Organization of Healthcare Services for Children, Adolescents and Young Adults with Cancer: Santa Catarina West Region

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Organização dos Serviços de Saúde para Assistência de Crianças, Adolescentes e Adultos Jovens com Câncer: Região Oeste de Santa Catarina

Organización de Servicios de Salud para la Asistencia de Niños, Adolescentes y Adultos Jóvenes con Cáncer: Región Oeste de Santa Catarina

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ABSTRACT

Introduction: The organization of the health care services network is essential for children, adolescents and young adults with cancer. Health Regions need to be organized to ensure adequate care. **Objective:** To understand the organization of the health care network for children, adolescents and young adults with cancer in the *Oeste* Region of Santa Catarina. **Method:** Documentary, exploratory study with analysis of documents and hospital records of cancer were carried out in the years 2008, 2017 and 2018. Descriptive statistics were utilized, in addition to identification of the flow and spatial distribution. **Results:** Chapecó is the reference of the oncology care network for the health Macro-region of the *Grande Oeste* and *Meio-Oeste*. Consultations were intensified in the period, but it was not identified the existence of a highly complexity unit for pediatric oncology after reviewing the documents. **Conclusion**: There is no evidence that the healthcare network is structured and organized for the age range in the documents analyzed. The municipality of Chapecó is the reference for the West Region with increase of access to oncological care and more services offered in the rural area.

Key words: comprehensive health care; neoplasms; regional health planning; health policy; hospital records.

RESUMO

Introdução: A organização da rede de serviços de saúde é fundamental para realização de assistência de crianças, adolescentes e adultos jovens com câncer. As Regiões de Saúde precisam estar organizadas, contendo todos os serviços necessários para garantir adequado cuidado. **Objetivo:** Compreender a organização da rede de atenção à saúde da criança, adolescente e adulto jovem com câncer, na Região Oeste de Santa Catarina. **Método:** Pesquisa documental, exploratória, com análise de documentos e registros hospitalares de câncer, referente aos anos: 2008, 2017 e 2018. Utilizaram-se estatísticas descritivas, identificação dos fluxos e distribuição espacial. **Resultados**: Chapecó foi indicado como referência da rede assistencial oncológica para a Macrorregião de saúde do Grande Oeste e Meio-Oeste. Os atendimentos foram intensificados no período, porém não foi identificada a existência de uma unidade de alta complexidade de oncologia pediátrica após a análise dos documentos. **Conclusão:** Não há evidência de que a rede assistencial esteja estruturada e organizada para a faixa etária com base nos documentos analisados. O município de Chapecó é referência para a Região Oeste, tendo sido observado aumento do acesso à assistência oncológica e interiorização da assistência.

Palavras-chave: assistência integral à saúde; neoplasias; regionalização da saúde; política de saúde; registros hospitalares.

RESUMEN

Introducción: La organización de la red de servicios de salud es fundamental para brindar asistencia a los niños, adolescentes y adultos jóvenes con cáncer. Es necesario organizar las regiones sanitarias, para garantizar una atención adecuada. **Objetivo:** Comprender la organización de la red de atención a la salud de niños, adolescentes y jóvenes con cáncer en la Región Occidental de Santa Catarina. **Método:** Investigación documental, exploratoria, con análisis de documentos y registros hospitalarios de cáncer, referidos a los años 2008, 2017 y 2018. Se utilizó estadística descriptiva, identificación de flujo y distribución espacial. **Resultados:** Chapecó es referencia de la red de atención oncológica para el Macrorregión de salud del Gran Oeste y Medio Oeste. La asistencia se intensificó en el período, pero no se identificó en los documentos la presencia de una unidad de alta complejidad para oncología pediátrica. **Conclusión:** La estructuración y organización de la red asistencial para el grupo de edad no fue presentada de manera específica en los documentos analizados. El municipio de Chapecó es el referente para la Región Oeste para accesibilidad a asistencia oncológica con más servicios en el área rural.

Palabras clave: atención integral de salud; neoplasias; regionalización; política de salud; registros de hospitales.

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INTRODUCTION

The Health Attention Network in Brazil (RAS) is defined as the organization of health-related actions and services with different technological densities which integrated through technical, logistic and management systems attempt to ensure full care. RAS was redefined according to Directive number 483 of 2014[1] in thematic hubs and cancer is in the axis of Health Attention to Individuals with Chronic Diseases at the National Health System (SUS) with guidelines for lines of care.

The National Policy for Cancer Prevention and Control (PNPCC) created by Directive number 874 of 2013[2] described that cancer treatment should be provided through full care, regionalized and decentralized in approved health clinics as Oncology High Complexity Care Clinics (Unacon) or Oncology High Complexity Center (Cacon). Health State and Municipal Secretaries are in charge of organizing the care through pacts, defining through which service they will have access to SUS[3].

Population, operational structure and model of healthcare are components of RAS to understand its dynamic: attention to the population in its territory and how life is lived, to the operational structure formed by services which communicate through Primary Health Care (PHC), secondary and tertiary clinics, support, logistic and governance systems and practice of attention to health as logic systems of organization, articulation and intervention[4,5].

Cancer is one of the first causes of death by disease in children, adolescents and young adults in Brazil and developed countries[6]. Nearly 80% of the cases of neoplasms in this age-range can be cured if diagnosed and treated early with good perspectives of quality-of-life after the correct treatment[7]. After the confirmation of the diagnosis, the oncologic treatment should begin quickly, each individual responds and copes differently to the challenges of the therapeutic[8]. The oncologic treatment creates several demands to the patients and their families due to its effects and necessity to travel. More encompassing public policies to ensure the oncologic treatment occurs are urgent, it is quite evident the gap between the recommendation and the actual access to the different instances of oncologic care[9].

The access to health services is essential to cancer treatment with a structured service network to ensure full care to the population. Many municipalities of the State of Santa Catarina offer approved hospitals and clinics for cancer as part of SUS, one of them is Chapecó – *Oeste* Region of the State and 530 km[7,10] far from the capital, Florianópolis.

The theoretical backbone of the study – organization of the network for children, adolescents and young adults with cancer – was the current debate about geography of health based in the hypothesis that health services exist in the territory as base to the formulation of health policies. It is hypothesized that the relation space-territory contributes to the evaluation of the services and coverage of the care offered. The space under administrative control is, therefore, the space-region[11].

The objective of the study was to understand the organization of the health network for children, adolescents and young adults with cancer in the *Oeste* Region of Santa Catarina.

METHOD

A document-based study about the organization of the oncologic network and register of cases of children, adolescents and young adults who were consulted at the oncology high complexity clinics in the State of Santa Catarina in 2008, 2017 and 2018 was conducted.

Data were collected from public, free-access available websites. The analysis proceeded through the following phases[12]: 1) selection of public documents related to the study object including the Action Plan of Health Attention to Individuals with Cancer in Santa Catarina[13], the Master Plan of Regionalization (PDR)[10], the Assurance of Access to Outpatient Care of the Health Municipal Secretary (TCGA) of Chapecó[14], and Decree 7,508/2011 which addresses the organization of SUS[15]; 2) preliminary evaluation of the documents based in the historical context and cultural and socioeconomic conjuncture that allowed the generation of the documents and socio-political universe of the documents; 3) full reading of the documents selected; 4) analysis and synthesis of each document based in the objectives of the study.

Documents not in force within the time frame of registers identified at the integrator system of Hospital-Based Cancer Registers (RHC)[16] of the National Cancer Institute José Alencar Gomes da Silva (INCA) from 2008 to 2018 were excluded and for other age-ranges not addressed by the study.

Cases consulted at Unacon and Cacon of the State were collected through "*Integrador RHC*[16]" of public domain found at the app TabNet developed by the Computer Department of the National Health System (DATASUS).

The RHC gathers information from patients consulted at hospitals with confirmed diagnosis of cancer, being possible to obtain the number of cases of children and adolescents (0 to 19 years) and young adults (20 to 29 years) per year of the first consultation and clinic for the years 2008, 2017 and 2018, in order to encompass possible differences found in one decade. Data were

collected in October and November 2020 and as 2018 was still being processed, the data of 2017 were included. This period is consistent with the year of publication of the documents analyzed.

The hospitals were the visits occurred and the municipalities were identified at the RHC and the name at the National Registry of Health Clinics (CNES)[17].

To devise the pathways of oncologic care of the children, adolescents and young adults, it has been defined the municipality of origin and the municipality of destination were the visit was made; the concept of flow is based in the cases who needed to travel considering the interconnection of the health networks[18,19]. Cases originated in other States in the period investigated were excluded and/or ignored.

The geographic unit of analysis was the municipality, based in the geographical grid offered by "*Instituto Brasileiro de Geografia e Estatística* (IBGE)[20] which allowed the elaboration of thematic maps. Data processing and maps of results utilized public domain software Libre Office Calc and Quantum GIS. The Institutional Review Board approved the study, CAAE 15944719.4.0000.5564, report number 3.444.122/2019.

RESULTS

REGIONALIZATION IN THE STATE OF SANTA CATARINA

Decree number 7,508/2011[15] disposes about the organization of the health network and creates the Health Macroregions in PDR[10], which initially had the objective to organize and structure the slots in their organizational structures based in some criteria which eventually became the PDR[10] that gathers one or more regions systematically. It organizes the Health Regions in nine Macroregions in the State of Santa Catarina (Figure 1); the target of the study is the Macroregion *Grande Oeste* formed by three regions with 64 support clinics of the referral system described below:

a. Health Region *Extremo-Oeste* – with 30 municipalities with estimated population of 231,848 inhabitants[21], it counts with 24 support referral clinics, only two offer oncologic care: "*Hospital de Iporã*" in the city *Iporã do Oeste* and "*Hospital Cedro*" in *São José do Cedro*. No oncologic consultations for under 29 years old were identified in 2008, 2017 and 2018.
b. Health Region *Xanxerê* – with 21 municipalities with estimated population of 200,114 inhabitants[21], it counts with 13 support referral clinics but none of them offers oncologic treatment.
c. Health Region *Oeste* – with 27 municipalities and estimated population of 360,933 inhabitants[21], it counts with 27 support referral clinics; there are only two oncologic clinics in Chapecó – *Hospital Regional do Oeste (HRO)* and *Hospital da Criança Augusta Muller Bohner* –, under management by "*Associação Hospitalar Lenoir Vargas Ferreira*". The first is still unlisted at the PDR[10], as children specialized hospital . The Health Macroregion *Grande Oeste* encompasses

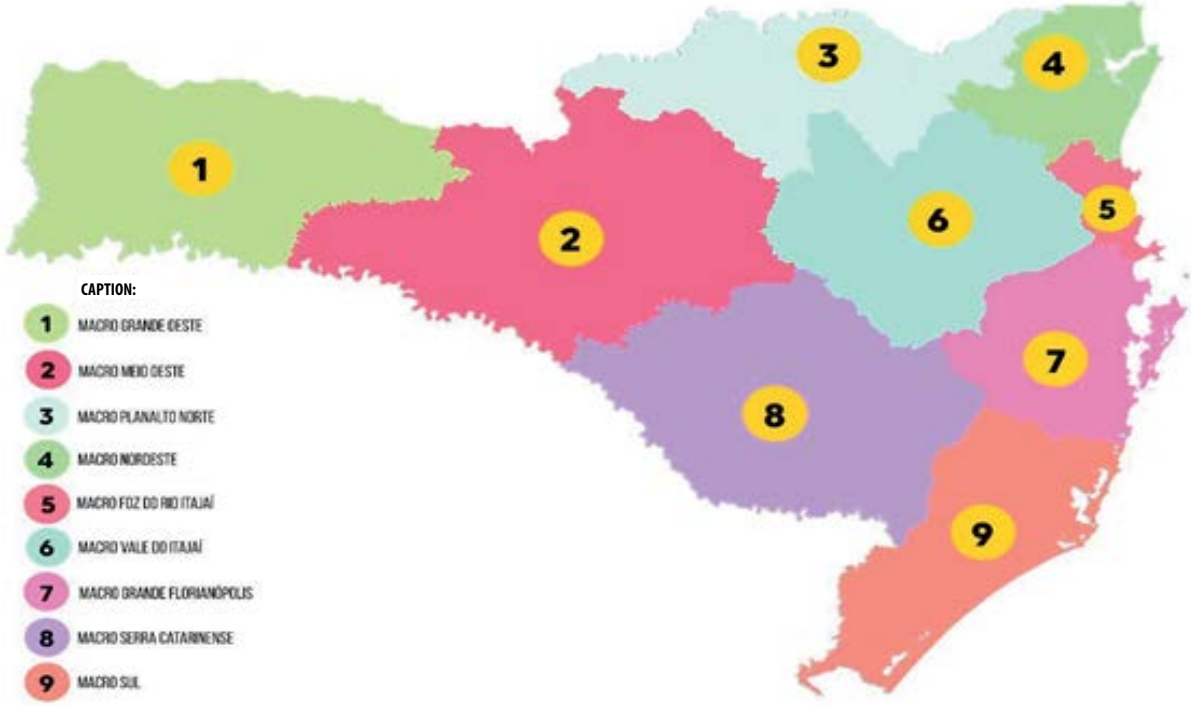

Figure 1. Health macroregions of the State of Santa Catarina. Chapecó, SC, Brazil, 2020

services for 78 municipalities, there are only four oncologic hospitals but none for children and adolescents; demands for oncology are concentrated in these municipalities.

ONCOLOGIC CARE FOR CHILDREN, ADOLESCENTS AND YOUNG ADULTS

According to IBGE populational estimates, the State of Santa Catarina reached 7,001,161 inhabitants[21] in recent years. As a consequence, oncologic cases of children and adolescents have risen accordingly, being necessary improvements in the access to treatment.

In 2016, it was created the Action Plan of Health Attention to Individuals with Cancer in the State of Santa Catarina[13] with estimates of expansion and approval of hospitals, including the "*Hospital da Criança Augusta Muller Bohner*" in Chapecó, that needed to adjust to the demands for beds and meet the current legislation.

TCGA is the guiding document for oncologic care in the State and materialization of RAS. The Health State Secretary issues specific Conducts for each reference hospital at RAS and for *HRO* of the *Associação Hospitalar Leonir Vargas Ferreira*, of Chapecó, it was identified the TCGA covered by Directives GM/MS numbers 874[2] and 876, both dated May 16, 2013[22] and SAS/MS, number 140, December 27, 2014[23], that addresses the hospital consultations for these municipalities, number of patients, procedures and costs[14].

HRO is classified as Unacon, it is necessary a registration to ensure the consultation to the patients. Chapecó is a reference of pediatric oncology for 131 municipalities utilizing TCGA, ensuring oncologic consultations to nearly 1.4 million individuals from 131 municipalities, offering pediatric oncology, chemotherapy, anesthesiologists, pediatric surgeon, clinical oncologist, anatomopathology, endoscopy and ultrasound[14] as shown in Figure 2.

No specifications for consultations were identified while analyzing TCGA according to the age-range, except information about pediatric oncology. For this, the general oncology consultations were considered to find the consultations for young adults (20 to 29 years).

In this direction, TCGA indicates Chapecó as reference for pediatric oncology, chemotherapy, consultations and exams for 47 municipalities of the health regions *Alto Uruguai Catarinense, Oeste* and *Xanxerê* with 560,366 inhabitants. For hematology, 84 municipalities are accepted for consultations, including the *Extremo-Oeste* region.

However, for radiotherapy, Chapecó is assigned as reference for 105 municipalities, including those of the regions *Alto Vale do Rio do Peixe* and *Meio-Oeste*, corresponding to a population of 1,135,411 inhabitants[21].

During the period investigated (2008, 2017 and 2018) 579 cases of cancer were identified in under 19 years old and 744 cases between 20 and 29 years old consulted at Santa Catarina hospital network.

The consultations concentrated in the municipalities of *Florianópolis, Joinville, Itajaí, Blumenau, Jaraguá do*

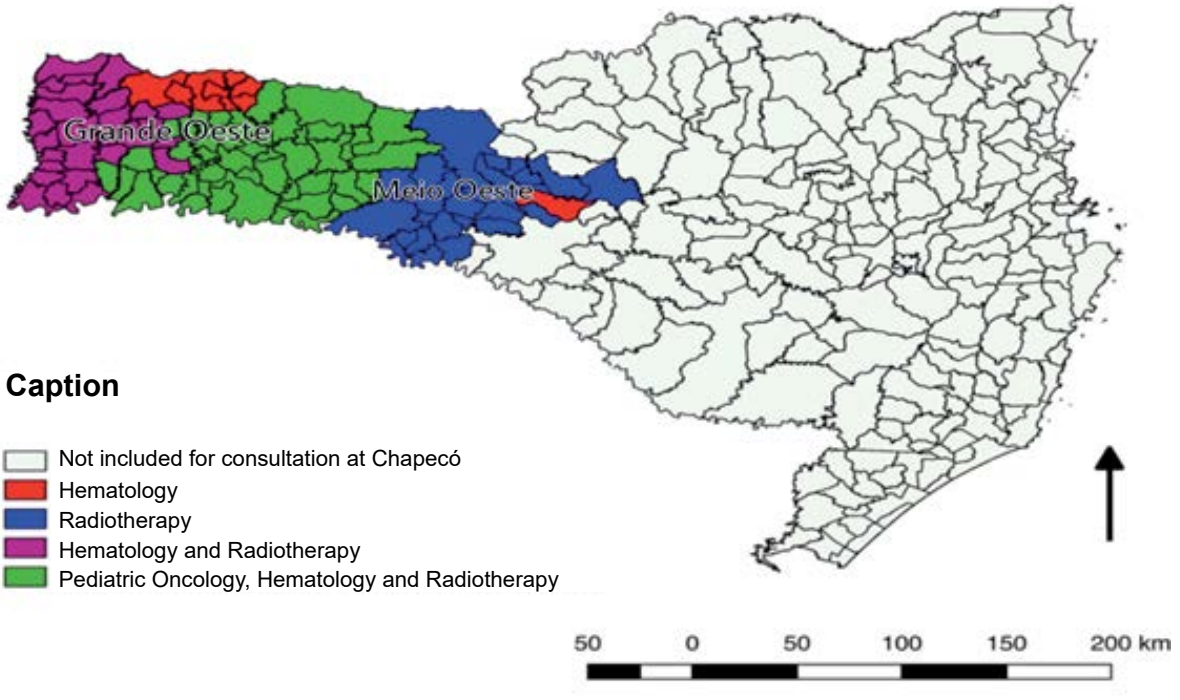

Figure 2. Reference Municipalities for consultations at Chapecó according to the Term of Commitment of Access

Sul, Tubarão, Porto União, Lages, Joaçaba, Chapecó and *São Miguel do Oeste*, as presented in Chart 1.

The offer of oncology services for children, adolescents and young adults changed in the last years and in 2008, only *HRO* had nine oncologic consultations for the ages investigated (Table 1). However, according to the pacts and approvals through the analysis of the documents mentioned, consultations in the municipalities of *Joaçaba* and *São Miguel do Oeste* were registered since 2017, both of the Health Macroregion of *Grande Oeste*. The increase of the number of registries for under 19 years old in Chapecó is remarkable, which went from 13 registries in 2017 to 41 in 2018; and for the age-range from 20 to 29 years, 42 registries were identified for 2017 and 51 registries in 2018 as shown in Table 1.

Regarding the flows, the coastline was identified as the general reference for the State. Most of the cases is concentrated at the State's capital, Florianópolis.

At the *Oeste* region, the municipality of Chapecó is a reference for oncologic treatment for the municipalities of the Health Macroregion of *Grande Oeste* and *Meio-Oeste*. Reflecting the policies of organization of oncologic care networks, this position as reference for children, adolescents and young adults is changing along the years with territorial expansion for consultations from other origin municipalities. Figure 3 shows the territorial expansion of the consultations for the years investigated and according to the age-range of the patients.

DISCUSSION

The results show that the municipality of Chapecó in the *Oeste* region, is an oncologic reference for children, adolescents and young adults. Oncologic care branched out to the countryside for this age-range regarding policies and organization of visits and registers.

Regional demands that need to be met are the structural core for the organization of health regions and

Chart 1. Hospital and municipality of oncologic visit identified in the study period according to the age-range. Santa Catarina, Brazil, 2008, 2017 and 2018

CNES	Hospital	Municipality	Age range		Year		
			0 to 19	20 to 29	2008	2017	2018
2537788	*Hospital Regional do Oeste*	*Chapecó*	✔	✔	✔	✔	✔
6683134	*Hospital Regional Terezinha Gaio Basso*	*Sao Miguel do Oeste*		✔			✔
2560771	*Hospital Universitário Santa Terezinha*	*Joaçaba*	✔			✔	
19283	*Maternidade Carmela Dutra*	*Florianópolis*	✔		✔		
19402	*Imperial Hospital de Caridade*	*Florianópolis*	✔	✔	✔	✔	
19445	*CEPONSC*	*Florianópolis*	✔	✔	✔	✔	
2691868	*Hospital Infantil Joana de Gusmão*	*Florianópolis*	✔			✔	✔
3157245	*Hospital Universitário Prof. Polydoro Ernani de São Thiago*	*Florianópolis*	✔	✔	✔	✔	
2691841	*Hospital Governador Celso Ramos*	*Florianópolis*	✔		✔	✔	✔
2305674	*ONCOJS*	*Jaraguá do Sul*	✔	✔	✔	✔	
2436469	*Hospital Municipal São José*	*Joinville*	✔	✔	✔	✔	✔
6048692	*Hospital Infantil Dr. Jeser Amarante Faria*	*Joinville*	✔			✔	✔
2491710	*Hospital Nossa Senhora da Conceição*	*Tubarão*	✔	✔	✔		
2504332	*Hospital e Maternidade Tereza Ramos*	*Lages*	✔	✔	✔		
2522691	*Hospital e Maternidade Marieta Konder Bornhausen*	*Itajaí*	✔	✔	✔	✔	✔
2558246	*Hospital Santa Isabel*	*Blumenau*	✔	✔	✔	✔	
2558254	*Hospital Santo Antônio*	*Blumenau*	✔	✔	✔		
2758164	*Hospital São José*	*Criciúma*	✔	✔	✔	✔	✔
2543044	*Hospital de Caridade São Braz*	*Porto União*	✔			✔	✔

Table 1. Number of cases in children, adolescents (0 to 19 years) and young adults (20 to 29 years) according to the year of the first consultation and municipality. Santa Catarina, Brazil, 2008, 2017 e 2018

Municipality	0 to 19 years			20 to 29 years		
	2008	2017	2018	2008	2017	2018
Blumenau	23	6	0	41	15	0
Chapecó	9	13	41	32	42	51
Criciúma	16	16	0	15	28	0
Florianópolis	59	133	90	145	150	24
Itajaí	7	0	0	12	0	0
Jaraguá do Sul	6	0	0	21	0	0
Joaçaba	0	9	0	0	19	0
Joinville	26	51	52	22	32	33
Lages	14	0	0	18	0	0
Porto União	0	1	6	1	17	12
São Miguel do Oeste	0	0	0	0	0	3
Tubarão	1	0	0	6	5	0
Total	**161**	**229**	**189**	**313**	**308**	**123**

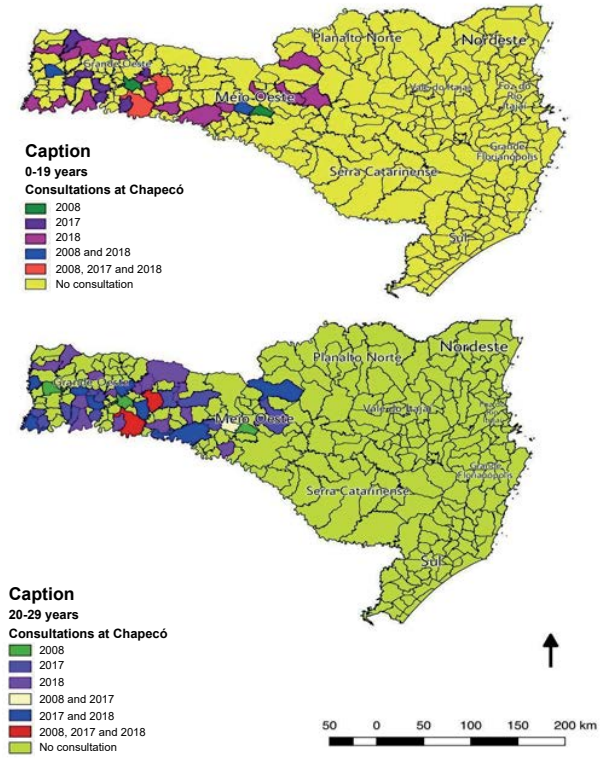

Figure 3. Hospital flows for oncology in the age-range of 0-19 years old and from 20-29 at Chapecó according to the origin municipality. Santa Catarina. Brazil. 2008, 2017 and 2018.

its potential regionalization for better effectiveness[24]. RAS for pediatric oncology needs to be strengthened as the scientific literature has already concluded, the public managers should stimulate the use of information systems because they help decision-taking to meet regional demands, avoiding the travel of this population to the great cities, potentially reducing the inequalities of access and encouraging decentralization.

The guarantee of access to oncologic treatment and adjustment of the services to the population demands were present in the documents analyzed. The organization of the health network require that managers are aware of the possible structure in the region including the discussions to expand RAS[26].

Although the results of this study have portrayed the reality between 2008 and 2018, adjustments are necessary to align the services offered to SUS principles[27]. Because of political constraints, public managers quite often deal with challenges the players of the process live while attempting to meet the actual necessities and what is offered[26].

Most of the clinics is concentrated in the State's coastline. The difficulty of access and poor availability of high complex oncology services clearly impact the quality-of-life of the patients, their survival and mortality[28,29] which reinforces the importance of the health structure for children, adolescents and young adults with cancer.

A study analyzed the public health policies in the State of Rio de Janeiro from 2013 to 2021 within the context of pediatric oncologic care and showed the importance of counting with specific pediatric cancer strategies; after the diagnosis, the family is involved as well in caring for the child affected and its education, among other aspects[30]. The documents analyzed had fragilities as absence of an exclusive regulation organ for pediatric cancers, generic language addressing cancer as a whole with specific guidelines for the pediatric population, similar to the findings in Colômbia[31].

Since the creation of SUS and some advances, innumerous difficulties have been found in regard to the concept of integral care, an obstacle to strengthen oncologic attention in the country. The increase of health clinics and expansion of oncology RAS is still insufficient within the current epidemiological scenario. Funding problems and difficulty of implementation of public health policies negatively impact the consolidation of the care to oncologic patients[32]. Pediatric oncologic care barely advanced nationally considering the time the government has to meet PNPCC[2], mainly in relation to diagnosis[33]. Comparing with developed or even Latin American countries, Brazil has significant limitations because of poor interaction among hospitals and research, necessity to expand RAS and low representativeness of the child and adolescents in the national health agenda[32].

In addition to documents that organize the oncologic care for children, adolescents and young adults in the State's *Oeste* region, the study detected the branching out of the medical consultations to the countryside. The number of municipalities that offer oncology services closer to the patients' residence increased along the years, avoiding travels to access chemotherapy, radiotherapy and medical consultations.

Notwithstanding the State's decentralization of pediatric oncology care, there are still challenges for RAS to fully fulfil its goals not different from the reality of other country regions. The problematic crosses many instances of power and popular organization itself. Social players should fight and ensure that pediatric oncology is continuous, commensurate to each region socioeconomic inequities for full care to the families and society in general[34].

The lack of information in the RHC system is a limitation of this investigation because the data identified failed to portray the actual number of cases in the entire State, which hampers the analysis of the impact in the health region. It was decided to pursue other sources of reference to add additional information to the database.

Based in this, the cornerstone of healthcare is the connection among spatial aspects and the region, essential to organize health systems, particularly oncologic attention. These analyzes have contributed to materialize healthcare which, from an hermeneutic relation between spaces and human beings, recognize the complex interactions that gather social and physical characteristics, connecting local necessities and the reality the population live[34,35].

Although the results are specific for a Brazilian region, similar studies should be carried out in other regions periodically to produce information about the dynamics of the healthcare network to support the formulation of policies consistent to population needs.

CONCLUSION

Through document analysis, it was revealed that the structuring and organization of healthcare for children, adolescents and young adults were not addressed considering the specificities, but it was possible to identify in the cancer hospital registries that the municipality of Chapecó is the reference for a large area of municipalities of the health macroregions of *Grande Oeste* and *Meio-Oeste*. In addition, it was noticed that the flow of consultations for the age-range investigated has increased in the *Oeste* region, which shows that it is is branching out towards the countryside and more accessibility of children, adolescents and young adults to oncologic care, reducing the necessity of travels to referral hospitals and clinics for diagnosis and continuation of the treatment.

CONTRIBUTIONS

Jane Kelly Oliveira Friestino, Maíra Rossetto and Ana Paula Barasuol Rodrigues contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Vander Monteiro da Conceição, Jeane Barros de Souza and Priscila Maria Stolses Bergamo Francisco contributed to the study design, acquisition, analysis and interpretation of the data. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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