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Public Health

journal homepage: www.elsevier.com/puhe

Original Research

Underascertainment, underreporting, representativeness and timeliness of the Iranian communicable disease surveillance system for tuberculosis

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ARTICLE INFO

Article history:
Received 20 July 2018
Received in revised form
4 March 2019
Accepted 14 March 2019
Available online 14 May 2019

Keywords:
Surveillance system
Tuberculosis
Timeliness

ABSTRACT

Objectives: A well-functioning disease surveillance system is essential for effective control of diseases. Therefore, conducting evaluation studies on the performance of disease surveillance systems is necessary. This study was conducted to evaluate the performance of the Iranian syndrome-based surveillance system for tuberculosis (TB) in rural areas of Fars, the third largest province located in southern Iran.

Study design: This was an evaluation study.

Methods: Two independent sources of information (data from a population-based survey and data from the surveillance system) were used in this evaluation. A group of trained female nurses used a specially designed interview-administered questionnaire to obtain data on the health status of family members from mothers or other adult women in rural houses. Subsequently, the nurses obtained data from individuals who reported a history of TB during a specified period and defined whether the patients presented themselves to a rural or urban health centre or clinic.

Results: A total of 48,771 individuals participated in this study. Of 156 cases who reported a history of TB, 137 (87.82%) presented themselves to at least one medical care provider seeking diagnosis and treatment services. Of patients who visited a health or medical centre, only 18 (13.14%) were reported to the highest level of the surveillance system. Accordingly, the rates of underascertainment and underreporting of the Iranian surveillance system for TB were 12.18% and 86.86%, respectively. Moreover, underascertainment was significantly higher for men (19.40%) than for women (6.74%). The mean time between the date at which TB was noticed and the date of diagnosis was 56.24 days, which was longer for men (79.29 days) than for women (40.10 days). The highest and lowest levels of underreporting were observed for private general practitioners (100%) and the health centres run by the government (87%), respectively.

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https://doi.org/10.1016/j.puhe.2019.03.008

Conclusion: The quality of the communicable disease surveillance system for TB in Iran is facing important challenges, including underascertainment, underreporting and timeliness, in addition to different types of bias. Informing the general population and health workforce about TB and the importance of timely diagnosis is a good approach to improve the performance of Iran's national communicable disease surveillance system.

Introduction

Tuberculosis (TB) is one of the oldest known diseases of both humans and animals. Despite all efforts, TB remains a major global health issue.[1] As a result of this, the United Nations (UN) has included controlling the TB epidemic in their Sustainable Development Goals for 2030.[2] In 2014, the Word Health Organization (WHO) approved the 'End TB' Strategy, aiming for a 90% reduction in deaths due to TB and an 80% reduction in new cases of TB by 2030, compared with 2015.[3] According to the global tuberculosis report (GTR) published by the WHO in 2016, there were about 10.4 million TB cases in 2015, which included 1.0 million (10%) children.[4] These estimates are based on data from several individual studies and many national surveillance systems. The other important aspect of TB is that a much more complicated situation can arise (with regards to the prognosis and transmission of the infection) when a patient is coinfected with HIV.[5] Worryingly, it is estimated that about 1.2 million (11%) of all new TB cases in 2015 were also infected with HIV.[5] According to the estimates provided by the GTR, in 2015, about 13,000 (95% confidence interval [CI] = 9800–16,000) new cases of TB occurred in Iran, of which 350 (95% CI = 250–460) were also infected with HIV. Noticeably, these estimates were based on the results of a national survey in 2014 and not the statistics provided by the Iranian communicable diseases surveillance system (CDSS) working under the Iranian Ministry of Health.[4] According to the 'End TB' Strategy, availability of reliable data from a surveillance system is essential in achieving the TB-related goals. As a result, to implement an effective control measure, a well-performing surveillance system is necessary.

It is believed that in any effective surveillance system, the presence of several features, including complete and representative detection and reporting cases to the CDSS within a reasonably short period, is crucial.[6] As a result, the quality of any surveillance system is defined by several main indices, including sensitivity, underreporting, underascertainment, representativeness and timeliness of the reporting procedures.[7] Sensitivity of a disease surveillance system in a specific population is defined as the proportion of cases of a disease (or other health-related event) that are detected by the surveillance system.[8] Timeliness of a disease surveillance system is defined as the mean time elapsing between a disease occurrence and report of the disease to a specific level of the surveillance system.[7]

Studies conducted on the quality of Iranian diseases surveillance systems revealed considerable differences in the performance of the surveillance systems for different diseases.[9–12] In this regard, evaluation of the performance of the Iranian TB surveillance system is necessary.[8] According to the Centre for Communicable Diseases Control (CDC), which is under the Iranian Ministry of Health, all cases of TB should be referred immediately to the county's health centre for final diagnosis and subsequently reported to the highest level of CDSS via a Web-based reporting system. Thus, any patient with suspected TB who visits a health or medical centre is referred to the county's health centre to undergo well-defined TB diagnostic procedures. The county health centre should then report the cases (irrespective of the final diagnosis) to the provincial health centre via a phone call and also via a specially designed form. The provincial health centre receives data from different sources and sends the data to the ministerial CDC office via a Web-based reporting system. More details of the CDSS procedures for data collection and reporting are explained elsewhere.[11,13] The aforementioned procedures are universally applied in all provinces in Iran.

This study was conducted to evaluate the performance of the Iranian CDSS for TB in rural areas of the Fars province. Fars is located in the south of the country and is the third largest province in Iran, with a population of 4,850,000, of whom 1,430,000 (316,079 families) are rural residents.

Methods

This population-based evaluation study was conducted on 7500 randomly selected families (48,771 participants) in the Fars province to measure the four main indices of performance of the Iranian CDSS for TB (i.e., underascertainment, underreporting, representativeness and timeliness). More information about settings and methods is provided in a recently published study.[13] In addition, the methods, instruments, and validity and reliability of the questionnaires and the self-reported data were evaluated in a pilot study.[11] Briefly, approximately one year before the current research, a pilot study was conducted with a relatively large sample size to evaluate the questionnaires, study procedures and required sample size. It should be noted that owing to the time dependency of TB and lag in time between the pilot and main study, the results of the pilot and present study were considered incomparable. As a result, the data from the pilot study were not included in the analysis of the present study and, similar to the other counties in the province, the rural population of Marvdasht (the county in which the pilot study was conducted) was resampled for the present study.

Setting

In this study, the rural population of Fars was selected as the source population. Information about the incidence of TB in the rural population of the county was gathered (independently to the CDSS) via conducting population-based probability sampling based on a population registry database available at the deputy of heath office in Shiraz University of Medical Sciences, Shiraz, Iran. Door-to-door interviews were conducted using an interview-administered questionnaire. Sample size was determined based on the results of the pilot study. Clinical data of patients with TB who reported a visit to any rural health centre or urban clinic were obtained, and only those patients with a confirmed visit to a centre were included in the analysis for underreporting. No independent source of data was available for those who did not seek medical services. As a result, underascertainment was merely based on self-reporting information. Data were also obtained from the CDSS database, which provided information on the cases that had been officially reported.

Definitions

Different terminologies are provided for the indices of a disease surveillance system.[7,8,14] The terms and definitions that are used throughout this article are as follows: (1) as one of the main indicators of sensitivity, underascertainment is calculated as the proportion of TB cases who, despite having the defined syndrome, did not visit any healthcare/medical care provider; (2) underreporting is the other important index for sensitivity, which is calculated as the proportion of TB cases who visited at least one health/medical service provider because of the defined syndrome but were not reported to a higher level of the surveillance system[15]; (3) timeliness of the CDSS for TB was defined as the time lag between occurrence of TB and visiting a health service provider and between visiting a health service provider to the date that the case was reported to a TB diagnosis centre and (4) with the assumption of representativeness of the reported cases to the CDSS, a multiplication factor is calculated to be used to obtain a relatively valid estimate of the total symptomatic cases of TB in the population regardless of visiting a health provider.[15]

Case definition

TB was defined based on the latest Iranian Ministry of Health's guidelines for reporting communicable diseases to the CDSS. According to the guidelines, anyone with 'chronic cough (for more than two weeks)' is considered as a probable case of TB and is to be immediately referred to a TB diagnosis centre for final diagnosis.[16] The TB diagnosis centres register cases in the CDSS via a Web-based reporting system, irrespective of the diagnosis test results. The syndromic approach was adapted by the Iranian Ministry of Health because of its excellent practicality, accessibility and feasibility compared with an aetiological approach.

Population-based data collection

An interview-administered questionnaire was used to obtain data on the health status of households. The questions were asked to mothers or other adult women who were permanently living in the house. Accordingly, the mother was asked if she or any of her family members experienced the defined symptoms of TB between April 2014 and March 2015 (a year to the date of interview). If the responder reported that one or more of the household members suffered from the defined symptoms during this period, a second interview would be conducted with the affected member of the family. Information about the TB symptoms, the date of its occurrence, whether the patient sought medical help and, if so, the name and address of the health or medical centre that they attended was obtained from the affected family members. The interviews were carried out by 50 teams, each consisting of two experienced public health nurses, one male and one female. The aims of the study and confidentiality of the patient's information were explained to participants before the interview. A significant number of participants were illiterate. As a result, verbal informed consent was obtained from the responding woman and family members who experienced TB symptoms during the study period.

Health system–based data collection

To obtain data on the patients who presented themselves to a medical centre, the research team gained access to the registration forms of the medical centres that had been visited by the patients. The research team also had access to the electronic database of the CDSS for TB cases. Thus, based on the addresses provided by the patients with TB who presented themselves to at least one (rural or urban) health centre or clinic, the research team visited the named centres and the information was obtained from the registration forms. In addition, registration forms from local, county and province health centres were compared with the CDSS database to find out whether patients who visited a centre were reported to the CDSS. The extracted information included the date at which the patient visited a medical or health centre and the date of reporting the case to the county's TB diagnosis centre. This information provided the time lags and proportion of patients who visited at least one medical centre and proportion of patients who were referred to a specialised TB diagnosis centre.

Results

Of 1,475,350 rural citizens, 48,771 individuals were included in the study sample. Within the sample, 156 individuals reported that they experienced TB during the specified time period. However, among the patients with TB, only 18 were reported to the CDSS (total sensitivity = 11.54%).

Table 1 – Sensitivity of Iranian communicable diseases surveillance system (CDSS) according to different levels of surveillance system for tuberculosis.

No. of detected cases (A)	No. of cases who visited a health service provider (B) [underascertainment = 1-B/A]	Visits to initial health service provider: Total no. of visits	Service provider	No. of visits (% of total visits)	No. of cases reported to county's health centre (C)	Underreporting to the next level [1-C/B×100]	No. of reported cases to county's health centre[a] (E)	No. reported to the CDSS (F)	Underreporting from county to CDSS [1-F/E×100]	Total underreporting to CDSS [1-F/B×100] (MF = A/F)
156	137 [12.18%]	201	Rural health centre/ health houses	100 (49.75%)	13	87%	18	18	0%	86.86% (8.67)
			General practitioner in private sector	17 (8.46%)	0	100%				
			Specialist practitioner in private sector	44 (21.89%)	2	95.45%				
			Hospital	40 (19.90%)	3	92.50%				

CDSS, communicable diseases surveillance system; MF, multiplication factor.
[a] Duplicates excluded.

Underascertainment and underreporting of the CDSS for TB

Of 156 suspected cases of TB who were identified during the door-to-door interviews, 137 cases (87.82%) presented themselves to at least one medical care provider to receive treatment services. Of the patients who visited a health or medical centre, only 18 (13.14%) were referred to a TB diagnosis centre and therefore reported to the CDSS. Accordingly, underascertainment and underreporting of the CDSS for TB among the study population were 12.18% and 86.86%, respectively (Table 1).

Timeliness of the CDSS for TB

As presented in Table 2, the mean time elapsing between the date of onset of TB symptoms and the date of visiting a healthcare provider was 53.83 days. Providing the cases were reported to the diagnosis centres, the mean time elapsing from the first visit to a healthcare facility to the date when the patients took a test at a TB diagnosis centre was 2.41 days.

Representativeness of CDSS for TB

Of those patients who presented themselves to a health service provider, almost half (49.75%) preferred to visit public rural health centres or rural health houses. Sex-specific incidence and proportions of underascertainment and underreporting of study participants are presented in Table 3. Underascertainment was significantly higher among men (19.40%) than among women (6.74%) [$P < 0.017$]. In addition, as can be seen in Table 2, sex-specific elapsing time from the onset of TB symptoms to the first visit to a medical centre suggested a longer delay among men (75.43 days) than among women (38.70 days) [$P < 0.01$]. Similarly, elapsing time between visiting a health centre and taking a diagnostic test was longer (by about twofold) for men (3.86 days) than for women (1.40 days). However, no significant difference was observed between men and women in terms of the incidence of TB or underreporting. The highest level of reporting cases to TB diagnosis centres (or CDSS) was from public rural health centres or health houses, even though only 13% of suspected cases were referred to the diagnosis centres. The lowest rate of case reporting was from general practitioners in the private sector (0%).

Discussion

This study was conducted to evaluate the Iranian CDSS for TB by measuring four important indices of the performance of a surveillance system (i.e., underascertainment, underreporting, representativeness and timeliness) in rural populations of the Fars province. In this study, the following two sources of data, independent to CDSS, were used: (1) data from a population-based survey via door-to-door interviews and (2) data from registration forms, obtained from public and private medical clinics and TB diagnosis centres. In addition, data were also extracted from the CDSS database. The results suggest that a large proportion of patients with TB visited medical care providers seeking diagnosis and

Table 2 – Timeliness by sex of the Iranian communicable diseases surveillance system (CDSS) for tuberculosis.

	Male	Female	Total
Participants (n)	23,381	25,390	48,771
Time in days between the onset of TB symptoms to the first visit to a medical centre [mean (median)] N = 137	75.43 (30)	38.70 (40)	53.83 (37.00)
Time in days between the first visit to a medical centre and diagnostic test [mean (median)] N = 18	3.86 (4)	1.40 (1)	2.41 (2.00)
Total in days elapsing time from the onset to diagnosis [mean (median)] N = 18	79.29 (34)	40.10 (41)	56.24 (39)

TB, tuberculosis.

Table 3 – Rates of incidence and reporting of suspected cases of tuberculosis (TB) by sex in rural areas of the Fars province.

	Male	Female	P-value	Total
Households (n)	23,381	25,390		48,771
TB cases detected (n)	67	89		156
Visited a health centre [n (%)]	54 (80.60)	83 (93.26)	0.017	137 (87.82)
Reported to CDSS [n (%)]	7 (12.96)	11 (13.25)	0.96	18 (13.14)
Age in years [mean (SD)]	41.38 (23.56)	43.74 (17.77)	0.48	42.73 (20.41)
Incidence rate (per 100,000 population)	286.56	350.53	0.21	319.86

CDSS, communicable diseases surveillance system; SD, standard deviation.

treatment services. However, a significant ascertainment bias was observed in the CDSS because, compared with men, more women seek medical care. The patients preferred public rural health centres and specialists practicing in private sectors or hospitals for seeking medical care. The results also suggest that a very small proportion of patients were reported to the CDSS by clinics and health centres, irrespective of patient gender. As a result, only a small fraction of all patients with TB were reported to the CDSS. The highest rate of reporting symptomatic TB cases to diagnosis centres and the CDSS was from public rural health centres and health houses. According to the results of this study, the overall sensitivity of the Iranian CDSS is low (13.14% of syndromic cases who visited a health provider) when compared with that of developed countries such as Finland (93% for confirmed cases) and Italy (79.1% for physicians notification system).[17,18]

With regards to the timeliness of the CDSS, the results suggest that patients with TB waited about 56 days (mostly self-medicating with herbal medicines, home-stored medicines or non-prescription medicines from pharmacies) before seeking medical help.[19] However, the estimated elapsing time from occurrence to diagnosis of TB is shorter than that in many developed (e.g., Japan and USA) and developing countries (mean=72 days for developed and developing countries).[20] Also, the elapsing time from visiting the first centre to the time of diagnostic test was noticeably shorter for Iranian patients (2.41 days) than the corresponding elapsing time for many other countries.[20] It seems that the main problem of elapsing time for reporting TB cases in Iran is the delay among patients in seeking medical services. The issue is more serious among men because they have not only a higher degree of underascertainment but also a longer elapsing time before visiting a medical centre. It is possibly because, compared with women, men are less likely to seek medical services, and they do it with a longer delay. A study reported that men also have poorer adherence to treatment.[21]

Another, even more serious, problem with the Iranian CDSS is that a very large portion of patients who visited a medical centre were not referred to the TB diagnosis centres. Comparing the results of the present study with the WHO GTR (2015)[22] reveals a major discrepancy. According to the present study, the public and private service providers in Iran make no or very little contribution to the surveillance of TB. However, according to the WHO's report, the contribution of Iranian private sectors to reporting TB was 29% of notified cases. A possible reason for this noticeable discrepancy is that the present study was based on a population-based survey among rural residents. In this approach, an individual was considered notifiable if he/she was suffering from TB as defined by the CDSS, whereas the WHO's report was based on data from health sectors in both rural and urban populations. Moreover, the WHO considered a patient as a TB case only when it was microbiologically confirmed.[4] The results of the present study also suggested that the contributions of the private and public sectors to the surveillance of TB are significantly different, and therefore, the representativeness of the reported cases of TB to the CDSS is seriously under question.

With regards to the status of the four indices of the Iranian CDSS for TB, a comparison of the results of the present study with a previously published report of zoonotic diseases[13] suggests that underascertainment was much higher for TB than for brucellosis (0.00%). Also, underreporting of TB is much higher than for leishmaniasis (42.50%) and brucellosis (41.82%). In addition, the time lag between the onset of TB to the first visit to a health service provider is much longer than that for leishmaniasis (32.66 days) and

brucellosis (34.5 days). This is possibly due to the more worrying and painful symptoms of the zoonotic diseases. For example, in leishmaniasis, a scar on the skin, especially when on the face, makes the patient seek medical help more urgently. In brucellosis, patients experience severe pain and fever, which again make them to seek medical care more quickly. The aforementioned comparisons suggest lack of awareness among the public and healthcare workers about the importance of timely diagnosis and reporting cases of TB (compared with relatively less serious zoonotic diseases with a better prognosis).

In summary, the results of the present study suggest a relatively acceptable timeliness in performing the diagnostic test for those patients who visited health or medical centres, providing they were referred to the diagnosis centres. However, the performance of the CDSS for TB in Iran is facing very important challenges with regards to sensitivity and representativeness of the system because low and disproportionate ascertainment was observed among men and women. Also, public and private sectors reported a very low and disproportionate number of TB cases to the diagnosis centres and CDSS. Accordingly, healthcare workers in both private and public sectors need periodical and well-designed training courses aimed at learning and understanding the definitions and strategies for reporting notifiable diseases to the CDSS. In addition, the study revealed a relatively long delay in seeking medical care after the onset of symptoms among patients. As a result, there is also a need for raising public awareness about TB and the importance of early diagnosis.

Strengths and weaknesses

The present study was conducted in rural areas of a large province in southern Iran (the Fars province). Data were obtained via a population-based survey, which was independent of the CDSS database. However, no attempt was made to confirm the final diagnosis of the disease among the participants. In addition, all indices are calculated based on the presence of symptomatic TB cases in the population. As a result, patients with asymptomatic TB were not included when the performance of the Iranian CDSS was evaluated.

Conclusion

Based on the results of the present study, the performance of the Iranian CDSS for TB is relatively low because the indices show that the system is suffering from many problems, including high underascertainment and underreporting, long diagnosis delay and significant ascertainment and timeliness biases. The performance of the Iranian CDSS must be routinely evaluated, and adequate measures implemented to improve the contribution of both public and private sectors. For example, health personnel, especially physicians, should be periodically trained in the procedures of the surveillance system and the importance of their contribution. In addition, developing and implementing programmes to raise public awareness about the importance of early diagnosis of selected diseases, including TB, will help the Ministry of Health to improve the performance of the CDSS.

Author statements

Acknowledgements

The authors are thankful for the cooperation and support of the managers and staff in private and public sectors of healthcare and medical care providers.

Ethical approval

The study was evaluated and approved by the Shiraz University of Medical Sciences Ethical Committee.

Funding

The present study was financially supported by Shiraz University of Medical Sciences, Shiraz, Iran.

Competing interests

No conflict of interest is declared.

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