



St. Jude Global Scholars Projects: **Rosdali Diaz Coronado**



Barriers to Timely Diagnosis and Referral for Patients with Central Nervous System Tumors in Peru: A Mixed Methods Research Study

This project aimed to identify drivers of diagnostic and referral delays among children with central nervous system (CNS) tumors in Peru. A prospective, convergent mixed-methods study was conducted at the National Institute of Neoplastic Diseases (INEN) in Lima and two additional national pediatric institutes that handle CNS tumor referrals in the country. The project combined semi-structured interviews with parents and healthcare professionals, provider surveys, and medical record reviews.

While the specific challenges for patients varied by location, delays were driven primarily by health system and structural barriers rather than patient-related factors. These findings informed practical system-level improvements. Of note, the introduction of a patient navigation system addressed referral delays and complexities in navigating the healthcare system, ultimately fostering better care coordination and streamlined referrals.

With stakeholder support, the project is now transitioning into a new phase focused on sustaining and building on these improvements.

Project Details



Location
Lima, Peru



Setting
Multiple Centers within a Country



Health Condition
Childhood Cancer



Focus Areas
Access, Equity, Quality, Timeliness



Target Age Group
All Pediatric Patients

Systems-Level Change

Participants

76 Children

37 Health Care Workers

15 Caregivers

UN Sustainable Development Goal

Goal 3: Good Health and Well-Being

Goal 10: Reduced Inequalities

Goal 17: Partnerships for the Goals

WHO Health System Building Blocks

Health information systems

Health service delivery

Health system financing

Leadership & governance



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Key Findings

The following are key findings from this Global Scholars Project which aimed to examine the determinants of delays in diagnosis, referral, and treatment for children with CNS tumors at INEN in Lima, Peru.

Participant characteristics and vulnerability:

- 76 pediatric patients aged 0 to 18 years were included in the study. The most represented age group was 9-11 years, accounting for 32% of the total, and there was a nearly even split in gender, with 51% male.
- 72% of study patients were from rural areas, and 78% of study families reported a monthly household income of less than S/2000 (about USD 570), underscoring a high level of socioeconomic vulnerability.
- Parental education levels varied widely, with approximately one-quarter of parents having completed high school and a small proportion having no formal education.

Systems-Level Change

GLCC CureAll Projects

1. Analysis of cancer health system
4. National network and referral pathway strengthening
10. Local/regional advocacy portfolios: case studies, awareness campaigns



Key Findings

Clinical characteristics of pediatric CNS tumors:

- Most tumors were found in the brain (55%) and cerebellum (22%).
- The most common diagnosis was low-grade gliomas, which made up 16% of cases, followed closely by high-grade gliomas and medulloblastoma, each at 14%.
- In terms of histological grades, grades 4 (34%) and 1 (26%) were the most prevalent.
- Gross total resection was achieved in 29% of the patients.

Diagnostic and treatment intervals:

- On average, it took 90.5 days from the onset of symptoms to arrival at INEN, with a range from 10 to 863 days.
- Families typically sought medical care right after noticing symptoms, with a median of 0 days to the first consultation.
- The most extended wait was between the first medical consultation and getting diagnostic imaging, which took a median of 32 days, followed by a median delay of 28 days from surgery to arrival at INEN.
- Patients were evaluated by an average of 4 professionals (IQR 3-5, range 1-9), 33% Pediatricians, 34 % general physicians.

Socioeconomic and geographic barriers to timely care:

- Both quantitative and qualitative data revealed that poverty, living in rural areas, long travel distances, and high indirect costs (such as transportation, lodging, food, and lost income) were significant factors contributing to delays in diagnosis and referral.
- For some families, geographic isolation meant traveling for many hours or even days to reach specialized care.



Key Findings

Health system and diagnostic barriers:

- There is a limited availability of diagnostic imaging, especially MRI scanners outside of Lima.
- The limited access to diagnostic imaging, especially MRI scanners outside of Lima, has caused significant delays in getting diagnoses.
- The lack of trained staff and specialized facilities in regional centers has led to a disjointed referral process.
- Many primary care providers were not fully aware of CNS tumors, which resulted in initial misdiagnoses and postponed referrals.
- Families have shared their struggles with complicated and burdensome administrative tasks, often having to navigate referrals without any formal assistance.

Sociocultural and caregiver-related factors:

- Caregivers with lower educational backgrounds often found it hard to grasp the diagnosis and treatment options, which sometimes led to denial or the pursuit of alternative therapies.
- The combination of a perceived poor prognosis and the heavy financial burden made some caregivers think about abandoning treatment altogether.

Prognostic factors:

- One-year overall survival rates were closely linked to where patients lived, the location of the tumor, its pathology, and how much surgical resection was done.
- Interestingly, the time taken before diagnosis didn't show a significant connection to sociodemographic or tumor-related factors, indicating that systemic issues, rather than how patients sought care, are the main reasons for diagnostic delays.



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