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Difficulties coping with leprosy during treatment and post-discharge

Dificuldades no enfrentamento da hanseníase no tratamento e pós-alta

Dificultades para afrontar la lepra durante el tratamiento y en el período posterior al alta hospitalaria

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Abstract

Objective: To identify the main difficulties and the epidemiological profile during treatment and post-discharge in patients with leprosy treated at the Secondary Care level in Teresina-Piauí. **Methods:** This is a cross-sectional and quantitative study that identified needs and surveyed data from patients undergoing leprosy treatment in a reference service located in Teresina-Piauí. **Results:** In the sample, there was predominance of male patients (58.5%), married or in a stable union (54.7%), with complete Elementary School (62.3%), incomes of 1 to 2 minimum wages (66.0%) and residents of Teresina-Piauí (90.6%). The mean age of the patients was 53 years old. 9.4% abandoned the treatment. 90.6% of the patients presented some type of sequelae post-discharge. It was noticed that lack of knowledge about leprosy delayed access to the health system. A significant association was verified between the "presence of sequelae" variable and change in sensitivity ($p = 0.014$). The reports about prejudice were more frequent during the treatment (41.5%) than in the post-discharge period (15.1%). **Conclusion:** Leprosy is still a neglected, stigmatized and difficult to diagnose disease, with a need for greater investments in public policies to disseminate knowledge about the disease.

Descriptors: Leprosy; Therapy; Health Profile; Knowledge; Social Stigma.

Whats is already known on this?
Leprosy is stigmatized and associated with low schooling and socioeconomic levels, which contributes to late diagnosis and treatment with worse prognosis, in addition to the prejudice suffered by the patients.

What this study adds?
In the sample analyzed it can be seen that the main difficulties during treatment were delayed diagnosis and the prejudice suffered and, post-discharge, disease sequelae in addition to prejudice.

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Resumo

Objetivo: *Identificar as principais dificuldades durante o tratamento e pós-alta de pacientes com hanseníase atendidos na Atenção Secundária em Teresina-Piauí e seu perfil epidemiológico.* ***Métodos:*** *Trata-se de um estudo transversal, quantitativo, que identificou necessidades e levantou dados de pacientes em tratamento de hanseníase em um serviço de referência localizado em Teresina-Piauí.* ***Resultados:*** *Na amostra, observou-se predomínio de pacientes do sexo masculino (58,5%), casados ou em união estável (54,7%), com ensino fundamental completo (62,3%), renda de 1 a 2 salários mínimos (66,0%) e residentes em Teresina-Piauí (90,6%). A idade média dos pacientes foi 53 anos. 9,4% abandonaram o tratamento. No pós-alta, 90,6% dos pacientes apresentaram algum tipo de sequela. Notou-se que a ausência de conhecimento sobre a hanseníase retardou o acesso ao sistema de saúde. Verificou-se associação significativa entre a variável presença de sequela e alteração de sensibilidade (p = 0,014). Os relatos de preconceito foram mais frequentes durante o tratamento (41,5%), em relação ao pós-alta (15,1%).* ***Conclusão:*** *A hanseníase ainda é uma doença negligenciada, estigmatizada e de difícil diagnóstico, sendo necessário maiores investimentos em políticas públicas para a difusão de conhecimentos sobre a doença.*

Descritores: *Hanseníase; Terapêutica; Perfil de Saúde; Conhecimento; Estigma Social.*

Resumén

Objetivo: *Identificar las principales dificultades durante el tratamiento y el período posterior al alta hospitalaria en pacientes con lepra atendidos en el nivel de Atención Secundaria de Teresina-Piauí, además de su perfil epidemiológico.* ***Métodos:*** *Estudio transversal y cuantitativo que identificó necesidades y relevó datos de pacientes en tratamiento para la lepra en un servicio de referencia ubicado en Teresina-Piauí.* ***Resultados:*** *En la muestra se observó predominio de pacientes del sexo masculino (58,5%), casados o en unión estable (54,7%), con Escuela Primaria completa (62,3%), ingresos de 1 a 2 salarios mínimos (66,0%) y residentes de Teresina-Piauí (90,6%). La media de edad de los pacientes fue 53 años. El 9,4% abandonó el tratamiento. En el período posterior al alta hospitalaria, el 90,6% de los pacientes presentó algún tipo de secuela. Se notó que la falta de conocimiento sobre la lepra demoró el acceso al sistema de salud. Se verificó una significativa asociación entre la variable "presencia de secuelas" y alteración en la sensibilidad (p = 0,014). Los testimonios relacionados con prejuicio fueron más frecuentes durante el tratamiento (41,5%) que en el período posterior al alta hospitalaria (15,1%).* ***Conclusión:*** *La lepra sigue siendo una enfermedad desatendida, estigmatizada y de difícil diagnóstico, siendo necesario implementar mayores inversiones en políticas públicas para difundir conocimientos sobre la enfermedad.*

Descriptores*: Lepra; Terapia; Perfil de Salud; Conocimiento; Estigma Social.*

INTRODUCTION

Leprosy is one of the oldest diseases of humanity, being reported even in biblical times, and has a prolonged course with chronicity and infection occurring from the installation of *Mycobacterium leprae*, a highly reactive bacillus that affects the superficial and peripheral skin nerves, which can cause physical disabilities and affect visual and internal organs of the body, in addition to the different complications that may arise, such as neurological or so-called leprosy reactions.(1,2)

The *Mycobacterium leprae* infection primarily affects the skin (resulting in erythematous papules or macules), the peripheral nerves (resulting in loss of sensitivity or a "pins and needles" sensation), and the upper respiratory tract mucosa.(3,4)

As there used to be no treatment, people with leprosy were socially excluded and started to live alone, which generated a significant stigma about the disease that lasts until current time, as part of the population still has little information about the disease, its transmission and its treatment. Gerhard Hansen's studies and, later in 1980, the introduction of polychemotherapy treatment (PCT), with positive effects, led to a reduction in prevalence of the disease; however, Brazil is still the second country in number of cases worldwide and leprosy is still perpetuated as a public health issue.(5,6)

As of 07/01/2021, the leprosy treatment, offered by the Unified Health System (*Sistema Único de Saúde*, SUS), began to be performed with Single Polychemotherapy (PCT-S), both for paucibacillary (PB) and multibacillary (MB) cases, with a rifampicin + dapsone + clofazimine association. In PB, the treatment consists of 6 monitored doses for 6 months, with the possibility of extending to 9 months. In MB, it consists of 12 monitored doses for 12 months, with the possibility of extending to 18 months, in addition to the self-administered daily doses.(2)

In cases of leprosy reactions, when type 1, treatment with non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics is performed if the manifestations are mainly cutaneous; if these manifestations are accompanied by neuritis or more severe reactions (ulcerations or edema), prednisone (1 mg/kg/day or 40 mg/day) is used, with a gradual reduction according to clinical improvement, until total withdrawal in a period of nearly 4 – 6 months; for type 2 reactions, thalidomide (100 – 400 mg/day) is used in male patients, children and older adults with skin lesions only.(7,8)

In women of childbearing age, the use of NSAIDs and analgesics is initially tried; if there is no therapeutic response, prednisone (40 mg/day) is introduced, with a gradual reduction according to clinical improvement. In cases of skin lesions associated with neuritis, uveitis, orchitis and reactional hand, treatment is performed with prednisone 1 mg/kg/day, with a gradual reduction. When the prednisone dose is around 20 mg/day or below, thalidomide 100 – 400 mg/day is usually associated to prevent recrudescence of the reaction, always avoiding thalidomide in women of childbearing age. Therefore, it is noted that the leprosy treatment is long and complex.(7,8)

Type 1 leprosy reaction generates inflammation (associated ocular inflammations can lead to blindness), pain in pre-existing lesions (it can generate ulcers) and, if damaging facial nerves, it causes facial paralysis; type 2 leprosy reaction results in acute inflammation of the skin and nerves and can form painful subcutaneous nodules; it is more difficult to treat than type 1 due to its systemic and recurrent nature and, thus, it is observed that a patient with leprosy presents an extremely debilitating condition.(9)

It is worth noting that the prevalence of leprosy is also associated with a low schooling levels, low health system quality and/or reach, insufficient investment in prevention and precarious housing conditions.(10) In Brazil, facilitating access to Primary Health Care (PHC) resulted in a lower prevalence between 2000 and 2021, although it is still insufficient for the disease to stop being a public health issue.(11) It is also worth mentioning that, in Brazil and due to the significant sociodemographic heterogeneity across its regions, the distribution of leprosy is heterogeneous. The prevalence coefficients in 2021 were as follows: North (1.95/10,000), Northeast (1.66/10,000), Midwest (2.63/10.000), Southeast (0.44/10,000) and South (0.28/10,000).(12,13)

Thus, due to the stigma associated with leprosy, added to lack of knowledge, people with the disease may delay seeking help, and diagnosis and treatment in the early stages of the disease are essential to avoid unwanted deficiencies and reactions, in addition to assisting in surveillance and control of the pathology.(14)

In addition, the Northeast region is a leprosy endemicity focus in Brazil, a fact illustrated by the general trend of increasing mortality rates between 2001 and 2017.(15) In order to reverse this statistic, as well as to improve the patients' prognoses to avoid disabilities, deformities and psychological sequelae, early diagnosis and treatment as well as psychological monitoring are necessary.(16) For this, it is necessary for health promotion actions to be better planned and for epidemiological surveillance to be strengthened, as well as offering more comprehensive care to the individual.(15)

In view of the above, the objective of this study was to identify the main difficulties during treatment and post-discharge in patients with leprosy treated at the Secondary Care level in Teresina-Piauí and the epidemiological profiles.

METHODS

A cross-sectional and quantitative study was carried out, seeking to identify needs and collect data from patients undergoing leprosy treatment treated in a secondary care center, which is a reference for the treatment and rehabilitation of leprosy patients and has a multiprofessional team, in addition to being a practice and research field in Teresina-Piauí. The population consisted of a convenience sample, in which patients undergoing treatment or who were already in the leprosy post-discharge period treated at the service were included; those who were attending appointments but lived in another state were excluded.

Approaches to the patients were carried out during the service period, and the participants who voluntarily wanted to participate in the research were handed in the Free and Informed Consent Form (FICF). The data were collected by the researchers themselves from October to December 2021, with the help of semi-structured forms, which were filled out using diverse information collected in direct contact with the patient. The forms corresponding to each patient were identified with cardinal numbers in increasing order: Pat. 01, Pat. 02, Pat. 03..., until reaching the limit of patients found in all three data collection months.

The collection form consisted of three blocks with questions related to the study objectives. Block I (sociodemographic data): gender, age, ethnicity, marital status, schooling, family income and origin. Block II (clinical data): associated comorbidities, medication in use and mobility. Block III (initial evaluation due to an objective question of the patient regarding the difficulties found during treatment and in the post-discharge period).

The data collected were incorporated into databases with double typing in a Microsoft Excel 2013 spreadsheet, in order to evaluate possible errors. Subsequently, they were processed in the *Statistical Package for the Social Sciences* (SPSS) software, version 22.0. In order to characterize the sample, descriptive statistics was performed, with absolute and relative frequency measures. To verify the association between the qualitative variables, Pearson's chi-square test (χ^2) was used, adopting 0.05 as significance level.

This study was approved by the Research Ethics Committee of the Piauí University Hospital (*Comitê de Ética em Pesquisa do Hospital Universitário da Universidade Federal do Piauí*, CEP-HUUFPI), Teresina-Piauí, under opinion number 4,576,272 and CAAE 42667320.8.0000.8050. In order to carry out data collection, the participants were informed about the objectives, procedures, benefits and possible risks or discomforts arising from the study, in addition to the consent of their voluntary participation, expressing their agreement through the FICF, respecting the ethical issues related to the participants' anonymity, data reliability and use of the results for scientific purposes. Institutional authorization to use the medical charts was requested by means of the Data Use Commitment Form (DACF).

RESULTS

Table 1 presents the sociodemographic characterization of the sample of patients with leprosy included in the study. There is predominance of male patients (58.5%), married or in a stable relationship (54.7%), with complete Elementary School (62.3%), incomes of 1 to 2 minimum wages (66.0%) and living in the municipality of Teresina-Piauí (90.6%). The mean age of the patients was 53 years old.

Figure 1 indicates the distribution of the patients regarding the "leprosy treatment abandonment" variable, in which 9.4% abandonment is evidenced. Figure 2 below shows that, post-discharge, 90.6% of the patients with leprosy presented some type of sequelae.

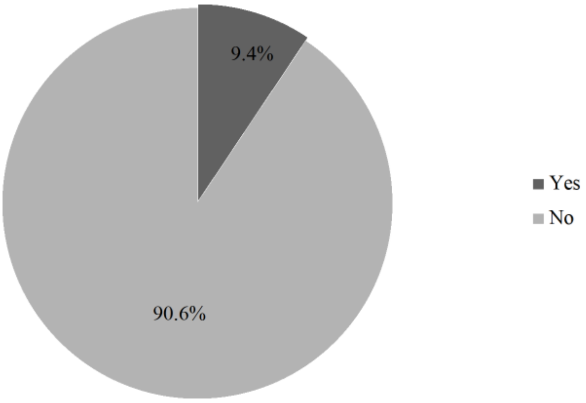
Higher percentages of sequelae were found among the patients with comorbidities, who walked with assistance, who had changes in sensitivity, wounds and spots on the head, trunk and limbs, and who reported lack of medication and treatment abandonment (Table 2). In the bivariate analysis, a significant association was verified between the "presence of sequelae" variable and change in sensitivity (*p*=0.014).

Table 1. Sociodemographic characterization of the patients included in the study. Teresina, Piauí, Brazil, 2021.

Sociodemographic variables	N	%
Gender		
Female	22	41.5
Male	31	58.5
Marital status		
Single	15	28.3
Married/Stable union	29	54.7
Separated/Divorced	5	9.4
Widowed	4	7.6
Schooling		
No studies	9	17.0
Elementary School	33	62.3
High School	11	20.7
Income		
No income	9	17.0
Less than 1 minimum wage	5	9.4
1-2 minimum wages	35	66.0
3-5 minimum wages	4	7.6
Place of residence		
Teresina-Piauí	48	90.6
Inland Piauí	5	9.4

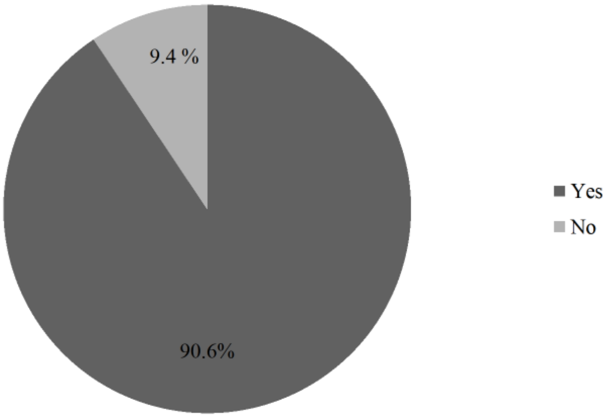
Source: Prepared by the authors (2022).

Figure 1. Distribution of the patients included in the study regarding the “leprosy treatment abandonment” variable. Teresina, Piauí, Brazil, 2021.



Source: authors (2022).

Figure 2. Distribution of the patients included in the study regarding the “presence of sequelae during leprosy treatment post-discharge” variable. Teresina, Piauí, Brazil, 2021.



Source: authors (2022).

Table 2. Association of the “presence of sequelae” dependent variable with clinical variables of the study patients undergoing leprosy treatment. Teresina, Piauí, Brazil, 2021.

	Sequelae			p^1
	Yes N (%)	No N (%)	Total	
Comorbidities				0.087
No comorbidities	26 (86.7%)	4 (13.3)	30 (100.0)	
SAH	8 (100.0)	-	8 (100.0)	
DM	3 (100.0)	-	3 (100.0)	
SAH + DM	8 (100.0)	-	8 (100.0)	
Fibromyalgia	-	1 (100.0)	1 (100.0)	
SAH + DM + heart disease	1 (100.0)	-	1 (100.0)	
Fibromyalgia + rheumatism	1 (100.0)	-	1 (100.0)	
HIV	1 (100.0)	-	1 (100.0)	
Walking				0.664
Without assistance	44 (89.8)	5 (10.2)	49 (100.0)	
With assistance	4 (100.0)	-	4 (100.0)	
Change in sensitivity				**0.014**
Yes	45 (93.8)	3 (6.3)	48 (100.0)	
No	3 (60.0)	2 (40.0)	5 (100.0)	
Presence of spots				0.155
No spots	8 (88.9)	1 (11.1)	9 (100.0)	
Head, trunk and limbs	35 (94.6)	2 (5.4)	37 (100.0)	
Lower and upper limbs	1 (50.0)	1 (50.0)	2 (100.0)	

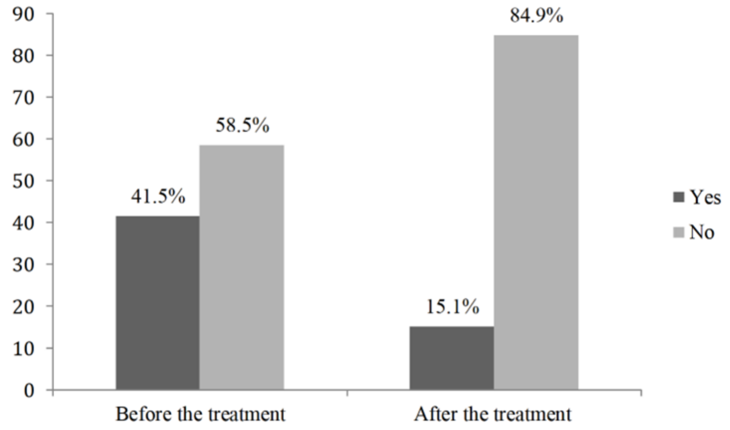
Lower limbs	4 (80.0)	1 (20.0)	5 (100.0)	
Presence of wounds				0.946
Yes	9 (90.0)	1 (10.0)	10 (100.0)	
No	39 (90.7)	4 (9.3)	43 (100.0)	
Lack of medication				0.725
Yes	10 (90.9)	1 (9.1)	11 (100.0)	
No	38 (90.5)	4 (9.5)	42 (100.0)	
Abandonment				0.597
Yes	5 (100.0)	-	5 (100.0)	
No	43 (89.6)	5 (10.4)	48 (100.0)	

[1] Pearson's Chi-square test with 0.05 as significance level.

Source: authors (2022).

As it shows the comparative analysis of reports about prejudice, Figure 3 indicates that there was a reduction at the post-discharge moment (15.1%), when compared to the reports during the treatment (41.5%).

Figure 3. Percentage comparison of reports about prejudice during the treatment and in the post-discharge period among the study patients. Teresina, Piauí, Brazil, 2021.



Source: authors (2022).

According to the data collected, it was observed that the main difficulties during the treatment period were diagnosis delay and the prejudice suffered and, after discharge, in addition to prejudice, it was noticed that these patients still have to live with the sequelae arising from the pathology.

DISCUSSION

It is observed that the results obtained are in line with the literature, given the higher prevalence of leprosy in the male gender and the fact that most of the patients reported variables associated with lower socioeconomic and schooling levels, such as income less than or equal to 2 minimum wages and studies up to complete Elementary School.(2,10)

In the patients' testimonies, it could be observed that the little knowledge they had about the disease delayed their access to the health system due to the difficulty recognizing the signs and symptoms of the disease, such as presence of spots, which was found in 83.0% of the patients. It was also observed that 90.6% of these had changes in sensitivity before emergence of the spots, and this variable was the only one associated with the presence of sequelae in a statistically significant way.

In a study carried out on the perceptions and knowledge about leprosy in endemic districts from India and Indonesia, a low level of knowledge about leprosy was also noticed, especially with regard to the cause, mode of transmission, first symptoms and contagiousness, with high levels of stigma, mainly due to lack of adequate knowledge about the disease, misconceptions, local beliefs and fear of contagion.(17)

Piauí is going through a process of leprosy territory internalization, as most of the current cases already come from the inland.(18) It was noticed that 90.6% of the patients are residents of the state capital city, a fact that can be related to the geographical study locus. As for the patients' clinical characterization, 10 (18.9%) developed wounds due to the presence of leprosy reactions, complications resulting from the body's immune responses due to contact with the bacteria and its reactivity, which can cause scaly and erythematous lesions, as well as leprosy erythema nodosum.(12,13,19,20) These complications further affect quality of life. It is to be noted that the patients reported ending up isolating themselves as a way to avoid prejudice. 56.6% did not present comorbidities and, of those who did, all were controlled and monitored by a multiprofessional team.

A previous study carried out in Indonesia showed that patients with PB leprosy had lower adherence to the treatment when compared to those with MB leprosy, possibly due to the fact that the signs and symptoms are less complex among patients with the PB type of disease, as shown in the literature review carried out by these authors. Early diagnosis and treatment increase patients' adherence to the medication regime and there was no relationship between social stigma and adherence to the treatment among patients with leprosy, according to the results found by these authors. However, as raised in the discussion of the study, the social stigma and consequent isolation of these patients affect social and cultural aspects of personal training.(21)

The data collected in this research showed good adherence to the treatment, given that 90.6% of the patients did not abandon treatment and 79.2% had no problems with lack of medication, factors that corroborate effectiveness of the treatment. It is to be noted that the strategies listed by the patients were always to seek the health service even before running out of the previous medication and to regularly follow the consultations and multiprofessional monitoring. However, a complex social context was perceived in those who reported prejudice due to family and social isolation and even more impacts on treatment and quality of life, leading to greater distancing from health services. It is worth mentioning that the sample of this study consisted of patients treated in Secondary Care and, therefore, already with some disability degree, which is a motivator both for the search and for adherence to the treatment, as shown by data already discussed in the literature by other authors.(21)

In this study, 90.6% of the patients had sequelae after the end of the treatment and 7.5% walked with assistance for having myasthenia and foot drop. Failure to early recognize leprosy signs and symptoms and the difficulty getting the diagnosis contributed to this situation, as a good part of the patients reported attending two or three places until they were in fact referred to a specialized health center to carry out the necessary consultations and tests for the diagnosis.

As shown by the results of a previous study carried out in India, the delay in diagnosing leprosy, whether due to issues related to the patients or to health care, is an important factor for the presence of disabilities in adults affected by the disease. In the data surveyed by the authors, a large proportion of disability cases were unaware of the initial symptoms, mainly for believing that they would regress spontaneously, showing the importance of health promotion and prevention programs in this context.(22)

The study limitations are the sample size and the fact that the research was carried out in a single center. Although the study locus serves a large number of people monthly, it was not possible to have a larger sample due to the very purpose of the study, as most of the patients are in the phase to search for the diagnosis, or even initiating the treatment.

Consequently, the study contributed to helping identify the main difficulties during treatment and post-discharge in patients with leprosy assisted in Secondary Care at the local level and in the construction of the epidemiological profile of these individuals, as well as in the vision of their perceptions about the disease, also showing that further research studies are required on the difficulties inherent to these other phases not covered by the objectives of this study.

CONCLUSION

The main difficulties during leprosy treatment and post-discharge in the sample analyzed were diagnosis delay and the consequent presence of disabilities, which reduces effectiveness of the treatment. The study patients were mostly men and had variables associated with low socioeconomic and schooling levels. In addition to that, most of the patients reported facing prejudice due to leprosy, even after discharge.

Given the above, it was possible to observe that, despite the years elapsed, leprosy still remains a neglected and difficult to diagnose disease. Therefore, it is necessary to invest in public policies for the dissemination of information about the forms of transmission and symptomatology in a simple and accessible language to all population groups, especially those in vulnerability, which are the most affected by the disease, in addition to also being a way to mitigate prejudice around leprosy.

In addition, it is necessary to invest in permanent training and education for health professionals, especially those in PHC, for promotion and early diagnosis in the daily routine consultations at Basic Health Units (BHUs). With this, it will be possible to obtain early diagnoses to reduce disabilities, with a consequent improvement in the quality of life of these patients.

CONTRIBUITIONS

Contributed to the conception or design of the study/research: Sousa JN, Costa REAR, Muniz RKB, Oliveira FTR. Contributed to data collection: Sousa JN, Costa REAR, Muniz RKB, Oliveira FTR. Contributed to the analysis and/or interpretation of data: Sousa JN, Costa REAR, Muniz RKB, Oliveira FTR. Contributed to article writing or critical review: Sousa JN, Costa REAR, Muniz RKB, Oliveira FTR, Lima SM, Bezerra SMG. Final approval of the version to be published: Sousa JN, Costa REAR, Muniz RKB, Oliveira FTR, Lima SM, Bezerra SMG.

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