The coordination of care for tuberculosis control*

A COORDENAÇÃO DA ASSISTÊNCIA NO CONTROLE DA TUBERCULOSE

LA COORDINACIÓN DE LA ATENCIÓN EN EL CONTROL DE LA TUBERCULOSIS

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ABSTRACT

This descriptive epidemiological study analyzed the coordination of tuberculosis (TB) patient care in primary healthcare services according to 23 patients, 16 professionals, and 17 administrators from Ribeirão Preto, Sao Paulo, using an instrument adapted to evaluate TB. According to the informants, the coordination of healthcare provided to patients under the treatment of the Tuberculosis Control Program team was considered satisfactory; however, when there is a need to refer the patient to other care units there are weak points in the coordination of healthcare, which include: interruption of communication flow; and patients' incipient participation in the care process, with a need to increase the sense of responsibility for patient care and encourage patients to become active agents in the process.

DESCRIPTORS

Tuberculosis
Intersectorial action
Primary Health Care
Health Services Evaluation
Primary Care Nursing

RESUMO

Estudo epidemiológico descritivo que analisa a coordenação da assistência ao doente de Tuberculose em Serviços de Atenção Primária segundo 23 doentes, 16 profissionais e 17 gestores em Ribeirão Preto-SP, através de instrumento adaptado para avaliar a tuberculose. De acordo com os informantes, a coordenação da assistência ao doente em tratamento pela equipe do programa de controle da tuberculose foi considerada satisfatória. No entanto, quando há necessidade de encaminhar o doente a outros pontos de atenção, a coordenação da assistência apresenta pontos deficientes como descontinuidade do fluxo de comunicação e participação incipiente do doente no processo de atenção, havendo necessidade de aumentar a responsabilização pelo cuidado do doente e estimulá-lo como agente ativo do processo.

DESCRITORES

Tuberculose
Ação intersetorial
Atenção Primária à Saúde
Avaliação de Serviços de Saúde
Enfermagem de Atenção Primária

RESUMEN

Estudio epidemiológico descriptivo que analiza la coordinación de la atención al enfermo de tuberculosis en Servicios de Atención Básica, según 23 enfermos, 16 profesionales y 17 gestores en Ribeirão Preto-SP, mediante instrumento adaptado para evaluar la tuberculosis. Según los informantes, la coordinación de la atención al enfermo en tratamiento por parte del equipo del programa de control de la tuberculosis fue considerada satisfactoria. Sin embargo, cuando existe necesidad de derivar al enfermo a otros puntos de atención, la coordinación de la atención exhibe signos deficientes, como discontinuidad del flujo de comunicación y participación incipiente del enfermo en el proceso de atención, habiendo necesidad de aumentar el grado de responsabilidad por la atención del enfermo y estimularlo para ser agente activo en tal proceso.

DESCRIPTORES

Tuberculosis
Acción intersectorial
Atención Primaria de Salud
Evaluación de Servicios de Salud
Enfermería de Atención Primária

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INTRODUCTION

One of the Unified Health System's (SUS) guidelines is that the organization of services should be based on the principle of integration, that is, actions and services should be jointly performed in a cooperative manner to establish preventive and healing actions directed to individuals and to the collective at all the system's complexity levels to ensure continuous and global services performed by different professionals, but connected in time and space[1], according to the local availability of technology. What is observed, however, is that health actions developed during the care process still occur in a discontinuous manner, strongly polarized at care levels in which there is a greater technological density with low integration and connection among care services, evidencing the predominance of a fragmented care model focused on the care of acute and one-time event cases[2].

It is therefore important that care developed in Primary Health Care services (PHC) should occur in an integrated and connected manner through a coordinator, which is a management tool[3]. Coordination in the international scope is seen as the ability of health services to ensure continuity of care to patients within a health system[3-4], ensuring the availability of resources, inputs, intra and extra sector connections, and the flow of information required to meet the needs of users[3-4].

One study addressing the coordination of care conducted in 12 countries verified that 81% of coordination problems are related to care delivered to patients in an acute condition at the long term, 69% of these is in emergency care, 65% in outpatient care, 42% between primary care and outpatient specialists, 35% in long term care (nursing care and home care) and 31% in outpatient care and emergency care[5].

Patients with chronic diseases such as tuberculosis need management to foresee care over time, that is, they require continuous care to ensure adherence to treatment over the long term. One study revealed that the centralized care system faces difficulties providing continuous care to patients with multidrug-resistant tuberculosis (MDR-TB), facing failure in disease treatment and the follow-up of patients[6].

In Brazil, adherence to treatment and the search for respiratory symptoms has become a great challenge for the control of tuberculosis (TB) despite investments and actions implemented by the government through the Ministry of Health and other instances of the SUS's focus on the decentralization of some actions to PHC services[8-7].

According to the World Health Organization (WHO), 1.7 million people died due to TB in 2009. In Brazil, the average incidence of cases in the population per year has been 72/100,000, the incidence of new cases with a positive sputum smear is 48/100,000 per year and there is an average prevalence of 36/100,000 cases over all forms of TB. Mortality due to all forms of TB is 8.4/100,000 per year. Of the cases diagnosed in 2009, 64% are cases with a positive sputum smear; 71% of these achieve success in treatment. An estimated 72% of cases were detected in 2009[9].

The WHO argues that the problem of TB is not related to the forms of detection and treatment but to the way health services are organized to detect and treat TB[10]. One study concerning the organization and structure of Tuberculosis Control Programs (TCP) identified a lack of material and human resources in addition to a lack of qualified human resources[11], which compromises the coordination of care provided to patients.

Because this is a disease of great transmissibility, affected individuals require constant monitoring, as well as their families. Care delivered by TCP and by other services should be integrated among the different teams so that the disease is efficaciously and efficiently controlled. Coordination stands out as a determinant instrument in this process, since it permits integration among the actions and, jointly with this process, the use of technologies and resources to achieve organizational objectives and efficient services[12].

Patients with chronic diseases such as tuberculosis need management to foresee care over time, that is, they require continuous care to ensure adherence to treatment over the long term.

The study aimed to identify the perception of TB patients, workers in the TCP and managers of PHC units in the city of Ribeirão Preto, SP, Brazil in 2007 concerning the coordination of care delivered to patients with TB.

METHOD

This is a descriptive epidemiological survey. One hundred TB patients were interviewed out of 133 who were undergoing treatment at the time of data collection (June to August 2007). Only 23 of these answered the instrument's questions concerning the coordination of care. Therefore, 23 TB patients monitored by the TCP in Ribeirão Preto, SP, Brazil composed the sample in addition to 16 health workers and 17 managers of PHC units. The inclusion criteria were: being older than 18 years old, residing in Ribeirão Preto, with at least one month of treatment, agreeing to participate in the study (inmates were excluded); all the professionals working in the TCP (physicians, nurses, nursing technicians and technicians) delivering care to TB patients and managers of PHC units with at least three years of experience in the function.

The Primary Care Assessment Tool (PCAT) adapted and validated in Brazil for tuberculosis care, was used to collect data[13]. The interviewees answered each question according to a pre-established Likert scale, in which zero was

assigned to answers such as *I do not know* or *it does not apply*, and values 1 to 5 expressed the degree of preference or agreement with statements. A score was assigned to each answer, for example never=1, almost never=2, sometimes=3, almost always=4 and always=5. Explanatory scripts concerning the scale were used.

Fourteen indicators were developed to analyze the coordination of care: *C1 the same professional provides the consultation; C2 the professional talks about other problems during the consultation; C3 the professional uses the medical file during the consultation; C4 the professional takes notes of complaints on the medical file; C5 the results of exams are available at the health unit; C6 the patient is informed of the consultation schedule; C7 referral to a specialist; C8 discussion/indication of a service in the event of a referral; C9 the patient is assisted in scheduling a consultation with a specialist; C10 the patient receives a confirmation the consultation is scheduled with a specialist; C11 the health worker provides written information to the specialist*; *C12 the patient returns with written information provided by the specialist; C13 the health professional discusses the outcomes of consultation provided by the specialist with patients; C14 the professional is concerned and interested in the care provided to the patient in another service.*

Data were analyzed by the Statsoft program version 9.0. Exploratory analysis was performed to verify potential inconsistencies in the database and descriptive analysis to determine the value of the indicator (average of scores), with a confidence interval at 95%. The indicators were classified as *unsatisfactory* (values between 1 and 2), *regular* (value 3) and *satisfactory* (values between 4 and 5).

Ethical considerations

This study was submitted to and approved by the Research Ethics Committee at the University of São Paulo at Ribeirão Preto, College of Nursing in accordance with resolution 196/96, National Council of Health, Ministry of Health (protocol 0762/2007).

RESULTS

The averages of the indicators and confidence interval for the coordination of TB care from the perspective of TB patients, health workers and managers of PHC units are shown in Table 1 and Figure 1.

Table 1- Label of variables, value of averages and respective confident intervals of the indicators of Care Coordination according to TB patients, health workers and managers, Ribeirão Preto, SP, Brazil, 2007.

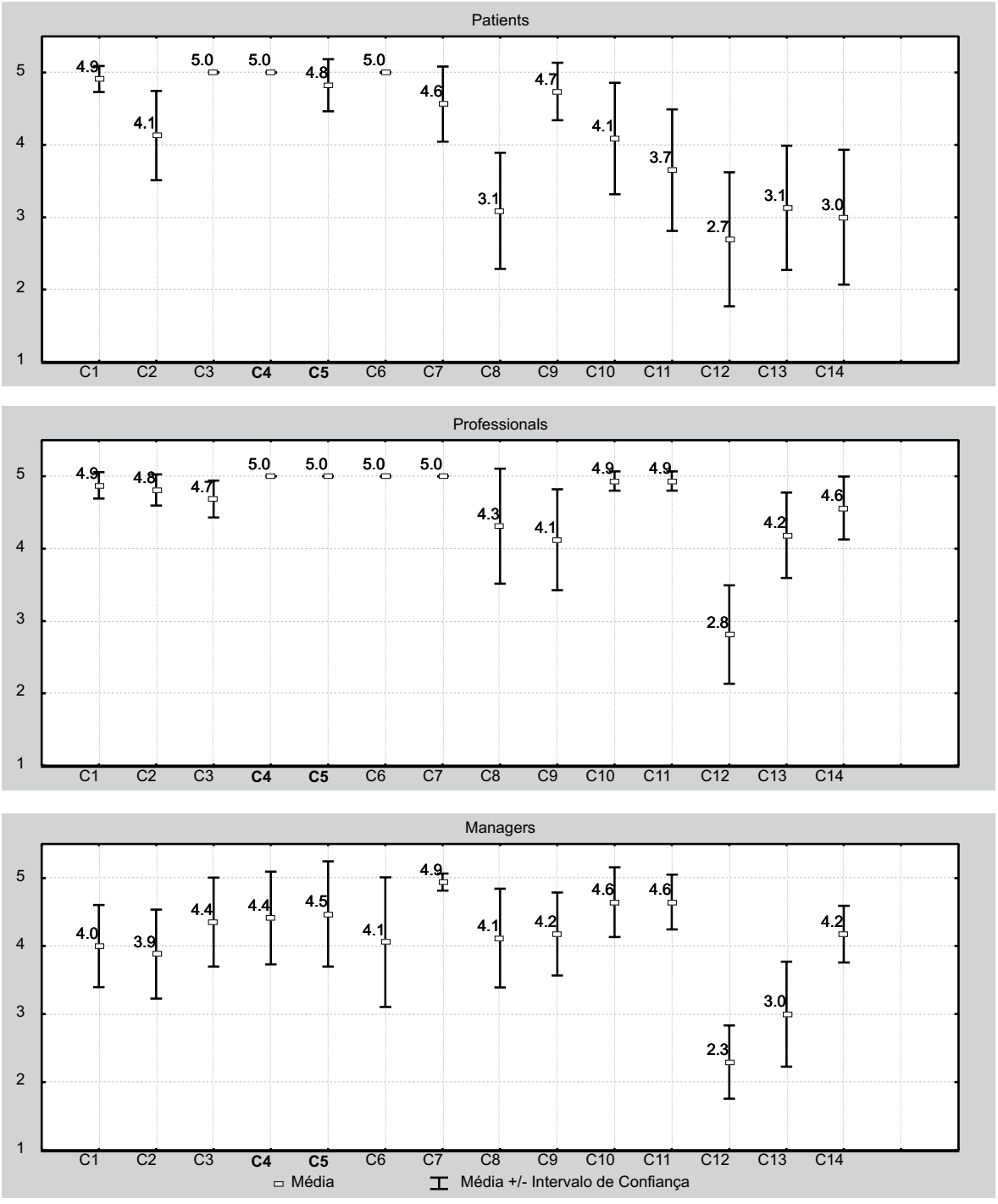
Label of Variables	TB Patients Average/CI	Health Workers Average/CI	PHC Managers Average/CI
C1	4.91 [4.73 ; 5.09]	4.87 [4.69 ; 5.05]	4.00 [3.39 ; 4.60]
C2	4.13 [3.51 ; 4.74]	4.81 [4.59 ; 5.02]	3.88 [3.22 ; 4.53]
C3	5.00 [5.00]	4.68 [4.43 ; 4.94]	4.35 [3.69 ; 5.00]
C4	5.00 [5.00]	5.00 [5.00]	4.41 [3.73 ; 5.09]
C5	4.82 [4.46 ; 5.18]	5.00 [5.00]	4.47 [3.69 ; 5.24]
C6	5.00 [5.00]	5.00 [5.00]	4.05 [3.10 ; 5.01]
C7	4.56 [4.04 ; 5.08]	5.00 [5.00]	4.94 [4.81 ; 5.06]
C8	3.08 [2.28 ; 3.88]	4.31 [3.51 ; 5.10]	4.11 [3.39 ; 4.84]
C9	4.73 [4.34; 5.13]	4.12 [3.42 ; 4.82]	4.17 [3.56 ; 4.78]
C10	4.08 [3.31 ; 4.85]	4.93 [4.80 ; 5.07]	4.64 [4.13 ;5.15]
C11	3.65 [2.81 ; 4.49]	4.93 [4.80 ; 5.07]	4.64 [4.24 ; 5.05]
C12	2.69 [1.76 ; 3.62]	2.81 [2.13 ; 3.49]	2.29 [1.75 ; 2.83]
C13	3.13 [2.27 ; 3.98]	4.18 [3.59 ; 4.77]	3.00 [2.22 ; 3.77]
C14	3.00 [2.06 ; 3.93]	4.56 [4.12 ; 4.99]	4.17 [3.76 ; 4.59]

Source: TB patients, PHC workers, and managers of PHC units managers – Ribeirão Preto, SP, Brazil, 2007

The results shown in Table 1 indicate that when the participants were asked about TB patients being cared for by the same health worker in the TCP (C1), whether the TCP professional takes notes of complaints in the patient's medical file (C3), whether the medical file is used during consultation with the TCP professional (C4), whether results of exams become available to patients in the health unit (C5); whether patients are informed of the consulta-

tion scheduled to continue care (C6); whether patients are referred to a specialist when needed (C7); are assisted by the TCP professionals to schedule a consultation with such a specialist (C9); and whether TCP professionals provide written information to take to the specialist (C11), the answers provided by the three groups were considered satisfactory with values ranging from 4.00 to 5.00 (Table 1).

Figure 1- Distribution of averages and confidence intervals of indicators of coordination according to the participants – Ribeirão Preto, SP, Brazil – 2007



Source: Patients, TCP Professionals, and PHC managers – Ribeirão Preto, SP, Brazil, 2007

However, in relation to the remaining indicators, the groups provided different answers. The managers considered the indicator *the professional talks about other problems during the consultation (C2)* to be regular. The patients also considered the indicator *discussion/indication of a service in case of referral (C8)* to be regular. The patients consider written information provided by the TCP professionals directed to the specialists to be regular (C11) as well as the indicator *the professional is concerned and interested in the care provided to the patient in another service (C14)*.

There was agreement among the answers of the three studied groups concerning counter-referral with written information provided to the TCP professional (C12); all three groups considered it to be unsatisfactory. Only the professionals considered the indicator 'the health professional discusses the outcomes of consultation provided by the specialist with patients (C13)' to be satisfactory.

These results are presented in figure 1 to better visualize the pattern of answers provided by the different informants in relation to the analyzed indicators.

Figure 1 shows there are many consistent indicators among the three groups as discussed earlier. Only the indicators *the health worker provides written information to the specialist (referral) C11* and *the professional is concerned and interested in the care provided to the patient in another service (C14)* presented a statistically significant difference showing disagreement among patients and professionals, which is demonstrated by the confidence intervals presented in Table 1.

No statistically significant differences were found for the remaining indicators. The participants considered most indicators to be satisfactory and provided consistent opinions, with the exception of the following indicators: *the patient returns with written information provided by the specialist (C12)*, *discussion/indication of a service in case of referral (C8)*, and *the health professional discusses the outcomes of consultation provided by the specialist with patients (C13)*, which were evaluated as *unsatisfactory, regular* and *regular* by patients, professionals and managers respectively.

DISCUSSION

When we analyze the performance of variables and indicators of the coordination of care provided to TB patients from the perspective of the patients themselves, from the professionals who provide such care, and from the perspective of PCH managers, we verify that there is a set of consonant indicators among the three groups of informants, which indicate care elements and support for the treatment provided to TB Patients, which enables continuity in the process of care delivered to patients throughout the health system through the management of cases or disease as the health system offers care centered on the patient over time and in various care services[5].

The three groups of participants recognize the existence of a specialized health team, who are a reference point of excellence in care provided to TB patients, and an organization of the system of local information that permits knowing the patients concerning various aspects, which is seen in the satisfactory evaluation of a large part of actions related to the work process of care delivered to TB patients. We verify through these elements that the organization of health services provided to TB patients enables the coordination of care to be characterized by elements that enhance the bond established between health workers and patients. The internal organization of the local TCP teamwork enables knowing patients and provides information to the referral system when required by patients and the appropriate management of cases.

The authors of one study addressing the coordination of care in different countries state that the management of cases is a coordination tool that includes *responsibility for referrals, consultations, prescription of therapies, admission into hospitals* and *follow-up of care*[5].

When there is a need to refer TB patients to other specialties, sectors or services, we note there is concern on the part of workers and managers to ensure actions and services solve the case, which make them a health team of reference for TB patients. It is worth noting that the reference team may be an organizational and methodological arrangement for the management of health work, which is composed of professionals considered essential to manage health problems within a given field of knowledge, with the purpose of increasing the possibilities of developing a clinic with a broader reach, where the team providing care perceives the differences among people with the same disease and produces different and appropriate therapeutic proposals. It should be related to the capacity of the team to dialog and the subjects' autonomy[14].

However, the referral and counter-referral process may be customized as health workers encourage and facilitate direct contact between the referrer responsible for the case and the support specialist, changing the function of the regulation centers that would then only have the function of regulating urgent cases. These professionals are called *matrix support* and are required to have specific knowledge and be able to aggregate knowledge resources, opening opportunities for active communication and sharing knowledge with referral professionals, contributing with interventions that increase the problem solving capacity of the health team responsible for the case, ensuring greater efficiency and efficacy of health work and encouraging the autonomy of users[14].

In relation to the flow of information among services in the referral and counter-referral mechanisms for care provided to TB patients, this study indicates there is discontinuity of information, the services' teams face difficulties ensuring that such information is recorded and patients do not participate in this process, which becomes

an obstacle for the continuity of care. Even though this mechanism occurs in the context of a regulator complex in the studied city, it needs to be improved.

Em relação ao fluxo de informações entre os serviços, durante os mecanismos de referência e contra-referência para o atendimento do doente de TB, este estudo assinala a descontinuidade desta informação, dificuldade das equipes dos serviços em garantir o registro dessas informações e a não-participação do doente neste processo, o que pode se configurar em obstáculo para a continuidade da assistência. Apesar deste mecanismo ocorrer mediante um complexo regulador no município em estudo, se faz necessário aprimoramento do mesmo.

Therefore, the study indicates that the perception of TB patients in relation to their participation in the therapeutic process was considered to be regular and indicates that the way the TBC team organizes care does not offer conditions for patients to effectively participate in the decision-making process or choose the service to which they would be referred, evidencing a strong predominance of the curative model focused on technique and disease instead of the individual, as well as indicating poor and merely insipient co-responsibility. When users of the health system in Holland were asked about the referral and counter-referral process among primary and secondary health care services, they pointed out the discontinuity of care between these two types of services. Coupled with it, they did not feel apt to choose a hospital or health service; they stated they could judge the type of hospital but not the performance of specialists working in these services[15].

One study conducted in the United States with 250 patients with chronic conditions revealed that the transfer of information during the referral of patients in primary health care to specialists has been critically important. Most patients (85%) were satisfied with the information received during this process. In contrast, 16% considered the written information provided to be incomplete and 15% did not receive any written information, at all. The authors indicate a strong association of quality of information offered by the physician in primary health care when referring patients to a specialist, showing satisfaction with the coordination of care[16].

The TB patients interviewed in this study considered the quantity of written information available in the medical file to be regular, both to take to the specialist (referral) and also the information provided by the specialist to the TCP worker (counter-referral). The difficulty in ensuring the recording of information by the teams in the different services during this mechanism may hinder the actions to be taken by these workers. There are studies indicating the dissatisfaction of users in relation to the time taken by specialists at the secondary level to send information to generalist physicians at the primary level, dissatisfaction concerning the content of information (incomplete), and complaints of professionals at the primary health care level for not receiving information from specialists from another level of care[15]. Studies show that there are problems in the completion of forms (referral forms) originating at the PHC level such as *illegibility, lack of information concerning the duration of the patient's complaint* and information important to reach a diagnosis or to solve the problems presented [17].

The practice of referral and counter-referral in Brazil is exercised as an agreed guideline of a service, as one of the focuses of management, to ensure the continuity of care. For this to happen, qualification and continuing education to improve clinics and master relationship techniques is required[18]. The importance of a physician, primary health care provider or specialist who is capable of coordinating the transfer of information from one service to another to improve care coordination, was reported in some studies[14-16]; it would be crucial within TB services. Care coordination should be systematically performed and be structured with clarity of roles, responsibility and strong monitoring.

Yet in relation to the flow of information, we note that there is no system of information integrating the network of SUS services in the studied city, which could help managers and health workers to carefully plan actions and services, reduce costs and increase the effectiveness and efficiency of services that compose the public system, since the various systems of information used at each hierarchical level hinder the monitoring of patients and the integration of services. Studies addressing tuberculosis indicate the discontinuity of information in care provided to TB patients and the need to organize the flow and counter-flow of patients among the different services and care levels[8,19].

This lack of involvement with the patient during the care process was also verified in another study in which the interviewed patients (most with chronic conditions) considered it important to be treated with seriousness by PHC physicians and specialists and these should listen to them attentively, providing resources and precise information, informing them concerning the advantages and disadvantages of treatments and referrals, enabling their participation in the decision-making process[15]. Curiously, another study conducted in Holland indicated that most referred patients became involved in the decision-making process concerning their treatment with the specialist and also brought information concerning their follow-up to the referring physicians or PHC provider[16].

The services that use protocols tend to be great in urgency and emergency situations or when dealing with severe diseases because protocols are highly respected management tools. However, they tend to be limited in more complex situations or when dealing with chronic diseases because the work incorporate to the routine lead workers to perform their work in an uncritical manner[20].

Yet, it is important to encourage TB patients to become active agents in this context, sensitizing professionals and managers to empower patients through their active participation and also encourage them to become co-responsible for the needs and problems identified during care.

CONCLUSION

The analysis of care coordination from the perspective of TB patients, professionals of the TB control program and managers of PHC units enabled us to identify the organization of health services and the way actions to control the disease are developed, as well as which resources are necessary to continue the care process.

The reports indicate that a large part of coordination actions during the care process has been satisfactory. However, the flow of information within the referral and counter referral process of TB patients is discontinuous without a system of information integrating the services and optimizing the coordination of patients within the system. There is also a need to increase the participation of patients during treatment decision-making. Hence, the care coordination of TB cases requires a flexible model based on the integration of care with professionals imbued with knowledge willing to listen patients and play their role of educators, encouraging patients to become autonomous and share responsibility in care.

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