

# Utilisation of nutritional support scheme among the patients of tuberculosis: A myth or a truth

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## ABSTRACT

**Introduction:** Under-nutrition increases the susceptibility to active tuberculosis and delays recovery. Nikshay Poshan Yojana provides a financial incentive of Rs. 500/month for each notified TB patient for a duration until the patient is on anti-TB treatment. **Objectives:** 1. To find out the utilization of the nutritional support scheme among TB patients. 2. To give evidence-based recommendations. **Methods:** It is a retrospective cross-sectional study conducted among TB patients. 2 DMC's in each of the 2TU (randomly selected from 12 TUs) were chosen. 83 patients responded to telephonic interview out of all patients registered in the last six months. The demographic details were collected from TB treatment cards and registers and other information by telephonic interview of 10-15 min each conducted over a period of 15-20 days. The quantitative data thus collected was analysed in terms of frequency, percentage and Chi-square test and qualitative data from patients and providers were analysed by thematic analysis. **Results:** Majority were of 40-60 years of age and were males. A total of 76 patients were aware of the scheme but only 17 patients had received their first instalment after two months in their account. Among the 17 who faced difficulty while getting the money, 13 TB patients spent it on nutrition. Lack of communication, stigma, unawareness, ignorance, illiteracy, multistep approval process and technical issues were few themes that emerged as difficulties encountered while utilisation. **Conclusion:** There is a large gap between demand and supply chain of services. A majority were unsatisfied and thus the administrative scale up for proper implementation of services and measures to bring down the stigma attached with the disease was recommended.

**Keywords:** Installment, Nikshay Poshan Yojana/Nutritional support scheme, stigma, telephonic interview, utilization, TB patients

## Background

Tuberculosis has been present among humans since antiquity. India bears a major brunt of this disease, with the highest burden in the world.<sup>[1]</sup> But even with the availability of powerful ATT and RNTCP on the run, India still has a long road to achieve its targets of National Strategic Plan (NSP) which aims to reduce the TB incidence to 44 per 100,000 population by 2025.<sup>[2]</sup> Tuberculosis can lead to weight loss and micronutrient

deficiencies by increasing the nutritional requirements, changing the metabolic processes and decreasing appetite resulting in the reduction of food intake.<sup>[3]</sup> Under-nutrition increases the susceptibility to active tuberculosis, delays recovery, contributes to treatment failure, multi-drug-resistant tuberculosis because of the poor bioavailability of key drugs like rifampicin also to defaulters and the patient being at high risk of drug side effects like hepatotoxicity.<sup>[4-6]</sup> The Ministry of Health and Family Welfare, Government of India has announced the Nikshay Poshan Yojana, a centrally sponsored nutritional support scheme under the National Health Mission (NHM) for nutritional support to TB patients notified on or after 1<sup>st</sup> April 2018 at NIKSHAY portal. Rs. 500/- per month in Cash (only via DBT preferably through Aadhaar-enabled bank accounts) or in-kind for each TB patient for the duration until which the patient is on anti-TB

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treatment. The payment schedule includes the first incentive upon notification, the second after the intensive phase follow-up results and the third at the end of the six-month treatment follow-up results. There are subsequent incentives for extensions, previously treated patients and drug-resistant TB.<sup>[7]</sup>

This study was planned in virtue of scant literature on the utilization of the nutritional support scheme among TB patients to help the primary care physicians addressing the identified gap between implementation and utilization of the scheme at ground level.

## Objectives

1. To find out the utilization of nutritional support scheme among TB patients
2. To give evidence-based recommendations

**Study design:** Retrospective cross-sectional

**Study setting:** 4 Designated Microscopy Centres (DMCs) near the field practice area

**Study duration:** Aug 2019–Sept 2019

**Sampling frame:** TB patients registered at four DMCs

**Sample size:** 83

**Sampling method:** Complete enumeration.

## Methodology

Ethical approval was obtained from the Institutional Ethics Committee and due permissions were obtained from the respective Medical Officer-in-charge of DMCs. Then a retrospective cross-sectional study was conducted from August 2019 to September 2019. Of 12 TU's of Srikakulam district, two TUs were randomly selected. Two DMCs in each TU were chosen near the field practice area. All patients registered in the last six months under these four DMCs were included in the study and those who did not have their own mobile number enrolled or did not respond to multiple (more than twice) calls or did not give consent were excluded from the study which constituted the study sample (83). The demographic details were collected from the TB treatment registers and cards. Other information were obtained by telephonic interview with prior information by the administrative staff to the patients regarding the interview over a period of 15–20 days. Verbal consent was obtained first after explaining the purpose of the call and ensuring data confidentiality. The actual interview went on for 10–15 minutes each in the local language (Telugu) starting with an introduction, followed by questions (pre-validated and semi-structured questionnaire) on utilisation of the scheme, difficulties encountered, suggestions for improvement and a closure at the end. The in-depth face to face interview of

the related administrative and RNTCP staff was also done. Each patient was given a unique identification number and data was entered in Microsoft Excel after verifying the forms for completeness. Those having missing data in their forms were contacted again for specific information and the data was analysed then through the Epi info software.

## Results

Of the 189 registered cases, it was possible to contact only 83 cases after considering the inclusion and exclusion criteria, thus leading to a 56.08% non-response rate. The socio-demographic data showed that a majority (44%) of them are in the age group of 41–60 yrs and were males (63.8%). A total of 62.6% were literate and employed (60%), but the socio-economic status calculated using the modified Kuppaswamy scale showed that a majority belonged to the upper lower class (83.1%). BMI was calculated for each case and of the 83 cases, only 40 (48.3%) were in the normal range [Table 1].

All patients were linked to the Nikshay portal with their unique Nikshay ID number; yet, 91.5% were aware of the cash incentive given as per Nikshay Nutritional scheme [Figure 1]. And those who are aware mostly got the information from the healthcare workers (84.3%), followed by neighbours (3.6%), friends and family (2.4%), and media (1.2%).

Out of all the patients who are aware of the scheme, only 17 (22.4%) had their money deposited (1<sup>st</sup> incentive, only after two months of intensive phase) and the rest 77.6% did not get any sort of money until now [Figure 2]. The median time of the first instalment after diagnosis was 2 months.

Similarly, of all the patients who got their money through the scheme, only 58.8% got their money without any difficulty and the rest faced difficulties while getting the money.

When it comes to drawing money from the bank account of the patient, 68.2% drew it by themselves but 20% got it with the help of healthcare workers (ASHA) and 11.8% patients got it done by their husband/father/family member.

The majority (76%) of them spent the money on buying food for nutrition, while the rest 24% spent it on personal and family need fulfilments [Figure 3].

When asked about the overall satisfaction and money being sufficient for the purpose of nutrition during ATI, all of them were not satisfied and they also agreed to the statement that it was not sufficient to meet their nutritional requirements.

We found a significant association of BMI and literacy with the utilization of scheme (P value < 0.05). Those who are having low BMI or are illiterate are not availing the scheme in terms of getting money, thus utilizing the incentives. But occupation, SES, age and gender had no relation with the utilisation of the scheme [Table 2].

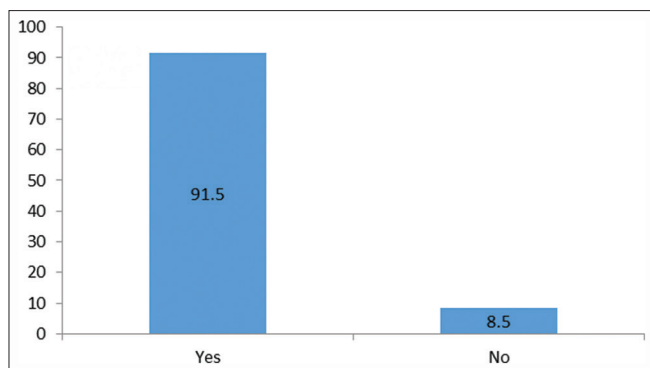


Figure 1: Awareness of scheme (n = 83)

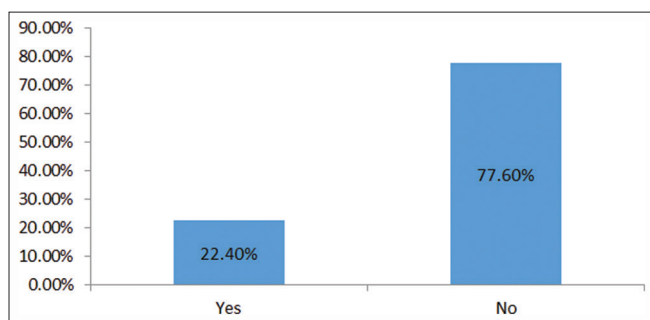


Figure 2: Deposition of money (N = 76)

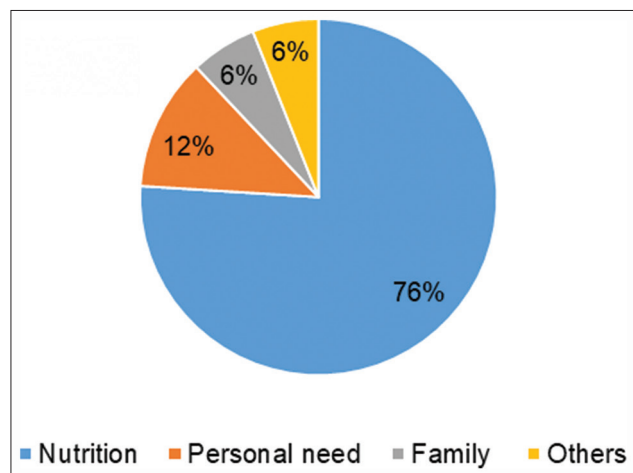


Figure 3: Expenditure of 1<sup>st</sup> instalment (n = 17)

There are a few open-ended questions regarding the difficulties encountered while availing the scheme and suggestions for improvement. The qualitative data thus collected was analyzed by thematic analysis that threw light on a few major difficulties faced by the patients. They were delay in getting the money in the account, unawareness on the scheme, timeline, schedule of payments along with a huge communication gap between patient and providers.

The suggestions given by patients for the improvement of the implementation of scheme were to increase the amount of money, timely incentives and an effective grievance redressal system.

Table 1: Socio-demographic details of TB patients (n=83)

SL	Criteria	Percentage	Frequency
1. Age	<20 yr	17	14
	21-40 yr	25	21
	41-60 yr	44	36
	>60 yr	14	11
2. Sex	Male	63.8	53
	Female	36.2	30
3. Literacy	Literate	62.6	52
	Illiterate	37.4	31
4. Occupation	Employed	60	49
	Unemployed	40	34
5. SES	Lower middle	9.7	8
	Upper lower	83.1	69
6. BMI	Lower	7.2	6
	<18.5	44.5	37
	normal	48.3	40
	>25	7.2	6

Table 2: Association of different factors with the utilisation of (NPY) scheme (n=17)

Variable	Category	Utilisation of money	P
Age	Middle age (21-60)	12	P=0.9431
	(<20 or >60)	5	
Gender	Male	8	P=0.1824
	Female	9	
Education	Literate	16	P<0.05*
	Illiterate	1	
SES	Upper middle	5	P=0.0863
	Upper lower and lower	12	
Occupation	Employed	11	P=0.7259
	Not employed	6	
BMI	Normal	13	P<0.05*
	Malnourished	4	

\*The association was found to be statistically significant

Few open-ended questions to respective administrative and other staff related to the scheme on their views on the implementation of the scheme, challenges encountered and suggestions for improvement revealed the different side of the issue. The core themes emerged through the thematic analysis of the qualitative data of these interviews were illiteracy of the people, ignorance on part of the patients and their family members (not knowing whether money is deposited in their account or not, being confused with getting money deposited as by other schemes), the huge stigma attached with the disease (not coming to get their scheduled ATT drugs), non-cooperation of patients and delay in the flow of money due to technical issues or multistep approval process of money disbursement and lack of effective follow-up.

The suggestions provided for the improvement of the smooth implementation of the scheme were follow-up of patients and a convenient way to notify about the money deposition, direct communication desk to address the issue, sensitization of patient, training of HCW and technical advancement.

## Discussion

The non-response rate was 56.08% which could be due to the stigma attached to TB or due to telephonic interview which lacks live face to face interaction. Similar results found in a study where 10 out of 40 newly diagnosed TB patients were difficult to contact through telephone.<sup>[8]</sup> Stigma occurs because of societal norms about undesirable or disvalued behaviours or characteristics. When diseases are stigmatised, the fear can create the reluctance to seek medical care and attention, thus affecting health adversely.<sup>[9]</sup> About the telephonic interview, studies have revealed that telephone interviews yield high-quality data.<sup>[10,11]</sup>

As the study explored the views of service providers, who suggest telephonic interview could rather be a suitable way to get information when the patient did not want to get identified because of the fear of losing the job or social discrimination.

The majority of the TB patients were males and belonged to the 41–60 year age group. Many studies have shown that tuberculosis is more prevalent among males and elderly people.<sup>[12,13]</sup> Similarly, the majority were from upper lower or lower class as found in other studies and there is increased risk of TB in persons with a lower socio-economic background.<sup>[14]</sup>

This study found that around 52% of patients were malnourished and thus is a matter of concern as we have known that malnutrition adversely affects treatment outcome and compliance of tuberculosis patients.<sup>[4,6]</sup> However, another study found the prevalence of undernutrition as 35.8% among adult TB patients and low food frequency per day as one of the factors that increase the odds of undernutrition, and thus recommends the assessment of comorbidity and nutritional status of every TB patient as a part of the treatment process.<sup>[15]</sup> We found a significant relationship between low BMI and non-utilization of the scheme in terms of money deposition and using it for nutrition [Table 2]. Likewise, few other studies have shown malnutrition being more prevalent among TB suspected and confirmed patients in rural India and the importance of addressing the issue properly and in a timely fashion to reduce the morbidity and mortality of TB patients.<sup>[16,17]</sup>

Although enrolled in the Nikshay program, few (8.5%) were still unaware of the nutritional scheme, which shows the ignorance of the patient and the lack of sensitization from the staff towards the benefits of the schemes. A similar gap was found among patients of pulmonary tuberculosis regarding the cause, mode of transmission, preventive measures of the disease and the duration and dosage schedule of the therapy. Another study highlighted the associated factors like literacy status, distance from home, informal consultation and poor knowledge of the disease which predicts the delay in seeking treatment initiating the need for community awareness through health education of all stakeholders.<sup>[18,19]</sup> While a majority got the information about the scheme from the healthcare workers (ASHA), another study found television to be the main source of information on tuberculosis.<sup>[20]</sup>

Of those who were aware of the scheme, only 22.4% got any sort of money (1<sup>st</sup> instalment) and that too after two months of intensive phase. This could be due to the delay in money flow or the patient's ignorance and illiteracy. The association between literacy status and utilization of the scheme in terms of knowledge about money deposition and using it for their nutrition was found statistically significant [Table 2]. Similar results were found in a study, where only 42.2% of the patients had received at least one instalment of DBT irrespective of the time of disbursement. Another study showed that knowledge was significantly higher among those who were literate.<sup>[21,22]</sup>

Among those who got the incentive, 41.2% faced difficulty in getting the money deposited in accounts, such as unnecessary visits to hospital and bank, delay in getting the money in the account due to unavailability of identity proof or mobile number etc., This could be attributed to the lack of communication between the patient and provider or unawareness towards the scheme, and the fear and stigma as well. A similar study also stated that difficulties in opening bank accounts, reluctance to share personal information and inadequate support from private providers were the challenges identified towards the implementation of direct benefit transfer (DBT) cash incentive scheme for patients with tuberculosis. Majority of patients drew the money by themselves and spent it on buying nutritive things. Similar findings were noticed in a study where patients had spent the money buying milk, fruits and food out of their incentives through NPY.<sup>[22]</sup>

Illiteracy of people, ignorance on part of patients and their family member, the huge stigma attached with the disease, non-cooperation of patients along with delay in the flow of money due to technical issues or the multistep approval process and the lack of effective follow-up were the important challenges under the perspective as a part of the provider side of the chain. Similarly, another study showed that the delays were related to the complexity of processes requiring multiple layers of approval and paper-based documentation which overburdened the staff, bulk processing once-a-month, and technological challenges (poor connectivity and issues related to NIKSHAY and PFMS portals).<sup>[23]</sup>

## Conclusion

Although the NPY scheme was initiated to support the nutrition of the TB patient, there was a large gap identified between the demand and supply chain of services at different levels of health care. Underutilization of services at the patient level with the majority being unsatisfied and challenges at the provider level in terms of timely disbursement of money, adversely affect the implementation of the scheme. This study recommends the following strategies based on evidence to overcome the challenges and better utilization of services.

## Recommendations

1. Administrative scale-up.



- Measures to bring down stigma.
- An effective grievance redressal system
- Creating awareness towards the scheme among TB patients
- Effective follow-up of patients and a convenient way to notify about the money deposition to their account in relation to the instalments of the scheme.
- Direct communication desk to address the issues related to the scheme
- An initial sensitization programme for newly diagnosed TB patient
- Training of HCW & health education of all stakeholders related to the scheme, about the process, schedule of payment, conditions to be fulfilled and assessment of nutritional status and comorbid conditions.
- Technical advancement in terms of upgraded software and uninterrupted internet facility
- Maintenance of smooth flow, regularity of funds and timely instalments.

**Key Message:** Although nutritional support scheme has been initiated for the benefit of TB patients, at the ground level its utilization is questionable. Therefore, administrative scale up, de-stigmatization of the disease along with awareness towards the scheme should be given priority for its successful implementation.

### Limitations

Small sample size, telephonic interview, non response due to stigma.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

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