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SISTB: an ecosystem for monitoring TB

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Abstract

Tuberculosis (TB) is a curable disease, although it still kills thousands of people every year. There are several information systems and applications developed to assist the TB treatment, but many of these systems are isolated and are not able to exchange relevant information. In this way, a set of interoperable applications and decision support modules have been developed. A socio-technical approach was applied to incorporate key stakeholders in all development stages so that final tools fit the health service reality. A set of systems and applications, called the SISTB Ecosystem, has been designed to assist in the treatment of TB and to improve the routine of health professionals.

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1. Introduction

Tuberculosis (TB) is a bacterial infectious disease that illustrates one of the world's largest public health problems. Despite TB can usually be completely cured, most deaths cases may be prevented with early diagnosis and appropriate treatment. In 2017, 1.3 million tuberculosis deaths were estimated among HIV-negative people and an additional 300,000 deaths among HIV-positive people [1]. Brazil, specifically, is considered a country with a high TB burden. In 2017, Brazil notified almost 73 thousand new cases, while the previous year more than 4 thousand deaths was confirmed, with 74.6% cure rate and 10,8% abandoned the treatment [2].

The treatment of TB is long and, in most cases, lasts about six months. The poor treatment adherence leads to increased mortality, ongoing disease transmission, and drug resistance [3]. In this context, Brazil follows the strategy of Directly Observed Treatment (DOT) as recommended by WHO. This strategy consists of daily observation of medication intake, i.e. medication intake should be supervised. Several consequences of non-adherence or non-treatment of TB may extend transmission, rise risk of drug resistance and lead to patient death. Additionally, due to inadequate treatment, there are new concerns about increasing of drug-resistant and extensively drug-resistant TB rates. Nowadays, Brazil TB treatment covers 87% of the population. However, the WHO target is to accomplish more than 90% by 2025 for all countries. In Ribeirão Preto, city where this study is being developed, each health region (5 regions) provides one professional per day for home visits to perform the DOT.

In Brazil, there are some tools that allow the TB patients data registration, such as the Notification of Injury Information System (SINAN), where cases of diseases included in national list of compulsorily notifiable diseases are investigated; the Special Tuberculosis Treatment Information System (SITETB), where it is possible to notify, follow and monitor the special TB cases; and the Notification and Monitoring System for Tuberculosis Cases in the State of São Paulo (TBWEB). These systems only work when there is internet access and are focused on disease notification and treatment follow-up through a compilation of information, and do not store daily data of medication taking. The healthcare team also uses other systems throughout the treatment, such as systems for requesting and receiving test results, electronic medical records, as well as paper medical records. In this way, it is not possible to monitor daily treatment in real time and to share information quickly and easily between the health team members, because the systems do not exchange the data among themselves. There is also the problem of rework, due to the need of repetitive data input in several systems. Thus, one of the challenges in TB monitoring is the lack of operational interoperability, that is, there is no data exchange between the different systems and there is a lack of semantic interoperability, where the data significance between the platforms is different.

Considering this context, the present study is a proposal for an ecosystem to monitor TB treatment. The SISTB ecosystem consists of several modules. Information about the treatment and DOT may be recorded online or offline, as well as self-registration by the patient. Through web semantic techniques, it will be possible to interoperate with other national and international repositories. A predictive model of treatment abandonment will be used to assist professionals in the management of TB cases.

In the next section, we present the background for the research development. Then, the third section describes the methodological approach applied on this this project. The fourth section shows the results so far. The fifth section presents the discussion of the observed results. Finally, the sixth section contains the conclusion, as well as future work.

2. Background

2.1. Software Ecosystem

Software ecosystem (SECO) may be defined as a technological platform that results in a number of software solutions or services where a set of actors interact and contribute to its construction. Each actor is connected to the rest of the actors and the ecosystem as a whole with symbiotic relationships. The technological platform is structured in a way that allows the involvement and contribution of the different actors. [4].

SECO allows different institutions and organizations to contribute rich solutions and innovations in diversity of content, services, experience and ability to find resources adhering to the real needs of users in a defined domain. The use of SECO makes it possible to centralize services and solutions, facilitating the reuse, creation and evolution of techniques and approaches of their context [5]. The most mentioned SECO benefits are: to promote co-evolution, innovation and to increase attractiveness for new actors. Other benefits include enabling companies to decrease costs while supporting architectural decision making, sharing knowledge, and communicating requirements among players [6].

The requirement elaboration is a challenge in the SECO concept as the stakeholders are multiple and distant from the central ecosystem management [4]. Some studies indicate difficulties in relation to the ecosystem modeling, architectural challenges, heterogeneity of licenses and software evolution [6].

2.2. TB monitoring

There are several information system initiatives that help in TB treatment management. Examples include e-TB manager [7], where it is possible to monitor cases, manage medicines, generate reports and perform data analysis. It has a desktop and mobile access with offline mode and was developed with open source tools to allow countries to customize the program to solve their specific needs. The PIH-EMR [8] is a Web-based system to support MDR-TB management. It contains information such as patient clinical data, laboratory tests, TB history, previous treatment and surgery, physical examination, and medication regimen. It is possible to upload digital images, perform analysis and display data graphically, or download spreadsheets. The OpenMRS MDR-TB module [9] is a module developed to assist the care of multidrug-resistant tuberculosis patients and was based on WHO reports. Another tool that assists the TB treatment is the Video Directly Observed Therapy (VDOT). The VDOT allows patients to record and transmit medication ingestion via videos watched remotely by health care professionals [3,10,11].

Built a collaborative network and supportive ecosystem making it possible to steer improvements for TB stakeholders through analysis, monitoring, and decision support systems integrated services isn't an easy task. Some efforts to improving the management of TB are making real differences in clinical practice. In their review study, Chapman highlights five key TB areas who's have receive some digital works focused on fields like diagnosis, treatment ,contact tracing and epidemiology ,service performance monitoring and quality assurance and teaching and training [12]. However, the evidence base from studies on digital technologies targeting TB is slowly growing. Despite interest in the use of digital technologies to improve the care of persons with TB, their reported impact has been variable and evidence from implementation studies remains sparse.

3. Research methods

For the development process, the ethnography technique was applied, which is characterized as an observation technique. By doing that, the analyst is within the working environment in which the system will be used and then observe and record the actual tasks. Ethnography is a requirements elicitation, extremely effective when you want to find out how people work within the environment and how they work together to achieve goals. The main objective is the discovery of implicit system requirements that reflect the actual processes rather than formal processes in which people are involved [13–15]. Involvement in a real meeting with health professionals can enable an understanding of the social and organizational requirements, i.e., the understanding the organizational policy, as well as the institutional culture, in order to become familiar with the work process.

Another method adopted for requirements elicitation was the interview with potential users. The interview is a simple and traditional technique that produce good results in requirements collection step. The interview aims to understand user's profile, find out what the user - in this case health professionals and patients - expect from a TB information system, how pleased he is with the current procedure and what can be improved. The model chosen for the interview was provided like an open questionnaire, i.e., a set of direct questions, but also leave room for the interviewer to suggest information beyond what was asked.

In this way, the socio-technical approach was used in the construction of the systems, that is, the potential users collaborated actively with the technical developers, through several strategies, such as regular group meetings, where potential users were motivated to use and improve the system, integrating workflows and making suggestions based on experience [16].

4. Preliminary Results

The SISTB ecosystem is composed of several technologies designed to assist in the follow-up of TB treatment. SISTb, SISTB mobile and GuideTB were developed for use by healthcare professionals. WebDOT and Virtual assistant will be used by patients to improve adherence to DOT. The layers of interoperability and security ensure more accurate and secure information. The decision support layer may assist in offering a more individualized treatment per patient. The elements of the repository will allow the intelligent processing of information through systems capable of interpreting structured information. The SISTB ecosystem modules will be explained in detail in the next topic. Fig. 1 presents the ecosystem model and its components. At any time, new support tools and data structures can be incorporated to meet the needs of specific users (doctors, nurses, students and patients).

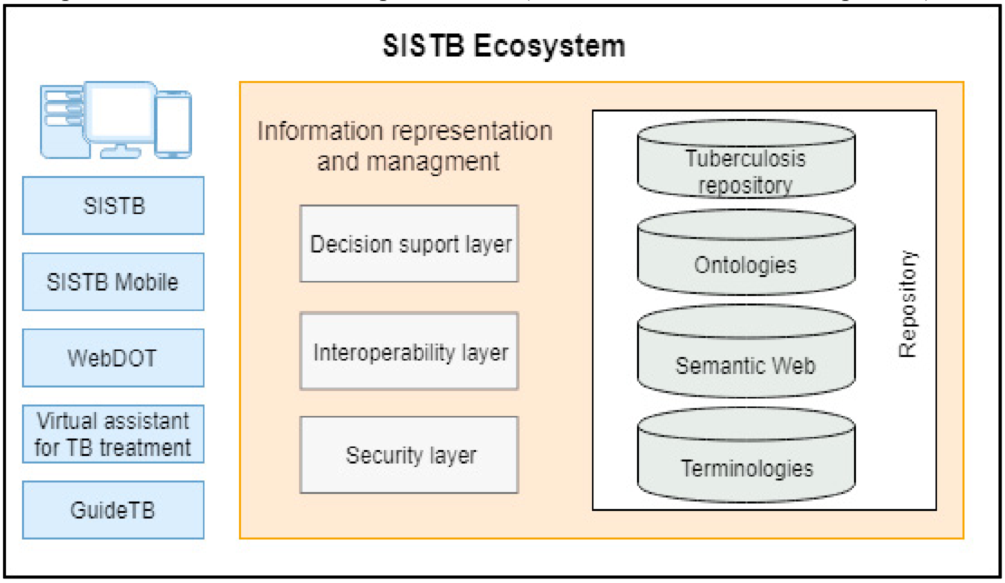

Fig. 1. The ecosystem SISTB model and its components.

4.1. SISTB

SISTB is an information system for monitoring TB treatment. It was created from the need to store and consult information and the need to make this information available quickly and easily in order to generate reports automatically. It was developed based on the forms recommended by the Brazilian Ministry of Health. The development of the SISTB was carried out in partnership with the health professionals from the city of Ribeirão Preto - Brazil. The SISTB was implanted in three outpatient referrals for TB in the city of Ribeirão Preto. To evaluate the implantation a protocol was followed [17], where the evaluation is performed from the point of view of the health professionals and the patients, who are interviewed before and after the implantation of the system. The evaluation of the software by the professionals was satisfactory [18]. The analysis from the point of view of the patients was indirect, that is, it was evaluated if there was improvement in the care and in the health service. The results after the implantation were better, but were not considered statistically relevant [19].

4.2. The TB Mobile Information System or SisTB Mobile

SISTB Mobile is considered a SISTB extension, helping health professionals to provide home care visits to patients, allowing them to search for and register patient's data, such as personal information, treatment and DOT data. This version can be used anywhere through an Android mobile device. The access is offline, so when the professional performs a home visit, the system functions can be executed regardless availability of internet connection. The SISTB Mobile evaluation was carried out together with SISTB. Some screens of the SISTB Mobile can be seen in Fig. 2.

Fig. 2. (a) SISTB Mobile main menu; (b) SISTB Mobile registration of daily medication intake (drug supervision); (c) GuiaTB main screen; (d) GuiaTB calculator functionality

4.3. The WebDOT

WebDOT is a VDOT platform, which enables the sending of video records using a smartphone by a patient and the validation of these records by a health professional through the Web platform [11][14]. An automatic medication intake recognition using computer vision techniques is in development [10], in order to optimize the working time of health professionals. The WebDOT can be used in cases of inability to perform the daily home visit by the health professional, also a viable alternative to the patient who seek self-efficacy and empowering.

4.4. Virtual assistant for TB treatment

The purpose of the virtual assistant is to assist the patient through remote monitoring. It should be able to interpret the patient's interaction and return a response within the context created. The assistant will disseminate information about TB treatment with the help of an artificial intelligence. The patient will be able to ask questions, seek advices and treatment information through conversations with a chatbot, with natural language processing. Thus, it will be possible to provide care to the patient at any time, promoting a complementary condition to the treatment already practiced.

4.5. GuiaTB

GuiaTB is a digital manual for Android devices that allows quick queries to TB treatment protocols and procedures, enabling content finding in a focused, orderly and interactive way. In addition to the structured information for a dynamic navigation, these manuals include additional tools, such as specific calculators, to help the user, for instance, calculating drug dosage. GuiaTB also provides a flowchart navigator to enhance TB tracking process, allowing the user to insert notes in each diagnosis/treatment stage [20]. The manual was based on the Quick Guide for Health Professionals - Recommendations for Tuberculosis Control, provided as a PDF document file by the Brazilian Ministry of Health. Fig. 2 shows the (c) guideline main screen and (d) a calculator feature example.

4.6. Decision support layer - Abandonment prediction model

The idea is to incorporate into the SISTB an abandonment prediction model, developing a decision support module for health professionals. The goal is to identify early treatment abandonment. The model will be developed based on knowledge discovery in databases, heuristics, and information provided by health professionals. Once a list of factors has been identified, a survey will be carried out to identify a weight attributed to each of the previously identified factors and, also, to recognize new factors. The factor versus weight matrix will be used to create a heuristic model to determine the probability of treatment abandonment by the patient. A previous study regarding the data quality of the repositories has already been carried out [21].

4.7. Interoperability and security layer

These layers are responsible for the safe data exchanging capability between the SISTB and other systems such as TBWEB and e-SUS AB (Basic Attention Health management software at a national scope). The interoperability layer is based on standards advocated by the W3C and the semantic web paradigm. Thus, it is possible to extract knowledge in an optimized way for machines through APIs and query endpoints [22].

Semantic interoperability is achieved by the definition and use of a domain specific ontology, allowing computer-based inferences and knowledge extraction. This ontology represents TB concepts and specificities from the Brazilian National Tuberculosis Control Program. Data can be integrated from several data sources (applications, data portals, structured files) by mapping it through this ontology. On the other hand, functional interoperability is achieved by using communication protocols, APIs and semantic query endpoints, such as SPARQL endpoints. Also, all APIs are compatible with semantic data formats, such as Resource Description Framework (RDF) and JSON for Linking Data (JSON-LD).

The security layer shall provide a secure way to transfer data from and to other applications through the internet. In this way, mechanisms for authentication, authorization, confidentiality (cryptography) and data integrity check are available [23].

The Table 1 below shows a summary of the ecosystem's development and the results achieved for each module.

Table 1. Development summary of the SISTB ecosystem modules.

	In progress	Testing/validation phase	Implemented	Main outcomes
SISTB			x	Usability evaluation was satisfactory; the evaluation of health care and service from the patients perspective indicated that after the implantation there were improvements, but were not considered statistically relevant.
SISTB mobile			x	
WebDOT		x		
WebDOT with computer visionfacial recognition	x			
Virtual assistant				
GuiaTB		x		
Decision support layer	x			Several inconsistencies between different data sources used in the tuberculosis control in the Brazilian healthcare system
Interoperability layer	x			
Security layer	x			

5. Discussion

In general, the computerized systems available in Brazil to address the treatment of TB are not open source and interoperable, which makes it difficult to exchange data and reuse relevant information. International treatment management initiatives are not fully adequate for the Brazilian reality, due to the use of specific forms for case notification and treatment follow-up. In addition, these initiatives are focused on specific issues related to TB treatment, that is, they are independent initiatives and many of them do not implement interoperability features.

The SISTB Ecosystem was designed to assist in the treatment of TB through several tools. Each tool has a specific purpose, but they can be used together, i.e., in a integrated environment where patients' data is available over all systems, or independently. The development method makes the final product fit the reality of the health service, due to frequently iterations with key stakeholders.

The implementation of an information system can generate both positive and negative impacts in a service, given that it has the ability to modify work processes. Therefore, it is extremely important to build tools in compliance with the workflow of each care unit, in order to effectively improve it.

6. Conclusion and future work

A set of systems and applications has been designed to assist in the treatment of TB. The SISTB Ecosystem is composed of tools that assist in the follow-up of TB treatment. The modules and layers were designed to improve the routine of health professionals by using the tools together or independently. The SISTB, SISTB mobile and GuiaTB are already developed. WebDot is in the testing phase. The other modules presented are in the development phase.

As future work, it is intended to test and evaluate all tools that are still under development and to optimize the ones that are already in use. The continuous improvement aims to update resources according to the needs of the users and new health service processes, encouraging their usage in adequate scenarios.

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