

# Management of children with brain tumors in Paraguay

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**Background.** Cure rates among children with brain tumors differ between low-income and high-income countries. To evaluate causes of these differences, we analyzed aspects of care provided to pediatric neuro-oncology patients in a low middle-income South American country.

**Methods.** Three methods were used to evaluate treatment of children with brain tumors in Paraguay: (1) a quantitative needs assessment questionnaire for local treating physicians, (2) site visits to assess 3 tertiary care centers in Asunción and a satellite clinic in an underdeveloped area, and (3) interviews with health care workers from relevant disciplines to determine their perceptions of available resources. Treatment failure was defined as abandonment of therapy, relapse, or death.

**Results.** All 3 tertiary care facilities have access to chemotherapy and pediatric oncologists but lack training and tools for neuropathology and optimal neurosurgery. The 2 public hospitals also lack access to appropriate radiological tests and timely radiotherapy. These results demonstrate disparities in Paraguay, with rates of treatment failure ranging from 37% to 83% among the 3 facilities.

**Conclusions.** National and center-specific deficiencies in resources to manage pediatric brain tumors contribute to poor outcomes in Paraguay and suggest that both

national and center-specific interventions are warranted to improve care. Disparities in Paraguay reflect different levels of governmental and philanthropic support, program development, and socio-economic status of patients and families, which must be considered when developing targeted strategies to improve management. Effective targeted interventions can serve as a model to develop pediatric brain tumor programs in other low- and middle-income countries.

**Keywords:** brain tumors, children, low-income country, Paraguay.

Pediatric cancer is the leading cause of disease-related childhood mortality in most high-income countries (HIC) and is becoming increasingly important in low- and middle-income countries (LMIC), including many in Latin America, because of continuing improvements in public health that decrease infant and childhood mortality associated with malnutrition and infection.<sup>1,2</sup> Unfortunately, the 80% cure rate among children with cancer in HIC does not apply to the 80% of pediatric patients in LMIC.<sup>1</sup>

Studies have investigated barriers to care and methods to optimize treatment of children with acute lymphoblastic leukemia in LMIC. However, minimal advances have been made to improve treatment of children with brain tumors, the second most common type of childhood cancer, largely because of underdiagnosis, incorrect clinical assessment, and a lack of

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availability of appropriate radiological, neurosurgical, and radiotherapeutic services.<sup>2-4</sup> Moreover, these patients require multidisciplinary care for optimal outcomes. A recent survey demonstrated that LMIC were less likely to have dedicated teams or disease-specific guidelines to deliver specialized care for children with brain tumors.<sup>5</sup> In this study, we evaluate the barriers to care that exist for children with brain tumors in an LMIC.

A partnership was formed between pediatric hematology-oncology physicians in Paraguay and the Children's Hospital Los Angeles (CHLA) to develop a pediatric brain tumor program to optimize diagnosis and treatment of children with brain tumors based on available resources. The first step in this process was to accurately define these obstacles by a comprehensive needs assessment.

## Materials and Methods

To identify deficiencies in resources that would be amenable to targeted interventions, access to care for children with brain tumors was evaluated at 3 hospitals in Asunción, the capital of Paraguay, and 1 satellite clinic in Eastern Paraguay.

### *Site Visits*

A partnership was developed between pediatric oncologists from Paraguay and the Neural Tumors Program at CHLA. An initial onsite evaluation was performed in June 2009, followed by 2 subsequent site visits in 2010 for additional assessments. Two pediatric oncologists and a pediatric oncology nurse from CHLA visited 3 participating tertiary care centers in Asunción, the Instituto de Prevision Social (IPS), Centro Materno Infantil (CMI), and the Instituto Nacional de Cancer (INC), and 1 satellite clinic in Ciudad del Este that is associated with CMI. IPS is a social security facility for patients with governmental health insurance, and CMI and INC are public hospitals for children without medical insurance. During these visits, the CHLA medical team toured the facilities, met the faculty and administration, and gave lectures on various topics relating to treatment of children with brain tumors.

### *Key Informant Interviews*

Key participants from relevant disciplines involved in the treatment of children with brain tumors were identified and interviewed, including pediatric oncology, radiology, pathology, radiotherapy, neurosurgery, and palliative care specialists. Semi-structured interviews were arranged in which each participant was asked to comment on the overall status of the care provided at their facility to children with brain tumors and the specific obstacles that they encountered in their particular discipline. These data were gathered as written notations

and analyzed in conjunction with the information from the comprehensive needs assessment.

### *Development and Implementation of a Quantitative Needs Assessment Questionnaire*

The initial step in the design of the quantitative survey was to identify key components of the multidisciplinary team required for a pediatric brain tumor program, such as pediatric oncology, neurosurgery, neuroradiology, neuropathology, radiation oncology, nursing, and supportive care services.<sup>5,6</sup> A set of relevant questions was developed on the basis of a list of appropriate topics to evaluate available resources in each topic area. The survey was designed to gather easily accessible, relevant information in a manner that would be easy to comprehend and feasible to complete quickly. It consisted of a series of closed-ended questions, followed by 3 open-ended questions.

Initial questions focused on the quantity, training, and availability of treating oncologists; the use of chemotherapy protocols;<sup>5,6</sup> and evaluation of neurosurgical services, including the neurosurgeon's experience and training, availability of the necessary facilities and equipment, and supportive peri- and postoperative care.<sup>7</sup> Types of imaging tests available, quality of the equipment, and time required to obtain necessary tests were also assessed.<sup>8</sup> The ability to differentiate among the various neuropathologies, which depends on the availability, experience, and training of the pathologist and availability of essential immunohistochemical stains, was also addressed.<sup>9</sup> Questions regarding radiotherapy focused on evaluation of safety and efficacy of therapy based on the experience and training of staff in the planning and administration of therapy, the availability and quality of the equipment used, and time to initiation of therapy.<sup>10</sup>

Aspects of supportive care were also assessed, including infection control programs and access to medications.<sup>11</sup> Medication availability was evaluated via a list of essential medications, including anti-cancer chemotherapy, antimicrobials, anti-seizure drugs, antiemetics, and additional supportive care drugs based on the World Health Organization list of essential medications updated in 2009.<sup>12</sup>

The quality and availability of specialized nursing staff, rehabilitation services, and physicians trained in palliative care practices were also evaluated. Socioeconomic support available to patients was evaluated, including housing, food, transportation, and temporary employment.<sup>11,13</sup>

The questionnaire underwent preliminary expert review prior to initial implementation. Reviewers included 2 pediatric neuro-oncologists, 1 pediatric oncologist, and 1 infectious diseases physician, each with experience in childhood cancer care in LMIC, and 1 professor of preventive medicine who has additional expertise in the development of needs assessment surveys.

The final questionnaire (see Supplementary material, Appendix #1) was officially translated into Spanish and completed by oncologists at the 3 facilities in Paraguay;

several physicians from each hospital worked together to complete 1 questionnaire for their hospital. The survey was administered via E-mail, and results were discussed through E-mail, phone contact, and online meetings.

## Results

### *Site Visits*

All 3 facilities are staffed by trained pediatric hematologist-oncologists and have dedicated inpatient areas for pediatric oncology patients and day clinics for infusions and transfusions. Neither public hospital has magnetic resonance imaging (MRI) available in the hospital. Radiotherapy equipment is only available at 1 of the public hospitals, and the other 2 facilities rely on contracts with a private facility to provide these services to the majority of their patients. Both public hospitals provide housing for families from out of town when needed, although there is variability in the extent in which they are able to offer these services.

The satellite clinic, located in Ciudad de Este, in the eastern region of the country, covers a catchment area that includes primary care clinics that refer patients for management of potential malignancies. There is a consultation office staffed by a pediatric oncologist and a small infusion center that was scheduled to open shortly after this study was completed. Patients who received a diagnosis of a malignancy are referred to Asunción for initial treatment, followed by shared care as appropriate. Patients with therapy-related complications are admitted to the community hospital in Ciudad de Este and transferred to Asunción for further treatment if necessary.

### *Key Informant Interviews*

Twelve physicians were interviewed: 4 pediatric oncologists, 1 radiologist, 2 neurosurgeons, 2 pathologists, and 1 adult palliative care physician. Recurring comments addressed the lack of a multidisciplinary care approach, gaps in the referral pathway, and a lack of awareness regarding the diagnosis and appropriate treatment in the surrounding communities. Another major obstacle is the lack of specialized training in neuropathology and access to immunohistochemical stains, which are not readily available in Paraguay. Lastly, it was elicited that neurosurgeons were determined to have adequate training but often lacked necessary equipment and faced difficulties with postoperative supportive care.

### *Quantitative Needs Assessment Questionnaires\**

In the 3 facilities surveyed, 35–50 children receive a diagnosis of brain tumor each year. The majority of patients at 2 hospitals presented with localized disease, and

\*See Supplementary material, Appendix #2 for complete 225 questionnaire results.

public hospital 2 (PH2) reported that half of their patients presented with disseminated disease. All 3 facilities are staffed by pediatric oncologists and reported access to most of the necessary chemotherapy agents. Two centers reported that few of their patients with brain tumors had experienced relapse or abandoned therapy over the previous 5 years, and public hospital 1 (PH1) reported that the majority of their patients abandoned therapy or had experienced relapse (Table 1).

Neurosurgical services are available at the social security hospital (SSH) and PH2 but are not available at PH1, where all patients receive their surgical care at an outside facility. SSH and PH2 reported minimal delays with initiation of either chemotherapy or radiation therapy, whereas there were significant delays at PH1. All 3 hospitals have trained pathologists; however, none has subspecialty training in neuropathology or access to essential diagnostic immunohistochemical stains.

SSH has access to all the necessary imaging equipment, and both public hospitals have only computerized tomography (CT) and must rely on outside private facilities for magnetic resonance imaging (MRI), which affects timing and availability of these tests (Table 2). There is variability in access to radiation therapy. PH1 has radiotherapy machines in the hospital but frequently experiences the most significant delays (Table 3). PH2 has access to the public radiotherapy facilities, but as a result of considerable delays, also contracts with a private facility. SSH also uses a private facility.

As for supportive care, all 3 hospitals have a social worker and psychologist and access to medications for pain and palliative care services, although only 2 hospitals have a palliative care physician available (Table 4). Few rehabilitation services are available at 2 hospitals, and only 1 hospital uses pediatric oncology–trained nursing staff. Through private philanthropic support, PH2 has increased availability of support services, such as housing, transportation, and meals to families.

## Discussion

Paraguay is an LMIC with a population of 6.5 million persons, ~35% of whom are <14 years of age.<sup>14</sup> The leading cause of mortality among children nationwide is trauma, followed by cancer, except in rural areas, where infections continue to be the second most common cause of death.<sup>15</sup> On the basis of this population, there is an estimated incidence of 300–350 new cases of childhood cancer per year. However, of those who receive a diagnosis, only 50% survive more than a few months after diagnosis, and prior to current interventions, many abandoned therapy.<sup>16,17</sup> According to preliminary data, this is particularly a problem in children with brain tumors among whom treatment failure rates range from 37% to 83%, as defined by relapse, progression, abandonment of therapy, or death.

On the basis of the results of the comprehensive needs assessment, common and discrete deficiencies in resources available for the treatment of children with brain

**Table 1.** Epidemiology results of the quantitative questionnaire

Variable	SSH	PH1	PH2
Patients per year	10–15	15–20	13–16
Pediatric oncologists	Yes	Yes	Yes
Essential medications	Yes	Yes	Yes
Patients that present with metastatic disease	Few (1%–35%)	Few (1%–35%)	Half (36%–66%)
Overnight physician coverage	Pediatric resident	None	Pediatric Hematologist –Oncologist
Patients that relapse per year	Few (1%–35%)	Majority (66%–99%)	Few (1%–35%)
Patients that abandon therapy per year	Few (1%–35%)	Half (36%–66%)	Few (1%–35%)

Abbreviations: SSH, Social Security Hospital; PH1, Public Hospital #1; PH2, Public Hospital #2.

**Table 2.** Radiology results of the quantitative questionnaire

Variable	SSH	PH1	PH2
Imaging availability in the hospital	CT & MRI Scans	CT Scan only	CT Scan only
Quality of machines	Very good	Very good	Very good
Time to obtain			
In-patient CAT Scan	2–7 d	2–7 d	1 d
In-patient MRI Scan	2–7 d	Not available	1–2 wk
Out-patient CAT Scan	1–2 wk	2–3 mo	2–7 d
Out-patient MRI Scan	1 mo	2–3 mo	1 mo
Availability of anesthesia for optimal imaging test	Yes	Yes	Yes

Abbreviations: SSH, Social Security Hospital; PH1, Public Hospital #1; PH2, Public Hospital #2; CT, computed tomography; MRI, magnetic resonance imaging.

tumors in Paraguay were identified. Under-diagnosis and delayed diagnosis of pediatric cancer, particularly brain tumors, is a significant problem in Paraguay, as in other LMIC.<sup>3,4,18,19</sup> On the basis of a pediatric population of ~2.3 million, one would expect ~70–80 new diagnoses of pediatric brain tumor each year in Paraguay,<sup>20,21</sup> but according to these data, only half that number (35–50) are diagnosed. Although a small percentage of patients receive a diagnosis and are treated at private facilities, 1 other major children's hospital, and neighboring countries, a significant portion of brain tumors in children remain undiagnosed. Recognizing that the overwhelming majority of children who do not receive a diagnosis will subsequently die of their malignancy, one can predict that the mortality rate among these children is dramatically higher than that currently documented. In addition, one of the public hospitals noted that approximately half of their patients present with disseminated disease, which is significant considering that cure rates are diminished in patients with extensive disease.<sup>22</sup>

Although there are newly developed hospital-based registries and personal databases, there is no national tumor registry for brain tumors. Consequently, there is a lack of data regarding patient outcomes and complications, and these results are merely an approximation of incidence and outcomes for pediatric brain tumors in Paraguay. The lack of concrete data makes advances in care more challenging. For this reason, implementation of a data management program is a key element

of the strategy that has been developed on the basis of this study.

Delays in diagnosis and treatment are attributable to a variety of factors. One possible barrier is the lack of recognition of presenting signs and symptoms among community health care workers.<sup>23,24</sup> Deficiencies may exist in the referral pathway because of a lack of knowledge regarding the availability of specialized care and lack of communication with the referral centers. As a result, there are patients who never enter the pediatric oncology system and whose outcomes are unknown (but likely poor). For example, a patient with a history of a surgically removed posterior fossa mass was not initially referred to a pediatric oncologist and did not receive any additional therapy or follow-up. This patient presented 2 years later with a second posterior fossa mass found to be an anaplastic ependymoma, which may have been a relapse from initial presentation, and the patient subsequently died of treatment-related complications. Misperceptions regarding efficacy of available therapy may also prevent referral and subsequent treatment.

Common deficiencies in neuropathology in Paraguay were demonstrated, including a lack of subspecialty-trained neuropathologists and access to essential immunohistochemical stains that are essential to maximize diagnostic accuracy, which impacts the efficacy of the therapy administered.<sup>9</sup> A patient with a large suprasellar tumor received an initial diagnosis of a pituitary carcinoma but was then re-evaluated after further discussion in

**Table 3.** Radiation therapy results of the quantitative questionnaire

Variable	SSH	PH1	PH2
Are radiation therapy machines available in your hospital	No	Yes	No
If not available, where do your patients receive radiation therapy	Outside private facility	N/A	Public hospital #1 or outside private facility
Who pays for the radiation therapy	Hospital	Hospital	Foundation
Which types of machines are available to your patients	Linear accelerator and cobalt machine	Linear accelerator and cobalt machine	Linear accelerator and cobalt machine
How would you rate the quality of these machines	Acceptable	Acceptable	Good
What type of irradiation therapy is available to your patients	2-dimensional and conformal irradiation	2-dimensional irradiation	2-dimensional and conformal irradiation
How is simulation performed for radiation therapy planning	With CT-Scan (3-dimensional)	With CT-Scan (3-dimensional)	Unknown
How often is there a delay in initiation of radiation therapy	Sometimes	Almost always	Sometimes

Abbreviations: SSH, Social Security Hospital; PH1, Public Hospital #1; PH2, Public Hospital #2; CT, computed tomography.

**Table 4.** Supportive care results of the quantitative questionnaire

Variable	SSH	PH1	PH2
Is there a palliative care program	Adult program	Adult program	No
Are there rehabilitation services	Some	None	Some
Is there an Intensive Care Unit available	Yes (7 beds)	No	Yes (11 beds)
Are there psychosocial services available	Yes	Some	Yes
Do nurses receive specialty training in pediatric oncology	No	No	Yes
Is there family support (housing, meals, transportation, temporary employment)	No	Some	Yes
What is the average distance your patients travel to get to the medical center	1–7 h	>4 h	3–4 h
Who pays for therapy	Insurance	Hospital and non-profit foundation	Patient/family, hospital, and non-profit foundation

Abbreviations: SSH, Social Security Hospital; PH1, Public Hospital #1; PH2, Public Hospital #2.

an online meeting. The child subsequently received a diagnosis of a pituitary adenoma based on expert review of the pathology and supporting immunohistochemical stains, demonstrating how these resources may dramatically impact patient diagnosis and treatment, considering that these 2 entities are treated differently.

The low rates of gross total resection and increased rates of infection found at 2 of the participating hospitals in preliminary data may reflect some of the deficiencies in neurosurgery, including availability of appropriate equipment, and education regarding postoperative management. A common scenario for patients with medulloblastoma is a lack of gross total resection and the consequent requirement to treat on a high-risk protocol, thereby increasing their exposure to radiation and chemotherapy and the risk for relapse. An 8-year-old child who received a diagnosis of medulloblastoma was found to have only a 30% reduction in tumor size after surgery and ultimately required not only high-risk

therapy, but also a second surgery. A recent study clearly demonstrates that patients with medulloblastoma who have a postoperative residual tumor  $>1.5 \text{ cm}^2$  had a significantly inferior prognosis, compared with patients with a residual tumor  $<1.5 \text{ cm}^2$  (EFS  $0.68 \pm 0.08$  vs.  $0.86 \pm 0.02$ ,  $P < .01$ ), indicating the importance of complete resection whenever possible.<sup>25</sup>

Neurosurgical outcomes are complicated further by high rates of nosocomial infections, noted recently to be a more frequent cause of mortality than the underlying disease in 1 of the participating hospitals. Studies have demonstrated that pediatric neurosurgical experience, the necessary tools and operating room infrastructure, and supportive care are associated with higher rates of complete resection and improved patient outcomes, indicating that these resources are necessary for appropriate patient treatment.<sup>7</sup>

There was also significant variation in the resources available to patients treated at the 3 different facilities in Paraguay. The public hospitals have decreased access

to optimal neuro-imaging studies, specifically MRI scans, which are essential for neurosurgical guidance and assessment of extent of resection. Decreased access to appropriate, timely radiotherapy was also noted at all 3 facilities, although more significantly at the public facilities. A recent study involving patients with medulloblastoma clearly indicates that patients with a delay in radiation therapy of >49 days had poorer outcomes than did those who initiated therapy within 49 days (EFS  $0.67 \pm 0.09$  vs.  $0.81 \pm 0.02$ ,  $P = .04$ ).<sup>25</sup> Although there are radiotherapy machines available at 1 of the public hospitals, the lack of access for the pediatric patients and the below-average quality of the machines used may lead to suboptimal care.<sup>10,26</sup> For example, after completion of therapy, 1 patient with high-risk medulloblastoma was discovered to have received an insufficient dose of radiotherapy and subsequently relapsed within 6 months of completing chemotherapy.

There were discrepancies in the socioeconomic support provided to patients and families. PH2, through organization, program development, and substantial private philanthropic foundation support, provides food, housing, transportation, and temporary employment for patients' families, which may have contributed to their recent decrease in treatment abandonment rates and improved patient outcomes, because abandonment is a leading cause of treatment failure.<sup>13</sup> PH1 continues to strive to provide these resources to their patients and families in need but currently lacks sufficient resources to meet their patients' needs, which may contribute to their higher rates of relapse and abandonment. Addressing some of these issues may diminish this problem and improve patient outcomes. The SSH does not provide these services; however, their higher socioeconomic patient population often does not require this kind of support.

### *Potential Interventions*

The development of ReNaci, a childhood cancer network; establishment of a twinning program with a major pediatric oncology program in Madrid; and implementation of regional satellite clinics affiliated with PH2 has already begun to address the problem of underdiagnosis of pediatric cancer in Paraguay. Building on what has already been initiated will enable us to increase awareness regarding pediatric brain tumors in particular. Educational seminars are being developed for local clinicians and surgeons to address presenting signs and symptoms of brain tumors in children, the availability of treatment in Paraguay, and how to navigate the referral pathway. Efforts are underway to increase awareness regarding pediatric brain tumors in Paraguay, including the first Spanish-language International Pediatric Brain Tumor Symposium held in Asunción, Paraguay, in August 2010. Through educational lectures, small group sessions, and case presentations, the collaborative approach to patient care was emphasized to facilitate development of local multidisciplinary teams and provide more comprehensive care. Developing and strengthening

a local multidisciplinary team, in which cases are discussed before initiation of any intervention, may improve outcomes.<sup>5,6</sup>

In Paraguay, the nationwide deficiency in training in neuropathology affects diagnostic accuracy and, thereby, impacts management and patient outcomes. A systematic central review of pathology specimens, which could initially start at an experienced partner institution while developing local expertise, should be established to address this issue. In addition, a list of essential immunohistochemical stains will be developed and used to petition for increased access through the health ministry.

Lastly, national treatment guidelines based on available resources should be developed. Results from a Web-based survey indicated a lower availability of disease-specific guidelines in LMIC, even though it has been well established that uniform guidelines contribute to improved patient outcomes.<sup>5,13,27</sup> Therefore, in an effort to standardize care in Paraguay, the development of treatment guidelines for the more common pediatric brain tumors based on available resources has been initiated. Important considerations when developing guidelines for LMIC include their ability to address treatment toxicities, timing of initiation of radiotherapy, and prudent use of limited imaging resources, particularly advanced modalities, such as MRI.

### *Global Use of the Survey*

The ultimate goal is to develop a model that can be used in similar LMIC settings. For global use of these assessment tools, rigorous validation is required to ensure applicability, feasibility, and utility, after which they can be implemented in other LMIC with similar demographic characteristics to evaluate the state of pediatric brain tumor management on a wider scale. Treatment guidelines developed can be made available to other LMIC for use if found to be locally applicable.

## **Conclusions**

These data demonstrate common and discrete deficiencies in resources available for the treatment of children with brain tumors in 3 treating facilities in Paraguay. Moreover, it appears that poor outcomes are associated with lack of resources and support. These findings will aid in the development of targeted strategies, such as increased training and tools for neuropathology and improved access to neuro-imaging and radiotherapy, to improve early diagnosis and optimal therapy. Interventions to increase family support may also improve outcomes, because this is a factor that has been shown to be effective in Paraguay and other LMIC.<sup>13,23,27</sup> Some supportive measures already in place include the development of local multidisciplinary teams, commencement of online conferences, and the implementation of standardized treatment guidelines. If effective, these strategies will serve as a model for the development of pediatric brain tumor programs in similar low-income settings.

## Supplementary Material

Supplementary material is available at *Neuro-Oncology Journal* online (<http://neuro-oncology.oxfordjournals.org/>).

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