

Description of the Health Care Network for Cancer Control in Children and Adolescents in the City of Rio de Janeiro

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Descrição da Rede de Atenção à Saúde para o Controle do Câncer em Crianças e Adolescentes no Município do Rio de Janeiro
Descripción de la Red de Atención a la Salud para Control del Cáncer en Niños y Adolescentes en el Municipio de Rio de Janeiro

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Abstract

Introduction: Cancer in children and adolescents is the leading cause of deaths by disease in the 0-19 age group. Delayed identification of signs and symptoms and late referral of diagnostic suspicions may adversely affect the prognosis and be responsible for more aggressive treatment. **Objective:** This study aimed to know the structure, functioning and access flows of the healthcare network (HCN) for the control of cancer in children and adolescents in the city of Rio de Janeiro. **Method:** Descriptive study that used public documents, online bulletins and information systems to describe and show the logical structuring of information about this HCN. **Results:** The results show an installed capacity that includes the regulations, the existence of flows ordered by the Primary Health Care, the regulation of care with partial offer of outpatient and hospital availability of diagnosis and treatment of childhood and juvenile cancer. **Conclusion:** This research points out the fragmentation of the access systems within the HCN, the necessity to update the cancer-related information systems and indicates that studies of analysis and prospection of the future scenarios can improve the current functioning, besides helping to build the outflows of licensed hospitals.

Key words: Neoplasms; Children; Adolescents; Health Services; Health Management.

Resumo

Introdução: O câncer em crianças e adolescentes é a primeira causa de mortes por doença na faixa etária de 0-19 anos. O atraso na identificação dos sinais e sintomas e a demora no encaminhamento das suspeitas diagnósticas podem alterar negativamente o prognóstico e serem responsáveis por um tratamento mais agressivo. **Objetivo:** Este estudo objetivou conhecer a estrutura, o funcionamento e os fluxos de acesso da Rede de Atenção à Saúde (RAS) para o controle do câncer em crianças e adolescentes no município do Rio de Janeiro. **Método:** Trata-se de um estudo descritivo, que utilizou dados públicos de documentos, boletins on-line e dos sistemas de informações, para descrever e mostrar a diagramação das informações sobre essa RAS. **Resultado:** Os resultados mostram uma capacidade instalada que contempla as normativas, a existência de fluxos ordenados pela atenção primária em saúde, a regulação da assistência com oferta parcial da disponibilidade ambulatorial e hospitalar de diagnóstico e o tratamento do câncer infantojuvenil. **Conclusão:** Esta pesquisa aponta a fragmentação dos sistemas de acesso dentro da RAS, a necessidade de atualização dos sistemas de informação relacionados ao câncer e indica que estudos de análise do cenário atual e a prospecção de cenários futuros podem melhorar o funcionamento atual, além de auxiliar na construção dos fluxos de saída dos hospitais habilitados.

Palavras-chave: Neoplasias; Crianças; Adolescentes; Serviços de Saúde; Gestão em Saúde.

Resumen

Introducción: El cáncer en niños y adolescentes es la primera causa de muertes por enfermedad en el grupo de edad de 0-19 años. El retraso en la identificación de los signos y síntomas y demora en el encaminhamiento de las sospechas diagnósticas pueden alterar negativamente el pronóstico y ser responsable de un tratamiento más agresivo. **Objetivo:** Este estudio objetiva conocer la estructura, el funcionamiento y flujos de acceso de la Red de Atención a la Salud (RAS) para controlar el cáncer en niños y adolescentes en el municipio de Río de Janeiro. **Método:** Se trata de un estudio descriptivo que utilizó datos públicos de documentos, boletines en línea y de los sistemas de información para describir y mostrar la diagramación de la información sobre esta RAS. **Resultados:** Los resultados muestran una capacidad instalada que contempla las normativas, la existencia de flujos ordenados por la Atención Primaria en Salud, la regulación de la asistencia con oferta parcial de la disponibilidad ambulatorial y hospitalaria de diagnóstico y tratamiento del cáncer infanto-juvenil. **Conclusión:** Esta investigación apunta fragmentación de los sistemas de acceso dentro de la RAS, necesidad de actualización de los sistemas de información relacionados al cáncer e indica que estudios de análisis del escenario actual y prospeción de escenarios futuros pueden mejorar el funcionamiento actual además de auxiliar en la construcción de los flujos de salida de los hospitales habilitados.

Palabras-clave: Neoplasias; Niño; Adolescente; Servicios de Salud; Gestión en Salud.

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INTRODUCTION

Cancer in children and adolescents is rare, its treatment demands physical structures and high complexity and technological density equipment, in addition to specialized multiprofessional team¹. The study of the incidence, hospital mortality and morbidity in the age-range of children, adolescents and young adults indicates a median percentage of neoplasms of 2% in the childhood population (from 0 to 14 years), 3% in the population of children and adolescents (from 0 to 19 years) and shows that the children-adolescents tumors (from 0 to 19 years) corresponded to 2.8% of all the reported neoplasms².

For a timely and effective cancer control of children and adolescents it is necessary that, in addition to the treatment, other modalities of care are offered and organized in the Healthcare Network (HCN), with emphasis in early detection. Early diagnosis consists of three stages: first, the awareness about cancer symptoms with access to care; second, clinical evaluation with diagnosis and staging and third, access to treatment, including pain relief³.

The National Policy for Cancer Prevention and Control in the Healthcare Network of Individuals with Chronic Diseases created by Directive MS/GM 874 of 2013⁴, presents some responsibilities and competences related to the healthcare facilities. The identification of suspected signs and symptoms of types of cancers is within the scope of Primary Healthcare (PHC).

There are evidences that children and adolescents experience a prolonged diagnosis time with great variations in the first symptoms and time to investigate and treat. Some factors of this delay are related to the inability to report symptoms, limited awareness and heterogeneous and unspecified symptoms that are similar to benign conditions³.

The Ministry of Health launched in 2017 a publication titled "Protocol of early diagnosis for pediatric oncology"⁵ that attempts to help professionals of HCN to conduct suspected and confirmed cases within the scope of care, showing the actions since basic until high complexity care⁵. The municipality of Rio de Janeiro offers the initiative United by Cure that promotes the early diagnosis of children and adolescent with cancer with the participation of the National Health System (SUS) managers in the three spheres, specialized services and civil society⁶. This initiative was integrated into the Municipal Health Plan of Rio de Janeiro in 2010 and is included in the State Oncologic Attention Plan through training of basic healthcare professionals to facilitate the early diagnosis of childhood cancer.

This study had the objective of knowing the HCN structure, functioning and access flows to control children and adolescents cancer in the municipality of Rio de Janeiro.

METHOD

Cross-sectional, descriptive approach study developed through documental analysis, investigation of public information about the functioning of the HCN to control cancer in children and adolescents in the municipality of Rio de Janeiro. The flow of data and processes were described and presented later through a graphic tool used in systems analysis⁷. The data flow diagram, which organized the phenomenology of the information encountered in a model as abstract representation of part of the reality can be used to understand its functioning⁸.

To elaborate the data flow diagrams the following documents were utilized: Health Municipal Plan (2010-2014) and (2014-2017)^{9,10} and the State Oncologic Plan (2017)¹¹. The available information from "Instituto Desiderata" online publications were also used: Bulletin year 2, number 2, November 2015; Bulletin year 8, number 14, 2016; Bulletin year 3, number 3, November 2016; Bulletin year 9, August 2017 and Bulletin volume 4, number 4, November 2017¹²⁻¹⁵.

The construction of this model has also relied on data collection in the Computer Department of the National Health System (DATASUS) to obtain population data. Data about the physical structure of the health services provided were obtained from the National Registry of Healthcare Facilities (CNES)¹⁶ and from the Platform of the Sub-Secretary of Health Primary Attention and Promotion (SUBPAV)¹⁷ of Rio de Janeiro.

The data available in Integrator RHC¹⁸ served as source of information to construct the flows as shown in Figures 4 and 5 where the National Cancer Institute José Alencar Gomes da Silva (INCA) receives children referred from other sources, in addition to United by Cure or Regulation of Health Services in Rio de Janeiro (REUNI-RJ).

The study complies with the guidelines of Resolution 466/12 of the National Health Council¹⁹ (CNS). All the data and information utilized in this study are public and are available online mostly. The data offered by public entities and by non-governmental organizations are information that do not involve human subjects directly or indirectly and were granted after quoting the source.

The results presented also considered important references for children and adolescents healthcare as the National Policy of Child Full Health Attention, National Policy of Adolescent and Youth Full Health Attention and the Statute of the Child and Adolescent (ECA)²⁰.

RESULTS

Based in the information encountered in the documents, diagrams, analyzes and descriptions were developed, presenting the existing HCN in the municipality of Rio de Janeiro.

Figure 1 shows the information collected about the pediatric population and the trajectory in the current structure to investigate suspected child and adolescent with cancer in the municipality of Rio de Janeiro. The difficulty of unique identification of the population and implementation of electronic chart in the hospitals and urgency facilities is concrete.

Figure 2 was elaborated based in the population, age-ranges and information about the services structure and considers the search the user performs in the two main access systems and still shows the interface of PHC with United by Cure and secondary and tertiary care with REUNI-RJ.

In Figure 2, it is observed the shortening of the trajectory when the access is through the flow of municipal action of United by Cure. However, the initiative for early diagnosis does not cover all the hospitals of diagnosis and treatment of children and adolescents with cancer, and the offer of resources is split between the two main types of access: REUNI-RJ and United by Cure.

Figure 3 details the interaction of REUNI-RJ with the health services network and shows its action as requester and performer of the offer of outpatient services and hospitalization related to diagnosis and treatment of children and adolescents with cancer in the Municipality of Rio de Janeiro. The presence of external entities can change the actions of the HCN and the treatment performed by United by Cure. Even with the creation of SUS National Regulation Policy in 2008, there are still specialized resources either in outpatient or for diagnosis and therapeutic not fully offered by REUNI-RJ.

Figure 4 shows the diagram representing the United by Cure as a process within the HCN for cancer control in the municipality of Rio de Janeiro. It was attempted to detail the flow of submission, the training actions either for PHC or REUNI-RJ and the system United by Cure utilized by the Coordination of Programmatic Areas (CPA) as form of electronic scheduling of pediatric oncologic consultations to clarify suspected cases. The diagram shows also the access of the Health Municipal Secretary to the data of the system United by Cure to search for children and adolescents actively that missed the visit, information forwarded to PHC, responsible for contacting the family and/or legal guardian.

Figure 5 was elaborated from the data of Integrator RHC and represents the flow of children and adolescents

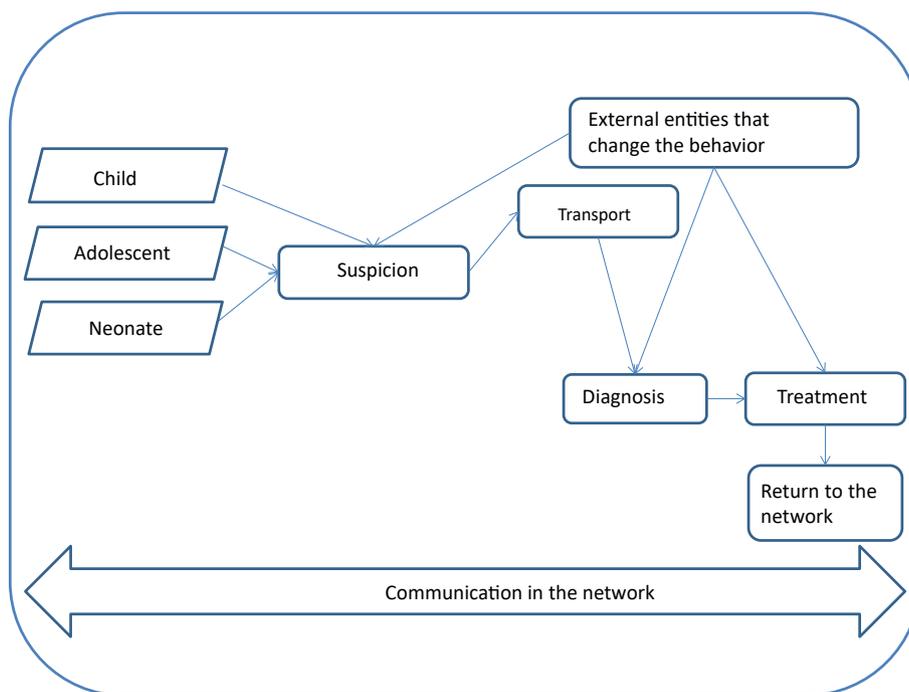


Figure 1. Population and flow in the network services structure for cancer control of the Municipality of Rio de Janeiro

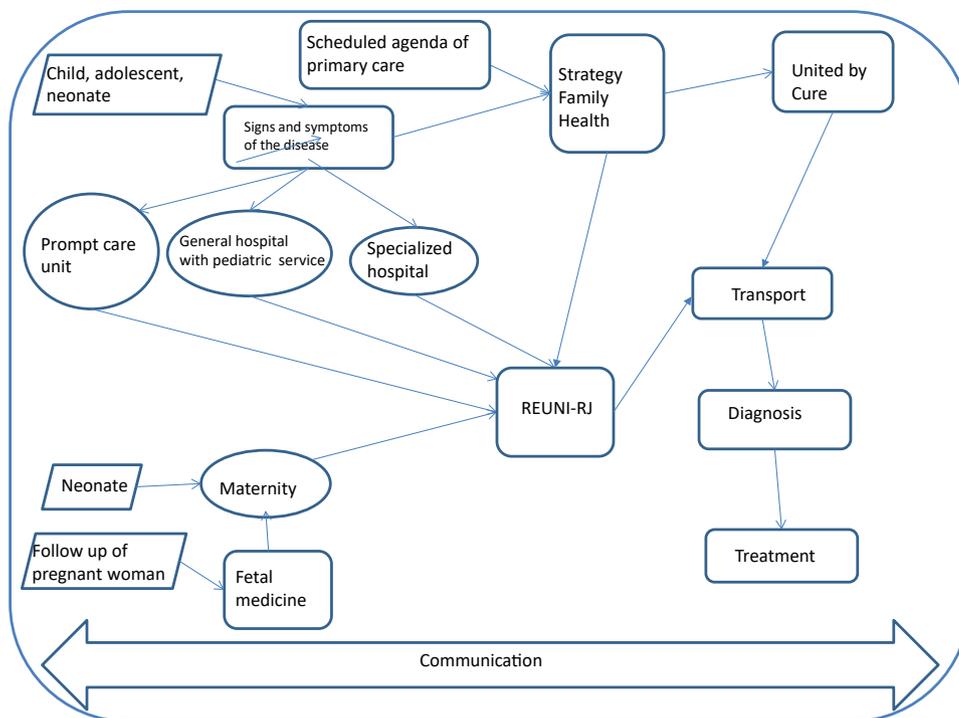


Figure 2. Diagram of the network structure for cancer control in the Municipality of Rio de Janeiro

Caption: REUNI-RJ - Regulation of Health Services in Rio de Janeiro.

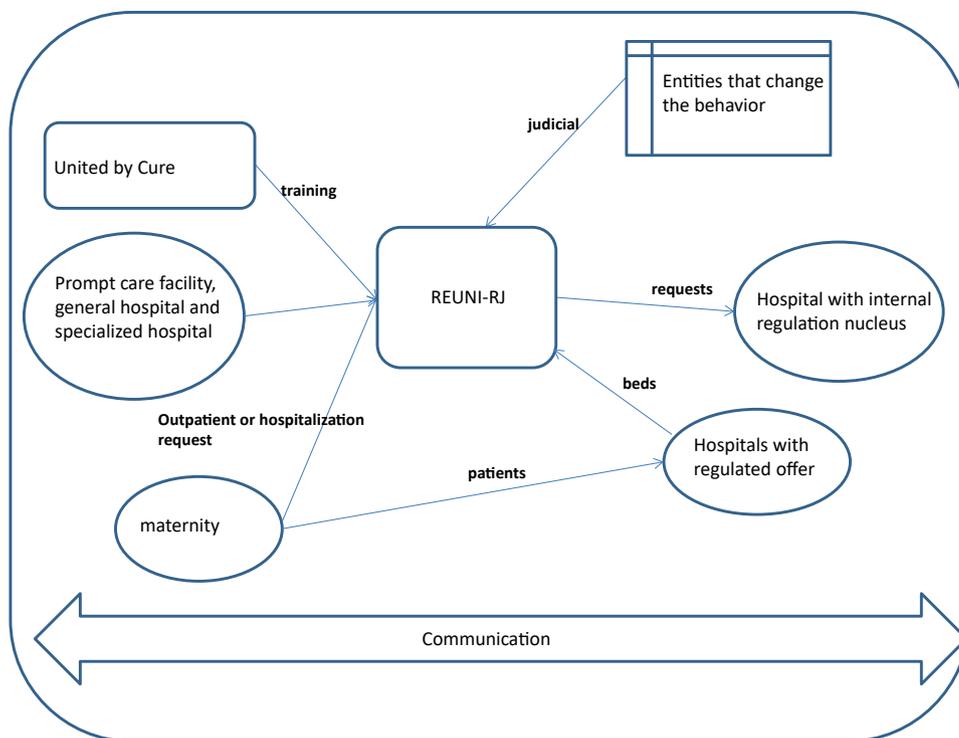


Figure 3. Diagram of regulation of network care for cancer control in the Municipality of Rio de Janeiro

Caption: REUNI-RJ - Regulation of Health Services in Rio de Janeiro.

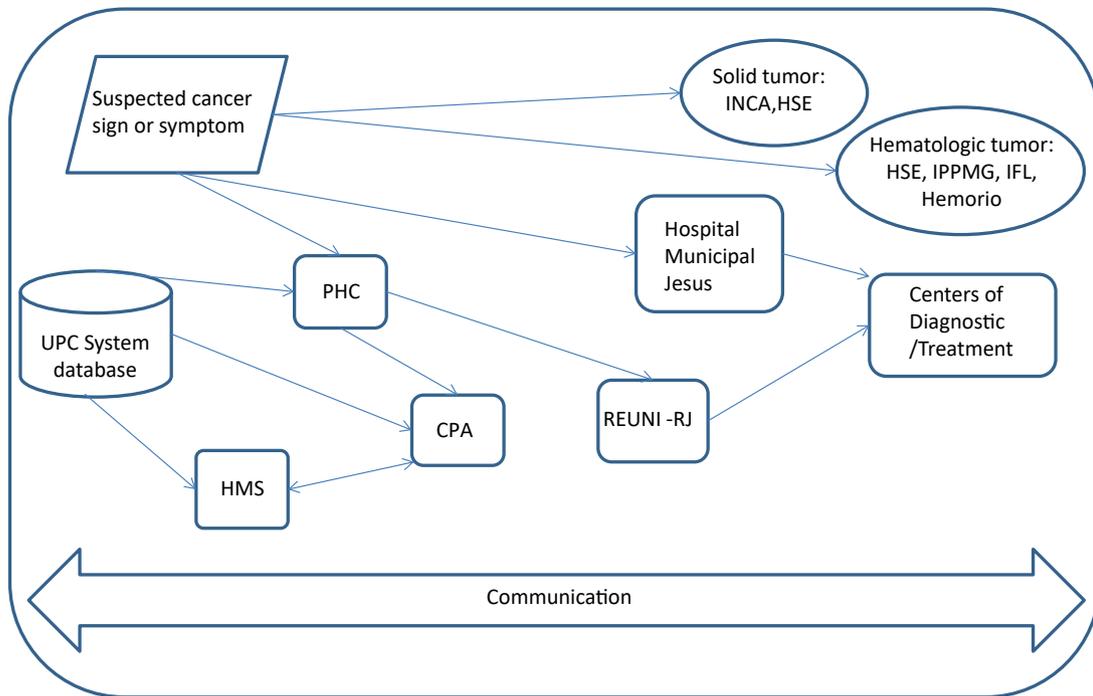


Figure 4. Diagram of the United by Cure in the network for cancer control in the Municipality of Rio de Janeiro

Captions: APS – Primary Healthcare; CPA – Coordination of Programmatic Area; IPPMG – Institute of Childcare and Pediatric Martagão Gesteira; IFL – General Hospital of Lagoa; INCA – National Cancer Institute José Alencar Gomes da Silva; Hemorio – State Hematology Institute Arthur Siqueira Cavalcanti; HSE - Federal Public Employees Hospital; SMS – Health Municipal Secretary; UPC – United by Cure.

who submitted to the oncologic treatment in the HCN of the municipality of Rio de Janeiro. In addition to the access by the system United by Cure and by REUNI-RJ, there are cases treated in unauthorized hospitals as High Complexity and Oncology Healthcare Units or Centers (UNACON/CACON).

The information show INCA as responsible for more than 60% of the cases treated in the Municipality of Rio de Janeiro. The access to this CACON authorized as service of pediatric oncology is done through “Open Door”, term utilized by “Instituto Desiderata”.

In Figure 5, it is possible to observe the flow of suspected cases incoming directly within the process represented by INCA and the number of cases treated by this CACON is shown by the thickness of the arrow indicating the flow.

It is necessary to elaborate specific flows for the unconfirmed diagnosis demanding specialized follow up or treatment in the hospital in the existing health services network. The elaboration of this flow needs to be agreed with the services able to meet this demand as part of the planning and organization of this HCN.

This study elaborated a flow diagram considering some hypothesis with hospitals withdrawing from the diagnosis and treatment network to treat child and adolescent with cancer in Rio de Janeiro. This hypothesis addresses the

possibilities of non-malignant diagnosis. The current study failed to respond to queries about the organization of HCN for late control of the treatment which, in the diagram, is represented by an interrogation mark.

DISCUSSION

It is not within the scope of this study, but it is known that there are aspects about flows among health regions in the State of Rio de Janeiro for which the Municipality provides care that need to be addressed to meet the necessities of pediatric oncologic care for the population.

Actions for early diagnosis of child and adolescent with cancer have grown from 2008 to 2018 calling the attention of the investigators. Nevertheless, the feeding of the existing registries is delayed which is a limitation for the elaboration of studies that use recent data. The findings show the necessity of implementing the Population-Based Cancer Registries (PBCR)²¹ in the State of Rio de Janeiro for proper elaboration of management and planning actions in this HCN.

The communication among the HCN services does not focus the management of care given the informal modality utilized. There are problems to implement the unique identifiers and discrepancies to utilize clinical electronic information at the different levels of attention .

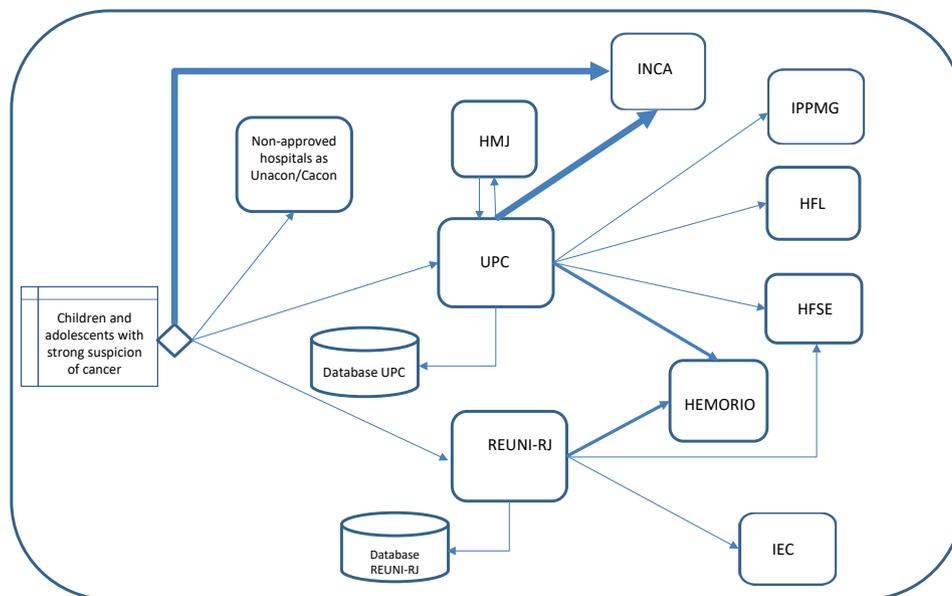


Figure 5. Flow diagram of the treatment of children and adolescents in the cancer control network in the Municipality of Rio de Janeiro

Captions: IEC – State Brain Institute Paulo Niemeyer; HFL – Federal Hospital of Lagoa; HFSE – Federal Public Employees Hospital; Hemorio – State Hematology Institute Arthur Siqueira Cavalcanti; INCA – National Cancer Institute José Alencar Gomes da Silva; IEC – State Child Hospital; HMJ – Municipal Hospital Jesus; UPC – United by Cure; IPPMG – Institute of Childcare and Pediatrics Martagão Gesteira; REUNI-RJ – Regulation of Health Services in Rio de Janeiro.

The referral through regulation of the care or with the card United by Cure does not offer possibility of effective communication between the referral from the HCN and the high complexity centers for warnings of low suspected cases of child and adolescent with cancer. It is necessary to consider the possibilities of current communication to draw attention to the referrals of low suspected cases to high complexity centers in order to strengthen the HCN and its capacity of resolution.

In regard to the access, the study shows there is a process connected to REUNI-RJ and another connected to United by Cure and both do not offer the totality of the capacity of treatment and diagnosis of the child and adolescent with cancer in the municipality. Apparently, this reinforces the historical fragmentation of the health system.

In the State Oncologic Plan of 2018 it was predicted the identification of problems experienced by the approved entities with low production in each modality of care. For pediatric cases, some problems are already known and are related to the structure of the facilities (limitation of the production for lack of bed in intensive care unit in the health facility is an example). The existing physical structure and furniture hamper the expansion of the age-range to receive care and the availability of a complete multi-disciplinary team or in enough quantity to provide care.

The increasing importance of drugs in healthcare, the inequality of access, logistic cycles and interface

with the clinical management to meet the necessities of the population and the processes involving the purchase of drugs and inputs and their relation with budget and financial support because of the influence of the judiciary shift the flows and can also be represented by diagrams.

Strategic actions are necessary, as Godet²² points out “the ambition of the will is carved into the principle of the reality of predictable evolutions (...) and prospection of scenarios “able to estimate the desires and anguishes in face of the future”. To think about the changes evaluating the possible strategic options, elaborating organizational plans to be prepared for the anticipated changes, provoking the desired changes.

CONCLUSION

It is understood that it is necessary to think in developing prospective studies about the scenario for improvement of the HCN with simulations of scenarios of flows to receive different diagnosis, modification of the profiles of hospital care, possible changes in the access systems among other.

The advances or progress or improvement of the capacity of computers and techniques of computer simulations allow the use of the method as planning tool and support to the decision, utilizing a significant number of concomitant variables in a controlled environment. This study shows the path to construct a model of simulation

of the phenomenology of this scenario and attempts to use this tool in the future to test strategies and actions that contribute to control the cancer in children and adolescents.

CONTRIBUTIONS

Monique Abreu Silvino and Fabiano Saldanha Gomes de Oliveira Engenheiro participated of the conception or design of the study; gathering, analysis and/or interpretation of the study data. Cid Manso de Mello Vianna, Tania França and Gerson Nunes da Cunha participated of the wording and/or critical review with intellectual contribution. All the authors approved the final version to be published.

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DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare

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