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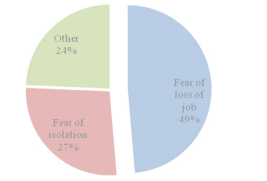
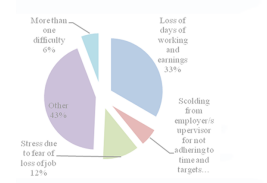
POLICY BRIEF - 64

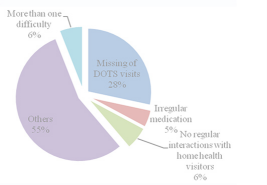
How can Tuberculosis Treatment Adherence be Improved for Women Working in Informal Arrangements?

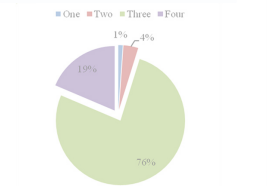
Insights from a Primary Study Conducted in Bengaluru City

Sobin George[1]









1. Introduction

There is evidence that the successful compliance with the directly observed therapy short-course (DOTS) regimen undertaken by tuberculosis (TB) patients is affected by several social, economic, cultural, gender-related and work-related factors (Deshmukh et al. 2018, George et al. 2023, George et al. 2022). While there is sufficient research available on the influence of these factors on delayed diagnosis and unsuccessful treatment outcomes, not much attention is given to the question of women's precarious employment in informal arrangements and its implications for TB burden and treatment adherence. Further, a limited understanding of the employability of women TB patients in informal work settings could affect the ongoing TB elimination measures. In this light, a study was conducted among female TB patients in the city of Bengaluru to understand the intersection of informality, gender and other systemic issues that hinder women's successful adherence to TB treatment. The present policy brief is extracted from this study.

2. Data and Methods

Data for the study have been collected through an initial baseline survey of 188 female patients who were undergoing treatments in18 DOTS centres in Bangalore region from January to May 2019 (see table 1). The average age of participants was 34 years. Nearly 60% of them were in the age group of 14 to 34 years. Most participants were married and the majority were educated, with a notable proportion above secondary level. The sample consisted of patients from different religions and caste groups. Majority of them were from Hinduism, followed by Islam and Christianity. Most of them were from non-forward caste groups. Majority of the participants belonged to the below poverty line group (BPL). Nearly 30% of them were earning members at the time of the interview and 11% were main/sole earners for their family. Nearly 51% of the female TB patients in the sample were "currently working" or had recently stopped working and all of them were informal workers. They mostly worked in factories (*agarbathi*, chemical, garment), shops, households, restaurants, beauty parlours and haircut saloons, old age homes, clinics and hospitals. Some of them were sanitation workers or street vendors.

3 Findings

The study revealed that informal work arrangements impacted the health and treatment adherence of female TB patients (refer to Figures 1 and 2). Conflict between work responsibilities and treatment schedules emerged as a key factor behind poor adherence to the treatment regimen. A primary issue was the clash between work timings and DOTS visits, leading to missed visits, reduced attendance, reliance on unsupervised DOTS, and skipped follow-up examinations. Further, participants highlighted that the strict and inflexible nature of the DOTS regimen did not accommodate the challenges faced by informal workers. Many expressed dissatisfaction with the scheduling and delivery of medicines at DOTS centres, noting that the long waiting times, sometimes exceeding an hour, were particularly burdensome. Morning visits to DOTS centres were especially stressful, as participants had to complete household chores, prepare for the day, and reach their workplace on time.

The informal work environment also posed challenges to TB prevention protocols. Evidence suggests that occupational safety and health are often overlooked in informal work settings (George and Sinha 2017). The present study found that workplaces often required close physical proximity

[1] Associate Professor, Centre for Study of Social Change and Development, Institute for Social and Economic Change. Email: sobin@isec.ac.in

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among workers and lacked adequate health measures, such as medical care facilities or sick leave provisions. Additionally, certain employers displayed poor risk perception, which hindered proper prophylaxis practices. Also, patients frequently concealed their TB status and avoided prophylaxis measures due to fear of stigma and potential job loss.

Work-related conflicts further impacted food intake patterns among female patients. Despite being aware of the dietary requirements associated with the DOTS regimen, many were unable to meet these needs due to their combined responsibilities. The initial months of treatment were particularly challenging, with the conflict between work expectations and treatment demands contributing to poor compliance with the DOTS protocol.

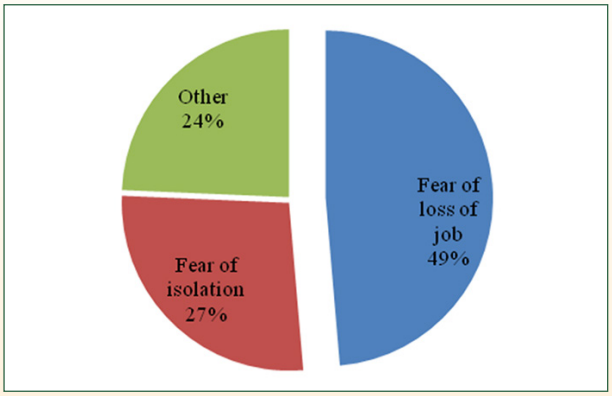
Table 1: Participants' profile

	Details	Frequency	Percentage
Age (years)	14-24	56	29.8
	25-34	56	29.8
	35-44	36	19.1
	45-54	23	12.2
	55-64	11	5.9
	Above 65	6	3.2
Education	Non-literate	31	16.49
	Primary	25	13.3
	Secondary	64	34.04
	Higher Secondary	32	17.02
	Graduation and above	36	19.15
Marital status	Currently Married	128	68.09
	Never Married	47	25
	Divorced	2	1.06
	Widowed	11	5.85
Religion	Hindu	130	69.15
	Islam	50	26.6
	Christian	8	4.26
Caste	SC	39	20.74
	ST	6	3.19
	OBC	119	63.3
	General	24	12.77
Income Class	BPL	177	94.15
	APL	11	5.85
Major earning member in the family	Husband	93	49.5
	Self	20	10.6
	In-laws	2	1.1
	Father	22	11.7
	Mother	18	9.6
	Other (siblings/ relatives)	33	17.6

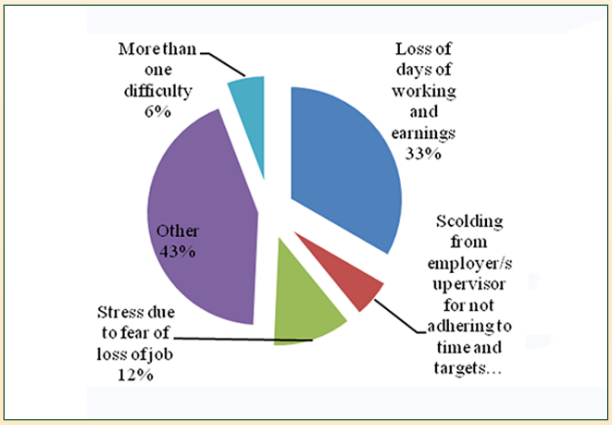
Source: Field data

Figure 1: Difficulties faced in treatment due to work

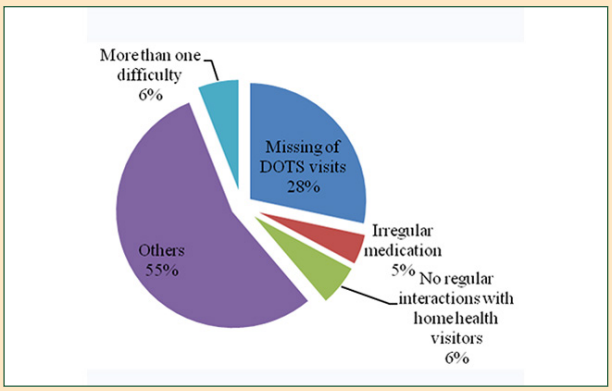
Reasons for not revealing about the disease at workplace



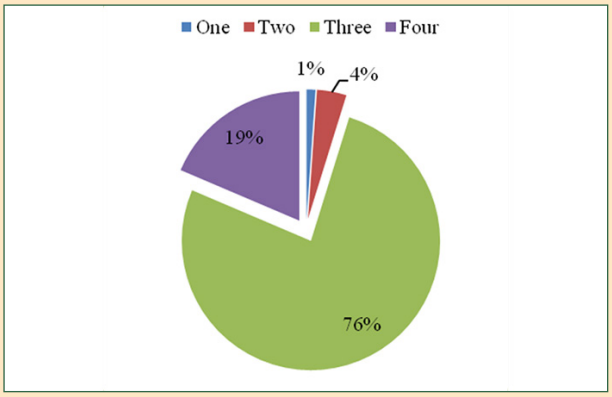
Difficulties faced at workplace due to treatment



Difficulties faced in treatment due to work

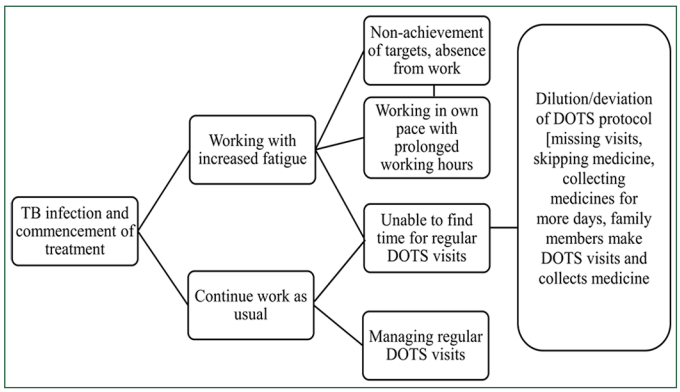


Number of meals taken in a day (the week prior to interview)



Source: Baseline Survey

Figure 2: Pathways of working with TB and poor treatment compliances



Source: Author's illustration from study findings

Balancing work, life, and treatment emerged as a major challenge for female patients, significantly affecting treatment outcomes. Married working women, in particular, reported a lack of empathy and support from family members. They expected more assistance with household chores, care, and emotional support from their families, especially their significant others. Many believed that family members could play a crucial role in ensuring timely medication and proper nutrition. Emotional support was deemed especially vital for women struggling to juggle home, work, and treatment responsibilities.

4 Policy Suggestions

TB elimination programme needs to adopt a comprehensive approach in which family, living environment and workplace should be integral parts.

The first critical step is to ensure the dissemination of accurate information about TB in the workplace to prevent employers and co-workers from reacting inappropriately to patients' health conditions. The study found that exaggerated perceptions of infectiousness were particularly common among employers of maids and care workers in households. While practising proper prophylaxis is essential, it is equally important to educate employers that individuals who are no longer infectious can safely work, including in close-contact environments, depending on their overall physical health. This approach can help reduce stigma and promote effective preventive measures at the workplace.

The second key step involves addressing the conflicts between DOTS treatment schedules and work commitments. DOTS visits posed a significant challenge for working patients, as these often clashed with work hours, necessitated unpaid leave, increased travel time and expenses, and caused additional fatigue. Integrating workplace support into the DOTS program can effectively mitigate these challenges. For instance, provisions can be made to distribute medication directly at the workplace or designate a treatment support person within the work environment, thereby reducing the burden on patients and improving treatment adherence.

Ensuring enabling environment at workplace

The study underscores the urgent need to improve working conditions in informal employment arrangements. As it is well known, many informal work settings remain either invisible or beyond the scope of labour laws. Even in registered enterprises, compliance with labour law provisions—such as those governing working conditions, hours, wages, health protection, maternity benefits, and sick leave—is often bypassed by maintaining informal employment relationships through contractors. Participants expressed a strong desire for a more supportive workplace environment, enabling them to work and adhere to their treatment regimen without fear or anxiety. A primary concern was the informal nature of their employment, which heightened their vulnerability. While most working patients wished to take a break during the initial months of treatment—due to severe fatigue and side effects—many were unable to do so, fearing job loss. Participants also advocated for measures such as flexible working hours, paid leave, work breaks, and rest periods, alongside the crucial need to eliminate workplace stigma. These changes, they believed, would not only support their recovery but also allow them to balance their health needs with their work responsibilities more effectively.

Flexibilities required in DOTS regimen for resolving work-treatment conflicts

The modalities and practices of treatment posed significant challenges for working female patients in balancing their work, personal lives, and medical care. Many felt that healthcare providers should be more considerate of these conflicts and suggested several adjustments to ease the burden. These included flexible timings for accessing treatment, such as making personnel and medicines available during lunch breaks or evenings, and allowing the supply of medications for extended durations.

Working patients often expressed a preference for collecting medicines for longer periods to minimize disruptions to their work schedules. However, the current DOTS protocol does not accommodate this need. It is crucial to explore ways to adapt the DOTS program to make treatment more accessible, such as providing medications at patients' residences or workplaces.

The study also highlighted a general lack of trust between patients and DOTS service providers. Strengthening this relationship is essential. DOTS personnel should actively engage with patients, fostering trust and providing reassurance to ensure adherence to the treatment regimen without gaps or delays.

Leverage the existing Employees' State Insurance (ESI) scheme to address the financial needs of patients

The study revealed that tuberculosis was the primary reason for nearly 70% of the patients discontinuing their work, while 62% of working female TB patients reported a reduction in earnings. This highlights the critical importance of addressing the financial needs of working patients to ensure treatment adherence. Fear of losing workdays, jobs, and income was a significant factor, causing delays in diagnosis among female patients who were the principal earners in their families. The financial burden was found to peak during the diagnostic phase and the initial two months of treatment.

Although many patients wished to prioritize their health, financial constraints often prevented them from seeking timely care. This suggests that mere awareness campaigns, without addressing the underlying structural issue of poverty, are unlikely to reduce diagnostic delays or improve treatment completion rates.

While employer-based insurance could be a robust solution, it is often unfeasible in informal work settings, where many women are employed. These settings are typically unregistered, home-based, or temporary, with employers who themselves operate with limited capital and face vulnerabilities to market fluctuations. As a result, providing paid leave or arranging insurance for workers is often beyond their capacity.

The study suggests leveraging the existing Employees' State Insurance (ESI) scheme to address this gap by extending to TB patients. Salaries could be paid for a two-month period from the start of treatment, helping patients manage the financial burden during their most vulnerable phase. While registered factories are already covered under ESI, informal workers in these arrangements often fall outside its scope due to unclear employer-employee relationships. Therefore, it is essential to expand the ESI system to include all informal sector workers, including those in small-scale, home-based, and other non-formal work arrangements. Additionally, a special wage allowance as part of the TB elimination program could further ensure financial support for patients during their treatment.

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Institute for Social and Economic Change
Dr. V K R V Rao Road, Nagarabhavi PO, Bangalore 560072
Phone: 23215468, 23215519, Fax: +91-80-23217008; Web: http://www.isec.ac.in