ORIGINAL ARTICLE

Direct Benefit Transfer Scheme for Tuberculosis Patients – Performance Challenges observed by the Providers and Patients

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Abstract

Introduction: Government of India launched an Aadhar-linked Direct Benefit Transfer (DBT) scheme from 1st April, 2018. Under this scheme, all notified TB patients would receive Rs 500 per month (~US$7) throughout the course of their treatment for nutritional support. **Aim and Objectives**: To determine the challenges faced by the health providers and patients in the implementation of Direct Benefit Transfer scheme. **Methods:** This was a mixed method cross-sectional study conducted on all public and private TB patients notified during the year 2019 under RNTCP (now NTEP) in district Amritsar, Punjab. Quantitative data about the availability and validation of bank accounts was obtained from the Nikshay portal after having permission from the District TB Officer. Qualitative data was obtained from the focus group discussion and in-depth interviews with the involved staff members (17) and patients (20) registered in Tuberculin units of Amritsar. **Results:** From the Nikshay reports, it was observed that there was significant difference between the public and private sector and between rural and urban areas. Focus group discussion was done with the TB Health Visitor (TBHV) and Senior TB supervisors (STS) and asked about the hurdles they faced. Items were identified and tabulated. In-depth interviews were conducted on 20 patients, 10 each from public and private sector respectively. Data collected was transcribed and arranged as per the themes or questions and then the information was recorded under those sub-headings. **Conclusion:** The major challenges observed by the providers were lack of support from the private sector, lack of awareness among people, technical issues and more work burden. Patients mostly mentioned about confidentiality issues, lack of awareness, social stigma of the disease, less amount and long and complex process.

Keywords

Tuberculosis; Poverty; Government incentives; Patients; Providers

Introduction

India is the highest TB burden country in the world having an estimated incidence of 26.9 lakh cases in 2019 (WHO).(1) TB is the disease of poverty and is a significant cause of loss of health, and economic well-being of India's population. The disease usually affects people in their productive age group (15 - 45 years) causing socio-economic consequences for the household. Various studies in India have shown that on an average, 3-4 months of work-time is lost as a result of TB, resulting in an average potential loss of 20-30% of the annual household income. This leads to increased debt burden, particularly for the poor and marginalized sections of the population.(2) WHO launched the 'End TB Strategy' in line with United Nations health-related

Sustainable Development Goal 3 and one of its goals is to ensure that no TB affected families face catastrophic expenditure by 2020.(3)

Evidence from a study has shown that cash incentives from government have been found to be successful in improving the outcomes in HIV and enhancing nutritional and growth status of children.(4)

Taking this into consideration, Government of India launched an Aadhar-linked Direct Benefit Transfer (DBT) scheme from 1stApril, 2018. DBT involves four incentive-based support schemes – Nikshay Poshan Yojana, Transport support for TB patients in notified tribal areas, incentive for private sector providers and informants, and treatment supporters' honorarium.(5)

We know that undernutrition and underlying food insecurity are among the most important determinants of TB.(2)Under this scheme, all notified TB patients would receive Rs 500 per month (~US$7) throughout the course of their treatment for nutritional support. (6) The purpose was not only to provide social protection and nutritional support but also to increase compliance and improve treatment outcome.(7)

Every notified TB patient is a beneficiary for DBT. TB Health visitor is the Maker who collects the details of the patient He prepares the list of beneficiaries and enter them into NIKSHAY. The Checker (Medical Officer Incharge) validates the details of the beneficiaries and sends the list to the District TB Officer (DTO). DTO acts as the Approver who further verifies the beneficiary details and approves the payment. This approved list is then sent to Public Financial Management System (PFMS) portal via the NIKSHAY-PFMS interface. After approval by PFMS, payment vouchers are generated and sent to District Account Officer who again verifies and after signatures of Chief Medical Officer (CMO), payment is submitted in the accounts of the beneficiaries.(8,9,10)

Thus, DBT scheme comprises of multiple steps in the verification and transfer of money to the right beneficiary in a timely manner. Certain conditions like availability of a bank account and Aadhar card (Aadhar is 12-digit random number issued by Unique Identification Authority of India for its residents)(11) was mandatory to receive the benefit. Because of multiple steps and requirements as mentioned, it is necessary to assess the coverage of the scheme and identify the challenges at the patient and provider's level to inform the policy makers. Therefore, for the better understanding and get the deep and complete evidence of the facts; the present mixed-method study was planned to assess the implementation of DBT scheme in the Amritsar city, Punjab, India.

Aim & Objective

To determine the challenges faced by the health providers and patients in the implementation of Direct Benefit Transfer scheme.

Material & Methods

Type of study- Explanatory sequential type of mixed method study

Study participants- All public and private TB patients notified during the year 2019 under National Tuberculosis Elimination Programme in district Amritsar, Punjab. Total notified patients were –

1596 in 1st quarter; 1661 in 2nd quarter; 1417 in 3rd quarter; 1146 in 4th quarter

Senior Treatment Supervisors (STS) & TB health Visitors (TBHV)- Out of the total 22 staff members, 17 who were present and gave consent, participated in the study.

Patients – 10 each registered under public sector and private sector respectively were selected randomly after informed consent.

Quantitative Data Collection and Analysis- Data about the availability and validation of bank accounts of the patients was collected from the reports obtained from the Nikshay portal after obtaining permission from the District TB Officer. Data collected was analysed using Microsoft excel and SPSS version23.0. Chi square test was applied and p value of <0.05 was considered significant.

Qualitative Data Collection and Analysis- The pre-tested semi-structured questionnaires were prepared in the vernacular language for the staff members and patients respectively. The questions framed were open-ended and peer validation was done before subjecting them to the participants. Informed consent was taken from the participants and confidentiality was ensured.

Focus Group discussion (FGD) with the STSs and TBHVs, who were present and gave consent were 17 in number. FGD was conducted in two groups of 8 and 9 members respectively after confirming the comfortable time and place from the participants. Each discussion lasted for approximately 60 min. Audio recordings and notes were taken simultaneously. Open ended questions were framed and about the challenges they are facing during the implementation of the DBT scheme and what in their opinion are the reasons for lower bank account availability and validation.

In-depth interviews were conducted on 20 patients, 10 each selected randomly from public and private sector respectively. Interview was conducted at a convenient place and time by both the researchers. Wherever audio-recording was not possible, detailed notes were taken by the researcher. Repeat interviews as and when required were conducted and paraphrasing of the content was done to the participants to ensure their validation.

Qualitative Data Analysis- Conceptual analysis was done manually. The collected data was transcribed and arranged as per the themes or questions. Investigators re-examined the data by again going through the audio-tapes and field notes and then the information was recorded under those sub-headings.

Ethical Clearance was obtained from the Institutional ethical committee and permission was also taken from the District TB Officer, Amritsar before the commencement of the study. Informed consent was obtained from the study participants after explaining them about the nature and the purpose of the study.

Results

Quantitative data was collected on all the notified TB patients during the year 2019. Focus group discussion was done with 17 staff members, out of which 9 (53%) were males and 8 (47%) were females. Mean age of the participants was 41 years. In depth interviews were conducted on 20 patients, out of which 13 (65%) were males and 7 (35%) were females. Mean age of the participants was 42 years. Out of the total, 6 patients who forgo the benefit; for the rest of the 14 patients, the median (IQR) delay in getting the benefit was 84 days (45-120 days).

Figure 1 shows that bank account availability (80%-85%) and validation (71%-78%) was significantly ($p<0.01$) more in public sector as compared to private sector where the account availability ranges from 1%-5% and validation was 1%-3% in all the four quarters (1Q-4Q).

Figure 2 shows that bank account availability ranges from 78%-80% in rural areas as compared to 59%-65% in urban areas in all the four quarters. Similarly account validation was higher in rural areas as compared to urban areas and results were found to be significant ($p=0.02$).

Table 1 depicts the challenges observed by the providers during the implementation of DBT. When asked that why there is less availability of bank accounts in private sector; many replied about lack of awareness about the scheme among the private practitioners and lack of time. Moreover, patients going in the private sector also are not aware and don't want to reveal their disease because of social stigma attached with TB. When enquired about less availability of bank accounts in urban sector, many replied that most patients with TB are from urban slums, inmates of jail, orphanages or old age homes who don't have the bank accounts. Also in some family there is account only in the name of male head of the family and not for every member so less availability. Reasons given by the staff for less validation of bank accounts were account not Aadhaar linked, dormant accounts and no online banking. Other challenges observed in the implementation of scheme were patients' ignorance, lack of interest pf private practitioners, technical issues and overburden staff.

Perusal of Table 2 reveals the challenges observed by the patients during implementation of DBT scheme. In the private sector patients' issues observed were confidentiality issues, social stigma, less amount of benefit, fear of hacking the account and lack of awareness. Challenges seen in the public sector patients were dormant accounts and accounts not linked to Aadhaar card, lack of awareness and confidentiality issues. When enquired about the delay in getting the benefit, most of the patients' replied about the initial ignorance about the scheme, time delay in activating the dormant accounts or linking them with Aadhaar number, long and complex process and delay on the part of government as there are budget constraints. Common reasons observed for forgoing the benefit are less money, no time for completing the documents, don't want to share about the disease and account number with anyone.

Discussion

Bank account availability and validation- Our study revealed that bank account availability and validation was significantly higher in public sector as compared to private sector. This may be due to lack of awareness about the scheme and social stigma attached with the disease. Begum J et al in their study also found low response in utilization of services due to stigma attached to TB.(12) Dumpeti S et al in their study also revealed the poor utilization of programmatic services by the people and only 12.6% were aware about the DBT scheme. (13)

The bank account availability and validation were also found to be significantly lower in the urban areas as compared to rural areas. Again, the reason could be that the tuberculosis is the disease of poverty and so more prevalent among urban poor who are usually migrants not having their bank accounts.(14,15) The median delay in getting the benefit was 84 days (45-120 days) in our study. Another study by Sumalata C et al also identified the barriers like lack pf awareness about the scheme, having validated bank accounts and delayed receipt of first instalment of the benefit.(16) Similarly, Torrens et al also reported that one-fifth of the patients received cash benefits only after the end of treatment.(17)

To further have the better and in depth understanding of the challenges observed on the part of providers and patients, qualitative data was collected by conducting the focus group discussion with the providers (the subjects of similar background) and in - depth interviews with the patients.

Challenges observed by the providers and patients - Table 1 shows the challenges faced by the staff members in the implementation of DBT scheme. Most common challenges observed were lack of support from the private sector, lack of awareness among people, social stigma associated with tuberculosis, technical issues and more work burden. Table 2 reveals the challenges observed by the patients in availing the benefits of the scheme. Most commonly seen were confidentiality issues, lack of awareness, social stigma of the disease, less amount, long and complex process and requirement of many documents and time.

Patel BH et al in their study identified the challenges observed by staff like ignorance of patients, lack of identity/residence proof, their reluctance to share personal information and inadequate support from

private providers whereas doubts of confidentiality, lack of trust and disinterest in availing the benefit were the challenges faced by the patients.(18)

Nirgude AS et al and Kumar R et al in their studies observed almost similar challenges on the part of providers like technical issues, lengthy procedure and overburden due to work

and patients in the implementation of DBT scheme. Patients revealed concerns about sharing bank details, perception that the money is less, lack of awareness and refusal to receive the benefit.(19,20)

Conclusion

Present study showed that the coverage was low in the private sector and in the urban areas.

The challenges identified by the staff members in the implementation of the scheme were lack of awareness among patients, non-availability of bank accounts, lack of support from the private sector, need of separate account for every patient, overburden and technical issues. The challenges observed by the patients in private sector were confidentiality concerns, social stigma, inadequate amount and fear that account may be hacked where as those in public sector were largely having lack of awareness, dormant accounts, long and complex process and budget constraints causing delay. There is an urgent need to address these challenges to enhance the utilization of DBT.

Recommendation

Measures need to be taken to create awareness among the private practitioners and TB patients about the direct benefit transfer scheme. Sensitization of the newly diagnosed TB patients about the scheme. Grievance redressal system to tackle all the issues related to the implementation of the scheme. More staff with digital advancements to deal with the issues of overburdening and smooth implementation of the scheme is needed.

Limitation of the study

Bringing out the challenges regarding the implementation of scheme will help the programme managers to plan strategies to overcome these and create awareness among the community regarding TB related programme services. This can be an essential step towards TB elimination. Limitations of the study include that the challenges observed are from the local study settings that might not be generalizable.

Relevance of the study

By knowing about the challenges in the utilization of DBT scheme at the patients as well as the provider levels, policymakers can take measures to address those challenges. Administrative scale up, tackling with the stigma of the disease along with creating awareness towards the scheme should be at priority for the successful implementation of the scheme.

Authors Contribution

MN contributed in the manuscript designing, data collection and data analysis. HS supported in the literature search. SC and NK contributed in carrying out the research and compilation of results. NC provided his overall support in carrying out the research and identifying the key literature. PD guided in conceiving the manuscript and contributed to its draft. All authors read and approved the manuscript.

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Tables

TABLE 1 CHALLENGES IN THE IMPLEMENTATION OF DIRECT BENEFIT TRANSFER SCHEME FOR STAFF (N= 17)

Factor	Items
Why do you think availability of bank details is less in private sector?	- "Private practitioners are less aware". - "Private practitioners have shortage of time so don't tell the patients about the scheme". - "Lack of awareness among patients also". - "When someone from government sector calls the patient, he/she thinks this is a fraud call". - "As social stigma is attached to the disease so many forgo the benefit and don't reveal their disease"
Why do you think bank account availability is less in urban areas as compared to rural areas?	- "Many patients from urban slums/peri urban areas don't have bank accounts". - "Inmates of orphanages, mental asylum and central jail prisoners don't have the bank accounts and disease is very common at these places". - "If some other family member is having TB, separate bank account is needed which is sometimes not there as only head of the family is having the account" - "Most housewives having the disease don't have separate accounts".
What do you think are the reasons for less validation of the bank accounts?	- "Some bank accounts are not Aadhar linked". - "Some of the accounts are dormant due to non-activity". - "Some of the banks where online banking is not there, PFMS doesn't validate them".
What challenges do you face in the implementation of the scheme?	- "Ignorance on the part of the patients, inspite of the counselling some don't understand". - "Careless attitude and lack of interest of private practitioners" - "Technical issues" - "Overburden due to too much online working".

TABLE 2 CHALLENGES IN THE IMPLEMENTATION OF DIRECT BENEFIT TRANSFER SCHEME FOR TUBERCULOSIS PATIENTS (N= 20)

Themes	Items
Patient related issues in Private sector	"Confidentiality issues" "Social stigma of the disease" "Amount is very less" "Didn't want to share account number" "Fear that account may be hacked" "Lack of awareness about the scheme"
Patient related issues in public sector	"Lack of awareness about the process" "Dormant accounts"

Themes	Items
	"Confidentiality issues" "Accounts not linked to Aadhar card"
Causes of delay	"Not aware initially" "Bank account lying dormant specially of patients in rural areas" "Accounts not Aadhar linked" "The process is long and complex" "Budget constraints"
Reasons to forgo the benefit (n=6)	"Confidentiality issues" "Amount very less" "No time to prepare all related documents" "Didn't want to share account number"

Figures

FIGURE 1 TB NOTIFICATION, BANK ACCOUNT AVAILABILITY AND BANK ACCOUNT VALIDATION IN PUBLIC VS PRIVATE SECTOR

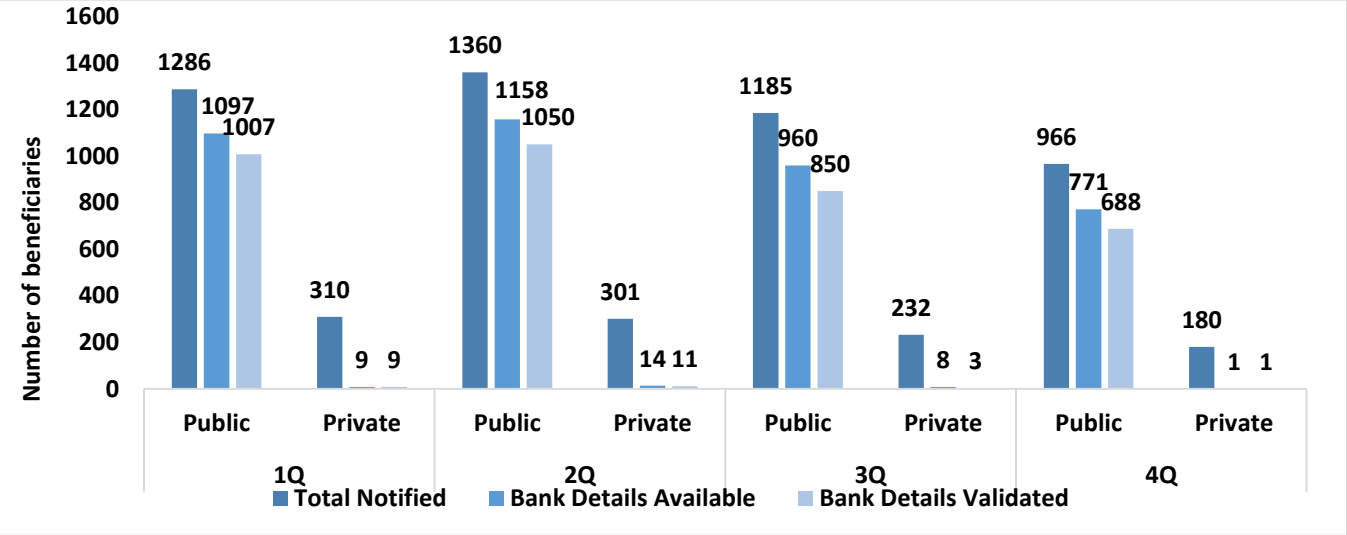

FIGURE 2 TB NOTIFICATION, BANK ACCOUNT AVAILABILITY AND BANK ACCOUNT VALIDATION IN RURAL VS URBAN AREAS