Original article

TB RELATED COSTS, SOCIAL PROTECTION, COPING STRATEGIES, AND SOCIAL CONSEQUENCES – A SURVEY AMONG TB PATIENTS ATTENDING DISTRICT CHEST CLINICS IN SRI LANKA

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ABSTRACT

Introduction: Drivers of TB epidemic are closely linked with the social determinants of health. One of the End TB targets is to reach "Zero" catastrophic cost due to TB by 2035. The current study was planned to describe the TB related costs, the social protection, coping strategies and the social consequences experienced by TB patients.

Methodology: A longitudinal study was conducted among 736 drug sensitive TB patients in nine districts from September 2021 to February 2022 using a multistage cluster sampling with probability proportional to size of the patients detected in the previous year. Data were collected using an interviewer administered questionnaire and the results were presented as proportions, median and inter quartile range (IQR).

Results: Out of 750, 634 responded (84.5%). The median age (IQR) was 50 (23-27) years and one quarter (n=162, 25.6%) was in the age group of 55-64 years, majority (n=372, 58%) were males. Direct medical cost was the highest during pre-treatment period, whereas indirect costs increased over the TB episode contributing to 75% of per patient cost which was 127 USD. Around 16.8% of the patients experienced catastrophic cost due to TB. Around 30% of the participants who employed previously lost their jobs after diagnosis. Less than a quarter of patients had social protection by means of financial support and adopted coping strategies such as use of savings (46%) and loans from relatives (29%).

Conclusion: Pre-treatment direct medical costs and indirect costs after diagnosis are considerable while social protection is sub optimal for TB patients which need policy reforms.

Key words: TB, Catastrophic cost, Direct Medical costs, Indirect costs, Social protection

INTRODUCTION

TB is a disease which is closely related to social determinants of health. Therefore, it is said to be the disease of poor and marginalized. The major social determinants of TB include food insecurity, malnutrition, poor housing and environmental conditions, interlinked with financial, geographic and cultural barriers to health care access[1]. At the household level, TB is mostly associated with smoking, alcohol consumption, low body mass index, lower level of personal education, unemployment, and lower household wealth[2]. Therefore, higher incidence of TB is noted in societies with high economic inequalities and low Socio economic Status (SES). The incidence is notably reducing in countries with high human development index and better access to healthcare[3].

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Globally, Tuberculosis is most prevalent among the age group of 15–54, among economically productive sector of the population[4-6]. When a patient with tuberculosis experiences productivity loss causing loss of income and forced to spend on medical and other costs related to TB, that particular patient will be overburdened economically leading to further deterioration of SES causing a vicious cycle. Evidence suggests that the average expenditure incurred by patients in low- and middle-income countries on diagnosis and treatment of TB ranges from $55 to $8198[7]. In countries where government spending on health is low and with a larger presence of private players, patients may be forced to spend out-of-pocket (OOP) to meet the expenditure on health [8]. Catastrophic health expenditures is defined as out-of-pocket expenditure for health care that exceeds a specified proportion of household income, with the consequence that the household may have to sacrifice the consumption of other goods and services necessary for their wellbeing[9-12]. Catastrophic health expenditures do not necessarily mean high health care costs. Relatively small expenditures for common illnesses may have serious financial implications for poor households[13,14].

In 2014, the 67th World Health Assembly adopted a resolution to make the world free of TB by the year 2035. WHO's "End TB Strategy" provides a holistic overview of this resolution and has four principles and three pillars. The three high-level target indicators of the End TB Strategy are reductions in TB deaths by 95%, reductions in the TB incidence rate by 90% from 2015 level and the percentage of TB patients and their households experiencing catastrophic costs (exceeding 20% of annual household income) being maintained at zero[15].

Sri Lanka is a lower-middle-income country with a GDP per capita of USD 3,853 (2019) and a total population of 21.8 million. Sri Lankan health and social indicators rank among the highest in South Asia and compare favorably with those in middle-income countries[16]. The country has a well-developed free health care system and spend 3% of the GDP on health[17]. Under universal health coverage, accessibility to health care services is highly ensured in the country. As per the evidence available, the private sector provides around one–half of outpatient curative care and around 5–10% of inpatient care. Most private healthcare is paid for by individuals out of pocket, as health insurance is not widely available. Patients usually have to pay private institutions up-front for treatment. It was found that 0.1% or approximately 14 000 people are being pushed into poverty because of out-of-pocket health spending and 5.3% of people spent more than 10% of their household's total expenditure on health care[18].

TB diagnostic and treatment services had been decentralized in Sri Lanka and provided free of charge for every citizen[19]. However, people have the freedom to choose the health care provider and may end up in either public sector or private sector according to their need and preference. As per the TB patient pathway survey, 37% of presumptive TB patients chose private health care providers as first contact point[20]. During this pre diagnosis period the financial cost would vary depending on the choice of health sector. However, once the diagnosis is made TB treatment is provided only through the government system and it is free of charge. Although Sri Lanka has committed to reach the End TB targets by the year 2035, a costing study to evaluate the baseline value in 2015 or thereafter has not been carried out. Therefore, the current study was planned to describe the TB related costs, the social protection measures and coping strategies adopted by the patients and the social consequences experienced.

METHODOLOGY

The study method was based on the handbook developed by the WHO on Tuberculosis patient cost surveys.

Study design and settings:

The study design was longitudinal, conducted in all 9 provinces from September 2021 to February 2022. The district with the highest TB case load was selected purposively from each province. As such, Colombo, Kandy, Galle, Rathnapura, Kurunegala, Anuradhapura, Badulla, Jaffna and Kalmunai were selected to conduct the study.

Study population:

All drug sensitive TB patients registered for treatment at the selected district institutions including children accompanied by a parent/ guardian was taken as the study population. Patients who cannot communicate rationally due to mental sub normality/psychiatric disorders unless they are presented with their guardians and patients who were in orphanages, elderly homes, prisons and other types of care homes were excluded from the study.

Sample size:

As there is no local data on catastrophic cost, assuming the proportion of drug sensitive TB patients who incurred catastrophic cost due to TB as 50%, the minimum sample size (n) required for the study after adjusting for a 10% non-response rate was 736[21]. As the cluster size was 15, it was decided to collect the sample from 50 clusters within the district from DCCs and the branch clinics.

Sampling technique:

The study followed a multi stage cluster sampling technique.

The district with the highest case detection in each province was selected for the study.

↓

Clusters were allocated proportionately to the number of cases notified annually by each selected district

↓

Clusters were allocated within the district according to the probability proportional to size of the detected TB cases (annual) by each institution within the district

↓

Study units were selected by recruiting consecutive drug sensitive TB patients attending DCCs and the branch clinics.

Study instruments:

Data collection was done using a structured interviewer administered questionnaire in both Sinhalese and Tamil languages. The face and content validity of the questionnaire was ensured through expert opinion. The questionnaire consists of socio-demographic and socio-economic question, TB related costs, social protection measures, coping strategies and social consequences. Pre-testing of the questionnaire was done in a sample of patients attending District Chest clinic Gampaha and the necessary changes were made thereafter.

A second study instrument (patient diary) was used to validate the data collected at the interview. Patients were instructed to update the diary daily by including all direct and indirect medical cost related to the management of the disease.

Data collection:

Data collection was done by the pre-interns. All diagnosed new TB patients registered for treatment, eligible and consented for the study were recruited after getting informed verbal consent. Consecutive patients who were registered for treatment were recruited to facilitate fair subject selection.

Two samples of patients were recruited at two time points. First sample when the patients were registered for treatment. Similar sample was recruited from the patients who were attending the clinic on completion of intensive phase.

In the first group, the data collection was done at the point of recruitment. Retrospective data collection was done at the point of recruitment Retrospective data collection about the cost on the pre-treatment phase was collected together with socio-demographic and disease information. The same group of patients were interviewed after one and two months during their follow up visits to the clinic to estimated due to TB during the intensive phase . Although retrospective date was collected by asking patients (bills were checked only if available) during prospective data collection patients were also given a diary to update TB related direct and indirect cost weekly and the data were validated when they presented for the interview.

In the second group, the data collection on sociodemographic and disease was done at the end of the intensive phase. This group of patients

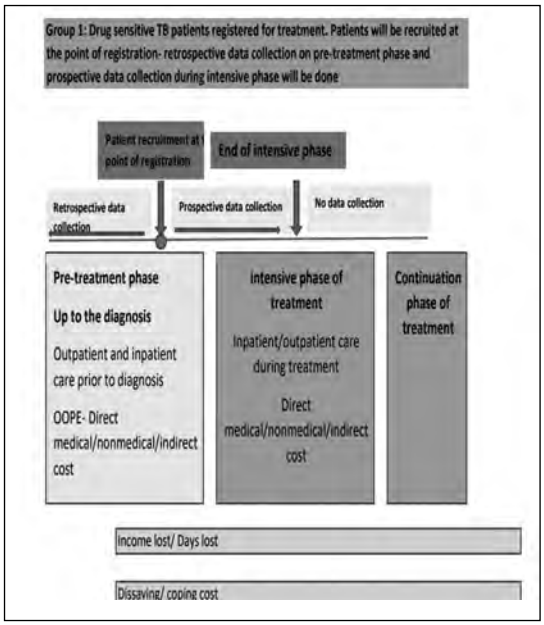

Figure 1. Schematic representation of recruitment and data collection on registration

were interviewed after one and two months of continuation phase during their follow up visits to the clinic to estimate the cost due to TB during the continuation phase . Patients were also give a diary to update TB related cost weekly to validated the date collected in the interview.

Ethical approval was received from the Ethics Review Committee of University of Shri Jayewardenepura.

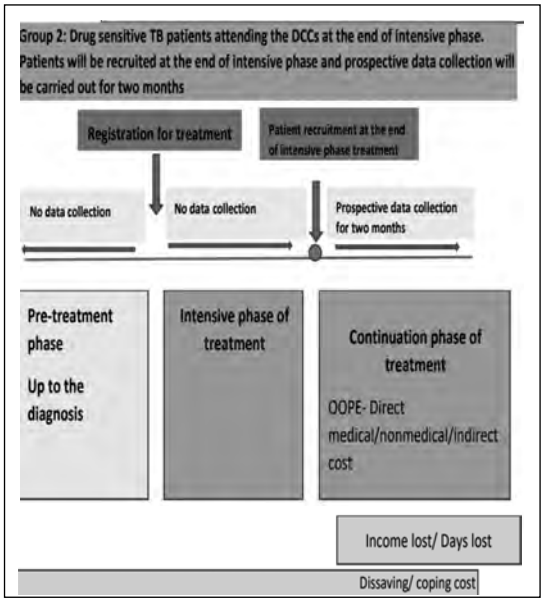

Figure 2. Schematic representation of recruitment and data collection at the end of intensive phase

Data analysis:

We used SPSS statistical software (version 24) to analyze the data. Univariate data analysis was done to provide descriptive information on the direct and indirect medical cost and the indirect cost related to TB. The cost estimation for the period in the continuation phase was done after extrapolating the gathered two months costs for the entire period. Catastrophic cost was calculated as follow

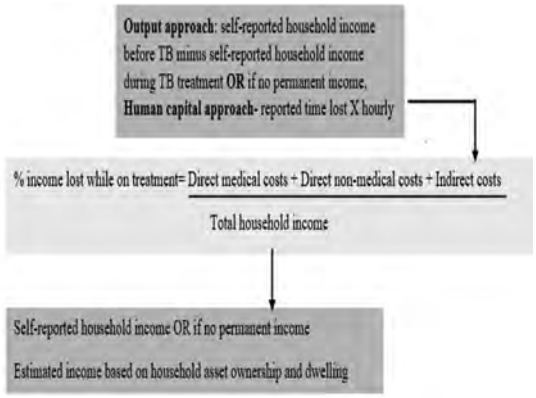

Figure 3. Schematic representation of calculation of presentations cost due to TB

RESULTS

Out of 750 participants, 634 responded with a response rate of 84.5%. The median age (IQR) was 50 (23-27) years and one quarter of the sample (n=162, 25.6%) was in the age group of 55-64 years. Just above half of the sample (n=372, 58%) were males. Majority were Sinhala (n=397; 62.6%) Buddhist (n=376; 59.2%) and married (n=481; 75.9%) and living in a household with 4-5 members (n=318; 50.2%). Only a minority (n=19; 3%) had not received formal education. Majority of patients were employed before being diagnosed as TB (n=356; 56.2%) and reported (n= 408; 64.4%) an average monthly family income of LKR 30,000.00 to 60,000. Around half of the study participants had one or more comorbidities (n=312; 49.2%), but only a minority (n=32; 5%) had another family member having TB at the time of interview .

Table 1: Distribution of study participants by socio-demographic and other characteristics		
	Frequency (n = 634)	**Percentage**
Age (years).		
0 – 14	19	3.0
15 – 24	58	9.1
25 – 34	71	11.2
35-44	102	16.1
45-54	125	19.7
55-64	162	25.6
65 and above	97	15.3
Gender.		
Male.	372	58.7
Female.	262	41.3
Ethnicity.		
Sinhala.	397	62.6
Tamil.	129	20.3
Muslim.	106	16.7
Burgher.	2	0.4
Religion.		
Buddhism.	376	59.2
Hinduism.	106	16.7
Islam.	106	16.7
Roman catholic/ Christian	46	7.3
Marital status.		
Married.	481	75.9
Unmarried.	126	19.8
Divorced/separated	13	2.1
Widowed	14	2.2
Level of Education		
No formal education	19	3
Grade 1- 5	76	12
Grade 6 -11	172	27.1
Grade O/L (Ordinary level- Grade 11 exam)	175	27.6
Grade 12-13	32	5
GCE A/L	109	17.2
Higher Education/PG	51	8
Employment status before being diagnosed as TB		
Employed	356	56.2
Not employed	278	43.8
Household income (Monthly in LKR)		
<30,000	175	27.6
30,001-60,000	408	64.4
60,001-90,000	31	4.9
90,001-120,000	8	1.3
120,001-150,000	7	1.1
>150,000	5	0.8
Presence of one or more comorbidities		
Yes	312	49.2
No	322	50.8
Household size		
Living alone	42	6.6
2-3 members	179	28.2
4-5 members	318	50.2
6-7 members	80	12.6
8 or more members	15	2.4
Any other members in the household currently suffering from TB		
Yes	32	5
No	602	95

Table 2. Distribution of study participants by job loss after being diagnosed as TB. Of the study participants, 30.9% (n=110) lost their jobs after being diagnosed as TB.		
	Frequency (n = 356)	**Percentage**
Loss of job after being diagnosed as TB		
Yes	110	30.9
No	246	69.1

Table 3. Distribution of study participants by cost incurred during the TB episode				
Cost category	**Phase of TB episode**			
	Pre-treatment	Intensive phase	Continuation phase	Total Episode
Direct medical cost	4,517,404	295,840	50,800	4,864,044 (16,213 USD) 25.5 USD per patient
Indirect Medical cost	815,077	664,325	1,962,024.00	3,441,426 (11,471 USD) 18 USD per patient
Indirect cost	236,334	6,072,450	11,827,400.00	18,136,184 (60,453 USD) 95.3 USD per patient
Total cost (LKR)	5,568,815	7,032,615	13,840,224.00	26,441,654 (81,706 USD)
Cost per patient (LKR)	8783.62	11,092.45	21,830	41,706
Cost per patient (USD)	26.7	33.81	66.5	127

TB related direct and indirect cost incurred by the drug sensitive TB patients

As per the **Table 3,** during pre-treatment phase the highest cost was due to direct medical cost which included consultation fee, payment for private hospitals, investigation etc. However, the direct medical cost reduced considerably during intensive and continuation phase. The total cost during intensive and continuation phase have gone up mainly due to indirect cost.

Table 4. Distribution of study participants by the percentage of cost incurred out of total annual income		
	Frequency (n = 634)	**Percentage**
Cost incurred as a proportion of annual income		
Up to 10%	487	76.8
10.1% to 20%	40	6.4
20.1% to 30%	50	7.9
30.1% to 40%	32	5.0
40.1% to 50%	19	3.0
>50%	6	0.9

Catastrophic cost incurred by the drug sensitive TB patients during the TB episode

As per the **Table 4** (Annex IV), majority (83.2%) spent less than 20% of their annual income for the expenditure caused due to TB episode. Hence, the proportion of households that spent > 20% of their household income or the households that experience catastrophic cost due to TB is 16.8%

Coping strategies

When the patients were inquired whether they could manage the cost with the household income, majority, 61.2% (n=388) responded saying that they could cover the expenses with household income

Table 5. Distribution of study participants by ability to cover the expenses with household		
	Frequency (n = 634)	**Percentage**
Ability to cover the expenses with household income		
Yes	388	61.2
No	246	38.8

When different types of coping strategies were inquired from the patients, 14.4% (n=91) responded saying that they have taken bank loans, 29% (n=184) had borrowed loans from relatives, 5.8% (n=37) had sold one of their assets, 13.4% (n=85) had pawned their jewelleries, and 46.1% (n=292) had used their savings

Table 6. Distribution of study participants by coping strategies		
	Frequency (n = 634)	**Percentage**
Sale of the assets		
Yes	37	5.8
No	597	94.2
Pawning of jewelleries		
Yes	85	13.4
No	549	86.6
Use of savings		
Yes	294	46.3
No savings/ not used savings	340	53.7
Bank loans		
Yes	91	14.4
No	543	85.6
Loans from relatives		
Yes	184	29.0
No	450	71.0

Social protection:

With regards to social protection, 9.6% (n=61) of the participants responded saying that they have insurance coverage, while 116 (18.3%) said that they received TB allowance. Only a minority, 3.2% (n=20) of patients said that they received funding support from local donors. Of the study participants, 30.4% (n=193) had received "Thriposha" as nutrition supplementation

Table 7. Distribution of study participants by availability of social protection strategie		
	Frequency (n = 634)	**Percentage**
Insurance coverage		
Yes	61	9.6
No	573	90.4
Receipt of TB allowance		
Yes	116	18.3
No	518	81.7
Funding from local donors		
Yes	20	3.2
No	614	94.2
Nutrition supplementation (Thriposha)		
Yes	193	30.4
No	441	69.6

Social consequences:

Of the study participants who were employed, 110 (30.8%) responded saying that their occupation was always affected due to the diseases and they either resigned or lost the job due to different reasons. Around 65 (18.3%) patients said that it was often/sometimes affected while 169 (47.5%) said that it was rarely affected and 12 (3.4%) responded saying it was not affected at all

Table 8. Distribution of study participants by the response on impact of the disease on occupation		
	Frequency (n = 356)	**Percentage**
Impact of the disease on occupation		
Always affected (resigned or lost the job)	110	30.8
Often/sometimes affected (4 days or more)	65	18.3
Rarely affected (1 to 3 days per week)	169	47.5
Not affected at all	12	3.4

When the impact of the disease on day-to-day personal activities was inquired, majority, 25.7% (n=163) responded saying it didn't affect the day-to-day activities at all. Only 58 (n=9.1%) patients said that the day-to-day activities were always affected because of the disease

Table 9. Distribution of study participants by the response on impact of the disease on day-to-day personal activities		
	Frequency (n = 634)	**Percentage**
Impact of the disease on day-to-day personal activities		
Always affected (all 7 days)	58	9.1
Often affected (5-6 days)	103	16.2
Sometimes affected (3-4 days)	156	24.6
Rarely affected (1-2 days)	154	24.3
Not affected at all	163	25.7

Under social consequences, patients were further inquired about perceived stigma and discrimination. Of the total participants, 132 (20.8%) responded saying that they were treated differently due to current illness at any point up to the date of interview while majority, 47.9% (n=304) responded saying "No" to this. However, 198 (31.8%) participants didn't respond to this question.

Table 10. Distribution of study participants by the response on whether they were treated differently at any point in the illness

	Frequency (n = 634)	Percentage
Whether you were treated differently		
Yes	132	20.8
No	304	48.0
No response	198	31.2

DISCUSSION

Drivers of TB epidemic are multifactorial and majority closely linked with the social determinants of health. This study primarily aimed to describe the TB related costs at different stages of TB care cascade, to assess the catastrophic cost and also to explore the aspects of social protection, coping strategies, and the psycho-social consequences.

The sample included majority male patients with a female to male ratio of 1.4 and around 41% are representing the age group of 55 years and above which are comparable to national figures, 1.8 of female to male ratio and 45% of age group 55 years and above. Just over 50% of the study participants had studied up to Ordinary level and this indirectly shows the real socioeconomic background of the affected population. Around 56% of the study population were employed prior to the diagnosis and majority of families get an income of around 30,000 to 60,000 LKR which also shows the poor socio-economic background of the study population. Nearly 50% of the patients are suffering from one or more comorbidities indicating the cost for the patients is not purely for TB but also for other diseases, especially if they don't seek care from the state sector.

As per the TB patient pathway survey, 37% of patients initially seek care at the private sector and the majority go to part time private practitioners[22]. This evidence is further supported by the results of current study which shows that the highest direct cost incurred by the patients was during the pre-treatment period. This includes costs for investigations, hospital stays in the private sector, antibiotics and other medicines. This also show the increasing trend of people seeking care in private sector and also support findings of Sri Lanka health system review that the majority (95%) of inward care is provided by the public sector and around 50% of outpatient care is provided by the private sector. However, the direct medical cost during the intensive and continuation phase was the minimum and this reflects the free health services especially the free treatment services provided by the National TB programme. In Sri Lanka, only the NTP provides TB drugs and it is free of charge. Even the patients diagnosed in the private sector are catered and therefore the total direct medical cost per patient for the TB episode was 25.5USD in this study and it is only 20% of total cost per patient.

The highest indirect medical cost was observed during continuation phase, which is for 4 months. However, it is only 18 USD per patient indicating only 15% of total expenditure per patient. Out of all types of costs, the indirect cost was the highest and it shows an increase over the TB cascade, the lowest during pre-treatment and the highest during continuation phase. The contribution of indirect cost to the total cost is considerable and it is 75%. This is slightly higher than the proportion of indirect cost as the total cost for TB in Bangladesh which is 68%[23]. This clearly indicates the loss of income over the care cascade especially towards continuation phase is remarkable. Loss of income due to job loss may have contributed immensely as 30% of study participants who were occupied previously had lost their jobs after being diagnosed as TB. In contrast, the Thailand TB catastrophic cost survey showed that the highest cost was due to direct non-medical costs and the indirect cost was the second highest[24]. Total cost during the entire episode per patient was 127 USD in the current study which is slightly higher than the cost incurred by TB patients in Bangladesh which is 124 USD. However, the

total cost incurred by a TB patient in Thailand was 903 USD and this study sample also included the Drug resistance patients. Present study revealed that 16.8% of TB patients and their families have experienced catastrophic cost due to TB whereas in the Thailand study it was 29.6%. The findings of current study showed that the government should put additional effort to minimize cost due to TB.

Although the majority of patients had responded saying that they could manage the expenses with the household income, patients used different mechanisms as coping strategies, while only less than 50% had used their savings. They used different mechanisms such as borrowing loans from banks, relatives and pawning their jewelleries. It was mentioned that pledging jewels and borrowing money were major coping strategies in an Indian study[25]. All TB patients had been provided TB allowance from the past and the amount varied from LKR 1000 to 5000 depending on the province as the allowance is funded by the provincial council funds. However, less than one fifth of the study participants had responded saying that they receive TB allowance. This scenario should be further explored to find out the reasons why the smaller number of patients were funded with TB allowance, whether due to challenges in providing provincial allocation due to existed economic crisis. On the other hand, only 9.2% of patients had insurance coverage and in Si Lanka, mostly the people working in private sector are opted with health insurance. Further, the standard is to provide nutrition supplementation for all TB patients and it is funded by the government. However, only one third of the patients had received nutrition supplementation.

When it comes to social consequences, impact on the disease on earning is the most affected area. Around one-third of the patients responded saying the illness had an impact on their occupation and they either resigned or lost the job due to different reasons. An Ethiopian study also found that TB patients' mean productivity and income reduced by 37% and 10 %, respectively, compared with pre-treatment level, while mean household expenditure increased by 33 % and working hours reduced by 78 % due to TB illness[26]. However, the disease didn't affect the day-to-day activities much as per the findings. Stigma and discrimination were not a major concern as per the study findings, however over quarter of patients sometimes felt that they were treated differently.

CONCLUSION

Indirect costs contributed the highest for the total cost in a TB episode. On average, a TB patient spend around 127 USD during the entire TB episode, while the catastrophic cost due to TB experienced by the TB patients and their households was 16.8%. Existing social protection methods for TB patients, such as insurance policy, TB allowance, funding from local donors etc are suboptimal. The government should formulate policies to minimize OOE during pretreatment and more importantly measures to reduce indirect cost caused by loss of income.

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CONFLICT OF INTEREST

There is no any financial interest or any conflict of interest related to this paper.

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