1. Prognostic factors of pediatric ependymomas at a National Cancer Reference Center in Peru

Factores pronósticos de ependimomas pediátricos en un Centro Nacional de Referencia del Cáncer del Perú.

INVESTIGADORES: Eduardo Perez-Roca, Tatiana Negreiros, Sandro Casavilca-Zambrano, Luis Ojeda-Medina, Rosdali Díaz-Coronado.

LINK: https://pubmed.ncbi.nlm.nih.gov/38298447/

REVISTA: Front Oncol. 2024 Jan 17:13:1331790. doi: 10.3389/fonc.2023.1331790. eCollection 2023.

ASTRACTO: Background: Ependymomas are central nervous system tumors that significantly impact the quality of life and carry a high mortality rate. Both the disease itself and its treatment cause significant morbidity. At a national level in Peru, there are no reports on clinical characteristics of the disease. Methods: This retrospective study captured patient aged less than 19 years with a diagnosis of ependymoma from 2012 to 2022 at a tertiary center in Lima. Results: 85 patients were included with a median follow-up time was 51.6 months. The 5-year overall survival and progression-free survival were 55.89% (95% CI: 44.28 - 65.99) and 37.71% (95% CI: 26,21-49,16) respectively. The main prognostic factors identified were completed treatment (p=0.019), adjuvant chemotherapy (p=0.048), presence of metastasis (p=0.012), and disease recurrence (p=0.02). Conclusions: The survival of patients with ependymoma is below that reported in high-income countries. Incomplete treatment and treatment abandonment are factors that negatively impact the prognosis. Further studies are needed to identify barriers in the referral and treatment process for patients with ependymoma.

2. Use of retrograde dorsalis pedis as recipient vessels for pediatric free flap lower leg reconstruction

Uso del dorsal del pie retrógrado como vasos receptores para la reconstrucción pediátrica de la parte inferior de la pierna con colgajo libre

INVESTIGADORES: Abraham Zavala, Lucero Machaca, Ray Tornero, Wieslawa De Pawlikowski.

LINK: https://pubmed.ncbi.nlm.nih.gov/38413994/

REVISTA: Microsurgery. 2024 Mar;44(3):e31158. doi: 10.1002/micr.31158.

3. International Society of Paediatric Oncology (SIOP) Global Mapping Programme: Latin American Society of Pediatric Oncology (SLAOP) country-level report Programa de mapeo global de la Sociedad Internacional de Oncología Pediátrica (SIOP): Informe a nivel de país de la Sociedad Latinoamericana de Oncología Pediátrica (SLAOP)

INVESTIGADORES: Andrea Cappellano, Maite Gorostegui, Oscar Gonzalez-Ramella, Nevicolino Pereira Carvalho Filho, Diana Valencia, Luisa Chantada, Claudia Sampor, María J Serrano, Carla Macedo, Oscar Ramirez, Susan Sardinas, Eva Lezcano, Patricia Calderón, Yessika Gamboa, Ligia Fu, Wendy Gómez, Magdalena Schelotto, Cecilia Ugaz, Pablo Lobos, Simone Dos Santos Aguiar, Katiuska Moreno, Julia Palma, Gissela Sánchez, Filomena Moschella, Pascale Yola Heurtelou Gassant, Thelma Velasquez, Karina

Quintero, Florencia Moreno, Milena Villarroel, Soad Fuentes Alabi, Liliana Vasquez, Julia Challinor, Guillermo L Chantada.

LINK: https://pubmed.ncbi.nlm.nih.gov/38556746/

REVISTA: Pediatr Blood Cancer. 2024 Mar 31:e30973. doi: 10.1002/pbc.30973. Online ahead of print.

ASTRACTO: Background: Latin American countries are improving childhood cancer care, showing strong commitment to implement the Global Initiative for Childhood Cancer, but there are scant publications of the situation at a continental level. Methods: As part of the International Society of Paediatric Oncology Global Mapping project, delegates of each country participating in the Latin American Society of Pediatric Oncology (SLAOP) and chairs of national pediatric oncology societies and cooperative groups were invited to provide information regarding availability of national pediatric cancer control programs (NPCCP), pediatric oncology laws, pediatric oncology tumor registries, and training programs and support to diagnosis and treatment. Results: Nineteen of the 20 countries participating in SLAOP responded. National delegates reported nine countries with NPCCP and four of them were launched in the past 5 years. National pediatric tumor registries are available in eight countries, and three provided published survival results. Fellowship programs for training pediatric oncologists are available in 12 countries. National delegates reported that eight countries provide support to most essential diagnosis and treatments and 11 provide partial or minimal support that is supplemented by civil society organizations. Seven countries have a pediatric oncology law. There are three international cooperative groups and four national societies for pediatric oncology. Conclusion: Despite many challenges, there were dramatic advances in survivorship, access to treatment, and availability of NPCCP in Latin America. Countries with highest social development scores in general provide more complete support and are more likely to have NPCCP, training programs, and reported survival results.

4. Quality of Life After Lower Leg Reconstruction With the Latissimus Dorsi Free Flap in Pediatric Patients

Calidad de vida después de la reconstrucción de la parte inferior de la pierna con el colgajo libre de dorsal ancho en pacientes pediátricos

INVESTIGADORES: Atenas Bustamante, Abraham Zavala, Martin Iglesias, Ray Tornero, Lucero Machaca, Wieslawa De Pawlikowsk.

LINK: https://pubmed.ncbi.nlm.nih.gov/38527349/

REVISTA: Ann Plast Surg. 2024 Apr 1;92(4):418-423. doi: 10.1097/SAP.000000000003812.

ASTRACTO: Background: The latissimus dorsi free flap is a widely used reconstructive technique for complex lower leg defects in the pediatric population due to its reliability and anatomical features. However, the impact of this technique on the postoperative quality of life in children and adolescents, who require appropriate lower extremity function during their developmental period, remains to be analyzed. Methods: Patients who underwent microsurgical lower leg reconstruction using the latissimus dorsi flap were analyzed retrospectively. The quality of life of these patients was assessed prospectively using the Lower Extremity Functional Scale (LEFS) at a minimum of 18 months after surgical reconstruction. Results: Sixteen pediatric patients who had severe lower extremity injuries and underwent latissimus dorsi free flap reconstruction met the

inclusion criteria. The mean follow-up period was 33.9 months (22-64 months). Two patients experienced postoperative complications: one had partial flap necrosis and surgical site infection, while the other developed a surgical site infection. The LEFS scores ranged from 26 to 80, with a mean score of 64.6. Remarkably, 14 of 16 patients achieved LEFS scores consistent with at least the 10th percentile when compared with normative data. Patients with severe associated fractures presented with the lowest scores. Conclusions: Based on our findings, the latissimus dorsi flap is reaffirmed to be an excellent choice for lower leg reconstruction in the pediatric population. It effectively restores the quality of life in patients who have experienced moderate to severe lower extremity injuries.

5. Connecting Clinical Capacity and Intervention Sustainability in Resource-Variable Pediatric Oncology Centers in Latin America

Conectando la capacidad clínica y la sostenibilidad de la intervención en centros de oncología pediátrica con recursos variables en América Latina

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LINK: https://pubmed.ncbi.nlm.nih.gov/38566954/

REVISTA: Glob Implement Res Appl. 2024 Mar;4(1):102-115. doi: 10.1007/s43477-023-00106-2. Epub 2023 Nov 14.

ASTRACTO: Clinical capacity for sustainability, or the clinical resources needed to sustain an evidence-based practice, represent proximal determinants that contribute to intervention sustainment. We examine the relationship between clinical capacity for sustainability and sustainment of PEWS, an evidence-based intervention to improve outcomes for pediatric oncology patients in resource-variable hospitals. We conducted a cross-sectional survey among Latin American pediatric oncology centers participating in Proyecto Escala de Valoración de Alerta Temprana (EVAT), an improvement collaborative to implement Pediatric Early Warning Systems (PEWS). Hospitals were eligible if they had completed PEWS implementation. Clinicians were eligible to participate if they were involved in PEWS implementation or used PEWS in clinical work. The Spanish language survey consisted of 56 close and open-ended questions about the respondent, hospital, participants' assessment of clinical capacity to sustain PEWS using the clinical sustainability assessment tool (CSAT), and perceptions about PEWS and its use as an intervention. Results were analyzed using a multi-level modeling approach to examine the relationship between individual, hospital, intervention, and clinical capacity determinants to PEWS sustainment. A total of 797 responses from 37 centers in 13 countries were included in the analysis. Eighty-seven percent of participants reported PEWS sustainment. After controlling for individual, hospital, and intervention factors, clinical capacity was significantly associated with PEWS sustainment (OR 3.27, p < .01). Marginal effects from the final model indicate that an increasing capacity score has a positive influence (11% for every additional CSAT point) of predicting PEWS sustainment. PEWS is a sustainable intervention and clinical capacity to sustain PEWS contributes meaningfully to PEWS sustainment.

6. Pediatric neuro-oncology in Latin America and the Caribbean: a gap to be filled Neurooncología pediátrica en América Latina y el Caribe: un vacío por llenar

INVESTIGADORES: Rosdali Díaz-Coronado, Rosangela Correa Villar, Andrea M Cappellano.

LINK: https://pubmed.ncbi.nlm.nih.gov/38571497/

REVISTA: Front Oncol. 2024 Mar 20:14:1354826. doi: 10.3389/fonc.2024.1354826.

eCollection 2024.

7. Differences in Childhood Growth Parameters Between Patients With Somatic and Heritable Retinoblastoma

Diferencias en los parámetros de crecimiento infantil entre pacientes con retinoblastoma somático y hereditario

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LINK: https://pubmed.ncbi.nlm.nih.gov/38662390/

REVISTA: Multicenter Study Invest Ophthalmol Vis Sci. 2024 Apr 1;65(4):39. doi: 10.1167/iovs.65.4.39.

ASTRACTO: Purpose: Little is known regarding differences in childhood growth between somatic and heritable retinoblastoma (Rb) populations. We aimed to compare childhood growth parameters between somatic and heritable Rb cohorts at birth and at time of diagnosis with Rb.Methods: A multinational, longitudinal cohort study was conducted with patients from 11 centers in 10 countries who presented with treatment naïve Rb from January to December 2019. Variables of interest included age, sex, and size characteristics at birth and at time of presentation, as well as germline mutation status. After Bonferroni correction, results were statistically significant if the P value was less than 0.005. Results: We enrolled 696 patients, with 253 analyzed after exclusion criteria applied. Between somatic (n = 39) and heritable (n = 214) Rb cohorts, with males and females analyzed separately, there was no significant difference in birth weight percentile, weight percentile at time of diagnosis, length percentile at time of diagnosis, weight-for-length percentile at time of diagnosis, or change of weight percentile from birth to time of diagnosis. Patients with heritable Rb had a smaller mean weight percentile at birth and smaller mean weight and length percentiles at time of diagnosis with Rb, although this difference was not statistically significant. All cohorts experienced a slight negative change of weight percentile from birth to time of diagnosis. No cohort mean percentiles met criteria for failure to thrive, defined as less than the 5th percentile. Conclusions: Children with Rb seem to have normal birth and childhood growth patterns. There is no definitive evidence that somatic or heritable Rb has a biological or environmental impact on childhood growth parameters.

1. International Society of Paediatric Oncology (SIOP) Global Mapping Program: Analysis of healthcare centers in countries of the Latin American Society of Pediatric Oncology (SLAOP)

Programa de Mapeo Global de la Sociedad Internacional de Oncología Pediátrica (SIOP): Análisis de centros de salud en países de la Sociedad Latinoamericana de Oncología Pediátrica (SLAOP)

INVESTIGADORES: Maite Gorostegui-Obanos, Luisa Chantada, Nevicolino Pereira Carvalho Filho, Oscar Gonzalez-Ramella, María J Serrano B, Diana Valencia, Claudia Sampor, Carla Macedo, Oscar Ramirez, Susan Sardinas, Eva Lezcano, Patricia Calderón, Yessika Gamboa, Ligia Fu, Wendy Gómez, Magdalena Schelotto, Cecilia Ugaz, Pablo Lobos, Katiuska Moreno, Julia Palma, Gisella Sánchez, Filomena Moschella, Pascale Yola Heurtelou Gassant, Thelma Velasquez, Karina Quintero, Mariuska Forteza, Milena Villarroel, Florencia Moreno, Soad Fuentes Alabi, Liliana Vasquez, Jennifer Lowe, Andrea Cappellano, Julia Challinor, Guillermo L Chantada.

LINK: https://pubmed.ncbi.nlm.nih.gov/39133030/

REVISTA: Pediatr Blood Cancer. 2024 Aug 12:e31262. doi: 10.1002/pbc.31262. Online ahead of print.

ABSTRACTO: Background: The International Society of Paediatric Oncology Society Global Mapping Program aims to describe the local pediatric oncology capacities. Here, we report the data from Latin America. Methods: A 10-question survey was distributed among chairs of pediatric oncology services. Centers were classified according to patient volume into high- (HVC; 100 or more new cases per year), medium- (MVC; 31-99 cases), and low-volume centers (LVC; 30 cases or less), respectively. National referral centers (NRC) were identified. Results: Total 307 centers in 20 countries were identified (271 responded), and 264 responses were evaluable, accounting for 78% of the expected cases (21,359 cases per year). Seventy-seven percent of patients are treated in public centers, including additional support by civil society organizations. We found that 66% of the patients are treated in 70 centers of excellence, including 21 NRC. There was a median of one pediatric oncologist every 21 newly diagnosed patients (44 for NRC), and in 84% of the centers, nurses rotated to other services. A palliative care team was lacking in 25% of the centers. LVC with public funding have significantly lower probability of having a palliative care team or trained pediatric oncology surgeons. Psychosocial, pharmacy, and nutrition services were available in more than 93% of the centers. No radiotherapy facility was available on campus in nine of 21 NRC. Conclusions: Most children with cancer in Latin America are treated in public HVC. There is a scarcity of pediatric oncologists, specialized nurses and surgeons, and palliative care teams, especially in centers with public funding.

2. High-Risk Histopathological Features of Retinoblastoma following Primary Enucleation: A Global Study of 1426 Patients from 5 Continents

Características histopatológicas de alto riesgo del retinoblastoma después de la enucleación primaria: un estudio global de 1426 pacientes de 5 continentes

INVESTIGADORES: Swathi Kaliki, Vijitha S Vempuluru, Komal Rajendra Bakal, Samten Dorji, Vishakha Tanna, Charlotte N Shields, Samuel J Fallon, Vishal Raval, Alia Ahmad, Asma Mushtaq, Mahvish Hussain, Yacoub A Yousef, Mona Mohammad, Soma Rani Roy, Fahmida Huque, Ushakova Tatiana, Serov Yuri, Polyakov Vladimir, Sandro Casavilca

Zambrano, Sandra Alarcón-León, Cinthya Valdiviezo-Zapata, Maria Vargas-Martorellet, Cynthia Gutierrez-Chira, Mario Buitrago, Joana Sánchez Ortiz, Rosdali Diaz-Coronado, Devjyoti Tripathy, Suryasnata Rath, Gaurav Patil, Jesse L Berry, Sarah Pike, Brianne Brown, Mika Tanabe, Shahar Frenkel, Maya Eiger-Moscovich, Jacob Pe'er, Carol L Shields, Ralph C Eagle Jr, Andrea Laiton, Ana Maria Velasco, Katherine Vega, Joseph DeSimone, Kavya Madhuri Bejjanki, Anasua Ganguly Kapoor, Anusha Venkataraman, Victoria Bryant, M Ashwin Reddy, Mandeep S Sagoo, G Baker Hubbard 3rd, Corrina P Azarcon, Thomas A Olson, Hans Grossniklaus, Olivia Rolfe, Sandra E Staffieri, Roderick O'Day, Anu A Mathew, James E Elder, John D McKenzie, Ido Didi Fabian, Rachel Shemesh, Vicktoria Vishnevskia-Dai, Mohammed Hasnat Ali, Saumya Jakati, Dilip K Mishra, Vijay Anand Reddy Palkonda. LINK: https://pubmed.ncbi.nlm.nih.gov/39151183/

REVISTA: Retina. 2024 Aug 14. doi: 10.1097/IAE.000000000004250. Online ahead of print.

ABSTRACTO: Purpose: To evaluate high-risk histopathological features (HRHF) following primary enucleation of eyes with retinoblastoma (RB) and assess the patient outcomes across continents. Methods: Retrospective study of 1426 primarily enucleated RB eyes from five continents. Results: Of all, 923 (65%) were from Asia (AS), 27 (2%) from Australia (AUS), 120 (8%) from Europe (EUR), 162 (11%) from North America (NA), and 194 (14%) from South America (SA). Based on the continent (AS vs. AUS vs. EUR vs. NA vs. SA), the histopathology features included massive choroidal invasion (31% vs. 7% vs. 13% vs. 19% vs. 27%, p=0.001), post-laminar optic nerve invasion (27% vs. 0% vs. 16% vs. 21% vs. 19%, p=0.0006), scleral infiltration (5% vs. 0% vs. 4% vs. 2% vs. 7%, p=0.13), and microscopic extrascleral infiltration (4% vs. 0% vs. <1% vs. <1% vs. 4%, p=0.68). Adjuvant chemotherapy with/without orbital radiotherapy was given in 761 (53%) patients. Based on Kaplan-Meier estimates in different continents (AS vs. AUS vs. EUR vs. NA vs. SA), the 6-year risk of orbital tumor recurrence was 5% vs. 2% vs. 0% vs. 0% vs. 12% (p<0.001), systemic metastasis was reported in 8% vs. 5% vs. 2% vs. 0% vs. 13% (p=0.001), and death in 10% vs. 3% vs. 2% vs. 0% vs. 11% (p<0.001) patients. Conclusion: There is a wide variation in the infiltrative histopathology features of RB across continents, resulting in variable outcomes. SA and AS had a higher risk of orbital tumor recurrence, systemic metastasis, and death compared to AUS, EUR, and NA.

3. Exploring treatment decision-making at diagnosis for children with advanced cancer in low- and middle-income countries

Exploración de la toma de decisiones sobre el tratamiento en el momento del diagnóstico para niños con cáncer avanzado en países de ingresos bajos y medios

INVESTIGADORES: Marta Salek, Amy S Porter, Essy Maradiege, Mae Concepcion J Dolendo, Diego Figueredo, Fadhil Geriga, Sanjeeva Gunasekera, Roman Kizyma, Hoa Thi Kim Nguyen, Irene Nzamu, Muhammad Rafie Raza, Khilola Rustamova, Nur Melani Sari, Carlos Rodriguez-Galindo, Dylan Graetz, Nickhill Bhakta, Erica C Kaye; CATALYST Advisory Group.

LINK: https://pubmed.ncbi.nlm.nih.gov/39472335/

REVISTA: Support Care Cancer. 2024 Oct 29;32(11):753. doi: 10.1007/s00520-024-08951-z.

ABSTRACTO: Purpose: Global childhood cancer survival outcomes correlate with regional contextual factors, yet upfront treatment decision-making for children with advanced or poor prognosis cancer in low- and middle-income countries (LMICs) is not

well understood. This study aimed to (1) characterize the landscape of contextual factors that shape physician decision-making at diagnosis for these children in LMICs and (2) describe physician rationales for if/when to offer treatment with non-curative intent, including how they define "poor prognosis" during treatment decision-making. Methods: An international panel of pediatric oncologists practicing in LMICs participated in two focus groups structured for the collaborative generation of factors influencing treatment decision-making, including consideration of non-curative treatment pathways at diagnosis. Thematic analysis of qualitative data was conducted, followed by member checking. Results: Eleven pediatric oncologists participated, representing all global regions defined by the World Health Organization. Participants identified a broad range of factors influencing decision-making across multiple levels, including the individual, hospital, health system, community, and country levels. All participants agreed that treatment with non-curative intent could be offered at diagnosis in certain contexts, and diverse definitions for poor prognosis were described. Conclusions: Upfront treatment decision-making for children with advanced or poor prognosis cancer in LMICs is variable and challenging. Difficulties with decision-making in LMICs may be amplified by inconsistent definitions of poor prognosis and underrepresentation of the factors that influence treatment decision-making within existing decision-making frameworks or childhood cancer treatment guidelines. Future research should explore decision-making approaches, preferences, and challenges in depth from the perspectives of pediatric cancer patients, families, and multidisciplinary clinicians.

4. Documenting adaptations to an evidence-based intervention in 58 resource-variable pediatric oncology hospitals across implementation phases

Documentación de adaptaciones a una intervención basada en evidencia en 58 hospitales de oncología pediátrica con recursos variables en todas las fases de implementación

INVESTIGADORES: Alejandra Catalina Quesada-Stoner, Sayeda Islam, Amela Siječić, Sara Malone, Maria F Puerto-Torres, Adolfo Cardenas, Kim Prewitt, Yvania Alfonso Carreras, Shilel Y Alvarez-Arellano, Deiby Argüello-Vargas, Gloria I Ceballo-Batista, Rosdali Diaz-Coronado, Maria do Céu Diniz Borborema, Jacqueline Estefany Toledo, Ever Fing, Zunilda Garay, Cinthia J Hernández-González, Yajaira V Jimenez-Antolinez, María S Juárez Tobías, Laura Lemos de Mendonça E Fontes, Norma A Lopez-Facundo, Jose Miguel Mijares Tobias, Scheybi T Miralda-Méndez, Erika Montalvo, Zairie Niguelie Cawich, Carlos Andres Portilla Figueroa, Marcela Sahonero, María Sánchez-Martín, Marcia X Serrano-Landivar, Valeria Soledad García, Annie Vasquez, Daniela María Velásquez Cabrera, Bobbi J Carothers, Rachel C Shelton, Dylan Graetz, Carlos Acuña, Douglas A Luke, Virginia R R McKay, Asya Agulnik; INSPIRE Study Group.

LINK: https://pubmed.ncbi.nlm.nih.gov/39482794/

REVISTA: Implement Sci Commun. 2024 Oct 31;5(1):122. doi: 10.1186/s43058-024-00664-y.

ABSTRACTO: Background: Adaptation of evidence-based interventions (EBIs) often occurs when implemented in new local contexts and settings. It is unclear, however, during which phase of implementation adaptations are most frequently made and how these changes may impact the fidelity, effectiveness, and sustainability of the EBI. Pediatric Early Warning Systems (PEWS) are EBIs for early identification of deterioration in hospitalized children with cancer. This study evaluates adaptations of PEWS made

among resource-variable pediatric oncology hospitals in Latin America implementing and sustaining PEWS. Methods: We conducted a cross-sectional survey among pediatric oncology centers participating in Proyecto Escala de Valoración de Alerta Temprana (EVAT), a collaborative to implement PEWS. Adaptations to PEWS were assessed via 3 multiple choice and 1 free text question administered as part of a larger study of PEWS sustainability. Descriptive statistics quantitatively described what, when, and why adaptations were made. Qualitative analysis of free text responses applied the Framework for Reporting Adaptations and Modifications Expanded (FRAME) to describe respondent perspectives on PEWS adaptations. Results: We analyzed 2,094 responses from 58 pediatric oncology centers across 19 countries in Latin America. Participants were predominantly female (82.5%), consisting of nurses (57.4%) and physicians (38.2%) who were PEWS implementation leaders (22.1%) or clinical staff (69.1%). Respondents described multiple PEWS adaptations across all implementation phases, with most occurring during the planning and piloting of EBIs. Adaptations included changes to PEWS content (algorithm, scoring tool, terminology, and use frequency) and context (personnel delivering or population). Respondents felt adaptations streamlined monitoring, enhanced effectiveness, improved workflow, increased comprehension, and addressed local resource limitations. Qualitative analysis indicated that most adaptations were categorized as fidelity consistent and planned; fidelity inconsistent adaptations were unplanned responses to unanticipated challenges. Conclusion: Adaptations made to PEWS across implementation phases demonstrate how EBIs are adapted to fit dynamic, real-world clinical settings. This research advances implementation science by highlighting EBI adaptation as a potential strategy to promote widespread implementation and sustainability in hospitals of all resource levels.

5. Development of the pediatric neuro-oncology services assessment aid: An assessment tool for pediatric neuro-oncology service delivery capacity

Desarrollo de una herramienta de evaluación de la capacidad de prestación de servicios de neurooncología pediátrica: una herramienta de evaluación de la capacidad de prestación de servicios de neurooncología pediátrica

INVESTIGADORES: Revathi Rajagopal, Rosdali Diaz Coronado, Syed Ahmer Hamid, Regina Navarro Martin Del Campo, Frederick Boop, Asim Bag, Alma Edith Benito Reséndiz, Vasudeva Bhat K, Danny Campos, Kenneth Chang, Ramona Cirt, Ludi Dhyani Rahmartani, Jen Chun Foo, Julieta Hoveyan, John T Lucas Jr, Thandeka Ngcana, Rahat Ul Ain, Nuha Omran, Diana S Osorio, Bilal Mazhar Qureshi, Noah D Sabin, Ernestina Schandorf, Patrick Bankah, Mary-Ann Dadzie, Hafisatu Gbadamos, Hend Sharafeldin, Mahendra Somathilaka, Peiyi Yang, Yao Atteby Jean-Jacques, Anan Zhang, Zeena Salman, Miriam Gonzalez, Paola Friedrich, Carlos Rodriguez-Galindo, Ibrahim Qaddoumi, Daniel C Moreira.

LINK: https://pubmed.ncbi.nlm.nih.gov/39534540/

REVISTAS: Neurooncol Adv. 2024 Oct 4;6(1):vdae171. doi: 10.1093/noajnl/vdae171. eCollection 2024 Jan-Dec.

ABSTRACTO: Background: To enhance the quality of care available for children with central nervous system (CNS) tumors across the world, a systematic evaluation of capacity is needed to identify gaps and prioritize interventions. To that end, we created the pediatric neuro-oncology (PNO) resource assessment aid (PANORAMA) tool.

Methods: The development of PANORAMA encompassed 3 phases: operationalization, consensus building, and piloting. PANORAMA aimed to capture the elements of the PNO care continuum through domains with weighted assessments reflecting their importance. Responses were ordinally scored to reflect the level of satisfaction. PANORAMA was revised based on feedback at various phases to improve its relevance, usability, and clarity. Results: The operationalization phase identified 14 domains by using 252 questions. The consensus phase involved 15 experts (6 pediatric oncologists, 3 radiation oncologists, 2 neurosurgeons, 2 radiologists, and 2 pathologists). The consensus phase validated the identified domains, questions, and scoring methodology. The PANORAMA domains included national context, hospital infrastructure, organization and service integration, human resources, financing, laboratory, neurosurgery, diagnostic imaging, pathology, chemotherapy, radiotherapy, supportive care, and patient outcomes. PANORAMA was piloted at 13 institutions in 12 countries, representing diverse patient care contexts. Face validity was assessed by examining the correlation between the estimated score by respondents and calculated PANORAMA scores for each domain (r = 0.67, P < .0001). Conclusions: PANORAMA was developed through a systematic, collaborative approach, ensuring its relevance to evaluate core elements of PNO service capacity. Distribution of PANORAMA will enable quantitative service evaluations across institutions, facilitating benchmarking and the prioritization of interventions.