

# 'They didn't look at me with good eyes' – experiences of the socioeconomic impact of tuberculosis and support needs among adults in a semi-rural area in Mozambique: A Qualitative Study

Pedroso Nhassengo<sup>a,b,c,\*</sup>, Clara Yoshino<sup>a,c,\*</sup>, Américo Zandamela<sup>b</sup>, Verónica De Carmo<sup>b</sup>, Bo Burström<sup>a,c</sup>, Knut Lönnroth<sup>a,c</sup>, Tom Wingfield<sup>a,c,d,e</sup>, Celso Khosa<sup>b</sup> and Salla Atkins<sup>a,c,f,g</sup>

<sup>a</sup>WHO Collaborating Centre in Tuberculosis and Social Medicine, Department of Global Public Health, Karolinska Institutet, Stockholm, Sweden; <sup>b</sup>Instituto Nacional de Saúde, Marracuene, Mozambique; <sup>c</sup>Health and Social Protection Action Research and Knowledge Sharing Network ([www.sparksnetwork.ki.se](http://www.sparksnetwork.ki.se)), Stockholm, Sweden; <sup>d</sup>Departments of International Public Health and Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, UK; <sup>e</sup>Tropical Infectious Diseases Unit, Liverpool University Hospital NHS, Foundation Trust, Liverpool, UK; <sup>f</sup>Health Sciences, Faculty of Social Sciences, Tampere University, Tampere, Finland; <sup>g</sup>WHO Collaborating Centre on Health in All Policies and Social Determinants of Health, Tampere University, Tampere, Finland

## ABSTRACT

Tuberculosis is recognised as a disease of the economically disadvantaged people due to its association with financial vulnerability. Mozambique still faces the challenge of the high burden of TB and associated costs. We aimed to understand the social and economic impacts of TB and the need for social support among people with TB in Mozambique. We conducted a qualitative study using a phenomenological approach focusing on the lived experiences and perceptions of people with TB. A total of 52 semi-structured one-to-one in-depth interviews were conducted and data were analysed using a reflexive thematic analysis. Three themes were drawn from the analysis: (i) TB has a social and economic impact that requires adaptation and resourcefulness amongst those affected; (ii) People with TB have different preferences and needs for social support, and (iii) People with TB have different knowledge of, and experiences with, formal social support. TB affects family and community relationships mainly due to impacts on the household's finances. People with TB in Mozambique are not entitled to any form of social support, and they need to rely on help from family and the community which is often insufficient. Further investigation is needed on how social support schemes can be developed in Mozambique.

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Tuberculosis; social support; need of support; coping strategies; Mozambique

## Background

Tuberculosis (TB) is recognised as a disease that affects economically disadvantaged people due to its strong association with financial vulnerability (Lönnroth et al., 2009) and increased risk of getting TB among those people (Hoa et al., 2011; Muniyandi & Ramachandran, 2008; Siddiqi et al., 2001; Spence et al., 1993). The World Health Organization's (WHO) End TB Strategy aimed to have zero TB-affected families experiencing catastrophic costs (WHO, 2015), defined as total

**CONTACT** Pedroso Nhassengo  [pedroso.pedro.nhassengo@ki.se](mailto:pedroso.pedro.nhassengo@ki.se)  WHO Collaborating Centre in Tuberculosis and Social Medicine, Department of Global Public Health, Karolinska Institutet, Stockholm SE-171 77, Sweden

\*Joint first authors.

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TB-related costs exceeding 20% of a household's annual income prior to TB disease, by 2020. However, by 2021, 52% of people and families affected by TB still experienced catastrophic costs globally (WHO, 2022a). These catastrophic costs can cause families to spiral into financial ruin and create distress for individuals (Tanimura et al., 2014). For people with TB, they can be predisposed to poor treatment outcomes, treatment abandonment, and even death (ILO, 2017; Lönnroth et al., 2010; Wingfield et al., 2014). Low- and middle-income countries (LMICs) have the highest incidence of TB. Thirty LMICs, including Mozambique, were defined by the WHO as high TB burden countries and account for approximately 86% of the global TB incidence and 85% of deaths (WHO, 2022b). Mozambique is a country with high incidence of TB, TB/HIV co-infection and DR-TB (Drug-Resistant Tuberculosis). In 2021, Mozambique had 97,000 cases of TB and an incidence rate of 305 TB cases per 100,000 people (MISAU, 2022; WHO, 2022a). Despite this, Mozambique managed to reach the first End TB Strategy milestone of reducing TB deaths by 35% in 2020 compared to 2015 (WHO, 2022a). However, no national TB Patient Cost Survey has yet been conducted to provide data on Mozambique's progress towards achieving the WHO catastrophic cost target. Additionally, there is a dearth of qualitative data to understand how the costs associated with TB treatment are experienced by individuals and households and how they cope with such costs. There is, however, substantial evidence of the barriers people with TB from Mozambique and other low-and middle-income settings face to access TB services. A study from two provinces in Mozambique identified challenges such as delays in diagnosis, stigma, long waiting time, lack of nutritional and psychosocial support and overall lack of knowledge about the disease (Schacht et al., 2019). Studies from the BRICS countries (Brazil, Russia, India, China and South Africa) have identified similar economic and social challenges during the disease journey, including economic hardship, stigma and disruption to family life (Addo et al., 2022). In South Africa, studies indicated that TB has a physical burden and a burden on families of caring for a household member with TB through emotional, physical and financial support, which could lead to or exacerbate food insecurity in the household (Vanleeuw et al., 2022).

Social protection, defined as a set of policies and programmes aiming to prevent and reduce poverty and vulnerability throughout the life course (ILO, 2017), is a key strategy to mitigate catastrophic costs and other stresses associated with TB care-seeking and illness (Lönnroth et al., 2010). In order to understand this phenomenon in the Mozambican context, we needed to examine how the different elements of the social and economic burden interact and impact families with a person with TB. Therefore, we chose to ground our findings in the conceptual framework for analysing the households' economic burden of illness, proposed by Russel (2004). In this framework, the household is the unit of analysis as decisions regarding treatment and coping strategies are made within the household, with costs falling both on the individual's and the household's finances. The individual and family sphere is impacted by external factors, such as health system and social resources. Adoption of coping strategies often requires individuals to rely on social networks to mediate the financial impact of TB.

There is a lack of comprehensive understanding of the economic burden impact on individuals and households, the mechanisms of resource mobilisation and their ability to pay their loans back. Similar to many low- and middle-income settings (Wingfield et al., 2016), Mozambique does not currently have policies specifically designed to support people with TB (Lönnroth et al., 2009). The economic strain faced by individuals and households due to TB is not only a local concern but also has broader implications for global health and socio-economic development (George et al., 2012). To aid the development of such policies and to bring the situation of people with TB to the local and international policymaking and research community, we conducted a qualitative study among people with TB in two provinces of Mozambique, Gaza and Inhambane. The overall aim of this study was to understand the social and economic impacts of TB and the needs for social support amongst people with TB in Gaza and Inhambane. Additionally, we sought to understand how people with TB perceive their social and economic situation during the TB treatment and what kind of support needs they identify.

## Method

This was a qualitative study with a phenomenological approach using semi-structured in-depth interviews with people with TB in two provinces of Mozambique. This study was part of a larger project entitled Coordination of Health and Social care for TB patients in Mozambique (CHEST, <https://shorturl.at/rzFL3>), whose main objective was to develop a bi-directional referral system between health and social services to increase access of grants by people with TB, improve their health and wellbeing, and increase TB notification rates.

### Context and setting

Mozambique is a sub-Saharan country with an estimate of 31 million people in 2021 and 62.8% of the population living under the national poverty line (The World Bank., 2023). Treatment for TB is provided free of charge at primary healthcare facilities by the Mozambican Ministry of Health through the National TB Programme (NTP). Overall, the country has a low social support coverage and data on social support amongst people with TB and their households are scarce. TB is not a stated eligibility criterion for social support, but if people with TB have comorbidities such as HIV or malnutrition, they may be eligible for support. This study was conducted in two districts conveniently selected in southern Mozambique: Chókwe and Maxixe, in the provinces of Gaza and Inhambane, respectively. The provinces together had 28 districts providing TB services and collectively contributed with 12.8% of the country's TB notifications (MISAU, 2022). Gaza has 68% of its inhabitants living in rural area and an illiteracy rate of 26.1% (INE, 2021a). It has a total of 163 healthcare facilities, of which 39.9% provide TB services. Inhambane has 67% of inhabitants living in rural area and an illiteracy rate of 30% (INE, 2021b). It has 130 healthcare facilities, of which 47.7% provide TB services. Healthcare facilities can provide TB services if they have an equipped laboratory, capability for sample referrals and trained human resources for TB services provision. We selected healthcare facilities to represent rural and urban context of each province, and all had a dedicated room for TB services.

### Data collection

Between November 2020 and February 2022, participants were conveniently recruited from four primary outpatient healthcare facilities that provide TB services. Due to logistical challenges and travel restrictions related to Covid-19, data collection was conducted in two phases. In the first phase, during the second wave of Covid-19, from November 2020 to March 2021, 18 participants were recruited during their follow-up visits for TB treatment and enrolled in the study. In the second phase, during the third Covid-19 wave, from January to February 2022, eligible participants were identified through the National TB Programme registers, contacted, and invited to participate in the study via phone. A total of 34 participants were enrolled during this phase. Participants were eligible if they were (i) adults (above 18 years old), (ii) diagnosed with drug-susceptible or drug-resistant TB, and (iii) had undergone at least two weeks of treatment at the time of enrolment. After confirming their eligibility, participants provided written informed consent and were invited to a face-to-face interview at a quiet place in the healthcare facility.

Data were collected using a semi-structured interview guide, with interview durations ranging from 8 to 55 min (See interview guide in Supplementary file 1). The shorter interviews were attributed to some participants' difficulty in expressing their thoughts effectively, and one respondent even requested to interrupt the interview due to the inability to answer some questions. The interview guide consisted of questions related to TB diagnosis and treatment, social support experiences and needs, TB-associated costs, financial impact on patients and their families, and changes in participants' relationships with close acquaintances during TB illness. Interviews were conducted in Portuguese or the participant's local language by three authors (AZ, PN, and VC). Interviews were audio recorded while field notes were taken to capture non-verbal communication and

other relevant information. The final sample size was determined by data saturation (Fusch & Ness, 2015; Malterud et al., 2016).

### Study participants

A total of 52 adults diagnosed with TB were enrolled in the study, with roughly 60% recruited from Inhambane. The demographic characteristics of participants are presented in table 1. From the total, 50% were female, with a median age of 40 years old. About 65.4% had primary-level education. During the TB episode, 32.7% were employed and had a source of income, while 63.5% were the primary income earners in their households.

### Analysis

Interviews conducted in Portuguese were transcribed verbatim, while those conducted in local languages were directly translated into Portuguese during transcription. All transcripts were checked against the original records by the research assistants (AZ and VC). Transcripts were coded by AZ, CY and VC using Dedoose software and excerpts from Dedoose were first summarised in English and then analysed by AZ, CY, PN, SA and VC. Seven interviews were coded by more than one researcher to verify the common understanding of the codes. For independent coding, regular discussions were held to clarify understandings of the codes in an iterative process. During this process, notes were taken on coding diaries with the initial interpretation of the data. The team used a reflexive thematic analysis to analyse the data (Braun & Clarke, 2019). Inductive coding was conducted by including codes that emerged from the data. Later, the data were organised into categories and sub-categories. Data from each subcategory was collated and summarised, followed by the examination of the summaries within each category. Through a latent approach, themes reflecting the patterns of shared meaning from the data were developed in a recursive process moving back and forth between the phases and checking the data and summaries when developing the themes. Lastly, some quotes from participants were selected to illustrate the themes. This paper is reported according to the COREQ guidelines (Tong et al., 2007) (see the COREQ checklist in supplementary file 2).

### Patient and public involvement

The TB coordinator and counsellors at healthcare facilities were involved in identification of study participants. However, patients and the general public were not involved in the design or planning of the study.

**Table 1.** Socio-demographic characteristics – People with TB.

Demographic Characteristics	Gaza <i>n</i> = 21	Inhambane <i>n</i> = 31	Total <i>n</i> = 52
Age, Median (IQR)	46 (31-57)	39 (30-50)	40 (30.5-56)
Sex			
Male (%)	10 (52.4)	16 (51.6)	26 (50.0)
Female (%)	11 (47.6)	15 (48.4)	26 (50.0)
Education			
Primary (%)	15 (71.4)	19 (61.3)	34 (65.4)
Secondary School or more (%)	6 (28.6)	8 (25.8)	14 (26.9)
None (%)	00 (0)	4 (12.9)	4 (7.7)
Employment at the time of the interview			
Yes (%)	5 (23.8)	12 (38.7)	17 (32.7)
No (%)	16 (76.2)	19 (61.3)	35 (67.3)
Waiting time in health facility in hours, Median (IQR)	60 (30-90)	20 (10-40)	30 (15-60)
Primary income earner in the household			
Patient (%)	13 (61.9)	20 (64.5)	33 (63.5)
Other (%)	8 (38.1)	11 (35.5)	19 (36.5)

## Researcher's characteristics and reflexivity

The research team consists of male and female researchers with diverse backgrounds and experience. Three members are local from the area and possess a strong understanding of the context. AZ is an anthropologist with five years' experience in qualitative data collection in other fields. VC is a psychologist with two years' experience in in-depth interview techniques. PN is a medical doctor and PhD candidate with seven years' experience in qualitative research and five years' clinical experience in the tuberculosis field. SA is a senior researcher and social scientist with extensive experience in qualitative research and tuberculosis. CY is a social scientist and public policy researcher. CY and SA have experience in qualitative and international social protection systems. The data collection was conducted by AZ, PN and VC in Portuguese or in the participant's mother tongue, as appropriate. AZ and VC were both trained in qualitative data collection techniques, the study protocol and tools by PN. They familiarised themselves with the topic guide and the context before commencing data collection. Coding was conducted using original transcripts by AZ, CY and VC, who are native Portuguese speakers. Data analysis was conducted by AZ, CY, PN, SA and VC.

## Ethical considerations

Prior to the interview, all study participants received comprehensive information about the study and provided written informed consent. For those who were unable to read, write, or speak Portuguese, the study was explained to them in their native language in the presence of a literate witness, after which their fingerprints and the witnesses' signatures were obtained. The study protocol adhered to the Declaration of Helsinki (last updated in October 2013) and was approved by the Institutional Ethics Committee of the Instituto Nacional de Saúde (National Institute of Health) in Maputo, Mozambique (Ref. no. 001/CIBS-INS/2020) and the Swedish Ethical Review Authority in Stockholm, Sweden (Ref. no. 2022-03297-01). To safeguard the identity of the participants, the interviews were anonymised and stored in password-protected computers.

## Results

Participants shared their broad experience and trajectory of care, including choices of healthcare facility and pathways to diagnosis, matters about which there is already considerable knowledge in the literature. The results below are organised according to three themes, focusing only on the social and economic burden of TB and the needs for social protection from the perspective of people with TB (Table 2).

### Theme 1: TB has a social and economic impact that requires adaptation and resourcefulness amongst those affected

- a. TB can complicate social relationships at individual, family and community levels.

**Table 2.** Example of themes and sub-themes.

Themes	Sub-themes
<b>Theme 1:</b> TB has a social and economic impact that requires adaptation and resourcefulness amongst those affected.	<ol style="list-style-type: none"> <li>1. TB can complicate social relationships at individual, family and community levels.</li> <li>2. TB results in out-of-pocket costs and loss of income.</li> <li>3. Mitigating TB costs requires adaptation of people with TB.</li> </ol>
<b>Theme 2:</b> People had different preferences and needs for social support.	None
<b>Theme 3:</b> People with TB have different knowledge of, and experiences with, formal social support.	None

TB profoundly impacted the social relationships of affected people, their households and communities. Participants reported that their families had different reactions towards their diagnosis, spanning from fear to sadness. These reactions resulted in negative experiences such as isolation, stigma, prejudice, discrimination, social distancing from family, divorce and rumours about HIV status. Changes in their relationships were often worsened by loss of income and other financial difficulties. Social distancing and isolation were result of fear of contagion due to the disease. Some participants pointed to need of education and increase of awareness for better understanding of the course of the disease.

They [Friends] moved away when I got sick, they didn't look at me with good eyes, only one person stayed with me, who is the one that takes care of me, supports [me in] everything, all the others left because of my illness. (Female, 34 years old, Chókwe District)

When I was diagnosed with this disease [TB], my relatives took me to the hospital to start taking the pills, while at the same time they kept social distance, separated households' utensils they used because it could contaminate them if I used the same [...]. (Female, 24 years old, Chókwe District)

Most respondents also perceived separation of utensils as a protective measure to avoid transmitting the disease to the ones around them.

*b. TB results in out-of-pocket costs and loss of income.*

Out-of-pocket costs and income loss were the most reported financial impact caused by TB. Both formal and informally employed participants emphasised that they had to stop working due to the disease-related weakness and adverse effects of treatment. This had a severe negative financial impact on the livelihood of the household, especially in circumstances in which the person with TB was the primary income earner or lived alone with limited external support, often struggling to have enough money and food without relying on relatives and neighbours.

On top of income loss, most participants reported incurring transport costs related to visits to healthcare facilities. These costs ranged from 0.3 United States Dollars (\$) for public transport to \$6.5 for private transport for a one-way trip to the TB healthcare facility, depending on the distance. Higher transport costs were reported when the sick person was accompanied to the healthcare facility by a caregiver or when the person was too ill to take public transport or walk and opted for taking a taxi. Some participants described being unable to cover transport costs and having to walk to the TB healthcare facility or hitchhike.

... There are days we don't have transport money, I have to walk from there [home] to here [healthcare facility]. (Female, 29 Years old, Maxixe District)

In addition to transportation costs, people with TB also needed enriched food, supplements or other TB-related dietary intake recommended by the healthcare providers (e.g. instant porridge, juice and fruits) and additional medication that was unavailable in public services. These needs added a burden to them and their household's already precarious financial situation and were perceived as contributing to pushing them deeper into impoverishment.

*c. Mitigating TB-related costs requires coping strategies.*

Participants adopted several strategies to mitigate TB-related costs, and some strategies were reported as key to remain in care. Some participants shared examples of dissaving after the TB illness and taking loans. Most participants borrowed money from close people, such as family members, neighbours, and friends. A few people resorted to loan sharks or microcredit sums. Depending on the needs of the person, borrowed money ranged from \$1.5 to \$94.

When other strategies had been exhausted, participants resorted to the sale of goods. A variety of goods were mentioned by participants; livestock, and household belongings were the most

frequently mentioned. One respondent reported selling clothing and another one sold the building material intended for their house construction. Participants could not estimate the amount earned with the sales.

[...] I asked my neighbour that I already consider a friend because she takes care of me, it's like she's my mother, even my mother trusts her ... I asked for a loan of 6,000 meticaïs [\$100] that I still struggle to pay off, I still could not pay it back, I pay little by little because when I have my salary, I must buy food and a small part I will use to pay back my debt [...]. (Female, 34 years old Chókwe District)

Some people mentioned that they had not yet paid back the borrowed money by the time of the interview, and one person was able to pay off previous debts with the support of relatives.

### **Theme 2: people had different preferences and needs for social support**

Participants had different needs and priorities for social support according to personal challenges. Food and direct cash were the main preferred types of support. Some participants considered cash and food equally important, as they thought good nutrition and transportation were fundamental to treatment success. Commonly, people who prioritised cash said that food would be the second option and those who prioritised food said that cash would be the second option. Preference for cash was reported mainly due to the freedom of its use since people could prioritise and spend on what they perceived as the most important. Participants stressed that cash would be used to cover transport cost, which was seen as necessary for treatment adherence. Cash was used not only for transport but also for food purchases and other TB-related direct costs. A few participants said that they would use the cash to start a business or for savings. People considered different amounts as suitable for the cash support, ranging from \$23 to \$78 per month.

The first thing would be money, because I know that with money you can do anything, you might have food, but if you have other needs and you don't have money, there is nothing you can do. (Female, 36 years old, Maxixe District)

On the other hand, those who prioritised food based their choices on the need of improving the quality and variety of their diet during the TB treatment. In case of food provision, some people preferred soybeans and related, as the preparation is easy and practical for an ill person. One person also mentioned that the provision of food could prevent people from seeking money from unsafe sources or asking family members for money or food, suggesting that food support could prevent people from adopting unsafe coping strategies. While some participants had clear preferences for specific foods and nutrition support, such as soybeans, *xima* (a dish made of corn flour), oil, flour, corn, sugar, beans, juices, oranges, and fish, others would be happy with any type of food. One respondent mentioned that food is as important as medication, and it should be provided at the hospital as motivation to remain in care.

Because food is also medication. Let's not neglect food! (Male, 63 years old, Chókwe District)

Both things are important, but the most important thing is food. [...] there are times when hunger strikes at my house and I can't have anything to eat, you see, but continuing to take the medication and needing food. (Female, 40 years old, Maxixe District)

Few participants prioritised employment and others considered psychological support as having a broader impact on improving their adherence to treatment and care. Although psychological support was perceived as important, it seemed to lack at the study healthcare facilities.

### **Theme 3. People with TB have different knowledge of, and experiences with, formal social support**

Even though participants could clearly articulate their support needs, their knowledge and perceptions of state-provided support varied. Some had no knowledge of the existence of social support



schemes, and some did not even know what a social support scheme was. Some of those who had no knowledge of formal social support did not perceive themselves as entitled to a formal social protection scheme due to their TB status. When explained about its concept, people reported it to be necessary, helpful and important to adhere to treatment and counter difficulties faced due to the disease. Some also expressed gratitude about the possibility of receiving social support. This suggests that most participants face difficulties to the extent of needing external support, but its provision is limited by lack of information among other factors.

The second group of participants with knowledge of social support, heard about it for other health conditions, such as HIV and malnutrition. Others were aware of different people (children, mothers, elderly or people with disability) who had received some sort of support (food or money). They had heard about it on the radio, television, at the community and some called it a 'rumour'. Some people reported having heard about other people with TB receiving some type of social support (food or psychosocial support), but most of them could not give details about it, as it was based on hearsay.

I have never heard it; I haven't talked to anyone. I haven't had the talk about receiving help if you have this disease [...] What I saw the other day is those with HIV receiving soy, when the kids are not feeling well, they are given food, peanuts, like peanut butter. I saw these people receiving it, but not me. (Female, 55 years old, Chókwe District)

A third group of participants had knowledge of social support schemes as they themselves had already received it. Two people knew about social support schemes, such as food and money, as they were TB/HIV co-infected and had already received food from a social support scheme for people living with HIV. This suggests that TB/HIV co-infection is the preponderant criterion for social support provision, and that people with TB might be receiving the support they need to encounter the illness-related challenges as long as they are HIV positive.

## Discussion

This study supports that TB has social and economic impacts on the lives of affected people. The economic impact is due to a combination of factors including loss of income, given that most people have informal jobs in our setting, and incur out-of-pocket costs and dissaving, which push them further into poverty. To counter these costs and challenges, people with TB need to be resourceful and adapt to different situations imposed by the disease. They exhaust their own resources, which makes them turn to the help of family, friends and neighbours. Food and money are their main and immediate needs and the most common type of help received from family and friends. However, despite this need for support, people with TB have different perceptions and knowledge of formal social support schemes. Most of them perceive support as informal help from family and community, and the few ones aware of the existence of formal social support associate it with HIV or malnutrition.

When analysing the TB-related economic burden on individuals and households based on the framework proposed by Russel (Russell, 2004), a cycle between disease, costs and livelihood was identified. Characteristics of the health system and the person's care-seeking and treatment behaviour drive direct and indirect costs, which in turn pressure people to adopt coping strategies. As direct impact of the incurrence of costs and adoption of coping strategies, the livelihood of people with TB becomes compromised with the occurrence of food insecurity, loss of income and dissaving. Adding a social dimension to the framework, the disease also places a social burden in the dynamics of the household. From the moment of reported illness, family relationships change, initially driven by feelings of fear or sadness, but intensified later by the impacts of the economic burden (Kipp et al., 2007). People with TB need to rely on their families at the same time as some of them are not able to provide for their families. The family sphere is followed by social resources through social networks, which many people with TB also need to resort to (Wingfield et al., 2016).



Studies in other high TB burden countries also showed that TB has social and economic impacts on the individual and the household. Isolation of people with TB was reported both in India and Zambia, due to discrimination and stigma (Mainga et al., 2022), but also voluntarily to avoid spreading the disease (Samridhi et al., 2021). The economic impact was also reported worldwide through the occurrence of catastrophic costs and adoption of coping strategies (WHO, 2022c). A study carried out in East Timor showed that four out of five people incur catastrophic costs due to TB, and the poorest were the most likely to resort to mitigation strategies such as selling goods, taking loans and using their savings (Viney et al., 2019). In a study in Zambia, where people with TB had informal jobs, people similarly faced income and job losses (Mainga et al., 2022). Coping strategies were also reported as common practices in China (Hutchison et al., 2017) and Ghana (Pedrazzoli et al., 2018).

### **Strengths and limitations**

We sought to address the trustworthiness of the study in terms of the credibility of the findings, considered in the sampling strategy through data saturation, which was reached with 52 in-depth interviews out of a total of 60 predicted. We also reported our study and findings following the COREQ checklist (Tong et al., 2007). Since the interviews were of different quality, the ones with higher quality contributed more to the findings compared to the shorter ones and with lower quality. Additionally, to avoid any social desirability bias, as people with TB were responding to people working for the government, the interviewers presented clear information about their occupation and the purpose of the interview. They emphasised that the goal of the interview was knowledge production and not any type of enquiry or evaluation from the government. They also stated that the interview would not interfere with their treatment and that their answers would only be used for research purposes. The study was conducted by a multidisciplinary team with different backgrounds that contribute to a multiplicity of perspectives on the topic. We enrolled people with both drug-susceptible and drug-resistant tuberculosis. However, the number of participants diagnosed with drug-resistant tuberculosis was relatively small. Furthermore, none of the enrolled participants underwent treatment that extended beyond six months. Consequently, we were unable to comprehensively elucidate differences in the financial impact faced by people under treatment for drug-susceptible tuberculosis compared to those with drug-resistant tuberculosis. Therefore, the results of this study may lack details to draw definitive conclusions about the comparative financial impact between those groups of people.

### **Conclusions**

TB has social and economic impacts both on the individual and the household. It affects family and community relationships, not only due to the TB status, but also due to impacts on the household finances especially in settings where informal employment is prevalent. The disease-cost-livelihood cycle undermines the entire household, exposing the household to financial and food insecurity and the person with TB to worsened health. Our study suggests that in Mozambique, people with TB require support mainly in terms of food and cash. However, they are currently not entitled to any form of support and people with TB need to rely on the help from family, friends and neighbours, which is insufficient. The lack of knowledge and information about governmental social support schemes, even if for other conditions, and not perceiving themselves as entitled reinforce the reliance of people with TB on family and friends. Therefore, need of social support for people with TB should be advocated to policymakers so that the eligibility criteria to be enrolled in social support schemes can be expanded beyond HIV or chronic diseases, as evidence shows that TB poses a burden greater than the individual physical one. Communication and promotion of such forms of support should also be strengthened, especially to those most vulnerable and those living in rural areas with limited access to public services. Development and implementation of policies aimed at

supporting people affected by TB, especially those in informal employment, could help to alleviate the financial impact and reduce the risk of individuals falling into deeper poverty during TB illness.

Our study sheds light on the support preferences and needs of people with TB, but further investigation is needed, with a design that allows the most relevant aspects of the financial impact to be addressed considering the context of rural Mozambique.

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## Disclosure statement

No potential conflict of interest was reported by the author(s).

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## Authors' contribution

SA, PN, CK, TW, BB and KL acquired the funds and designed the study design. PN, CY, AZ, VC, and SA conducted the study and drafted the manuscript. All authors reviewed, edited, and approved the final version of the manuscript.

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