ARTIGOS ORIGINAIS

The reliability of information records in the Health Information System: surveillance of intra-domiciliary leprosy contacts

A confiabilidade dos registros de informações no Sistema de Informação em Saúde: vigilância de contatos intradomiciliares de hanseníase

La confiabilidad de los registros de las informaciones en sistema de Información en Salud: vigilancia de los contactos intradomiciliares de hanseniase

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Abstract

The objective of this study was to compare intra-domiciliary contacts (IDCs) in the Health Information System (SIS) with records of people diagnosed with leprosy. This was a cross-sectional, retrospective, and quantitative study based on the physical information collected in medical records and the SIS records in 2015 and 2016, in a municipality in the countryside of the State of São Paulo. We used an instrument with variables related to IDCs such as gender, age, relationship, disease, BCG-ID vaccine, SIS records, and descriptive analysis. Out of the 81 IDCs from 40 diagnosed patients, 72 were evaluated, and 71 were included in the SIS. One IDC became ill after the end of treatment of the index case. The prevalent gender among IDCs was female, young adults, and children. A difference of 12.4% as observed between the physical and SIS records; a difference of 11.1% was observed when correlating 81 records with the frequency of the 72 evaluated IDCs. It is concluded that the IDC and SIS records are in disagreement.

Keywords: Leprosy; Health communication; Health Information System; Public health surveillance; Epidemiology.

Resumo

O objetivo deste estudo foi comparar os contatos intradomiciliares (CIs) do Sistema de Informação em Saúde (SIS) com os registros de pessoas diagnosticadas com hanseníase. Estudo transversal, retrospectivo e quantitativo, baseado nas informações coletadas em registros físicos e do SIS em 2015 e 2016, em um município do interior do Estado de São Paulo. Foi utilizado um instrumento com variáveis relacionadas aos CIs: sexo, idade, relacionamento, doença, vacina BCG-ID, registros SIS e análise descritiva. Dos 81 CIs de 40 pacientes diagnosticados, 72 foram avaliados e 71 foram incluídos no SIS. 01 CIs adoeceu após o término do tratamento do caso índice. O sexo prevalente dos CIs é feminino, adulto jovem e filho. Entre os registros físicos e do SIS, houve uma diferença de 12,4%; e correlacionando os mesmos registros (81) com a frequência dos CIs avaliados (72), há uma diferença de 11,1%. Conclui-se que existe discordância entre os registos de CIs nos registos com o SIS.

Palavras-chave: Hanseníase; Comunicação em Saúde; Sistema de Informação em Saúde; Vigilância em Saúde Pública; Epidemiologia.

Resumen

El estudio tiene el objetivo de comparar las anotaciones de comunicantes intradomiciliares (CI) del Sistema de Información en Salud (SIS), con las de los prontuarios de las personas diagnosticadas con leprae. En el presente trabajo se analizaron los resultados obtenidos en el análisis de los resultados obtenidos en el análisis de los resultados obtenidos, evaluados en los registros del SIS. De los 81 CI de 40 pacientes diagnosticados, 72 fueron evaluados y 71 fueron incluidos en el SIS. Y en el caso de las mujeres, El grado de parentesco frecuente fue infantil, mujeres y adultos jóvenes. Entre las anotaciones del SIS y los prontuarios, hay diferencia del 12,4%; y correlacionando los mismos registros (81) con la frecuencia de los CI evaluados (72), hay una diferencia del 11,1%. Se concluye que hay discordancia entre los registros de CI en los prontuarios con el SIS.

Palabras clave: Lepra; Comunicación en salud; Sistema de Información de Salud; Vigilancia de la salud pública; Epidemiología.

Introduction

Leprosy is one of the most ancient diseases that affect man and continues to be a public health problem worldwide. In Brazil, the Unified Health System (SUS) provides free treatment to all patients, which can lead to healing[1,2]. The diagnosis is based on clinical physical, neurological, and dermatological evaluation to identify lesions or areas in the body with spots, changes in sensitivity and/or impairment of sensory and motor peripheral nerves, followed by consideration of the epidemiological disease profile in the region[3].

The World Health Organization[4] confirmed 210,758 new cases of leprosy worldwide in 2016 with the rate of detection of 3.2/100,000 inhabitants. Brazil ranked second place in the global ranking, with 26,395 cases diagnosed, representing 13% of all cases. In the State of São Paulo[5], 1,213 new cases were detected through 3,656 intra-domiciliary communicators (IDC); from these, only 91.2% had a physical-neurodermatological evaluation and prevalence of 0.38/10,000 inhabitants. In the Group of Epidemiological Surveillance (GES29), which covers 67 municipalities in the mesoregion of Sao Jose do Rio Preto, São Paulo, 90 new cases were registered through 207 IDCs, being 95.8% evaluated.

The health sector in Brazil still faces many challenges; among them, the proper use of Information Technology. In this aspect, Information Technology is becoming a market requirement because it is an important tool for the management of services by providing elements for prevention actions and diseases control, and thus, its quality needs to be improved[6].

Hence, the data on the surveillance of contacts related to leprosy should be consolidated, analyzed, and feedbacked methodically in order to become a trusted source of information to guide health professionals in making responsible decisions about primary care through diagnosis, prevention, and treatment of disabilities. In addition to surveillance, this source can stimulate communication, health education, and social mobilization[3,7].

The proportion of IDCs examined in newly diagnosed cases of leprosy is an indicator that was used to assess the quality of services to assist in disease aggravations, and the ability to perform the surveillance of contacts related to new cases. The parameters used were: good: ≥ 90.0%, regular: ≥ 75.0 to 89.9%, and precarious: < 75.0%[2]. All IDCs of individuals diagnosed with leprosy should undergo a physical-neurodermatological evaluation and receive guidance on disease progression. Professionals should record the information in the notification record and the National Information System of Reportable Diseases (SINAN).

For operational purposes IDCs are any person who resides with a leprosy patient or has resided with someone with leprosy in at least the last five years. Thus, the importance of training health professionals is emphasized for the effectuation of the correct completion of reporting forms and forms that compose the patient's medical records as well as recording this information in the SINAN[7]. Studies on the transmission of leprosy demonstrate that those living with and in contact with leprosy patients are to 3.5 times exposed to higher risk of becoming ill compared with those in the general population. Household individuals in contact with multibacillary cases (MB) represent a group characterized by high exposure to the bacillus[8,9,10].

Therefore, from the epidemiological point of view, one of the key activities to avoid the increase of transmission of this disease is the surveillance of contacts, which can increase the opportunity to early leprosy diagnosis and treatment[11]. Researchers say that the control of ICs has been devalued and ignored because health services focus on the control of the disease in the patient, relegating the surveillance of contacts to a secondary level[11-15]. This study aimed to compare the records of intra-domiciliary communicators in the SINAN that represent annotations in the form of notification and/or in the medical records of people diagnosed with leprosy.

Material and methods

This was a descriptive and cross-sectional study with a quantitative approach. The data collection was carried out in June and July of 2017, covering 2015 and 2016, in São José do Rio Preto, a city in the countryside of the State of São Paulo (SP) Brazil with an estimated population of 450,657,000 inhabitants. Data were collected in the SINAN 5.2.0.0 and notification records of the specialized service of chronic diseases, in Unit II of tuberculosis and leprosy, using a specific instrument developed and validated by the research group. During the study period, 41 cases of leprosy were reported, all of them residing in the municipality and encompassing all forms of entry used for the analysis of IDCs annotations.

One medical record was excluded due to the lack of information on the studied variables. The following variables were considered for data collection: gender, age, relationship to the reported case, IDC disease, indication and application of BCG-ID, and records of existing and evaluated IDCs. These variables were collected in the SINAN database and in the medical records of those who underwent physical, neurological, and dermatological evaluation.

The data were tabulated in Excel© 2016 spreadsheets and submitted to descriptive analysis. The Epi Info 7 ™ software was used to calculate absolute and relative frequency, which were presented in a chart and analysed by the team. The research project was approved by the ethics committee of the School of Medicine of Rio Preto (FAMERP - CAAE. 5415/2017) and the Municipal Health Secretary, in compliance with the rules of laws in force in Brazil[16,17].

Results

Forty medical records were analyzed in the chronic diseases outpatient clinic - Unit II, all records and descriptions of cases of illnesses; within these records, 81 IDCs were informed by the patients and out of these, 71 were evaluated and recorded in the SINAN. A loss of 12.3% of records in the system was evident when compared with the information contained in the medical records.

Out of the 81 studied IDCs, the female's frequency was higher than males (N=48; 59.3%), and the predominant age group was that of young adults (N=35; 43.2%). Among the IDCs (N=81), 72 (88.9%) were evaluated with the physical-neurodermatological exam at some time in the health unit. The annotations in the records identified one IDC (1.2%) who fell ill after the end of treatment of the index case. The degree of kinship most present in this study was of children (N=31; 38.4%) followed by the spouses (N=19; 23.5%), Table 1.

Table 1– Distribution of frequencies of gender, age, and kinship in the recorded IDCs in the leprosy patients' records

	Variables	Total sample (81)	
		N	%
Sex	Feminine	48	59.3
	Male	33	40.7
Age	0 a 19	29	35.8
	20 a 49	35	43.2
	50 a 64	10	12.3
	65 or more	04	4.9
	Missing	03	3.7
Kinship	Conjugate	19	23.5
	Son (a)	31	38.4
	Brother (ã)	07	8.6
	Mather/Dad	04	4.9
	Grandson (a)	07	8.6
	Nephew (a)	06	7.4
	Others	03	3.7
	Missing	04	4.9

Source: medical records, leprosy notification form, tuberculosis outpatient clinic, and leprosy in the Municipality of São Jose de Rio Preto, SP in 2017.

Out of the 81 IDCs registered in the medical records, 72 (88.9%) were evaluated by a health professional; 66 (81.5%) received at least one dose of BCG-ID, three (3.7%) did not receive any dose, two (2.5%) did not have this information recorded in their medical records, and 10 (12.3%) were not evaluated by the health team, Table 2.

Table 2 – Distribution of BCG vaccine application at the time of the IDCs evaluation (n = 81)

Doses	N	%
Zero dose	03	3.7
One dose	66	81.5
Have not been evaluated	10	12.3
Missing	02	2.5
Total	**81**	**100**

Source: medical records, leprosy notification form, tuberculosis and leprosy outpatient clinic in the Municipality of São Jose de Rio Preto, SP in 2017.

When comparing the quantity of IDCs described in the medical records with the quantity recorded in the SINAN, it is observed that the higher the number reported in the medical record, the lower it is informed in the information system, Figure 1.
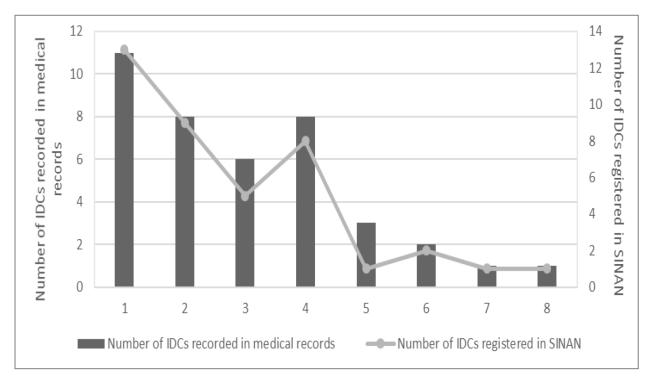
Figure 1 – Comparative chart of the number of IDCs registered in the medical records/notification form of patients vs. the number of IDCs registered in the SINAN
Source: The authors (2017).

A difference of 11.1% was observed when comparing the same numbers of IDCs registered in the patient's medical record (N = 81) with the number of those who had been evaluated by the health service (N = 72). Figure 2 shows that the higher the number of IDCs recorded in the medical records, the lower the number of those evaluated.
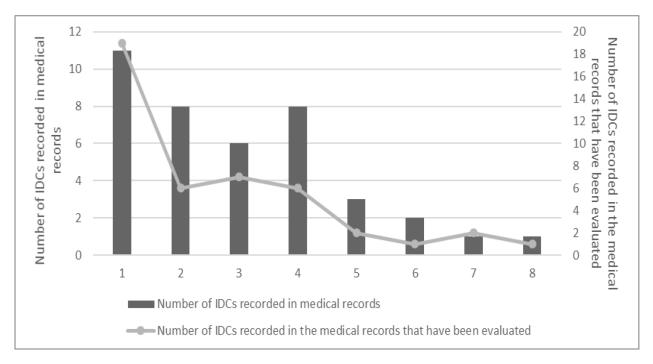

Figure 2 – Graph comparing the number of IDCs recorded in the medical records vs. IDCs evaluated in the health service and recorded in the medical records
Source: The authors (2017).

Discussion

Health Information Systems becomes an essential tool in the 21st century, especially in the area of health, where communication is used as a strategy to ensure continuity of care. However, it is believed that, in practice, there is a need to improve and refine information between the physical and digital realms. This study was conducted in a city in the countryside of São Paulo state, with a leprosy prevalence coefficient of 0.44/10,000 inhabitants in 2015 and 0.55/10,000 inhabitants in 2016, based on the Ministry of Health (MH) and the WHO parameters. Since 2007, the municipality keeps the goal of eliminating the disease until it reaches less than one case per 10 thousand habitants[18]. The indicator above is performs the monitoring and the progress in the elimination of leprosy as a public health problem[2,4].

The WHO[19] launched the 2016/2020 global strategy of aggravation, aiming at the acceleration into a world without leprosy, emphasizing the importance of early detection of cases before the onset of visible disability, especially in children younger than 15 years old, to achieve what is necessary to reduce transmission. Among other goals, the development of national plans to ensure the examination of all close contacts is the objective of 100% evaluation in IDCs.

The epidemiological investigation of reported cases should be carried out through the evaluation of persons who live or have lived in the household or outside it with the patient. This leads to the source of infection and recognizes other cases originating from the same index case, the communicant, which, when diagnosed early, can break the chain of transmission[20] In this study, the IDCs were mostly females; in other investigations, females were also predominant with reports of 59.1%,[21] 59.6%,[22] 50.3%,[23] and 51.1% [24]. A similar study was conducted in Colombia[25].

The importance of checking the gender of IDCs is clear in an analysis from the MS, which showed that the chances of presenting forms of MB are approximately two times higher in both males and individuals over sixty (60) years of age or older; therefore, the need for an active search of cases through the examination of contacts in males is essential because they attend fewer health service consultations based on cultural aspects. It adds to the difficulties of access to health units which, in large part, do not offer alternative operating hours such as hours outside of the business days[26].

We identified in the records/notification form that 88.9% of the patients passed through an evaluation at one time. Based on the MS parameters, the municipality has a surveillance of contacts determined as "Regular"[2]. Other studies show smaller percentages and considered precarious as reported by Lozano[22], whose percentage was 30.8%, and among other studies, these were; 36.8%,[27] 38.4%[23,] and 56.7%[28]. A recent survey with different analysis showed that only 52.9% underwent dermatological examination and 38.5% neurological exam[21].

The evaluation of IDCs is a challenge for the leprosy control program when considering the separation of cohabiting along the years and the difficulties for the health service to locate them and bring them to the clinic for evaluation and administration of the BCG vaccine. In recent years, the monitoring of leprosy IDCs outside their domicile has been widely discussed by researchers in the area, stressing that the recovery of control and expansion beyond the family circle, involving social contacts in routine activities is important[2, 23, 24].

In the analysis of documents, we saw that one (01) IDC fell ill during the treatment of the index case. In literature, this number extends to other new cases both in studies with larger[22,23] and smaller populations[28]. The illness in persons close to the index case identifies the presence of other individuals possibly infected and not treated, and already in the MB phase.

The IDCs have greater risk of illness than those outside of their domicile due to most intimate coexistence, whereas, these individuals should be examined for signs of disease and be advised about the symptoms in the aggravation phase, and to seek the health service when any "cutaneous lesion or any motor change or of sensitivity" is presented, despite the fact that 95% of the population are naturally

resistant to infection by M. leprae.[4,29,30] A recent study in Pará, with a different scenario and methodology, showed an increased risk of disease in this population[31].

Young adults were predominant among the IDCs, which corroborates the reports in the literature of similar proportions such as 79%[27], 66.5%[23], and 47,8%[25]. The population of adolescents and young adults prematurely exposed can develop the disease in their productive age due to the long incubation period[32].

According to this and other studies, the majority of IDCs, in the fertile phase, may be subject to complications from aggravations if they fall ill and are diagnosed late, which is considered of great incapacitating potential, reinforcing the seriousness of the variable and affirming the importance of all contacts to be examined.

The frequency of individuals younger than 19 years old was high. A study in the State of Maranhão[33,34] with 183 cases showed 12.5% while another in the State of Para showed 5.4% among 222 cases. The high M. leprae bacillary load of the disease allows multiple exposures in the population, including in the first years of life, favoring disease transmission and maintenance of its magnitude. The detection of cases in patients younger than 15 years old means that the focus of transmission is active, and its monitoring is relevant to control the spread of the disease[27,4]. The age range is an important indicator when patients are detected.

The analysis of kinship showed a predominance of children; according to other studies,[21,28] these percentages were classified as 59.1% first-grade consanguineous, 22.6% second-grade, and 16.2% non-consanguineous[23].

"Continuous surveillance" of IDCs with BCG-ID vaccination, detection of anti-PGL1 IgM antibodies, the follow-up of patients after treatment by measuring the bacilloscopy index, and studies to improve methods of analysis with the use of biomarkers are necessary to break the chain of transmission and aggravation and to reduce indicators of prevalence and incidence[35,36].

Out of the 72 evaluated IDCs, 81.5% received at least one dose of the vaccine. Femina[28] describes the lowest rate. The health professional should be skilled and cautious in the indication of BCG-ID, which needs to be indicated when any possibility of leprosy diagnosis has been excluded. Continuation of case research rather than BCG administration should proceed if the patient shows signs and symptoms characteristic of the disease[2,3,24].

Although there is no specific vaccine against the disease with high levels of protection, BCG-ID provides variable protection; two doses offers three times greater protection against the disease and other forms of the disease, particularly if they are administered in children under 15 years of age[4,37]. The nursing staff has an important contribution in the control of leprosy effecting the surveillance of contacts and maintaining vaccine application coverage[38].

The Health Information Systems are complex tools and compounds, which aim at the promotion, organization, operation, and production of information[38]. In this study, we compared the number of IDCs recorded in medical records with those registered in the system. It was identified that the greater the number described in the record, the lower the number recorded in the SINAN. A recent study also noted this discrepancy of information between medical records and the SIS[28] The lack of knowledge about communication does not allow effective surveillance, and thus, makes an early diagnosis and breaking the chain of transmission difficult.

In order to meet the contacts examined in SIS, this evaluation method is also insufficient to analyze other diseases[39]. The findings reinforce that the system requires an improvement in addition to increased demand in professional training and in strengthening their link with primary care.

Among many other IDCs surveillance actions to achieve the elimination of leprosy, appropriate recording in the SIS is fundamental to understand the reality of this disease and formulate relevant policies based on improved decision-making, planning, implementation, and evaluation of health programs in all spheres of government; however, this is not recognized and practiced as such[40,41,42]. The problematization can be related to organizational issues, lack of staff training, and lack of knowledge about the importance of recording all data that are recommended by the MS[43].

The SINAN covers only the amount of records of examined IDCs, leaving the description of the entire patient's follow-up to the patient's medical records. A considerable amount of sub-notification of these elements was

observed in this and other studies. This makes the data susceptible to errors and not trustworthy because the information may not represent the population assisted and prevent proper management, care, and planning[44,45].

Thus, it is necessary that the existing gaps are fulfilled. The absence of monitoring in the process configures the loss of opportunities to assess the severity of an illness or disease, causing possible damage to its effectiveness. What is needed is the qualification and consecutive monitoring of these records so that they fulfill their aims with quality and credibility[44].

A considerable difference is observed when comparing the number of IDCs records in the patient's medical records and those who underwent evaluation in the health service; it is understandable that several were not evaluated, and those who were evaluated through the physical-neurodermatological examination were not considered in the physical records. The absence of surveillance of IDCs data in the medical records is noticed. This discrepancy of information was also scored in the literature[21,22]. The need for an effective surveillance to achieve the WHO goal of 100% of evaluation of household contacts until 2020 is highlighted.

Medical records are considered as the main place of follow-up recordings for patients affected by leprosy, including various parameters such as surveillance of contacts (name, age, kinship, and evaluation). It is recommended that the information should be updated whenever there are evaluation and identification of new contacts; the verification of inconsistencies in the SIS should also be recorded[2,4]. The literature had already reported, at the beginning of the 21st century, that an efficient surveillance of contacts and quality of records of information should constitute one of the pillars of the actions for eradication of leprosy[15].

We emphasize that epidemiology is a tool for controlling endemic diseases such as the disease in this study. The appreciation of the quality of the data and the completion of forms are essential. The nursing team, which monthly accompanies diagnosed patients and, therefore, acts directly on the maintenance and updating of their epidemiological findings, is supposed to be the fundamental axis in this context[46].

The constant and detailed recording of data and the follow-up of diagnosed cases in their IDCs are indispensable to collaborate in breaking the chain of transmission of leprosy. Multi-professional teams target the nursing service with the meticulous work of these recordings. We emphasize that the small sample size in this study due to difficulties in time availability did not allow results with statistical significance and represent a limitation in this study.

Conclusion

Considering the evaluated scenario, it was observed that there is a 12.4% disagreement between the records referring to IDCs in medical records and the Information System. In the physical records, important information for contact surveillance is absent, or incomplete when described.

In the SINAN, only quantitative information from IDCs is reported. One of the difficulties for management is to obtain further information about the responsibility of the professional who operates in the disease control program.

Discordant information hinders the continuity of the care because health communication has to be effective so that all actors involved in the care can act appropriately.

We consider the real need for training and qualification of human resources to understand the importance of contact surveillance and relevance of communication. There are few studies in the literature on the quality of medical records and information systems in order to actively monitor and seek IDCs.

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