

1 **Title:** Beyond TB-treatment completion: The lasting impact of pulmonary TB on incomes and
2 livelihoods in an urban setting in sub-Saharan Africa

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4 **Authors:** Jamilah Meghji^{1,2}, Stefanie Gregorius^{1,3}, Jason Madan⁴, Fatima Chitimbe², Rachael Thomson¹,
5 Jamie Rylance^{1,2}, Ndazona PK Banda⁵, Stephen B Gordon^{1,2}, Elizabeth L Corbett^{2,9}, Kevin Mortimer^{1*},
6 S Bertel Squire^{1*}

7 ¹Department of Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, UK

8 ²Malawi Liverpool Wellcome Trust Clinical Research Programme, Blantyre, Malawi

9 ³Gesellschaft für Internationale Zusammenarbeit, Bonn, Germany

10 ⁴Warwick Clinical Trials Unit, University of Warwick, Warwick, UK

11 ⁵Department of Medicine, Queen Elizabeth Central Hospital, Blantyre, Malawi

12 ⁹Department of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine,
13 London, UK

14 *Joint last authors

15

16 **Corresponding author:** Dr Jamilah Meghji; Department of Clinical Sciences, Liverpool School of
17 Tropical Medicine, Pembroke Place, Liverpool. United Kingdom. L3 5QA; Tel: 0151 705 2632; Email:
18 Jamilah.meghji@lstm.ac.uk

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30 **Abstract**

31 **Background**

32 Mitigating the socioeconomic impact of tuberculosis is key to the WHO End TB Strategy. However,
33 little known about socioeconomic wellbeing beyond TB-treatment completion. In this mixed-methods
34 study we describe socioeconomic outcomes after TB-disease in urban Blantyre, Malawi, and explore
35 pathways and barriers to financial recovery.

36 **Methods**

37 Adults ≥ 15 years successfully completing treatment for a first episode of pulmonary TB under the
38 National TB Control Programme were prospectively followed-up for 12-months. Socioeconomic,
39 income, occupation, health-seeking and cost data were collected. Determinants and impacts of
40 ongoing financial hardship were explored through illness narrative interviews with purposively
41 selected participants.

42 **Results**

43 405 participants were recruited from February 2016 - April 2017. Median age was 35-years (IQR: 28-
44 41), 67.9% (275/405) were male, and 60.6% (244/405) were HIV-positive. Employment and incomes
45 were lowest at TB-treatment completion, with limited recovery in the following year: fewer people
46 were in paid work (63.0% [232/368] vs. 72.4% [293/405], $p=0.006$), median incomes were lower
47 (\$44.13 [IQR: \$0-106.15] vs. \$72.20 [IQR: \$26.71-173.29], $p<0.001$), and more patients were living in
48 poverty (earning $< \$1.90/\text{day}$: 57.7% [211/366] vs. 41.6% [166/399], $p<0.001$) 1-year after TB-
49 treatment completion compared to before TB-disease onset. Half of the participants (50.5%, 184/368)
50 reported ongoing dissaving (use of savings, selling assets, borrowing money) and 9.5% (35/368)
51 reported school interruptions in the year after TB-treatment completion. Twenty-one participants
52 completed in-depth interviews. Reported barriers to economic recovery included financial insecurity,
53 challenges rebuilding business relationships, residual physical morbidity, and stigma.

54 **Conclusions**

55 TB-affected households remain economically vulnerable even after TB-treatment completion, with
56 limited recovery in income and employment , persistent financial strain requiring dissaving, and school
57 interruptions. Measures of the economic impact of TB-disease should include the post-TB period.
58 Interventions to protect the long-term health and livelihoods of TB survivors must be explored.

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60 **Key words:** Pulmonary tuberculosis, TB sequelae, post-TB lung disease, health economics, social
61 determinants

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64 **Key messages**

65 **What is the key question?**

66 What is the lasting socioeconomic impact of TB-disease on patients and households: can we assume
67 full economic recovery after successful treatment completion, and what are the pathways and barriers
68 to this recovery?

69 **What is the bottom line?**

70 Many TB-affected households experience a limited recovery in income and employment in the year
71 after TB-treatment completion, with ongoing dissaving and school interruptions. Barriers to economic
72 recovery include persistent financial insecurity, challenges rebuilding business relationships, residual
73 physical morbidity, and stigma.

74 **Why read on?**

75 The socioeconomic impact of TB disease persists well beyond TB treatment completion –
76 understanding this process, and developing strategies to mitigate this, will be crucial if we are to meet
77 the WHO End TB Strategy target of eliminating TB-related catastrophic costs by 2030, and improve
78 the long-term wellbeing of TB survivors.

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88 **Introduction**

89 An estimated 10 million incident cases of tuberculosis (TB) disease occurred globally in 2018, one
90 quarter of which occurred in Africa where 29% of patients are HIV co-infected.(1) The early costs
91 associated with TB-disease in low-income settings are well recognised: despite provision of free TB-
92 treatment services within the public sector, patients incur direct costs related to health seeking,
93 indirect costs from lost income, and dissaving (the use of savings, borrowing of money, or sale of
94 household assets) over the course of illness, diagnosis, and treatment.(2, 3) These early costs are
95 widespread, frequently profound, and have been associated with adverse TB-treatment outcomes
96 including treatment failure, loss to follow-up or death.(4) However surprisingly little is known about
97 the lasting economic impact of disease beyond TB-treatment completion, and facilitators or barriers
98 to economic recovery.

99 The physical effects of pulmonary-TB (PTB) are felt long after treatment completion: mortality rates
100 are three to four fold higher amongst TB survivors compared to TB-naïve adults,(5) TB survivors have
101 a high risk of disease recurrence,(6) and the burden of residual post-TB lung disease (PTLD) is
102 marked.(7, 8) Limited data are available on long-term psychosocial morbidities, but reports from TB-
103 affected communities suggest these are considerable.(9, 10) It is plausible that the ongoing physical
104 and psychosocial impact of TB disease is accompanied by long-term economic harm. Understanding
105 this link will be key to improving the overall wellbeing of TB survivors,(11, 12) and essential if we are
106 to meet the WHO End TB Strategy target of eliminating catastrophic costs for all TB-affected
107 households by 2030.(13)

108 Malawi is one of the poorest countries in the world,(14) with an estimated national TB incidence of
109 181/100,000 in 2018.(15) In this mixed-methods study, nested within a prospective cohort of adults
110 successfully treated for PTB in urban Blantyre, Malawi,(16) we describe economic morbidity in the
111 year after TB-treatment completion, and explore its determinants and impacts.

112 **Methods**

113 Full methods of the parent cohort study have been described previously.(16) In brief, 405 sequential
114 HIV-positive and -negative patients successfully completing treatment for PTB were recruited
115 between February 2016 and April 2017 in urban Blantyre, Malawi. Inclusion criteria were age ≥ 15 yrs,
116 and successful completion of treatment for a first episode of TB as defined by the National TB Control
117 Programme (NTP). We excluded patients who had been treated for multidrug resistant disease.

118 Study visits were conducted within one-month of TB-treatment completion, and at 6- and 12-months
119 thereafter. Questionnaires were completed in the local language, Chichewa. We collected data on
120 demographics, socioeconomic situation (SES), TB and respiratory symptoms, quality of life, main
121 occupation and income at each study visit. Patients provided information on occupation and income
122 prior to TB illness from memory. Data on ongoing health seeking and associated direct and indirect
123 costs were collected prospectively. Occupation was described using categories defined by the Malawi
124 Demographic Health Survey 2015-16.(17) Income and dissaving questions were adapted from the
125 STOP TB costing questionnaire.(18) Monthly income was defined as money received by the individual,
126 from work or other means, and was standardised into US dollars (S1 Appendix). Socioeconomic status
127 was defined at TB-treatment completion using the Malawi EquityTool 2012.(19) Information on TB
128 microbiology at diagnosis was collected from NTP registers. HIV care is provided in a separate vertical
129 programme in this setting, and patient-held health passports were therefore reviewed to ascertain
130 HIV and ART status, with HIV testing offered to all those with unknown serostatus who had not had a
131 documented test within the past 1-month (Serial testing with Determine 1/2™; Alere, USA / Uni-
132 Gold™; Recombigen® HIV, Trinity Biotech, Ireland). CD4 counts were measured in all HIV-positive
133 participants.

134 Illness narrative interviews were conducted with purposively selected patients who had completed
135 TB-treatment ≥ 12 -months previously, in order to explore their experiences of TB illness and
136 recovery.(20) Recruitment ensured variation in gender, HIV status and socioeconomic status, and was

137 stopped at the point of saturation. Interviews were conducted in Chichewa by a Malawian research
138 assistant in a private location of the participant's choice, most frequently their home, using a pre-
139 designed interview guide structured around the illness trajectory (life before, during and after TB-
140 treatment), which addressed issues of health, healthcare seeking behaviour and experiences,
141 socioeconomic wellbeing, family and community life (S2 Appendix). Interviews were audio-recorded,
142 transcribed into Chichewa, and translated into English. Notes and observations recorded by the study
143 team were included as primary data.

144 All participants were compensated for their time and travel costs, in keeping with local ethics
145 guidelines. The amount received over the 1-year study period was the equivalent of \$15.30 USD per
146 participant.

147 **Sample size**

148 The sample size of 400 was pre-determined by the parent study, in order to allow the prevalence of
149 post-TB lung disease (PTLD) to be estimated with +/- 5% precision and 95% confidence.

150 **Data analysis**

151 Quantitative data were analysed using Stata 15 (StataCorp). Health economic parameters are
152 presented for each time point using median (interquartile range [IQR]) values. Chi-square, Fisher's
153 exact or Wilcoxon rank sum tests were used for comparisons between participant groups, and
154 McNemar's test used for within-group comparisons over time. Individuals were classified by
155 occupation into those with paid work (self-employed, formally employed (in government, non-
156 governmental organisations, private sector), farming, domestic work, informal piece-work), unpaid
157 work (housework, students), and no work (retired, unemployed). Participants were considered to be
158 living in poverty if earning <\$1.90/day.(21)

159 Logistic and linear regression models were used to explore the relationship between post-TB lung
160 disease and economic outcomes, controlling for pre-specified covariates recorded at TB treatment

161 completion (age, gender, HIV status, TB microbiology, educational level). Qualitative data were
162 analysed thematically using an inductive framework approach(22): transcripts were discussed, a
163 coding and thematic framework was developed iteratively, relationships between codes and themes
164 were identified manually, and emerging links were cross-checked by discussion with the study team
165 and triangulation with study team notes.

166 **Approvals & permissions**

167 The Liverpool School of Tropical Medicine (LSTM) sponsored the study. Ethical approval was obtained
168 from the LSTM (15.040RS) and Malawi College of Medicine Research Ethics (P.10/15/1813.
169 P.06/17/2020) Committees. All participants provided written informed consent.

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172 **Results**

173 **Patient population**

174 450 PTB survivors were screened, and 405 met inclusion criteria (Figure 1). The 37/405 (9.1%)
 175 participants who did not complete the final study visit had similar characteristics (age, sex, HIV status,
 176 TB microbiology, SES) to those who completed the study, but lower average CD4 counts at TB
 177 treatment completion (113 cells/ μ L [IQR: 62-197] vs. 244 cells/ μ L [IQR: 137-398], $p=0.007$) (S3
 178 Appendix).

179 The majority of participants (67.9% [275/405]) were male, 77.3% (313/405) had microbiologically
 180 proven PTB disease, and 60.6% (244/403) were HIV-positive. Over half were from the lowest three
 181 urban wealth quintiles (54.3% [202/372]) and 38.0% (154/405) had not attended school beyond
 182 primary level. The 21 participants purposively selected for in-depth interviews had similar
 183 demographic and socioeconomic characteristics to other study participants, but a longer duration of
 184 illness prior to TB-treatment (13.0 vs. 8.7 weeks, $p<0.001$), and less formal education (38.1 [8/21] vs.
 185 63.3% [243/384] beyond primary school, $p=0.021$) (Table 1).

Table 1: Participant characteristics for participants included/ not included in nested qualitative work (n=21)

Participant characteristic	Parent study only (n=384)	Parent & qualitative study (n=21)	p-value [∞]
Demographic data			
Age (yrs) (median, IQR)	34 (28 - 41)	35 (32 - 41)	0.246
Male sex (n, %)	261 (68.0%)	14 (66.7%)	0.901
Positive TB microbiology* at diagnosis (n, %)	299 (77.9%)	14 (66.7%)	0.233
Self-reported illness duration prior to TB-treatment (weeks) (median, IQR)	8.7 (4.3 – 13.0)	13.0 (13.0 – 52.2)	<0.001
HIV-infected at TB-treatment completion (n=403) [^]	232 (60.7)	12 (57.1)	0.743
Antiretroviral treatment use at TB-treatment completion (n, %) (n=244)	215 (92.7)	9 (75.0)	0.030
CD4 if HIV-positive at TB-treatment completion (cells/ μ L) (n=242)	229 (127 - 397)	214 (126 – 420)	0.941
Maximum education level > primary school (n, %)	243 (63.3%)	8 (38.1%)	0.021
Urban SES quintile (n=372) [†]			0.449
- Poorest	21 (6.0%)	1 (4.8%)	
- 2 nd poorest	79 (22.5%)	6 (28.6%)	
- Middle	87 (24.8%)	8 (38.1%)	
- 2 nd most wealthy	111 (31.6%)	3 (14.3%)	
- Most wealthy	53 (15.1%)	3 (14.3%)	

*Microbiology positive if smear, culture or Xpert MTB/RIF positive; [^]HIV status missing for 2 study participants; [†] Urban household wealth quintiles calculated from household characteristic and asset data, using a tool validated by the Malawi

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187 **Economic morbidity, after TB-treatment completion**

188 Occupation and income

189 The proportion of participants in paid work fell during TB disease to a nadir of 54.8% (222/405) at TB-
190 treatment completion, with 36.5% (148/405) unemployment (National unemployment rates 5.4 –
191 5.7% between 2016-2018) (Table 2).(23) One year later, fewer participants were in paid work than
192 prior to disease (63.0% [232/368] vs. 72.4% [293/405], p=0.003), and the proportion of self-employed
193 business people had not returned to previous levels (pre-illness: 32.8% [133/405]; TB-treatment end
194 26.9% [109/405]; 1-year post treatment completion 25.8% [95/368], p=0.026). Patterns were similar
195 for HIV-positive and negative participants (Figure 2).

196 A fifth of participants (20.7%, 74/358) moved from paid or unpaid work prior to TB disease, to no work
197 by 1-year after TB-treatment completion. Half of these individuals lost work during TB disease and
198 treatment (47.3%, 35/74), and half lost work in the year after treatment completion (52.7%, 39/74).
199 Loss of work was more common in the lowest two vs. highest three socioeconomic quintiles (28.6%
200 [30/105] vs. 15.9% [39/245], p=0.004). Amongst those who were employed prior to disease, 11.0%
201 (17/154) had become self-employed by the end of follow-up.

202 Many participants did not know their total household income, including 40.7% (53/130) of women.
203 However, individual incomes followed a similar pattern to that seen with work: median income was
204 highest prior to TB illness, falling to a nadir at TB-treatment completion, with minimal recovery in the
205 following year (Figure 3). Monthly incomes fell by a median of \$11.59 (IQR for income difference: -
206 72.20 to +12.89) from pre-illness to 1-year post treatment completion, with the greatest loss amongst
207 those who were originally self-employed (-\$74.96 [IQR: -231.99 to -7.01]). There was little difference

208 in the median income loss experienced by the poorest two and wealthiest three socioeconomic
209 quintiles over this period (-\$11.78 [IQR: -56.73 to +16.63] vs. -\$10.77 [IQR:-77.23 to +11.60], p=0.556).

210 The proportion of participants living in poverty increased from 41.6% (166/399) to 57.7% (211/366)
211 over this time (p<0.001), but the proportion of participants reporting that they were the highest
212 earner in the household did not change (pre-illness: 57.0% [231/405]; TB-treatment end 54.6%
213 [221/405]; 1-year post treatment completion 60.6% [223/368]).

214 Health care costs

215 Direct health care costs in the year after TB-treatment completion were limited. Amongst those
216 contributing any follow up data, two thirds of participants (66.8%, 254/380) had ≥1 outpatient visit,
217 including 264 planned and 173 unscheduled visits, and 6.3% (24/380) had ≥1 inpatient admission. The
218 majority of both outpatient visits (95.0%, 415/437) and admissions (88.9%, 24/27) occurred within the
219 public sector. The majority of planned visits (87.1%, 230/264) were for appointments at ART clinics.

220 The median direct cost of an outpatient visit, including both planned and unscheduled visits, was \$1.05
221 (IQR: 0.14 to 2.09), including expenditure for clinic fees and medications, and travel, accommodation,
222 food, and phone time for patients and guardians. The median time taken for any outpatient visit was
223 three hours (IQR: 2 to 4), and loss of income was reported for 53.1% (232/437) of these visits, with
224 average income time loss of one hour (IQR: 0 to 1) only. Guardians attended with study participants
225 for a minority (8.2%, 36/437) of outpatient visits, and on these occasions rarely reported income time
226 lost (5.6%, 2/36).

227 The median duration of the 27 inpatient admissions was four nights (IQR: 2 to 19), with median direct
228 costs of \$19.62 (IQR 13.30 to 61.91). Lost income was reported by participants for under a third of
229 admissions (29.6%, 8/27), and although participants were accompanied by a guardian for the majority
230 of these admissions (88.9%, 24/27) only one guardian reported lost income.

231 The proportion of participants attending ≥ 1 outpatient visit was similar in the lowest two, and top
 232 three socioeconomic quintiles (66.2% [73/107] vs. 66.8% [177/265], $p=0.790$), and median per-visit
 233 costs were similar between socioeconomic groups (\$0.84 vs. \$1.12, $p=0.578$). A higher proportion of
 234 participants from the lowest two socioeconomic quintiles required hospital admission compared to
 235 the top three quintiles (10.3% [11/107] vs. 4.9% [13/265], $p=0.056$) but median per-admission costs
 236 were similar between groups (\$19.27 vs. \$19.97, $p=0.750$).

237 **Impact of economic morbidity, on patients and households**

238 Interruption of a child’s schooling due to the financial impact of illness was reported by 17.0% (69/405)
 239 and 9.5% (35/368) of TB-affected households in the years prior to and after TB-treatment completion,
 240 respectively. School interruptions were more common in the lowest two, compared to the top three,
 241 socioeconomic quintiles (32.1% [34/106] vs. 17.7% [45/255], $p=0.003$).

242 Over a third of participants (37.0%, 150/405) reported that TB had had a severe financial impact on
 243 their household, graded $\geq 4/5$ on a Likert scale, at TB-treatment completion. This proportion was 16.9%
 244 (62/368) 1-year later. Self-reported severe financial impact was more common in the lower
 245 socioeconomic strata (58.5% [62/106] vs. 37.4% [96/257], $p<0.001$).

246 Almost three quarters of participants reported dissaving by the point of TB-treatment completion
 247 (73.6%, 298/405), and half reported dissaving in the following year (50.5%, 186/368), at values of
 248 54.9% (IQR:24.3 to 146.4%) and 53.2% (IQR:19.0 to 125.7%) of the baseline monthly income prior to
 249 TB illness respectively. Over a quarter (26.7%, 27/101) of those with no dissaving during TB disease
 250 and treatment did go on to report dissaving in the year after treatment completion. Dissaving was
 251 more common in lower SES quintiles, but with lower absolute and relative values (Table 2).

Table 2: Prevalence of dissaving in the years prior to and after TB-treatment completion, stratified by wealth quintiles, and standardised into USD or by pre-TB individual income with median(IQR) values given #

Time period	Malawi urban wealth quintile (Q1 - Q5)*					All participants*
	Q1 (n=56) Wealthiest	Q2 (n=114)	Q3 (n=95)	Q4 (n=85)	Q5 (n=22) Poorest	
Prior to TB illness (n=372)						

Pre-disease monthly income (USD)	108.30 (0 – 270.76)	83.03 (39.71 – 287.73)	63.18 (25.27 – 158.84)	61.37 (25.27 – 111.91)	41.52 (10.83 – 121.30)	72.20 (25.27 – 173.29)
During TB illness and treatment (n=372)						
Proportion incurring any dissaving	28 / 56 (50.0%)	83 / 114 (72.8%)	75 / 95 (79.0%)	68 / 85 (80.0%)	20 / 22 (90.9%)	274/372 (73.7%)
Value of dissaving, if experienced (USD)**	166.9 (94.58 – 423.50)	69.54 (34.77 – 173.85)	38.94 (15.30 – 115.44)	27.82 (16.69 – 80.95)	33.38 (13.91 – 100.39)	55.63 (20.86 – 139.08)
% of pre-disease monthly income	89.2% (34.1 – 266.0)	58.2% (24.1 – 152.3)	53.9% (20.7 – 111.2)	41.6% (23.4 – 104.6)	44.1% (35.0 – 173.4)	54.9% (24.3 – 146.4)
Year after TB-treatment completion (n=360)						
Proportion incurring any dissaving	12 / 55 (21.8%)	48 / 107 (44.9%)	61 / 92 (66.3%)	50 / 84 (59.5%)	13 / 22 (59.1%)	184 / 360 (51.1%)
Value of dissaving, if experienced (USD)**	167.6 (59.36 – 272.35)	69.83 (24.1 – 152.3)	39.11 (20.95 – 92.18)	37.71 (13.97 – 69.83)	20.95 (11.17 – 31.42)	41.9 (20.95 – 94.97)
% of pre-disease monthly income	112.5% (49.0 – 232.1)	77.6% (19.0 – 198.7)	59.3% (24.2 – 89.3)	41.9% (13.6 – 120.7)	29% (15.0 – 58.0)	53.2% (19.0 – 125.7)

#Values given for those who experienced dissaving, only;

*Baseline SES missing for 33 participants – data included for 372 participants only;

**Standardisation into USD using exchange rates at mid-points of first and last study visits

252 Patterns of dissaving varied by SES group, and over time (Figure 4). All wealth strata used savings
253 during the period of TB illness and treatment, but only the wealthiest quintiles used savings during
254 the subsequent year. Borrowing money was most common amongst lower socioeconomic strata, and
255 over half of those in the lowest quintiles reported borrowing money in the year after TB-treatment
256 completion. The most common sources of borrowed money were friends (44.8%, 172/384), family
257 (26.8%, 103/384), and the black market (10.2%, 39/348) – use of the latter increased from 10.7%
258 (19/177) in the first year to 17.1% (25/246) in the second year. The sale of assets to cover costs due
259 to illness during the period of TB illness and treatment was also more common in poorer groups. The
260 most common items sold were household items (35.0%, 134/383) and mobile phones (10.7%, 41/383).
261 Potentially income-generating assets sold included land (1.3%, 5/383), livestock (3.7%, 14/383), and
262 means of transport (4.7%, 18/383).

263 Relationship with TB-retreatment

264 TB-retreatment was initiated in 15/405 (3.7%) of participants, of whom five died, one relocated, and
265 nine completed study follow-up. Socioeconomic outcomes were worse amongst those who survived
266 and completed follow-up: by one year after TB-treatment completion, a higher proportion of those
267 receiving retreatment had lost work (33.3% [3/9] vs. 20.3% [71/349], $p=0.342$), experienced dissaving
268 (100% [9/9] vs. 79.4% [285/359], $p=0.128$), or reported a severe financial impact from TB disease
269 (33.3% [3/9] vs. 16.4% [59/359], $p=0.181$), compared to those who did not receive retreatment.
270 However, none of these differences were statistically significant.

271 **Relationship between physical and economic morbidity**

272 Almost a third of participants had abnormal spirometry (30.7%, 103/336) or regular respiratory
273 symptoms (30.7%, 113/368) 1-year after TB treatment completion. Those with abnormal spirometry
274 were more likely to have lost work in the period from TB-illness onset, compared to those with normal
275 spirometry (OR 1.87, 95% CI: 1.02 to 3.41). Those with residual symptoms were more likely to report
276 that TB had had a severe financial impact on the household, compared to those without symptoms
277 (2.02, 95% CI: 1.10 to 3.68). Those with chest symptoms limiting their ability to keep up with peers
278 (17.4%, 64/368), interfering with work (12.2% , 45/368), or limiting activities (4.4%, 16/368) at 1-year
279 were significantly more likely to have experienced both of these outcomes. No significant association
280 was observed between these measures of physical morbidity and the use of dissaving or change in
281 income from pre illness to 1-year post TB-treatment completion (Table 3).

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Table 3: Adjusted odds ratios for associations between respiratory morbidity and economic outcomes over the study period / at 1-year post treatment completion, in separate multivariate analyses controlling for pre-specified covariates recorded at TB treatment completion (age, gender, HIV status, baseline TB microbiology, educational level)

Physical morbidity	Economic outcome from prior to TB illness, to 1-year post treatment completion			
	Loss of work (OR, 95% CI)	Use of dissaving (OR, 95% CI)	Income difference (β -coefficient, 95% CI)	Self reported severe financial impact of TB at 1-year (OR, 95% CI)
Abnormal spirometry at 1-year				
- No	1.0	1.0	11.64 (-50.80 – 74.09)	1.0
- Yes	1.87 (1.02 – 3.41)	1.31 (0.71 – 2.43)		1.85 (0.96 – 3.58)
	p=0.042	p=0.393	p=0.714	p=0.066
Respiratory symptoms at 1-year				
- No	1.0	1.0	-6.34 (-63.01 – 50.33)	1.0
- Yes	1.26 (0.72 – 2.20)	0.79 (0.45 – 1.37)		2.02 (1.10 – 3.68)
	p=0.412	p=0.399	p=0.826	p=0.022
Difficulty keeping up with peers when walking at 1-year				
- No	1.0	1.0	7.26 (-62.80 – 77.31)	1.0
- Yes	2.39 (1.27 – 4.49)	0.61 (0.32 – 1.18)		2.04 (1.03 – 4.04)
	p=0.007	p=0.145	p=0.839	p=0.041
Chest symptoms interfering with / stopping work at 1-year				
- No	1.0	1.0	32.73 (-47.09 – 112.56)	1.0
- Yes	4.13 (2.06 – 8.28)	1.04 (0.45 – 2.39)		4.24 (2.08 – 8.66)
	p<0.001	p=0.934	p=0.421	p<0.001
Chest symptoms limiting most / all daily activities at 1-year				
- No	1.0	1.0	12.51 (-118/28 – 143.29)	1.0
- Yes	9.35 (3.02 – 28.95)	0.56 (0.17 – 1.85)		11.82 (3.74 – 37.33)
	p<0.001	p=0.340	p=0.851	p<0.001

Income difference: USD standardised change in monthly income from prior to TB disease, to 1-year post TB treatment completion; Use of dissaving: any use of savings, borrowing of money, or selling of assets from the onset of TB disease to 1-year post TB-treatment completion; Loss of work: No longer working, having been in work (employed or self-employed) prior to TB disease (Chi² test)

283 **Illness narratives**

284 The persistent socioeconomic impact of TB disease was evident in the illness narrative data (Table 4).

285 The shift to a lower standard of living after TB disease was raised as a barrier to ongoing health and

286 wellbeing. The need for further dissaving and withdrawal of children from school to release extra

287 funds were highlighted as areas of concern.

288 Anxiety around loss of financial security, debt, and the challenge of ongoing dependence on family
 289 and friends for support emerged as strong themes. A gendered response was seen with a perceived
 290 loss of social standing due to this dependence particularly common and problematic for men.

291 Reasons for limited recovery of income and work were explored. Ongoing physical morbidity was
 292 noted as a challenge to patients' livelihoods, however participants largely continued to work despite
 293 residual symptoms in order to maintain income. Stigma was widely experienced and resulted in
 294 delayed return to work, or loss of work for those previously employed, with discrimination from
 295 colleagues often rooted in the perception that TB and HIV disease are linked. Loss of business
 296 infrastructure and the lack of capital to rebuild and re-invest was highlighted. Participants reported
 297 challenges in rebuilding business relationships which had been lost after a prolonged absence during
 298 the illness period, including those with employers, employees and customers.

Table 4: Quotes from in-depth interviews with TB survivors

Theme	Quote
Impact of TB-related financial hardship on participants & households	
Reduced standard of living	<p>"Since the time I was diagnosed with TB until now, I am staying in a bad looking house, with bad sleeping environment along with bad food" (<i>Female participant, 39yrs</i>)</p> <p>"As [name of participant] hasn't been able to find work since he completed his treatment, the family had to move up the hill, where housing is cheaper. They also had to sell most of their furniture. There was only a mat on the floor, a little stool and a couple of mugs for a family of four...Another interesting observation we made relates to his relocation. Moving to cheaper accommodation on top of the hill means that he leaves the house less, as physical exercise remains a big challenge for him. This in turn limits his occupational activities and affects his health seeking behavior" (<i>Research assistant, relating to male participant, 32yrs</i>)</p>
Anxiety around debt and financial insecurity	<p>"I never used to have financial difficulties. Now, my business is just so small with borrowed capital and the creditors keep coming to my house, saying they want their money. If I fail to pay, there will be bigger interest. I have been in debts ever since I completed the treatment [...]" (<i>Female participant, 29yrs</i>)</p> <p>"Now, I am not having anything to eat and sometimes I don't have money to pay for rent. For example, I haven't paid rent yet. In the past, before I became sick, I could pay rent in advance" (<i>Male participant, 34yrs</i>)</p> <p>"I have been facing financial challenges, lack of food and so on. In 2016, my girl failed to write her form two exams, due to lack of schooling that I couldn't pay for. So, I have faced so many difficulties from the time that I was diagnosed with TB until now" (<i>Female participant, 39yrs</i>)</p> <p>"I used to sell our house equipment to sustain my family. So, we sold our TV and some small items. Others who could help us were living far from us and they can't just be helping you every day. Our children stopped going to school, so we had to sell whatever household equipment we had to sustain our living" (<i>Male participant, 32yrs</i>)</p>

Dependence on others	<p>“As of now, I have difficulties to get food, but I do try my level best to hunt for money to buy the food. My family supports me since I’ve completed treatment. Whenever I say that I don’t have money to pay rental expenses and to buy food, they do send me the money” (<i>Female participant, 27yrs</i>)</p>
Loss of social standing	<p>“While I was sick and during the time when I completed my treatment people were not respecting me, but people were respecting me before I became unwell with TB. I think this is because I lost my income, and my family helps me. When you have money, people tend to respect you” (<i>Male participant, 34yrs</i>)</p> <p>“He feels, once you have money, you have so much power and you can tell your employees what to do. In his case, his employees overtook power while he got sick, which still affects him” (<i>Research assistant, relating to a male participant, 34yrs</i>)</p> <p>Another male participant replied, when asked about how the income loss affects his life: “It has affected me a lot. I just feel depressed and sometimes I wonder if I am the same person”. (<i>Male participant, 18yrs</i>)</p>
Barriers to income recovery	
Ongoing physical morbidity	<p>“There are so many problems, I am facing these days because everything needs money. [...] I still need to work, so I do some piece work, whether it means that I am still feeling pain, but I do work in order to get money to help myself [...] The most important thing is to get money, so if you don’t work then you have to do business in order to maintain your health and to fulfil your needs” (<i>Male participant, 37yrs</i>)</p>
Stigma	<p>“My boss said that I should wait at home during treatment [...]. My boss accepted my TB diagnosis, but she didn’t want me back after I completed” (<i>Female participant, 42yrs</i>).</p> <p>“I went back to my work, but my boss discriminated against me and he told me that he wouldn’t be helping me anymore financially, so I am just staying here at home” (<i>Male participant, 32yrs</i>)</p> <p>“They [colleagues] would be surprised to see my work performance, which was dropping as I could sometimes work well one day and sometimes, I could not work well [...] they were saying that it was AIDS” (<i>Male participant, 18yrs</i>)</p> <p>“The wife of the participant told us that she sells food items in front of the house and noted that some people don’t want to buy from her, because they know that her husband is sick (<i>Research assistant, relating to male participant, 32yrs</i>)</p>
Loss of social and work relationships	<p>“Our customers really had forgotten us, so I think it will take time for me to grow the business again” (<i>Male participant, 33yrs</i>)</p>
Lack of capital for re-investment	<p>“My life has changed now [...] I have little capital [...] I don’t do hard work now, so my employees help me do business. My business isn’t the way it was before, because some of my business centers are closed now, I stopped selling Irish potatoes, I closed my take-away shops and I only have one bench of chips [...] (<i>Male participant, 48yrs</i>)</p> <p>“The TB symptoms affected my business so much, to the extent that it went down up to date and it’s not at all growing, though I was cured [...]. My husband cannot even afford to give me MK 20,000.00 to start up a new business. I went to borrow money from someone on interest, but I haven’t paid the person back. The capital you have determines what kind of business one engages in. So, instead of starting up a business with the little money borrowed, you start buying maize to feed children at home” (<i>Female participant, 39yrs</i>)</p>

301 **Discussion**

302 In this study we explore the long-term socioeconomic consequences of TB disease after TB-treatment
303 completion. Our data show that the substantial financial insult experienced during TB illness extends
304 to 12-months post-treatment completion. Economic recovery in the year after TB-treatment was slow
305 and incomplete, with many patients continuing to experience income loss and reduced work.
306 Persistent dissaving was widely observed and suggests increasing financial vulnerability. A substantial
307 minority of patients experienced ongoing respiratory morbidity after treatment completion, and this
308 was significantly associated with economic morbidity. Additional barriers to recovery after TB
309 treatment completion included ongoing financial insecurity from initial TB disease, reduced social
310 capital, and TB-related stigma.

311 Even in settings where TB services are free of charge within the public sector, the financial impact of
312 TB disease is marked: a 2014 systematic review of 49 studies found that on average patients lost the
313 equivalent of 58% (range 5-306%) of annual individual income and 39% (range 4-148%) of annual
314 household income in direct and indirect costs during TB illness and treatment, with half of all costs
315 incurred prior to treatment initiation.(3) Those incurring 'catastrophic' costs ($\geq 20\%$ of annual
316 household income) have been shown to have higher odds of adverse TB-treatment outcomes (death,
317 treatment failure, or recurrence).(4)

318 Our results support these findings of a major initial TB related financial insult: during TB disease and
319 treatment employment decreased, average patient incomes fell, and three quarters of the cohort
320 incurred dissaving. This pattern was seen across socioeconomic and employment groups, and by the
321 end of TB-treatment the majority of TB survivors were living in poverty.

322 However, our data also show that this impact is sustained, even after TB-treatment completion.
323 Although the proportion of participants working increased in the year after TB-treatment completion,
324 it did not return to baseline: 1-year after TB-treatment almost a third of patients were unemployed,

325 with standardised individual incomes lower than prior to illness. Self-employed individuals appeared
326 particularly vulnerable, with large drops in income experienced by both those who were in work
327 through their disease, as well as those who stopped working.

328 Post-TB physical morbidity was associated with limited recovery: abnormal spirometry, ongoing
329 respiratory symptoms, and chest symptoms limiting activity at 1-year were strongly associated with
330 loss of work and perceived financial severity of the TB illness episode in multivariate analyses. Post-TB
331 physical morbidity is increasingly recognised as a key component of the overall number of Disability-
332 and Quality-Adjusted Life Years lost in relation to TB disease,(24) and our findings suggests that its
333 impact on long-term productivity and financial vulnerability should also be considered.(25) Recurrent
334 TB disease may also be detrimental to this group: socioeconomic outcomes amongst those receiving
335 TB retreatment were poor in this study, but our ability to explore this finding was limited by the low
336 numbers of retreatment patients identified, and further work is needed in this area.

337 In-depth interviews highlighted the loss of business assets during disease, with limited access to
338 capital to rebuild after treatment completion as a major barrier to recovery. The challenge of
339 rebuilding relationships with employers, employees and clients was emphasised, and attributed to a
340 prolonged period of absence during TB illness and treatment, as well as loss of social standing due to
341 impoverishment, disability, and the direct consequences of TB and HIV related stigma. The impact of
342 TB-related stigma on patients' emotional wellbeing has been documented elsewhere,(26) but our data
343 suggest that this also has socioeconomic repercussions.

344 Rather than promptly recovering, our data suggest that many TB survivors are at risk of further
345 financial and psychological decline after TB-treatment completion. Dissaving is a coping mechanism
346 for catastrophic costs,(2) and has been widely observed in TB-affected households during TB illness
347 and treatment.(27) However in this study, dissaving was observed in half of the cohort in the year
348 after TB-treatment completion, including several households who had resisted dissaving during initial
349 disease and treatment itself. Concern about dissaving was widely reported in the qualitative data.

350 These finding suggest that even after TB-treatment completion, households continue to deplete their
351 reserves or enter into further debt as they struggle to cover costs or seek to rebuild their lives and
352 livelihoods.

353 Of particular concern, both the use of savings and the sale of assets declined in the post-treatment
354 period, particularly amongst low socioeconomic strata, perhaps reflecting depletion of these
355 resources. Instead, borrowing of money remained widespread with increasing use of the black market
356 for loans, perhaps reflecting the exhaustion of more 'benign' sources of loans such as friends and
357 family.

358 Interruption of children's education continued in 10% of households in the year after TB-treatment
359 completion, and a high burden of anxiety related to financial insecurity, lower standard of living, and
360 school interruptions was observed amongst TB survivors. Men voiced concern around loss of social
361 standing, which is consistent with previous work describing high societal pressures on men to be
362 effective providers, regardless of the difficulties of their circumstances.(28) Taken together, our
363 qualitative and quantitative data suggest that TB disease may push patients into an ongoing cycle of
364 poverty, with many patients become increasingly financially vulnerable after TB-treatment
365 completion, rather than experiencing financial recovery.

366

367 This study was performed at a single site and work from other resource-limited settings is needed to
368 confirm findings. In the absence of a control group we cannot exclude the possibility that changes
369 observed were related to general changes in the economy, although this is unlikely as unemployment
370 within Malawi was falling over the study period, changes in income persisted despite time-dependant
371 standardisation into USD, and findings were consistent across qualitative and quantitative data.(23)

372 Data on incomes and occupation prior to TB-illness onset, and health care costs between study visits
373 were collected retrospectively, with some risk of recall bias. Our analyses used individual rather than

374 household level income data, perhaps leading us to underestimate participants' access to financial
375 resources. The financial compensation provided for study participation may have acted as an
376 additional source of income, cushioning participants from the full financial hardship which may have
377 been experienced under routine conditions.

378 Strengths of this study include its novel focus on patients' lives and livelihoods after TB-treatment
379 completion, and use of mixed methods to understand participant perspectives and experiences.
380 Qualitative data were collected to saturation, and the economic tools used were derived from
381 validated sources. The study was conducted in an unselected population, with broad inclusion criteria,
382 and minimal loss to follow-up, allowing broad generalisability.

383

384 Our findings have several key implications for TB research, policy and programmes. We recommend
385 that studies investigating costs associated with TB disease should measure economic outcomes
386 beyond TB-treatment completion. Recent data suggest that mortality amongst TB survivors is higher
387 than that of TB-naïve individuals, and the extent to which the socioeconomic impact of TB disease
388 contributes to this requires further investigation. Our findings suggest that interventions to protect
389 livelihoods and prevent dissaving during disease may be crucial to the long-term wellbeing of TB-
390 affected households. Microloans and training programmes to assist TB survivors to rebuild their
391 livelihoods after treatment completion must be explored. These interventions should be co-developed
392 with TB-affected communities, and must be accompanied by community level education programmes
393 to address TB-related stigma. Ultimately, a renewed focus on physical, psychological, and
394 socioeconomic wellbeing after TB-treatment completion is needed if we are to improve the long-term
395 outcomes of TB survivors.

396

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407 and SBS. SG and FC performed qualitative data collection and analysis, with senior input from RT.
408 JMeghji, JR and PB provided clinical oversight of the study cohort. SBS, KM, SBG and ELC provided
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414

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