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Coordinated care for tuberculosis: data registration and implementation of a computerized system

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Abstract *Objective: to analyze sources of data for tuberculosis (TB) before and after the implementation of the Computerized System to Record Care for TB in Ribeirão Preto - SP. Method: Intervention, descriptive-analytical epidemiological study. Data was collected from secondary sources using a structured form, and analyzed using Chi-squared or Fisher's Exact Test, with a significance level of 5%. Results: We found an association between the period before implementation of the system and placing the Directly Observed Treatment Card in the file, and registration of instructions for the return visit by the nursing team. The latter was associated with an increase in registered data regarding TB patient telephone number, address, end of treatment date, status at closing, sputum smear results for monthly control, HIV test, monthly checkups, tests ordered by physician, social worker visits, patient living conditions, contact control, social incentives and the use of drugs and alcohol. Conclusion: Implementing the system improved the registration of a number of variables, despite the fact that other sources of data other than the system continue to exist.*

Key words *Health information systems, Assessment of tuberculosis healthcare systems*

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Introduction

Tuberculosis (TB) is a chronic condition, requiring an integrated healthcare system that focuses on health maintenance and promotion, and is able to provide a measure of constant care for suitable handling[1]. In order to provide these, among other requirements are the use of information technology to improve data registration regarding patients and service providers, and the elimination of barriers that make it harder for data to flow within the healthcare system[2].

Regarding measures to control TB, professionals must complete forms that go from searching for cases to end of treatment. These include the clinical patient file and other forms required by the Ministry of Health, with data essential to plan, follow-up and assess disease control[3]. However, this multiplicity of forms can lead to data duplication or failure to record data, and vulnerabilities in using this data to subsidize decisions that must be made on a daily basis as part of routine healthcare[4].

It is important to point out that the problems mentioned are further accentuated when these tools are available only in paper format, which makes it harder to find and share data across the various categories of healthcare professionals and services[1,5,6], hampering horizontal (the members of the same team) and vertical (between different Healthcare Services) coordination of care.

Coordination requires the ability to ensure continued patient care by a healthcare team that is aware of a problem that is chronic and requires constant monitoring, as well as articulation between different types and levels of care[7,8]. To this end, coordination assumes data sharing, either through formal or informal mechanisms to share use data across the different healthcare services, and the recognition and use of this data to guide clinical decisions required to provide patient care[9].

In 2012, the SISTB (TB Support Information System) was created, a joint effort with the University of São Paulo in Ribeirão Preto GEOTB (Operational Epidemiology in TB Study Group), and LIS (Health Intelligence Lab), the coordinator of the TBCP (Tuberculosis Control Program), in response to gaps in the data available in the different tools, the fact that data was not centered in healthcare professionals, with care often split across the various health services.

The aim of the system was to improve the quality of the records, decentralize data from a local healthcare service into a single source of data, articulate the different levels (service -vigilance- coordination) in real time, with each one having access to the system, thus facilitating the process of data collection and information flows.

This study analyzed the data records in coordinated TB care before and after implementation of the new computerized system (SISTB) in the city of Ribeirão Preto, SP to verify the support provided from a technological innovation for monitoring, vigilance and control of TB.

Material and Methods

This is an interventionist, descriptive-analytical epidemiological study carried out in a TB Control Program (TBCP) in the city of Ribeirão Preto, covering an area with one of the highest incidences of TB in the city. In 2013, 38 new cases of TB were reported in this TBCP, with a cure rate of 78.9%, abandonment rate of 2.6%, death rate of 5.3%, change in diagnostic of 7.9% and transfer of treatment to another city or state of 2.6%. The Directly Observed Treatment (DOT) coverage rate was 78.9% and TB/HIV coinfection 13.1%[10].

Disease treatment and control actions in this TBCP were centralized in two nursing assistants working 30 hours a week, responsible for nursing care within the TB, HIV/AIDS and STD programs. DOT was performed daily in the homes of about 25 TB patients. Furthermore, these nurses were responsible for controlling notifying parties and entering the data in the information systems. The team also had two infectious disease specialists to care for patients in the TB and other Programs, each one working 20 hours a week.

This study was carried out in three steps:

- 2013: SISTB implemented in the TBCP, including training two nursing assistants, focusing on making the tool operational and its impact on the working process. Technical support offered in the form of two researchers, one a biomedical IT professional and the other a nurse. In this step the system was improved by finding and correcting errors.

It is important to point out that this system is an app used to monitor all cases of TB. The variables were defined in meetings with the local health team and city and state TBCP coordinators, based on the Individual Notification Card, DOT Follow-up File (yellow) and Monthly Progress Bulletin issued by TBWEB, a notification system specific for the state of São Paulo. In this way we were able to record TB patient id data,

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along with information about diagnostic, treatment, notifying parties, monthly sputum test, and hospitalization and medication supervision.

Two versions of the SISTB were developed: one for desktops (online) and one for mobile devices (offline), that can communicate by synchronizing data in real time, ensuring the quality of the information. The desktop version can be accessed online by healthcare professionals and managers, allowing them to monitor treatment and assess the quality of the care provided, with an overview of the actions developed by the TBCP for TB control. The mobile version was designed to run on Android© devices, allowing professionals to use system functionalities during home visits and control medication use.

It is worth pointing out that the system also issues indicators, reports, tables and charts to support decisions made by management and day-to-day service routines.

- March - June 2014: secondary data collected from Clinical Files, yellow files and the green book. In this step, data for 2012 was collected as a reference for the period prior to SISTB implementation.

- April 2015: secondary data gathered from the Clinical Files, green book and SISTB for 2014 was used as a reference of data gathered after SISTB implementation.

The study population were TB patients who started and completed treatment in 2012 (prior to SISTB implementation), and in 2014 (after SISTB implementation). Inclusion criteria were: patients living in Ribeirão Preto, and followed by the TBCP in the selected district. Prisoners were excluded from the study. We also excluded patients with a status at closing of change in diagnostic, and those transferred for treatment to another location. Thus the study population consisted of 22 TB patients for the pre-implementation stage, and 16 for the post implementation stage.

Data was gathered using a structured form prepared based on the Manual of Recommendations for Tuberculosis Control[11], which has 27 items in three sections, depending on the data source, as shown in Chart 1.

All of the data gathered was digitized, stored and analyzed using Statsoft Statistica 9.0, using a frequency distribution and Chi-Squared or Fisher's Exact test with a significance level of 5%.

This study was approved by the Research Ethics Committee of the University of São Paulo in Ribeirão Preto School of Nursing.

Results

Data in the SISTB DOT Records shows a statistically significant ($p<0.05$) association between the period prior to implementing the SISTB system and entering the DOT card in the clinical file. In the period following SISTB implementation, we found a statistically significant association ($p < 0.05$) with TB patient telephone and address data (Table 1).

Data in the Tuberculosis Case Treatment and Monitoring Book shows an association ($p < 0.05$) between the period following SISTB and an increase in the end of treatment data recorded, status at closing, monthly sputum test and HIV test (Table 2).

Clinical Files show a statistically significant association ($p < 0.05$), in the period following SISTB implementation, with a larger number of monthly physician visits and tests ordered, more social worker visits, and records of TB patient living conditions, drug and alcohol use, notifying party control and social incentives offered. There a statistically significant association ($p < 0.05$) between the period prior to SISB implementation and records with instructions for return visits made by the nursing team (Table 3).

Discussion

The innovative SISTB tool improved the registration of a wide range of data, including TB patient contact information and data related to case follow-up and closure. A number of hypotheses have been raised to explain this improvement, such as the training provided with the implementation of Healthcare Services, the inclusion of healthcare professionals in developing the system, and grouping three registration tools into a single data source, making the entire process easier to work.

The increase in data registration following SISTB implementation is extremely important, as it helps monitor and follow case progress from notification through closure.

Cecílio[6] argues that records and data use contribute and favor horizontal (between team members) and vertical (between different Healthcare Services) coordination of care, to the extent that in order to provide for user demands and needs, activities are split across professionals and services, which carries the risk of fragmented care.

Chart 1. Sources of the data and variables used for this study.

Sections	Variables
I - Data from the DOT follow-up file (yellow file) and the computerized SISTB system.	Records of DOTs performed The existence of the DOT card in the clinical file TB patient notifying party control data Contact data (address and telephone) for TB patients Location where the majority of the medication supervision was performed
II - Information in the TB patient registration and follow-up book (Green book).	TB patient i.d. records TB patient clinical information records Test results records (sputum test, X-Ray, HIV), including monthly control tests Status at closure records
III - Clinical File Data	Monthly physician, nurse and social worker visits Instructions given and procedures performed by the physician and nursing team Records of other Healthcare Services used by the TB patient Records of DOTs performed TB patient living conditions TB patient tests during treatment Records of notifying parties Social incentives offered to the TB patient Use of drugs and alcohol by the TB patient

Table 1. Distribution of the data found in the DOT cards and in the SISTB before and after system implementation. Ribeirão Preto, 2014 and 2015.

Variables		Before System Implementation* (n = 23)		After System Implementation (n = 16)		p***
		Yes N (%)	No N (%)	Yes N (%)	No N (%)	
Card stored in file		23 (100)	0	0	16 (100)	**0.000**
TB patient telephone contact		0	23 (100)	8 (50)	8 (50)	**0.000**
TB patient address		17 (73.9)	6 (26.1)	16 (100)	0	**0.031**
DOT		17 (73.9)	6 (26.1)	13 (81.3)	3 (18.7)	0.447
Medicinal supervision location	Home	16 (69.6)	7 (30.4)	13 (81.3)	3 (18.7)	0,331
	Healthcare Service	1 (4.3)	22 (95.7)	0	16 (100)	0,590
Information on notifying party		0	23 (100)	2 (12.5)	14 (87.5)	0.162

*Data collected in the DOT card. Once the SISTB was in place, this card was generated by the system. ** Data collected by the SISTB system. ***Fisher's Exact Test.

Mendes[8] argues that this division of activities and their coordination characterize a Mintzberg[12] model, which proposes a set of fie mechanisms to achieve coordinated care, among them communication, which the information system facilitates. Thus, this study found that the information system helped increase the records of measures that go beyond the merely clinical focus on the disease, with a social and family approach, by controlling notifying parties, offering social incentives, awareness of TB patient living conditions, and their use of drug and alcohol.

Such an approach can make it easier to foster care focused on TB patient needs, as it helps identify the vulnerabilities of the population served. These vulnerabilities should be viewed as challenges by Healthcare Services, and an incentive to adopt strategies to address them, either by reorganizing resources and healthcare itself, or by providing education and multi-professional care[13].

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Table 2. Distribution of the data in the TB Case Registration and Follow-up Book before and after SISTB implementation. Ribeirão Preto, 2014 and 2015.

Variables		Before SISTB implementation (n = 23)		After SISTB implementation (n = 16)		p
		Yes (%)	No (%)	Yes (%)	No (%)	
TB patient data	Name	23 (100)	0	16 (100)	0	
	Age	23 (100)	0	16 (100)	0	
	Gender	23 (100)	0	16 (100)	0	
	File number	23 (100)	0	16 (100)	0	
	SINAN number	0	23 (100)	0	16 (100)	
TB patient clinical information	Clinical Form	22 (95.7)	1 (4.3)	16 (100)	0	0.590**
	Type of Entry	23 (100)	0	16 (100)	0	
	Treatment start date	23 (100)	0	16 (100)	0	
	Treatment end date	7 (30.4)	16 (69.6)	13 (81.3)	3 (18.7)	**0.001***
	Status at closing	7 (30.4)	16 (69.6)	14 (87.5)	2 (12.5)	**0.000***
Results of the sputum test for diagnostic purposes		19 (82.6)	4 (17.4)	15 (93.7)	1 (6.3)	0.304**
Results of the sputum test for monthly control purposes		0	23 (100)	6 (37.5)	10 (62.5)	**0.002****
Results of the X-Ray		23 (100)	0	16 (100)	0	
Results of the HIV test		17 (73.9)	6 (26.1)	16 (100)	0	**0.031****

* Chi-squared test. **Fisher's Exact Test.

Implementing SISTB reduced the amount of data stored on the DOT card kept with the TB patient's clinical file. This is because healthcare professionals do not always print the card and place it in the file following treatment, but normally check the data directly in the SISTB system.

Regarding the activities of medical professionals, we found clinical progress notes and prescription data, however only few entries regarding instructions (except those regarding return visits) and referrals. Since all TB patients are seen by the nursing staff following physician visits, we believe that instructions regarding disease and treatment are being provided at that time. Regarding referrals, we presume TB patient needs are not being suitably identified, as severity is made more complex by poor living conditions, the use of drug and alcohols, and co-infection with immunosuppressive diseases such as HIV/AIDS or diabetes mellitus, among others.

Considering that no service has all of the resources and competences required to address and solve the problems of the population[8,14] and provide suitable care, it is essential that care be coordinated, articulating the different professionals and levels of care to provide global and continuous service, sharing responsibilities and assignments, and communicating via an agile and flexible information system[2,14-17].

Thus, coordinated care requires reference and counter-reference flows to access users in the different Healthcare Services (administrative coordination). It also requires that professionals follow users when they are referred to other services (coordinated care management), and transfer data to ensure continuity of care (coordinated information)[6,9].

This study also found that although the nursing team performs a number of TB follow-up and control measures, it only enters incidents and data before (date and weight) and after the physician visit in the clinical files. The absence of formal record entering by the nursing staff could compromise continuity of care, communication within the team, lead to duplicate procedures and difficulty monitoring the care provided. It is also an obstacle in analyzing the care provided, the conduct adopted, and the integration between vigilance, healthcare and information, as the professional becomes the normal source of care and not the record[13,18].

Although it is important to consider that the limited number of nurses available for the various programs of the Healthcare Services makes

Table 3. Distribution of the data in the TB patient clinical files before and after SISTB implementation. Ribeirão Preto, 2014 and 2015.

Variables		Before SISTB implementation (n = 23)		After SISTB implementation (n = 16)		p
		Yes (%)	No (%)	Yes (%)	No (%)	
Monthly physician visits (5 or more)		8 (34.8)	15 (65.2)	11 (68.7)	5 (31.3)	**0.037***
Monthly visits to the nurse		4 (17.4)	19 (82.6)	4 (25)	12 (75)	0.425**
Social worker visits		2 (8.7)	21 (91.3)	15 (93.7)	1 (6.3)	**0.000***
Physician instructions	General instructions***	1 (4.4)	22 (95.6)	2 (12.5)	14 (87.5)	0.363**
	Tests performed	4 (17.4)	19 (82.6)	0	16 (100)	0.108**
	Return visits	20 (87)	3 (13)	14 (87.5)	2 (12.5)	0.674**
Procedures performed by the physician	Clinical progress	20 (87)	3 (13)	15 (93.7)	1 (6.3)	0.452**
	Prescription	19 (82.6)	4 (17.4)	16 (100)	0	0.108**
	Referrals	4 (17.4)	19 (82.6)	0	16 (100)	0.108**
	Tests ordered	4 (17.4)	19 (82.6)	15 (93.7)	1 (6.3)	**0.000***
Instructions performed by the nursing team	General instructions***	5 (21.7)	18 (78.3)	1 (6.3)	15 (93.7)	0.196**
	Tests performed	5 (21.7)	18 (78.3)	0	16 (100)	0.058**
	Return visits	11 (47.8)	12 (52.2)	1 (6.3)	15 (93.7)	**0.005****
Procedures performed by nursing team	Nursing care	8 (34.8)	15 (65.2)	3 (18.7)	13 (81.3)	0.234**
	Other***	1 (4.4)	22 (95.6)	4 (25)	12 (75)	0.803**
Use by other Healthcare Services to follow other comorbidities, perform tests, etc.		4 (17.4)	19 (82.6)	2 (12.5)	14 (87.5)	0.522**
DOT performed		4 (17.4)	19 (82.6)	5 (31.3)	11 (68.7)	0.265**
TB patient test conditions		1 (4.4)	22 (95.6)	13 (81.3)	3 (18.7)	**0.000***
Tests performed during treatment	Sputum test	20 (87)	3 (13)	13 (81.3)	3 (8.7)	0.478**
	X-Ray	23 (100)	0	13 (81.3)	3 (8.7)	0.061**
	HIV test	21 (91.3)	2 (8.7)	8 (50)	8 (50)	**0.006****
Notifying parties		8 (34.8)	15 (65.2)	11 (68.7)	5 (31.3)	**0.037***
Social Incentives - Basic Basket of Food Items		2 (8.7)	21 (91.3)	15 (93.7)	1 (6.3)	**0.000***
Drug and alcohol use		2 (8.7)	21 (91.3)	9 (56.3)	7 (43.7)	**0.002****

* Chi-squared test. **Fisher's Exact Test. ***General instructions include instructions related to the disease, treatments and side effects, interactions with other drugs, taking the medication dose, and the importance of adhering to treatment. ****Other includes requests for tests, prescriptions, referrals, and specimen collection by the nursing team.

it harder to plan care, it is essential that they play a role in controlling TB, in terms of the care provided, overseeing the team focused on healthcare practice and vigilance measures, which includes carefully recording the care provided, and managing (individual and collective) care and healthcare services to enable coordination of the various elements involved[19-22]. This overview of the weaknesses of the nursing professionals is a complex process that starts with their training, which is focused on technical development, to the detriment of management skills[19].

Recording TB healthcare actions and vigilance, such as DOT and sputum tests during treatment could help monitor, plan and assess the care provided, especially for disease control[3,23-26].

In performing this study, we found that different sources of data provided to monitor and control TB by the Healthcare Services helps organize and coordinate care. However, we question

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the quality of these records and the communication between them, both essential for suitable and timely healthcare assessment, and to facilitate the working process and information flows[13,27,28].

We believe that the development and incorporation of new technologies requires the involvement of the different healthcare players. Thus, some considerations must be made regarding the progress achieved by implementing the SISTB system. These include involvement of the TBCP team in designing the SISTB, direct generation of reports, a monthly compilation of the number of DOT visits, fewer record keeping tools to be filled out, analysis of the care provided by local healthcare professionals and management, identification of unreported TB patients.

As challenges for implementing SISTB we would point out the difficulty changing the behavior of healthcare professionals as regards filling out the forms developed by the service, and adapting the reports and charts created by the SISTB system. Among the limitations of this study are the absence of a physician in the period before SISTB implementation, which may have influenced record-keeping, especially as regards clinical files.

Conclusions

Adding technological innovation, such as Healthcare Services, provides health vigilance support and control by monitoring care, in that it enables sharing information between Healthcare Services, providing continuity and flow. It also centralized the data from the three record-keeping tools, avoiding duplicate entries and facilitating the working process.

This is clear with better records of TB patient phone and address information, the date treatment ended, the status at closure, the results of monthly sputum tests and HIV tests. The system also records monthly physician visits, social worker visits, tests ordered by the physician, TB patient living conditions, notifying party control, social incentives and the use of drugs and also.

We believe that system implementation may have made professionals more aware of the importance of keeping records, as they participated in developing and adapting the system.

We point out the importance of implementing SISTB in other scenarios to understand how it contributes to proper clinical handling and vigilance, heal assessment and planning, and how it supports coordinated information and care management, based on different experiences of organizations within the healthcare system.

Collaboration

NH Orfão helped design the study, interpret the data and draft the article. RLP Andrade helped analyze the data and draft the article. NY Crepaldi, MEF Brunello, AA Monroe and TCS Villa helped design the study and outline the article. A Ruffino-Netto helped design the study and draft the article. All of the authors approved the final version for publication.

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