

Linking Poor TB Patients to Government Welfare Schemes to Improve Treatment Adherence in West Bengal, India

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Abstract

Among new smear-positive TB patients in 2010, 7% in West Bengal did not complete treatment. Some patients may discontinue treatment because side-effects of the medicine prevented them from working in the context of financial strain. The objective of the study was to ascertain whether linking TB patients to government welfare schemes was associated with completing the full course of treatment and reducing death rate and default rate. In 2009, CARE India worked with the Ministry of Health and the national TB Control Program to link TB patients to already-existing welfare schemes. TB patients received cash, food and/or employment. The study area was in Murshidabad District in the state of West Bengal. The study period was July 2009 to December 2011. The intervention subjects are those TB patients who received aid through welfare schemes while undergoing DOTS treatment. The comparison subjects are those who received the same DOTS treatment, but did not receive any aid. Data was derived from India's revised national TB Control Program. Data on the receipt of welfare benefit was ascertained directly by asking the patient. Effectiveness of the intervention was determined by comparing treatment success rate, default rate and death rate of both new and retreatment patients in the intervention and comparison groups. Treatment Success Rate among new patients was 92.2% for those who received welfare and 88.5% for non-recipients. Treatment Success Rate among retreatment patients was 83.4% in the intervention group and 72% in the comparison group. Among both new and retreatment patients, there is a statistically significant difference between the Treatment Success Rates of the comparison and intervention groups ($p < 0.01$). Treatment Success Rate increased for both new and retreatment patients when linked to welfare. The effect is seen to be modest for new patients, largely due to the 'ceiling effect', but much more in retreatment cases.

Keywords: Tuberculosis, Revised National TB control program, Panchayati Raj Institution (PRI), DOTS, welfare schemes, IMPACT project, CARE, treatment adherence, retreatment TB patients, treatment outcomes

Background

Socio-economic burden of TB

India has the highest burden of tuberculosis in the world. Due to its large population of 1.2 billion, India has by far the highest number of incident TB cases at 1.8 million per year, accounting for about a fifth of the global cases^[1]. The mortality rate in India was 23 deaths per 100,000 in 2009, while China's mortality rate was 3.5 and that of Bangladesh was 45 in 2012^[2].

India and West Bengal have a treatment success rate (TSR) of 88% and 86%, respectively, for all new smear-positive cases in 2010, meeting the global target of 85%^[1]. Among new smear-positive cases in 2010, 6% in India and 7% in West Bengal did not complete the treatment¹. Among smear-positive retreatment patients, 18% in India and 26% in West Bengal did not complete the second course of the treatment¹. Common reasons due to which patients discontinue their treatment are side-effects of the drugs, alcoholism, lack of motivation and distance from the treatment centre^[3, 4].

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¹ This figure refers to retreatment cases registered with the national TB program in 2010, and excludes those who did not complete the treatment due to death or because they moved out of the area.

The disease is a significant financial burden to many patients and their families in India primarily due to death, but also due to loss of work and income, and costs of diagnosis and treatment^[1]. TB infects the poorest and most marginalized, as well as those in their most productive years of life. More than two-thirds of TB patients are between the ages of 15 and 54 years^[5]. The Tuberculosis Research Centre of the Indian Council of Medical Research conducted a study which showed that the disease itself and the side effects of the medication caused an average annual loss of three months of work. Furthermore, more than half of the patients in the country incurred much debt to pay for diagnosis and treatment, comprising an average of 14% of mean annual income.²

Although the incidence of TB is lower in women, yet they are disproportionately affected by TB costs and child caring tasks compared to men. Women spent 20% more on medical and non-medical costs for diagnosis and treatment than men. Whereas before their illness, 79% of the women did domestic work, this fell to 38% after diagnosis. Moreover, there is an additional stigma of women having TB compared to men. It was estimated that 100,000 women in India are rejected from their families every year^[6].

Children of TB patients, particularly if such patients are male breadwinners, also feel the economic impact of the disease in India. One third of the patients reported that they could not afford to buy sufficient amount of food, clothing or books for their children due to loss of income^[5]. The Tuberculosis Research Centre also studied 276 Indian children of TB patients in 1999. The results revealed that 11% of the children had dropped out of school as a result of their parents' illness^[5]. It was estimated that 300,000 children drop out of school every year due to parental TB^[7]. The study also found that 8% of children found employment to support the family^[5]. Moreover, patients who default from treatment may die, develop anti TB drug resistance, or infect others with TB, further spreading the epidemic.

Incentives and enablers, such as cash, food, clothing and bus tokens, have been used for decades in the U.S. to improve patient treatment adherence^[8, 9, 10, 11, 12]. Professional bodies³ have

recommended the use of incentives and enablers to improve TSRs^[12,13]. A panel convened in 1995 to develop public health guidelines for tuberculosis treatment completion concluded from their research that the most effective approach to improve the treatment completion rates for pulmonary tuberculosis is patient-centered DOTS with a variety of enablers and enhancers^[13].

India's National TB Program, Social Welfare and IMPACT Project

India's Revised National TB Control Program (RNTCP) is based on the internationally recommended Directly Observed Treatment Short-course (DOTS) strategy. The TSR for new cases in India has improved from 25% at the beginning of the program in 1997 to 86% in 2010. Although the Government of India provides free of cost medicine to all TB patients along with diagnostic and treatment services, the above data indicates that the current government efforts, albeit well intentioned, are plausibly insufficient to support patients to complete treatment. An additional strategy is necessary to address this issue.

The Government of India provides social welfare schemes to those below the poverty line. Welfare schemes include cash transfers, food or employment. Panchayati Raj Institutions (PRIs), the lowest level of local rural governments, are the conduits through which such schemes are disbursed. The Initiative to Manage People Centered Alliances in Control of Tuberculosis (IMPACT) was a five-year project (2008-2013), funded by USAID, Child Survival and Health Grants Program. It was implemented by CARE India that worked with India's RNTCP to reduce morbidity and mortality due to TB, multi-drug resistant TB and TB-HIV co-infection in the state of West Bengal in India. The project covered a total population of 13.7 million⁴ in five districts. One of the project's components was to link indigent TB patients with these welfare schemes as incentives to improve treatment adherence and thereby success rates.

Objective of Study

The objective of the study was to ascertain whether linking TB patients to welfare schemes such as employment, cash or in-kind incentives for

² The Government of India provides diagnostic and treatment services and medicine free of cost to all TB patients. However, some patients seek health services from private providers.

³ These bodies are the American Thoracic Society, the medical section of the American Lung Association, The American Academy of Pediatrics, The Centers for Disease Control and Prevention, and the Infectious

Disease Society of America in 1992, and a panel convened by the Council on Linkages between Academia and Public Health Practice in 1995.

⁴ This is the population of the project area as of December 2012.

treatment adherence by the PRI was associated with completing the full course of treatment. CARE also sought to understand if this would reduce death rate and default rate in TB patients. The results indicated an increase in TSR and a decline in default rate and death rate.

Intervention

Study Area

The IMPACT project, implemented by CARE, took place in five of the 18 districts in the state of West Bengal, namely Murshidabad, Bardhaman, Haora, Hugly and Malda. The study area, however, is only in the Murshidabad District as it was the first district to achieve 100% coverage in terms of all PRIs having incentivized treatment adherence behavior of TB patients by linking them to welfare schemes. The district has a population of seven million, of which 80% live in rural areas [14]. In 2001, 18% of the employed persons were farmers on their own land and 28% were agricultural laborers [15]. Sixty-eight percent of the population over the age of six is literate [14].

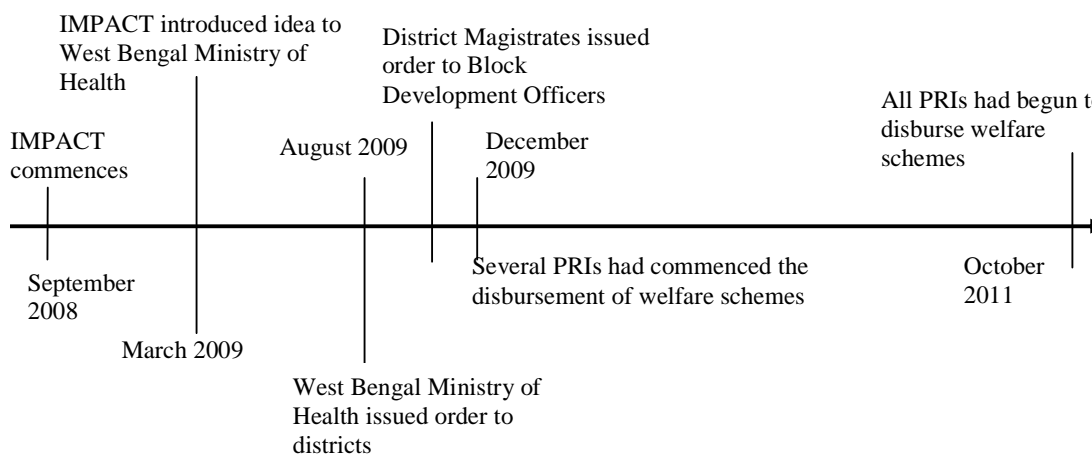
IMPACT was implemented in five out of twelve Tuberculosis Units (TUs) in Murshidabad District. Three of the five TUs in the project area are completely rural and the remaining two are also rural but they have an additional municipality or an urban administrative body. Almost every TU has at least two rural blocks in West Bengal.

Intervention

The Government of India has a diverse portfolio of social welfare schemes for the country’s poor and disadvantaged, including social security, education, employment, agricultural aid, housing, cash grants and food. In 2009 CARE/IMPACT introduced the idea of linking poor TB patients to already-existing welfare schemes made available to the PRIs. The Panchayati Raj system is a three-tier system in the Indian state with elected bodies at the district, block and village level. It was hoped that the welfare would compensate the patients for their financial losses due to loss of income, medical and non-medical expenditures related to TB, and thereby probably incentivize and improve treatment adherence.

In September 2008, the Central TB Division, the highest technical body for TB control in India, issued a letter to the State TB Officers and District TB Officers in West Bengal encouraging health workers to help TB patients gain access to social welfare schemes (see Figure 1 for timeline of events). As a result of this letter, CARE decided to include such linking of patients to welfare schemes as a strategy in the IMPACT project. In March 2009, CARE/IMPACT used the 2008 letter to advocate the strategy to the Additional Chief Secretary of the West Bengal Ministry of Health. In August 2009, the state official issued an official order to the District Magistrates to ensure that the Block Development Officers make the welfare schemes available to needy TB patients.

Figure 1: Timeline of process of linking TB patients to social welfare schemes



The length of time between the introduction of the idea by CARE/IMPACT to the state Ministry of Health and the disbursement of aid through social

welfare schemes by all rural self-governments, called Panchayati Raj Institutions (PRIs), was 18 months. The process shown in this figure was a

top-down process, whereby the state Ministry of Health issued an order to the District Magistrates, who then issued orders to the Block Development Officers to make available the social welfare schemes to TB patients in their constituency. In December 2009, some PRIs had started to disburse welfare schemes as a result of having been directly approached by CARE/IMPACT staff, who proposed the idea to them.

PRIs are mandated by the Constitution of India to oversee the development sector, including the functioning of the health facilities, health programs and health workers. Thus, in concert with the government orders at the state and district levels, CARE/IMPACT strategized to attend monthly PRI community health meetings to sensitize PRIs, by discussing individually with them the issue of TB, its socio-economic impact on their community and also proposing that PRIs link TB patients with social welfare schemes. In some cases, this strategy worked and individual PRIs came forward to support TB patients with existing schemes available under their jurisdiction.

RNTCP officials instructed the health workers to regularly provide a list of TB patients in their community to the PRIs. All PRIs decided that all the TB patients in their jurisdiction would receive aid, as opposed to only indigent patients. Some PRIs chose to give employment, cash grants, non-perishable food, and/or prepared food; some disbursed the aid once while some chose to disburse to the same patients on a monthly basis.

By October 2011, all PRIs in the project area in Murshidabad had begun to disburse aid through welfare schemes.

Methods

Study Design

The study compares the treatment outcomes of patients linked to welfare schemes and patients not linked to welfare schemes in the same area over the same period of time. Since not all PRIs disbursed welfare to patients for the entirety of the year in 2011, some patients did not receive aid through welfare schemes. Thus, the study takes advantage of a natural experiment, where the intervention subjects are those TB patients who received some incentives through the welfare schemes of the PRI while undergoing DOTS treatment. The subjects in the control group are those TB patients who also received the same DOTS treatment under the same RNTCP guidelines and agencies, but did not receive any incentives through their PRI. The time

period of the study was between July 2009 and December 2011.

Study Population

The intervention group includes all the TB patients under the jurisdiction of the 115 PRIs and two municipalities in the five Tuberculosis Units. These patients were registered for treatment when the local government disbursed welfare schemes. The comparison group includes those TB patients in the five TUs in which IMPACT operated, who did not receive welfare because their PRIs had not yet disbursed aid at the time the patients were undergoing treatment.

Among the 2,194 patients who received a social welfare scheme-based incentive, 86.2% (1,892 patients) were new patients and 13.8% (302 patients) were retreatment patients. Among the 4,643 patients who did not receive welfare, 86.2% (4,004 patients) were new and 13.8% (639 patients) were retreatment. The make-up of new and retreatment patients in West Bengal is similar—86.8% of the patients registered for treatment in 2010 were new and 13.2% were sputum-positive retreatment patients.

Data Collection

The RNTCP has a well-established and effective information system^[16]. Peripheral Health Institutes (Primary Health Centers which provide RNTCP services) and Designated Microscopy Centers (which reside in either Primary Health Centers or Block Primary Health Centers), are required to submit monthly reports to the TU. The reports include data on all cases of TB detected during the reporting period, those who initiated treatment and the outcome of the cases. Such data is generated from the laboratory registers, individual patient treatment cards held at local DOTS Centers and RNTCP TB Registers, which track all data on the patient.

The study used outcome data monitored by the RNTCP on all new and retreatment patients who registered for the treatment from July 2009 to December 2011. Health workers identified patients who received welfare schemes from PRIs and as a double confirmation, the DOTS patients confirmed whether they received the incentives or not.

Statistical Analysis

Statistical analysis was performed to determine if there is a statistically significant difference in the outcomes between intervention and comparison

groups. A statistical test, the chi square two-way, was performed on an online calculator.

Results

The TSR among new patients was 92.2% (1745 patients) for those who received welfare and 88.5% (3544 patients) for those who did not receive aid (see Table 2). There is a statistically significant difference between the TSRs of the comparison and intervention groups ($p < 0.01$). The TSR among retreatment patients was 83.4% (252 patients) in the intervention group and 72% (460 patients) in the comparison group. There is also a statistically

significant difference in the TSRs between the two groups ($p < 0.000$). The treatment default rate (TDR) among new patients was 2.9% (55) for those linked to welfare schemes and 5.5% (220 patients) for those not linked. The TDR among retreatment patients was 3.6% (11 patients) in the intervention group and 9.4% (60 patients) in the comparison group. There is a statistically significant difference in the TDRs of comparison and intervention groups among both new ($p < 0.01$) and retreatment patients ($p < 0.001$).

Table 1

Treatment Outcomes of TB Patients Not Linked and Linked to Welfare Schemes, Murshidabad District, July 2009 to December 2011						
	New			Retreatment		
	Not Linked	Linked	p-value	Not Linked	Linked	p-value
No. of TB patients	4004	1892	-	639	302	-
Treatment Success Rate (n)	88.5% (3544)	92.2% (1745)	$p < 0.01$	72% (460)	83.4% (252)	$p < 0.000$
Default Rate (n)	5.5% (220)	2.9% (55)	$p < 0.01$	9.4% (60)	3.6% (11)	$p < 0.001$
Death Rate (n)	5.5% (221)	2.3% (43)	$p < 0.001$	12.8% (82)	4.6% (14)	$p < 0.000$

Among new patients, the death rate was 2.3% (43 patients) for linked patients and 5.5% (221 patients) for not linked patients ($p < 0.001$). Among retreatment patients, the death rate was 4.6% (14 patients) for welfare recipients and 12.8% (82 patients) for non-welfare recipients ($p < 0.000$). There is a statistically significant difference in the death rates of new and retreatment patients between those not linked and those linked to welfare.

Discussion

Based on the results, had all patients in the project area in Murshidabad been linked to social welfare schemes, an additional 218 new patients and 107 retreatment patients would have completed treatment and 153 fewer new patients and 55 fewer retreatment patients would have defaulted. Furthermore, 189 deaths of new patients and 77 deaths of retreatment patients in the study area could have been avoided had all the patients been linked.

Benefits of improved treatment success rate

If all patients in India were provided welfare schemes, 46,354 additional new patients and 22,741 additional sputum-positive retreatment patients would complete treatment every year.⁵ These additional new patients comprise 3.8% of all registered new patients and the additional retreatment cases comprise 11.3% of all registered sputum-positive retreatment cases in India in 2010. This increase comes at no cost to the RNTCP and minimal cost to the PRIs.

⁵ The number of new and sputum-positive retreatment cases registered in 2010 in West Bengal and India was used to calculate the number of additional cases that would have completed treatment that year, had all cases been linked. The number of cases registered in 2010 in West Bengal and India that actually completed treatment was subtracted from the number that would have completed treatment, had all cases been linked. The difference is the number of additional patients in West Bengal and India that would have completed treatment had all cases been linked to welfare schemes.

Moreover, the benefit of additional cases that would complete treatment—and likely be cured—is extended to those who will not become infected by the additional cured case. The RNTCP estimates that each infectious case (those who are sputum smear-positive) infects ten or more people in a year^[17].

Financial assistance not only assists the patient to complete treatment, but also helps his family. Sometimes children of TB patients have to work to compensate for the loss of the family's income^[5]. It was estimated that 300,000 children drop out of school every year due to parental TB^[7]. It is likely that the receipt of aid through the welfare schemes prevented children from having to take up employment and possibly having to leave school.

This innovative strategy of linking TB patients with already-existing government welfare schemes is a win-win situation for all stakeholders—the TB patients, their families, the RNTCP of India and the population at large, at low to minimal costs.

Contribution to Literature

Various studies attempt to demonstrate the effect of the provision of cash and non-cash incentives and enablers to TB patients on treatment completion rates, or attribute incentives to improve TSRs^[10, 11, 18, 19, 20, 21, 22, 23]. Authors of a 2012 Cochrane review of studies of the effect of material incentives and enablers for TB patients on treatment outcomes concluded that there is limited evidence to support that the material incentives and enablers improve TSRs and such studies are limited to the U.S. context. While most studies examine treatment outcomes of providing incentives to patients, such as food, clothing and cash, which are not required to complete treatment, few studies examine treatment outcomes of providing enablers, which serve as actual support in completing treatment, such as free transport to appointments and food for poor, malnourished patients^[20].

This study contributes to the limited research on the effect of the provision of enablers to TB patients on treatment outcomes. This study specifically adds the contributions and roles of local government above and beyond a vertical TB control program to improve treatment success, to reduce TB deaths and defaults effectively both for new and retreatment cases. Not many studies have focused exclusively on tuberculosis and to the best of our knowledge none have been done at a large scale in India, which has the world's largest number of TB cases.

Limitations of the study

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The study works within the confines of existing health structures and human resources which are at times less than ideal. Interventions as enablers were not designed for maximal impact but left to the PRI to select for themselves. Also, the Panchayati Raj system in West Bengal is considered to be more accountable to its constituents than that in other states in India.

Thus, though all village-level PRIs in India have social welfare schemes to provide to their constituents, a smaller proportion of PRIs in other states may choose to disburse them to TB patients. Lesser coverage of the intervention will lead to smaller improvements in TSR.

The weakness of this study design is that provision of welfare schemes was not randomly assigned to patients.

It is unknown if there is any statistically significant difference in factors that would affect treatment completion between those patients whose PRIs provided them welfare and those whose PRIs did not.

Questions remaining to be explored include which type of welfare scheme—cash, employment, meal, or take-home ration—do patients prefer and which are associated with the highest TSR. The cost-effectiveness of the intervention must also be determined. It is also to be explored that which welfare scheme has the lowest cost for the greatest increase in treatment success.

Endorsement and scale-up of intervention from Government of West Bengal

The improvement in medication adherence has led the State TB Officer to encourage District TB Officers in all districts in the state to replicate the strategy. One district in which CARE IMPACT does not operate has initiated this strategy. Two non-governmental organizations, German Leprosy and TB Relief Association, and Southern Health Improvement Society are advocating this strategy through the Axshya project for TB control.

Conclusion

The DOTS strategy is a comprehensive organization of health services designed to ensure complete treatment and cure of the patients. For example, the strategy supports patients with taking their medicine by having health workers or volunteers visit them when they miss their dose. However, it is also necessary to support those patients financially who perhaps are unable to fulfill their usual work responsibilities due to the disease and the side-effects of the treatment. The effect is seen to be modest for new smear-positive

patients, largely due to the 'ceiling effect,' but much more in retreatment cases. The approach of not increasing cost to vertical programming but involving local governments for their mandated function of welfare can be integrated to provide increased treatment success, less default and death. Furthermore, this new strategy augurs well to reduce multidrug-resistant TB and may benefit areas where poverty and loss of wages are found to be the reasons for discontinuation of DOTS treatment.

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