

Childhood Leukemia and Non-hodgkin Lymphoma Survivors Lack of Knowledge About Their Past Disease and Possible Late Effects. I-BFM ELTEC Study With Chilean and Croatian Participation.

Ana Becker (✉ anabecker@yahoo.com)

Complejo Asistencial Doctor Sotero del Rio <https://orcid.org/0000-0003-1594-7988>

Claudia Paris

Hospital Luis Calvo Mackenna

Jelena Roganovic

University of Rijeka: Sveuciliste u Rijeci

Cristina Bustos

Complejo Asistencial Doctor Sotero del Rio

Amaia Rosas

Complejo Asistencial Doctor Sotero del Rio

Paula Contreras

Complejo Asistencial Doctor Sotero del Rio

Ana J. Zepeda-Ortega

Valparaiso University: Universidad de Valparaiso

Edit Bardi

S. Anna Hospital: S Anna hospital

Research Article

Keywords: childhood cancer survivors, health knowledge, late effects, self-care

Posted Date: October 20th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-869039/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License. [Read Full License](#)

Abstract

Purpose

Late effects in childhood cancer survivors are a major cause of morbidity and mortality. The objective was to establish knowledge about the disease, late effects, self-care practices, application of health knowledge/education, sources of information, and biopsychosocial impact of cancer, and compare the results of Chile and Croatia.

Methods

one hundred and seventy-one, five-year survivors who were treated for leukemia or non-Hodgkins lymphoma responded to a questionnaire (119 in Chile and 52 in Croatia). The questionnaire was reviewed by BFM- ELTEC.

Results

health knowledge about past diagnosis and general treatment had 96% Chilean and 85% Croatian survivors. Ninety percent of Chilean and 73% of Croatian survivors were unaware of possible late effects, and half did not know which specialist to visit for follow-up. Forty-six percent of Chilean and 35% of Croatian survivors knew about healthy lifestyles, but most did not practice them. The 74% of Chileans and 87% of Croatian survivors recalled having received health education during treatment. About 50% survivors in both groups was afraid or anguish, but it was also a growth experience for 60% of Chilean and 42% Croatian survivors. Eighty-seven percent Chilean and 77% Croatian survivors considered themselves physically independent, while 76% and 75% felt psychologically independent, respectively.

Conclusion

It was detected a significant lack of knowledge about the specific treatment, late effects, and future health in both countries. They did not achieve significant learning with the education received. Psychological sequelae were found that are important to prevent.

Introduction

Childhood cancer treatment has achieved successful results with overall survival exceeding 80%. This has created the need for long-term survivor care, as these patients are at risk of late effects that can compromise their health, expectations, and quality of life [1]. Already at end of the 1980s a lack of knowledge had been detected in childhood cancer survivors regarding specific health risks, which could result in poor self-care [2]. This led to the development of standardized clinical guidelines for follow-up care programs in various international cancer centers and groups, facilitating the identification and early intervention of possible late complications [3-4].

However, despite this, it has not resulted neither in the improvement of adherence by adolescents and young adults (AYAs) to follow-up, nor their empowerment regarding their health care [5].

Chilean public collaborative pediatric oncology group (PINDA) cares for 83% of children and adolescents with cancer in Chile (annual incidence 510), and Croatian group (SEPHO) cares for 100% of them (annual incidence 120). Current global survival rates from leukemia and lymphomas in children and adolescents (age range 0-15 years) is around 72% and 83% respectively [6,7]. Both national groups have always been a part of International BFM (I-BFM) Study Group using their protocols. In 1998 the first biopsychosocial follow-up care guide was established by PINDA group and since 2014 the childhood cancer survivor guide emphasizes prevention and health education from the diagnosis. SEPHO group has not established national follow-up guidance [8].

The objective of this research was to establish the knowledge about past disease, possible late effects, usefulness of the health education received, knowledge about sources of information in case of doubts, self-care practices and biopsychosocial impact of cancer and, compare the results in Chilean and Croatia survivors of childhood leukemia and non-Hodgkin's lymphomas. Besides, this is the first publication on survivors of leukemias (ALL-AML) and non-Hodgkin's lymphoma (NHL) treated with I-BFM protocols in two countries.

Methods

A descriptive cross-sectional study was carried out in adolescents and AYAs treated for childhood leukemia and non-Hodgkin's lymphoma, who attended a follow-up at PINDA and SEPHO centers between August 2017 and September 2020. A questionnaire was designed and approved by the Ethics Committees of the participating centers.

Inclusion criteria were being 16 years of age or older at the time of applying the questionnaire. Survivors had to be diagnosed after January 1, 2000, and treated with I-BFM protocols for acute lymphoblastic leukemia (ALL), acute myeloid leukemia (AML), and non-Hodgkin's lymphoma (NHL) and be at least 5 years post-diagnosis at the time to apply the questionnaire.

Exclusion criteria were a neurological compromise that disables to understand and answer the questions autonomously, neuropsychiatric pathology, illiterate or not meeting the inclusion criteria.

A questionnaire consisted of five sections that inquired about the following:

Section A: general information, education, and employment history.

NEETs (not in education, employment, or training) were considered as the population between 15 and 29 years old who neither study nor work.

Section B: survivors' awareness of their specific disease, treatments, and potential risks.

Section C: knowledge and self-care practice.

Section D: health education received during the disease process, satisfaction with this and preference for consultation in case of doubts.

Section E: AYAs perception of the repercussion of cancer on the psychological and occupational aspects and future projects.

This instrument was reviewed by the ELTEC group of I-BFM (Early and Late Toxicity Education Committee of BFM Study Group) and then locally and culturally validated in Chile and Croatia by AYAs with similar characteristics to the group under study. The questionnaire was self-reported in an estimated time of 45 minutes. During the self-reporting, a health professional, was present to clarify doubts about the questionnaire and to confirm that the responses were consistent with the clinical history.

Data Analysis

Sections A and D show a descriptive analysis of the data.

Section B and C, the following scale was used:

* Sufficient knowledge: if the correct answer is greater than two thirds of the options raised in the question.

** Some knowledge: if the correct answer is of between one third and two thirds of the options raised in the question.

*** No knowledge: if the correct answer reaches only a third or less of the possibilities stated in the question.

Section E uses the Likert scale. In each Likert scale the meaning of the extreme values is specified [9].

Survey carried out in Annex.

Statistical analysis was done with the chi-square or Fisher's exact tests, as appropriate, and for quantitative variables they were analyzed with the median test, with a significance level of 5%. All analyzes were done with STATA version 16 software.

Results

From August 1st, 2017, to September 30th, 2020, one hundred and ninety-nine surveys were conducted in 9 PINDA and 2 SEPHO pediatric oncology centers. Twenty-eight patients did not meet the inclusion criteria by age and post-diagnosis interval; thus 171 surveys were analyzable, no survivors refused the interview. Of the 171 survivors surveyed, 122 had ALL (87 Chile and 35 Croatia) 108 were in first remission, and 14 were in second remission. Twenty-six had AML (22 Chile and 4 Croatia), 25 in first remission and one in second remission. Twenty-three young people were treated for NHL (10 Chile and 13 Croatia). The analysis of the surveys was carried out with all the diagnoses since there were few cases separately.

General information, education and employment history are summarized in Table 1.

Educational background: Forty-six Chilean survivors (39%) and three (6%) Croatian survivors had repeated a school year, the main causes were learning difficulties and prolonged hospitalization. There was no school dropout in both groups.

In Chile, 106 AYAs (89%) were living with their parents, the median age was 18 years (range 16-30 years). Five survivors over the age of 25 were living with their parents. Eleven young people were living with other relatives, one teenager was living with her partner and another alone.

In Croatia, 49 (94%) AYAs were living with their parents, the median age was 17 years (range 16 to 28 years).

In both, Chile, and Croatia, almost all the AYAs knew their diagnosis and general treatment, but only the minority knew the name of the chemotherapy received and its possible late effects (Figure 1).

Knowledge about healthy eating and physical activity habits was similar in both countries (Table 2). Despite knowing unhealthy habits, 92% of patients practice them.

In Chile, 74% of survivors thought they had received health education during their illness. Most of them were educated during hospitalization. Only 11% thought they had received education during their outpatient follow-up. Education was personalized in 25% of the patients, and the others did not remember how they had received education. This education was considered satisfactory in 79.5% of the survivors. Only 3 patients felt that it had been unsatisfactory.

In Croatia, 87% of survivors thought they had been educated, majority of them during hospitalization. The education was personalized in 80% of survivors, and 73% preferred personalized education. The survivors considered that their health education was satisfactory in 79.5%, partially satisfactory in 16.5% and only 2 (4%) were completely unsatisfied with the education.

In the health-educated group of both countries, there were no significant differences in knowledge about their specific treatment, late effects of treatment, and the specialist they should consult in their adult life.

Figure 2 shows survivals most frequent options of consultation in case of doubts about the disease and / or treatment.

Having had cancer meant much for the survivors (Figure 3). When comparing the emotional consequence according to age at diagnosis, it was observed in Chile and Croatia that 43% and 52% of children older than 6 years were greatly affected by the fact of having had cancer. On the other hand, in patients diagnosed before 6 years of age, 29% of Chile and 26% of Croatia felt very affected by having cancer. The predominant emotion when thinking about cancer was fear or anguish in 50% of the Chilean and 52% of the Croatian survivors.

About physical, psychological, and economic independence, eighty-seven percent Chilean and 77% Croatian survivors considered themselves physically independent, while 76% and 75% felt psychologically independent, respectively. Forty-five (38%) patients of Chilean survivors considered themselves to be financially independent, and 11 of them had a job. The median age for this group was 19.5 years. Eighteen (35%) Croatian survivors considered them financially independent, and 8 (median age 19,4 years) had paid job.

When analyzing future projects of this group, 97% of the Chilean AYAs saw themselves studying or starting a family. Only 3% of these survivors did not have future project yet. Sixty percent of Croatian survivors wanted to study and/or start a family, 17% had other plans and 23% did not know what their future projects would be.

Discussion

This study shows the results of two national pediatric oncology networks in Chile and Croatia. In both countries, survivors of childhood cancer know their diagnosis and general treatment, but do not know the type of chemotherapy and / or radiotherapy received. They also do not have sufficient knowledge about possible late effects and therefore do not know which specialist they should go to for their specific health checks.

Both groups of survivors had a satisfactory level of formal education and received health education during their disease process, despite which, significant learning about their health self-care was not achieved [10].

This has been previously reported by several authors. As early as 1989, a study by Byrne J et al. concluded that there is a lack of knowledge of the disease and its possible sequelae in childhood cancer survivors [11]. Almost 30 years later (2016) in Canadian study 250 AYA survivors of childhood cancer were interviewed, a third of them did not know the therapy administered or it derived late effects [12, 13]. Therefore, it is essential to develop innovative educational therapies to reverse this situation.

Almost half of the respondents knew what healthy eating and physical activity habits were but almost all had bad self-care habits, especially eating junk food and a sedentary lifestyle.

It is important to encourage survivors' changes in habits, since both exercise and a healthy diet contribute to a better quality of life and may prevent and/or delay late effects [14]. The most frequent late co-morbidities were obesity, metabolic syndrome, arterial hypertension, dyslipidemia, type 2 diabetes mellitus (DM2), osteopenia and osteoporosis. Chemotherapy and radiotherapy may be partly responsible for these co-morbidities, but in addition to cancer and treatment, other risk factors must be considered, such as genetics, race, gender, age at diagnosis, and lifestyle. On the other hand, physical activity, avoiding the consumption of tobacco, alcohol and drugs, and other risky behaviors should be considered [14-16]. In a recent Swiss study, physical activity was evaluated in 766 adolescent survivors of childhood cancer. Only half were engaged in age-appropriate physical activity and a third spent excessive screen time. In German study only one quarter of 89 childhood cancer survivors participated in school sports and many did not participate because of medical indications. Both studies highlight the importance of reverse this situation by educating children, adolescents, their families, and health professionals, to highlight the multiple preventive benefits of adequate physical activity [17, 18].

Since the start of childhood cancer management in both countries, the treating teams have provided patient health education to parents, caregivers, and patients, through talks, workshops and educational material designed for personalized or group education. Most patients in both countries received personal health education during hospitalization. Many of them were satisfied with the type of education received [19]. Despite this, adequate learning about prevention, self-care and adherence to healthy lifestyles have not been achieved as well as knowledge and management of specific potential risks. This lack of awareness and "empowerment" of self-care has also been highlighted in other studies on childhood cancer survivors and may lead them to follow poor self-care behaviors that can subsequently affect their future quality of life [20].

Therefore, a great challenge is being faced. It is essential to implement strategies that ensure adequate learning about the specific health risks. This learning should begin with diagnosis and continue throughout disease progression and be evaluated periodically to reinforce what is lacking. In addition, it is important to study the learning barriers that may explain the lack of patient knowledge acquisition. According to Puigdellívol from University of Barcelona, learning and participation barriers are multiple: attitudinal, methodological, organizational, and social, so it is relevant to know and understand the types of barriers that limit student learning [21]. Therefore, it is important to investigate at the local level what are the possible barriers to learning in health care and then implement changes that lead to effective learning in health [22, 23].

We are not only interested in the cognitive part, but also in adherence to follow-up. Health professionals must be aware that involving the patient, the family and the community is essential for the success of adherence to the treatment of chronic diseases [24,25]. Informed patients who participate in therapeutic decisions have a higher degree of adherence to their treatment [26]. In this survey, patients asked their pediatric oncologist and parents about their health issues. This provides an opportunity to build positive allies in health education and adherence to long-term follow-up of survivors.

On the other hand, internet consultations often clarify health doubts. In this survey it was still an option with a low percentage, but will surely assume greater importance, especially under current pandemic circumstances, which make it necessary to familiarize a high percentage of the population with virtual

education. Moreover, the internet is a tool to be considered in health education, but in a targeted way, making reliable sites known, and guiding patients about them [27, 28]. A recent work on health information suggests that this may incorporate various methodologies, but in the current era must include digital strategies. The information should be coordinated by trained health educators in this field [28]. It is important that health education has clear basic objectives, is programmed from diagnosis, continues over time, and has formative evaluations carried out throughout the disease process to reinforce areas that have not been learned [29].

The experience of having cancer can put children and young people at risk of short- or long-term social, emotional, or behavioral difficulties. Physical changes, repeated absence from school, and withdrawal from peer groups can negatively impact social skills and psychological adjustments.

Both children and adolescents with cancer and childhood cancer survivors may experience anxiety, withdrawal and behaviors associated with post-traumatic stress. Predominant emotions are anxiety and frustration, often leading to unhealthy habits such as smoking and alcohol abuse in addition. Also, fatigue and sleep disturbances are highlighted as other predominant symptoms that can constitute learning barriers related to self-care behaviors [30].

However, majority of young survivors are psychologically healthy, and even post-traumatic growth and long-term positive psychological effects were reported. Among these, on that stood out was that for them having had cancer meant "an experience to grow", to develop resilience and has shown them what is truly important in life, making them change their priorities [31-33].

When analyzing the meaning of cancer in AYAs surveyed in this joint study, for half of them it was an opportunity to grow. On the other hands, about half of both group of survivors, when remembering the cancer, have felt fear or anguish. These emotions, in turn, are the most predominant for parents at the time of diagnosis and in the adaptation process, so it may be that in part these emotions in survivors were reflecting on family dynamics and stories from their parents and relatives [34].

According to the respondents' report in both countries, the emotional repercussions were more intense in children over 6 years old at diagnosis. However, longitudinal studies show that the greatest psychological and psychiatric effects occur in children aged 0 to 4 years at diagnosis, which could be related to the toxic effects of the treatment on brain development. Also, non-biological causes cannot be ruled out in young children related to the impact of cancer diagnosis on parental behavior. Parents may adopt more lax and overprotective parenting practices, which have been associated with emotional and behavioral difficulties in children and young people [35, 36].

It is important to mention in this aspect, the limitations of this research, since it was a self-report and not an evaluation by an expert. Regarding the perception of autonomy, the results show that more than three-quarters of surveyed AYAs in both countries, considered themselves independent from the psychological and physical point of view. Regarding economic autonomy, this was one third in both countries. When asking about future, it was noted that the most of survivors had plans for the future, either studies or starting a family.

As conclusions, despite the health education received by most of survivors, a significant lack of knowledge was detected regarding the specific treatment received and possible late effects. Although they knew about healthy lifestyle habits there was little adherence to practice them, and their knowledge was lacking in relation to health controls that must be carried out according to specific risks. All this leads to possible late consultations for potentially preventable situations. The oncologist is the main reference to clarify health doubts. It is important to work with the feelings such as fear and anguish in both patients and parents/caregivers, throughout the disease process, to prevent or reduce subsequent psychosocial sequelae.

Regarding future challenges, it is important to design an interdisciplinary educational intervention involving all interested parties, to improve knowledge in survivors about their past diseases, treatments, self-care practices and autonomy. The internet is a tool to consider in health education, but only in a targeted way. Health education is an investment for the future since an informed person may prevent or delay certain sequelae and consequently have a positive impact on public health.

Abbreviations

PINDA	Chilean collaborative pediatric oncology Group
I-BFM	International German Berlin, Frankfurt, Muenster Group
BFM-ELTEC	Early and Late Toxicity Education Committee of BFM Study Group
AYAS	Adolescents and young adults
SEPHO	Croatian Group
ALL-AML	Acute Lymphoblastic Leukemia-Acute Myeloblastic Leukemia
NHL	Non-Hodgkin Lymphoma
NEETs	Not in education, employment or training
CT	Chemotherapy
RT	Radiotherapy
SX	Surgery
M	Male
F	Female
NR	Not respond
NS	Not significant

Declarations

Funding: 'Not applicable' for that section.

Conflicts of interest: the authors declare that they have no conflict of interest.

Availability of data and material are available for review.

Code availability: 'Not applicable' for that section.

Authors' contributions:

Ana Becker: she has worked in the clinical design and approval by the ethics committee in Chile, coordination of the collaboration between cohorts of different countries, design of the survey to collect the data throughout different countries, distribution of the survey, collection of data and analysis all throughout, analysis of the data collected from both countries and writing and editing the manuscript that summarizes the main findings.

Claudia Paris: she has worked in the clinical design and approval by the ethics committee in Chile, coordination of the collaboration between cohorts of different countries, distribution of the survey, collection of data and analysis all throughout Chile, analysis of the data collected from both countries and writing and editing the manuscript that summarizes the main findings.

Jelena Roganovic: she has worked on the coordination of the collaboration between cohorts of different countries, distribution of the survey, collection of data and analysis all through Croatia, and writing and editing the manuscript and abstract that summarizes the main findings.

Cristina Bustos: She has worked in the clinical design of the project, distribution of the survey, collection of data and analysis in that hospital and editing the manuscript that summarizes the main findings.

Amaia Rosas: she has worked in the clinical design of the project, she was responsible for the psychological aspect of the project, distribution of the survey, collection psychological data and analysis. Also participated in editing the manuscript that summarizes the main findings.

Paula Contreras: she has worked in the clinical design of the project, distribution of the survey, collection of data and analysis, as well as in the interpretation of data and final reviewed of the manuscript.

Ana Zepeda: she worked in analysis and interpretation of data.

She performed all the statistical analysis, tables and graphs and revision of the manuscript.

Edit Bardi: she has worked in design of the project, coordination of the collaboration between cohorts of different countries, stimulated international collaboration, editing the manuscript that summarizes the main findings. As well as interpretation of data and drafting and final approved the manuscript.

ACKNOWLEDGMENTS thanks to all collaborators in the Chilean (PINDA) network: María Soledad Fernández, Magdalena Fernández, Laura Neira, Maite Rosas, Verónica Oyarce, Paulina Fuentes, Tamara Inostroza, Nuri Moliné, Marcela Venega and Rodrigo Donoso, all of them contributed to obtaining informed consent, applying the questionnaire, and collecting data. As well as, thanks to collaborators Lucija Ruzman and Ernest Bilic from the Croatian Group (SEPHO), also contributed to obtaining informed consent, applying the questionnaire, and collecting data and Julie Byrne to review this article.

Additional declarations for articles: 'Not applicable' for that section.

Ethics approval: This study has been approved by the Ethics Committees of the different participating centers.

Consent to participate: Informed consent was requested from each patient before enrolling them in the study.

Consent for publication: All authors, collaborators and patients agree to the publication of this article in this journal.

Structured Abstract: relevance of their manuscript.

The authors consider that this article is interesting because it shows that health education methods in two different realities, are not sufficient for self-care and autonomy in adulthood. This result represents a challenge in finding effective techniques in health education.

References

- 1.- Bhakta N, Liu Q, Ness KK et al. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet*. 2017; 390:2569-2582.
- 2.-Landier W, Wallace WHB, Hudson MM. Long-term follow-up of pediatric cancer survivors: Education, surveillance, and screening. *Pediatr Blood Cancer*. 2006;46:149-158.
- 3.- Children's Oncology Group Long-Term Follow-Up Guidelines (October 2018) www-survivorshipguidelines.org Version 5.0. Accessed April 2, 2021
- 4.- International guideline Harmonization Group for Late Effect of Childhood Cancer. <https://www.ighg.org>. Accessed April 2, 2021.
- 5.- Reppucci ML, Schleien CL, Fish JD Looking for trouble: Adherence to late-effects surveillance among childhood cancer survivors. *Pediatr Blood Cancer*. 2017; 64:353-357.
- 6.-Primer informe de registro nacional de cancer infantil de Chile, menores de 15 años, RENC. http://www.ipsuss.cl/ipsuss/site/artic/20180117/asocfile/20180117150429/informe_renci_2007_2011registro_nacional_cancer_infantildepto_epidem Accessed May 2, 2021.
- 7.- Roganović Jelena. Epidemiologij a malignih bolesti u djece. *Pedij atri j a danas*. 2009; 5:12.
8. Guías de prevención y seguimiento de sobrevivientes de cáncer infantil PINDA 0314. <https://www.fnh.cl/publicaciones/GUIASOBREVIVIENTESCANCERINFANTIL.pdf>. Accessed May 2, 2021.
- 9.- Likert Scale Definition, Examples and Analysis. <https://www.simplypsychology.org>. Accessed April 2, 2021.
- 10.- American Academy of Pediatrics. Long-term Follow-up Care for Pediatric Cancer Survivors. *Pediatrics*. 2009; 123:906-915.
- 11.-Byrne J, Lewis S, Halamek L, Connelly R, Mulvihill J. Childhood cancer survivors' knowledge of their diagnosis and treatment. *Ann Intern Med*. 1989; 110:400-403.
- 12.-Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood cancer survivors' knowledge of their past diagnosis and treatment: Childhood Cancer Survivor Study JAMA. 2002; 287:1832-1839.
- 13.- Syed IA, Klassen AF, Barr R, et al. Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *J Cancer Surviv*. 2016 ;10 :363-374.
- 14.-Arroyave WD, Clipp EC, Miller PE, et al. Childhood Cancer Survivors' Perceived Barriers to Improving Exercise and Dietary Behaviors. *Oncol Nurs Forum*. 2008;35:121-130.
- 15.-Cohen JE, Wakefield CE, Cohn RJ. Nutritional interventions for survivors of childhood cancer. *Cochrane Database Syst Rev*. 2016;2016:CD009678.
- 16.-Gibson T, Mostoufi-Moab S, Stratton K, et al. Temporal patterns in the risk of chronic health conditions in survivors of childhood cancer diagnosed 1970-1999: a report from the Childhood Cancer Survivor Study cohort. *Lancet Oncol*. 2018;19(12):1590-1601.
- 17.-Schindera C, Weiss A, Hagenbuch N, et al. Physical activity and screen time in children who survived cancer: A report from the Swiss Childhood Cancer Survivor Study. *Pediatr Blood Cancer*. 2020;67: e28046.
- 18.- Kesting SV, Gotte M, Seidel CC, Rosenbaum D, Boos J. One in four questioned children faces problems regarding reintegration into physical education at school after treatment for pediatric cancer. *Pediatr Blood Cancer*. 2016; 63:737-739.
- 19.-Programa nacional del cáncer. www.pindachile.cl. Accessed May 2, 2021.
- 20.- Golchin M, Sharifi N, Ziaee S, Taheri P. The effect of self-care on the lives of children suffering from acute lymphocytic leukemia. *Iran J Nurs Midwifery Res*. 2011; 16:71-78.

- 21.-Puigdemívol I. La educaci3n especial en la escuela integrada: una perspectiva desde la diversidad/. Barcelona Editorial Gra3 2007; 7ª ed.
- 22.-Rodr3guez, M. La teor3a del aprendizaje significativo: una revisi3n aplicable a la escuela actual., Revista Electr3nica d'Investigaci3 i Innovaci3 Educativa i Socioeducativa. 2011;3(1): 29-50.
- 23.-Y3pez M. Aproximaci3n a la comprensi3n del aprendizaje significativo de David Ausube. Revista Ciencias de la Educaci3n. Primera Etapa 2011; 21:43-54.
- 24.-Ortega JJ, S3nchez D, Rodr3guez 3A, Ortega JM. Adherencia terap3utica: un problema de atenci3n m3dica. Acta Med. 2018;16: 226-232.
- 25.-Reyes E, Trejo R, Arguijo S, et al. Therapeutic adherence: concepts, determinants and new strategies. Biblioteca Virtual en Salud Honduras. 2016; 84(3-4):125-132.
- 26.-Brown M, Sharp L, Sniehotta F, Skinner R, Ara3jo-Soares V. The development of health behaviour change interventions for childhood cancer survivors: The need for a behavioural science approach. *Pediatr Blood Cancer*. 2020; e28500.
- 27.-Stinson JN, White M, Breakey V, et al. Perspectives on quality and content of information on the internet for adolescents with cancer. *Pediatr Blood Cancer*. 2011; 57:97–104.
- 28.-Grace J, Schweers L, Anazodo A, Freyer D. Evaluating and providing quality health information for adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2019;66: e27931.
- 29.-Bizarro W, Sucari W, Quispe-Coaquira A. Evaluaci3n formativa en el marco del enfoque por competencia. Revista Innova Educaci3n.2019(1); 374-390. DOI: <https://doi.org/10.35622/j.rie.2019.03.r001>
- 30.-Zeltzer LK, Recklitis C, Buchbinder D, et al. Psychological Status in Childhood Cancer Survivors: A report from the Childhood Cancer Survivor Study. *J Clin Oncol*. 2009; 27:2396-2404.
- 31.-Brinkman T, Recklitis C, Michel G, Grootenhuis M, Klosky J. Psychological Symptoms, Social Outcomes, Socioeconomic Attainment, and Health Behaviors Among Survivors of Childhood Cancer: Current State of the Literature. *J Clin Oncol*. 2018; 36:2190-2197.
- 32.-Bitsko M, Cohen D, Dillon R, Harvey J, Krull K, Klosky J. Psychosocial Late Effects in Pediatric Cancer Survivors: A Report from the Children's Oncology Group. *Pediatr Blood Cancer*. 2016; 63:337–343.
- 33.-Ljungman L, Cernvall M, Gr3nqvist H, Lj3tsson B, Ljungman G, Von Essen L. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PLoS ONE*, 2014 ;9: e103340.
- 34.-Morhun JM, Racine NM, Guilcher GMT, Tomfohr-Madsen LM, Schulte FSM. Health-related quality of life and well-being in parents of infants and toddlers with cancer. *Curr Oncol*. 2020;27(2): e 206-e215.
- 35.-Friend A, Feltbower R, Hughes E, Dye K, Adam W Glaser. Mental health of long-term survivors of childhood and young adult cancer: A systematic review. *Int. J. Cancer*. 2018; 143:1279–1286.
- 36.-Nathan PC, Nachman A, Sutradhar R, et al. Adverse Mental Health Outcomes in a Population-Based Cohort of Survivors of Childhood Cancer. *Cancer* 2018; 124:2045-57. pen access funding enabled and organized by Projekt DEAL.

Tables

TABLE 1 Section A - General Information

Variable	Chile		Croatia		P-value
	N	%	N	%	
Gender					
Male	63	52,9	29	55,8	NS
Female	56	47,1	23	44,2	
Current occupation					
Study	100	84,0	46	88,5	NS
Study and work ⁽¹⁾	7	5,9	1	1,9	
Work	7	5,9	4	7,7	
NEETS ⁽²⁾ /unemployed	5	4,2	1	1,9	
Total	119	100,0	52	100	
Current grade at survey					
Basic school education*	3	2,5	3	5,8	<0,001
Middle school education**	76	63,9	45	86,5	
Higher education***	40	33,6	4	7,7	
Total	119	100,0	52	100,0	
Age at diagnosis (years)					
Median	8		9		NS
Range	1 to 14		2 to 18		
Age at survey (years)					
Median	18		17		NS
Range	16 to 30		16 to 28		
Years between diagnosis and the moment of the survey					
Median	11		9		0,02
Range	5 to 27		5 to 19		

(1) Of the young people who study and work, 3 are in higher education and 4 are in middle school education and their age fluctuates between 19 and 26 years.

(2) NEETs population between 15 and 29 years old who neither study nor work

* Basic education: consider the first 8 years of study from the age of 6.

** Middle education: consider the last 4 years of study at school.

*** Higher education: consider technical or university education (ongoing or complete) carried out after the end of school education.

TABLE 2 Section C-Knowledge questions about habits/versus gender

Chile					Croatia				
		Sufficient knowledge	Some knowledge	No knowledge	Total	Sufficient knowledge	Some knowledge	No knowledge	Total
Knowledge about healthy eating									
Male	N	24	13	26	63	5	10	14	29
	%	38,1	20,6	41,3	100	17,2	34,5	48,3	100
Female	N	31	12	13	56	13	8	2	23
	%	55,4	21,4	23,2	100	56,5	34,8	8,7	100
TOTAL	N	55	25	39	119	18	18	16	52
	%	46,2	21,0	32,8	100	34,6	34,6	30,8	100
Knowledge about healthy physical activity									
Male	N	23	23	17	63	7	9	13	29
	%	36,5	36,5	27,0	100	24,1	31,0	44,8	100
Female	N	28	20	8	56	14	4	5	23
	%	50,0	35,7	14,3	100	60,9	17,4	21,7	100
TOTAL	N	51	43	25	119	21	13	18	52
	%	42,9	36,1	21,0	100	40,4	25,0	34,6	100

There were no statistically significant differences neither between countries and gender.

Figures

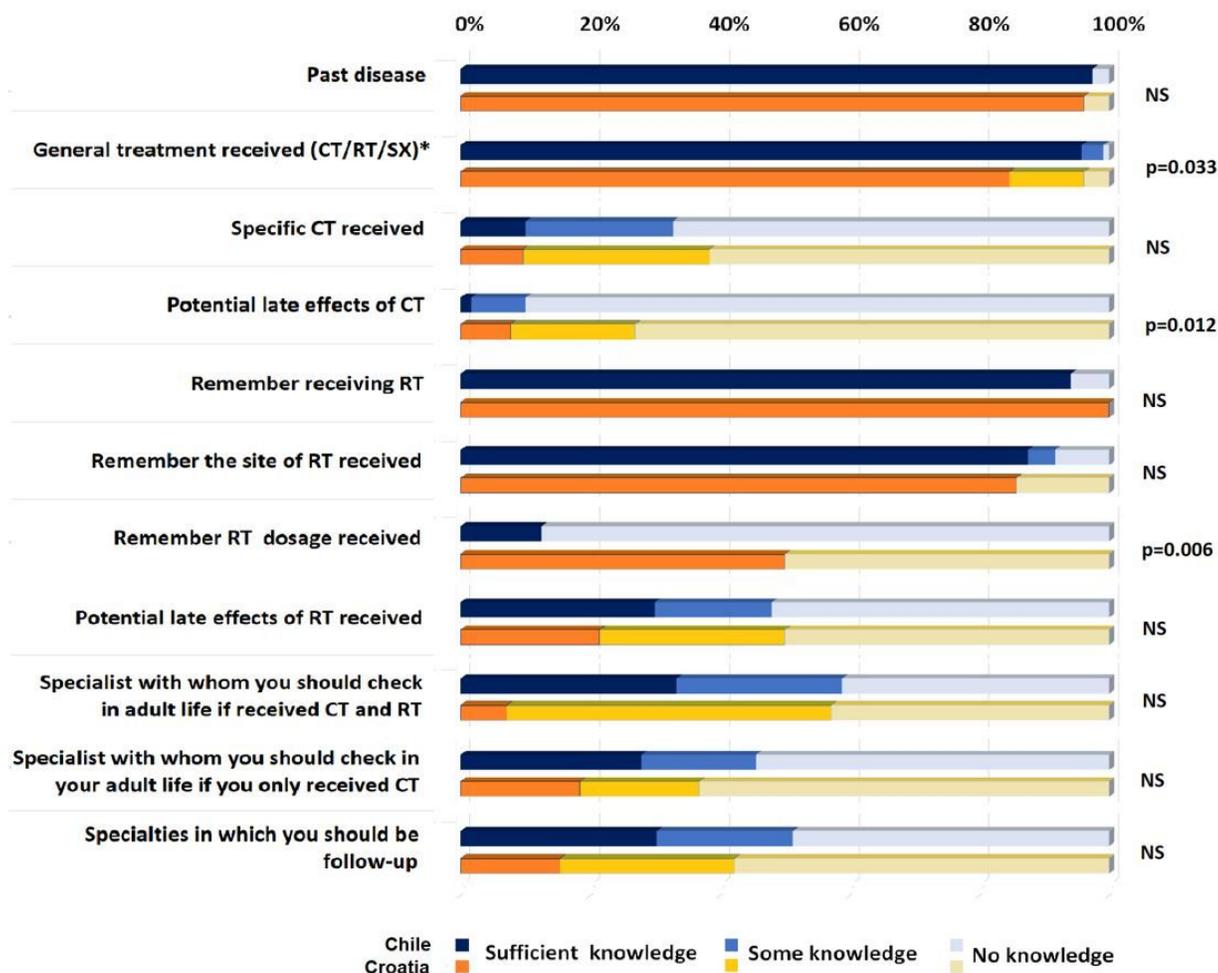


Figure 1

Section B-Knowledge of survivors about their disease, treatments, and potential late effects. *CT: chemotherapy, RT: radiotherapy, SX: Surgery, NS: no significant between the countries (p>0.05)

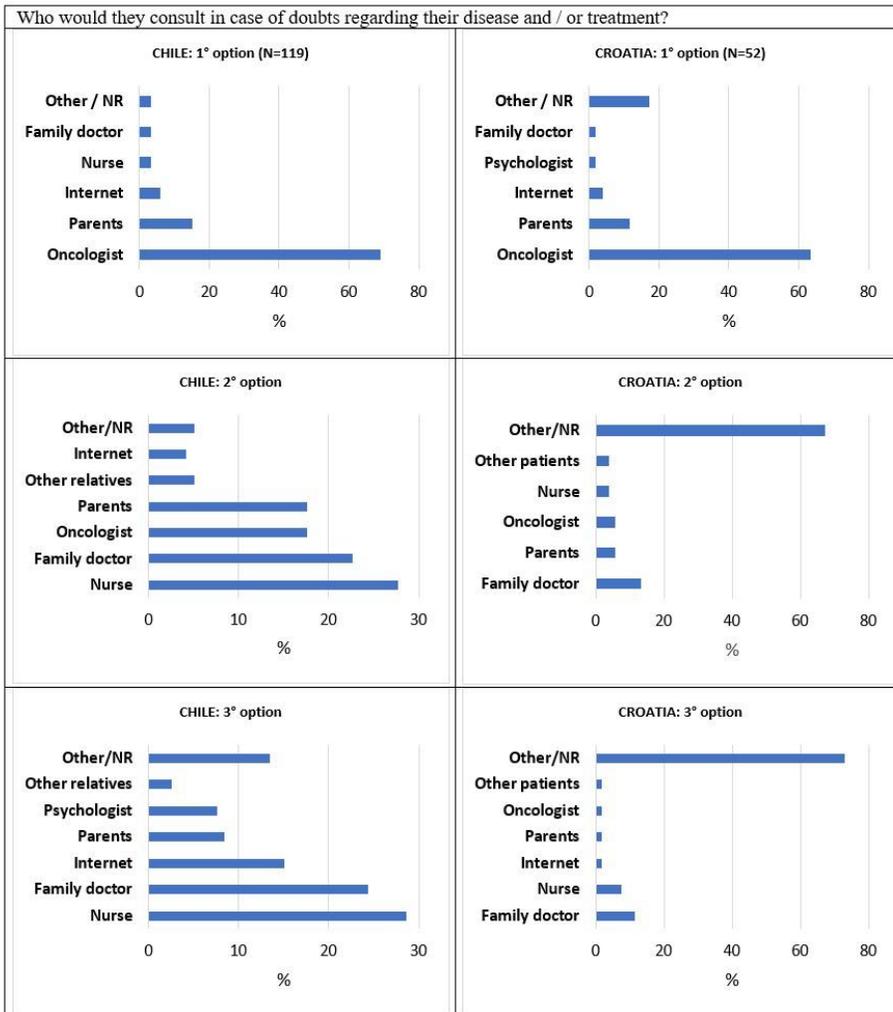


Figure 2

Section D:Survivals option of consultation in case of doubts about their disease and/or treatment. *Option 2, p<0,001, option 1 and 3 not statistically significant between Croatia and Chile. NR: not respond.

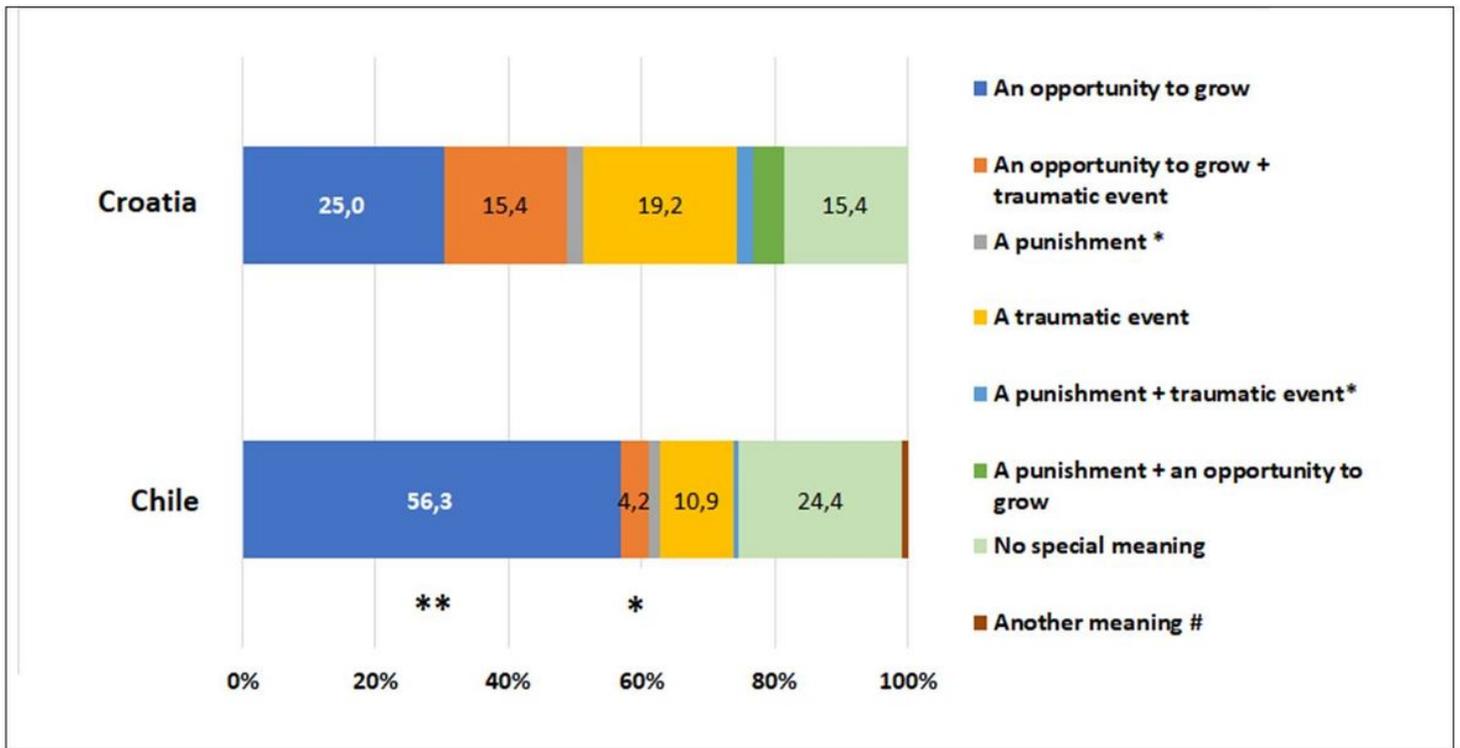


Figure 3

Section E: Meaning of Cancer for Childhood Cancer Survivors. The significant differences between the two countries were: an opportunity to grow (**p=0.0002) and a traumatic event (*p=0,011).

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Annex.docx](#)
- [ICMJEDFAnaBecker.pdf](#)
- [ICMJEDFClaudiaParis1.pdf](#)
- [ICMJEDFClaudiaParis2.pdf](#)
- [coidisclosureAmaiaRosas.pdf](#)
- [coidisclosureAnaZepeda.pdf](#)
- [coidisclosureCristinaBustos.pdf](#)
- [coidisclosureEditBardi.pdf](#)
- [coidisclosureJelenaRoganovic.pdf](#)
- [coidisclosurePaulaContreras.pdf](#)