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DISTRIBUTION OF THE DEATHS FROM CHILDHOOD AND ADOLESCENT CANCER ACROSS THE REGIONAL HEALTH AGENCIES FROM THE *RIO DE JANEIRO* STATE, BRAZIL

Distribuição de óbitos de câncer infanto-juvenil nas regionais de saúde do estado do Rio de Janeiro

Distribución de óbitos de cáncer niños y adolescentes en las regionales de salud del estado del Río de Janeiro

Bianka Queiroz da Silva[1], Rayssa Goulart Valente[2], Aline Cerqueira Santos Santana da Silva[3], Virginia Maria de Azevedo Oliveira Knupp[4], Leila Leontina do Couto Barcia[5], Isabel Cristina Ribeiro Regazzi[6]

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ABSTRACT

Introduction: Despite the increase in patients' survivability, childhood neoplasms continue to occupy the second position in terms of deaths in developing countries. **Objective:** The study's main purpose has been to analyze the spatial distribution of deaths from malignant neoplasms in patients aged up to 19 years old across the regional health agencies of *Rio de Janeiro* State. **Methods:** This ecological study analyzed the spatial distribution of deaths from January to December 2015 through data of the *Sistema de Informações sobre Mortalidade (SIM)* [Mortality Information System]. The data were tabulated in Tabnet and analyzed using the R statistical software. **Results:** Considering the 101 deaths observed, 24 (23.8%) were from central nervous system cancer. The Metropolitan I regional health agency had the highest death rates (63.3%), and *Baixada Litorânea* had the highest proportion of deaths from leukemia (27.9%). **Conclusion:** Identifying the most frequent deaths from malignant neoplasms makes it possible to formulate public policies aimed at prevention, diagnostics, and treatment consistent with the local reality.
Descriptors: Neoplasms, information system, child, adolescent, mortality.

1 Nursing Graduate by the *Universidade Gama Filho (UGF)*, PhD in Nursing by the *Universidade Federal do Rio de Janeiro (UFRJ)*, Associate Professor at *Universidade Federal Fluminense (UFF)*. ORCID: https://orcid.org/0000-0003-2531-0665

2 Nursing Graduate by the *UFF*. ORCID: https://orcid.org/0000-0002-3532-3606

3 Nursing Graduate by the *UFF*. ORCID: https://orcid.org/0000-0002-8119-3945

4 Nursing Graduate by the *Universidade Federal do Estado do Rio de Janeiro (UNIRIO)*, PhD in Health Sciences by the *UNIRIO*, Associate Professor at *UFF*. ORCID: https://orcid.org/0000-0001-5512-2863

5 Nursing Graduate by the *UFF*, PhD in Nursing by the *UFRJ*, Associate Professor at *UFF*. ORCID: http://0rcid.org/0000-0002-8948-5054

6 Nursing Graduate by the *UNIRIO*, PhD in Health Sciences by the *UNIRIO*, Associate Professor at *UFF*. ORCID: http://orcid.org/0000-0002-0662-9446

RESUMO

Introdução: apesar do aumento da sobrevida as neoplasias infanto-juvenil continuam ocupando a segunda posição em óbitos nos países em desenvolvimento. **objetivo:** analisar a distribuição espacial de óbitos de neoplasia maligna em pacientes de 0 a 19 anos de idade entre as regionais de saúde do estado do Rio de Janeiro. **Método:** estudo ecológico, que analisou a distribuição espacial de óbitos no período de janeiro a dezembro de 2015 através do Sistema de Informações sobre Mortalidade. Os dados foram tabulados no Tabnet e analisados no programa estatístico R. **Resultados:** dos 101 óbitos observados, 24 (23,8%) foram por neoplasias malignas do Sistema Nervoso Central, e a maior taxa de óbito geral foi na Metropolitana I (63,3%), e por leucemia na Baixada Litorânea (27,9%). **Conclusão:** a identificação de óbitos mais frequentes por neoplasia maligna torna possível a construção de políticas públicas, visando medidas de prevenção, diagnosticas e tratamento condizente com a realidade local.

Descritores: Neoplasias; Sistema de informação; Criança; Adolescente; Mortalidade

RESUMÉN

Introducción: a pesar del aumento de la supervivencia las neoplasias infanto-juvenil continúan ocupando la segunda posición en muertes en los países en desarrollo. **Objetivo:** analizar la distribución espacial de los óbitos de neoplasia maligna en pacientes de 0-19 años de edad entre las regiones de salud del Estado de Rio de Janeiro. **Método:** estudio ecológico, que analizó la distribución espacial de los óbitos del período de enero a diciembre de 2015 a través del Sistema de Información sobre la Mortalidad. Los dados fueron tabulados en el Tabnet e analizado en el programa estadístico R. **Resultados:** de los 101 fallecimientos observados, 24 (23,8%) por neoplasias malignas del Sistema Nervioso Central, y la mayor tasa de muerte general fue en la Metropolitana I (63,3%), y por leucemia en la Bajada Litoránea (27,9 %). **Conclusión:** la identificación de muertes más frecuentes por neoplasia maligna hace posible la construcción de políticas públicas, buscando medidas de prevención, diagnósticos y tratamiento acorde con la realidad local.

Descriptores: Neoplasias; Sistema de Información; Niño; Adolescente; Mortalidad.

INTRODUCTION

Childhood cancer is considered a rare event despite being a major public health problem due to its profound physical, psychological and social impacts.[1] This disease has its own characteristics, especially in relation to histopathology and clinical behavior.[2]

It is estimated that 420,000 new cases of cancer will occur in Brazil in 2018 and 2019. Nonmelanoma skin cancer was not considered in this estimate.[3]

According to the *Registros de Câncer de Base Populacional (RCBP)* [Population-Based Cancer Registries], the median percentage of childhood and adolescent tumors is 3%, which allows us to infer that there will be approximately 12,500 new cases of cancer among children and adolescents (people aged up to 19 years old). The Southeast and Northeast Regions of Brazil will have the highest number of new cases: 5,300 and 2,900, respectively. The Center-West Region will have 1,800 new cases, followed by the South Region (1,300) and finally the North Region (1,200).[3]

Among the types of cancer affecting children worldwide, leukemia is the most common one, followed by lymphoma, which is the second most common type in developing countries and the third in developed countries.[4] As in most populations, leukemia was the most frequent type of cancer in Brazil, followed by other epithelial tumors, lymphoma and the central nervous system (CNS) cancer.[1]

On the other hand, it is understood that cancer mortality among children and adolescents has different geographical patterns. In developed countries, neoplasia is considered the second cause of death among children, corresponding from 4% to 5% of the deaths among children aged from 1 to 14 years old. In developing countries, cancer is the leading cause of death from disease in this age group, representing 1% of all types of cancer.[5]

Although survival has increased over the years, reaching approximately 70% due to early diagnosis and access to appropriate treatment, malignant neoplasms continue to be the second cause of death in this age group, being surpassed only by the deaths from external causes. So, malignant neoplasms have great lethality.[6]

This might be associated with the availability and quality of health services, which influence the survival of patients and vary depending on access to health services, the existence of prevention programs, the effectiveness of interventions, and the availability of diagnostic and treatment procedures. Thus, determining death tolls in certain regions points to the problems related to geographic access to cancer care, indicating areas with few options or opportunities for deconcentration and alternative regionalization.[7]

In this sense, considering childhood cancer as a public health problem, it is essential to monitor the spatial distribution of deaths in a given region, which is an indication of access to health services. Building an important tool for analyzing patterns of cancer care is also essential.

Considering the aforementioned, the following question was developed: "What is the most frequent and lethal malignant neoplasm in children and adolescents across the regional health agencies from the *Rio de Janeiro* State, Brazil?"

Based on these considerations, the objective of this study was to analyze the spatial distribution of deaths from malignant neoplasms in patients aged up to 19 years old across the regional health agencies from the *Rio de Janeiro* State.

METHODS

This is an ecological, descriptive, population-based study that analyzed the spatial distribution of deaths of patients aged up to 19 years old. Ecological studies use data to represent population groups' features. Therefore, these

data refer to groups of people. Moreover, the study unit is a geographical area. Raw and/or time-series data from one area were compared with those from other ones.[8]

The analyzed units were the regional health agencies from the *Rio de Janeiro* State. Brazil is divided into 5,570 municipalities, of which 92 are located in such State. The Brazilian municipalities were covered initially by 337 regional health agencies as established by the *Norma Operacional da Assistência à Saúde (NOAS)* [Operational Standard for Health Care] in accordance with the Ordinance of the *Gabinete do Ministro (GM)* [Minister's Office] No. 95, January 26th, 2001. *Rio de Janeiro* State is divided into 92 municipalities and have nine regional health agencies: *Baía da Ilha Grande* [Big Island Bay], *Baixada Litorânea* [Coastal Flat Land], *Centro-Sul* [Center-South], *Médio* [Middle] *Paraíba*, *Metropolitana* [Metropolitan] *I*, *Metropolitana II*, *Noroeste* [Northwest], *Norte* [North], and *Região Serrana* [Mountainous Region]. There were 15,989,920 people living in *Rio de Janeiro* State in 2010 according to last demographic census.[9]

The study population was composed of patients aged up to 19 years old living in the municipalities covered by all nine regional health care agencies from January to December 2015. For the study, we used the *Sistema de Informações sobre Mortalidade (SIM)* [Mortality Information System], which has the *Declaração de Óbito (DO)* [Declaration of Death] as a standard document.

The *SIM* is a major tool for nationwide epidemiological surveillance. It provides data on mortality in Brazil. Despite the possibility of underreported cases, incomplete coverage, *DO*s partially filled, and data transmission loss, the *SIM* remains useful for analysis of the population's health situation.[10] The causes of the death are classified according to the tenth revision of the International Classification of Diseases (ICD) chapter II: Neoplasms, categories C00 to C97.

The mortality was analyzed with the help of five variables: patient's age, patient's gender, patient's race, place of occurrence, and type of neoplasms. The *SIM* data were tabulated using Tabnet and analyzed using the R statistical software. Proportions and central tendency measures were calculated and univariate analysis was performed. The data were presented in charts, tables, and maps. Data mapping was performed through the use of the regional health agency territorial maps of *Rio de Janeiro* State in TabWin software, which is free and available on the website of the *Departamento de Informática do Sistema Único de Saúde* [Information Technology Department of the Unified Health System] *(DATASUS)*.

This study was not submitted to a Research Ethics Committee as it was not necessary to follow the guidelines stated in the Resolution No. 466, December 12th, 2012. The reason is that unidentified secondary data from *DATASUS* were used.

RESULTS

A total of 101 deaths were observed across the areas covered by the regional health agencies of *Rio de Janeiro* State in 2015. *Metropolitana I* regional health agency presented the highest number of deaths (63.3%), followed by *Metropolitana II* (14.8%), *Serrana* (6.9%), Norte (4.9%), and *Médio Paraíba* (3.9%). *Baía da Ilha Grande* and *Baixada Litorânea* with 1.9%. As can be seen in Table 1, *Centro Sul* and *Noroeste* had the lowest proportion of deaths (0.9% each).

Table 1 - Distribution of deaths from malignant neoplasms in people aged up to 19 by regional health agency in 2015.

Regional health agency	N	%
Baía da Ilha Grande	2	1,9
Baixada litorânea	2	1,9
Centro-Sul	1	0,9
Médio Paraíba	4	3,9
Metropolitana I	64	63,3
Metropolitana II	15	14,8
Noroeste	1	0,9
Norte	5	4,9
Serrana	7	6,9
Total	**101**	**100**

Source: *SIM/Coordenação-Geral de Informações e Análises Epidemiológicas (CGIAE)* [General Coordination of Information and Epidemiological Analysis]/*Departamento de Análise de Saúde e Vigilância de Doenças Não Transmissíveis (DASNT/SVS/MS)* [Department of Health Analysis and Surveillance of Noncommunicable Diseases] (2018).

In relation to the distribution of deaths by type of neoplasm, other types of malignant neoplasm predominated with 52.4%, followed by malignant neoplasms of meninges, brain, and other parts of the SNC, malignant neoplasms of the respiratory system and those of the liver and bile ducts with 5.9%, and malignant neoplasms of the lip, oral cavity and pharynx with 3.9%. Malignant neoplasms of the stomach, ovary, and prostate obtained presented the lowest proportion (0.9%) (Table 2).

Table 2 - Distribution of deaths by type of neoplasm in people aged up to 19 years old in *Rio de Janeiro* State in 2015.

Neoplasms	N	%
Malignant neoplasms of the lip, oral cavity, and pharynx	4	3,9
Malignant neoplasms of the stomach	1	0,9
Malignant neoplasms of the colon, rectum, and anus	2	1,9
Malignant neoplasms of the liver and bile ducts	6	5,9
Malignant neoplasms of the trachea, bronchi, and lungs	6	5,9
Malignant neoplasms of the ovaries	1	0,9

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Distribution of the deaths from childhood and adolescent...

Neoplasms	N	%
Malignant neoplasms of the prostate	1	0,9
Malignant neoplasms of meninges, brain, and other parts of the SNC	24	23,7
In situ neoplasms, benign neoplasms, neoplasms with uncertain behavior	3	2,9
Other types of malignant neoplasm	53	52,4
Total	**101**	**100**

Source: SIM/CGIAE/DASNT/SVS/MS (2018) (2018).

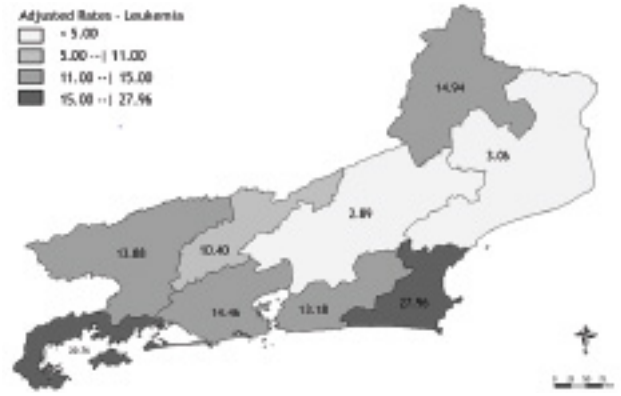
Concerning the analysis of the death rates adjusted by the world population, it was found that leukemia stood out. The *Baixada Litorânea* and *Baía da Ilha Grande* regional health agencies also stood out with 27.9 and 20.7 per 100,000 people, respectively. *Noroeste* had 14.9 per 100,000 people, followed by *Metropolitana I* had 14.4, *Médio Paraíba* had 13.8%, and *Metropolitana II* had 13.1. The agencies with the lowest rates were *Centro-Sul*, *Norte*, and *Serrana* with 10.4, 3, and 2.8, respectively (Table 3 and Map 1).

Table 3 - Distribution of deaths from leukemia in people aged up to 19 years old by regional health agency in 2015.

Regional health agency	Taxa ajustada
Baía da Ilha Grande	20,7
Baixada litorânea	27,9
Centro-Sul	10,4
Médio Paraíba	13,8
Metropolitana I	14,4
Metropolitana II	13,1
Noroeste	14,9
Norte	3,0
Serrana	2,8

Rate adjusted by world population per 100,000 people. Source: SIM/CGIAE/DASNT/SVS/MS (2018).

Figure 1 - Spatial distribution of deaths from leukemia in people up to 19 years old by regional health agency in 2015.



Source: SIM/CGIAE/DASNT/SVS/MS (2018). Rate adjusted by the world population per 100,000 people.

In regard to the variable "gender", most patients are male (58.3%). In relation to the variable "race", a predominance of white people who died from malignant neoplasms was observed (46.8%), followed by brown people (37.5%), and black people (13.5%). These results are shown in Table 4.

The distribution of deaths by age group revealed a high proportion of people aged 15 to 19 years old (45.5%), followed by children aged 1 to 4 years old (17.8%). The proportion of children aged 5 to 9 years old and 10 to 14 years old was 15.8%. Children under one year of age constituted the lowest proportion (4.9%). In relation to the length of education, it can be seen that "4 to 7 years" predominated (44.7%), followed "8 to 11 years" (25.3%), "1 to 3 years" (23.8%), "none" (4.4%), and "12 years or more" (1.4%). As for the place of occurrence, most of the deaths (88.5%) occurred in hospitals, followed by homes (8.3%), and other places (3.1%). These results are shown in Table 4.

Table 4 - Distribution of variables related to the profile of people aged up to 19 years who died from malignant neoplasms in *Rio de Janeiro* State over 2015.

AGE	N	%
< 1 year old	5	4,9
1 to 4 years old	18	17,8
5 to 9 years old	16	15,8
10 to 14 years old	16	15,8
15 to 19 years old	46	45,5
GENDER	**N**	**%**
Male	56	58,3
Female	40	41,6
RACE	**N**	**%**
Black	13	13,5
White	45	46,8
Brown	36	37,5
Ignored	2	2,0
LENGTH OF EDUCATION	**N**	**%**
None	3	4,4
1 to 3 years	16	23,8
4 to 7 years	30	44,7
8 to 11 years	17	25,3
12 more	1	1,4
PLACE OF OCCURRENCE	**N**	**%**
Hospital	85	88,5
Home	8	8,3
Other	3	3,1

Source: SIM/CGIAE/DASNT/SVS/MS (2018).

DISCUSSION

The *Metropolitana I* regional health agency covers 12 municipalities. They are surrounded by the municipalities

covered by *Médio Paraíba*, *Centro-Sul*, and *Serrana* agencies. The area covered by the *Metropolitana I* agency corresponds to 5.16% of the total area of *Rio de Janeiro* State and have 61.50% of its population. Its high population density has generated social pressure because the economy has grown while the basic needs of the population have not been met. The capital of the *Rio de Janeiro* State stands out in this region.[11]

The *Baixada Litorânea* regional health agency covers an area with a demographic density of 370.75 inhabitants/km^2 and is a traditional place for vacationers. *Baixada Litorânea* has reference institutions in oncology surgeries. However, cases involving pediatric oncology and head and neck cancer surgery are referred to *Metropolitana I*, while cases involving chemotherapy, radiotherapy, and hematology are referred to *Metropolitana II*.[11]

Hence, these agencies covered areas characterized by a high proportion of deaths. Nevertheless, the analysis of the data on deaths from leukemia showed that the region does not have so many specialized services, which led to the highest mortality rates.

There was also a significant number of deaths in the municipalities covered by the *Metropolitana I* regional health agency, followed by *Metropolitana II*, *Região Norte* and *Serrana*.[12] This figure is related to the fact that *Metropolitana I* agency has a relevant number of specialized treatment units compared to other agencies, which have few or no specialized treatment units to deal with cases.

The existence of these reference units for patient care is essential for understanding the reported deaths because high death rates were observed in regional health agencies that are considered large centers with a great number of reference units. The reason is that children with malignant neoplasms need to move from their homes to health care units. In view of this, the possibility of receiving adequate treatment in units recognized as large centers makes peoples move, which may justify the increased death rates in these locations.

The *Metropolitana I* and *Metropolitan II* regional health agencies have reference institutions in oncology and other medical specialties. Most of the reference institutions belong to *Metropolitana I*, probably due to the presence of the State Capital, which is the municipality that offers the largest number of services due to the great number of reference federal institutes. The other municipalities that have reference institutions are *Nova Iguaçu*, *Duque de Caxias* and *São João de Meriti*.[11]

Due to the difficulty of access to health services, patients seek care in other locations, which impairs the accuracy of *SIM* data. Diagnosis of cancer is often seen as a death sentence by patients and family members. The lack of reference units and vacancies in various regions are contributing factors for death.[13]

Access is another contributing factor, which indicates the degree of ease or difficulty of receiving health care. It depends on the relationship between the demand for and entry into health services. The same authors addressed the access barriers, which can be geographic, organizational, cultural, etc., expressing characteristics in an interrelated way and facilitating or hindering the use of these services. It is inferred that there are geographical barriers, considering that people are more likely to go to health facilities. As a result, the death data indicated inequality.[14]

It is understood that malignant neoplasms affecting children and adolescents differ in type and location, causing them to contract other diseases. Leukemia, CNS cancer, and lymphomas were highlighted in this study, which accounted for more than half of the causes of death from malignant neoplasms in this age group.[1,5,15]

It is inferred that deaths from childhood cancer occur because they have more aggressive characteristics such as the short latency period. Another contributing factor is the time from the onset of symptoms until the diagnosis of the disease and the accuracy of the methods used. The symptoms can be unspecific, which means that they can be mistaken for those of another illness found in this age group. Thus, the study results are corroborated by the literature on epidemiology, highlighting the demand for services at all levels of health care, especially regarding early diagnosis among the analyzed age groups.[12]

Leukemia, especially lymphoid leukemia (LL), greatly contributed to the death rates due to its pathophysiology. The analysis of the data on infant mortality from LL revealed that 2,177 deaths from the disease in the period 2011 to 2014 in Brazil among children aged 0 to 19 years old were notified. It was also observed that there was a predominance of cases in males, totaling 1,247 deaths. Moreover, there was a high incidence of deaths among people aged up to 9 years old, which agrees with the study findings.[16]

Nonetheless, leukemia etiology is complex, and its cause is not completely known, which allows us to infer that leukemia originates from the association between genetic and environmental factors.

It is inferred that age has great importance in the planning and implementation of public policies. Accordingly, considering the organization of the health care network for children and adolescents, including its type of organization and care delivered by professionals, it is necessary to understand these data in order to develop and implement care plans tailored to the real needs of the population.[17]

Regarding the race, most of the children and adolescents who died from cancer were white, agreeing with the studies cited.[15,17] In Brazil, statistics on childhood cancer have been little analyzed despite the existence of data sources such as the *SIM* and *RCBP*.[18]

With respect to the location of death, hospitals predominated. As the disease advances, its aggressiveness has increasingly negative impacts on the patients' quality of life, making them go to health care units in search of emergency and palliative care.[19]

According to the study results, the highest proportion of deaths occurred among males aged 15 to 19 years old as verified in another study.[12]

The spatial distribution of health services seems to maintain high mortality rates. The regional health agencies across Brazil, especially across *Rio de Janeiro* State, present an extremely heterogeneous pattern in relation to the geographic distribution of the population and health care units. Therefore, the health care units' geographical location resulted in an unequal distribution of beds: there were areas with an excessive amount of beds (city centers), contrasting with areas with a shortage of beds (city outskirts). This pattern generates a large flow of patients seeking care. The need to travel long distances makes it more difficult for patients to access health services. More importantly, this need makes it difficult to tailor health services to the needs of these patients.[7]

Ecological studies that use secondary data has some limitations, such as the possibility of underreported deaths and incorrect basic cause of death. However, the *SIM* coverage in the municipality of *Rio de Janeiro* reaches approximately 100% and, for cancer cases, the basic cause of death has been reported satisfactorily.[7]

Bearing in mind the aforesaid, the way data is sent to these platforms needs to be reviewed and adapted to the reality of each health region by verifying the real location of the patients' homes. The reason is that several malignant neoplasms are directly related to local characteristics, such as the location of the patients' homes, which is of great relevance in determining the number of deaths and their causes, aiming at preventing events.

CONCLUSIONS

The analysis of the spatial distribution of deaths from malignant neoplasms in patients aged up to 19 years old indicated that the *Metropolitana I* regional health agency covered an area with a significant number of deaths. Most of the people who died from cancer aged 15 to 19 years old, followed by children aged 1 to 4 years old.

The use of *SIM* data allowed verifying that most of the people who died from cancer were white males. The leading cause of death was leukemia, followed by CNS cancer, respiratory system cancer, urinary system cancer, and other types of malignant neoplasms. Nonetheless, it was not possible to clarify the reasons why white males predominated and were more vulnerable.

A clear relationship was also observed between the high death rates and the health regions having large urban centers with a great number of reference health care facilities. This fact is explained by the need for children with malignant neoplasms to move from their homes to where the health care unit is located in the hope of receiving treatment.

Although the study achieved the proposed objective, its limitation involved the little research on the subject available, which hindered the understanding of the data collected. It is also important to emphasize that the information platforms need to provide data specific to the health regions as the movement of patients to the reference regions makes the data on cases of death unreliable, which directly influences the demands for interventions in the localities that would have high cancer rates. As a consequence, the local population's health and the demand for prevention, diagnosis, and treatment of the disease are compromised.

Nevertheless, this study is important because it was possible to identify the main types of malignant neoplasms among children and adolescents, as well as the dimension of neoplasm mortality in this population and its distribution.

Further research on this subject should be implemented, contributing to more comprehensive discussions so as to create public cancer control strategies and programs tailored to the real needs of the local population.

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Corresponding author
Aline Cerqueira Santos Santana da Silva
Address Rua Zaco Paraná, 79, Barra da Tijuca
Rio de Janeiro/RJ, Brazil
Zip code: 22.620-250
Email address: alinecer2014@gmail.com
Telephone number: +55 (21) 99974-5139

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