Lílian (...) I took her out of school, she spent a year without study” – Machado et al 2015; Brazil

### Psychosocial impact: Stigma and mental wellbeing

<table>
<thead>
<tr>
<th>Stigma - Perceived and enacted (discrimination)</th>
<th>14 qualitative studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma in general</td>
<td>China, South Africa, Nepal, Brazil</td>
</tr>
<tr>
<td>Impact on marriage potential of adolescents and young adults</td>
<td>Ghana; India; Vietnam</td>
</tr>
<tr>
<td>Worry and anxiety, prevented disclosure and potentially treatment</td>
<td>Lesotho, Brazil, Peru, South Africa</td>
</tr>
</tbody>
</table>

- Parental anxiety over separation/infecting child/finances/stigma
  - South Africa, China, Peru, Egypt, Malaysia

- Adolescent stress and anxiety – school and dependence
  - China

> “Patients and families were unable to avert poverty and the total-and potentially catastrophic-costs of accessing care, while experiencing a significant social emotional and psychological toll, for some in the form of strained familial relationships and social stigma.” (Hutchinson 2017; China)
Psychosocial impact: Separation and childcare

**Separation**  
11 qualitative studies

- Transport cost prohibitive to visit a child in hospital  
  - South Africa
- Self imposed distancing within the household  
  - India; Bangladesh; VietNam; Thailand; China; Peru; Egypt (Sudan)
- Children not being allowed to play with friends (stigma)  
  - China; Peru; Nepal; South Africa
- Child not being able to see their caregiver  
  - South Africa; Vietnam; Egypt; Bangladesh; Ghana

**Childcare**  
5 qualitative studies

- Parents’ TB impacting on their caregiving  
  - Nepal, Ghana, China, Venezuela
- Change of caregiving roles  
  - Ghana, Bangladesh, China, Nepal, Egypt, Vietnam, Peru,
- Challenges in medication administration  
  - Brazil, South Africa, Botswana
- Adolescents’ dependence on their parents  
  - China, (Botswana)

Impact findings: quantitative studies

<table>
<thead>
<tr>
<th>Socioeconomic domain</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Financial</strong></td>
<td>Costs</td>
</tr>
<tr>
<td></td>
<td>Job loss / income loss</td>
</tr>
<tr>
<td></td>
<td>Costs</td>
</tr>
<tr>
<td></td>
<td>Malnutrition</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>Reduced cognitive skills due to malnutrition</td>
</tr>
<tr>
<td></td>
<td>School withdrawn</td>
</tr>
<tr>
<td></td>
<td>Cognitive skills impairment from medication and disease</td>
</tr>
<tr>
<td><strong>Psychosocial – mental health and wellbeing</strong></td>
<td>Anxiety, depression, attention deficit disorder, antisocial behavior</td>
</tr>
<tr>
<td><strong>Psychosocial – stigma</strong></td>
<td>Isolation, discrimination</td>
</tr>
<tr>
<td></td>
<td>Discrimination</td>
</tr>
<tr>
<td></td>
<td>Loss of marriage potential / opportunities</td>
</tr>
<tr>
<td><strong>Psychosocial – childcare limitations</strong></td>
<td>Increased caregiver responsibility</td>
</tr>
<tr>
<td><strong>Psychosocial – attachment and separation</strong></td>
<td>Fear of contagion</td>
</tr>
</tbody>
</table>
Findings from 7 reviews

- Impact on:
  - Child caregiving
  - Economic activity
  - Health
  - Education
  - Nutrition

- Effect on caregiving and children’s outcomes poor when affecting their mothers (N.3)

- Cognitive, motor, language and behaviour sequelae for TB Meningitis

- Households changing consumption patterns to finance illness, impacting on nutrition and possibly growth and development
Discussion

- As expected, there is little focus on TB among children or adolescents
- Most studies had children or adolescents as part of a larger sample without disaggregation
- Studies among/about adolescents were severely underrepresented
- The socioeconomic impacts of TB disease, whether directly for children or adolescents are interrelated
- Key areas require more research: including how family economics in context of TB impact specifically on children and adolescents
- Findings suggest that TB affects a household economically, but also causes substantial psychological distress and severe damage at multiple levels
Conclusions

- Results are preliminary, but scale of problem likely to be big
- Key barriers persist to fully quantify and understand the problem:
  1. Significant methodological heterogeneity in terms of design, impact operationalisation and different measurement strategies
  2. Unclear understanding of how these measures overlap and interact with each other
  3. No evidence of how experiencing TB in childhood affect the life trajectory of these children, other words whether this impact is long-term and somewhat affects opportunities in life
  4. No study as yet on the role of social protection at mitigating this impact or indeed intervention studies in the area

Acknowledgements

And the WHO Global TB programme for support