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Characterization of children and adolescents with cancer and their families staying in temporary lodgings in Colombia

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Abstract

Objective: To characterize the sociodemographic, economic, educational, healthcare, and social support services factors of children and adolescents with cancer and their families staying in temporary lodgings in eight cities in Colombia.

Methodology: This study employed a descriptive cross-sectional survey-type approach. Forty-two surveys were administered to caregivers (all family members) of children under 18 years of age with a presumptive or confirmed cancer diagnosis. The survey consisted of 55 questions validated by a pilot test. Data collection was carried out between June and August 2023.

Results: Thirteen temporary lodgings were identified. All families belonged to socioeconomic strata 1 and 2, and most of them spent over three hours traveling to the temporary lodging from their place of origin (97.6%); 85% reported incomes below the minimum wage, and 62% of the families received some form of government subsidy. A high percentage of the children (93%) were enrolled in the state-subsidized healthcare system; 71.4% received care in only one health institution, and most were referred to the temporary lodgings by the hospital (83.3%). The main reason for using these lodgings was a lack of accommodation in the city of treatment. Only one family discontinued treatment, and 71.4 % of the children were not attending school.

Conclusion: The sociodemographic conditions of the families of children and adolescents with cancer who require temporary lodging services are characterized by limited financial resources and distant residences from cancer treatment centers. This situation poses challenges to treatment continuity and evidences the importance of the social support provided by temporary lodgings.

-----**Keywords:** social support, socioeconomic factors, family, children, neoplasms.



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Caracterización de niños y adolescentes con cáncer y sus familias en hogares de paso en Colombia

Resumen

Objetivo: Caracterizar los factores sociodemográficos, económicos, educativos, de atención en salud y servicios de apoyo social de niños y adolescentes con cáncer y sus familias, hospedados en hogares de paso en ocho ciudades del país.

Metodología: Estudio descriptivo transversal tipo encuesta. Se efectuaron 42 encuestas a cuidadores (todos familiares) de menores de 18 años con diagnóstico presuntivo o confirmado de cáncer. La encuesta contenía 55 preguntas validadas mediante prueba piloto. La recolección de información fue entre los meses de junio y agosto de 2023.

Resultados: Se identificaron 13 hogares de paso. La totalidad de las familias pertenecía a los estratos socioeconómicos 1 y 2, y la mayoría empleaba más de tres horas para llegar al hogar de paso desde su lugar de procedencia (97,6 %). El 85 % reportó ingresos menores al salario mínimo y el 62 % de las familias contaba con algún subsidio del Gobierno. Un gran porcentaje de los menores (93 %) pertenecía al régimen de salud subsidiado por el Estado. El 71,4 % recibía atención en una sola institución de salud, en su mayoría remitidos al hogar de paso por el hospital (83,3 %), siendo la razón principal de uso del hogar no disponer de un hospedaje en la ciudad de tratamiento. Solo una familia había abandonado alguna vez el tratamiento. El 71,4 % no se encontraba estudiando.

Conclusión: Las condiciones sociodemográficas de las familias de niños y adolescentes con cáncer que requieren un alojamiento temporal están enmarcadas en recursos financieros limitados y residencias distantes de los centros oncológicos, situación que desafía la continuidad del tratamiento y evidencia la importancia del apoyo social brindado por los hogares de paso.

-----*Palabras clave:* apoyo social, factores socioeconómicos, familia, menores de edad, neoplasias.

Caracterização de crianças e adolescentes com câncer e suas famílias em casas de passagem na Colômbia

Resumo

Objetivo: Caracterizar os fatores sociodemográficos, econômicos, educativos, de atenção em saúde e serviços de apoio social de crianças e adolescentes com câncer e suas famílias alojados em casas de passagem em oito cidades do país.

Metodologia: Estudo descritivo transversal tipoquete. Realizaram-se 42 enquetes a cuidadores (todos parentes) de menores de 18 anos com diagnóstico presuntivo ou confirmado de câncer. A enquete continha 55 perguntas validadas por meio de teste piloto. A coleta de informação teve lugar entre os meses de junho e agosto de 2023.

Resultados: Identificaram-se 13 casas de passagem. A totalidade das famílias pertencia aos estratos socioeconômicos 1 e 2, e a maioria gastava mais de três horas para chegar na casa de passagem desde seu lugar de procedência (97,6%). 85% declararam ingressos menores ao salário-mínimo e 62% das famílias contava com algum subsídio do Governo. Uma grande porcentagem dos menores (93%) pertencia ao regime de saúde subsidiado pelo Estado. 71,4% recebiam atenção em uma única instituição de saúde, a maioria (83,3%) tinha sido encaminhada à casa de passagem pelo hospital, sendo o motivo principal do uso da casa de passagem o fato de não dispor de hospedagem na cidade do tratamento. Apenas uma família tinha abandonado uma vez o tratamento. 71,4% não estavam estudando.

Conclusão: As condições sociodemográficas das famílias de crianças e adolescentes com câncer que precisam de uma hospedagem temporária caracterizam-se pela limitação de recursos financeiros e pelo fato de morarem em locais afastados dos centros oncológicos; essa situação desafía a continuidade do tratamento e evidencia a importância do apoio social oferecido pelas casas de passagem.

-----*Palavras-chave:* apoio social, fatores socioeconômicos, família, crianças, neoplasias

Introduction

Cancer involves several types of tumors that constitute one of the main causes of death in childhood and adolescence [1], with an age-standardized mortality rate between 0 and 19 years of age for all cancers in minors, estimated at 4.1 worldwide and 5.3 for Colombia [2].

According to data from the Global Cancer Observatory, there were 273,051 new cases of cancer in children and adolescents in 2022 worldwide, 29,936 in Latin America and the Caribbean, and 2,115 in Colombia. The most frequent types of childhood cancers observed in the country during 2022 were leukemia, central nervous system tumors, testicular tumors, thyroid cancer, non-Hodgkin lymphoma, and Hodgkin lymphoma, followed by kidney, stomach, and ovarian cancers [2].

There is a relationship between the survival rate of childhood cancer and the countries' degree of development. In Colombia, the survival rate between 2015 and 2020 increased from 40% to 61% [3], a figure higher than that reported for low- or middle-income countries, where less than 30% survive, as reported by the World Health Organization [1]. Determinants of this difference between countries have been identified, such as treatment abandonment, toxic death, and barriers to accessing health services. Among the latter, difficulties in timely and adequate diagnosis, financial restrictions, long distances between the patients' homes and the care centers, and the unavailability of drugs stand out [1,4].

Treatment abandonment in pediatric cancer has been one of the main challenges in cancer control in Colombia. A study published in 2011 reported a dropout rate close to 18%; it observed that 77% of patients who did not drop out of treatment survived, while only 28% of children with treatment abandonment survived. The same study reported that the risk of dying or relapsing from the disease was 3.9 times higher in patients who dropped out of treatment, evidencing a direct association between dropout and the likelihood of relapse or death [4].

In Colombia, there is a lack of information on the situation of treatment abandonment in childhood cancer, with limited literature examining the determinants of this abandonment. However, the Childhood Cancer Epidemiological Surveillance System (Vigicancer) was developed in 2009 in Cali and later extended to ten other cities in the country, which allowed for systematizing and monitoring different clinical outcomes, including treatment abandonment [5]. Based on the information obtained in this surveillance system, studies have emerged, such as the one published in 2016 [6], which explored the relationship between the absence of social support networks and the abandonment of pediatric oncology treatment, finding a strong association between these factors; this allows understanding the importance of social support to establish measures that impact the survival of children and adolescents with cancer.

Thus, to safeguard the permanence of the child in treatment, ensure survival, and reduce the impact of the disease, in recent decades, Colombia has issued a wide range of regulations concerning the detection, treatment, and comprehensive control of childhood cancer, where social support institutions play an important role in treatment continuity. In the country, this support is provided by temporary lodgings, which are part of the National Family Welfare System, defined by Resolution 1440 of 2013 [7].

Temporary lodgings support processes that guarantee healthcare, such as accommodation, food, and displacement, with the authorization of the insurance company or the territorial entity for those not affiliated to the General Social Security Health System (sgsss, for its initials in Spanish) [7]. At present, there is still no national census of temporary lodgings; however, the Ministry of Health and Social Protection is leading the draft resolution for constructing a registry of institutions providing social and socio-sanitary services, which seeks to characterize and locate the supply of these institutions to facilitate the organization and coordination of the services offered and integration with the health system [8].

There have been few studies in Colombia that examine different factors that affect the population with childhood cancer and their families. Thus, this research aimed to characterize the sociodemographic, economic, educational, healthcare, and social support services factors of children and adolescents with cancer and their families staying in temporary lodgings in eight cities in the country. It is imperative to know these factors to establish public health policies and strategies to strengthen social assistance services and support networks for families of children with cancer, as well as to address other predictors of cancer treatment continuity.

Methodology

In this descriptive cross-sectional survey-type study, thirteen temporary lodgings were included in eight main cities of Colombia: Barranquilla, Bogotá, Bucaramanga, Cali, Cartagena, Ibagué, Medellín, and Pasto, given that these cities have reference oncology centers in the country. They were identified based on information provided by health insurance companies, institutions providing oncology services for children under 18 years of age, territorial health entities, and support foundations. The temporary lodgings with the highest capacity and occupancy at data collection were selected.

A non-probabilistic convenience sample was established based on the information provided by the managers or administrators of these temporary lodgings, which included 42 caregivers (all family members) of children under 18 years old with a presumptive or con-

firmed cancer diagnosis staying in these homes. The study included caregivers of children and adolescents with cancer who authorized their participation in the research and met the inclusion criteria (parent or family caregiver of a child under 18 years old with a suspected or confirmed cancer diagnosis staying in a temporary lodging and who spoke Spanish).

Data was collected between June and August 2023 through a self-completed physical survey by the caregivers included in the study.

Description of the instrument

The survey (see Annex) was designed for this study and adjusted through a pilot test carried out in a temporary lodging for children and adolescents diagnosed with cancer. This test aimed to evaluate the feasibility of the methodology, improve the study design, and corroborate the instrument in real-life conditions to adjust it to avoid errors in data collection.

This survey consisted of 55 questions: 52 closed-ended questions with single or multiple-choice answers and three open-ended questions that sought the narrative elaboration of the participants. The questions were grouped into five modules and variables.

Sociodemographic conditions of the family nucleus: It refers to the circumstances in which the family members live and develop, as well as the factors that characterize them within a social group, including general data of the caregiver (nationality, ethnicity, educational level, and religious orientation), place of origin, area of residence, means of transportation and travel time to reach the temporary lodging, socioeconomic stratum, housing conditions, and availability of public services.

Family and economic dynamics: This refers to family and financial situation and economic involvement during the oncological process. It includes family composition, the relationship of the caregiver with the child, the reason for accompaniment, occupation or trade, the income of the family nucleus, main income contributor, allocation of resources to medicines and transportation, and impact on the economic dynamics due to the child's illness.

School and educational dynamics of the child: It involves the child's current school situation and changes in the educational environment (curricular and extracurricular) after the oncological diagnosis. It includes educational level, current education, interruption of school activities, study modality, requirements to improve the quality of education, and abandonment of extracurricular activities.

Care provided to the child by the healthcare system: It refers to aspects concerning the oncological diagnosis, treatment, and prognosis, as well as the provision of services and fulfillment of health demands both in

the administrative and service delivery areas. It includes health affiliation regime, oncological diagnosis, age at diagnosis, treatment status, understanding of treatment and prognosis, treatment expectations, treatment abandonment and interruption, inconveniences with authorizations, and legal actions filed.

Social support to the child and their caregiver in the temporary lodging: It implies the use and resources provided by a social assistance institution that offers temporary accommodation to minors under 18 years old with an oncological diagnosis in the city where they receive healthcare. It includes the mechanism of referral to the temporary lodging, travel financing, the frequency and reason for using the social support service, level of satisfaction, and services received in the temporary lodging.

Data analysis

Data were captured digitally in the web application of the Research Electronic Data Capture or REDCap® software (version 13.8.1). A research assistant verified and validated the information, comparing the physical and digital data to ensure concordance. Subsequently, a descriptive analysis of the established variables was performed using frequencies and percentages. This electronic data capture software was developed by Vanderbilt University (Tennessee, USA) and licensed under a proprietary license distributed to the consortium's international partners.

The results were processed with Excel® statistical software (version 2013), and the maps were created using the ArcGIS Pro® software (version 3.1), developed and commercialized by the Environmental Systems Research Institute (California, USA).

Ethical considerations

This study was approved by the Research Ethics Committee of the Instituto Nacional de Cancerología (Minute No. 0015-20 of June 24, 2020) after receiving informed consent from the caregivers of children and adolescents with cancer.

The rights of the participants were respected by protecting the privacy and confidentiality of the information. The recommendations of the Declaration of Helsinki [9] and the Council for International Organizations of Medical Sciences [10] were followed, as well as the guidelines for health research set forth by Resolution 8430 of 1993 [11].

Informed consent was not necessary from minors, given that the survey was not administered to the children with cancer but to their caregivers.

Results

The study included thirteen temporary lodgings located in eight cities in Colombia, with the participation of 42 caregivers (all family members) of children and adolescents diagnosed with cancer who were temporarily staying in these temporary lodgings: Medellín (16.7%), Pasto (16.7%), Cartagena (14.3%), Cali (14.3%), Bogotá (14.3%), Bucaramanga (11.9%), Barranquilla

(9.4%), and Ibagué (2.4%). All the caregivers staying in these temporary lodgings at the time of data collection agreed to participate; no caregiver was excluded, and no one refused to participate in the study. Table 1 summarizes the main characteristics of the participants.

The survey variables were grouped into the following modules: sociodemographic conditions of the

Table 1. Description of participants

	Variable (N=42)	n	%
Nationality	Colombian	38	90.5
	Venezuelan	4	9.5
Age (years)	22-29	9	21.4
	30-49	31	73.8
	>50	2	4.8
Sex	Woman	40	95.2
	Man	2	4.8
Relationship to the child	Mother	39	92.8
	Father	2	4.8
	Uncle/Aunt	1	2.4
Religion	Catholic	24	57.1
	Christian	11	26.2
	Pentecostal movement	1	2.4
	Jehovah's Witnesses	2	4.8
	None	4	9.5
Ethnicity	Indigenous	9	21.4
	Black, mulatto, Afro-descendant	5	11.9
	None	28	66.7
Educational level	Completed elementary school	5	11.9
	Incomplete elementary school	4	9.5
	Completed secondary school	12	28.6
	Incomplete secondary school	13	31.0
	Technician or technologist	3	7.1
	Professional or postgraduate	1	2.4
	No education	3	7.1
	No data	1	2.4
Occupation/trade	Housewife	35	83.2
	Farmer or farm-related activities	2	4.8
	Nurse	1	2.4
	Nanny	1	2.4
	Self-employed	1	2.4
	Technician	1	2.4
	Various trades	1	2.4

family nucleus, family and economic dynamics, school and educational dynamics of the child, care provided to the child by the healthcare system, and social support for the child and their caregiver in the temporary lodging.

Sociodemographic conditions of the family nucleus

Of the family members surveyed, 90.5% said they had Colombian nationality, and 9.5% were of Venezuelan origin. In turn, 23.7% of Colombians belonged to Indigenous communities, and 13.2% were categorized as black, mulatto, or Afro-descendant.

About 90% of the respondents had no more than secondary education. Regarding religious orientation, 57.1% of the caregivers identified themselves as Catho-

lic, 28.6% belonged to a Christian movement, 4.8% recognized themselves as Jehovah’s Witnesses, and 9.5% did not belong to any religion.

The caregivers surveyed came from 16 departments and 37 cities, according to the administrative and political division of the country, and resided mainly in urban areas (57.1%), followed by rural areas (42.9%). According to the location of their places of residence, they needed to use different means of transportation to get to the temporary lodging. Most children and their caregivers (95.2%) used land transportation alone or in conjunction with river and air transportation (see Table 2).

The families spent up to 1 hour (2.4%), 3 to 6 hours (40.5%), 7 to 12 hours (33.3%), and more than 12 hours

Table 2. Place of residence of the family nucleus and means of transportation to reach the temporary lodging

City of temporary lodging	Department of origin	Area of residence and means of transportation*		Total
		Urban	Rural	
Barranquilla	Cesar	2a	1a	3
	Magdalena	1a		1
	<i>Subtotal</i>	3	1	4
Bogotá	Boyacá		2a	2
	Casanare	2a,b		2
	Córdoba		1a	1
	Tolima	1a		1
	<i>Subtotal</i>	3	3	6
Bucaramanga	Bolívar	1a,c		1
	Cesar	1a	2a	3
	Santander	1a		1
	<i>Subtotal</i>	3	2	5
Cali	Bolívar	1b		1
	Caquetá	2a		2
	Cauca	1a,b,c	1a	2
	Vaupés	1a,b		1
	<i>Subtotal</i>	5	1	6
Cartagena	Bolívar	2a	1a	3
	Córdoba		1a	1
	Sucre		2a	2
	<i>Subtotal</i>	2	4	6
Ibagué	Tolima	1a		1
	<i>Subtotal</i>	1		1
Medellín	Antioquia	3a	2a	5
	Chocó	1a,c	1b	2
	<i>Subtotal</i>	4	3	7

City of temporary lodging	Department of origin	Area of residence and means of transportation*		Total
		Urban	Rural	
Pasto	Nariño	2a	1a	3
	Putumayo	1a	3a,c	4
	Subtotal	3	4	7
Total		24	18	42

*a: land; b: air; c: river

(23.8%) to get from their places of residence to the temporary lodging.

Figure 1 shows the map of Colombia, broken down by regions, depending on the distance traveled by the children and their caregivers from their different places of residence to reach the city where they temporarily stayed while receiving healthcare. It also shows the travel time reported between the family’s place of residence and the location of the temporary lodging in the eight cities included in the study: Medellín (a), Pasto (b), Cartagena (c), Cali (d), Bogotá (e), Bucaramanga (f), Barranquilla (g), and Ibagué (h).

The families of children and adolescents with cancer belonged to low socioeconomic strata (1 and 2), according to the housing characteristics and access to public services; 93% of them were classified as stratum 1 and 7% as stratum 2.

The condition of the walls and floors of the family’s dwelling varied. Nearly half of the children resided in dwellings with concrete infrastructure (walls, 47.6%; floors, 40.5%), followed by wooden walls (38.1%) and earthen floors (23.8%); 52.4% of the households had one or two public utilities: electricity (26.2%) or electricity and water (26.2%). Only 11.9% of the households had all public services, including gas, sewage, and internet, and 7.1% had no public services at all.

Family and economic dynamics

Of the families, 54.7% identified themselves as nuclear or biparental; the remaining families reported single-parent (26.2%), extended single-parent (14.3%), and reconstituted (4.8%) families.

The caregivers were mainly mothers (92.8%) and, in fewer cases, fathers (4.8%) and uncles (2.4%). The reason for accompaniment was mostly related to the mother’s role in terms of motherhood and security in caregiving. In other families, it was because the father worked to support the household or because they had no other family support. The mothers surveyed were mainly engaged in caregiving and housework (83.3%)

and, to a lesser extent, in diverse activities: agriculture, nursing, childcare, and various trades.

Although fathers were the main income earners in the households (57.1%), some mothers had this economic responsibility (19%). Other households were financially dependent on different family members, such as grandparents (11.9%), stepparents (4.8%), uncles and aunts (2.4%), or exclusively on the temporary lodging (4.8%).

Eighty-one percent of the families reported that the child’s cancer diagnosis affected the economic dynamics of the household, including resignation or dismissal from work of some members of the family, applications for loans, changes in working hours, or changes in the place where they work; nineteen percent reported that their household economy was not affected by the child’s illness.

In general, about 85% of the households had incomes below the current legal monthly minimum wage (SMLMV, for its initials in Spanish), and 62% of the families had at least one government subsidy: 57.1% received subsidies from Familias en Acción (Families in Action), 2.4% from Ingreso Solidario (Solidarity Income), and 2.4% from Jóvenes en Acción (Youth in Action). Thus, nearly half of the households that did not exceed a monthly income base of one SMLMV were not beneficiaries of any government subsidy; at the same time, 83% of families with incomes between 1 and 2 SMLMV benefited from a government subsidy.

Totaling the income earned per family, in 52.4% of the households, less than 10% of the income was spent on transportation and medication due to the child’s illness. Table 3 shows the income, government subsidies, and household expenditure.

School and educational dynamics of the child

Of the children and adolescents with a presumptive or confirmed diagnosis of cancer staying at temporary lodgings, 73.8% had some educational level, while 26.2% had not started formal education. Of the total of children with an educational history, 54.8% had not completed elementary school, 9.7% had completed elementary



Figure 1. Maps of origin-destination linkages disaggregated by city: distance and travel time from the place of residence to the temporary lodging

school, 32.3% were in secondary education, and one child had completed secondary school (3.2%). However, 71.4% of children and adolescents were not studying.

About half of the children temporarily suspended their studies while the management plan for their treatment was defined (50%); others dropped out of school due to the disease and family dynamics (23.3%).

As for the children and adolescents who were studying, it was reported that they used various spaces for education: school, clinic or hospital, temporary lod-

ging, and synchronous or asynchronous virtual education, using guides.

When the family members of the actively studying minors were asked about the elements that would improve the quality of education during treatment, they mainly expressed the availability of a personalized teacher or tutor (58.3%) and access to digital media (25.0%).

In addition, due to their illness, 42.9% of the children had to give up physical and sports extracurricular activities, and 14.3% leisure and recreational activities.

Table 3. Income, government subsidies, and household expenditure

Total family income	Government subsidy	Percentage allocated to transportation and medicines				Total
		Less than 10%	10% to 30%	30% to 50%	More than 50%	
1 to 2 SMLMV	No subsidy				1	1
	Familias en Acción	2		1	1	4
	Ingreso Solidario				1	1
Less than 1 SMLMV	No subsidy	7	2	4	2	15
	Familias en Acción	13	5	1	1	20
	Ingreso Solidario			1		1
Total		22	7	7	6	42

SMLMV: current legal monthly minimum wage.

Care provided to the child by the healthcare system

The total number of caregivers indicated that the children were affiliated to the SGSSS: 7% belonged to the contributory health affiliation regime (private) and 93% to the subsidized regime (public).

A total of 93% had a confirmed oncologic diagnosis, while 7% had a presumptive or suspected diagnosis of childhood cancer; 42.9% of the children were diagnosed between 0 and 5 years of age, 35.7% between 6 and 11 years of age, and 21.4% had a diagnosis in the adolescent stage.

For all ages, the most common diagnosis was acute lymphoid leukemia (50.0%), followed by acute myeloid leukemia (7.1%), non-Hodgkin lymphoma (7.1%), neuroblastoma (4.8%), brain tumor (4.8%), Wilms tumor (4.8%), Hodgkin lymphoma (2.4%), Burkitt lymphoma (2.4%), retinoblastoma (2.4%), and Ewing sarcoma (2.4%). In addition, 14.2% had some other unspecified malignant neoplasm (see Table 4).

Of the children, 83.3% were under active treatment. Most caregivers reported that they understood the treatment and prognosis of the child given by the treat-

ing physician (94.3%). Of these, the majority expected the treatment to cure the child (88.6%), and others expected the treatment to improve their quality of life (8.6%) or increase the life expectancy of the child or adolescent (2.8%). Although a small number of those responsible for the child did not understand the treatment and clinical prognosis (5.7%), they also expected the child to recover.

Even though only one of the families had once abandoned the treatment due to dissatisfaction with it and because they preferred the use of alternative and complementary medicine, none of the caregivers thought, in the last month before the survey, of abandoning the treatment plan, nor did they perceive any treatment interruption in most cases (81%). In addition, 26.2% had problems with the authorizations given by the health insurance company, related to delays in the management and provision of services or service denial, and resorted to legal mechanisms, in a higher number, *tutela* action (21.4%) or petition rights (7.1%). Despite this, 19% of the caregivers stated that, at some point in the care pathway, they perceived treatment discontinuity due to causes inherent to the provision of health services (16.7%) or factors specific to the patient (2.3%).

Table 4. Cancer diagnosis by age range

Age of the child at diagnosis (years)	Diagnosis	Type of diagnosis		Total
		Confirmed	Suspected	
0-5	Acute lymphoid leukemia	9		9
	Acute myeloid leukemia	1		1
	Burkitt lymphoma	1		1
	Neuroblastoma		1	1
	Other malignant neoplasms	2	1	3
	Retinoblastoma	1		1
	Ewing sarcoma	1		1
	Wilms tumor	1		1
	<i>Total</i>	16	2	18
6-11	Acute lymphoid leukemia	10		10
	Acute myeloid leukemia	1		1
	Other malignant neoplasms	1		1
	Wilms tumor	1		1
	Brain tumors	2		2
	<i>Total</i>	15		15
>11	Acute lymphoid leukemia	2		2
	Acute myeloid leukemia	1		1
	Hodgkin lymphoma	1		1
	Non-Hodgkin lymphoma	2		2
	Neuroblastoma	1		1
	Other malignant neoplasms	1	1	2
	<i>Total</i>	8	1	9
Total		39	3	42

Social support for the child and their caregiver in the temporary lodging

Of the children, 83.3% were referred to the temporary lodging by the hospital or clinic, 9.5% by a foundation, and 7.2% had a personal referral. However, they received financing to travel from their places of residence from one or more sources: own money (61.9%; n=26), insurance company (52.4%; n=22), and foundation (9.5%; n=4).

A total of 64.3% of the caregivers indicated that this was the first time they used the temporary housing service, while the remaining 35.7% had stayed there 10 or more times. About 88% of the children did not have any accommodation in the city where the medical treatment was provided, this being the main reason why the minors and their caregivers used the housing service in a temporary lodging. Other factors for use were proximity to the institution where the child was being cared for (9.5%) and preference for the temporary lodging instead

of a hotel provided by the health insurance entity as the primary option (2.4%).

Most minors received care in one medical institution (71.4%), a smaller percentage attended up to two clinics or hospitals to receive care (16.7%), and 11.9% of the children and adolescents were treated by three or more healthcare providers. Among the children, 30% did not require financial support to travel from the temporary lodging to their respective places of clinical care due to the proximity of the respective health entity. The children who did require resources to transfer from the temporary lodging received financial support from one or more sources: foundation (40.5%; n=17), their own money (26.2%; n=11), and the insurance company (19%; n=8).

The companions expressed being satisfied or very satisfied during their stay in the temporary lodging (95.2%), while a smaller percentage reported being dissatisfied (2.4%) or neither satisfied nor dissatisfied (2.4%). The services the children received in the tem-

porary lodgings in addition to accommodation were alim-entation (100 %; n=42), recreational activities (73.8 %; n=31), psychological support (38.1 %; n=16), and medical or nursing care (14.3 %; n=6).

Among the caregivers, 57% did not perceive a need to improve any service of the temporary lodging, and 43% reported that they would like to improve aspects such as infrastructure, food menu, and medical or psychological services.

Discussion

Childhood cancer does not only affect the sufferer; it affects the entire family. Family members often struggle with excessive responsibilities and less time to care for other family members, which increases with the natural progression of the disease and subsequent outcomes. To cope with the problem, families use coping mechanisms influenced by multiple factors, such as sociodemographic, financial, educational, work, family functionality, and availability of support networks, among others, which are determinants in the processes of adaptation and resilience [12].

Evidence allows associating some of these factors with childhood cancer survival, indicating higher mortality among children and adolescents from lower socioeconomic strata [13]. In countries such as Colombia, even though survival has been reported to be higher than that generally reported for middle- and low-income countries, it is still not comparable with the figures for high-income countries due to health inequities [14]. The factors with the highest impact in middle- and low-income countries are mainly low socioeconomic status, limited parental education level, and long travel time to the health center [15-18]. These characteristics are shared by the participants in the present research, where all respondents belonged to low socioeconomic strata, and most of them, although coming from urban areas, were required to make long trips to reach the oncology service center due to geographical conditions and the lack and deterioration of access roads in the country.

Because of the limited supply of pediatric oncology services [19] and given that the center of care is assigned according to the network of providers of the insurance company, some minors received treatment in institutions far from their places of residence. This finding has been described in various publications that consider the distance to the center of care as an influential element in the decision of treatment abandonment in childhood cancer [20-22]. Therefore, according to its context, each country should establish strategies to harmonize the supply of health services and the assignment of oncologic treatment centers that respond to the needs of the child and their family.

Likewise, the present study found that most of the children and adolescents staying in these temporary lodgings belonged to the state-subsidized health system, which is significant for their clinical outcomes since, despite the existence of a universal national health system, there are gaps in care between the two affiliation systems. These differences translate into increased mortality for the most disadvantaged populations, as evidenced in a study conducted in the country, which found a three-times higher risk of death in minors with public health insurance compared to those with private insurance, as well as a six-fold increase in treatment abandonment, with disparate overall survival rates, depending on the type of insurance: 62% for minors with private insurance, 43% with public insurance, and 23% for patients without insurance [23].

On the other hand, it has been shown that the parents' educational level can determine a better knowledge of the disease, develop problem-solving skills, and broaden communication in networks, which could contribute to generating alternatives for coping with the disease [12]. This research found that, although most caregivers had not completed secondary education, they understood the diagnosis, treatment, and prognosis of the child, positively recognizing the explanations provided by the treating physicians, which is highlighted in a study that explored parental involvement in the treatment of childhood cancer, finding that effective communication of healthcare personnel helps to overcome factors that impede the therapy and the effect of this on disease recovery [24].

Regarding disease recovery, previous studies describe the importance of spiritual guidance in a situation of illness as a source of comfort in times of uncertainty, hopelessness, or exhaustion typical of the cancer process [25]. This study found that almost all caregivers practiced some form of creed and had as their greatest expectation regarding cancer treatment and recovery, thus highlighting the role of religion in the hope of survival.

Despite the desire for healing, the families face a heavy burden derived from the care of the child. Parents, siblings, and other family members must assume new roles and transform the family routine to dedicate time to feeding, care, and grooming activities, transportation, medication administration, scheduling, and accompanying the child to medical appointments and chemotherapy or radiotherapy treatment sessions [26]. Consequently, some family members have to reduce their working hours or abandon work [27,28], as was evident in most families in this study, which affected the household economy due to the child's diagnosis.

In addition, various situations increase the financial challenges for families of children or adolescents with cancer. This study found that the majority of households had incomes below minimum wage and just under half

of the participants received no government subsidy. Families had to make additional efforts to meet needs with high out-of-pocket expenses, which affected the ability to pay and put the household at risk of poverty [26]. The financial burden might also be exacerbated by living in locations distant from the care facilities, which generates another expense associated with the disease [26].

Another relevant aspect of the pediatric population with cancer is the interruption of the educational process. In this study, most of the children suspended or abandoned their education once treatment had begun to focus all the attention of the family and the healthcare team on curing the disease. It should be considered, however, that cancer treatment can last for years, taking the child or adolescent away from school and extracurricular activities for long periods. Nevertheless, school is part of their daily life, and its continuation reaffirms hope for the future and recovery [29]. Even so, not all health and social assistance institutions have hospital classrooms that allow face-to-face and specialized education with sufficient technology and teaching staff, which were the principal needs expressed by caregivers to improve the quality of education. Thus, it is essential to strengthen this strategy to ensure continued and personalized education [29], not only in clinics or hospitals but also in temporary lodgings.

In addition to facilitating the educational process of children and adolescents, temporary lodgings are a vital component in reducing access barriers, increasing treatment adherence, and favoring continuity of care for the pediatric cancer population. The literature has described the importance of social support services as a means of encouraging parents to face the complex circumstances of childhood cancer [30,31]. In that sense, this study evidenced that families experience great satisfaction with temporary lodgings and, consequently, a high probability of permanence in these social support institutions. Although there is legislation on this aspect in the country, there are evident regulatory gaps for their operation and financing, ranging from the absence of registration and location of these institutions to the limited definition of payment mechanisms and integration with the healthcare system. As a result, these institutions are characterized by being private entities financed mainly by individuals or non-governmental organizations; therefore, it is necessary to continue searching for strategies to strengthen their social assistance role in the care pathway to achieve a greater impact on health outcomes.

In Colombia, the law for the right to life of children with cancer (Law 1388 of 2010) focuses on two main axes: guaranteeing comprehensive care for childhood cancer and implementing social support services [32]. From this perspective, the study was able to identify two determining facts in the healthcare pathway: 1) most of the children received therapeutic management in a sin-

gle institution, which may favor comprehensive care, and 2) there was little evidence of families abandoning treatment, which highlights the positive influence that temporary lodgings can have on treatment continuity, an aspect described in the literature as a result of the application of a holistic approach to social support. This has been shown to significantly reduce treatment abandonment by including a systematic and prospective dropout monitoring system, which is essential to prevent and follow-up treatment refusal [33].

In conclusion, children and adolescents with cancer and their families who require temporary housing services are characterized by having a low socioeconomic status, which is accentuated after the oncological diagnosis. In addition, there are other factors and changes in their social, family, and educational dynamics that, together with territorial uprooting due to living in places distant from the care centers, pose a major challenge for the healthcare sector and society.

On the other hand, even though, by definition, temporary lodgings represent a short-term service, the reality of the families shows that they become an almost permanent and indispensable service for timely access and continuity of cancer treatment.

The characterization of sociodemographic, economic, educational, healthcare, and social support factors in children and adolescents with cancer and their families is fundamental for designing and implementing health policies and childhood cancer care pathways to highlight the need to strengthen the role of temporary lodgings during the therapeutic process of childhood cancer.

This study has some limitations, such as the limited generalization of the results, so they should be analyzed in the context in which the information was collected and considering the sample and the characteristics of the participants. Therefore, future research of this nature must include a greater diversity of social contexts and the perspective of other actors in the socio-sanitary system to present results with a more comprehensive vision.

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Declaration of conflict of interest

The authors declare that they have no conflicts of interest

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Authors' contribution statement

Eliana Marcela Murcia Monroy: Consolidation, processing and interpretation of data and drafting of the manuscript

María Camila Garzón Herrera: Data collection (visit to households, inclusion of participants and application of surveys) and drafting of the manuscript

Luz Amparo Arias López: Review of relevant national and international publications on the subject and drafting of the manuscript

Amaranto Suárez Matos: Verification of data output, drafting, versioning, drafting and approval of the final document

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Annex: Survey

Module 1: Sociodemographic conditions of the family nucleus

1. Nationality of the survey respondent:	Colombian	Other	Which?
2. Completed years of age of the respondent: years			
3. Sex of respondent:	Woman	Man	
4. Which religion do you identify with?	Catholic	Jehovah's Witnesses	
	Christian	None	
	Other. Which?		
5. Which ethnic group do you identify with?	Indigenous	Rom	
	Raizal people	Palenquero	
	Black, mulatto, Afro-descendant	None of the above	
6. What is the level of education of the survey respondent?	No education	Incomplete elementary school	
	Completed elementary school	Incomplete secondary school	
	Completed secondary school	Technician or technologist	
	Professional or postgraduate degree	No data	
7. What is your occupation?	Technician	Housewife	
	Worker	Professional	
	Farmer or farm-related activities	Other. Which?	
8. Do you live with the child?	Yes	No	
9. The child's usual place of residence:	Municipality, Department		
10. Area of usual residence of the child	Head of municipality		
	Populated center		
	Dispersed rural		
11. Socioeconomic stratum of the child	Stratum 1	Stratum 4	
	Stratum 2	Stratum 5	
	Stratum 3	Stratum 6	
12. Select those items that match the characteristics of the floor and walls of the dwelling where the child resides.	Floor of the dwelling	Walls of the dwelling	
	Earthen floor	Concrete walls	
	Wooden floor	Wooden walls	
	Tile floor	Cardboard or plastic bag walls	
	Other. Which?	Other. Which?	

13. Access to public services in the child's dwelling: (Multiple choice answer)

- | | |
|-------------------------|---------------|
| Electricity | Water |
| Gas | Internet |
| Sewerage and sanitation | Other. Which? |

14. How long does it take to travel from the child's usual place of residence to the temporary lodging?

- | | |
|--------------------|---------------|
| Up to 1 hour | 1 to 2 hours |
| 3 to 6 hours | 7 to 12 hours |
| More than 12 hours | |

15. Which means of transportation does the child need to use to get to the temporary lodging from their usual place of residence? (Multiple choice answer)

- Animal or animal-drawn vehicle
- River transport (boat, canoe, or ship)
- Land transport (car, bus, intercity bus)
- Air transport (light aircraft, airplane, helicopter)

Module 2: Family and economic dynamics

16. Who make up the child's nuclear family?

- | | |
|--------------------------|--------------------------------------|
| Father, mother, siblings | Mother and siblings |
| Father, mother, siblings | Father and siblings and grandparents |
| Other. Which? | |

17. Respondent's relationship with the child:

- | | |
|----------------|-------------------------|
| Mother | Father |
| Brother/sister | Grandfather/grandmother |
| Uncle/aunt | Other. Which? |

18. Indicate the reason you are accompanying the child:

19. Who is the primary income earner in the child's household?

- | | |
|----------------|-------------------------|
| Mother | Father |
| Brother/sister | Grandfather/grandmother |
| Uncle/aunt | Other. Which? |

20. How much is the total household income of the child? (smlmv: Minimum Legal Monthly Minimum Wage) (1 SMLMV = 1,160,000 Colombian Pesos)

- | | |
|-------------------|-----------------------|
| Less than 1 SMLMV | Between 1 and 2 SMLMV |
| More than 2 SMLMV | |

21. What percentage of the household's overall income is spent on transportation and medication due to the child's illness?

- | | |
|---------------|---------------|
| Less than 10% | 30% to 50% |
| 10% to 30% | More than 50% |

22. Does the child's nuclear family receive any subsidy from the Government? (Multiple choice answer)

- | | |
|-------------------------|--------------------------------------|
| Familias en Acción | Política de Gratitud en la Matrícula |
| Programa Colombia Mayor | Programa Mi Casa Ya |
| Ingreso Solidario | Programa Subsidio al Desempleo |
| Jóvenes en Acción | Bono de Alimentación Estudiantil |
| Other. Which? | |
-

23. Has the presumptive or confirmed diagnosis of the child affected the economic dynamics of the household? (Multiple choice answer)

- | | |
|-----------------------------------|-------------------------------|
| Not affected | Change of working hours |
| Loan application | Change of place of employment |
| Resignation or dismissal from job | Other. Which? |

Module 3. Care provided to the child by the healthcare system

24. Type of insurance affiliation regime of the child:

- | | |
|------------|--------------|
| Exception | Contributive |
| Subsidiary | Not insured |

25. Does the child have a confirmed or suspected cancer diagnosis?

- | | |
|-----------|-----------|
| Confirmed | Suspected |
|-----------|-----------|

26. At what age was the child diagnosed? At the age of

27. What type of presumptive or confirmed diagnosis does the child have?

- | | |
|-------------------------|---------------------------------------|
| Acute lymphoid leukemia | Acute myeloid leukemia |
| Hodgkin lymphoma | Non-Hodgkin lymphoma |
| Brain tumors | Neuroblastoma |
| Retinoblastoma | Wilms tumor |
| Osteosarcoma | Burkitt lymphoma |
| Ewing sarcoma | Other unspecified malignant neoplasms |

28. Is the child currently under active treatment?

- | | |
|-----|----|
| Yes | No |
|-----|----|

(If "No," please go to question 31.)

29. Do you understand the child's treatment and prognosis as reported by the treating physician?

- | | |
|-----|----|
| Yes | No |
|-----|----|

30. What is your greatest expectation regarding the child's treatment?

- | | |
|--------------------------|---------------------------|
| Recovery | Increased life expectancy |
| Improved quality of life | Pain management |
| Other. Which? | |

31. Have you had any problems with the authorizations given by the EPS [health promoting entity] that attends your child (medical appointments, consultations, or procedures)?

- | | |
|-----|--------|
| No | |
| Yes | Which? |

32. Have you had to take legal action to ensure access to health services for the child?

- | | |
|-----|--------|
| No | |
| Yes | Which? |

33. To how many clinics or hospitals must the child be referred for medical care?

- | | |
|------------------------|----------------|
| 1 institution | 2 institutions |
| 3 institutions | 4 institutions |
| 5 or more institutions | |

34. Have you ever felt that the treatment has been interrupted?

- | | |
|-----|------|
| No | |
| Yes | Why? |

35. Has the child ever dropped out of treatment?

- | | |
|-----|----|
| Yes | No |
|-----|----|

(If "No", please go to question 37.)

36. What was the reason for dropping out of treatment? (Multiple choice answer)

- | | |
|---|---|
| Barriers by the insurance company or treating institution | Dissatisfaction with the treatment received |
| Financial problems | Family difficulties |
| Use of alternative medicine | Other. Which? |

37. In the last 30 days, did you consider the possibility of the child dropping out of treatment?

- | | |
|-----|----|
| Yes | No |
|-----|----|

(If "No", please go to question 39.)

38. What is the main reason you have thought about not continuing the treatment your child is receiving?

- | | |
|---|---|
| Barriers by the insurance company or treating institution | Dissatisfaction with the treatment received |
| Economic and labor problems | Family difficulties |
| Relapses or no improvement | Lack of support networks |
| Use of alternative medicine | Other. Which? |

Module 4. Social support for the child and their caregiver in the temporary lodging

39. Is this the first time you use a temporary lodging?

- | | |
|-----|----|
| Yes | No |
|-----|----|

(If "Yes", please go to question 41.)

40. In the past, how many times have you used the temporary housing service?

- | | |
|--------------|--------------------|
| 2 to 3 times | 7 to 10 times |
| 4 to 6 times | More than 10 times |

41. Why is the child using the housing service in this temporary lodging?

- | |
|---|
| No accommodation in the city. |
| Proximity of the temporary lodging to the institution where the child is treated. |
| Other. Which? |

42. Who directed you to the temporary lodging?

- | | |
|--------------------------------|--------------------|
| Hospital or clinic | Insurance company |
| City hall or governor's office | Personal reference |
| Foundation | Temporary lodging |
| Other. Which? | |

43. Who pays for the travel from your place of residence (municipality and department of origin)? (Multiple choice answer)

- | | |
|--------------------------------|-------------------|
| Hospital or clinic | Insurance company |
| City hall or governor's office | Own money |
| Foundation | Other. Which? |

44. Who pays for the travel from the temporary lodging to the hospital or facility where the child is treated? (Multiple choice answer)

- | | |
|--------------------------------|-------------------|
| Hospital or clinic | Insurance company |
| City hall or governor's office | Own money |
| Foundation | Other. Which? |

45. What services other than accommodation does the child receive at the temporary lodging where they stay? (Multiple choice answer)

- | | |
|-------------------------|-----------------------|
| Alimentation | Psychological support |
| Recreational activities | Medical care |
| No additional service | Other. Which? |

46. How have you felt with the temporary lodging?

- | | |
|------------------------------------|-------------------|
| Very satisfied | Dissatisfied |
| Satisfied | Very dissatisfied |
| Neither satisfied nor dissatisfied | |

47. What services would you improve in the temporary lodging where you are staying? (Multiple choice answer)

- | | |
|------------------------------------|-----------------------|
| Relationship with personnel | Infrastructure |
| Food menu | Psychological support |
| Spaces for recreational activities | Medical care |
| Other. Which? | |

Module 5. School and educational dynamics of the child

48. What is the child's educational level?

- | | |
|-------------------------------|--------------------------------|
| No education | Incomplete primary education |
| Completed primary education | Incomplete secondary education |
| Completed secondary education | |

49. Is the child currently attending school?

- | | |
|-----|----|
| Yes | No |
|-----|----|

(If "Yes", please go to question 51; if "No", please answer question 50 and not need to answer items 51 through 54).

50. Why does the child not study?

Never had any kind of education

Dropped out of school due to their condition

Studies were temporarily suspended while procedures are resolved and a management plan for their condition is defined

Do not have the economic resources

Other. Which?

51. What space does the child use for education? (Multiple choice answer)

Home education with private teacher

School

Home education with parents or relatives

Clinic or hospital

Temporary lodging

Virtual education

Other. Which?

52. Do you believe that it is possible to obtain a quality education with the child's health condition?

Yes

No

Why?

53. What do you think the child in your care needs to improve the quality of their education during treatment?

54. From your perspective, what is the factor that has had the greatest impact on the normal development of the child's academic activities?

55. Has the child had to give up any extracurricular activities or hobbies because of their condition?

No.

Yes. Which?
