

Akhtar et al.

## Pediatric Neurosurgery in Pakistan: Current Status and a Call-To-Action for Inclusion in The National Surgical Plan

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### Abstract:

The pediatric population in Pakistan is vulnerable to premature morbidity and mortality due to ineffective neurosurgical health system performance. Approximately 7 per 1000 children in Pakistan have epilepsy, cerebral palsy, and central nervous system infections. The ramifications are dire when this incidence rate is paired with a scarcity of skilled pediatric neurosurgeons, resources, and infrastructure. Traumatic Brain Injuries (TBI) are one of the leading causes of death in children under three years of age. 76% of which are avertible with timely surgical access. The National Surgical, Obstetric, and Anesthesia Plan (NSOAP) provides a framework to facilitate access to surgical treatment and improve surgical system resilience. This paper presents a commentary on the status of pediatric neurosurgery in Pakistan and a seminal framework for policy reform to advocate its inclusion in the NSOAP.

**KEYWORDS:** *Pediatric; Neurosurgery; NSOAP; Pakistan; GlobalSurgery* 

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#### Introduction

The global burden of neurological disorders is approximately 6.5%<sup>1</sup>. In low-income countries (LICs), the prevalence rate ranges between 5 to 8.4% compared to a range of 10-11% in high-income countries (HICs)<sup>1</sup>. LICs report higher mortality and morbidity ratios than HICs. The principal reason is the unavailability and inaccessibility of timely neurosurgical treatment by the affected population. Safe and affordable surgery is not accessible to approximately 1.7 billion children worldwide. Considering that 40% of the population in LICs is under the age of 15, the ramifications are catastrophic regarding Survival and Disability Adjusted Life Years (DALY) and death<sup>2</sup>. Currently, there is insufficient global and country-wide data on the age-standardized incidence, prevalence, and mortality rates specific to neurological disorders in LICs in particular. In a global context, the pediatric neurosurgical burden worldwide is alarming. Approximately 400,000 new cases of hydrocephalus are recorded each year<sup>3</sup>. The incidence of hydrocephalus is reported as 123 per 100,000 births in low- and middle-income countries (LMICs) alone<sup>4</sup>. The incidence of epilepsy and traumatic brain injury (TBI) in children is estimated to be 1.4 million and 3 million. respectively<sup>4</sup>. Pakistan has a population of around 207 million. 35% are below the age of 15 years<sup>5</sup>.

It is, therefore, alarming that there are currently no national surveys on the epidemiological data of pediatric neurology and neurosurgery in Pakistan. Most surveys, research, and reports can be sourced from hospital-based studies. According to one survey. 4-5% of Pakistan's noncommunicable diseases (NCDs) are neurological disorders<sup>6</sup>. Other developing countries, such as India, report a mean prevalence rate of neurological conditions as 2,394 per 100,000 population<sup>6</sup>. There is no data on the prevalence rate particular to the pediatric population, however. Diseasespecific surveys, however, report that 7 per 1000 children in Pakistan have epilepsy, cerebral palsy, and central nervous system infections<sup>6</sup>. Health indicators in Pakistan also remain high. The under-five mortality rate is 94 per 1000 births. The Infant Mortality Rate (IMR) is 78 per 1000 live births. Primary causes of mortality include diarrheal diseases and acute respiratory infections (ARI)<sup>7</sup>. There are no national surveys on the ratio of IMR attributed to pediatric neurosurgical conditions. However, Wagas et al.<sup>8</sup> reports head injuries in infants as a predominant cause of in-hospital mortality, at 7.3%. 76% of these head injuries are preventable through improved parental safety measures<sup>8</sup>.

Unfortunately, the vast need for understanding and improving the pediatric neurosurgery infrastructure in Pakistan has relatively remained unexplored and understudied. For this reason, the 'Global Surgery 2030' report by The Lancet Commission on Global Surgery (LCoGS) was much-needed step forward<sup>9</sup>. а The development of the National Surgical, Obstetrics, and Anesthesia Plans (NSOAPs) has brought surgery to the table for national health policy reform. Pakistan and Nigeria are among the forerunners in integrating the NSOAP process into their National Surgical Plans and incorporating pediatric surgery into the agenda<sup>10</sup>. There are several challenges ahead, however. Pediatric neurosurgical diseases should be incorporated to reach the NSOAP target of 80% essential anesthesia and surgical services coverage<sup>9</sup>.

Pediatric neurosurgery is grossly underrepresented in Pakistan. Access to timely and quality treatment for patients and accurate data for crucial health stakeholders and policymakers is severely compromised. Acute surgical illnesses alone result in 187 deaths per 100,000 population in Pakistan<sup>9</sup>. Death and disability in pediatric neurosurgery only add to the high IMR. It is essential to conduct neurological epidemiological studies in Pakistan. To identify and address the critical deficits in knowledge, policy, and action. All factors considered, there is a dire need for Pakistan's pediatric neurosurgical sector to be included in the National Surgical Plan. Inclusion in the National Surgical Plan will also help financing options for pediatric neurosurgery under the recently introduced Universal Health Coverage Program, known as The Sehat Sahulat Program<sup>11</sup>. Currently, only general neurosurgeries are covered under this program<sup>11</sup>. Amending policies to include pediatric neurosurgery cover will be a substantial step towards sustainability.

#### Pakistan's Healthcare System

Pakistan has a two-tier healthcare system. There are approximately 920 hospitals in the public sector and around 800 in the private sector. Bringing the estimated total number of beds to 100,000 only<sup>7</sup>. Being the sixth most populated country in the world, Pakistan is one of 57 countries with a critical deficit in health workforce and resource deficiency<sup>7</sup>. Only 2.8% of Pakistan's gross domestic product (GDP) goes to health expenditure (12). The per capita health expenditure is US\$37, and the government covers only 37%. Approximately 78.8% of healthcare financing is dominated by out-ofpocket payments<sup>12</sup>. The remaining is covered by government taxation and revenues, private insurance, and global funding. However, only 2% of foreign aid is allocated for health<sup>7</sup>. Medical insurance cover is rudimentary, which makes financing surgeries a considerable challenge in particular. Approximately 50% of Pakistan's population resides below the poverty line, that is, US\$2 per day per capita income<sup>12</sup>, which is catastrophic for the financial risk protection of the population. Where covering basic medical expenses proves difficult, affording technical neurosurgical procedures seems impossible for patients.

The socio-economic and logistic disparity also present challenges for the rural community, in particular, to access health. Difficulties in referrals to tertiary hospitals due to the unavailability of transport facilities are shared. In an attempt to curb this, there are around 5336 basic health units, 595 rural health centers, and 1138 mother and child centers nationwide7. Owing to poor management, however, the provision of adequate healthcare in these centers is ineffective. The most significant challenges Pakistan's health system faces are poverty, an increase in the burden of noncommunicable diseases where communicable diseases are already prevalent, and a lack of quality health services. Even though there has been improvement, lessons should be taken from the failures of achieving the Millennium Development Goals of 2015 in order to achieve the targets of the surgical vision of 2025<sup>7</sup>.

# The Pediatric Neurosurgery Infrastructure in Pakistan

Neurosurgery was established as a distinct surgical discipline only six decades ago in Pakistan. The first center was established by Omar Vali Jooma, in Karachi, at the Jinnah postgraduate medical center in 1951<sup>13</sup>. Expansion followed shortly after. The Combined Military Hospital, Lahore, was established as the second center by Brigadier G.D. Qazi in 1955. In 1963, Bashir Ahmad established three more centers across Pakistan's second largest province, Punjab. These included Nishtar Medical College and Hospital, Multan, King Edward Medical College, and Lahore General Hospital<sup>13</sup>.

There are around 42 neurosurgery centers across Pakistan, 150 practicing neurosurgeons, and approximately 1500 neurosurgery beds<sup>13</sup>. Resource allocation toward pediatric neurosurgery is compromised due to the lack of pediatric neurology-specific facilities. There are only two specialized neurology and spine centers in the country. The largest and most wellequipped neurology healthcare center is the Punjab Institute of Neurosciences<sup>14</sup>. It is a 500-bed hospital with an output of approximately 7000 neurosurgeries per annum. However, there is no data on the percentage allocation of beds and services to pediatric patients. Nor the pediatric patient turnover rate. Neuro-diagnostics is equipped with only 3 CT scans, 2 MRIs, and multiplanar angiography<sup>14</sup>.

There is no hospital in the country exclusive to pediatric neurology or neurosurgery. Pediatric neurosurgery is a part of multidisciplinary tertiary care hospitals. Most of these are in the public sector. Renowned hospitals include the National institute of child health (Karachi), Children hospital (Karachi), the Institute of Child Health and Children's Hospital (Lahore), Children Hospital Complex and Institute of Child Health (Multan), National Institute of Child Health (Karachi) and Children's Hospital (Quetta). Pediatric neurosurgery is also catered to in general hospitals and private neurology clinics. However, on average, there are only 40 beds allocated for pediatric neurosurgery patients in such settings<sup>15</sup>.

Pakistan's division of neurosurgeons to the population is 1/1,130,000, whereas the global recommended ratio is 1/230,000<sup>13</sup>. While this places Pakistan ahead of Africa at 1/1,352,000, a stark difference can be seen with Europe at 1/121,000 and North America at 1/81,000<sup>13</sup>. This disproportion causes neurosurgery residents to manage the patient load of pediatric neurosurgery without supervision. Subsequently affects patient safety, the quality of surgeries performed, and health outcomes. Some of the more innovative neurosurgical options are available to children in Pakistan. These include deep brain stimulation (DBS), minimally invasive spine surgery, and endoscopic tumor and eyebrow keyhole brain surgery. These procedures are, however, performed by general neurosurgeons. Pediatric neurosurgeons primarily cater to standard procedures- such ventriculostomy as the third for hydrocephalus, craniosynostosis, and myelomeningocele correction<sup>16</sup>.

present, there At is no national epidemiological data on pediatric neurology and neurosurgery in Pakistan. A handful of studies report institution-based data. In Wasay et al. <sup>17</sup>, a survey was conducted for 46021 patients on the prevalence of neurological disorders in a tertiary care hospital. The most common condition was benign epilepsies syndrome (33%), and the least common was developmental disorders (4.8%)<sup>17</sup>. Hussain et al. corroborates this data<sup>18</sup>.





#### Epilepsy

The prevalence of epilepsy in children in Pakistan is around 15.5 to 23 per 1000 children<sup>19</sup>. It is exceptionally high in children in the rural population. Treatment disparity is such that 27.5% of patients in urban areas are treated, whereas only 1.9% of patients in rural areas. The etiology is idiopathic in 21 to 76% of cases<sup>19</sup>. According to Jawaid et al.<sup>20</sup>. the most common causes are neonatal encephalopathy with an incidence rate of 28.3%, CNS infections at 19.3%, and febrile seizures at 12.7%. Secondary seizures are more common compared to primary seizures. Around 75.4% of children suffer from generalized onset tonic-clonic seizures, 5.7% from mixed seizures, and 5.2% from focal or bilateral tonic-clonic seizures<sup>20</sup>.

Treatment options are limited due to the high cost of surgery. However, the cost of neurosurgery epilepsy in Pakistan is comparatively less than compared to countries like Chile and India<sup>21</sup>. A pediatric anterior temporal lobectomy costs around US\$1644 in the public sector and US\$3044 in the private sector. This procedure costs around US\$5,020 in Chile and US\$5000 in neighboring India<sup>21</sup>. Neurosurgical options are, however, limited. Vagus Nerve Stimulator (VNS) surgery for refractory epilepsy is almost non-existent in Pakistan. There has been only one reported case of a 7-year-old patient<sup>22</sup>. The procedure was successful and encouraged the need for neurosurgeries to help improve the quality of life for children with epilepsy in Pakistan. Considering the extrapolated number of epileptic children waiting for surgery is around 34,000-45,000, the limitation for treatment is dire<sup>23</sup>.

#### Cerebral palsy

Cerebral palsy (CP) is one of the most common motor disabilities in children in Pakistan<sup>24</sup>. This burden is due to the high incidence of birth trauma and asphyxia, low birth weight (LBW) in neonates, and maternal and intracranial infections like meningoencephalitis and kernicterus in the region. CP is more prevalent in females and affects children with a mean age of 5.6±2.25 years<sup>24</sup>. Spastic guadriplegic CP is the most prevalent type due to the high incidence of birth asphyxia and trauma in the region. This is followed by atonic, ataxic/mixed CP, and finally athetoid CP. In terms of etiology, birth asphyxia in premature infants results in a high incidence of spastic diplegic CP, LBW, kernicterus, and intracranial hemorrhage contribute to a high incidence of spastic hemiplegic CP<sup>24</sup>. Even though procedures like intrathecal baclofen pump surgery are available, no evidence suggests that it has been applied to the pediatric population in Pakistan<sup>25</sup>. Other surgical options, such as selective dorsal rhizotomy, have only recently become available in Pakistan<sup>25</sup>. That too in a private setting, with limited accessibility due to long waiting times and limited surgeons.

#### Hydrocephalus

In a survey by Asif et al.<sup>26</sup>, 70% of hydrocephalus patients in a sample of 200 patients were congenital, while 30% were acquired. Spinal dysraphism accounted for 40% of congenital hydrocephalus. The most common causes of acquired hydrocephalus were post- meningitis (20%), brain tumors (5%), and post-traumatic (3%). The neoplastic group consisted of 10 patients. 8 of these had posterior fossa tumors, and two had craniopharyngiomas. 50% of patients with congenital hydrocephalus had associated congenital anomalies.

post-operative complications Common included shunt obstruction (24%), infection (20%) intracerebral hemorrhage (0.5%) and  $(0.5\%)^{27}$ . subdural hematoma Such postoperative complications are more common in low-socioeconomic settings like Pakistan. Fundamental reasons include late follow-up presentation of patients, late intervention, and lack of aseptic surgical conditions. Many patients do not seek timely medical attention because of social taboos<sup>28</sup>. At the same time, others are intimidated by the cost of treatment. According to this study, the rate of shunt blockage in congenital and post-meningitis patients was also high. Common blockage causes included shunt infection (14%) and shunt failure (10%). 50% of blockages occurred within the first year of surgery. The most common type shunts used in Pakistan of are ventriculoperitoneal (VP), medium pressure of 50-100 mm shunts<sup>27</sup>.

The use of an endoscopic third ventriculostomy (ETV) shunt for obstructive hydrocephalus is considered a routine procedure with a 30-90% success rate<sup>29</sup>. It is, however, not as commonly used in Pakistan. Even though the comparative cost with VP shunt is almost similar at US\$ 2,177<sup>30</sup>. One reason could be the lack of availability of the ETV shunt or the lack of skilled pediatric neurosurgeons available to perform the procedure. ETV shunts require more technical expertise in maneuvering the endoscope and the endoscopic anatomy <sup>30</sup>. VP shunts also prove more expensive in the long run due to multiple surgeries needed to correct postoperative complications <sup>29</sup>.

#### Brain tumors

Pediatric brain tumors are one of the most of oncology-related common causes mortality and morbidity globally and in Pakistan. They present added challenges for the pediatric population in Pakistan, however. There is no central pediatric tumor registry in Pakistan. The paucity of data and weak neurosurgery infrastructure leads to delayed diagnosis and treatment. These factors affect the prognosis of patients, even in uncomplicated cases. While nationwide data is not available, Riaz et al.<sup>31</sup> is a singlecenter study that reports the clinical data of primary CNS tumors in children from 0-16 years between 2004 to 2014. From a sample of one hundred seventy-five children, glial tumors were the most common at 105 (60%). Embryonal tumors were at 40 (22.9%), craniopharyngiomas at 25 (14.3%), and germ cell tumors 1 (0.6%)<sup>31</sup>. The most common glial tumor was astrocytoma (25.7%), and the medulloblastoma (15.4%) was the most common embryonal tumor. Mortality was at 24%, while 11.4% of patients went into remission<sup>31</sup>.

#### Pediatric TBI

According to Khan et al. <sup>32</sup>, the incidence rate of TBI in Pakistan is 50/100,000 per annum. 73% of these injuries occur in male children under the age of 12. In another survey by Wani et al. <sup>33</sup>, the incidence of 'falls' was 63% in pre-school children. Inferring falls in children is the most common cause of pediatric TBI. 25% of TBIs in children were caused by road traffic accidents (RTAs), and 11.6% were caused by other forms of injury, such as sports or collisions. Only about 30% of children had moderate to severe head injuries, and a Glasgow Coma Scale (GCS) score between 9-12 <sup>33</sup>. Most of the children

in these categories had poor surgical outcomes. Common injuries ranged from 10% of children having depressed fractures and contusions, 7.5% of children having extradural hematomas, 5% having subdural hematomas with brain contusions, and 6.66% of children having brain edema <sup>33</sup>. 7.5% of patients underwent craniotomies and hematoma evacuation, and 10% underwent dural repairs and elevation of depressed fractures. Only 5% of children underwent decompression craniotomies <sup>33</sup>. It is noteworthy to mention that according to the survey, 30% of deaths were avertible. Delays in surgery caused by long waiting times increase mortality by enhancing secondary injuries to the brain, such as hypotension and hypoxia <sup>33</sup>.

#### Challenges

Pediatric neurosurgery is a particular niche and a technical specialty. In Pakistan, it is a part of multidisciplinary tertiary care hospitals, which results in gross differences between departments. In terms of skilled professionals, resource allocation, budgetary preference, and infrastructure. General neurosurgeons and pediatric surgeons perform surgeries such as VPS and spinal dysraphism instead of pediatric neurosurgeons. As a result, pediatric neurosurgeons do not cover even high-risk, specialized surgeries such as detethering an asymptomatic cord and the excision of intramedullary spinal cord tumors. Improved between pediatric coordination neurologists, neurosurgeons, and pediatricians can help navigate things more efficiently but cannot cover the overall shortage<sup>34</sup>. Covering the skilled professionals' deficit is also challenging because of inadequate training programs for pediatric neurosurgery trainees. The existing

panel of pediatric neurosurgeons and trainees struggle to manage the patient volume as it is. It is inadvertently compromising the quality of care for patients. Additionally, there are no regularized morbidity meetings or cutting-edge undertaking of research projects and presentations to help improve the existing standard of care <sup>13</sup>.

Infrastructure issues are predominantly related to the basic infrastructure of hospitals in LICs. According to a World Health Organization (WHO) survey of 800 facilities in LICs, 31% of hospitals did not have continuous electricity, 22% did not have running water, and 24% did not have oxygen cylinders <sup>35</sup>. Essential services such as accidents and emergency care. postoperative care, pathology, and blood transfusion services are also compromised <sup>35</sup>. Corruption is also prevalent in the healthcare sector. It manifests itself in the form of bribes for preferential treatment and resource allocation within specialties.

According to Haque et al.<sup>2</sup>, most pediatric departments in Pakistan are equipped with equipment, incubators, essential and phototherapy equipment. However, most pediatric Intensive Care Units and operation theatres do not have vital equipment such as ventilators, anesthetic equipment, and patient monitors<sup>2</sup>. There is a lack of availability of designated pediatric intensive care units (PICU). For around 500,000 children, there is only 1 PICU bed per ICU. In comparison, the allocation ratio is one bed/10,000 children in the USA and 1bed/1000 in the UK<sup>2</sup>. The availability of pediatric neurosurgical procedures is, however, also limited. Awake craniotomy or minimally invasive surgery is not even an option for children in Pakistan. Subdisciplines such as functional neurosurgery, epilepsy and stereotactic surgery,

radiosurgery are almost non-existent. There is a shortage of neuronavigational facilities and endoscopy. To overcome this deficit, departments such as radiology, ENT. ophthalmology, and anesthesia support surgery coordination as much as possible <sup>13</sup>. Another example includes the limited availability of autologous bone grafts for pediatric cranioplasties. It is a better choice due to better osseointegration in the skull and easy storage. In Pakistan, however, neurosurgery is adapted to manage the burden of low resources. During craniectomy, the ovariectomized bone flap is inserted into the abdominal subcutaneous fat instead<sup>36</sup>.

Neurosurgical emergency care and admissions are delayed extensively due to the lack of protocols for pre-hospital services. The absence of implementation of postoperative management in ICUs reduces patient turnover. Lack of transport, such as ambulances, is a debilitating aspect for TBI patients. If the TBI is complicated or severe, emergency care often refuses to take the patient because of a lack of skilled personnel for surgical treatment. The patient usually dies waiting.

In terms of equipment, there is only one tesla MRI machine in the public sector in Pakistan<sup>37</sup>. Including DTI imaging, which has proven essential for tumor resection. There is also only one reported Cavitron ultrasonic surgical aspirator (CUSA)<sup>37</sup>. There are added challenges for the rural population, such as diagnosing conditions. Patients have to travel long distances just for a simple X-ray. In Pakistan, it is also common practice for the late presentation of pediatric neurosurgical patients to neurosurgeons. Cultural stigmas, fear of the cost of treatment and the treatment itself, and lack of knowledge of the disease and treatment options are common reasons.

Implications for Advancing Pediatric Neurosurgery Towards the Sustainable Development Goals

Α forward trajectory should involve minimizing losses and making the current pediatric neurosurgical infrastructure more efficient. For example, large-scale surveys can help identify key problem areas. Data from these surveys can allow targeted investment for the most impact generated with limited economic buy-in. International stakeholder engagement should also include incorporating the niche of the targeted population, that is, children. Such as The Global Initiative for Children's Surgery and Global PaedSurg<sup>38</sup>. A similar approach should be applied to pediatric neurosurgical capacity building. The frequency of training programs and international medical missions should be increased. For example, the Foundation for International Education is currently running projects such as the Tanzania Neurosurgery Project, the Duke East Africa Neurosurgery Program, and the Cambodia Neurosurgery Support Project <sup>39</sup>. Programs such as The World Federation of Neurosurgical Societies (WFNS) provide training for early career neurosurgeons in LICs<sup>39</sup>.

Similar programs can be put together in Pakistan. For retention of the workforce,

learning should be competency-based with appropriate incentives. Apart from this, the standardization of protocols can be a lowcost driver to help reduce system losses and increase accountability. According to Fezeu et al. <sup>40</sup>, there is an array of mapping techniques for epilepsy. There is also no consensus on a fixed protocol of anesthesia craniotomies<sup>40</sup>. awake in Nonstandardization can affect the best neurosurgical approach to addressing the condition. Service delivery can be improved through electronic statistical records. Particularly in computerized neurology charts, which are lacking in Pakistan. These tools can also improve multidisciplinary communication within tertiary care Coordination hospitals. between neurosurgeons and pediatricians, for example. Financing solutions should include minimizing recurrent losses. For example, in Uganda, the cost per DALY averted for neurosurgical intervention ranged from \$59 to \$126 in a survey<sup>41</sup>. The economic benefit incurred for treating hydrocephalus alone ranged from \$930 million to \$1.6 billion<sup>41</sup>. Pakistan can implement such strategies by minimizing shunt infections and blockages, providing timely surgeries, and increasing use of antibiotic-impregnated the hydrocephalus shunts.

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Figure 2. A Seminal Framework Incorporating Pediatric Neurosurgery with the PSOAP Framework

#### Conclusion

The inherent need to include this vital subspecialty in the NSOAP is reiterated in examining the current status of pediatric neurosurgery in Pakistan. Engaging local leaders and stakeholders can provide a comprehensive and collaborative approach. The first step in adopting a decentralized NSOAP framework to a provincial model (PSOAP) has already laid the groundwork for a positive trajectory. This model can promote public-private partnerships within Provincial competition provinces. for funding is also reduced as stakeholder engagement is based on shared interests in investment. Which can subsequently help drive policies and legislation to bring sustainability to the pediatric neurosurgical infrastructure in the region.

Standardized protocols for quality management can help streamline processes and policy frameworks. Since pediatric epilepsy and cerebral palsy are the predominant neurosurgical disorders, addressing the following patient population can help alleviate the patient volume. Surgical outcomes should also be evaluated and monitored to set a precedent for future guidelines. Health financing models should be adapted to minimize losses incurred. Bridging weaknesses in the current infrastructure and utilizing a strategic reorganization protocol can help include pediatric neurosurgery in the national surgical program in Pakistan.

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