

DECENTRALIZATION OF ACCESS TO SPECIAL TUBERCULOSIS TREATMENT INFORMATION SYSTEM

DESCENTRALIZAÇÃO DO ACESSO AO SISTEMA DE INFORMAÇÕES DE TRATAMENTOS ESPECIAIS EM TUBERCULOSE

DESCENTRALIZACIÓN DEL ACCESO AL SISTEMA DE INFORMACIÓN DE TRATAMIENTOS ESPECIALES EN TUBERCULOSIS

Daniela Wilhelm¹
Mauricio Vieira Rodrigues²
Priscila Tadei Nakata¹
Sabrina da Cunha Godoy³
Carine Raquel Blatt⁴

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Objectives: discuss the decentralization process of access to the Special Tuberculosis Treatment Information System (SITETB) and to characterize the patients notified and treated. **Method:** quantitative study using data from the SITETB databases, from 2013 to 2016, in the city of Porto Alegre, Rio Grande do Sul, Brazil, carried out in four stages: elaboration of flows, choice of institutions receiving access to the system, training of the teams and monitoring of notifications and case monitoring. **Results:** the Special Tuberculosis Treatment Information System was decentralized to five referral centers in tuberculosis, nine general hospitals and the Central Prison. Most of the notified patients are in the economically active age group, are men and the pulmonary form of tuberculosis is predominant. **Conclusion:** decentralization of information systems can raise challenges that require changes in the management and care relationships involved in this process.

Descriptors: Tuberculosis. Comprehensive Health Care. Decentralization. Health Information Systems.

Objetivos: discutir o processo de descentralização do acesso ao Sistema de Informações de Tratamentos Especiais em Tuberculose (SITETB) e caracterizar os pacientes notificados e tratados. *Método:* estudo quantitativo realizado com dados das bases do SITETB, no período de 2013 a 2016, no município de Porto Alegre, Rio Grande do Sul, Brasil, realizado em quatro etapas: elaboração de fluxos, escolha das instituições contempladas com o acesso ao sistema, capacitação das equipes e monitoramento das notificações e acompanhamento dos casos. *Resultados:* o Sistema de Informações de Tratamentos Especiais em Tuberculose foi descentralizado para cinco centros de referência em

¹ Nurses at Hospital Sanatório Partenon, Rio Grande do Sul State Health Department, Coordination Department of State Hospitals. Porto Alegre, Rio Grande do Sul, Brazil. daniela.wilhelm@yahoo.com.br

² MD at Hospital Sanatório Partenon and in the State Program for Tuberculosis Control, Rio Grande do Sul State Health Department, Coordination Department of State Hospitals. Porto Alegre, Rio Grande do Sul, Brazil.

³ Pharmacist at Hospital Sanatório Partenon, Rio Grande do Sul State Health Department, Coordination Department of State Hospitals. Porto Alegre, Rio Grande do Sul, Brazil. sabrina.godoy@gmail.com

⁴ Adjunct Professor, Universidade Federal de Ciências da Saúde de Porto Alegre. Tutor, Integrated Residency Program in Health – Emphasis on Intensive Care. Professor, Graduate Program in Hepatology. Collaborator in the Graduate Nursing Program, Professional Master's Degree. Universidade Federal de Ciências da Saúde de Porto Alegre. Porto Alegre, Rio Grande do Sul, Brazil. carine.blatt@gmail.com

tuberculose, nove hospitais gerais e para o Presídio Central. A maioria dos pacientes notificados está na faixa etária economicamente ativa, são homens e predomina a forma pulmonar da tuberculose. Conclusão: a descentralização de sistemas de informação pode trazer desafios que exigem modificações nas relações de gestão e assistência envolvidas nesse processo.

Descritores: Tuberculose. Assistência Integral à Saúde. Descentralização. Sistemas de Informação em Saúde.

Objetivos: discutir el proceso de descentralización del acceso al Sistema de Información de Tratamientos Especiales en Tuberculosis (SITETB) y caracterizar pacientes notificados y tratados. Método: estudio cuantitativo, con datos de las bases del SITETB, de 2013 a 2016, en el municipio de Porto Alegre, Rio Grande do Sul, Brasil, en cuatro etapas: elaboración de flujos, elección de las instituciones contempladas con acceso al sistema, capacitación de los equipos y monitoreo de las notificaciones y seguimiento de los casos. Resultados: Sistema de Información de Tratamientos Especiales en Tuberculosis descentralizado para cinco centros de referencia en tuberculosis, nueve hospitales generales y para el Presidio Central. Mayoría de los pacientes notificados en el grupo de edad económicamente activa, hombres y predominio de la forma pulmonar de la tuberculosis. Conclusión: la descentralización de los sistemas de información puede traer desafíos que requieren cambios en las relaciones de gestión y asistencia involucradas en este proceso.

Descriptorios: Tuberculosis. Atención Integral de Salud. Descentralización. Sistemas de Información en Salud.

Introduction

The National Tuberculosis Control Program (PNCT) uses two complementary information systems for the notification and follow-up of patients diagnosed with TB, with the objective of increasing tuberculosis (TB) control in Brazil⁽¹⁾: the National Disease Notification System (SINAN) and, more recently, the Special Tuberculosis Treatment Information System (SITETB). Patients using the basic regimen (BR) for TB treatment should be reported in SINAN and patients who have no indication for using BR, due to adverse reactions, certain comorbidities or resistance to any drug should be reported and monitored in the online system SITETB⁽²⁾.

SITETB is a web tool used in Brazil. It was developed based on the Brazilian experience with the multi-resistant tuberculosis information system (TBMR System) of the Professor Hélio Fraga Reference Center (CRPHF) and the international version of the e-TB Manager system, originating in the Management Sciences for Health (MSH) project, used in ten countries, which helps the professionals involved to monitor TB treatments in real time⁽²⁻³⁾. The SITETB allows the professional to notify, monitor and follow the outcomes of the special cases of the disease. This platform also allows for the notification of cases of non-tuberculous microbacteria (NTM),

especially cases with a differential diagnosis of TB⁽²⁾. This system is a tool to strengthen TB control through real-time integration of case notification and management, drug control and dispensing, and epidemiological surveillance in a single electronic platform.

In 2010, Porto Alegre, the state capital of Rio Grande do Sul (RS), had a population of 1,409,351 people⁽⁴⁾. In 2016, the incidence rates ranged around 80 cases per 100,000 inhabitants⁽⁵⁾. This municipality has also stood out in terms of high rates of TB/HIV coinfection, around 25%⁽⁶⁾. Although the PNCT advocates that primary health care should be the main gateway for TB cases, most diagnoses are still reached in tertiary care⁽⁷⁾. In 2013, 42% of the diagnoses were performed in Emergency Care and Hospitals; in 2014, 45%; and in 2015, 44%⁽⁸⁾.

The management of more severe TB cases or with the need to use different BR schemes is the responsibility of the professionals at the Reference Centers for TB treatment (CRTB), who are knowledgeable on the available therapeutic alternatives⁽⁷⁾. All confirmed TB cases have to be reported to SINAN. Cases that started treatment with BR and need to use some special regimen (SR) should be terminated in SINAN, in the form of “regimen change”, “failure”, “diagnosis

change” or “drug-resistant TB”. After termination in SINAN, TB cases with indication of SR or TBDR will be reported in SITETB. The coordination of Tuberculosis Control Programs (PCTs) in all spheres, laboratories and services responsible for patient care should have access to SITETB, contributing to the epidemiological surveillance of cases requiring SR⁽¹⁻²⁾.

This article aims to discuss the decentralization process of access to the Special Tuberculosis Treatment Information System and to characterize the patients notified and treated.

Method

This is a descriptive and exploratory study with a quantitative and retrospective design, carried out with data from the SITETB databases, from 2013 to 2016.

The study sample was developed by convenience⁽⁹⁾, that is, the researcher was responsible for selecting the sample units was the responsibility of the researcher. The selection criterion was to be a health institution of secondary and/or tertiary complexity for TB within the city of Porto Alegre, Brazil, and attending to and monitoring TB patients with TB in special use. In addition, notification of more than ten TB cases in SINAN annually was considered as a criterion, including the demands for special treatments of TB, NTM and TBDR treatment coming from these sites. Thus, five Reference Centers for Tuberculosis Treatment (CRTBs), nine general hospitals and the central prison of the city were the sample of institutions for the decentralization of access to SITETB.

Regarding the characteristics of the cases reported in the SITETB, the population consisted of all the cases reported in RS, resulting in 1,764 patients, of whom 1,693 were notified and initially attended in health services of Porto Alegre. The final sample consisted of the 735 patients reported and residing in Porto Alegre. Therefore, the inclusion criterion was living and being notified in Porto Alegre. Cases reported in Porto Alegre who did not live in the city were excluded from the process.

The technical team that organized and put the process in practice carried out the decentralization process of access to SITETB in four stages, according to PNCT guidelines. The stages included the preparation of local flows, the choice of institutions to be granted access to the system, the training of the teams and the monitoring of notifications and the follow-up of cases in the system.

Regarding the characteristics of the cases, the variables start year of disease treatment, place of residence, treatment location, age group, sex, clinical form of the disease and type of outcome were collected by means of a request to the Electronic System of the Citizen Information Service, from the portal of the Brazilian government, under protocol 25820.000470 / 2017-05. The SITETB databases were received on February 6, 2017. The patients' identification and personal data were preserved.

A temporal analysis was undertaken, using secondary data in Microsoft Excel spreadsheets, so that statistical calculations could be made. It is important to highlight that the characterization of the cases in this study is not intended to exhaust the theme, as the patients, whether TB, NTM or TBDR, were grouped without distinguishing the type of case.

Ethical aspects were respected in line with Resolution 466/2012⁽¹⁰⁾. The identification of the TB cases is not possible.

Results

Next, the description of the decentralization process of the access to SITETB and the characteristics of the patients notified in this system in Porto Alegre between 2013 and 2016 are presented.

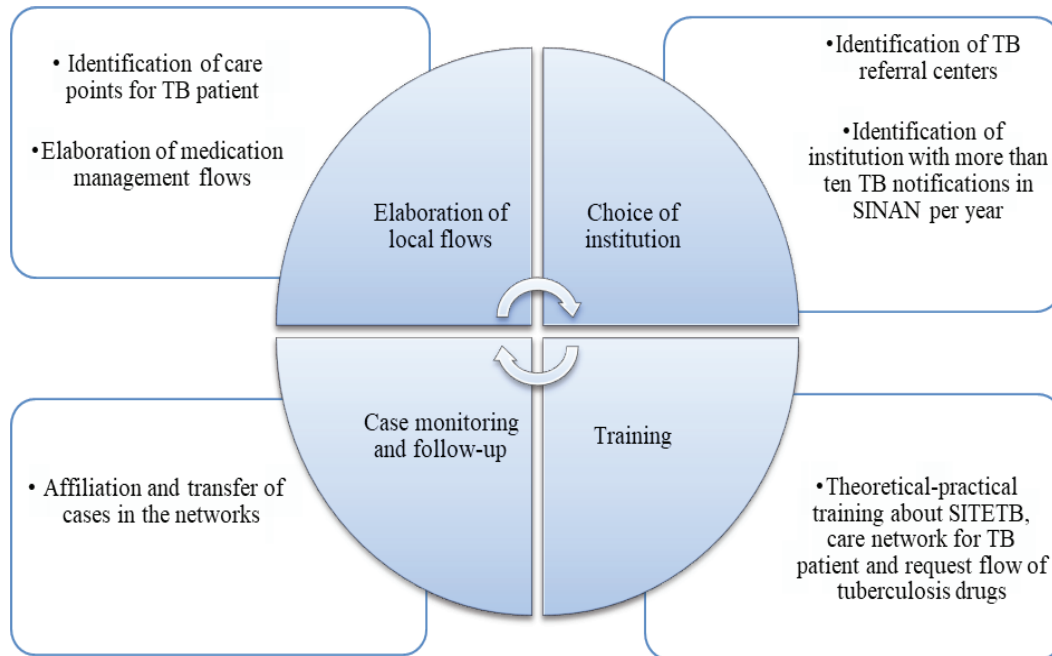
Description of the decentralization process of access to SITETB

As from 2013, the PCT in Porto Alegre, in cooperation with the RS State Tuberculosis Control Program (PECT/RS) started the decentralization of access to the SITETB to referral services in

the city. The construction phases of this process were: elaboration of flows, choice of institutions to be granted access to SITETB, team training

and monitoring of notifications and follow-up of cases in the system, as described in Figure 1.

Figure 1 – Phases in decentralization process of access to SITETB



Source: Created by the authors.

The elaboration or review of the flows was the first phase to trigger the decentralization process of access to SITETB. The local flows refer to the design of the patient care line or even the identification of the points of the care network in the city. The following TB patient care points were identified: in Basic Care, 141 Primary Health Care Units, 112 Family Health Units and 11 Primary Health Care Units to attend to specific populations (of which two prisons). Among the points of specialized outpatient care, five CRTBs were identified; in hospital care, there were five emergency care services and 24 general hospitals⁽⁸⁾.

Still in this first stage, the management of pharmaceutical care to TB patients had to be defined, in order to make it possible to point out and adjust the demand for tuberculostatic drugs in the city. After the decentralization of access to SITETB, the decentralization of access to medicines was also necessary. The agreement among the different stakeholders

involved in SITETB's special drug inventory management process (PCT, physicians, nurses and pharmacists) was important and resulted in adjustments in local flows, redirecting the request for medicines. Some aspects were observed (empirically), such as: greater agility at the beginning of treatments with special regimens, agility in solving divergences between prescribed regimens and standardized schemes by the Ministry of Health and the development, in institutions, of the culture of the importance of linking the dispensing and case reporting routines.

The second stage was the choice of institutions that would be granted access to SITETB. In 2013, as planned, this access was expanded to the PCT, to the three high-complexity general hospitals and five CRTBs. In 2014, the number of hospitals with access to the system was increased to seven, and professionals from referral centers were updated. In 2016, nine general hospitals had access to SITETB, plus the state referral hospital

for TB, Central Prison and four CRTBs, as a center was shut down in 2015.

These were identified as the care points of the network where the most severe cases of TB are treated, or which need to use different BR schemes. The decentralization of access to SITETB to all points in the care network was not considered advantageous for the city or for health institutions, as the system requires knowledge of teams experienced in TB management and knowledge on the range of available therapeutic alternatives. For institutions with a SINAN notification number of less than ten cases per year, the notifications and follow-up of cases in SITETB were kept centralized in the PCT.

The third stage of the process was the theoretical and practical training of the care teams, aiming to explain the SITETB tools and how they should be used for case management, medicines and epidemiological surveillance, according to the CRPHF and PNCT guidelines. One shift (4 hours) covered the theoretical concepts and important definitions of the system, and the other shift (4 hours) was aimed at practicing data entry into the system and explaining how the PCTs can use them, including monitoring and reporting. The PCT disseminated the local TB flows, both

in the care network and in pharmaceutical care, also in this stage.

The fourth stage of the process was case monitoring and follow-up in SITETB. *A priori*, this stage concerns the PCT's monitoring of the health institutions' compliance with notifications and follow-up of the cases in the system. In this stage, delays or gaps in the patients' affiliation with the network are also identified, in case transfer between services is necessary.

The process of decentralizing access to SITETB also entailed repercussions for the PCT's approximation with professionals who work directly in care. It was noticed that the care teams in the health institutions had gained a better understanding of the care network for TB patients and were more concerned with the patient's affiliation with the services for treatment monitoring after hospital discharge.

Characteristics of patients notified in SITETB in Porto Alegre between 2013 and 2016

Between 2013 and 2016, 1,764 patients were notified in SITETB. In this group, 1,693 were initially attended in health services in Porto Alegre, as shown in Table 1.

Table 1 – Number of cases notified in SITETB, per year of onset, treatment location and place of residence. Porto Alegre, Rio Grande do Sul, Brazil – 2013-2016. (N=1.764)

Year	Notified RS	Treatment Porto Alegre		Residence Porto Alegre	
	n	n	%	n	%
2013	328	328	100	144	42.9%
2014	440	436	99.1	184	42.0%
2015	523	511	97.7	202	38.7%
2016	473	418	88.4	205	43.4%
Total	1,764	1,693		735	

Source: Created by the authors.

During the period, according to Table 1, although notifications in the State were concentrated in the state capital, less than half of the patients lived in Porto Alegre.

In Table 2, it is highlighted that 66.5% of the patients were between 25 and 54 years of age. In terms of sex, 65.6% were men. As for the clinical form, 65.3% were diagnosed with pulmonary TB.

Table 2 – Number of cases notified in SITETB by age range, sex and clinical form. Porto Alegre, Rio Grande do Sul, Brazil – 2013-2016. (N=735)

Characteristics	n	%
Age range (in years)		
< 14	8	1.1
15-24	65	8.8
25-34	153	20.8
35-44	171	23.3
45-54	165	22.4
55-64	86	11.8
>65	87	11.8
Sex		
Male	482	65.6
Female	253	34.4
Clinical Form		
Pulmonary	480	65.3
Extrapulmonary	155	21.1
Pulmonary + Extrapulmonary	100	13.6
Total	735	100

Source: Created by the authors.

As regards the treatment outcomes, among the 735 reported cases, 150 were still being treated at the time of the research. Among the 585 closed cases, 45.3% were due to cure or complete treatment, 22.0% due to treatment abandonment (more than 30 consecutive days without medication use) and 19.5% evolved to death (due to TB or other causes).

Discussion

The process of decentralizing access to SITETB meets the guidelines of the Unified Health System (SUS), with emphasis on the principles of decentralization, regionalization and hierarchization of the health service network⁽¹¹⁾. The implementation of decentralization is opposed to the centralizing tradition of health care and has promoted the notion that the city is the best manager for this aspect, because it stands closer to the reality of the population than the state and federal spheres⁽¹²⁻¹³⁾.

It should be acknowledged that the current health model needs readjustment among its levels of care⁽¹⁴⁻¹⁶⁾. It should also be admitted that

computerized information systems that integrate the reporting, diagnostic procedures and follow-up of the treatments carried out, such as the SITETB, can help in the constitution of solid and interpenetrated care networks to combat the fragmentation of the transition of health care. The decentralization process of health does not only create a greater need for information in the cities, but has also stimulated the decentralization of health information systems⁽¹⁷⁾.

Information systems without mutual articulation make more specific epidemiological analyses impossible without the integration of the reporting, diagnostic procedures and follow-up of the treatments performed⁽¹⁾. SITETB, in turn, integrates the notification, case management, supply and control of drug inventories the patients enrolled in this system need, facilitating the constitution of TB treatment cohorts and resulting in a gain in the coverage and reliability of information on the treatment outcome⁽³⁾.

The use of SITETB has revealed the need to review the flow of requests for tuberculostatics in the city and, as planned by the Ministry of Health, to provide for the rationalization of medication

use, avoiding unnecessary waste and costs. In this process, the structuring of pharmaceutical care emerges as an essential strategy to expand access to medicines and consolidate the SUS⁽¹³⁾.

Another aspect that should be considered refers to the sustainability of health institutions, which need to maintain their organization regarding the reporting and follow-up of cases in SITETB. Despite the technological innovation incorporated into the information system, standardization of routines and incentives that can be guaranteed to health institutions, an information management and technical training policy of professionals is required^(1,3). The implementation of new systems should not be related to a particular health professional, but rather be an activity incorporated into the routines of the care teams. Equally important is the provision of minimal structural conditions for the process to be streamlined, such as access to computers and the internet.

The use of SITETB and the PCT approach to care has raised the questions: How does the team perceive the TB problem and forward it? How to guarantee the patient's affiliation upon discharge and provide the necessary information to ensure quality care? The intense use of the SITETB has made the care teams seek answers to these questions, which translates into an exercise for the production of care and reorganization of the work process and the care model. On the other hand, the records in the SITETB have made the work process of each institution more transparent, explaining the degree of commitment to TB control actions, which often reveals the low involvement of some professionals in the process and the resistance of others in the development of strategies that establish changes in the work process.

The development of tools to monitor the quality of TB control actions is a very useful strategy, as long as they are efficient, practical, easily accessible and in line with reality⁽¹⁾. A survey conducted among nearly 2,000 health professionals in nine countries among the ten that use e-TB Manager, including Brazil, found that 81% of users evaluate that this system

contributes positively to the treatment of TB patients⁽³⁾.

This consensus made it clear that the broad and rational use of SITETB may contribute to qualify the indicators and may be perceived as a way to systematically monitor and evaluate care for TB patients. The PCT, not only through the records in the system, but also through the daily observation of practice, can support the organization of the care teams' actions in the issues related to the TB care network.

Although there is increased interest in assessing the completeness of information system data, it is still insufficient to account for the volume and diversity of data that is produced. The monitoring and evaluation of this dimension is an important tool to ascertain whether the information is properly completed and, based on the results, to identify weaknesses and potentialities of the data the health services produce. Thus, the intention is to extend their use and/or recommend strategies to improve the quality of information⁽¹⁸⁾.

In any case, it can be inferred that the decentralization of the use of SITETB was enriching, as it mobilized the health professionals in the aspects related to care for TB users, and mainly in those aspects regarding the transition of care in the healthcare network. Registering the implementation of measures aimed at improving health care requires a broader view from managers, so that they take on the quality management of actions as a constant goal.

Porto Alegre concentrates most of the notifications in SITETB, although less than half of the patients live in the city. This is because the PECT/RS and the state referral hospital (most reporting services) are located in this city. The trend is that, as access to SITETB is decentralized to services in other cities of the State, the number of notifications concentrated in Porto Alegre decreases. Such situations are also evident in metropolitan areas, because they have large university hospitals equipped with comprehensive services that present an excessive demand of patients from the city and other cities in the region, who directly visit the

emergency room as a gateway for outpatient visits or hospitalizations⁽¹⁾.

Regarding the characteristics of the patients reported in SITETB, the majority comes from the economically active age group, with a higher incidence for men and a greater predominance of the pulmonary form. These results corroborate other studies carried out on the sociodemographic profile of TB patients⁽¹⁹⁾.

What the cases closed are concerned, data on treatment abandonment and mortality in this population are worrisome and impose great control challenges for a curable disease like TB. In that sense, SITETB is an important source of data for PCTs⁽³⁾. Ensuring the quality of information permits true knowledge on the epidemiological situation and the most appropriate planning of actions to control this epidemic.

Conclusion

The use of SITETB is part of an educational process, although knowledge on this activity can be considered recent. This platform can offer significant contributions to TB control as it articulates the notification and monitoring of cases with medication management and epidemiological surveillance in real time. The registers and monitoring of the system have served as fundamental elements for these empirical conclusions and have equally support communication between management and care professionals, as they sustain the high-quality transition of care among the care points in the health network.

Implementing the decentralization of the access to SITETB in the CRTB, prisons and hospital network, as well as the constant monitoring of this process by the TCP, requires the managers' political will and the care teams' acceptance. The decentralization of the access to SITETB depends on political decisions regarding the priorities set to use the health information systems and also requires investments in infrastructure and in the professionals' training. This process demands persistent work and the establishment of a culture of participation,

cooperation and co-accountability to consolidate such a recent activity.

Much has been achieved in the city in recent years through the decentralization of access to SITETB. Nevertheless, changes are always necessary in the management and care relationships involved. We believe that we are on the right track and that the proposal to decentralize the use of the system is able to achieve its final objectives, i.e. to contribute to TB control.

Therefore, we hope that there are groups engaged and interest in decentralizing and monitoring the SITETB activities. The larger objective is to improve TB indicators, with a view to satisfying the users' health needs, as an alternative for an effective care network for TB patients and the practice of the right to health.

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1. conception, design, analysis and interpretation of data: Daniela Wilhelm, Mauricio Vieira Rodrigues, Priscila Tadei Nakata, Sabrina da Cunha Godoy and Carine Raquel Blatt;
2. writing of the article and relevant critical review of the intellectual content: Daniela Wilhelm, Mauricio Vieira Rodrigues, Priscila Tadei Nakata, Sabrina da Cunha Godoy and Carine Raquel Blatt;
3. final approval of the version to be published: Daniela Wilhelm, Mauricio Vieira Rodrigues, Priscila Tadei Nakata, Sabrina da Cunha Godoy and Carine Raquel Blatt.

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