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"Honestly, this problem has affected me a lot": A qualitative exploration of the socioeconomic impacts of chronic respiratory disease among people and their communities in Sudan and Tanzania

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Research

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- 1 "Honestly, this problem has affected me a lot": A qualitative exploration of the socioeconomic
- 2 impacts of chronic respiratory disease among people and their communities in Sudan and
- 3 Tanzania.
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7 Abstract

- 8 Background: Over 500 million people live with chronic respiratory diseases globally and
- 9 approximately 4 million of these, mostly from the low- and middle-income countries including sub-
- 10 Saharan Africa, die prematurely every year. Despite high CRD morbidity and mortality, little is known
- about the socioeconomic impact of CRDs in sub-Saharan Africa. We aimed to gain an in-depth
- 12 understanding of the socioeconomic impact of CRDs among people with CRD to inform management
- 13 of CRDs in Sudan and Tanzania.
- 14 Method: We conducted in-depth interviews with people with known or suspected CRD and focus
- 15 group discussions with members of the community in Gezira state, Sudan and Dodoma region,
- 16 Tanzania, to share their understanding and experience with CRD. The data was analysed using
- 17 thematic framework analysis.
- 18 Results: People with CRD in both contexts reported a significantly diminished capacity to do hard 19 physical work, resulting in both direct and indirect economic impacts for them and their families. Direct costs were incurred while seeking healthcare, including expenditures on transportation to the 20 21 health facility and procurement of diagnostic tests and treatments, whilst loss of working hours and 22 jobs resulted in substantial indirect costs. Enacted and internalised stigma leading to withdrawal and 23 social exclusion was described by participants and resulted in part from association of chronic cough 24 with tuberculosis and HIV/AIDS. In Sudan, asthma was described as having a negative impact on 25 marital prospects for young women and non-disclosure related to stigma was a particular issue for 26 young people. Impaired community participation and restrictions on social activity led to 27 psychological stress for both people with CRD and their families.
- Conclusion: Chronic respiratory diseases have substantial social and economic impacts among
 people with CRD and their families in Sudan and Tanzania. Stigma is particularly strong and appears
 to be driven in part by association of chronic cough with infectiousness. Context-appropriate
 measures to address economic impacts and chronic cough stigma are urgently needed as part of
 interventions to address chronic respiratory diseases in these sub-Saharan African contexts.

33 Key words: socioeconomic, chronic respiratory disease, stigma, healthcare seeking, psychosocial

34 Introduction

Over five hundred million people globally live with chronic respiratory diseases (CRDs) such as 35 36 asthma, chronic obstructive pulmonary disease (COPD) and bronchiectasis(1). Approximately four 37 million of these die prematurely annually, most of whom are from low- and middle-income countries 38 (LMICs)(2), where the estimated socioeconomic burden is also high . In sub-Saharan Africa (SSA), the 39 increasing burden is driven by indoor air pollution due to domestic use of biomass fuel, which is used 40 for cooking by approximately 90% of rural households(3); tobacco smoke; and post tuberculosis lung 41 disease (4). Despite increasing recognition, CRDs are rarely prioritised by communities, health 42 systems, or governments in SSA and robust data with which to inform CRD interventions are 43 lacking(5). Reliable data on the prevalence of CRDs in Sub Saharan Africa (SSA) are scarce. A systematic review(6) estimated the prevalence of COPD in Sub Saharan Africa to be 13.4%, which is 44 45 similar to Western European and North American settings(7). Asthma incidence has been estimated to be approximately 10% in Khartoum, Sudan, (8) and recent data has shown a COPD prevalence of 46 47 16.5% in urban Sudanese adults who underwent spirometry(9). Similarly, a study in Tanzania showed an asthma prevalence of 17.6% in adolescents from urban areas(10). 48

49 CRDs are associated with severe economic burdens, including direct costs of seeking care and 50 indirect and opportunity costs, and a negative impact on quality of life (1, 11). Most of the studies on 51 CRD-associated socioeconomic burden have been conducted in high income countries whilst little is 52 known about these impacts in LMICs despite the heavy burden of CRD morbidity and mortality. On 53 the other hand, the negative socio-economic impacts of TB are relatively well documented. For 54 instance, in India, female patients with TB were rejected by their families and up to 11% of children 55 discontinued their studies with some taking up employment to support their family's finances(12). 56 TB patients have also been reported to experience stigma and social exclusion in their communities 57 (13). Similarly, a systematic review of the financial burden of TB in LMICs showed that families experienced catastrophic costs, with approximately 50% of the costs incurred before treatment(14). 58 59 But there is relatively little evidence relating to the socioeconomic impacts of CRDs in SSA where 60 pathways to diagnosis and care are generally much less well defined and resourced than for TB. A cross sectional study of the socioeconomic burden of CRD in four low-income populations including 61 62 Uganda, a SSA country, showed substantial disease-related productivity impairment and activity 63 impairment among patients(15). However, this study focussed only on spirometry-diagnosed COPD 64 and/or asthma patients. The lack of diagnostic and care pathways for CRD in most SSA countries 65 means that there are many symptomatic people without a diagnosis or consistent care whose

- 66 experiences may differ. More exploratory in-depth understanding of the circumstances, responses
- 67 and actions of patients and their communities is required to provide a broader context for
- 68 addressing CRDs within the health system in SSA.

69 We aimed to gain an in depth understanding of the socioeconomic impact of CRDs on patients, their

- 70 families and communities, as part of the development of context-specific interventions to integrate
- 71 CRD care into routine health systems in Sudan and Tanzania.
- 72

73 Methods

- 74 We used qualitative methods to explore the perceptions, experiences and priorities of community
- 75 members and people with known or suspected chronic respiratory disease to gain an in-depth,
- ⁷⁶ 'emic' understanding of their interpretation and experience of CRD. We used qualitative methods
- because they are best suited to answer questions about experience, meaning and perspectives from
- the standpoint of the participant (16). We used an interpretivist approach (17) in order to allow
- 79 participants to share their understanding and interpretation of CRDs and how these meanings
- 80 influenced their experiences. We chose in depth interviews (IDIs) with people suspected of, or
- 81 diagnosed with, CRD and focus group discussions (FGDs) with a representative group of community
- 82 members. The constitution of the FGDs into same gender and age groups encouraged open
- 83 discussions and allowed biases and beliefs to be freely discussed.

84 Study sites and context

85 This study was nested in the multidisciplinary "International Multidisciplinary Programme to Address 86 Lung Health and TB in Africa (IMPALA)" consortium, which focused on generating knowledge and 87 implementable solutions for CRDs in Sub Saharan Africa. Sudan and Tanzania were selected for the IMPALA's health systems research work package . Our baseline situation analysis in Dodoma region 88 89 of Tanzania and Gezira state in Sudan explored the readiness of health facilities in these areas to 90 deliver care for CRD(5). Both sites are mainly rural and semi-urban, with inhabitants engaged mostly 91 in informal livelihoods. The sites were selected in collaboration with the local Ministries of Health 92 because they were perceived to be exemplars of good practice that could be built on to develop CRD 93 services. Gezira State in Sudan was selected because of an existing pilot programme offering 94 integrated lung health services focusing on asthma standard case management (18). These services 95 were developed by the IMPALA collaborating institution, Epidemiological Laboratory (EPILAB), a 96 research non-governmental organization (NGO) with research infrastructure in Gezira. Dodoma 97 Region in Tanzania was selected due to an embedded regional TB Control Program infrastructure

- 98 and well-functioning community-based referral and follow-up system for people with chronic cough
- 99 suspected to have TB even when their TB investigations are negative. The community referral
- 100 system in Tanzania maintains contact with community members through designated community
- 101 health workers who identify people with chronic cough who were found to be negative for TB but
- 102 continue to seek care in the health facilities for on-going respiratory symptoms.

103 Participant selection and recruitment

- 104 For IDIs, purposive sampling was used to select participants with confirmed or suspected CRD(19). In 105 Sudan, patients were purposively selected from the asthma standard case management programme 106 at EPILAB sites to include men and women with varied asthma severity and from catchment 107 communities closer and farther away from the health facility. Diagnosis of asthma was made by 108 clinicians using diagnostic algorithms and peak flow meter measurements at the EPILAB sites. In 109 Tanzania, the research team selected patients in collaboration with health workers in the catchment 110 area health facility with the aim of ensuring balanced representation by gender, socioeconomic status and severity of symptoms. In Tanzania, clients with presumed CRD who had been investigated 111 112 for TB, were found to be negative but remained ill and continued to visit the health facility for treatment without a definitive CRD diagnosis, were purposively selected from catchment areas of 113 114 study health facilities.
- For FGDs, community representatives were selected to reflect the range of literacy levels and socioeconomic backgrounds within the community in both countries. In Sudan, an additional group of adolescent girls was constituted to create a socially safe and trusting environment for open discussion, based on the research team observations that young women and adolescent girls were particularly likely to experience negative social impact of asthma in the community.

120 Data collection

- We used common data collection methods across the two countries. Topic guides were used to guide semi-structured interviews and explored patients' and community understanding of CRD, impact of CRD on productivity, work life, finances, coping mechanisms, experiences with CRD and priorities for care. Additionally, in Sudan, patients' perceptions and experiences with the asthma management services were also explored.
- Training of research assistants already experienced in qualitative research was conducted in each
 study site and covered overall aims of the study, data quality, ethical issues in health facility
 research, informed consent, privacy and confidentiality. Training included hands-on practical

- sessions on qualitative interviewing, adapting topic guides and a data collection pilot in the
- 130 community. The pilot data was analysed and used to inform data collection in the main study.
- 131 Interviews were audio recorded and conducted in the local language (Swahili in Tanzania and Arabic
- in Sudan) in a quiet, private and secure room within the health facility premises. FGDs were
- 133 conducted in mutually agreed venues in the communities. A note taker took notes during the
- 134 interviews and a debrief session was observed after interviews to reconcile any inconsistencies. All
- 135 interviews were transcribed by the field team, quality checked and translated into English by
- 136 professional translators prior to data analysis.

137 Data analysis

138 We used the Framework Method(20) for the management and analysis of data as it facilitates 139 transparent analysis and allows teams of researchers to collaborate on analysis(21). To improve 140 trustworthiness, members of the research teams independently read and re-read manuscripts, 141 inductively identifying emerging codes and developed an analytical coding framework for coding the 142 rest of the data after reviewing a few transcripts together and resolving discrepancies. This process 143 was iteratively repeated till no new codes emerged. Separate analytical frameworks were developed 144 for patient interviews and focus group discussions. Codes were organised into categories and 145 themes for analysis by charting into a spreadsheet matrix. Separate coding frameworks were 146 developed for each country. Similar themes that emerged from the interviews were compared and 147 discussed to identify final common themes. Socioeconomic impacts were defined as those effects of 148 CRS that negatively influenced social life and means of livelihood of the patients with CRS and their 149 families in the community, including the psychological consequences of these impacts(22).

150

151

152 Results

153 Demographics of study participants

154 We conducted 23 in-depth interviews, 7 in Tanzania (4 males, 3 females) and 5 in Sudan (2 males, 3

155 females). The composition of the FGDs is shown in table 1 below. There were 128 FGD participants,

156 50 in Sudan and 78 in Tanzania, with each FGD group consisting of 7-12 participants. Youth

- 157 participants were defined as those aged less than 18 years. The FGD location and age, gender, and
- 158 number of FGD participants is shown in table 1.

160	Table 1: FGD	location and	characteristics	of FGD	participants
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FGD location	Age group	Gender	Number of participants
Sudan			
Al-Musalmia	>30	Male	7
	>30	Female	7
Masoudia	15 - 17	Female	10
Rihanna	15 - 29	Male	9
Sarasirr	>30	Male	9
	>30	Male	8
Tanzania			
Mvumi	18 – 30	Male	9
	18 - 30	Female	10
Chamwino	>30	Male	9
	>30	Female	11
Mpwayungu	18 - 30	Male	8
	18 - 30	Female	10
Haneti	>30	Male	9
Dabalo	>30	Female	12
Total			128

161

162 In general, participants described how CRDs impacted their activities of daily living, relationships and

163 interactions within the community, and the implications of this on their overall wellbeing. The

164 results are presented in the following themes: limitations on livelihoods; economic impacts of

165 healthcare seeking costs and CRD mortality on patients and their families; social exclusion,

discrimination and stigma; and impacts on social wellbeing, mental health, and sexuality.

167 *Limitations on livelihoods*

168 People with CRD in both countries reported a significantly diminished capacity to do hard physical

169 work. The impact on livelihoods was the same among males and females as both relied largely on

170 physical work. This resulted in both direct and indirect economic impact for people with CRD and

171 their families due to lost working hours and inability to continue with physical work. For most people

this was due to being unable to be as 'productive' in farming or informal work, but for some this

173 involved reduced working hours in formal employment. Many people with CRD had to stop work to

174 attend clinics, be hospitalised, recuperate after treatment and/or attend follow-up appointments.

175 While some people with CRD could change their work to involve less vigorous and less physically

176 demanding tasks, others stopped working entirely.

177 *"I have been affected terribly, especially in my daily responsibilities. Our job, especially we*

178 Tanzanians, most of our activities are heavy duties, most of the activities are performed in the sun,

- most of them are in dusty working conditions on the land. I find it difficult, I can't work effectively"(IDI, Male, Patient, Tanzania).
- 181 Subsistence farming was common in our study sites with any surplus produce being sold for cash'.
- 182 Therefore, reduced ability or inability to work impacts on both the family's food supply and their
- 183 cash income. Loss of income also meant inability to pay school fees for dependent children and
- 184 inability to take care of dependents, including aged or infirm older relatives. A female cleaner
- 185 working in a local primary school reported that she stopped working when she developed CRD
- 186 because of the associated fatigue and breathlessness:
- *"In the past, I used to do any work and move around. Since I developed this lung problem, I stopped"*(IDI, Female, Patient, Sudan).
- A male patient lost working days to illness and reported a negative impact on employer perceptionsof his ability: even when he made himself available to do some work:
- 191 *"Honestly, this problem has affected me a lot because I can't engage in activities to earn my income*
- since I fear for the problem I am having. When you go to the sites looking for a job, you may miss for
- some days because of your health problem, someone looks at you and says; 'This one can't do this
- 194 *job'*. Therefore, I am being affected in many ways such as taking care of myself and my family
- 195 *financially."* (IDI, male CRD patient, Tanzania).

196 The economic impact of healthcare seeking and mortality from CRD

- Many people with CRD reported several costs incurred while seeking healthcare, including
 expenditures on transportation to the health facility and procurement of diagnostic tests and
 treatments.
- 200 A teacher with asthma in Sudan reported huge transportation costs resulting from long distance 201 travel to access specialist treatment: "And even if I want to go to Khartoum or Madani to see a 202 specialist, I'd need to pay 1000 SDG [2.4 USD] for transportation only, and that's almost my salary, 203 let alone the doctor's fee and medications and tests" (IDI-Male, Patient, Sudan). In both countries, 204 transportation costs were especially high when the health facility was located far away from the 205 patient's community and this challenge was so significant that some community members suggested 206 that they would be willing to pay specialist consultation fees if the specialist could come to a health 207 facility nearer to them, obviating the need for transportation. In some cases, people with CRD were 208 reportedly accompanied on their multiple health facility visits and admissions by bread-winning
- 209 family members who also incur transportation costs and loss of working hours during these periods.

- 210 *"The family will also be affected; they (relatives) will accompany the patient when s/he falls ill. All*
- 211 livelihood activities will be put on hold whether these activities are in the private or public work...The
- 212 whole family will all be at hospital. Financially and physically, they will be exhausted." (FGD-Female-
- 213 Sudan)
- 214 Participants described multiple visits to seek care in different health facilities. This journey would
- usually start with the local pharmacy and may end up in high level health facilities often located far
- away from the person with CRD. This involved not only transportation costs but also costs of
- 217 medications and tests which are often beyond the ability of the person with CRD to afford . A
- 218 participant mentioned that treatment could cost an entire month's salary:
- 219 "I'm dependent on my salary, but medications are very expensive and so is the doctor's appointment,
- in addition to the original expenses of life in general. Some way or another it'll affect you because the
- 221 cheapest medicine is worth a month's salary." (IDI, Female, Patient, Sudan).
- 222 The death of a relative with CRD was also reported to impact the economy of the extended family in
- 223 Tanzania. A participant reported that, in the event of death of a patient, relatives would be expected
- to take over their responsibilities such as care of the family, parenting, payment of school fees,
- provision of basic needs and management of assets, all of which exert major economic pressures onthe patient's relatives.
- 227 "I had a relative who had such a problem, we came to realize when it was too late, and she had a
- family. When she felt sick, she used to go to the hospital to perform some tests and get medication.
- 229 In the end, they realised that her lungs were badly damaged. Unfortunately, she died, and we, as
- 230 relatives, have started helping and supporting the kids left behind for their education. So, it affects
- 231 *the family"* (FGD, female adult, Tanzania).

232 Social exclusion, discrimination, and stigma

- 233 Many participants described a sense of exclusion from community social life related to their inability 234 or reduced ability to participate in routine personal and community activities such as going to work, 235 attending social gatherings, and doing household chores and cooking . A participant in Sudan 236 reflected on limitations on her social activities after being discharged from hospital following an 237 exacerbation of asthma: "You see now after the two months I spent at the hospital, whenever I go to 238 an occasion I'll only participate in the conversation, I can't help and serve as I used to. I used to help 239 with cooking the food and washing the dishes, but now even the conversation might start a coughing 240 seizure for me" (IDI-Female, Patient, Sudan). Similarly, in Tanzania, a male patient expressed
- frustration at his inability to participate in the digging of grave, an important activity for men when

- there is a death in the community. "I may participate in community activities by just being there and
- 243 see what is going on, but I can't fully participate because, for instance, there might be a funeral, I
- 244 attend the funeral, but I can't participate in digging a grave." (IDI, Male, Patient, -Tanzania).

Stigma was described by participants in both countries as a major social impact of CRD and resulted in part from association of chronic cough with infectiousness. Stigma was both enacted (actions of discrimination by others) and internalised (withdrawal by affected individual because of their own negative feelings or anticipation of others' negative responses) and resulted in isolation from peers and the wider community.

250 In Tanzania, some people with CRD described how they excluded themselves from community

251 gatherings such as the market or church, as chronic cough is mostly associated with TB and HIV in

- the community and raised concerns about transmitting infections among members of the
- community.

254 "I used to go to church, but when I went there, I was coughing a lot, and everybody used to look

- around to see who was coughing frequently? I decided not to go [anymore]. Since [then], I have never
 gone to church" (IDI, Female, Tanzania).
- 257 Participants commonly spoke of chronic cough as infectious and mentioned that people with chronic
- cough were stigmatised because they were presumed to have TB or HIV. A male participant in
- 259 Tanzania highlighted this:
- 260 "Stigmatization exists here to a great extent because coughing is also a symptom of HIV/AIDS." (FGD-
- 261 Male-Mvumi-Tanzania). Stigmatization here referred to people moving away from anyone coughing
- 262 openly and frequently for a prolonged period.
- 263 Community members also reported avoiding people with CRD for fear of getting infected. For
- 264 example, some male community participants referred to a scenario where people with CRD would
- 265 be avoided by potential sexual partners due to fear of contracting HIV:
- 266 "If someone is coughing frequently, people would suspect him to have acquired HIV and they will fear
- 267 him think he is HIV-positive, he will no longer participate in other issues. Even some girls would be
- 268 *fearing him and would not want to have sex with him*" (FGD, male youth, Tanzania).
- Similarly, in Sudan, asthma was believed to be infectious and people with CRD may be labelled as'TB' because of chronic cough:

271 *"For them, asthma is something infectious that needs to be treated or a disease that might be*272 *possible to cure. For instance, they tend to say that this person (is) living with tuberculosis or*273 *something else."* (IDI-Female-Sudan). 'Them' here refers to members of the community.

274 Some people with CRD who internalised their stigma mentioned that they did not disclose their 275 illness to family members and the community. In Sudan, some people with CRD reported that they 276 pretended to be well when in the company of other people, hiding their illness from family and 277 friends. They explained that this was to avoid attracting attention to themselves which may further 278 reinforce stigma, increasing their sense of themselves as a burden to their neighbours or family. A 279 young male with asthma highlighted how important it was to him for the family to be protected 280 from feeling his 'pain':

281 "Yes it does...it hurts me a lot, but I don't want my family to feel my pain." (IDI-Male, Sudan)

282 Of particular importance to female community participants in Sudan was the potential for loss of

283 marriage opportunities due to being discriminated against by potential suitors when a young woman

284 developed CRD or tuberculosis. This is because both CRDs (such as asthma) and tuberculosis are

stigmatising illnesses in the community . Marriage is a very important part of the identity of a

woman in Sudanese society and a symbol of her status both of her family and her own position

287 within it. A female participant who spoke of the impact of CRD on young unmarried women,

described the difficulties a young woman or girl with CRD would have in attracting a suitor:

289 *"It will lead to single marital status. It will lower the market value."* (FDG, Female adult, Sudan).

290 The impact of CRD-related stigma on marriage was reported to not only be limited to a prospective

wife but also to her family. This was reported as having the potential to jeopardise future maritalprospects for other women in the family:

293 "It is a social problem, solely a social problem. [Even] if the girl is so beautiful like the moon, they will

tell you not to marry from her family as they have so and so." (FGD, Female, Sudan).

295 Similarly, a male participant emphasised that prospective husbands may be discouraged from

296 marrying young women with asthma for fear that asthma may be passed on to the children:

297 "In another area, people start to avoid and say that person is contagious, this is a social part. They

say X shouldn't marry Y because she has asthma and may affect children after that, pulling them to

299 those diseases" (FGD, Male, Sudan).

301 Impact on psychosocial wellbeing

- Participants reported that inability to play the usual expected roles in the society had impacts on their sense of belonging and contributions to the society. This represents an important intersection between the economic, social and psychological impacts of CRD on the patient and their families. In both contexts, the social impacts of CRD such as impaired community participation and restrictions on social activity, led to psychological stress to both people with CRD and their families. People with CRD used terminologies such as 'moody', 'angry', and 'crying' to describe the impact of CRD on their psyche. A patient in Sudan described himself as always in a bad mood and angry:
- 309 *"I am always in a bad mood, and I feel exhausted to the point that I am not able to leave my bed.*310 *Very angry."* (IDI, Male, Sudan)
- For others, crying was a frequent means of communicating feelings at home when overwhelmedwith emotions because of CRD.
- 313 *"Sometimes we communicate only in tears. I feel like I can't talk and just want to cry "(IDI, Female,*314 Sudan)
- 315 The sense of uncertainty around the illness was also reported to be shared by the entire family:
- 316 *"if there is someone sick in the house, the whole of the family will be in stressful condition*
- 317 particularly if the patient could not breathe ... The whole family will be anxious; not only the patient
- 318 but all the family members will be in stressful condition." (FGD, Female, Sudan)
- 319 The impact of CRD symptoms on sexual activity was also reported to be a contributor towards
- 320 negative impacts on wellbeing. Several male community members in Sudan emphasised that CRD
- 321 symptoms could impact the desire and capacity for sexual activity, and this was gendered, as it was
- an important indicator of wellbeing and pride among men in the community.
- 323 "To get to the bottom of this issue, if I have the bad disease, I will be psychologically depressed. I
- have (something) in my head that I am going to die. I will not have the desire to sleep with my wife,
- 325 reproduce or have children." (FGD-Male-participant-Sudan). The use of the term 'bad disease' here
- highlights the participant's perception that chronic cough was 'bad' in line with the general
- 327 perception that chronic cough was due to tuberculosis or HIV which would invariably end in death.
- 328
- 329

331 Discussion

332 We found multiple socioeconomic impacts of chronic respiratory disease on people diagnosed or 333 suspected of having the disease, on their families and communities. Both CRD symptoms and 334 treatment seeking resulted in a significant economic toll on people with CRD and their families 335 because of impairment of physical fitness and ability to work, loss of working hours and jobs, and 336 direct and indirect costs of health seeking such as costs of transportation to the health facility and 337 treatment and opportunity costs of missed work. Our findings further show that stigma associated 338 with chronic cough resulted in social exclusion. The social impacts including inability to carry out 339 activities of daily living, impaired community participation, non-disclosure to families and restrictions 340 on sexual activity in the context of stigma and social exclusion, were found to be a source of 341 significant psychological stress on people with CRD and their families.

342 The strong association of chronic cough with TB in these settings is not surprising. Chronic cough was 343 widely presumed to be TB in a similar study among Ugandan communities(23). This highlights the 344 huge importance of TB as an ongoing public health challenge in the sub-Saharan African context. 345 Whilst Tanzania is one of the 30 high TB burden countries, Sudan has a moderate but also significant burden of TB (WHO Global TB report 2020). The common knowledge of TB in the communities may 346 347 be explained by the historicity of endemic TB disease and by the substantial investments into TB 348 control compared to CRD and other diseases in these contexts. A downside of this association, as 349 seen in this study, is the stigmatization and ostracism of people with CRD in the community. This 350 may lead to failure to attend health facilities for fear of being confirmed as having TB disease, which 351 further delays diagnosis and can lead to increased morbidity and mortality(13, 24). Misinformation 352 about chronic cough is another driver of stigma seen in this study. A study investigating knowledge and perceptions of asthma among secondary school students in Tanzania revealed that most 353 354 information about asthma had been passed on to students by their parents and non- asthmatic 355 students presumed that asthma was infectious and therefore avoided interactions with their 356 asthmatic colleagues for fear of contracting the disease (10). Systematic community sensitization 357 activities with trained and well-informed health personnel could help improve community 358 perception about chronic cough and contribute to tackling stigma in CRDs. Clear messages about the 359 causes of asthma and the availability and effects of treatment on controlling symptoms would help 360 to destigmatise asthma and other CRDs. The effect to seeing people being managed well with 361 affordable medicines and transform their lives can be more powerful than being told about 362 treatment effectiveness. Words also matter and consistent use of terms like 'people who have 363 asthma' rather than asthma 'victims' or CRD 'sufferers' can start to shift mindsets. There are many 364 transferable lessons to be learned from community de-stigmatisation efforts with HIV in the

antiretroviral therapy era(25) and, more recently, efforts being applied to COVID-19 relatedstigma(26).

367 The economic impact of CRD in these communities highlights the vulnerability of people with CRD in 368 mostly rural settings, who are self-employed or working in informal sectors of the economy such as 369 subsistence farming, and without recourse to any social security. Chronic diseases, including CRDs, 370 are known to incur significant economic costs for both patients and the health system (27, 28). In 371 Malawi, the mean care seeking cost for chronic cough per patient was found to be 2.3 times the 372 average cost per capita on health for the country and consisted mainly of transport and drug 373 costs(29). Similarly, TB-related catastrophic costs have been well recognised and documented. A 374 systematic review of financial impact of TB in LMICs revealed that on average the total cost was 375 equivalent to 58% of reported annual individual and 39% of reported annual household income(30). 376 To tackle catastrophic costs in TB context, poverty reduction strategies are increasingly being woven 377 into TB control programmes including social protection initiatives such as cash transfers, food 378 baskets and social insurance (31). Health systems could draw from these experiences and 379 interventions in TB to develop an integrated approach to addressing the economic impacts of CRDs 380 in the sub-Saharan African setting.

381 Transportation costs were strongly highlighted by our study participants as a major source of 382 economic loss, impacting people with CRD and relatives who accompany them on hospital 383 appointments. Our informants themselves made the that the transportation costs were often the 384 equivalent of their monthly salary. Transportation has been identified as an important social 385 determinant of health (32) and a well-documented barrier to engaging in the care of chronic 386 diseases especially among poor, vulnerable populations (33). Studies done in high income settings 387 have shown that interventions such as provision of bus passes, taxi vouchers and reimbursements 388 from insurance covers could improve healthcare utilization (34) but these interventions may not be 389 feasible in our study setting . because of lack of transport infrastructure. Policy makers in our study 390 context could consider decentralisation of services and investment in specialist mobile clinics to rural 391 areas and geographically distant communities as measures to reduce the impact of transportation 392 costs and improve health outcomes of people with CRD. In our study setting, the extended family 393 system and the social interconnectedness meant that any economic costs incurred by the person 394 with CRD could lead to a ripple effect within their social circle, potentially setting up or exacerbating 395 vicious cycles of poverty and ill-health. Life course studies have established that risk factors in 396 childhood and adolescence, including poverty, contribute to subsequent development of CRD in 397 adulthood (35). The economic impacts observed in this study risk perpetuating poverty and 398 worsening outcomes such as morbidity and mortality. Measures to mitigate these impacts would be

crucial in breaking the cycle of poverty and ill-health, improving outcomes in subsequent
generations. Developing a clear diagnosis and care pathway for CRD in our study setting would be an
important part of this mitigation.

402 Failure to engage in usual activities of daily living, disruptions in sexual activities and difficulties with 403 community participation reported in this study have also been shown to compound several chronic 404 diseases including asthma(36), COPD (37) and HIV/AIDS (38) Physical challenges of managing the 405 disease can sometimes affect mood and emotional health leading to anxiety and depression in both 406 people with CRD and the carers (39). Health system responses to CRD should include supporting 407 carers and families by telling them what to expect, encouraging them to present to care at the 408 earliest recognition of symptoms and patient-centred communication to support with self-409 management of symptoms where appropriate. Research in other contexts shows that recognising 410 and managing anxiety and depression can increase ability to stick with prescribed COPD treatment, 411 improve physical health and reduce medical costs(40).

412 The finding in this study that young Sudanese women with chronic cough and their families were 413 discriminated against by potential suitors further highlights the gendered nature of stigma 414 associated with chronic cough. The perception that asthma, a major cause of chronic cough well 415 known in this society, was primarily hereditary, has also been described in a previous study of 416 asthma in urban Sudan (41), where 67% of 490 asthmatic patients believed that asthma could be 417 transmitted within the family. The study also highlighted denial of asthma diagnosis and non-use of 418 inhalers by young female asthmatic patients as a coping mechanism to avoid stigma. This highlights 419 the disproportionate social burden of CRD born by young women. A related finding in our study is 420 the choice made by people with CRD to hide their symptoms from family and community members 421 in a bid to keep the emotional burden of illness away from them. Young people with chronic illness 422 have been shown to be particularly circumspect about disclosure of their illness, frequently choosing 423 non-disclosure because of perceived fear of rejection, pity, and perceptions of being seen as 424 vulnerable or different(42). In the context of stigma, non-disclosure could also be a coping 425 mechanism to avoid stigmatization while shielding the family from its effects, as observed in our 426 study.

427 Limitations of the study

As this was a qualitative study, quantitative costs were not collected, and quality of life not
measured. Quantification of economic impact through a cost of illness study would lay the
foundation for a future evaluation of the cost-effectiveness of interventions to address CRD within
the health systems in these settings. However, the direct testimony of the people with CRD and

- 432 members of their communities about their lived experience, provides important information about
- 433 the range of social, economic and psychological impacts that should be measured in our study
- 434 setting and insight into potential interventions to address them . Whilst the findings are not
- 435 statistically generalisable to populations in Sudan, Tanzania or sub-Saharan Africa more widely, the
- 436 common issues arising within these two different contexts are likely to be generalisable to similar
- 437 settings, whilst the context-specific issues point to the importance of locally developed
- 438 interventions.

439 Conclusion

- 440 Chronic respiratory diseases are associated with significant social and economic impacts among 441 people with CRD and their families in Sudan and Tanzania. While the impacts on livelihood and 442 economy resulted mainly from impairment of physical ability to carry out income-generating 443 activities and from expensive healthcare costs, the long-standing association of chronic cough with 444 TB and HIV/AIDs in our study settings was a major driver of stigma and social exclusion experienced 445 by people with CRD and their families. This highlights the negative central role of these chronic 446 stigmatizing diseases in framing perceptions and attitudes towards other illnesses in the community. 447 Context-appropriate social safety nets and systematic community health education and 448 sensitization would be required to address the economic and social impacts of CRD identified in this 449 study, as well as the broad causes and management of chronic cough in the communities. In 450 addition, provision of available, accessible and affordable care for CRD is necessary to break the
- 451 cycles of poverty, ill-health and stigma in these sub-Saharan African contexts

452 Declarations

453 Ethical considerations

454 The study was approved by the ethics committees of National Institute for Medical Research,

455 Tanzania (ref /Vol.IX/2922); the Ministry of Health of Gezira state, Sudan (ref 44/T/KH/1) and the

Liverpool School of Tropical Medicine (ref 18-043). Permission was also sought from the respective

457 district authorities. Written informed consent was obtained from all participants. Additional consent

- 458 for participation in the adolescent FGD group was provided by parents of the girls. We ensured
- 459 confidentiality of the IDIs by conducting interviews in secure locations away from third parties where
- the patients were comfortable and by not capturing names of the patients. Additionally, patients
- 461 were assured that the discussion would not be shared with any third parties and the identifying
- 462 characteristics such as occupation and town were securely locked away.
- 463 **Consent for publication**: Not Applicable

464 Availability of data and materials

- 465 The datasets used and/or analysed during the current study are available from the corresponding
- 466 author on reasonable request.

467 Competing interests

468 The authors declare that they have no competing interests.

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477 Author Contributions

MT, RT, NN, SM, AE, ES, and UE conceptualised and designed the study. ES, SM, RA and EH collected
all data with the help of research assistants in country. UE, ES, NN, SM, EH, MT and RT analysed the
data. UE prepared the first draft of the manuscript and coordinated reviews and comments on
subsequent versions. UE, ES, MC, JA, TW, RA, AO, MT and RT discussed and interpreted results of the
study. All authors reviewed versions of the manuscript and approved the final version for
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