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Self-reported tuberculosis in India: evidence from NFHS-4

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ABSTRACT

This paper reports self-reported levels and socioeconomic patterns in the distribution of tuberculosis (TB) cases in India, based on information collected under the National Family Health Survey-Round 4 (NFHS-4, 2014–2015). Based on a nationally representative sample of over 600 000 households comprising of about 2.9 million individuals, we estimate a self-reported point prevalence of 304 TB cases per 100 000 population, with a higher burden evident among households with poorer wealth status and among individuals with low educational levels. About 55% of the reported TB cases sought treatment from public services, with higher public service use observed in West Bengal, Kerala and Tamil Nadu. However, more than a third of the patients from poorest groups sought treatment from private sources. Results indicate a significant proportion of the general population, including those with completed school-level education continue to have incomplete knowledge on the routes of the spread of TB infection. Social stigma, such as reluctance to disclose about a family member being infected with the disease to others, also remains high. Imminent need for appropriate policy mechanisms for involving the private sector and raising consciousness through suitable advocacy measures is re-emphasised.

INTRODUCTION

The persistent burden of tuberculosis (TB) remains one of the major public health challenges in India.¹ According to WHO estimates, in 2017, an estimated 2.7 million people developed TB disease in India and over 400 000 people died.² By WHO estimates, India accounts for 27% of the global estimated 10 million cases and 25% of the estimated 1.6 million deaths. The Global Burden of Disease analysis estimated the number of incident cases to be 3 million for the year 2016, with in excess of 450 000 deaths.³

A major limitation of current estimates in India is the lack of a national TB prevalence survey. Such prevalence surveys in other Asian countries have provided rich insights and lessons.⁴ Another limitation is incomplete notifications from India's private health sector which uses enormous quantities of anti-TB medications, and, therefore, disease

Key questions

What is already known?

- ▶ India has the highest burden of tuberculosis (TB), but lack of a national prevalence survey is a major limitation of existing data.

What are the new findings?

- ▶ Using the largest-ever nationally representative household sample in India, we estimated a self-reported point prevalence of 304 patients per 100 000 population.
- ▶ While about half of all patients with TB sought treatment from the public sector, the private sector was an important source of care, even among the poorest.
- ▶ Stigma around TB seems to be an issue, with nearly 15% of men and women indicating that they would prefer to keep their TB status a secret.

What do the new findings imply?

- ▶ The study findings underscore the need for a large, national prevalence survey and the need to engage effectively with the private sector in ensuring appropriate quality of care.
- ▶ There is a need for community-based interventions to educate the public about how TB is spread and encourage early care seeking.

burden estimates based on TB notification data may be underestimated.⁵ Similarly, available information on care-seeking for TB also has been largely based on small-scale or health-facility based surveys.⁶

Recent data from the National Family Health Survey (Procedures and questionnaires for standard DHS surveys) have been reviewed and approved by ICF Institutional Review Board (IRB). Additionally, country-specific DHS survey protocols are reviewed by the ICF IRB and typically by an IRB in the host country; for example, in India, the National Family Health Survey-Round 4 (NFHS-4) survey protocol was approved by the IIPS Institutional Review Board of the International Institute for Population Sciences, the national coordinating agency for conducting the survey. ICF IRB ensures that the survey complies with the



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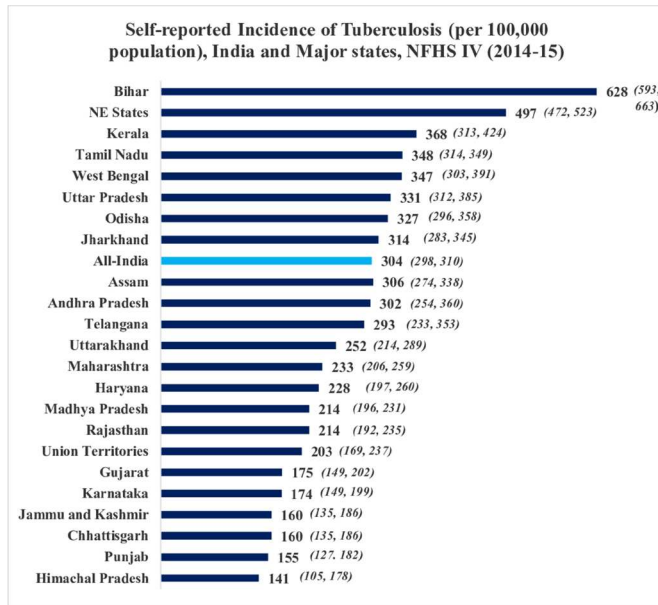
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Source: Authors' calculations from NFHS-IV data
 Note: Figures in parentheses denote 95% Confidence Intervals for the reported point estimates

Figure 1 Point prevalence of self-reported TB in India, NFHS-4 (2014–2015). NFHS-4, National Family Health Survey-Round 4; TB, tuberculosis. NE, North-Eastern

U.S. Department of Health and Human Services regulations for the protection of human subjects (45 CFR 46), while the host country IRB ensures that the survey complies with laws and norms of the nation' (source: <https://www.dhsprogram.com/What-We-Do/Protecting-the-Privacy-of-DHS-Survey-Respondents.cfm>) (NHHS-4, 2014–2015),⁷ the Indian version of the Demographic and Health Surveys conducted with the largest sample in the world, includes data on self-reported TB and might offer useful insights on the scale and distribution of TB, care-seeking patterns people affected by TB and public awareness about TB, building on similar prior research.⁸

METHODS

NFHS surveys are large-scale, multiround surveys conducted in representative samples of households throughout India. NFHS-4, the largest household health survey in India to date, was conducted by the Ministry of Health and Family Welfare, Government of India from January 2015 to December 2016 covering 601 509 households with ever-married women in the age-group of 15–49 years.⁷ Details of the sampling method and survey questionnaires are available from the NFHS-4 report.⁷ Differing from the earlier rounds of NFHS, which followed a multistage, stratified sample but with the indicator estimates valid only at the national and state levels, the NFHS-4 sample was designed to generate estimates representative at the level of districts, and for a subset of districts with higher urbanisation, even allowing urban-rural disaggregation. After forming the sampling stratum on the size of villages or urban wards and proportion of socioeconomically vulnerable groups such

as ethnic minorities and indigenous population, and the sampling clusters based on female literacy, 22 households were chosen randomly with systematic sampling from within each selected cluster or primary sampling unit. These households formed the base sample for most of the survey questions including those on self-reported TB. The questions on knowledge and attitudes regarding TB, however, are based on a subsample (referred as the *state module*) for which indicators can be only estimated at the state level. This subsample of 15% of the households from the main sample was arrived at by conducting interviews in every alternate selected household in 30% of the selected clusters.

In total, 699 686 women and 112 122 men (spouses of a subsample of the women) were interviewed using a structured interview schedule using Computer Assisted Personal Interviewing. The information on TB mostly comes from the household schedule⁹ where information was collected from any eligible women respondent for all household members or any visitors staying in the household the night preceding the survey. Respondents were asked a single screener question—'Does any usual resident of your household suffer from tuberculosis?'—followed by whether the person affected sought any medical treatment for TB and the source of such treatment, namely, public or private sector or from both.⁹

We have disaggregated the responses to these questions using selected background characteristics such as age and sex of the patients, social groups, geographic regions and place of residence, level of education of each reported TB case and socioeconomic status of the household denoted by a composite 'wealth index' based on household ownership of certain assets and durable goods. In order to observe the correlates of self-reported TB, we have used a multivariate logistic regression model with the above background factors as explanatory variables and calculated ORs for the probability of being reported to have TB.

We have also presented results based on a set of questions pertaining to knowledge/awareness about and perceptions towards TB asked separately to the women and men respondents. These questions included: (1) whether the respondent ever heard of a disease called tuberculosis, and based on an affirmative response (There were 115 inconsistent responses (6.1% of the affirmative cases) in the NFHS-4 data where respondents have indicated that any of their family member had TB in the household interview schedule, but responded in the negative when asked later in the individual questionnaire about whether they have ever heard of TB. We exclude these inconsistent cases and present the adjusted figures in the paper.), (b) how does TB spread from one person to other, without the options being read out, (c) whether TB can be cured and, finally, (d) if a member of the family contracted TB, whether they would want to keep it a secret.

Table 1 Percentage distribution of self-reported TB cases across demographic and socioeconomic attributes, India, NFHS-4 (2014–2015)

Background attributes	Percentage distribution of across subgroups for background variables			
	TB cases		Overall sample	
	%	N	%	N
Wealth Index Groups				
Poorest quantile	34.1	2973	20.0	609 790
Poorer quantile	23.4	2256	20.0	625 444
Middle quantile	18.4	1744	20.0	586 096
Richer quantile	14.7	1244	20.0	535 071
Richest quantile	9.3	756	20.0	512 642
Highest educational level				
No education	47.3	4087	30.2	879 880
Primary	19.7	1858	23.0	676 899
Secondary	29.1	2681	37.5	1 072 826
Higher Secondary or higher levels	3.7	315	9.2	232 787
Sex				
Male	65.0	5795	50.2	1 442 520
Female	34.9	3178	49.8	1 426 523
Age-groups				
0–5 years	1.1	119	10.9	320 613
6–17 years	6.1	628	23.4	694 263
18–29 years	12.4	1178	21.5	610 077
30–59 years	50.6	4606	34.0	959 987
60+	29.7	2442	10.3	284 103
Place of residence				
Urban	27.2	2013	33.0	804 654
Rural	72.8	6960	67.0	2 064 389
Social group				
Scheduled castes	25.2	1790	21.4	518 354
Scheduled tribes	11.6	2342	9.7	529 947
Other backward castes	42.4	3137	44.4	1 103 360
Other 'general' castes	20.0	1389	23.8	585 723
Total		8973		2 859 955

Note (A): OBC is a collective term used by the Government of India to classify castes which are educationally or socially disadvantaged. It is one of several official classifications of the population of India, along with Scheduled Castes and Scheduled Tribes (SCs and STs) (Wikipedia, accessed on 15 March 2019).

Note (B): The 'N' denotes unweighted number of observations, but the percentage distribution figures account for sampling weights. Source: Authors' calculations from NFHS-4 data.

NFHS-4, National Family Health Survey-Round 4; OBC, other backward class; TB, tuberculosis.

Patient and public involvement

No patients were involved in the development of the research question or the outcome measures nor the design of the study. There are no plans to disseminate the results of the research to study participants.

RESULTS

For a sample of 2.86 million individuals reported under the NFHS-4 household member roster, 8973 individuals¹ were reported to be suffering from TB on the date of

the survey, leading to a point prevalence of 304 per 100 000 population (95% CI 298 to 310). (There were 115 inconsistent responses (6.1% of the affirmative cases) in the NFHS 4 data where respondents have indicated that any of their family member had TB in the household interview schedule, but responded in the negative when asked later in the individual questionnaire about whether they have ever heard of TB. We exclude these inconsistent cases and present the adjusted figures in the paper). Among the states, Bihar had the highest

Table 2 Socioeconomic and demographic correlates of self-reported TB in India, NFHS-4 (2014–2015)

Independent variables	OR	SE
Female (Ref: Male)	0.536***	0.012
Age	1.036***	0.001
Education status (Ref: Illiterate/No schooling)		
Primary	0.854***	0.026
Secondary	0.796***	0.023
Higher Secondary and above	0.529***	0.034
Social Group (Ref: General (Upper) Castes)		
Scheduled Castes	1.205***	0.044
Scheduled Tribes	1.070*	0.041
OBC	1.066*	0.035
Wealth index quintiles (Ref: Poorest quintile)		
Poorer quintile	0.695***	0.020
Middle quintile	0.554***	0.018
Richer quintile	0.436***	0.017
Richest quintile	0.279***	0.014
Rural residence (Ref: Urban residence)	0.819***	0.024
Type of states (Ref: Developed states)		
EAG states	1.086***	0.030
North-eastern states	2.372***	0.091
N	2 737 384	
Pseudo R ²	0.0712	
Log-likelihood	-54 906.95	

Dependent variable: Individual reported to have TB=1, Else=0. ***, **, *statistically significant at 1%, 5% and 10%. Source: Authors' calculations from NFHS-4 data NFHS-4, National Family Health Survey-Round 4; OBC, other backward class; TB, tuberculosis.

prevalences (628 reported cases per 100 000 population; 95% CI 593 to 663) (figure 1). Most states in northern and eastern India and Kerala and Tamil Nadu in the south had higher than national average prevalence. In terms of aggregate state-groups, however, the highest reported burden of TB was among the states in north-eastern India (excluding Assam) (497/100 000 population; 95% CI 472 to 523), followed by the high-focus Empowered Action Group states (344/100 000; CI 335

to 353) and other non-EAG states (265/100 000; CI 255 to 278). (North-eastern India includes the states of Arunachal Pradesh, Mizoram, Manipur, Nagaland, Tripura, Meghalaya and Sikkim. Most of these states are hilly states with higher proportion of population from indigenous ethnic groups, known as Scheduled Tribes in India.) The Empowered Action Group (EAG) states include Bihar, Jharkhand, Uttar Pradesh, Uttarakhand, Rajasthan, Madhya Pradesh, Chhattisgarh and Assam. These states generally have poorer public health and socioeconomic indicators and considered high-focus states in national health and development sector policy planning such as the National Health Mission.

Table 1 compares the distribution of self-reported TB cases across different socioeconomic and demographic categories, comparing the proportions with the distribution of surveyed population across these groups. Results indicate that distribution of self-reported TB cases was disproportionately concentrated among the poor and illiterate individuals and those from traditionally disadvantaged social groups such as the other backward castes. The distribution of reported TB cases was nearly four times higher in the poorest 20% of the surveyed population as compared with the wealthiest 20%. TB was also more common among males and in rural areas and highest in the middle age group (30–59 years).

Table 2 presents further results on the association of socioeconomic factors with self-reported TB prevalence based on a logistic regression model. Results indicate that the probability of having TB significantly declines with increasing education and household wealth; an individual from the wealthiest group has about 63% lesser risks of reportedly having TB. Similarly, probability of having TB is higher among backward social groups and is lower among females. Interestingly, reported risks of TB appear to be about 20% less for an average rural resident than her urban counterpart.

Treatment-seeking for TB reveals interesting patterns (table 3). At a national level, 55% of all self-reported patients with TB had sought treatment from the public sector, while the remainder sought care from private or both public and private. In states such as West Bengal, Kerala and Tamil Nadu, there was high-reliance on public sources for TB treatment, but in Bihar and Uttar Pradesh, there was high reliance on the private sector.

Table 3 Treatment-seeking patterns for patients with TB in high-incidence states, India, NFHS-4 (2014–2015)

Source of treatment for TB	Bihar (N)	Uttar Pradesh (N)	West Bengal (N)	Tamil Nadu (N)	Kerala (N)	All-India (N)
None/No treatment	3.6 (42)	2.4 (34)	2.2 (10)	3.1 (5)	0.5 (2)	3.1 (288)
Public sector only	35.8 (410)	44.1 (594)	68.1 (215)	63.2 (167)	77.9 (124)	56.6 (5090)
Private sector only	55.6 (653)	42.7 (591)	24.3 (83)	27.0 (57)	16.9 (32)	32.4 (2878)
Both Pub and Pvt	5.0 (62)	10.5 (136)	4.6 (25)	6.7 (14)	3.7 (8)	7.6 (697)
Total (N)	1167	1358	333	244	167	8973

Source: Authors' calculations from NFHS-4 data. NFHS-4, National Family Health Survey-Round 4; TB, tuberculosis.

Table 4 Treatment-seeking patterns for patients with TB according to selected socioeconomic characteristics, India, NFHS-4 (2014–2015)

Background attributes (of households/patients with TB)	None/No treatment	Public sector only	Private sector only	Both Pub and Pvt
Wealth Index Groups				
Poorest quantile	4.4	52.4	36.4	6.6
Poorer quantile	2.9	56.4	32.2	8.0
Middle quantile	2.9	60.7	30.5	5.7
Richer quantile	1.7	53.9	37.5	6.5
Richest quantile	2.1	48.0	45.0	4.8
Highest educational level				
No education	4.4	53.7	34.4	7.1
Primary	2.2	57.6	33.1	7.0
Secondary	1.9	55.7	36.6	5.5
Higher Secondary or higher levels	2.6	43.7	49.6	4.0
Sex				
Male	3.0	56.8	33.3	6.7
Female	3.7	50.9	38.9	6.2
Place of residence				
Urban	2.9	56.3	34.5	6.0
Rural	3.3	54.1	35.6	6.8

Source: Authors' calculations from NFHS-4 data. NFHS-4, National Family Health Survey-Round 4; TB, tuberculosis.

As shown in table 4, while the public sector was the primary source for TB care across all but the wealthiest socioeconomic group, about a third of patients with TB from the poorest half of the population resorted to treatment from private sources. A similar pattern could be observed also across different educational levels of the patients; while most patients except those with higher than secondary level education received treatment from public sources, there was significant reliance on private sources of treatment, even in rural areas and noticeably higher among poorer states.

Table 5 shows data on knowledge, awareness and perceptions associated with the spread, treatment efficacy and social stigma associated with TB. Awareness about TB was high for both sexes, but about one in every five illiterate respondents in the survey had not heard about TB. Most respondents with higher educational levels were also aware that TB is an airborne infection, but such awareness levels were lower among less-educated men and women. Nearly one in every five individuals who had completed their schooling indicated that they would prefer not to disclose to others in case any family members had TB.

DISCUSSION

While self-reported TB data cannot substitute for national TB prevalence surveys, the NFHS data, because of the nationally representative sampling method and large scale, do provide an opportunity to better understand the

burden of TB, socioeconomic distribution and health-care-seeking patterns. In NFHS-3, which used similar methodology but with a much smaller sample, the self-reported prevalence was found to be 418 out of every 100 000 persons (http://rchiips.org/NFHS/NFHS-Data/VOL-1/India_volume_I_corrected_17oct08.pdf), indicating a decline of about 26% in the point prevalence between the two surveys, which—even acknowledging the limitations of self-reported estimates—suggests a positive downward trend. The results show a high prevalence of self-reported TB, with most states in northern and eastern India and Kerala and Tamil Nadu in the south reporting higher than national average prevalence. In line with previous studies,¹⁰ the distribution of self-reported TB cases was disproportionately concentrated among the poor and illiterate individuals.

The actual prevalence of TB in India is likely to be higher than the NFHS self-reported TB estimate of 308 per 100 000 for at least two reasons. First, due to the stigma associated with TB, under-reporting by survey respondents is a definite concern. A number of studies have found very high levels of stigma in India related to disclosing diagnosis of TB, particularly for women and culturally prevalent discriminatory attitudes towards patients with TB.^{11–13} Second, undiagnosed TB is a widely acknowledged problem. National prevalence surveys in Asian countries, that included chest X-ray screening followed by microbiological testing, found that a high proportion of cases (40%–79% across all surveys) did not

Table 5 Perceptions among adult men (15–59 years) and females (15–49 years) regarding TB, India, NFHS-4 (2014–2015)

Highest educational level	Heard about TB	Perception that TB is spread by:						Doesn't know how TB is spread	Believes TB can be cured	Would keep it a secret if family member has TB
		Air, when coughing or sneezing	Sharing utensils	Touching a person having TB	Food	Sexual contact	Mosquito bites			
No education	79.5	43.9	13.2	11.9	31.0	6.2	1.7	20.6	67.3	12.1
Primary	85.4	52.0	15.9	13.4	31.7	7.1	1.9	18.8	73.8	12.8
Secondary	90.1	66.0	19.4	16.4	32.0	8.2	2.6	12.4	80.7	14.4
Higher Secondary or higher levels	94.8	82.6	27.3	21.9	34.9	13.2	3.3	4.2	89.6	16.3
All women (15–49 years, n=6 99 686)	87.2	60.3	18.3	15.5	32.1	8.2	2.4	14.4	77.3	13.8
No education	78.5	45.9	11.2	13.3	25.9	5.4	1.7	16.5	68.1	16.1
Primary	85.0	52.8	13.6	14.2	27.6	5.5	2.0	16.3	74.7	16.7
Secondary	88.7	64.5	16.5	16.4	27.0	7.2	2.5	11.2	80.4	18.0
Higher Secondary or higher levels	92.5	76.8	21.3	20.1	28.0	10.9	3.1	5.1	87.8	17.8
All men (15–59 years, n=1 12 122)	87.6	62.8	16.3	16.4	27.1	7.4	2.5	11.5	79.3	17.5

Source: Authors' calculations from NFHS-4 data.
NFHS-4, National Family Health Survey-Round 4; TB, tuberculosis.

report TB symptoms and were only detected due to X-ray screening of all survey participants.⁴

Indeed, India's first state-wide prevalence survey was conducted in Gujarat in 2011 and the results showed a prevalence (adjusted for all ages and all forms of TB) of 390 cases per 100 000 population.¹⁴ This is higher than the NFHS-4 estimate of 177 per 100 000 for Gujarat, and the national estimate published by WHO in the 2015 Global TB Report of 250 prevalent cases per 100 000 population.¹⁴ Recently, India launched the process to conduct a large, national TB prevalence survey and the results should be valuable for identifying high prevalence areas and populations.

Recent research using NFHS-4 data has found high reliance on private sector for TB treatment across India, with poor quality of care in public sector offered as a primary explanation.⁸ Our findings also indicate that the preferred choice of the health provider for TB treatment is associated with the quality of health services in general, across the public and private sources of care. In states such as Tamil Nadu or Kerala where public sector health services are of better quality, we find that seeking care from public sources is more common among wealthier socioeconomic groups and for patients with higher educational levels, while in a significant proportion of the poor in states like Bihar and Uttar Pradesh with poorly functioning public sector health services, even the poor rely on private sources of treatment for TB. While awareness about TB was fairly high, a sizeable proportion of the respondents were unaware that TB is an airborne infection.

The Demographic and Health Survey datasets, the Indian version of which is the NFHS-4 data used here, although having the advantage of using standardised survey instruments used across more than 80 low-income and middle-income countries worldwide, are not designed for any epidemiological assessments and may not be the best information source to understand prevalence and clustering of TB, treatment-seeking behaviour and knowledge and social perceptions associated with the disease. Apart from being based on self-reported conditions rather than based on any clinical assessments, the reported measures may also suffer from likely bias arising due to proxy reporting by the main respondent on behalf of other household residents. Despite the limitations of the survey, the results suggest that India's TB programme must focus more on high prevalence states and greatly strengthen the public-sector response to TB. Previous studies show major gaps in the cascade of TB care in the public sector,¹⁵ and improving this must be a priority, as more than half of all patients with TB do seek public care and deserve better quality care than what they are currently getting.¹⁶

In addition, there is a clear need to engage India's private health sector, which is an important source of TB care, even for the poorest populations in the country, a finding that is corroborated by previous surveys and patient pathways analyses.^{6 17-19} Recent data using

standardised (simulated) patients reveal suboptimal quality of TB care in the private health sector,²⁰⁻²² and this is a matter of concern.

However, pilot projects in cities like Mumbai and Patna show great potential for increasing case notifications from the private sector and improving quality of care offered to patients treated in the private sector.²³ These public-private mix models are now being scaled to more than 40 cities with funding support from the Global Fund. A roadmap for engaging the private health sector has been recently published by WHO, Stop TB Partnership and other stakeholders.²⁴

In addition to improving quality of care in both public and private sectors, there is a need for community-based interventions to educate the public about how TB is spread and encourage early care seeking. An extensive literature indicates persistence of poor knowledge about spread and control of TB infection, both among health providers²⁵⁻²⁸ and among the patients.²⁹⁻³¹ Despite India's economic progress, stigma around TB seems to persist, with nearly 15% of men and women indicating that they would prefer to keep their TB status a secret, which is a marginal improvement from about 17% of men and women responding so almost a decade back in the earlier round of NFHS (NFHS-3, 2005-2006).³² Addressing this would require consciousness raising, which can take place when people with and affected by TB come together to share their experiences, identify common struggles and, based on this foundation, begin collectively organising to change practices that are stigmatising and harmful.³³ India will need to learn from the advocacy movement around HIV/AIDS and harness the potential of TB survivors and advocacy groups to address stigma and build a movement against TB.³⁴ Otherwise, TB will continue to remain in the shadows and take a toll on the most vulnerable.

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Data availability statement NFHS-4 Household Survey datasets are publicly available from the DHS Program at https://dhsprogram.com/data/dataset/India_Standard-DHS_2015.cfm?flag=0

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