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# Dissaving In the Era of "Free" Care for Tuberculosis (TB): A Qualitative Exploration of Financial Coping and Enablers Among Patients with Co-Prevalent TB-HIV/ TB-Diabetes in Bhavnagar Region, Western India

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## ABSTRACT

**Background:** India reports the highest number of cases of tuberculosis (TB) in India. Patients with TB employ negative financial coping mechanisms (dissaving) to make up for the costs of care. Our objectives were to explore the dissaving employed and enablers perceived by patients with TB-HIV, patients with TB-diabetes, and program managers of TB.

**Methods:** We conducted qualitative in-depth interviews among eight TB-HIV patients, eight TB-diabetes patients, and seventeen program managers of TB in the Bhavnagar region (western part of India). An interview guide focusing on the coping strategies and enablers was used. Interviews were audio-recorded, transcribed, and analyzed using thematic analysis (codes and categories).

**Results:** Borrowing money, taking a loan on interest, selling jewellery, taking up employment by the spouse, and mortgaging assets were the negative financial coping strategies employed by patients with TB-HIV co-infection/ TB-diabetes comorbidity. Free diagnosis, free treatment, accessible health facilities, support from health workers, bi-directional screening, and collaborative integration were some of the enablers perceived by patients and program managers.

**Conclusions:** Even in settings with a decentralized "free" model of TB care, patients with co-prevalent TB-HIV/ TB-diabetes employ dissaving to offset the costs of care. The cash transfer scheme for patients with TB should be realigned to meet the financial protection targets of zero catastrophic costs by the year 2030.

**Keywords:** tuberculosis-human immunodeficiency virus; tuberculosis-diabetes; negative financial coping; collaborative framework; financial protection

## INTRODUCTION

Tuberculosis (TB) is primarily considered an infectious disease of poverty. Nearly 5.8 million people worldwide are estimated to be suffering from TB in the year 2021.[1] As per estimates released by the World Bank, 176 million people in India were living in extreme poverty, with 13.4% of Indians living below the international poverty line (below $1.9 purchasing power parity/day).[2] With 1.5 million cases of TB in the year 2021, India is reporting the highest number of cases of TB worldwide.[1] The costs incurred due to TB has been reported to push families below the poverty line, termed 'catastrophic costs'.[3]

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On average, globally, 43% of families with a patient with TB incur costs defined as 'catastrophic', that is, exceeding 20% of their annual household income.[4] In India, the prevalence of catastrophic costs among families with a patient with TB ranges between 4% and 68%.[5,6]

To overcome the costs incurred, TB-affected families are forced to employ negative financial coping strategies, also called dissaving. Studies have reported various negative financial coping strategies such as borrowing money, selling assets such as jewellery, interrupting school, and others.[3,5,7-18] Such financial coping strategies are even considered a proxy indicator of catastrophic costs employed by patients with TB.[17] Further, dissaving serves as an indicator of the financial protection mechanisms employed by governments to help them balance such costs.[17]

A very few studies have explored the negative financial coping strategies employed by patients with TB using qualitative research methods[10], and among patients with TB comorbidities.[19,20] Evidence on enabling factors under the TB program is mainly focused on adherence to the treatment, barring a few studies.[21–23] Our study explored the negative financial coping mechanisms employed and the enabling factors perceived by patients with TB-HIV/ TB-diabetes co-prevalence and also explored the perceptions of program managers of TB in the Bhavnagar region (western India).

## METHODS

**Study design, setting, and theoretical framework:** We conducted a qualitative inquiry using the constructivist paradigm for exploring the enabling factors and negative financial coping strategies among TB-HIV/ TB-diabetes patients as well as program managers of the National TB Elimination Program (NTEP) in Bhavnagar region (western part of India). We used a descriptive design to describe the codes/ categories generated from the qualitative exploration. Bhavnagar region, which includes the district and city, has a population of ~2.8 and ~0.6 million respectively. It is largely a sparsely populated rural setting with urban conglomerates in the bigger taluks of the district. An average of 2000 patients with TB are notified in the Bhavnagar region every year. We used the theoretical concepts of 'social exclusion' proposed by Adam and Potvin.[24] The social exclusion theory proposes how social inequalities impact the rights, resources, and capabilities of families to access healthcare services.[24]

**Study population:** Seventeen program managers of NTEP, eight patients with TB-HIV co-infection, and eight patients with TB-diabetes comorbidity in the Bhavnagar region were included in the study. The program managers included the district TB officer, senior treatment supervisors, and TB health visitors working under the NTEP program in the Bhavnagar region. Patients and program managers who were more likely to respond, and who were perceived to be more knowledgeable were purposively selected for the study. All the study participants were included in the study with prior information and rapport building through the TB health visitors.

**Data collection:** We used in-depth interviews as the method of data collection for the qualitative exploration among the study participants. An interview guide focusing on the enabling factors and coping strategies was used for the in-depth interviews. The interviews were conducted by the first author at a place and time convenient to the study participants. The interviews were continued till saturation of responses was achieved. Both the investigators hold an MD degree in Community Medicine and are trained in qualitative research methods. At the time of the study, both the authors were teaching faculties in medical colleges. All the interviews were audio-recorded in the local language (Gujarati) after explaining the purpose and reasons for conducting the research. TB health visitors were present during the conduction of some of the interviews. The average duration of each interview was about 10 minutes.

**Analysis:** The audio-recorded interviews were transcribed to English in a Microsoft Word document. The analysis was inductive (not pre-defined). Both the investigators assigned the codes together. Codes were grouped into categories under pre-defined themes of enabling factors and coping strategies (thematic analysis). Participant checking was not done (transcript, coding, analysis, and interpretations were not shared with the participants for correctness).

**Ethical considerations:** The study was approved by the Ethics Committee of Government Medical College Bhavnagar. Written informed consent (including permission for the audio recording of the interviews) was obtained from all the study participants.

## RESULTS

Among the program managers, we interviewed the district TB officer, the district program coordinator, six TB health visitors, and nine senior treatment supervisors. Among the eight patients with TB-HIV co-infection and TB-diabetes comorbidity each, the mean age was 40 and 50 years respectively.

**Coping strategies:** Patients with TB-HIV co-infection perceived borrowing money and an increase in the burden of work on their spouse as the coping strategies employed for covering the costs incurred by them (Figure 1). For overcoming the costs of TB-diabetes comorbidity, the patients took a loan on interest, borrowed money, or, sold jewellery. The program functionaries also perceived those patients took a loan on interest, sold jewellery, borrowed money, or, mortgaged items for financing the costs incurred.

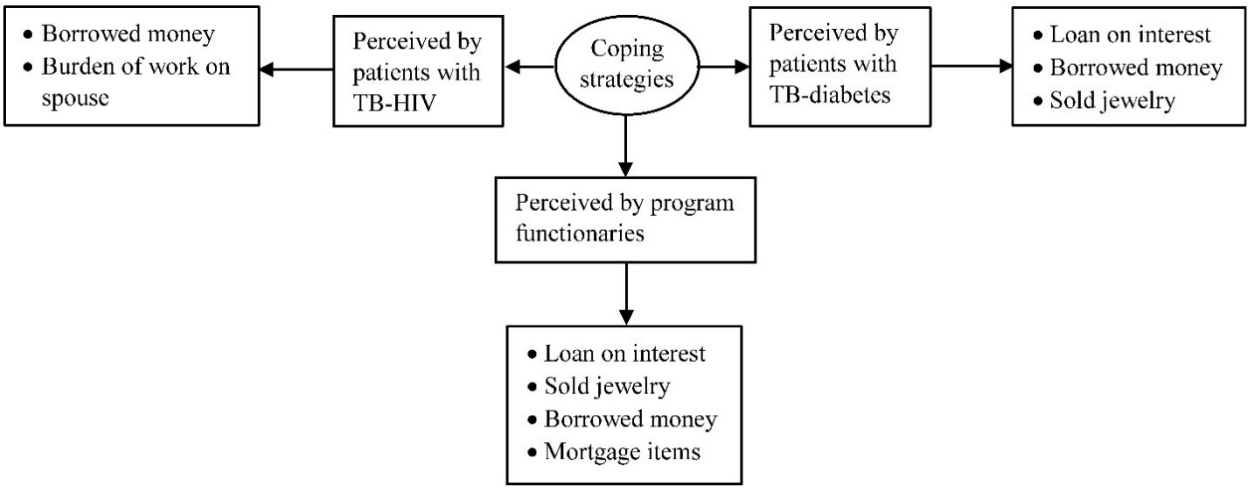


**Figure 1: Coping strategies as perceived by program functionaries and by patients with TB-HIV co-infection, and TB-diabetes comorbidity**

*"At that time, I borrowed 15000 rupees from my friend. After that when I got my salary from my diamonds, I gave the money back."* (42 years female TB-HIV co-infected patient)

*"My wife has to go out for kitchen work, and to 2-5 homes for work. I also had borrowed 10000 rupees from a person and returned in instalments of 500-1000 rupees."* (49 years male TB-HIV co-infected patient)

*"I have taken money on interest. To save my life, we had to do it. Still, we are paying for this. We have to look after our family, social responsibilities, etc."* (49 years female TB-diabetes comorbid patient)

*"We had to borrow money, take the money on interest, sold my wife's jewellery for the treatment."* (24 years female TB-diabetes comorbid patient)

*"With my experience of 10-15 years, I have seen that they take a loan on interest or sell their jewellery or borrow money from relatives or mortgage some items. In 10-15 days, they spend 8000-10000 rupees in private, then they come to us. Their daily wages stop as they are not able to go to work for 2-3 months."* (TB health visitor, 20 years of experience)

*"Patients who are living in remote areas like Sidsar and Nari, they are very poor, they are daily-wage laborers. Now, if the sole earner in the family gets TB, then their family gets shattered, then they borrow money from someone. Now, the government is giving 500 rupees per month, but if there are 5-6 members in the family, then it is very difficult for them."* (TB health visitor, 6 years of experience)

**Enabling factors**

Patients with TB-HIV co-infection perceived free diagnosis and treatment, accessible health facilities, TB-HIV integration, and a supportive environment as the enablers (Figure 2). Patients with TB-diabetes comorbidity perceived good care in government facilities, health worker support, effective medicines, and coping through cash assistance as some of the enablers. The enablers perceived by the program functionaries were similar to that of the patients - zero expenditures, accessible care, health worker support, and a collaborative framework.

**Zero expenditures**

The program functionaries as well as the patients felt that the diagnosis, as well as treatment, was free at the government health facilities. Additionally, the program functionaries perceived that transport reimbursement was also being provided for patients with HIV.

*"Not even diabetes, HIV testing is free and even TB testing is free of cost. All medicines are available free of cost."* (Senior treatment supervisor, 18 years of experience)

*"We do not have to spend more money on TB and HIV. Mostly it is the same, almost everything is free because it is a government medicine, available in the government hospital. No one gives it in a private hospital so the expense is nearly none."* (59 years male TB-HIV co-infected patient)

*"Treatment at Bhavnagar [government hospital] did not cost me a single rupee. They provided us with a free tiffin from the hospital. I only had to pay 5-10 rupees to drink tea in the morning, no other expenses, and no expenses on medicines."* (24 years female TB-diabetes comorbid patient)

**Accessible care**

The health centers were perceived to be nearby in our study setting by both the patients as well as program managers. The perception of health centers being closer to their home was especially true for the patients residing within city limits. Further that since the government has a network of health centers across the region, the patients had to pay minimal visits to the health centers. *"Health center was accessible, I went regularly. This would be my 22nd month that I have never skipped my medicine. On every date that they give me, I go to take the medicines."* (42 years male TB-HIV co-infected patient)

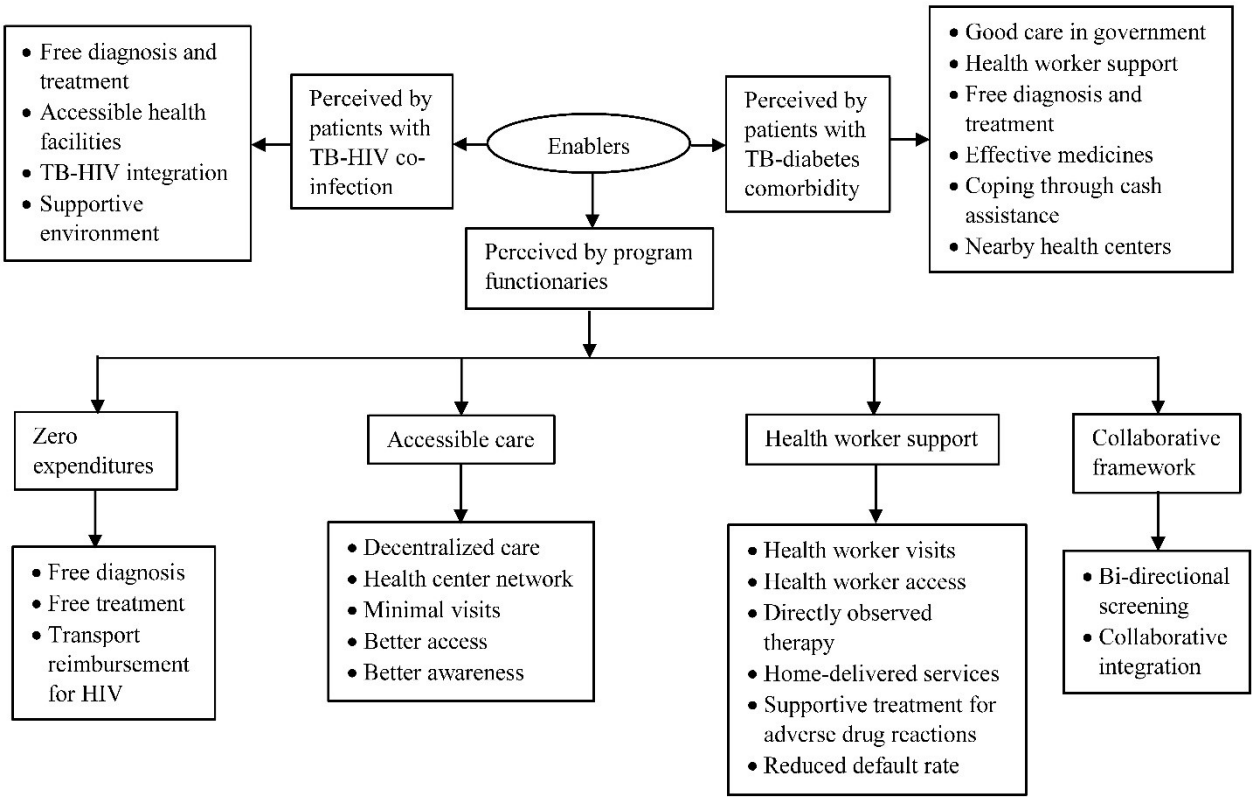


**Figure 2: Enablers perceived by program functionaries and by patients with TB-HIV co-infection, and TB-diabetes comorbidity**

*"I visit on the given time and date. If there is a problem in between, then I go to a nearby government center for fever, breathlessness, etc. I go to the govt. health center only, nowhere else. They also give me diabetes medicines from the center. The medicines are given for a month."* (45 years female TB-diabetes comorbid patient)

*"Health centers are near to the community. Patients have to go maximum at a distance of 1-1.5 kilometres for availing health services and everyone knows this now."* (TB health visitor, 10 years of experience)

*"The program has been designed in a way that patients have to make the least number of visits to health facilities and that too at centers nearest to the homes of patients - subcentre or PHC and now, health and wellness centers have also been started where these facilities are available. At these centers, patients can take treatment for minor or major diseases without any payment of money."* (District TB officer, 20 years of experience)

**Health worker support**

Patients perceived that the support of the field-level health workers in the NTEP program had been commendable. The medicines are delivered to the homes of the patients either by the TB health visitors or by the frontline health workers. The support received from employers was also appreciated. The program functionaries also agreed that the health workers played an important role in providing supportive treatment in the event of adverse drug reactions apart from their role in delivering the medicines at home.

*"I had huge support from my family and also support from my manager, he told me not to get anxious we all are there with you. My manager took care of all the expenses without even letting me know. At that time, we were not in the position to spend that much money. Later, I paid all the money back. Took rest for two months and then again joined work and from that salary, I paid all money back in instalments."* (26 years male TB-HIV co-infected patient)

*"The health workers' work is good. The previous health worker is the one who called me when I was going to a private doctor. He asked me to wait for some time. He would come immediately with the medicines. He asked, let us know if you have any problems. The new health worker is also good."* (60 years male TB-diabetes comorbid patient)

*"TB drugs are to be taken in the morning, medicines for diabetes can be taken in the afternoon or at any time of day, CPT to be taken in the afternoon and at night they take ART for HIV. So, due to this, there are chances of acidity or nausea/ vomiting among these patients, we give them medicines for these symptoms on monthly basis. So, they do not incur any costs for this, because as soon as patient informs us about these side effects, we deliver the medicines at their home for the entire month, especially to patients having HIV or diabetes along with TB."* (TB health visitor, 6 years of experience)

### Collaborative framework

The collaborative framework between TB and HIV was highlighted by the program functionaries as well as patients with TB-HIV co-infection as enablers. For TB-HIV, to reduce the number of visits of patients, the drugs for both diseases (AKT and ART) are available from the ART center itself. For TB-diabetes, only program managers perceived that there is an integration - for diagnosis as well as for treatment, however, patients with TB-diabetes comorbidity did not mention so.

*"We did not have to spend any money after starting treatment in govt. hospital. The diagnosis of TB was done immediately at the government hospital itself. Medication for HIV was continued by the govt. hospital, and after 1 year, TB was diagnosed. They were giving me the medicines for TB along with HIV pills. Both the medicines were available in one place itself. Every day I had to take 3 pills and after 6 months we did the reports and now I don't have TB."* (42 years male TB-HIV co-infected patient)

*"As far as costs are concerned, ART and TB drugs are given from one place itself, that is, from the ART center situated in the basement. Their schedule has been arranged in such a way that they get ART as well as TB medicines, their monitoring also happens at the ART center itself, at the field-level we do their monitoring."* (Senior treatment supervisor, 5 years of experience)

*"At all levels, even at subcentre level and health and wellness center level, patients with TB are being screened. At the health and wellness center level, we have even given anti-diabetic drugs to be given to such patients. At PHC, CHC-level, it is already available. So, overall, even for diabetes, all services can be availed free of cost. So, if patients take it from the government, then they do not have any burden related to costs. Now with the coordination of medical college and wherever the patients are on anti-diabetic drugs, they identify patients with cough and cold and screen them by sputum examination for TB. So, both ways, TB patients are screened for diabetes and diabetes patients are screened for TB."* (District TB officer, 20 years of experience)

## DISCUSSION

To summarize, dissaving such as borrowing money on interest, selling jewellery, mortgaging household assets, and commencing new employment by spouse were employed in our study setting to meet the costs incurred for the care of TB-HIV co-infection and TB-diabetes comorbidity. Several factors namely free diagnosis, free treatment, accessible healthcare facilities, home visits by healthcare workers, support from family/ employers, and TB-HIV/ TB-diabetes collaborative framework were perceived as enablers in our study. Despite the perceived "free" healthcare for TB and the associated comorbidities, negative financial coping strategies had to be employed by the patients.

Several aspects regarding the care-seeking behavior and demographics of our study setting explain the findings of the study. In our study, patients were suffering from two diseases - TB with HIV, or, TB with diabetes. This dual burden might have led the patients to incur additive costs for the twin diseases. Generally, the private sector is the first point of contact for many patients in our study setting. The onset of symptoms is gradual, thus, by the time patients reach the government health facilities for treatment, they must have already spent a fortune on the initial care for the diseases. The patients perceived the healthcare as accessible, however, this may not be true for those patients residing in remote villages. Even with the perceived "free" care, patients incur "hidden" costs like loss of wages, costs for food, transportation, and accommodation, and income loss due to the inability to work during the debilitating phases of the diseases. These "hidden" costs are higher for patients (and accompanying members) coming from far-off places to visit the government healthcare facilities. To balance such costs, TB-affected families are forced to employ one of the many negative financial coping strategies.

Apart from the coping strategies described in our study, interrupting school/ tuition/ education of children[5,7,13], cutting other expenses[10], use of savings[11,12,17], and donations[16] were reported for patients with TB in other studies. The coping strategies like borrowing money, selling assets, and mortgaging household assets were also reported to be employed by patients with TB in India, Myanmar, Soloman Islands, Nepal, Malawi, Tajikistan, Benin, Ghana, China, South Africa, Bangladesh, and Tanzania.[5,7–18] Our findings are also similar to the coping strategies described among patients with TB-diabetes comorbidity[19], and TB-HIV co-infection.[20]

Our study findings on enabling factors were supported by several other studies. Family support was identified as an enabler in the linkage between collaborative activities between TB and tobacco/ alcohol in India.[21] Various other enabling factors such as cash transfers, payments under a social welfare scheme, and travel reimbursement have been proved to improve treatment outcomes among patients with TB in Ghana and India.[22,25] Support of field workers, free treatment, free hospitalization, and family support were enlisted as enabling factors to access health services under the TB program in China.[23] The enabling factors reported in our study highlight the decentralized model of TB care in India.

The social exclusion model derives from the impact of the social position defined by education, income, occupation, gender, and ethnicity on health inequalities.[24] TB and the associated comorbidities, impact the income, employment, and working conditions of the patients, thereby making them vulnerable to further poverty, explaining the urge to use their savings to overcome the financial impact. As a cushion to the incumbent financial blow of catastrophic costs due to TB, a cash transfer scheme has been found to im-

prove the treatment outcomes among patients in India.[25] Our study, the first from India exploring dissaving among patients with TB-HIV/ TB-diabetes co-prevalence, follows the COREQ guidelines for reporting qualitative research.[26]

## CONCLUSIONS

We conclude that even in settings with a decentralized "free" model of TB care, patients with co-prevalent TB-HIV/ TB-diabetes employ dissaving to fund the anticipated and actual costs of care. We recommend further expanding the decentralized care by strengthening the collaborative TB-HIV/ TB-diabetes frameworks in India. We also recommend realigning the cash transfer scheme for patients with TB to meet the financial protection targets of zero catastrophic costs by the year 2030. Future studies should determine whether the negative financial coping mechanisms explain adverse treatment outcomes among patients with TB comorbidities using the constructs of the social exclusion theory.

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