

Sociodemographic factors affecting knowledge levels of tuberculosis patients in New Delhi

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Abstract

Background: Sociodemographic factors can significantly influence the knowledge level of tuberculosis (TB) patients, affecting the overall health outcomes. Due to lack of awareness and the stigma associated with TB, Indian TB elimination efforts are facing challenges. Patients with less information are more likely to experience delays in diagnosis and proper care. **Method:** A cross-sectional study was conducted in New Delhi across 26 operational National TB Elimination Program districts, involving 200 adult pulmonary TB patients receiving treatment from April to August 2020. A structured questionnaire guided the interviews, followed with bivariate analysis and descriptive statistics used for analysis. **Results:** Predominantly, residents of semiurban regions accounted for the highest proportion (70.5%), followed by urban areas (20.5%), with rural areas/slums comprising a minority (9%). Notably, a significant majority (94.5%) reported residing in individually owned dwellings, with shared accommodations limited to a minority (5.5%). Sanitary facilities varied, with 77% possessing personal toilets, 18.5% utilizing private facilities, and only 4.5% relying on public toilets. Awareness levels about TB reflected moderate awareness among 56% of participants, good knowledge among 41%, and minimal awareness (poor knowledge) among only 3% of respondents. **Conclusion:** Age, sex, socioeconomic level, kind of lodgings, malnutrition, and personal cleanliness should all be taken into account for TB treatment adherence. A new set of frameworks should be developed to enhance the living circumstances of high-risk populations and patients who are living in crowded locations since sharing a room or a house in a populated region increases the risk of TB transmission.

Keywords: Demographic, malnutrition, socioeconomic, treatment adherence, tuberculosis

Introduction

Tuberculosis (TB) is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*. It primarily affects the lungs, but it can also affect other parts of the body (extrapulmonary TB). TB spreads through the air when an infected person

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coughs, sneezes, or speaks, releasing tiny droplets containing the bacteria. $^{\left[1 \right]}$

Globally, TB ranks second among infectious disease-related deaths after coronavirus disease 2019 (COVID-19), causing approximately 1.4 million deaths annually.^[2] Despite being preventable and curable, it accounts for approximately 1.4 deaths each year.^[3] Based on the global report, 55% of all the cases of TB notified worldwide are among the adult population (aged \geq 15 years) in 2022, which is considered as a productive age group, and therefore contributing to high economic losses due to reduced productivity.^[4]

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In India, TB has the highest incidence among all infectious diseases, leaving behind diarrhea, malaria, and every other communicable disease. India hosts the biggest cohort of TB patients having a share of over 27% of the global TB burden, with TB incidence of 75 per 100,000 population and a mortality rate of 3.31 lakhs in 2022 for TB.^{15–71} Year 2017 reported 27.40 lakh TB incidences and 4.21 lakh TB deaths in the country. An estimated 65% of the total patients were covered with TB treatment and only 69% completed successful treatment. A total of 135 thousand patients were notified in the country with drug resistance TB including laboratory-confirmed 2650 XDR TB.^[8]

The National TB Elimination Program (NTEP) in India is trying to address many challenges impacting the program because of the stigma and lack of information about the disease. Low-knowledge patients may be more likely to experience delays in diagnosis and proper treatment. Age, sex (gender), race/ ethnicity, and variables, as well as problems with TB therapy completion and medication resistance, persistently impacted the rise in TB incidence in the country.^[9]

In 2012, the government initiated the National Strategic Plan (NSP) under the NTEP, requiring all TB patients to be notified and moved to the DOTS program in order to ensure the safety and continuous supply of antitubercular drugs. With NSP, diagnostic facilities were expanded, and a drug-resistant TB program was managed.^[8]

Over the years, it has been studied that factors like smoking can influence TB outcome. Active infection of TB is seen more commonly in people who smoke (7.9% of the active TB cases worldwide are attributable to smoking) and those who are immunocompromised like HIV-positive, malnourished, and diabetic people (who stand at 20–30% higher chance to develop active TB). Because of its association with immunity, age is also thought to play a role in the development of active TB. According to the literature, migrant populations are highly vulnerable to infection and poor adherence to TB treatment, resulting in treatment failure and, as a result, drug-resistant TB.^[9]

The environment is thought to play a role in infection because overcrowding and poor ventilation contribute to long periods of exposure. Passive smoking from indoor smoke often makes people living in such environments more susceptible to infection. Because of better living conditions, TB trends in European countries declined long before the discovery of antitubercular drugs.^[10]

To better understand the extent and contributing factors, the study was conducted to understand the sociodemographic features of pulmonary TB patients in Delhi and its association with the knowledge and perception of TB.

Understanding the sociodemographic factors influencing the knowledge level of TB patients in New Delhi holds immense significance for primary care physicians. By delving into these factors, physicians can tailor their approach to patient education and management, ensuring better outcomes. This paper aims to shed light on the intricate interplay between sociodemographic variables and TB knowledge, providing primary care physicians with valuable insights to enhance their patient care strategies.

Methodology

The national capital territory of New Delhi has 11 financial/ political districts, but due to the huge cohort of TB patients in the state, it has been divided into 26 functional NTEP districts. All the NTEP districts are functioning 26 public chest clinics, and each one is individually headed by a district TB officer, reporting to one state TB officer for Delhi. Ethical approval was obtained from the Delhi State TB Office on 18 February 2020 and from the Sree Chitra Tirunal Institute for Medical Sciences & Technology's Institutional Ethics Committee on 26 February 2020.

The study design used was a program-based cross-sectional descriptive survey among adult pulmonary TB patients enrolled under NTEP (formerly known as RNTCP) in New Delhi between April 2020 and August 2020. All the TB patients enrolled under 26 NTEP districts of New Delhi who were falling in the inclusion criteria and did not qualify for exclusion criteria formed the sampling frame. As per NTEP India annual report 2018, there were over 65 thousand incident cases from New Delhi, who were enrolled in the program.^[11] All the patients enrolled on the Nikshay App from all NTEP districts of Delhi, who are currently enrolled under the program and are getting treatment formed the sampling frame of the study. However, the exclusion criteria were TB patients less than 18 years of age, patients treated for extrapulmonary, patients not reachable, and those not willing to be part of the study.

All the other study designs would have led to possible selection bias since we may have only been able to reach and contact adherent patients in the case of retrospective cohort or case-control studies. Also, if the study is planned among patients who have completed the treatment, there would be again a high risk of selection bias since the majority of the approachable participants will be those who have completed the treatment without being defaulters. Therefore, the current beneficiaries enrolled in the program were kept as the target study population, and the cross-sectional study was kept as the optimal study design.

The sample size was calculated using an open epi website for the estimation of a single proportion to estimate the prevalence of different factors among nonadherent pulmonary TB patients in Delhi. The finite corrections were added for the population of 65,893, which is the number of patients enrolled in NTEP Delhi.^[5] Although the exact prevalence of nonadherent pulmonary TB patients in Delhi cannot be determined since there is a dearth of data from the region, the researchers have used different definitions for adherent since there is no common criterion for considering the patients adherent or nonadherent in NTEP. Some international studies estimate that close to 50% of Indian TB patients are nonadherent to the treatment, so the frequency is kept at 50% (P = 50%), which would have been the same in case of no estimation on the prevalence at all. Therefore, 50% frequency is kept optimal for the study.^[12,13]

A precision of 7.5% (d = 0.075) and a confidence interval of 95% were kept as per the suggestions by experts. Open Epi software was used for the calculation of the sample size, which came out to be 171. Another 10% nonrespondent rate was added to 171, and it reached to 190. It was further rounded to 200 and kept as the optimal sample size for the study.

Systematic random sampling was done to shortlist 200 participants from all the patients enrolled under NTEP Delhi. From the total patients enrolled in NTEP, Delhi (N = 65,893), patients getting treatment for extrapulmonary TB, patients aged less than 18, and patients who have completed the treatment were removed from the sampling frame, and from the remaining list of all eligible TB patients falling under the inclusion criteria and excluding the exclusion criteria, a subject was randomly selected from the first 200 patients enrolled in the study. From then on, every 200th patient was identified and included in the study to meet the sample size of 200. If the patient identified cannot be part of the study due to any reason, the very next patient from the registry was identified and contacted. Patients were called by the principal investigator for their consent, in front of the coguide. Once the patient agreed and gave their consent, they were enrolled in the study and were asked appointment for a date and time for the interview as per their preference and convenience. Any patient who was not willing to participate or who did not respond even after three telecalls was skipped, and the next patient in the list was called for consent.

Regular visits were made to the DOTS center as per appointed schedules, and data were collected on the hard copy of the interview schedule for the first 20 participants. The remaining 180 participants were contacted and interviewed on calls by the principal investigator; privacy was best ensured during the interviews and confidentiality of the data was maintained. The entire interview schedules were recorded on a hard copy of interview schedules, and a soft copy was made on Excel sheets by the principal investigator on the same day after interviews.

A new sim card and mobile phone was issued for the purpose of calling the patients, and the list of patient information (hard and soft copy), along with the mobile phone and sim card, was kept in the safe custody of DTO–NITRD Mehrauli, which were collected from him by the Principal Investigator daily in the morning to make calls and were left in the office every day before leaving. This process was repeated until the sample size of 200 was met. A soft copy of the patient's details was never taken out from DTO's office computer, a hard copy was submitted to him, the sim card was broken, and the mobile phone was formatted in front of DTO–NITRD Mehrauli after successfully interviewing 200 patients. Descriptive statistics were performed to understand the demography, socioeconomic status (SES), knowledge about the disease, ease of compliance, and reinforcement factors for medication adherence among pulmonary TB patients in Delhi. Bivariate analysis was conducted to estimate the treatment compliance across sociodemographic factors, socioeconomic factors, history with TB, knowledge about the disease, and positive and negative reinforcement factors.

Some categories were combined to perform the statistical analysis including the following:

- 1. Categories of 'Moderate knowledge' and 'Poor knowledge' were combined in the bivariate analysis of the variable 'Knowledge and awareness' with adherence.
- 2. All the categories of the 'Type TB' variable were divided into two headings, people who knew about their type of TB and people who did not. The participants who were unsure about the category of resistance were anyway placed under the category of participants who knew their type since they were aware that they have DR TB.
- 3. 'Bangalow' and 'Pakka house' were combined, while 'Semi-Pakka', 'Kachha house', and 'Juggis' were combined to form two categories, 'finished' and 'unfinished', respectively, while finding an association between 'Type of house' and Treatment compliance. Furthermore, the residential statuses of 'Semi-Urban' and 'Rural' were combined.
- 4. In the variable of the type of 'Toilet facility', categories of 'shared' and 'public' were combined while calculating the association with treatment compliance.
- 5. Frequency of being called at the DOTS center was combined for 'Daily' and 'weekly' in one category and for 'Monthly' and 'More than monthly' in another category.
- 6. 'Never' and 'sometimes' were combined to form a single category of 'Not always', in all the suitable reinforcement factors variables.
- 7. 'Not much' and 'Not at all' were combined to form a single category 'Not completely', in the appropriate reinforcement factors.
- 8. Negative change and no change were combined to form a single category, 'Not caring enough for the disease', under multiple variables from reinforcement factors.

P values of less than 0.05 were considered for statistical significance. The statistical analysis was done using Software IBM SPSS Statistics Version 25 for Windows. Online platforms like socscistatistics.com were used when access to Institutional SPSS was not available. Factors of TB treatment adherence and their association found in the study have been published earlier.^[13]

Results

Age, sex, and marital status

The age of participants is divided into two categories, 18 to 30 years old and above 30 years age group. Almost one-third of the participants (33.5%) were above 30 years of age, and the remaining two-thirds of them (66.5%) were from the 18 to

30 years of age group. More than half of the participants (53%) were males, and the remaining 47% were females. More than half of the participants (53%) were married, and only 47% of the participants were single, inclusive of widowed, divorced, and unmarried individuals [Table 1]. Age and sex distribution are represented in Figure 1.

| Table 1: Sociodemographic features | | | |
|------------------------------------|-------------------|------------------------|------------|
| Variables | Category | Number of participants | Percentage |
| Age (years) | 18-30 | 133 | 66.5% |
| | Above 30 | 67 | 33.5% |
| Sex | Female | 94 | 47.0% |
| 1 | Male | 106 | 53.0% |
| Marital status | Married | 106 | 53.0% |
| | Single or widowed | 94 | 47.0% |

Table 2: Acquaintance to the local culture and migration

| Variable | Category | Number of participants | Percentage |
|------------------------|-----------------|------------------------|------------|
| Mother tongue | Hindi | 190 | 95% |
| | Other languages | 10 | 5% |
| Hindi reading | Nil | 26 | 13% |
| level | Poor | 12 | 6% |
| | Average | 18 | 9% |
| | Good | 144 | 72% |
| Hindi writing level | Nil | 33 | 16.5% |
| | Poor | 11 | 5.5% |
| | Average | 13 | 6.5% |
| | Good | 143 | 71.5% |
| Hindi speaking | Nil | 2 | 1% |
| level | Poor | 0 | 0 |
| | Average | 3 | 1.5% |
| | Good | 195 | 97.5% |
| Hindi | Nil | 2 | 1% |
| understanding level | Poor | 0 | 0 |
| | Average | 2 | 1% |
| | Good | 196 | 98% |
| Place of birth | Delhi | 72 | 36% |
| | Outside Delhi | 128 | 64% |

Language and migration

Language

The majority of the participants (95%) were natives of the Hindi language, and only 5% had Hindi as their second (or third) language. Almost everyone can speak and understand Hindi with the exception of only two participants who could not. The majority of the participants were able to read and write Hindi since it is associated with literacy; still, only 13% could not read and 16.5% could not write Hindi at all [Table 2].

Migration

Only a little over one-third of the participants (36%) were born in Delhi and are therefore considered residents. The rest majority of the participants (64%) were born in different states of India and were therefore considered migrants as per the Census of India 2011 definition [Table 2].

Socioeconomic status (SES)

As per the modified Kuppuswamy scale for 2019, more than half of all the participants (52.5%) were from the lower class and more than one-fourth participants (27.5%) were from the lower middle class. The rest 17.5% were from the upper middle class, and only 2.5% were from the upper class. In the broader category, the majority of the participants (52.5%) were from the lower class and lower-middle class, and only 20% were from the upper and upper middle class. The socioeconomic status of participants is described in the belowmentioned box plot [Figure 2], and the outliers (upper class) can be appreciated [Table 3].

Living conditions

Demographic variables

Maximum participants were residents of semiurban regions (70.5%), followed by urban regions (20.5%), and only 9% identified themselves as living in rural regions/slums. Of all the interviewed participants, only 5.5% were living in shared accommodation; the rest all 94.5% had personal spaces of residence. The majority of the participants (59%) were living in



Figure 1: Age and sex distribution of participants

Zaidi, et al.: Tuberculosis knowledge in New Delhi: Socio-demographics



Figure 2: Socioeconomic status of the participants

a house owned by them or by their family members, and 41% were living in a rented house [Table 4].

Two-thirds of the participants (66.5%) were living in Pakka houses, over one-fourth of participants (27.5%) were living in Semi-Pakka houses, 3% participants were living in Kaccha houses, 2.5% participants identified themselves as living in slums, and only one participant (0.5%) claimed to be living in a bungalow. More than three-fourths of the participants (77%) had a personal toilet, 18.5% of participants were using a private toilet, which was shared by other houses/families too, and only 4.5% of participants were using a public toilet facility [Table 4].

Only one-eighth of the participants (12.5%) were living in a house with more than or equal to one bedroom per member, and 87.5% of the participants were living in a house with less than one room per member. More than half of the participants (60.5%) lived in a shared room with some other family member, and out of 39.5% of those who had a separate room, 30.5% had a separate room even before the disease and 9% were given the single room only after getting the disease. Close to four-fifths of the participants (79%) were living in a nuclear family, 18% of the participants were living in a joint family, and only 3% were living alone [Table 4].

Knowledge and awareness about TB

As per our scale used, more than half of the participants (56%) were moderately aware of the disease, 41% had good knowledge, and only 3% had poor knowledge about the disease. Out of our 12 questions asked, almost everybody (97.5%) answered correctly when asked if they knew that TB treatment and diagnosis are absolutely free in public facilities. Again, 95% of the participants answered correctly when asked if we can treat TB with medicines, but only 73% were aware of the duration of treatment. The majority of the participants (94.5%) knew TB can be transmitted from one individual to another, though only 38% knew the mode of transmission. On the other hand, only 17.5% of participants answered correctly when asked about the cause of TB. Only 42% believed adherence to medication was the most important aspect of treatment [Table 5].

| Table 3: Socioeconomic Status | | | |
|-------------------------------|------------------------------|------------------------|------------|
| Variable | Category | Number of participants | Percentage |
| SES grade | Upper class | 5 | 2.5% |
| | Upper Middle class | 35 | 17.5% |
| | Lower Middle Class | 55 | 27.5% |
| | Upper lower class | 101 | 50.5% |
| | Lower Class | 4 | 2% |
| SES combined | Upper and Upper-Middle class | 40 | 20% |
| | Lower-Middle and lower class | 160 | 80% |

| Table 4: Demographic variables | | | |
|--------------------------------|---------------------|------------------------|------------|
| Variable | Category | Number of participants | Percentage |
| Present | Rural | 18 | 9% |
| Residence | Semi-Urban | 141 | 70.5% |
| | Urban | 41 | 20.5% |
| Type of | Personal | 189 | 94.5% |
| Accommodation | Shared | 11 | 5.5.% |
| Ownership of | Own | 118 | 59% |
| House | Rented | 82 | 41% |
| Type of house | Bungalow | 1 | 0.5% |
| | Juggi | 5 | 2.5% |
| | Kacha | 6 | 3% |
| | Pakka | 133 | 66.5% |
| | Semi-Pakka | 55 | 27.5% |
| Toilet facility | Private | 154 | 77% |
| | Public | 9 | 4.5% |
| | Shared Private | 37 | 18.5% |
| People per room | <=1 | 175 | 87.5% |
| | >1 | 25 | 12.5% |
| Separate room | No | 121 | 60.5% |
| | Yes, after disease | 18 | 9% |
| | Yes, before disease | 61 | 30.5% |
| Type of | Alone | 6 | 3% |
| Household: | Joint | 36 | 18% |
| | Nuclear | 158 | 79% |

Discussion

According to a previous study and the WHO Global TB Report, 2023, approximately one-quarter of the world's population is believed to have contracted TB.^[3] Around 410,000 individuals worldwide contracted MDR or rifampicin-resistant TB (MDR/RR-TB), whereas in India, 63,801 MDR/RR cases in 2022.^[14] TB, even following quite a while of accessibility of treatment, is a challenge for public health personnel around the world. Constant exploration and evidence-based decision-making can be fundamental for tackling the issue of ensuring compliance with TB treatment.^[9]

In the current study, it was found that the majority of the participants (88.5%) admitted being unaware about disease and its types, and only a small percentage of participants (2%) were aware that they were being treated for MDR TB, and another 2% said they had drug resistance TB; however, the category of resistance

| Table 5: Knowledge of TB Score | | | |
|---|--|------------|--|
| Knowledge Score | Number of participants | Percentage | |
| Good (9 or above correct answers) | 82 | 41% | |
| Moderate (5-8 correct answers) | 112 | 56% | |
| Poor (4 or less correct answers) | 6 | 3% | |
| Questions and Correct respon | nses | | |
| Question | Number of participants with correct answers | Percentage | |
| What is the cause of TB? | 35 | 17.5% | |
| Can TB be transmitted from one person to another? | 189 | 94.5% | |
| If yes, how is TB transmitted from one person to another? | 76 | 38% | |
| Can we treat/cure TB with medicines? | 190 | 95% | |
| If yes, how long will it take to treat TB with medicines? | 146 | 73% | |
| How many times sputum follow-up is carried out after starting anti th treatment? | 71 | 35.5% | |
| Can inadequate/incomplete treatment increase the risk of spread to others? | 139 | 69.5% | |
| Can inadequate/incomplete treatment lead to reoccurrence? | 167 | 83.5% | |
| Can inadequate/incomplete treatment lead to death? | 87 | 43.5% | |
| Can inadequate/incomplete treatment lead to the development of resistant disease? | 88 | 44% | |
| According to your belief, which is the most important thing for the cure of TB? | 84 | 42% | |
| Do you know that the diagnosis and treatment for TB is absolutely free? | 195 | 97.5% | |

was unclear. Three participants (1.5%) and ten participants (5%) realized they had XDR TB and drug-susceptible TB, respectively. Among those who knew their type, only 8.7% were adherent as compared to 14.12% of those who did not know their TB type.

In earlier studies, it was observed that the age groups with the highest number of cases were 15–39 years and 40–59 years at 49.1% and 34.2%, respectively.^[10] However, in our study, we observed that 12.8% of nonadherence was seen among the younger age group (18–30 years old) as compared to 14.9% in the older age group (30 years and above).

In an earlier study, it was found that out of 133 patients, 84 (63.15%) were male and 49 (36.84%) were female. Among both genders, the most common age group was 21–30 years with 41 patients (30.82%) and the least common was pediatric TB (in the age group <10 years) with 10 patients (7.51%).^[11] In the current study, it was observed that almost two-thirds of the participants (66.5%) were above 30 years of age as compared to the remaining one-third of them (33.5%) who were from 18 to 30 years of age group, and the pediatric count cannot be determined since we did not enroll less than 18-year-old patients in this study. More than half of the participants (53%) were males, and the remaining 43% were females. More than half of the participants were single (inclusive of widowed, divorced, and unmarried individuals).

A previous study concluded that lower educational status, rented household, individuals per room (as a measure of overcrowding), and migratory status served as prominent risk factors for TB disease.^[15] In the present study, more than half of the participants (60.5%) lived in a shared room with some other family member, and out of 39.5% of those who had a separate room, 30.5% had a separate room even before the disease and 9%

were given the single room only after getting the disease. Close to four-fifths of the participants (79%) were living in a nuclear family, 18% of the participants were living in a joint family, and only 3% were living alone.

A potential limitation of this study is that conducting face-to-face interviews with the participants could have provided more comprehensive data for the study. Since the study was done during the lockdown, DOTS was not Directly Observed; medicines were distributed to patients even for months. There is a chance of missing out on defaulters who discontinued the treatment and were not reached.

Based on the present study findings, a multisectoral effort needs to be built to improve TB patients' compliance with the treatment. Sensitivity among the public and educational campaigns on prevention/treatment maybe of polio/HIV level would be key for TB elimination in India. Treatment of LTBI is another proposal and a point of discussion among policymakers, but improved nutrition and living conditions should give us the appropriate results in a cost-effective manner.^[16] A cost-analysis study can be piloted/planned for the same. Though long enough to continue for over a year, a prospective cohort study starting from the beginning of treatment till end results (in a maybe smaller cohort) will give us better elaboration on factors associated with TB treatment adherence since there would be lesser chances of missing out on potential information.

The findings of this study offer primary care physicians in New Delhi a deeper understanding of the sociodemographic factors influencing TB knowledge among patients. Armed with this knowledge, physicians can develop targeted interventions to address gaps in patient education, improve treatment adherence, and reduce TB transmission within communities. Additionally, by recognizing the impact of sociodemographic variables on TB knowledge, physicians can adopt a more holistic approach to patient care, considering not only medical but also social determinants of health in their treatment plans.

Conclusion

For TB treatment adherence, factors such as age, sex, socioeconomic status, type of accommodation, malnutrition, and personal hygiene are crucial considerations. Living in crowded areas where rooms or houses are shared increases the risk of TB transmission. Therefore, there is a need to develop new frameworks aimed at improving living conditions for high-risk populations and individuals residing in densely populated areas.

In the care of TB patients, factors such as knowledge and awareness about TB and its treatment, family support, access to DOTS services, and the role of health workers are significant. The Indian Government has set a goal to eliminate TB by 2025 as outlined in the National Strategic Plan. Improving patient compliance with TB care and treatment adherence is identified as the most critical challenge in achieving this goal.

According to the study, the NTEP has consistently met its objectives since 2007, with case detection rates exceeding 70% and treatment success rates surpassing 85% nationally, aligning with global TB control targets. Sustaining the program over the long term is essential to achieve the ultimate goal of TB control in India. This necessitates continued decentralization of program management and implementation, ensuring adequate financial support for the NTEP and mobilizing community participation in TB control efforts.

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Conflicts of interest

There are no conflicts of interest.

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