Care seeking in tuberculosis: Results from a countrywide sample survey in Bangladesh

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Care seeking in tuberculosis: Results from a countrywide sample survey in Bangladesh

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ABSTRACT

Objectives: To explore systematically the care seeking trajectories of TB cases up to four subsequent places of care and to assess the type of services provided at each place.

Methods: Tuberculosis cases detected actively during 2007-09 national tuberculosis prevalence survey and passively under routine programme at the same period were interviewed by administering a standardized questionnaire. Care seeking and services provided up to four subsequent points were explored. Care seeking was further explored by categorizing the providers into formal, informal and 'self care' groups.

Results: A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. Out of the 118 passively detected cases who first sought care from informal provider, 52(44.0%), 17(32.6%) and 5(29.4%) remained in the informal sector at second, third and fourth subsequent points of care. All the 33 actively detected cases had "self care' at the first point, 27 (82%) remained with "self care' up to the fourth point of care. Prescribing drugs (59%-99%) was the major type of care provided by the both formal and informal care providers at each point with limited to nonexistent practice of investigation or referrals.

Conclusions: Free TB services are still underutilized by TB cases and informal care givers remained the major care providers for such cases in Bangladesh. In order to improve case detection it is necessary that the NTP immediately take initiatives to engage all types of care providers, particularly informal providers who are the first point of care for majority of the TB suspects.

ARTICLE SUMMARY

Article focus

- Documented care seeking and types of management received by the persons with TB symptoms at subsequent places of care.

Key messages

- Initial care seeking by passively or actively detected TB cases happened at the informal sector or was limited to self care.
- About a third to half of the passively detected TB cases and majority of the actively detected TB cases utilized informal provider or self care for subsequent rounds of care.
- Case management in the informal sector was restricted to prescribing any medications, and almost without any diagnostic investigations or referrals.

Strengths and limitations of this study

- Included both actively and passively detected TB cases from all over the country and explored wide spectrum of care seeking.
- Clusters were selected from the rural or urban areas equally which might not reflect the underlying population distribution of the country.

INTORDUCTION

Bangladesh has successfully implemented Directly Observed Treatment, short-course (DOTS), the World Health Organization (WHO) advocated tuberculosis (TB) control strategy since 1993. By 2006, impressive case detection and cure rates were recorded. However, thereafter till date case notification became stagnant and even showed a declining trend.[1,2] It is likely that a large portion of cases still not reaching the National Tuberculosis Programme (NTP), and are probably getting treatment from private sector or not receiving care at all.[3-5]

The current TB control strategy is based, amongst others, on passive case detection, which is influenced by many heath system and patient factors. The awareness of a person of her symptoms, and intention to seek care will influence care utilization.[6,7] In addition, availability and access to anti-TB services, as well as factors related to the provider like manners and actions might influence care seeking practices and outcomes. [8,9] Care seeking therefore is an important determinant that influences not only the individual's disease status and its prognosis, but also reflects on the epidemiology of TB in a community.

Care givers play a crucial role in the care seeking pathway of individuals with symptoms of tuberculosis. Health services in Bangladesh are delivered by both formal and informal providers. Within the organization of TB-control in Bangladesh, formal providers are licensed medical practitioners (public or private) graduated from a medical college, or health workers (public or trough Non-Governmental Organizations) approved by the NTP, who received training to suspect, examine and refer TB cases to initiate TB treatment at DOTS centres.

Informal providers are non-qualified private practitioners who are not licensed or did not receive any formal training (e.g. village doctors, paramedics, pharmacy persons).[10,11] These informal providers are not accepted by the NTP to engage in TB-control activities.

Informal providers comprise 95% of the total health workers of Bangladesh. They are frequently the point of first care for TB and other chronic conditions due to many conditions including ease of access to their services. [4,12-15] However, case management within the informal sector remains unpredictable, and outcomes are hardly ever known.[13,16,17]

With freely available DOTS services throughout the country, it was expected all persons irrespective of socio economic status would access and utilize this service. However, recent findings of the National TB prevalence survey 2007-2009 of Bangladesh revealed that, only 9% actively identified TB cases were known to the NTP, [18] indicating the others were remaining in the community either without treatment or getting treatment from elsewhere. The same survey showed that care utilization from DOTS centres was mostly restricted to the cases belonging to higher socio economic position (SEP), while prevalent TB cases were mainly seen on the lower SEP strata.[5] These findings indicate that only availability of a service does not ensure its utilization, as it has also been observed in other sectors.[8]

With inadequate or absent initial care of TB cases fueling further transmission of the disease in the general population, it is important to understand the care seeking pathway of the persons with TB symptoms with respect to where care is initiated, and what action is taken by the care provider at presentation of an individual with chronic cough (as a strong marker for possible TB). The course of the disease is probably much determined in the point of first contact and in the subsequent points.

In this study we interviewed TB cases detected actively in a national TB prevalence survey, and cases detected passively under routine programme conditions. The objective was to explore their care seeking behavior up to four subsequent points of taking care. The study will identify areas to target by NTP for improved implementation of its activities to increase case finding and appropriate care.

METHODS AND MATERIALS

Setting and Study population: The study was embedded within the National TB prevalence survey, Bangladesh carried out throughout the country during 2007-2009. This was a cross sectional survey which included 40 randomly selected clusters.[18] Sub-districts were the primary sampling units which were selected proportional to population size. Nearly 52,000 adults (≥ 15 years) were included for sputum examination and 33 new smear positive TB cases were identified. For this analysis, we interviewed all these 33 actively detected cases and included 6 controls per cluster. The controls were the most recent passively detected cases under treatment from the TB registers of the each of 40 clusters' DOTS centres. All the cases were new smear positive pulmonary TB cases, and were diagnosed by direct sputum smear microscopy as per NTP guidelines. The detail of methodology is described elsewhere.[18]

Data collection: Data were collected by interviewing all detected survey cases at their households. A standard questionnaire was administered by trained survey coordinators immediately after the diagnosis of a case in the survey. The initial questionnaire was translated into Bangla, pre tested, and revised to incorporate review comments from users and experts. The survey coordinators received one week training at the Dhaka project office. The training included through understanding of the components of the questionnaire, and interview techniques to obtain reliable answers. The particulars of the 240 NTP cases were obtained from the TB register at the cluster-specific DOTS centre, after which the persons were visited at their home for an interview. Informed written consent was taken from all participants. All completed questionnaires were checked for completeness and appropriateness by a supervisor, who also re-interviewed a number of cases from randomly selected clusters for cross checking.

Measurements: The interviews provided information on the demographics, symptom profile of the cases, Socio-Economic Position (SEP), care utilization pattern, and services received at each point of care visited. The demographic data included age, sex, place of residence, levels of education and occupation. SEP was assessed by asset estimation.[19] The symptom profile recorded the symptoms presented at first care seeking. The care seeking data provided information on where care was sought, in what order, and what measures were taken by the providers at each point. The detail of socio economic data collection is described elsewhere.[5]

Statistical approach: Data were analyzed using the statistical package Stata 12.0 (Stata Corp., U.S.A.). The initial general description provides the characteristics of the study population. Age, education, occupation and symptoms variables were presented into natural sub groups. The asset estimation was based on set of assets the household possessed and a weight was allocated to each generated through a principal component analysis.[20] We included items and methods as standardized and followed by Bangladesh Demographic and Health Survey 2001.[20,21] The SEP of the study population was divided into quartiles. Care seeking from first to fourth subsequent points was explored. The types of providers were categorized as formal or informal as described earlier. We added a group as "self care" to denote the use of any treatment obtained outside the formal or informal health sector (eg. home remedies, self medication).

Measures taken at each point of care seeking were grouped in four categories. These were only advices offered, investigations ordered, medications given, or referred for further investigations. The care seeking and actions taken were reported by the patients at interview, we did not verify them either by checking prescription or by any other methods. We focused our analysis on the care seeking patterns of those cases who initiated their care seeking trajectory at the informal care sector.

RESULTS

A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. Among the participants 120 (44%) were below 34 years of age, and 176 (64.5%) were male. Participants were almost equally from rural and urban areas. Fifty percent of the cases presented with more than 5 symptoms. Most of the participants had cough, of which 81% for 15 days or more (Table 1). Among those, the mean delay from onset of symptoms to seek any care from any provider was 31 days, which was 20 days for survey case , and 33 days for the NTP cases under NTP.

Table 1: Socio demographic characteristics of NTP and survey tuberculosis cases

Characteristics	All		Survey cases		NTP cases		P value
	N(273)	%	n(33)	%	n(240)	%	
Age in years							
15-34	120	43.9	8	24.2	112	46.6	0.028
35-54	87	31.9	12	36.6	75	31.2	
55+	66	25.0	13	39.9	53	22.1	
Sex							
Male	176	64.5	24	72.7	152	63.3	0.290
Female	97	35.5	9	27.7	88	36.7	
Residence							
Rural	140	51.3	20	60.6	120	50.0	0.253
Urban	133	48.7	13	39.4	120	50.0	
Education							
0	71	26.0	15	45.5	55	23.0	0.039
1-5	71	26.0	8	24.2	65	27.1	
6-10	68	24.9	6	18.2	62	25.8	
10+	63	23.1	4	12.1	58	24.2	
Occupation							
Agri based	37	13.6	4	12.1	33	13.8	0.003
Daily wagers	89	22.3	14	42.4	75	31.3	
Sales and services	115	28.2	6	18.2	109	45.4	
Others	32	35.9	9	27.3	23	9.6	
Asset Quartiles							
1st (Lowest)	17	6.2	12	36.4	5	2.0	0.000
2nd	111	40.6	13	39.4	98	41.0	
3rd	113	41.4	5	15.1	108	45.0	
4th	32	11.8	3	9.1	29	12.0	
Presence of cough							
Yes	226	82.8	29	87.8	197	82.1	0.408
No	47	17.2	4	12.2	43	17.9	
Duration of cough							
Less than 14 days	51	18.7	6	18.2	45	18.2	0.937
≥ 15 days	222	81.3	27	81.8	195	81.8	
Number of symptoms							
≤ 2	44	16.1	4	12.1	40	16.7	0.556
3-4	79	29.0	8	24.2	71	29.6	
5+	150	54.9	21	63.7	129	53.8	

Among the 240 cases detected passively under NTP, 118 (49%) sought initial care from informal providers, 106 (44.2%) from formal providers, and 16 (6.7%) used self care. All of the 33 actively detected cases reported self care as the initial strategy, totaling this group to 49 (17.9%) of all cases (Fig 1). Out of the 118 passively detected NTP cases with initial care from the informal sector, 52 (44.0%) remained in the informal sector, while 61 (51.7%) switched to a formal provider for care at the second point care. Again, among the 52 who remained in the informal care sector, at the third point of care 32 (61.5%) migrated to formal care sector, while 17 (32.6%) remained in the informal sector. The proportion of patient who remained in the informal care sector up to the fourth point care was 29.4% of those stating their health seeking behavior in the informal sector. (Fig 1). Among the 16 (6.7%) of the NTP cases who reported self care as their initial strategy ultimately 4 (25%) remained in this stage up to fourth point of care, three (19%) moved to informal sector and nine (56%) migrated to formal care sector subsequently. Among the active detected cases, all of whom had self care as the initial strategy, 27 (81.8%) remained at this stage before being detected by the survey. Among the remaining six, three shifted to the formal sector at the second point of care, while the other three switched between informal and formal providers in the subsequent points of care (Not shown).

We looked into measures taken at each point of care by the formal and informal providers. In the formal care sector, the primary action was to prescribe drugs at each point of care starting with 79 (74.5%) at first point, 43 (70.5%) at the second point, 19 (59.4%) at the third and 10 (91%) at the fourth point of care. Ordering diagnostic investigations varied from 19 (17.9%) at the first point of care, to 14 (22.9%) at the second, 10 (31.2%) at the third, and 1 (9.0%) at the fourth point of care. Referral for further investigation was seldom done (0-2%). The informal providers on the other hand, prescribed drugs in 80% to 99% of the encounters, and seldom ordered

diagnostic investigations or referred the individual for further investigations at any of the four points of care. (Fig 2).

The reasons for not seeking care at all were available only from the 33 survey cases. The major reasons were not considering symptoms serious enough, and monetary constraints.

DISCUSSION

Our study showed that most of the initial care seeking by passively identified TB cases happened at the informal sector or was limited to self care. At each following round of care seeking a third to a half remained in the informal care sector. Among active detected cases, more than 80% remained in the self care sector up to the time of their identification by the survey. Case management in the informal sector was restricted to prescribing any medications, with non existence of any diagnostic investigations or referrals.

Preference for informal providers as initial place of care has been reported from Bangladesh and elsewhere.[3-5,9,12] In chronic conditions where the symptoms onset is slow and insidious like tuberculosis, people usually consult with an informal provider available at hand or consume over the counter drugs. This behavior can cause a marked delay to starting appropriate TB medication, given the fact that TB medication in line with the NP guideline is seldom present in the informal health sector. This has been observed in earlier studies from Bangladesh.[4] Our study adds the important finding that this preference of the informal sector persists throughout the care seeking trajectory. The lack of (referral for) diagnostic investigation can cause additional systems delay (between care seeking and starting appropriate treatment). In an earlier study this type of delay could be more than ten weeks.[4] Delay to reach appropriate care and treatment impacts on the course of the disease and may result in unfavorable outcomes and ongoing transmission.[22] From a programmatic point of view, this situation leads to a marked under reporting of TB cases.

Care seeking from the informal sector is not limited to TB only, but rather a common feature for all chronic conditions in Bangladesh.[15,23] It is suggested that the presence of huge numbers of informal providers in both rural and urban areas, their easy accessibility due to reduced cost, and

minimal levels of stigma when attending such providers, encourage people to seek care from this sector first.[15,23,24] A good portion of them are simple drug sellers providing drugs without further diagnostic procedures.[12] The easy access to informal providers paves the way "shopping for care", in which care is sought form sequential informal providers as observed in our study. In Malawi, care seeking among TB patients noted that multiple contactcs in range of 1-15 were made before the dagnosis.[25] Similarly in vietnam patients made on average 1.3 contacts and 2.5 visit per providers before getting appropriate TB serivecs, even though the size private sector was very small.[26]

We observed that the case management was not altogether different in the formal and informal sector with respect to prescribing drugs. However, unlike in the formal sector, there was almost a complete absence of diagnostic procedures and referrals in the informal sector. We need to carefully interpret these findings as we don't have information what drugs were prescribed by the providers. Retrospective recording of actual drugs through patient interviews is difficult and in most case unreliable. In Bangladesh, Fixed Dose Combination (FDC) anti TB drugs are almost exclusively available at DOTS centres. This implies that medication provided through the informal sector is unlikely to be adequate for the management of TB. But formal providers can manage TB cases outside the context of DOTS centers. As such mismanagement of TB can also occur in the formal sector, given the low occurrence of diagnostic investigations.

A study in Malawi provided insight in the type of mediation provided to individuals with TB symptoms but without a formal diagnosis. The authors reported that 61% of cases had been treated with atibiotics like co-trimoxazole, doxycycline, and penicillin.[25]

Despite the clear findings of the strong presence of the informal health sector in Bangladesh, the NTP does not strongly embark on initiatives to engage these providers in TB-control activities. The lessons learnt from studies aimed at establishing connections between formal and informal health care providers remain unexplored.[13,27] Our study indicates that despite the country coverage by DOTS, and public-private-partnership activities undertaken by the NTP, the impact did not result in reducing the disconnect between NTP and the informal health sector. In a recent attempt to improve the situation, NTP in partnership with icddr,b and United States Agency for International Development (USAID) is implementing a "Translating research into action (TRAction)" project to test different implementation strategies, with a clear role for the informal providers. This current study suggests that attempt is timely and needed.

One of the potential limitations of the study is the potential for minor selection bias. Although all participants were randomly selected, the selection of clusters was not stratified by urban/rural setting. The study sample therefore does not fully represent the 70% of the rural population in Bangladesh. There was also a slight overrepresentation of males. However the national case notification is more or less static at 3:1 male to female since the inception of DOTS in 1993.[1] The strengths of the study are that the cases were interviewed at home by trained research coordinators providing an enabling study setting. We explored the care seeking of both actively and passively detected cases which would cover care seeking from a wider perspective of two different kinds of cases, one who is probably in the early phase of the disease process and the other probably in a more advanced condition. Moreover we have covered the care seeking up to fourth point of care, which is expected to give a more comprehensive picture of the care seeking by the TB cases in Bangladesh.

In conclusions it can be said that most of the initial care seeking by different types of TB cases was sought form informal providers or was limited to self care, and that a large proportion of these cases remained in the informal sector during subsequent care seeking. It is imperative that the NTP should immediately take initiatives to engage all types of care providers, particularly the informal providers. It is also necessary to strengthen the ongoing advocacy communication and social mobilization (ACSM) activities to increase awareness on key TB symptoms, availability of diagnosis and free treatment in an attempt to stimulate appropriate care seeking, and prevent unnecessary delay in TB case management.

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Contributors Shahed Hossain was responsible for conception and design of the study, analysis and interpretation of data and writing the manuscript. Martien Borgdorff, Frank van Leth and K Zaman participated in the conception and design of the study, analysis and interpretation of data as well as revising the draft. Abdul Quaiyum, Sayera Banu, Ashaque Husain and Akramul Islam participated in the analysis and interpretation of data and substantially revising the paper.

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Competing interest: None

Ethics approval This study was approved through an Institutional Review Board of icddr,b (IRB, FWA-00001468) which is internationally accorded and participated by members from international and national experts. Verbal and written consent was obtained in all cases after informed appraisal.

Data sharing statement Additional data from this survey are being analyzed and will be published in future

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Fig 1: Care seeking at different points of care

Fig 2: Actions taken if care sought from formal and informal providers

Fig 1: Care seeking at different points of care

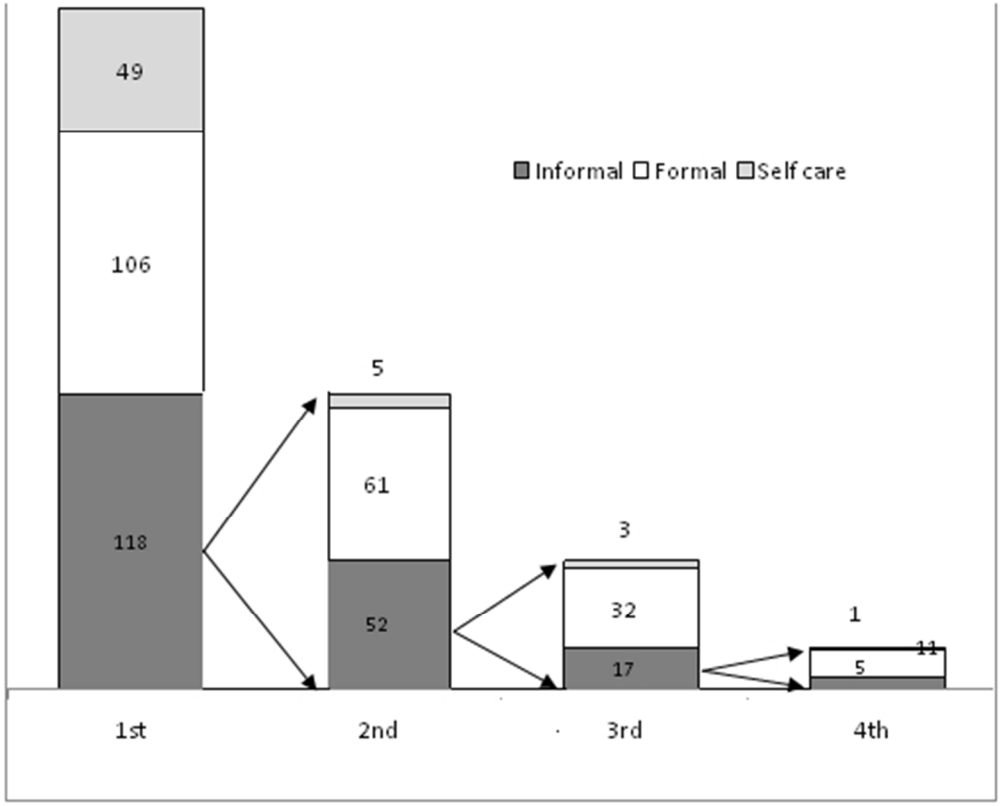

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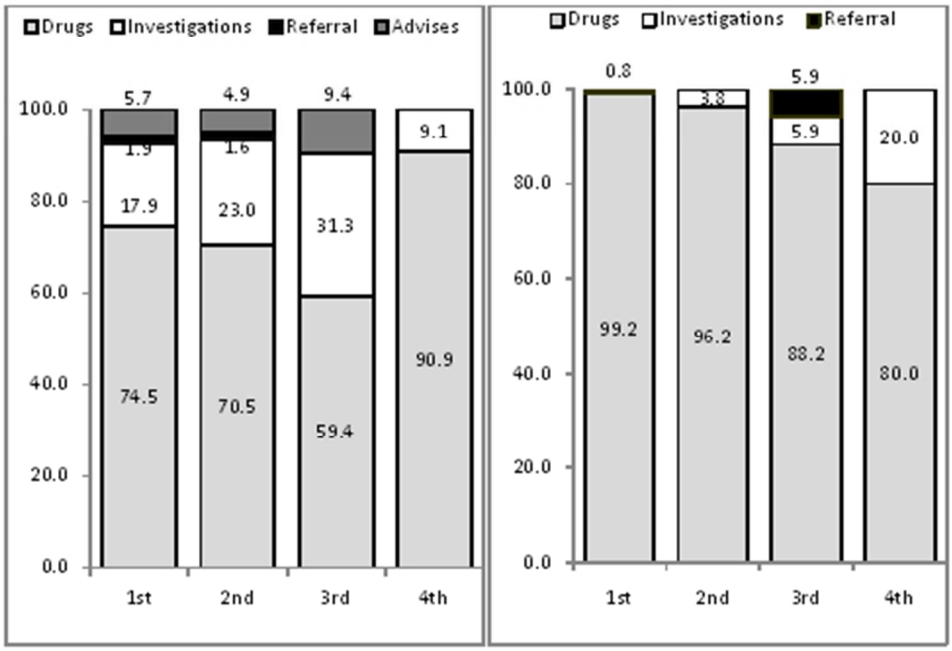
Fig 2: Actions taken if care sought from formal and informal providers



135x108mm (96 x 96 DPI)

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Study's design is mentioned in the title and abstract
		(*b*) Precise and concise information on study methods and findings given in the abstract
Introduction		
Background/rationale	2	Comprehensive background and rationale provided
Objectives	3	Specific objectives described
Methods		
Study design	4	Specific design adopted with relevant references are given
Setting	5	The setting is adequately described with all relevant information and references. One relevant document is uploaded.
Participants	6	(*a*) *Cross-sectional study*—Sources and methods of data collection are given as separate paragraphs.
Variables	7	All the variables are defined and adequate explanation given.
Data sources/ measurement	8*	A separate paragraph on measurement described details on methods of assessment.
Bias	9	Described in discussion and limitation section
Study size	10	Explained
Quantitative variables	11	A details description on statistical analysis is given
Statistical methods	12	(*a*) All statistical methods described
		(*b*) Described examination of subgroups
		(*c*) No possible missing data anticipated
		(*d*) *Cross-sectional study*—Not much impact for sampling was anticipated, so separate analytical approach to account for sampling strategy needed
		(*e*) There is no sensitivity analyses
Results		
Participants	13*	(a) All participants were eligible, no refusal, no missing data reported
		(b) Not applicable
		(c) Not necessary
Descriptive data	14*	(a) General characteristics of study participants given in Table 1
		(b) No such data
		(c) N/A
Outcome data	15*	
		Cross-sectional study—Summary measures reported
Main results	16	(*a*) The main analysis did not include any confounding estimates
		(*b*) Applicable description of variables given
		(*c*) No relevant
Other analyses	17	Report other analyses done—Graphical presentation given

Discussion		
Key results	18	Summarise key results given
Limitations	19	Discuss limitations of the study: Discussed
Interpretation	20	Possible and cautious interpretation of overall results given
Generalisability	21	Discuss the generalisability (external validity) of the study results: Discussed
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based: Given

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Care seeking in tuberculosis: Results from a countrywide cluster randomized survey in Bangladesh

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Care seeking in tuberculosis: Results from a countrywide cluster randomized survey in Bangladesh

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ABSTRACT

Objectives: To explore systematically the care seeking trajectories of TB cases up to four subsequent places of care and to assess the type of services provided at each place.

Methods: Tuberculosis cases detected actively during 2007-09 national tuberculosis prevalence survey and passively under routine programme at the same period were interviewed by administering a standardized questionnaire. Care seeking and services provided up to four subsequent points were explored. Care seeking was further explored by categorizing the providers into formal, informal and 'self care' groups.

Results: A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. Out of the 118 passively detected cases who first sought care from informal provider, 52(44.1%) remained in the informal sector at second point of care. Similarly, out of 52, 17(32.7%) and out of 17, 5(29.4%) remained in the informal sector at third and fourth subsequent points of care respectively. All the 33 actively detected cases had "self care' at the first point, 27 (81.8 %) remained with "self care' up to the fourth point of care. Prescribing drugs (59%-99%) was the major type of care provided by the both formal and informal care providers at each point with limited to nonexistent practice of investigation or referrals.

Conclusions: Free TB services are still underutilized by TB cases and informal care givers remained the major care providers for such cases in Bangladesh. In order to improve case detection it is necessary that the NTP immediately take effective initiatives to engage all types of care providers, particularly informal providers who are the first point of care for majority of the TB suspects.

ARTICLE SUMMARY

Article focus

- Documented care seeking and types of management received by the persons with TB symptoms at subsequent places of care.

Key messages

- Initial care seeking by passively or actively detected TB cases happened at the informal sector or was limited to self care.
- About a third to half of the passively detected TB cases and majority of the actively detected TB cases utilized informal provider or self care for subsequent rounds of care.
- Case management in the informal sector was restricted to prescribing any medications, and almost without any diagnostic investigations or referrals.

Strengths and limitations of this study

- Included both actively and passively detected TB cases from all over the country and explored wide spectrum of care seeking.
- Clusters were selected from the rural or urban areas equally which might not reflect the underlying population distribution of the country.

INTORDUCTION

Bangladesh has successfully implemented Directly Observed Treatment, short-course (DOTS), the World Health Organization (WHO) advocated tuberculosis (TB) control strategy since 1993. Since then, impressive case detection and cure rates were recorded under DOTS. However, from 2006 onwards, case notification became stagnant and even started to show a declining trend.[1,2] It is likely that a substantial number of cases are not notified under National Tuberculosis Programme (NTP), and are probably getting treatment from private sector or not receiving care at all.[3-5]

The current TB control strategy is based, amongst others, on passive case detection, which is influenced by many heath system and patient factors. The awareness of a person of her symptoms, and intention to seek care influences care utilization.[6,7] Similarly, availability and access to anti-TB services, and providers' behaviour also influence care seeking practices and outcomes. [8,9] Care seeking therefore is an important determinant that influences not only the individual's disease status and its prognosis, but also reflects on the epidemiology of TB in a community.

Care givers play a crucial role in the care seeking pathway of individuals with symptoms of tuberculosis. In Bangladesh, health care services are provided by both formal and informal providers. Within the organization of TB-control in Bangladesh, formal providers are licensed medical practitioners (public or private) graduated from a medical college, or health workers (public or trough Non-Governmental Organizations) approved by the NTP, who received training to suspect, examine and refer TB cases to initiate TB treatment at DOTS centres.

Informal providers are non-qualified private practitioners who are not licensed or did not receive any formal training (e.g. village doctors, paramedics, pharmacy persons).[10,11] However the NTP acknowledges the important role of private sector providers including informal providers and urged to involve them to achieve TB control objectives through a systematic public- private mix (PPM) approach.

Informal providers comprise 95% of the total health workers of Bangladesh. They are frequently the point of first care for TB and other chronic conditions due to many conditions including ease of access to their services. [4,12-15] However, case management within the informal sector remains unpredictable, and outcomes are hardly ever known.[13,16,17]

With freely available DOTS services throughout the country, it was expected all persons irrespective of socio economic status would access and utilize this service. However, recent findings of the National TB prevalence survey 2007-2009 of Bangladesh revealed that, only 9% actively identified TB cases were known to the NTP, [18] indicating the others were remaining in the community either without treatment or getting treatment from elsewhere. The same survey showed that care utilization from DOTS centres was mostly from higher socio economic position (SEP), while prevalent TB cases were mainly seen on the lower SEP strata. SEP was assessed by validated asset items for households and the actively identified cases from survey were compared with passively detected cases under NTP over the identical SEP quartiles. Among the actively detected cases 75.8% were from lower two quartiles, while among the passively TB cases more than half, 57.1% were from uppermost two quartiles, 40.8% from the second quartile, and 2.1% in the lowest quartile of the population. This distribution did not change after adjustments for

other factors or interactions among them. [5, 18] These findings indicate that availability of a service does not ensure its utilization, as it has also been observed in other sectors. [8]

With inadequate or absent of initial care of TB cases fueling further transmission of the disease in the general population, it is important to understand the care seeking pathway of the persons with TB symptoms with respect to where care is initiated, and what action is taken by the care provider at presentation of an individual with chronic cough (as a strong marker for possible TB). The course of the disease is probably much determined at the point of first contact and in the subsequent points.

In this study we interviewed TB cases detected actively in a national TB prevalence survey, and cases detected passively under routine programme conditions. The objective was to explore their care seeking behavior up to four subsequent points of taking care. The study will identify areas to target by NTP for improved implementation of its activities to increase case finding and appropriate care.

METHODS AND MATERIALS

Setting and Study population: The study was embedded within the National TB prevalence survey, Bangladesh carried out throughout the country during 2007-2009. This was a cross sectional survey which included 40 randomly selected clusters.[18] Sub-districts were the primary sampling units which were selected proportional to population size. Nearly 52,000 adults (≥ 15 years) were included for sputum examination and 33 new smear positive TB cases were identified. For this analysis, we interviewed all these 33 actively detected cases and included 6 controls per cluster. The controls were the most recent passively detected cases under treatment from the TB registers of the each of 40 clusters' DOTS centres. All the cases were new smear positive pulmonary TB cases, and were diagnosed by direct sputum smear microscopy as per NTP guidelines. The detail of methodology is described elsewhere.[18]

Data collection: Data were collected by interviewing all detected survey cases at their households. A standard questionnaire was administered by trained survey coordinators immediately after the diagnosis of a case in the survey. The initial questionnaire was translated into Bangla, pre tested, and revised to incorporate review comments from users and experts. The survey coordinators received one week training at the Dhaka project office. The training included **thorough** understanding of the components of the questionnaire, and interview techniques to obtain reliable answers. The particulars of the 240 NTP cases were obtained from the TB register at the cluster-specific DOTS centre, after which the persons were visited at their home for an interview. Informed written consent was taken from all participants. All completed questionnaires were checked for completeness and appropriateness by a supervisor, who also re-interviewed a number of cases from randomly selected clusters for cross checking.

This survey protocol along with the national TB prevalence survey was approved by the institutional review board (IRB, FWA-00001468) of the International Centre for Diarrhoeal Diseases Research, Bangladesh (icddr,b).

Measurements: The interviews provided information on the demographics, symptom profile of the cases, Socio-Economic Position (SEP), care utilization pattern, and services received at each point of care visited. The demographic data included age, sex, place of residence, levels of education and occupation. SEP was assessed by asset estimation.[19] The symptom profile recorded the symptoms presented at first care seeking. The care seeking data provided information on where care was sought, in what order, and what measures were taken by the providers at each point. The detail of socio economic data collection is described elsewhere.[5]

Statistical approach: Data were analyzed using the statistical package Stata 12.0 (Stata Corp., U.S.A.). The initial general description provides the characteristics of the study population. Age, education, occupation and symptoms variables were presented into natural sub groups. The asset estimation was based on **a** set of assets the household possessed and a weight was allocated to each generated through a principal component analysis.[20] We included items and methods as standardized and followed by Bangladesh Demographic and Health Survey 2001.[20,21] The SEP of the study population was divided into quartiles. Care seeking from first to fourth subsequent points was explored. The types of providers were categorized as formal or informal as described earlier. We added a group as "self care" to denote the use of any treatment obtained outside the formal or informal health sector (eg. home remedies, self medication).

Measures taken at each point of care seeking were grouped in four categories. These were only advices offered, investigations ordered and medications given, or referred for further investigations. The care seeking and actions taken were reported by the patients at interview, we did not verify them either by checking prescription or by any other methods. We focused our analysis on the care seeking patterns of those cases who initiated their care seeking trajectory at the informal care sector.

RESULTS

A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. Among the participants 120 (43.9%) were below 34 years of age, and 176 (64.5%) were male. Participants were almost equally from rural and urban areas. More than fifty percent of the cases presented with more than 5 symptoms. Most of the participants had cough, of which 81.3% for 15 days or more (Table 1). Among those, the mean delay from onset of symptoms to seek any care from any provider was 31 days, which was 20 days for survey cases , and 33 days for the NTP cases under NTP (not shown).

Table 1: Socio demographic characteristics of NTP and survey tuberculosis cases

Characteristics	All		Survey cases		NTP cases		P value
	N(273)	%	n(33)	%	n(240)	%	
Age in years							
15-34	120	43.9	8	24.2	112	46.6	0.028
35-54	87	31.9	12	36.6	75	31.2	
55+	66	25.0	13	39.9	53	22.1	
Sex							
Male	176	64.5	24	72.7	152	63.3	0.290
Female	97	35.5	9	27.7	88	36.7	
Residence							
Rural	140	51.3	20	60.6	120	50.0	0.253
Urban	133	48.7	13	39.4	120	50.0	
Education							
0	71	26.0	15	45.5	55	23.0	0.039
1-5	71	26.0	8	24.2	65	27.1	
6-10	68	24.9	6	18.2	62	25.8	
10+	63	23.1	4	12.1	58	24.2	
Occupation							
Agri based	37	13.6	4	12.1	33	13.8	0.003
Daily wagers	89	22.3	14	42.4	75	31.3	
Sales and services	115	28.2	6	18.2	109	45.4	
Others	32	35.9	9	27.3	23	9.6	
Asset Quartiles							
1st (Lowest)	17	6.2	12	36.4	5	2.0	0.000
2nd	111	40.6	13	39.4	98	41.0	
3rd	113	41.4	5	15.1	108	45.0	
4th	32	11.8	3	9.1	29	12.0	
Presence of cough							
Yes	226	82.8	29	87.8	197	82.1	0.408
No	47	17.2	4	12.2	43	17.9	
Duration of cough							
Less than 14 days	51	18.7	6	18.2	45	18.2	0.937
≥ 15 days	222	81.3	27	81.8	195	81.8	
Number of symptoms							
≤ 2	44	16.1	4	12.1	40	16.7	0.556
3-4	79	29.0	8	24.2	71	29.6	
5+	150	54.9	21	63.7	129	53.8	

Among the 240 cases detected passively under NTP, 118 (49.1%) sought initial care from informal providers, 106 (44.2%) from formal providers, and 16 (6.7%) used self care. All of the 33 actively detected cases reported self care as the initial strategy, totaling this group to 49 (17.9%) of all cases (Fig 1). Out of the 118 passively detected NTP cases with initial care from the informal sector, 52 (44.1%) remained in the informal sector, while 61 (51.7%) switched to a formal provider for care at the second point care. Again, among the 52 who remained in the informal care sector, at the third point of care 32 (61.5%) migrated to formal care sector, while 17 (32.7%) remained in the informal sector. The proportion of patient who remained in the informal care sector up to the fourth point care was five (29.4%) of those stating their health seeking behavior in the informal sector. (Fig 1). Among the 16 (6.7%) of the NTP cases who reported self care as their initial strategy ultimately four (25.0%) remained in this stage up to fourth point of care, three (18.8 %) moved to informal sector and nine (56.2%) migrated to formal care sector subsequently. Among the active detected cases, all of whom had self care as the initial strategy, 27 (81.8%) remained at this stage before being detected by the survey. Among the remaining six, three shifted to the formal sector at the second point of care, while the other three switched between informal and formal providers in the subsequent points of care (Not shown).

We looked into measures taken at each point of care by the formal and informal providers. In the formal care sector, the primary action was to prescribe drugs at each point of care starting with 79 (74.5%) at first point, 43 (70.5%) at the second point, 19 (59.4%) at the third and 10 (91%) at the fourth point of care. Ordering diagnostic investigations varied from 19 (17.9%) at the first point of care, to 14 (22.9%) at the second, 10 (31.2%) at the third, and 1 (9.0%) at the fourth point of care. Referral for further investigation was seldom done (0-2%). The informal providers

on the other hand, prescribed drugs in 80% to 99% of the encounters, and seldom ordered diagnostic investigations or referred the individual for further investigations at any of the four points of care. (Fig 2).

The reasons for not seeking care at all were available only from the 33 survey cases. The major reasons were not considering symptoms serious enough, and monetary constraints.

DISCUSSION

Our study showed that most of the initial care seeking by passively identified TB cases happened at the informal sector or was limited to self care. At each following round of care seeking a third to a half remained in the informal care sector. Among actively detected cases, more than 80% remained in the self care sector up to the time of their identification by the survey. Case management in the informal sector was restricted to prescribing any medications, with non existence of any diagnostic investigations or referrals.

Preference for informal providers as initial place of care has been reported from Bangladesh and elsewhere.[3-5,9,12] In chronic conditions where the symptoms onset is slow and insidious like tuberculosis, people usually consult with an informal provider available at hand or consume over the counter drugs. This behavior can cause a marked delay to starting appropriate TB medication, given the fact that TB medication in line with the NP guideline is seldom present in the informal health sector. This has been observed in earlier studies from Bangladesh.[4] Our study adds the important finding that this preference of the informal sector persists throughout the care seeking trajectory. The lack of (referral for) diagnostic investigation can cause additional systems delay (between care seeking and starting appropriate treatment). An earlier study reported that this type of delay could be more than ten weeks.[4] Delay to reach appropriate care and treatment impacts on the course of the disease and may result in unfavorable outcomes and ongoing transmission.[22] From a programmatic point of view, this situation leads to a marked under reporting of TB cases.

Care seeking from the informal sector is not limited to TB only, but rather a common feature for all chronic conditions in Bangladesh.[15,23] It is suggested that the presence of huge numbers of

informal providers in both rural and urban areas, their easy accessibility due to reduced cost, and minimal levels of stigma when attending such providers, encourage people to seek care from this sector first.[15,23,24] A good portion of them are simple drug sellers providing drugs without further diagnostic procedures.[12] This easy access to informal providers stimulates "shopping for care", when care is sought form informal providers subsequently one after one, as observed in our study. In Malawi, care seeking among TB patients noted that multiple contactcs in range of 1-15 were made before the dagnosis.[25] Similarly in vietnam patients made on average 1.3 contacts and 2.5 visit per providers before getting appropriate TB serivecs, even though the size private sector was very small.[26]

We observed that the case management was not altogether different in the formal and informal sector with respect to prescribing drugs. However, unlike in the formal sector, there was almost a complete absence of diagnostic procedures and referrals in the informal sector. We need to carefully interpret these findings as we don't have information what drugs were prescribed by the providers. Retrospective recording of actual drugs through patient interviews is difficult and in most case unreliable. In Bangladesh, Fixed Dose Combination (FDC) anti TB drugs are almost exclusively available at DOTS centres. This implies that medication provided through the informal sector is unlikely to be adequate for the management of TB. But formal providers can manage TB cases outside the context of DOTS centers. As such mismanagement of TB can also occur in the formal sector, given the low occurrence of diagnostic investigations.

A study in Malawi provided insight in the type of mediation provided to individuals with TB symptoms but without a formal diagnosis. The authors reported that 61% of cases had been treated with atibiotics like co-trimoxazole, doxycycline, and penicillin.[25]

NTP also recognizes the absence of standard practices in the private sector and the lack of sufficient interaction and formal linkages between NTP and these private sector providers. The lessons learnt from studies aimed at establishing connections between formal and informal health care providers remain unexplored.[13,27] Our study indicates that despite the country coverage by DOTS, and public-private-partnership activities undertaken by the NTP, the impact did not result in reducing the disconnect between NTP and the informal health sector. In a recent attempt to improve the situation, NTP in partnership with icddr,b and United States Agency for International Development (USAID) is implementing a "Translating research into action (TRAction)" project to test different implementation strategies, with a clear role for the informal providers. This current study suggests that attempt is timely and needed.

One of the potential limitations of the study is the potential for minor selection bias. Although all participants were randomly selected, the selection of clusters was not stratified by urban/rural setting. The study sample therefore does not fully represent the 70% of the rural population in Bangladesh. There was also a slight overrepresentation of males. However the national case notification is more or less static at 3:1 male to female since the inception of DOTS in 1993.[1] The strengths of the study are that the cases were interviewed at home by trained research coordinators providing an enabling study setting. We explored the care seeking of both actively and passively detected cases which would cover care seeking from a wider perspective of two different kinds of cases, one who is probably in the early phase of the disease process and the other probably in a more advanced condition. Moreover we have covered the care seeking up to fourth point of care, which is expected to give a more comprehensive picture of the care seeking by the TB cases in Bangladesh.

In conclusions it can be said that most of the initial care seeking by different types of TB cases was sought from informal providers or was limited to self care, and that a large proportion of these cases remained in the informal sector during subsequent care seeking. It is imperative that the NTP should immediately take initiatives to engage all types of care providers, particularly the informal providers. It is also necessary to strengthen the ongoing advocacy communication and social mobilization (ACSM) activities to increase awareness on key TB symptoms, availability of diagnosis and free treatment in an attempt to stimulate appropriate care seeking, and to prevent unnecessary delay in TB case management.

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Contributors Shahed Hossain was responsible for conception and design of the study, analysis and interpretation of data and writing the manuscript. Martien Borgdorff, Frank van Leth and K Zaman participated in the conception and design of the study, analysis and interpretation of data as well as revising the draft. Abdul Quaiyum, Sayera Banu, Ashaque Husain and Akramul Islam participated in the analysis and interpretation of data and substantially revising the paper.

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Competing interest: None

Ethics approval This study was approved through an Institutional Review Board of icddr,b (IRB, FWA-00001468) which is internationally accorded and participated by members from international and national experts. Verbal and written consent was obtained in all cases after informed appraisal.

Data sharing statement Additional data from this survey are being analyzed and will be published in future

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Figure legends

Fig 1: Care seeking at different points of care

Fig 2: Actions taken if care sought from formal and informal providers

Care seeking in tuberculosis: Results from a countrywide cluster randomized survey in Bangladesh

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Key words: Tuberculosis; Care seeking; Informal providers; Bangladesh

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ABSTRACT

Objectives: To explore systematically the care seeking trajectories of TB cases up to four subsequent places of care and to assess the type of services provided at each place.

Methods: Tuberculosis cases detected actively during 2007-09 national tuberculosis prevalence survey and passively under routine programme at the same period were interviewed by administering a standardized questionnaire. Care seeking and services provided up to four subsequent points were explored. Care seeking was further explored by categorizing the providers into formal, informal and 'self care' groups.

Results: A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. **Out of the 118 passively detected cases who first sought care from informal provider, 52(44.1%) remained in the informal sector at second point of care. Similarly, out of 52, 17(32.7%) and out of 17, 5(29.4%) remained in the informal sector at third and fourth subsequent points of care respectively.** All the 33 actively detected cases had "self care' at the first point, 27 (81.8 %) remained with "self care' up to the fourth point of care. Prescribing drugs (59%-99%) was the major type of care provided by the both formal and informal care providers at each point with limited to nonexistent practice of investigation or referrals.

Conclusions: Free TB services are still underutilized by TB cases and informal care givers remained the major care providers for such cases in Bangladesh. In order to improve case detection it is necessary that the NTP immediately take effective initiatives to engage all types of care providers, particularly informal providers who are the first point of care for majority of the TB suspects.

ARTICLE SUMMARY

Article focus

- Documented care seeking and types of management received by the persons with TB symptoms at subsequent places of care.

Key messages

- Initial care seeking by passively or actively detected TB cases happened at the informal sector or was limited to self care.
- About a third to half of the passively detected TB cases and majority of the actively detected TB cases utilized informal provider or self care for subsequent rounds of care.
- Case management in the informal sector was restricted to prescribing any medications, and almost without any diagnostic investigations or referrals.

Strengths and limitations of this study

- Included both actively and passively detected TB cases from all over the country and explored wide spectrum of care seeking.
- Clusters were selected from the rural or urban areas equally which might not reflect the underlying population distribution of the country.

INTORDUCTION

Bangladesh has successfully implemented Directly Observed Treatment, short-course (DOTS), the World Health Organization (WHO) advocated tuberculosis (TB) control strategy since 1993. **Since then, impressive case detection and cure rates were recorded under DOTS. However, from 2006 onwards, case notification became stagnant and even started to show a declining trend**.[1,2] It is likely that a **substantial number of cases are not notified under** National Tuberculosis Programme (NTP), and are probably getting treatment from private sector or not receiving care at all.[3-5]

The current TB control strategy is based, amongst others, on passive case detection, which is influenced by many heath system and patient factors. The awareness of a person of her symptoms, and intention to seek care influences care utilization.[6,7] **Similarly, availability and access to anti-TB services, and providers' behaviour also influence care seeking practices and outcomes.** [8,9] Care seeking therefore is an important determinant that influences not only the individual's disease status and its prognosis, but also reflects on the epidemiology of TB in a community.

Care givers play a crucial role in the care seeking pathway of individuals with symptoms of tuberculosis. **In Bangladesh, health care services are provided by both formal and informal providers.** Within the organization of TB-control in Bangladesh, formal providers are licensed medical practitioners (public or private) graduated from a medical college, or health workers (public or trough Non-Governmental Organizations) approved by the NTP, who received training to suspect, examine and refer TB cases to initiate TB treatment at DOTS centres.

Informal providers are non-qualified private practitioners who are not licensed or did not receive any formal training (e.g. village doctors, paramedics, pharmacy persons).[10,11] **However the NTP acknowledges the important role of private sector providers including informal providers and urged to involve them to achieve TB control objectives through a systematic public- private mix (PPM) approach.**

Informal providers comprise 95% of the total health workers of Bangladesh. They are frequently the point of first care for TB and other chronic conditions due to many conditions including ease of access to their services. [4,12-15] However, case management within the informal sector remains unpredictable, and outcomes are hardly ever known.[13,16,17]

With freely available DOTS services throughout the country, it was expected all persons irrespective of socio economic status would access and utilize this service. However, recent findings of the National TB prevalence survey 2007-2009 of Bangladesh revealed that, only 9% actively identified TB cases were known to the NTP, [18] indicating the others were remaining in the community either without treatment or getting treatment from elsewhere. **The same survey showed that care utilization from DOTS centres was mostly from higher socio economic position (SEP), while prevalent TB cases were mainly seen on the lower SEP strata. SEP was assessed by validated asset items for households and the actively identified cases from survey were compared with passively detected cases under NTP over the identical SEP quartiles. Among the actively detected cases 75.8% were from lower two quartiles, while among the passively TB cases more than half, 57.1% were from uppermost two quartiles, 40.8% from the second quartile, and 2.1% in the lowest quartile of the population. This distribution did not change after adjustments for other factors or**

interactions among them. [5, 18] These findings indicate that availability of a service does not ensure its utilization, as it has also been observed in other sectors. [8]

With inadequate or absent of initial care of TB cases fueling further transmission of the disease in the general population, it is important to understand the care seeking pathway of the persons with TB symptoms with respect to where care is initiated, and what action is taken by the care provider at presentation of an individual with chronic cough (as a strong marker for possible TB). The course of the disease is probably much determined at the point of first contact and in the subsequent points.

In this study we interviewed TB cases detected actively in a national TB prevalence survey, and cases detected passively under routine programme conditions. The objective was to explore their care seeking behavior up to four subsequent points of taking care. The study will identify areas to target by NTP for improved implementation of its activities to increase case finding and appropriate care.

METHODS AND MATERIALS

Setting and Study population: The study was embedded within the National TB prevalence survey, Bangladesh carried out throughout the country during 2007-2009. This was a cross sectional survey which included 40 randomly selected clusters.[18] Sub-districts were the primary sampling units which were selected proportional to population size. Nearly 52,000 adults (≥ 15 years) were included for sputum examination and 33 new smear positive TB cases were identified. For this analysis, we interviewed all these 33 actively detected cases and included 6 controls per cluster. The controls were the most recent passively detected cases under treatment from the TB registers of the each of 40 clusters' DOTS centres. All the cases were new smear positive pulmonary TB cases, and were diagnosed by direct sputum smear microscopy as per NTP guidelines. The detail of methodology is described elsewhere.[18]

Data collection: Data were collected by interviewing all detected survey cases at their households. A standard questionnaire was administered by trained survey coordinators immediately after the diagnosis of a case in the survey. The initial questionnaire was translated into Bangla, pre tested, and revised to incorporate review comments from users and experts. The survey coordinators received one week training at the Dhaka project office. The training included **thorough** understanding of the components of the questionnaire, and interview techniques to obtain reliable answers. The particulars of the 240 NTP cases were obtained from the TB register at the cluster-specific DOTS centre, after which the persons were visited at their home for an interview. Informed written consent was taken from all participants. All completed questionnaires were checked for completeness and appropriateness by a supervisor, who also re-interviewed a number of cases from randomly selected clusters for cross checking.

This survey protocol along with the national TB prevalence survey was approved by the institutional review board (IRB, FWA-00001468) of the International Centre for Diarrhoeal Diseases Research, Bangladesh (icddr,b).

Measurements: The interviews provided information on the demographics, symptom profile of the cases, Socio-Economic Position (SEP), care utilization pattern, and services received at each point of care visited. The demographic data included age, sex, place of residence, levels of education and occupation. SEP was assessed by asset estimation.[19] The symptom profile recorded the symptoms presented at first care seeking. The care seeking data provided information on where care was sought, in what order, and what measures were taken by the providers at each point. The detail of socio economic data collection is described elsewhere.[5]

Statistical approach: Data were analyzed using the statistical package Stata 12.0 (Stata Corp., U.S.A.). The initial general description provides the characteristics of the study population. Age, education, occupation and symptoms variables were presented into natural sub groups. The asset estimation was based on a set of assets the household possessed and a weight was allocated to each generated through a principal component analysis.[20] We included items and methods as standardized and followed by Bangladesh Demographic and Health Survey 2001.[20,21] The SEP of the study population was divided into quartiles. Care seeking from first to fourth subsequent points was explored. The types of providers were categorized as formal or informal as described earlier. We added a group as "self care" to denote the use of any treatment obtained outside the formal or informal health sector (eg. home remedies, self medication).

Measures taken at each point of care seeking were grouped in four categories. These were only advices offered, investigations ordered and medications given, or referred for further investigations. The care seeking and actions taken were reported by the patients at interview, we did not verify them either by checking prescription or by any other methods. We focused our analysis on the care seeking patterns of those cases who initiated their care seeking trajectory at the informal care sector.

RESULTS

A total 273 TB cases were included for this study, 33 (12.0%) were detected during survey and 240 (88.0%) from the TB registers. Among the participants 120 (43.9%) were below 34 years of age, and 176 (64.5%) were male. Participants were almost equally from rural and urban areas. More than fifty percent of the cases presented with more than 5 symptoms. Most of the participants had cough, of which 81.3% for 15 days or more (Table 1). Among those, the mean delay from onset of symptoms to seek any care from any provider was 31 days, which was 20 days for survey cases , and 33 days for the NTP cases under NTP (not shown).

Table 1: Socio demographic characteristics of NTP and survey tuberculosis cases

Characteristics	All		Survey cases		NTP cases		P value
	N(273)	%	n(33)	%	n(240)	%	
Age in years							
15-34	120	43.9	8	24.2	112	46.6	0.028
35-54	87	31.9	12	36.6	75	31.2	
55+	66	25.0	13	39.9	53	22.1	
Sex							
Male	176	64.5	24	72.7	152	63.3	0.290
Female	97	35.5	9	27.7	88	36.7	
Residence							
Rural	140	51.3	20	60.6	120	50.0	0.253
Urban	133	48.7	13	39.4	120	50.0	
Education							
0	71	26.0	15	45.5	55	23.0	0.039
1-5	71	26.0	8	24.2	65	27.1	
6-10	68	24.9	6	18.2	62	25.8	
10+	63	23.1	4	12.1	58	24.2	
Occupation							
Agri based	37	13.6	4	12.1	33	13.8	0.003
Daily wagers	89	22.3	14	42.4	75	31.3	
Sales and services	115	28.2	6	18.2	109	45.4	
Others	32	35.9	9	27.3	23	9.6	
Asset Quartiles							
1st (Lowest)	17	6.2	12	36.4	5	2.0	0.000
2nd	111	40.6	13	39.4	98	41.0	
3rd	113	41.4	5	15.1	108	45.0	
4th	32	11.8	3	9.1	29	12.0	
Presence of cough							
Yes	226	82.8	29	87.8	197	82.1	0.408
No	47	17.2	4	12.2	43	17.9	
Duration of cough							
Less than 14 days	51	18.7	6	18.2	45	18.2	0.937
≥ 15 days	222	81.3	27	81.8	195	81.8	
Number of symptoms							
≤ 2	44	16.1	4	12.1	40	16.7	0.556
3-4	79	29.0	8	24.2	71	29.6	
5+	150	54.9	21	63.7	129	53.8	

Among the 240 cases detected passively under NTP, 118 (49.1%) sought initial care from informal providers, 106 (44.2%) from formal providers, and 16 (6.7%) used self care. All of the 33 actively detected cases reported self care as the initial strategy, totaling this group to 49 (17.9%) of all cases (Fig 1). Out of the 118 passively detected NTP cases with initial care from the informal sector, 52 (44.1%) remained in the informal sector, while 61 (51.7%) switched to a formal provider for care at the second point care. Again, among the 52 who remained in the informal care sector, at the third point of care 32 (61.5%) migrated to formal care sector, while 17 (32.7%) remained in the informal sector. The proportion of patient who remained in the informal care sector up to the fourth point care was five (29.4%) of those stating their health seeking behavior in the informal sector. (Fig 1). Among the 16 (6.7%) of the NTP cases who reported self care as their initial strategy ultimately four (25.0%) remained in this stage up to fourth point of care, three (18.8 %) moved to informal sector and nine (56.2%) migrated to formal care sector subsequently. Among the active detected cases, all of whom had self care as the initial strategy, 27 (81.8%) remained at this stage before being detected by the survey. Among the remaining six, three shifted to the formal sector at the second point of care, while the other three switched between informal and formal providers in the subsequent points of care (Not shown).

We looked into measures taken at each point of care by the formal and informal providers. In the formal care sector, the primary action was to prescribe drugs at each point of care starting with 79 (74.5%) at first point, 43 (70.5%) at the second point, 19 (59.4%) at the third and 10 (91%) at the fourth point of care. Ordering diagnostic investigations varied from 19 (17.9%) at the first point of care, to 14 (22.9%) at the second, 10 (31.2%) at the third, and 1 (9.0%) at the fourth point of care. Referral for further investigation was seldom done (0-2%). The informal providers

on the other hand, prescribed drugs in 80% to 99% of the encounters, and seldom ordered diagnostic investigations or referred the individual for further investigations at any of the four points of care. (Fig 2).

The reasons for not seeking care at all were available only from the 33 survey cases. The major reasons were not considering symptoms serious enough, and monetary constraints.

DISCUSSION

Our study showed that most of the initial care seeking by passively identified TB cases happened at the informal sector or was limited to self care. At each following round of care seeking a third to a half remained in the informal care sector. Among **actively** detected cases, more than 80% remained in the self care sector up to the time of their identification by the survey. Case management in the informal sector was restricted to prescribing any medications, with non existence of any diagnostic investigations or referrals.

Preference for informal providers as initial place of care has been reported from Bangladesh and elsewhere.[3-5,9,12] In chronic conditions where the symptoms onset is slow and insidious like tuberculosis, people usually consult with an informal provider available at hand or consume over the counter drugs. This behavior can cause a marked delay to starting appropriate TB medication, given the fact that TB medication in line with the NP guideline is seldom present in the informal health sector. This has been observed in earlier studies from Bangladesh.[4] Our study adds the important finding that this preference of the informal sector persists throughout the care seeking trajectory. The lack of (referral for) diagnostic investigation can cause additional systems delay (between care seeking and starting appropriate treatment). An earlier study reported that this type of delay could be more than ten weeks.[4] Delay to reach appropriate care and treatment impacts on the course of the disease and may result in unfavorable outcomes and ongoing transmission.[22] From a programmatic point of view, this situation leads to a marked under reporting of TB cases.

Care seeking from the informal sector is not limited to TB only, but rather a common feature for all chronic conditions in Bangladesh.[15,23] It is suggested that the presence of huge numbers of

informal providers in both rural and urban areas, their easy accessibility due to reduced cost, and minimal levels of stigma when attending such providers, encourage people to seek care from this sector first.[15,23,24] A good portion of them are simple drug sellers providing drugs without further diagnostic procedures.[12] **This easy access to informal providers stimulates "shopping for care", when care is sought form informal providers subsequently one after one, as observed in our study.** In Malawi, care seeking among TB patients noted that multiple contactcs in range of 1-15 were made before the dagnosis.[25] Similarly in vietnam patients made on average 1.3 contacts and 2.5 visit per providers before getting appropriate TB serivecs, even though the size private sector was very small.[26]

We observed that the case management was not altogether different in the formal and informal sector with respect to prescribing drugs. However, unlike in the formal sector, there was almost a complete absence of diagnostic procedures and referrals in the informal sector. We need to carefully interpret these findings as we don't have information what drugs were prescribed by the providers. Retrospective recording of actual drugs through patient interviews is difficult and in most case unreliable. In Bangladesh, Fixed Dose Combination (FDC) anti TB drugs are almost exclusively available at DOTS centres. This implies that medication provided through the informal sector is unlikely to be adequate for the management of TB. But formal providers can manage TB cases outside the context of DOTS centers. As such mismanagement of TB can also occur in the formal sector, given the low occurrence of diagnostic investigations.

A study in Malawi provided insight in the type of mediation provided to individuals with TB symptoms but without a formal diagnosis. The authors reported that 61% of cases had been treated with atibiotics like co-trimoxazole, doxycycline, and penicillin.[25]

NTP also recognizes the absence of standard practices in the private sector and the lack of sufficient interaction and formal linkages between NTP and these private sector providers.

The lessons learnt from studies aimed at establishing connections between formal and informal health care providers remain unexplored.[13,27] Our study indicates that despite the country coverage by DOTS, and public-private-partnership activities undertaken by the NTP, the impact did not result in reducing the disconnect between NTP and the informal health sector. In a recent attempt to improve the situation, NTP in partnership with icddr,b and United States Agency for International Development (USAID) is implementing a "Translating research into action (TRAction)" project to test different implementation strategies, with a clear role for the informal providers. This current study suggests that attempt is timely and needed.

One of the potential limitations of the study is the potential for minor selection bias. Although all participants were randomly selected, the selection of clusters was not stratified by urban/rural setting. The study sample therefore does not fully represent the 70% of the rural population in Bangladesh. There was also a slight overrepresentation of males. However the national case notification is more or less static at 3:1 male to female since the inception of DOTS in 1993.[1] The strengths of the study are that the cases were interviewed at home by trained research coordinators providing an enabling study setting. We explored the care seeking of both actively and passively detected cases which would cover care seeking from a wider perspective of two different kinds of cases, one who is probably in the early phase of the disease process and the other probably in a more advanced condition. Moreover we have covered the care seeking up to fourth point of care, which is expected to give a more comprehensive picture of the care seeking by the TB cases in Bangladesh.

In conclusions it can be said that most of the initial care seeking by different types of TB cases was sought **from** informal providers or was limited to self care, and that a large proportion of these cases remained in the informal sector during subsequent care seeking. It is imperative that the NTP should immediately take initiatives to engage all types of care providers, particularly the informal providers. It is also necessary to strengthen the ongoing advocacy communication and social mobilization (ACSM) activities to increase awareness on key TB symptoms, availability of diagnosis and free treatment in an attempt to stimulate appropriate care seeking, and to prevent unnecessary delay in TB case management.

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Contributors Shahed Hossain was responsible for conception and design of the study, analysis and interpretation of data and writing the manuscript. Martien Borgdorff, Frank van Leth and K Zaman participated in the conception and design of the study, analysis and interpretation of data as well as revising the draft. Abdul Quaiyum, Sayera Banu, Ashaque Husain and Akramul Islam participated in the analysis and interpretation of data and substantially revising the paper.

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Competing interest: None

Ethics approval This study was approved through an Institutional Review Board of icddr,b (IRB, FWA-00001468) which is internationally accorded and participated by members from international and national experts. Verbal and written consent was obtained in all cases after informed appraisal.

Data sharing statement Additional data from this survey are being analyzed and will be published in future

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Fig 1: Care seeking at different points of care

Fig 2: Actions taken if care sought from formal and informal providers

Fig 1: Care seeking at different points of care

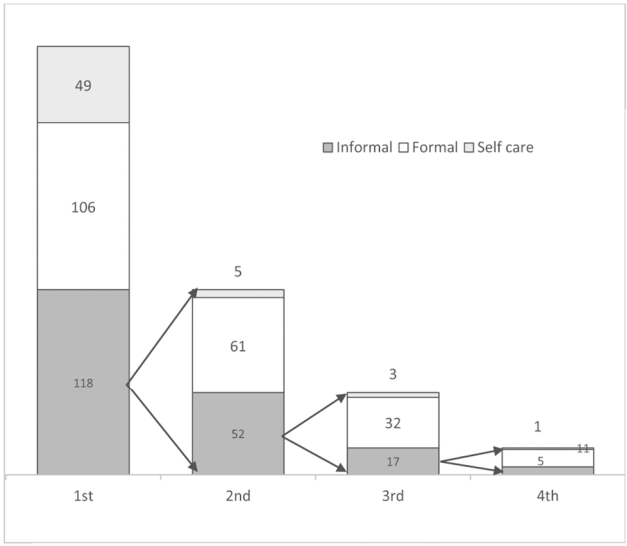

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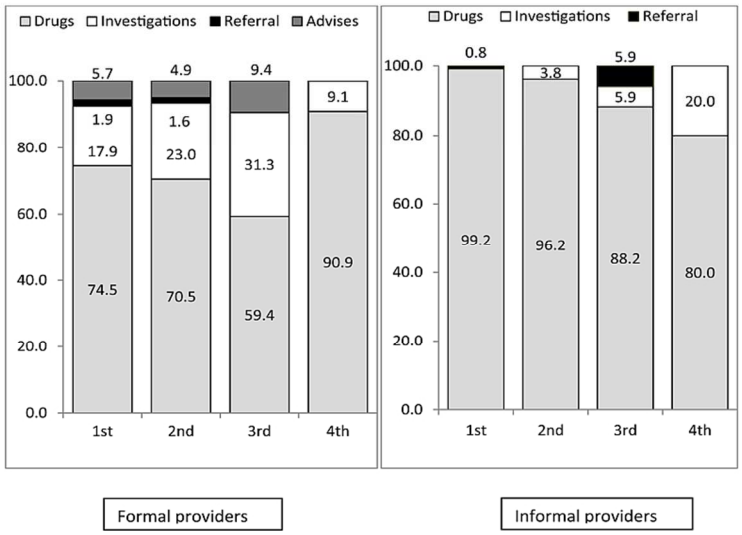
Fig 2: Actions taken if care sought from formal and informal providers



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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Study's design is mentioned in the title and abstract
		(*b*) Precise and concise information on study methods and findings given in the abstract
Introduction		
Background/rationale	2	Comprehensive background and rationale provided
Objectives	3	Specific objectives described
Methods		
Study design	4	Specific design adopted with relevant references are given
Setting	5	The setting is adequately described with all relevant information and references. One relevant document is uploaded.
Participants	6	(*a*) *Cross-sectional study*—Sources and methods of data collection are given as separate paragraphs.
Variables	7	All the variables are defined and adequate explanation given.
Data sources/ measurement	8*	A separate paragraph on measurement described details on methods of assessment.
Bias	9	Described in discussion and limitation section
Study size	10	Explained
Quantitative variables	11	A details description on statistical analysis is given
Statistical methods	12	(*a*) All statistical methods described
		(*b*) Described examination of subgroups
		(*c*) No possible missing data anticipated
		(*d*) *Cross-sectional study*—Not much impact for sampling was anticipated, so separate analytical approach to account for sampling strategy needed
		(*e*) There is no sensitivity analyses
Results		
Participants	13*	(a) All participants were eligible, no refusal, no missing data reported
		(b) Not applicable
		(c) Not necessary
Descriptive data	14*	(a) General characteristics of study participants given in Table 1
		(b) No such data
		(c) N/A
Outcome data	15*	
		Cross-sectional study—Summary measures reported
Main results	16	(*a*) The main analysis did not include any confounding estimates
		(*b*) Applicable description of variables given
		(*c*) No relevant
Other analyses	17	Report other analyses done—Graphical presentation given

Discussion		
Key results	18	Summarise key results given
Limitations	19	Discuss limitations of the study: Discussed
Interpretation	20	Possible and cautious interpretation of overall results given
Generalisability	21	Discuss the generalisability (external validity) of the study results: Discussed
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based: Given

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.