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ORIGINAL ARTICLE

# Risk factors associated with adherence to medical oncology treatment in pediatrics

## Factores de riesgos asociados a la adherencia al tratamiento médico oncológico en pediatría

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**What do we know about the subject matter of this study?**

In Chile, there is evidence related to the physical and psychological aspects of cancer. However, this disease also affects the family and social environment, and the evidence is scarce regarding family, socioeconomic, housing, and/or support network risk factors, which could affect adherence to medical treatment in children and adolescents with cancer.

**What does this study contribute to what is already known?**

This study investigates family, socioeconomic, housing, and support network risk factors that could affect the adherence to medical treatment of children and adolescents diagnosed with cancer, treated in four pediatric oncology hospitals of a national oncology program. This study broadens the perspective of the factors affecting children and adolescents with cancer and their families.

## Abstract

In Chile, between 450 and 500 cases of cancer are diagnosed annually in children and adolescents. Treatment is financed by the state, but there are non-financial elements that could condition adherence to treatment. **Objective:** to explore family, socioeconomic, housing, and support network risk factors that could affect adherence to medical treatment in children and adolescents diagnosed with cancer. **Patients and Method:** Descriptive observational study in pediatric oncology hospitals of a national cancer program. Through a "Social Care Form" applied to 104 caregivers of children

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and adolescents, between August 2019 and March 2020, socioeconomic data of children diagnosed with cancer were recorded in four dimensions: i) Individual/family/health; ii) Work/education/socioeconomic; iii) Housing/environment; and iv) Participation/support networks. **Results:** 99% of the children and adolescents were registered in the public health system; 69% belonged to the lowest income brackets. Care for children and adolescents was mainly provided by the mother (91%). 79% reported living in a house; 48% owned or were paying for their home. Housing quality was described as good (70%), with low levels of overcrowding. 56% of households had access to Wi-Fi internet connection, while 27% reported no access. The main support network reported was the family (84%). **Conclusions**: Family, socioeconomic, housing, and support network risk factors were observed in children and adolescents diagnosed with cancer; socioeconomic and gender aspects highlight the social inequalities in these families. Descriptive baseline results were obtained, so it is suggested to re-observe its evolution and thus measure its impact on adherence to treatment.

## Introduction

Cancer is a disease that has physical consequences but also affects the family and socioeconomic environment. In Chile, between 450 and 500 cases of cancer are diagnosed annually in children and adolescents, of which 80% are treated in the National Child Program of Antineoplastic Drugs (PINDA) of the country's public hospital network[1]. Currently, the survival rate of children treated in Chile is 73.5% at 5 years of treatment[2].

Although the costs of treatment are financed by the Explicit Health Guarantees (GES) system, there are additional elements that often cannot be afforded by the family, such as housing, food, and transportation, among others. For this reason, it is important to explore the risk factors that could be affecting children and adolescents, such as socioeconomic, family, housing conditions, and access to support networks in order to propose strategies or recommendations to complement the medical services provided by the State.

Considering the Chile National Socioeconomic Characterization Survey (CASEN) and other instruments that measure poverty and vulnerability, we were able to observe that, according to the dimensions it incorporates, there are risk factors associated with childhood cancer that could be explored through this study. Thus, it is possible to hypothesize that a correct intervention in public policies in these dimensions would allow children and adolescents to cope better with the disease and adhere to medical treatment.

The objective was to explore family, socioeconomic, housing, and support network risk factors that could affect adherence to medical treatment of children and adolescents diagnosed with cancer in four pediatric oncology hospitals of the PINDA Program.

## Patients and Method

### Design

Observational and descriptive study, which recorded the socioeconomic data of children diagnosed in four pediatric oncology units of the PINDA Program through the application of the "Social Care Form" (FAS) prepared by the PINDA Program's Subcommittee of Social Workers and tested in those units.

Regarding the measurements, the FAS incorporated four dimensions to determine these risk factors: i) Individual, family, and health; ii) Work, educational, and socioeconomic; iii) Housing and environment; and iv) Participation and support networks.

The sampling method was targeted and purposive of caregivers of children diagnosed with cancer in four units of the PINDA Program. The units selected correspond to those geographically located in the Metropolitan Region (MR), which makes up 63% of the children in treatment nationally and which receives patients from other regions of the country. The units incorporated were the following: *Hospital Dr. Luis Calvo Mackenna* (HLCM), *Hospital Dr. Exequiel González Cortés* (HEGC), *Hospital Dr. Sótero del Río* (HSDR), and *Hospital Roberto del Río* (HRDR).

The FAS was applied to 104 caregivers of children and adolescents, between August 2019 and March 2020. Table 1 shows their distribution by PINDA unit and at the total level.

### Ethical aspects

This project was approved by the Ethics Committee of the School of Public Health of the University of Chile. Informed consent and assent were obtained from caregivers and children, respectively. The data were anonymized and stored electronically by the main investigators. The information obtained in the FAS was entered in a template in order to systematize and later analyze the information.

### Data Analysis

Quantitative data were tabulated for each of the four PINDA oncology units separately and then jointly at the total level. The analyses performed correspond to descriptive statistics, which consider frequencies and percentage distributions observed in the study population for the different variables and their response categories, according to the FAS. The descriptive statistics of frequencies and percentages were analyzed using Microsoft Excel, then distribution tables were prepared for all the variables observed in the four dimensions considered in the study. No units of association between variables were used given the exploratory methodological design of the study.

## Results

### Individual, family, and health dimensions

A higher proportion of the children and adolescents with cancer were male (54%) and Chilean (92%). Most of the children and adolescents came from urban areas (83%), and 54% were from the MR; in contrast, the HLCM received children and adolescents from regions other than the MR since is a referral hospital for bone marrow transplant, osteosarcoma, and retinoblastoma (50%).

Regarding schooling level, most children and adolescents (53%) were 6 to 13 years old and attended elementary school, followed by preschool-age children (26%) and only 18% attended high school. 3% reported no information.

99% of the children and adolescents were users of the public health system (FONASA). Of these, 69% are in the lowest FONASA brackets (A and B), followed by 17% in FONASA D, and 13% in FONASA C. 1% belonged to the Program of Reparation and Integral Health Care (PRAIS) for victims of human rights violations.

Regarding residence during treatment, 33% indicated that they lived in a shelter house, 23% were living as *allegados*[i], and 19% paid rent (in addition to the home of origin); the remaining 15% reported no information.

With respect to the registry in the Social Registry of Households (RSH), 46% of the families belonged to the 40% or lower bracket and most of them were nuclear families with an average of 5 members (Figure 1).

### Work, educational, and socioeconomic dimensions

The mother is the main responsible for the care of the children and adolescents, with 91%, followed by the father with only 6%. The average age of the mothers was 37 years, their educational level was high school (42%), and only 25% had completed technical or higher education. Most of the caregivers were not the breadwinner (74%) and their employment dependence – if any - was on an indefinite-term contract (Figure 2). On average, each caregiver had two dependent children. A significant proportion of caregivers were housewives and were employed in low-skilled jobs (commerce, sales, and services). One in five caregivers was unemployed.

The father was the main breadwinner in 56% of the cases; only 25% of the cases was the mother, followed by 6% in which the main breadwinner was a grandparent. The educational level of the breadwinner was mainly high school. Only 25% of the breadwinners (fathers) had completed technical or higher education. The employment dependency reported by the breadwinners was an indefinite-term contract (49%), followed by self-employed (23%), and then fixed-term contract (10%). The occupations reported by the employees referred mainly to unskilled jobs such as sales and services (44%) and machine and plant operators (15%). Only 22% reported technical/professional jobs or office jobs in the public or private sector.

**Table 1. Population and sample of the study**

| Hospital PINDA | Population Diagnosis cases (N) August 2019-March 2020 | Sample Surveyed cases (N)* August 2019-March 2020 |
|---|---|---|
| Hospital Dr. Exequiel González Cortés | 39 | 32 |
| Hospital Dr. Sótero del Río | 21 | 17 |
| Hospital Luis Calvo Mackenna | 64 | 39 |
| Hospital Dr. Roberto del Río | 41 | 16 |
| Total | 165 | 104 |

*At the time of diagnosis.

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[i] A person who lives temporarily in someone else's house, being or not related to the owner, simultaneously.

### Housing and environment dimensions

79% reported living in a house; of these, 48% had their own home paid for or being paid for. In general, the quality of housing was described as good in 70% of the cases and with low levels of overcrowding. 65% of the cases reported that children and adolescents shared a bedroom, and one in four children and adolescents shared a bed.

There was almost complete access to drinking water and electricity in households (98% and 99%, respectively). More than half of the households (56%) had Wi-fi internet connection access. However, 27% reported having no internet access and 9% only had access through a mobile data plan or bundle minutes (Figure 3).

Liquefied petroleum (LP) gas use was mainly for cooking (91%) and for heating water (83%). A greater diversification of heating sources was observed, such as electricity, LP gas, or firewood; however, 25% reported not having any type of heating.

Regarding the use of transportation to the place of treatment from the temporary residence, 32% used public transportation (bus or subway), 21% used their own vehicle, and 13% indicated that they used institutional transportation. Those who used public transportation had bus shelters less than three blocks away, both at the place of origin and at the place of treatment.

### Family group support networks dimensions

The main support network reported was family (84%), followed by the institutional one (5%) (Figure 4). Other sources of support were youth groups, work groups, and church communities. The support provided by families was mainly monetary (38%) and housing (27%).

Instrumental support was mainly referred to care, such as the care of siblings (57%) and transportation (20%). Emotional support was referred to as affection (37%) and companionship (29%). Cognitive support was most often referred to as advice (30%) and exchange of experiences (9%). Spiritual support came mainly from family (51%) and churches (15%).

In terms of participation in social organizations, most stated that they did not participate in organizations (42%). Among those who did participate, religious organizations were the main referent (14%), followed by social organizations (7%) and sports organizations (5%).

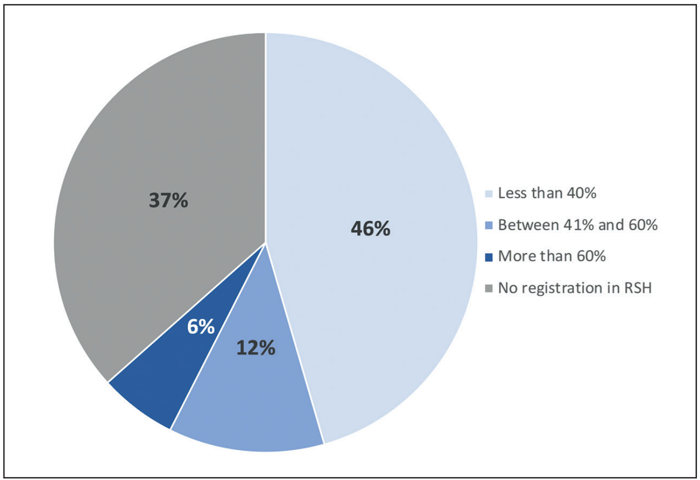

**Figure 1.** Distribution of income quintiles according to the Social Registry of Households (RSH).

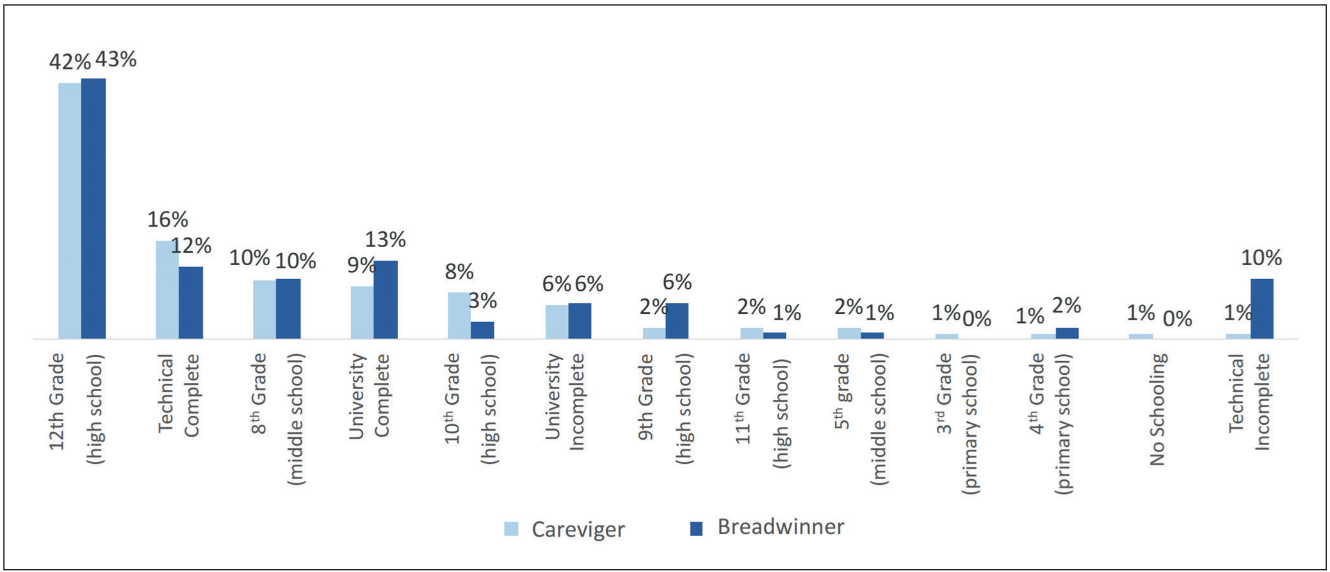

**Figure 2.** Comparative Educational Level (*) of caregivers and breadwinners. Note: * U.S. levels were used to represent educational levels.

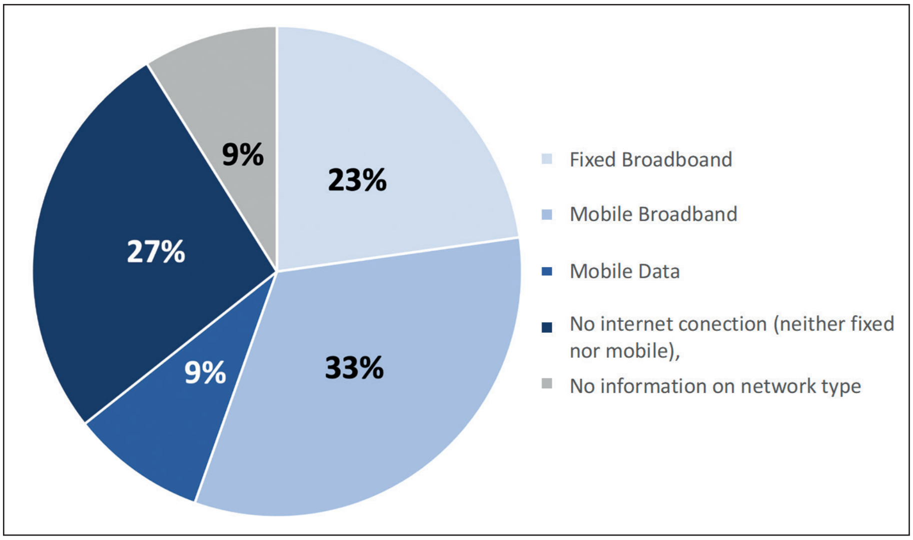

**Figure 3.** Internet connection type.

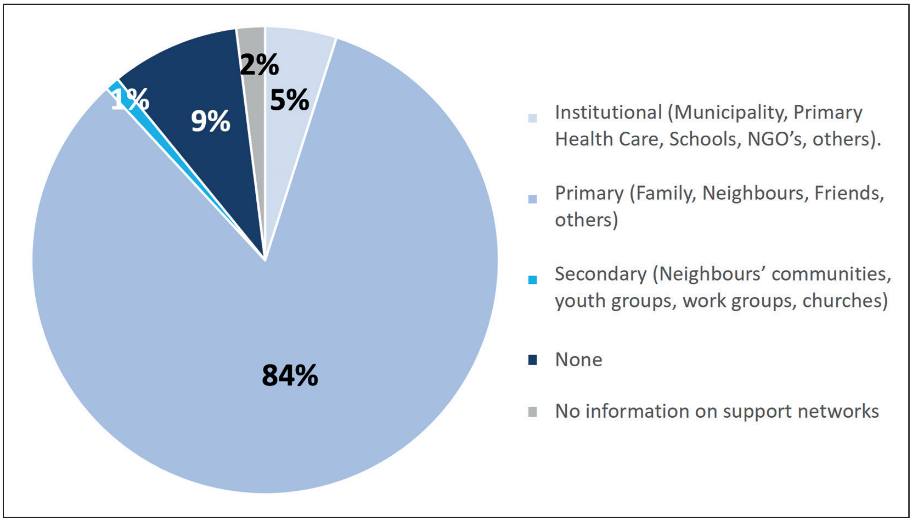

**Figure 4.** Main support networks.

## Discussion

### Sociodemographic characteristics of children and adolescents

Acute lymphoblastic leukemia is the most frequent cancer (50%) followed by lymphomas (11%) and central nervous system tumors (10%), which is consistent with national and international data[2,3].

75% of children and adolescents are between 3 and 13 years of age. This finding allows pointing out improvement guidelines for the response capacity and support of services additional to medical treatment, which both the State and civil society organizations can provide, such as shelter houses. Shelters houses are those places where children and adolescents and their caregivers stay when they must move from one region to another (or within the region) for treatment. Thus, mobility from one region to another, and thus changing of residence, continues to be one of the main elements that families must deal with, not only in socioeconomic terms but also in terms of accommodation and family adjustment, aspects that have been previously studied[4]. Although 33% of children and adolescents and their caregivers live in a shelter house during treatment, 42% live in the home of another family member or rent.

Regarding the health system, almost 70% of children and adolescents belong to the lower FONASA brackets (A and B), which is consistent with a previous study conducted in the MR[5]. A minority of children and adolescents from higher socioeconomic segments are treated in private healthcare centers.

According to data from the PINDA Program, children with cancer in Chile have a 73.5% of survival rate at 5 years (close to developed countries); according to estimates in other Latin American countries such as

Peru or Bolivia, survival rates reach 40% since records are scarce or non-existent in these countries[6,7]. The low results in these neighboring countries have generated migration, for example, from Bolivia to Chile since sometimes there is no access to treatment in the country of origin. In fact, 8% of the children treated in Chile come from another country.

This data shows that Chile has a robust public health system for pediatric cancer. This is interesting since the PINDA Program and the GES system operate as a facilitator of access to treatment. For example, in adults, a study shows how GES has an impact on gallbladder cancer and cervical cancer; however, there are no impact evaluation studies of GES pathologies that show these relationships[8].

Another finding is that 46% of the families belong to bracket 1 of the RSH, the lowest income bracket. This registry processes socioeconomic data on the population[9]. This data is of concern because these are families with a high level of social vulnerability. It is worth mentioning that this study was carried out in the pre-pandemic Sars-Cov-2 period, which suggests that these levels of poverty could have increased in the pandemic period, without knowing the consequences that this could have on families in the medium and long term, as has been identified in recent socioeconomic studies[11].

### Sociodemographic characteristics of the caregiver and breadwinner

Another finding consistent with previous studies is that the primary caregiver is the mother. Women have been responsible for carrying out caregiving tasks within the home. Studies in Brazil and Colombia show that in children and adolescents with cancer, all caregivers are mothers[11,12]. Another important element in relation to caregiving in this study is that the women caregivers have secondary education, but no higher education; they are usually housewives or unskilled workers. By devoting themselves full-time to caring for their children, they abandon any other occupation they may have - no matter how unskilled it may be - and leave aside income, and personal fulfillment, among others. This is consistent with previous studies in Latin America[4,10]; this shows that gender is a variable that markedly appears when it comes to caring for children with cancer.

The socioeconomic support provided by the State for families who have to care for a child with a catastrophic illness is extremely important. In Chile, a significant advance is the SANNA Law, a mandatory insurance system for working parents of children and adolescents affected by a serious health condition. However, there are still gaps not covered, as there is no subsidy or economic contribution for non-working housewives that take care of the children and for informal jobs, vendors in open-air markets, selling meals, etc. Not to mention the absence of contributions in their social security system, which could have an impact on the feminization of poverty.

In the case of breadwinners, the data show that fathers are the main ones. This finding reinforces to a certain extent the reproduction of gender-differentiated economic roles and their inequity. The woman takes care of the children and housework, and the man is the provider and breadwinner of the household. As of 2017, only 38.5% of households in Chile had a woman as the main breadwinner, and 1 in 5 women was out of the labor market due to family or household care. Female labor participation reached 48.9%, while the proportion in the case of men was 70%[13].

Our study shows that male breadwinners have a higher educational level that allows them access to occupations and/or activities with a higher labor qualification than female caregivers. Female caregivers (with a lower educational level) face structural barriers to entering the labor market and reaching jobs with a higher labor qualification.

### Housing and services

Although 32% indicated that they live in their own paid housing and 16% are paying for it, 41% indicated they are renting or living as *allegados*; this situation is a relevant factor when it comes to assessing the social vulnerability in which they are. Many of the benefits provided by the State and civil society organizations are oriented towards owned houses and not rented ones or living as *allegados*.

The level of overcrowding is low; however, one in four children and adolescents reported sharing a bed. This is of concern, not only because of the sanitary measures recommended for children with cancer but also due to other associated parasitic or viral health problems, as well as social problems related to incest or abuse. According to the recommendations of the Pan American Health Organization, it is important to consider that the distribution of space in the home guarantees privacy, independence, and healthy coexistence[14].

Regarding access to basic services, almost 100% of the families have access to drinking water and electricity. However, there are still 27% of families that do not have an internet connection (neither fixed nor mobile), which is of concern, especially in a pandemic period, where teleworking and remote connections have been relevant in educational, work, and social terms and considering that the use of technologies becomes especially relevant at the time of diagnosis due to the restriction in daily life activities suffered by children and adolescents, such as the constant use of central venous catheter and other clinical devices. Likewise, in the pandemic context, Chile presented important problems with mobile internet speed[15]. This would generate difficulties for families in the case of continuing medical evaluations, virtual classes, or telerehabilitation. According to our study, only 23% of families have broadband internet, with better quality for remote connection. This information is very similar to that shown by the Internet Access and Use Survey[16], where 28.9% of households have this type of connection.

**Support networks of the family group**

According to the study, families have low participation in social organizations and their main support is the family, which indicates a very poor institutional social protection network in their daily environment. This is in line with national data showing low levels of civil society participation in social organizations. According to data from the CASEN survey, only 21.9% of people aged over 12 years participate or have participated in social organizations or organized groups[12].

In conclusion, we consider that the risk factors mentioned above may have an impact on the adherence to treatment of children and adolescents, in addition to making the socioeconomic situation of families even more precarious before treatment.

It can also be deduced that women are put off due to their dedication to the care of children and adolescents with cancer. This could constitute a barrier to their personal development in different aspects. Therefore, it is important to recognize domestic work and care as paid work and to reduce gender inequality gaps. Likewise, it is suggested to deepen with qualitative studies on women caregivers of children and adolescents with cancer, in order to understand this phenomenon from their own experiences.

One in four children and adolescents shares their bed, so it is important to go deeper - beyond the material conditions of the home and the family group - into the hypothesis of the possible existence of socio-affective and/or emotional factors that could drive this behavior within the home. In addition, it is necessary to look at public policies and their relationship with the housing improvement that children and adolescents diagnosed with cancer require, due to the absence of specific programs from the State, having them resort to foundations or private initiatives.

Low access to fixed or mobile Internet at home could affect how families deal with access to education and remote work. In addition, there are effects on the continuity of control and treatment of children and adolescents with cancer. There is an urgent need for actions from the State, organizations, and civil society to reduce this Internet access gap and positively impact the connectivity of these families.

Considering the low levels of participation in social organizations and the few referents of local support networks of the families observed in the sample, the importance of the work of the psychosocial areas of the pediatric oncology units and civil society organizations with the families of children and adolescents with cancer is reinforced, which is channeled through material, cognitive, emotional, and spiritual support. This becomes very relevant as a complement to medical treatment and a potential equalizer of socioeconomic risk factors; however, we believe that there should be greater involvement of institutions at the central level, through their public policies that point in this direction.

This study can be considered as a baseline for the observation of family, socioeconomic, housing, and support network risk factors in children and adolescents treated in the four units of the PINDA Program. Considering the results, we propose to survey these factors (Post COVID-19) to observe their evolution and measure their impact on adherence to treatment and survival of children and adolescents of the current study sample.

## Ethical Responsibilities

**Human Beings and animals protection:** Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

**Data confidentiality:** The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

**Rights to privacy and informed consent:** The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

## Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

## Financial Disclosure

Authors state that no economic support has been associated with the present study.

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