

Childhood and adolescent cancer in Chile: examining challenges and shaping tomorrow

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ABSTRACT

Objective. The aim of this study was to describe the epidemiology of childhood cancer in Chile and the disease landscape, assessing achievements, collaborations, and future challenges to be addressed by the National Plan for Child and Adolescent Cancer Control.

Methods. This descriptive study provides a general overview of national and international collaboration strategies and discusses the results of the Third Childhood Cancer Surveillance Report (2017–2019), the St. Jude Pediatric Oncology Facility Integrated Local Evaluation Tool (or PrOFiLE) report, collaboration with the Pan American Health Organization within the framework of the Global Initiative for Childhood Cancer and the development of the National Plan for Child and Adolescent Cancer Control within the CureAll framework.

Results. The analysis reveals the impact of childhood cancer by considering the incidence between 2017 and 2019, encompassing gender disparities. Leukemia is the most frequently occurring type of cancer, accounting for 40.4% of cancers among children and adolescents younger than 15 years and with an incidence of 57.5 cases per 1 million children in this age group. Cancer is the second leading cause of death among those aged 5–14 years. Cancer survival increased between 2007 and 2019, with 78.4% survival at 5 years post-diagnosis in 2023. The development of the National Plan for Child and Adolescent Cancer Control involved assessing the situation, setting goals and devising an action plan to reduce mortality from cancer in childhood and increase survival rates through early interventions and smooth transitions to adult care.

Conclusions. Chile has made progress in childhood cancer indicators, particularly in increasing survival, demonstrating its commitment to improving care for children with cancer, and this has been achieved through legislative frameworks, national planning, collaborative partnerships and participation in global initiatives. Despite the progress made, ongoing research, strong policy implementation and multidisciplinary collaborations remain vital to addressing persistent challenges. This study highlights the need to refine health systems, data collection methodologies and global cooperation to ensure optimal care for every child facing cancer, thus improving their chances of survival and their overall quality of life.

Keywords

Neoplasms; child; Chile.

Cancer in childhood remains a global concern, with an estimated 280 000 children and adolescents aged 0–19 years diagnosed annually (1). This prevalent health challenge reveals a marked disparity in outcomes, with more than 80% of young patients in high-income countries achieving successful

outcomes, while patients in low- and middle-income nations struggle with survival rates that remain below 30% (2). In the context of this complex landscape, Chile has made significant progress in the fight against childhood cancer through efforts related to epidemiological surveillance and data collection that

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have allowed cancer in this age group to be described with respect to incidence, survival and mortality, showing that an estimated average of 500 new cases occur annually, the survival rate reaches 78.4% at 5 years after diagnosis, and incidence and mortality are highest for children and adolescents with leukemia. Other efforts relate to the development of protocols and the delivery of effective and timely treatment (3).

A fundamental pillar in Chile's fight against cancer in children and adolescents is the the Law of Explicit Health Guarantees (Régimen de Garantías Explícitas en Salud), contained in Law 19.966 (4). These comprehensive regulations cover the entire life cycle of a child and the entire health care process, from initial suspicion to follow up, providing a solid framework for the management of childhood cancer. Complementing these regulations is a collaborative and resilient Chilean public health system and the creation of the Program for Antineoplastic Medicines for Children (known as PINDA for its name in Spanish) in 1988, which provides funding for chemotherapy for the main childhood cancers, marking an important milestone in the development of pediatric oncology.

On the global level, the World Health Organization (WHO) and St. Jude Children's Research Hospital joined forces to launch the Global Initiative for Childhood Cancer (GICC) in 2018 (5). This strategic initiative seeks to help governments develop essential guidelines and to provide technical support to establish and nurture high-quality cancer care programs for children and adolescents worldwide. This study aims to provide a comprehensive exploration of the landscape of cancer among children and adolescents in Chile, describing current challenges and their potential to shape the trajectory of care for children with cancer in the future.

METHODS

This study summarizes data from the recently published Third Childhood Cancer Surveillance Report from the National Registry of Childhood Cancer (known as RENCI) for 2017–2019, which comprises information about 1 579 cases of childhood cancer (3). Leveraging rigorous statistical methods, we extracted actionable insights from these data sets.

Additionally, as part of the baseline for the situational assessment, we include insights from a report generated using the St. Jude Pediatric Oncology Facility Integrated Local Evaluation Tool (PrOFILe) (6), a management tool for care in childhood cancer; the tool was used by the clinical teams and managers of the public care network for child and adolescent cancer between October 2020 and March 2021, and showed there were objective opportunities for improvement.

Moreover, our collaborative efforts with the Pan American Health Organization (PAHO) within the GICC have been instrumental since Chile's engagement in 2021. The GICC, propelled by the *CureAll* technical package, seeks to enhance countries' capabilities to provide high-quality cancer care to children and adolescents, while emphasizing the primacy of childhood cancer in national, regional and global health care agendas to strengthen health care systems and enhance the well-being of young patients.

In 2021, Chile made decisive strides within the GICC framework by formulating the nation's inaugural national cancer plan, exclusively dedicated to addressing the needs of children and adolescents, and known as the National Plan for Child and

Adolescent Cancer Control (or PNCCIJ). This plan's core objective revolves around taking a holistic approach to combat cancer in children and adolescents, centering on curbing cancer-related mortality and bolstering survival rates through early identification, timely intervention and a seamless transition to adult care. The preparatory phase of this plan, conducted during the first half of 2022, brought together clinical experts from the health care sector, along with representatives from civil society, including academia, family groups and scientific associations. Furthermore, the plan's development was enhanced through engagement with various technical teams under the auspices of the Ministry of Health. Notably, Exempt Decree No. 1435 of October 11, 2022 (Decreto Exento N° 1435, del 11 de octubre del 2022), formally established a dedicated working group comprising 65 individuals tasked with crafting a robust proposal for the Plan's realization.

RESULTS

Analysis of epidemiology of childhood cancer

Within the 3 years between 2017 and 2019 in Chile, 1 579 children and adolescents were diagnosed with cancer, resulting in a rate of 142.3 cases per 1 million children younger than 15 years. There is a gender disparity in incidence, as males constituted 54.2% (856) of these cases. Age stratification revealed that children aged 0 to 4 years accounted for 43.1% (681) of cases and those aged 10 to 14 years accounted for 28.8% (455). Notably, 82.6% (1 304) of cases were diagnosed by public health care facilities, with 81.5% (1 287) of patients benefiting from care under the National Health Fund (known as FONASA; data not shown).

Between 2007 and 2019 in Chile, cancer was the second leading cause of death among those aged 5 to 14 years, after the category that includes injury, poisoning and other external causes (Figure 1). Cancer was the eighth leading cause of death in children aged 0 to 4 years (Figure 1).

From a state perspective, Los Lagos, Bío Bío and Atacama had the highest incidences of cancer per 1 million children younger than 15 years, at 179.7, 176.7 and 175.0 cases, respectively (data not shown).

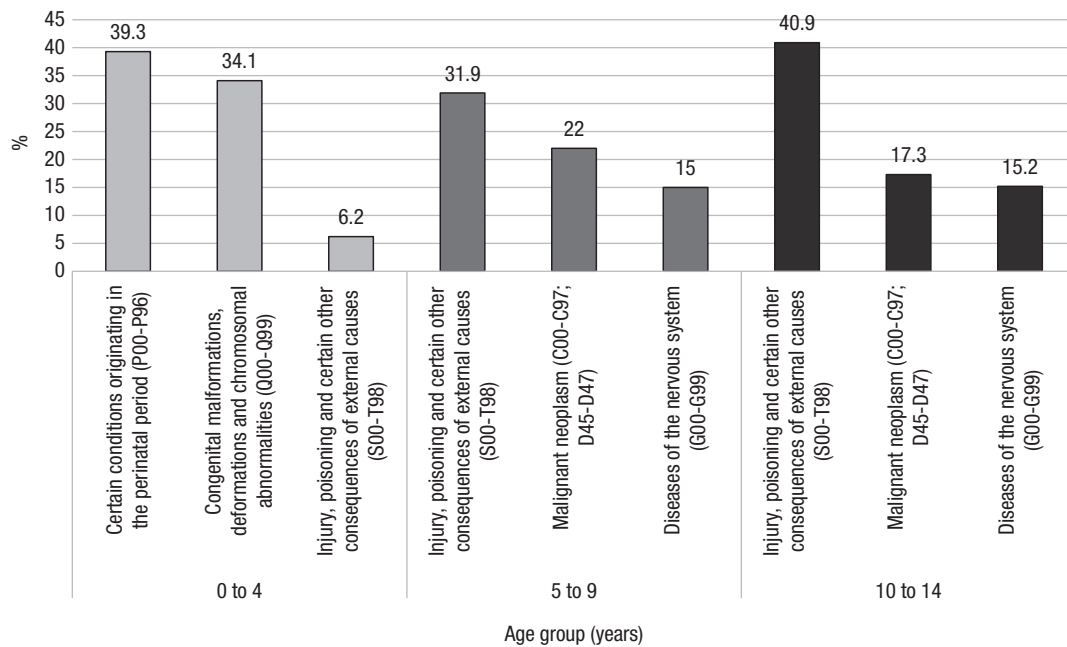
Leukemia was the most frequently occurring type of cancer, accounting for 40.4% (638/1 579) of all pediatric neoplasms, followed by central nervous system neoplasms at 20.1% (318/1579) and lymphomas at 9.6% (152/1 579) (Table 1).

Chile has made progress in improving survival among children and adolescents with cancer. Childhood cancer survival in Chile has increased from 71.4% during 2007–2011 to 73.5% during 2012–2016 and 79.7% during 2017–2019, achieving outcomes comparable to those of high-income countries today (Table 2, Figure 2) (4–8).

Development of the national cancer control plan for children and adolescents

A national working group was established to develop a national cancer control plan based on the *CureAll* technical package. *CureAll* is made up of the four pillars and three enablers of the GICC that will make it possible to assess the current situation in a country or region, develop an action plan, and implement and monitor progress. In childhood cancer care, the *CureAll* framework's pillars and enablers underscore its transformative mission. The pillars serve as keystones, each

FIGURE 1. Distribution of deaths (%) among children younger than 15 years, by cause of death, according to the International Statistical Classification of Diseases and Related Health Problems, tenth revision, by age group, both genders, Chile 2005–2019



Source: Prepared by the Department of Epidemiology, Ministry of Health, based on data from the National Registry of Childhood Cancer (known as RENC).

TABLE 1. New cases of cancer in children younger than 15 years, by International Classification of Childhood Cancer group, third edition (ICCC-3) and year of diagnosis, both genders, Chile, 2017–2019

ICCC-3 group	Year			Total	%	Incidence /1 million children aged <15 years
	2017	2018	2019			
I. Leukemias, myeloproliferative and myelodysplastic diseases	223	207	208	638	40.4	57.5
II. Lymphomas and reticuloendothelial neoplasms	43	52	57	152	9.6	13.7
III. Central nervous system and miscellaneous intracranial and intraspinal neoplasms	91	99	128	318	20.1	28.6
IV. Neuroblastoma and other peripheral nervous cell tumors	24	14	20	58	3.7	5.2
V. Retinoblastoma	11	15	14	40	2.5	3.6
VI. Renal tumors	15	23	11	49	3.1	4.4
VII. Hepatic tumors	7	11	8	26	1.6	2.3
VIII. Malignant bone tumors	28	28	28	84	5.3	7.6
IX. Soft tissue and other extraosseous sarcomas	21	23	23	67	4.2	6.0
X. Germ cell tumors, trophoblastic tumors and neoplasms of gonads	25	25	26	76	4.8	6.8
XI. Other malignant epithelial neoplasms and malignant melanomas	20	25	26	71	4.5	6.4
XII. Other and unspecified malignancies		1		1	0.1	0.1
Total	508	523	549	1,580	100	140.8

Source: Prepared by the Department of Epidemiology, Ministry of Health, based on data from the National Registry of Childhood Cancer (known as RENC).

embodying a critical facet of this endeavor. The first pillar encompasses centers of excellence and care networks, emphasizing the significance of proficient health care personnel and accessible expertise. The second pillar is universal health coverage, and it aims to bridge socioeconomic divides, delivering comprehensive, high-quality services to all. Regimens for management and road maps for diagnosis and treatment comprise the third pillar, which champions cutting-edge technologies and medicines to provide superior care. Evaluation and monitoring constitute the fourth pillar, establishing a robust information framework for effective implementation and ongoing enhancement.

The Initiative's enablers further its impact, with advocacy used to unite societal voices, leveraged financing ensuring financial sustainability, and linked governance providing a structured framework. Together, these pillars and enablers weave a narrative of transformative change, elevating the landscape of childhood cancer care.

The working group is following the three phases proposed by WHO for developing national plans (7). The first stage is a situational assessment. This stage had to answer the question, where are we? This stage sought to diagnose the national situation. Various inputs were used for this assessment, including PrOFiLE reports, which contain a diagnosis and proposals for improvement; 16 pediatric oncology services and units of the public health care network participated in generating this report during the second half of 2022.

The second stage was to determine the objectives by answering the question, where do we want to go? A hybrid in-person and virtual workshop was held on December 2, 2022, attended by the St. Jude manager for Latin America, Ms. Amalia Valdés, who provided methodological support to the Plan coordinating team at the Ministry of Health as well as to various

TABLE 2. Cancer survival in children younger than 15 years at 1, 3 and 5 years after diagnosis, by age group and gender, Chile, 2017–2019

Group	No. diagnosed	No. deceased	Survival					
			1 year		3 years		5 years	
			No. (%)	95% CI	No. (%)	95% CI	No. (%)	95% CI
Both genders	1 579	327	296 (90.4)	88.9 to 91.8	267 (81.7)	79.7 to 83.5	256 (78.3)	76.1 to 80.5
Boys	856	176	161 (91.5)	89.2 to 93	145 (82.4)	79.8 to 84.9	137 (77.8)	74.5 to 80.8
Girls	723	151	135 (89.4)	86.9 to 91.4	122 (80.8)	77.7 to 83.4	119 (78.8)	75.7 to 81.8
Age group (years)								
0–4	681	141	126 (89.4)	87.2 to 91.8	115 (81.6)	78.5 to 84.3	110 (78.0)	74.5 to 81.3
5–9	443	92	84 (91.3)	88.1 to 93.5	75 (81.5)	77.7 to 95	73 (79.3)	74.7 to 82.7
10–14	455	94	85 (90.4)	87.7 to 93.1	77 (81.9)	78.1 to 85.2	73 (77.6)	73.6 to 81.9

CI: confidence interval.

^a Tarone–Ware test used to test for equality of the survival function (i.e. early and late risk differences).^b Log rank test used to test for equality of the survival function.**Source:** Prepared by the Department of Epidemiology, Ministry of Health, based on data from the National Registry of Childhood Cancer (known as RENCIC).**FIGURE 2. Changes in survival of children younger than 15 years with cancer at 5 years after diagnosis, by report period and gender, Chile, 2007–2019****Source:** Prepared by the Department of Epidemiology, Ministry of Health, based on data from the National Registry of Childhood Cancer (known as RENCIC).

undersecretaries and staff at the headquarters of the National Cancer Agency (Agencia Nacional de Cáncer) and Department of Comprehensive Management of Cancer and other Tumors (Departamento de Manejo Integral del Cáncer y Otros Tumores). The first proposal listed 21 objectives, and two prioritization exercises were then carried out with different actors. Finally, two global health outcomes were defined: to reduce mortality and improve survival; 11 key secondary objectives for the action plan for the National Plan for Child and Adolescent Cancer Control were also defined, and these are shown by pillar in Table 3. Subsequently, the objectives were reviewed by the team focusing on each each pillar to ensure they were formulated correctly.

The third stage was to develop the action plan to meet the objectives. During February 2023, the divisions and institutions were defined that should be part of the team proposing actions at the political, regulatory, community and health care

levels. These include staff from the regional health secretariats (known as SEREMIS) and the regional health services to ensure representation from all parts of the country, which is unprecedented in terms of caring for children and adolescents with cancer.

DISCUSSION

Amid the global challenge of cancer in children and adolescents, Chile has taken significant strides to improve outcomes for young patients. Chile's public health care system and the national Program for Antineoplastic Medicines for Children have played crucial roles in securing access to diagnosis and treatment for children with cancer, marking a milestone in the development of pediatric oncology in the country. In this context, the key elements for success were the passage of the National Cancer Law (Ley Nacional del Cáncer) (8),

TABLE 3. Summary of proposed strategic objectives in the National Plan for Child and Adolescent Cancer Control, Chile, by CureAll framework pillar

Pillar	Strategic objectives
Centers of care excellence and care networks	<ul style="list-style-type: none"> Establish a comprehensive human resources standard encompassing the primary extended care team. Develop performance standards categorized by professional care areas within cross-sector components, such as palliative care, rehabilitation, mental health, fertility and reproductive health, oral health and nutrition. Create a specialized training plan to deliver care to children and adolescents, including palliative care, for professionals in the oncology field. Establish a baseline for infrastructure and equipment replacement. Enhance interdisciplinary team recruitment by 10%, based on assessed gaps in human resources across different child and adolescent cancer centers. Implement lifelong follow up for survivors, incorporating research and expedited access to clinical records. (Currently, follow up is covered by the Explicit Health Guarantees for up to 10 years after diagnosis.) Ensure 100% of cancer patients aged 0 to 19 who require specialized home-based palliative care, receive it.
Universal health coverage	<ul style="list-style-type: none"> Extend coverage of the Law of Explicit Health Guarantees for children younger than 14 years to include individuals up to 19 years of age, as research indicates that adolescents aged 15 to 19 years have improved health outcomes when provided with appropriate treatment delivered according to protocols and by specialized clinical teams.
Regimens for management and road maps for diagnosis and treatment	<ul style="list-style-type: none"> Incorporate new technologies and antineoplastic agents for the diagnosis, treatment and follow up of cancer in children and adolescents aged 0 to 19 years, based on the evidence and cost-effectiveness studies.
Evaluation and monitoring	<ul style="list-style-type: none"> Ensure that the National Registry of Childhood Cancer contains the necessary information – that is, a minimum set of updated data (e.g. whether the patient belongs to an indigenous group, their gender) – to allow reports to be generated every 2 years; also ensure that the analysis of data is shared at the territorial level to enable adequate decision-making. Ensure the interoperability of all registry platforms, both public and private, that contribute to clinical management in any way.

Source: National Cancer Agency, Ministry of Health.

international collaborations with St. Jude and PAHO, and the development of the National Plan for Child and Adolescent Cancer Control that included contributions from a multidisciplinary team of experts in childhood and adolescent cancer who aided in formulating policies, scientific research and implementation of strategies for early diagnosis and practices. This path has made Chile a pioneer and leader in Latin America in caring for children and adolescents with cancer, with long-term survival results comparable to those of high-income countries (Table 2) (9).

Local authorities demonstrated their strong political will when they declared childhood cancer to be an indisputable priority, and there is a commitment to strengthen the current national network

centers and to incorporate this specialty into other regional health care centers to facilitate access. Additionally, there is a clear interest in expanding the coverage of palliative care. In commemoration of International Childhood Cancer Day, Chile ratified its commitment to the GICC, developing public policies aimed at continually improving the health care delivered to our children and adolescents with cancer and to their families, ensuring that no one is left behind.

The development of the National Plan for Child and Adolescent Cancer Control represents an important milestone for Chile and Latin America. Chile's proactive engagement with the GICC and the CureAll technical package (2) aims to reduce mortality related to childhood cancer and enhance survival.

One strength of this study lies in its comprehensive exploration of care for children and adolescents with cancer in Chile, considering both local milestones and global collaborations. The study offers an understanding of the challenges to improving care and survival. However, limitations exist in the reliance on retrospective data, which may not capture the complete picture of the dynamics of cancer in children and adolescents. Additionally, future studies could provide a more in-depth analysis of potential barriers to effective implementation of the National Plan's initiatives.

In conclusion, Chile has made progress in childhood cancer indicators, particularly by increasing survival, thus demonstrating its commitment to improving care for children and adolescents with cancer, and these improvements have been achieved through the development of legislative frameworks, national planning, collaborative partnerships and participation in global initiatives. Despite this progress, however, research, strong policy implementation and multidisciplinary collaborations remain vital to addressing persistent challenges. This study highlights the relevant aspects of cancer epidemiology and the need to refine health systems, data collection methodologies and global cooperation to ensure optimal care for every child facing cancer, thus improving their chances of survival and their overall quality of life.

Authors' contributions. JP, OC and PC conceived the original idea for the study, and collected and analyzed the data. All authors interpreted the results, and wrote and reviewed the paper, and approved the final version.

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El cáncer en la población infantil y adolescente en Chile: un examen de los desafíos y la configuración del mañana

RESUMEN

Objetivo. El objetivo de este estudio fue describir la epidemiología del cáncer infantil en Chile y el panorama de la enfermedad mediante la evaluación de los logros, colaboraciones y desafíos futuros a abordar por el Plan Nacional de Cáncer Infanto-Adolescente.

Métodos. En este estudio descriptivo se proporciona una visión general de las estrategias de colaboración nacional e internacional y se analizan los resultados del Tercer Informe de Vigilancia del Cáncer Infantil (2017–2019), el informe de la herramienta de evaluación local integrada del Centro de Oncología Pediátrica del St. Jude Hospital (PrOFiLE, por su abreviación en inglés), la colaboración con la Organización Panamericana de la Salud en el marco de la Iniciativa Mundial contra el Cáncer Infantil y la elaboración del Plan Nacional de Cáncer Infanto-Adolescente en el marco *CureAll*.

Resultados. En el análisis se evidencia el impacto del cáncer infantil si se considera su incidencia entre el 2017 y el 2019, incluidas las disparidades según el género. La leucemia es el tipo de cáncer más frecuente, representa el 40,4% de los cánceres en la población infantil y adolescente menor de 15 años y tiene una incidencia de 57,5 casos por millón en este grupo etario. El cáncer es la segunda causa de muerte en la población de 5 a 14 años. Entre el 2007 y el 2019 se produjo un aumento de la supervivencia de los pacientes con cáncer, que en el 2023 alcanzó el 78,4% a los 5 años del diagnóstico. La elaboración del Plan Nacional de Cáncer Infanto-Adolescente implicó evaluar la situación, fijar metas y diseñar un plan de acción para reducir la mortalidad por cáncer en la infancia y aumentar las tasas de supervivencia mediante intervenciones tempranas y transiciones graduales al cuidado en la edad adulta.

Conclusiones. Chile ha logrado avances en los indicadores del cáncer infantil, en particular en cuanto al aumento de la supervivencia, que reflejan su compromiso de mejorar la atención prestada a la población infantil con cáncer. Esto se consiguió mediante marcos legislativos, planificación nacional, asociaciones de colaboración y participación en iniciativas mundiales. A pesar de los avances realizados, las investigaciones en curso, una sólida aplicación de las políticas y la colaboración multidisciplinaria siguen siendo cruciales para abordar los desafíos que subsisten. Este estudio subraya la necesidad de perfeccionar los sistemas de salud, las metodologías de recopilación de datos y la cooperación mundial a fin de garantizar una atención óptima para la totalidad de la población infantil que afronta un cáncer, con la consiguiente mejora de su probabilidad de supervivencia y su calidad de vida en general.

Palabras clave Neoplasias; niño; Chile.

Câncer infantojuvenil no Chile: analisando os desafios e moldando o futuro

RESUMO

Objetivo. O objetivo deste estudo foi descrever a epidemiologia do câncer infantil no Chile e o cenário da doença, avaliando conquistas, colaborações e futuros desafios a serem enfrentados pelo Plano Nacional de Câncer Infantojuvenil.

Métodos. Este estudo descritivo apresenta uma visão geral das estratégias de colaboração nacional e internacional e discute os resultados do Terceiro Relatório de Vigilância do Câncer Infantil (2017–2019), o relatório da ferramenta Pediatric Oncology Facility Integrated Local Evaluation (PrOFILe) [Avaliação Local Integrada de Estabelecimentos de Oncologia Pediátrica] do St. Jude Children's Research Hospital, a colaboração com a Organização Pan-Americana da Saúde no âmbito da Iniciativa Global para o Câncer Infantil da OMS e a elaboração do Plano Nacional de Câncer Infantojuvenil no âmbito do pacote técnico CureAll.

Resultados. A análise revela o impacto do câncer infantil com base na incidência entre 2017 e 2019, englobando disparidades de gênero. A leucemia foi o tipo de câncer mais frequente, responsável por 40,4% dos cânceres entre crianças e adolescentes com menos de 15 anos e com uma incidência de 57,5 casos por 1 milhão de crianças nessa faixa etária. O câncer é a segunda principal causa de morte entre crianças de 5 a 14 anos. A sobrevivência do câncer aumentou entre 2007 e 2019; em 2023, a sobrevivência cinco anos após o diagnóstico era 78,4%. A elaboração do Plano Nacional de Câncer Infantojuvenil envolveu a realização de uma avaliação da situação, a definição de metas e a elaboração de um plano de ação para reduzir a mortalidade por câncer na infância e aumentar as taxas de sobrevivência por meio de intervenções precoces e transições descomplicadas para a atenção ao adulto.

Conclusões. O Chile obteve avanços nos indicadores de câncer infantil, especialmente no aumento da sobrevivência, demonstrando seu compromisso com a melhora da atenção a crianças com câncer. Isso foi alcançado por meio de marcos legais, planejamento em âmbito nacional, colaborações e participação em iniciativas mundiais. Apesar do progresso alcançado, pesquisas contínuas, implementação de políticas sólidas e colaborações multidisciplinares continuam sendo fundamentais para enfrentar os desafios persistentes. Este estudo destaca a necessidade de aperfeiçoar os sistemas de saúde, as metodologias de coleta de dados e a cooperação mundial para assegurar a melhor atenção a todas as crianças que enfrentam câncer, melhorando assim suas chances de sobrevivência e sua qualidade de vida geral.

Palavras-chave Neoplasias; criança; Chile.
