Disparities in Cerebral Palsy Treatment: A Comparative Analysis of Pakistan and the United States

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

This research paper delves into the intricate landscape of cerebral palsy (CP) and its treatments, examining the disparities between the United States and Pakistan. CP, characterized by muscle weakness stemming from developmental brain damage, affects a significant portion of the population, with one in 345 children in the United States grappling with its challenges (Centers for Disease Control and Prevention, n.d.). The symptoms vary widely, encompassing difficulties in movement and posture maintenance. Diagnosis typically begins with parental observations of developmental delays, progressing to medical assessments and imaging tests, with the average diagnosis occurring by age two. The spectrum of CP symptoms necessitates a personalized treatment approach, ranging from physical therapy to corrective surgery, contingent upon the severity of the condition. However, access to technology and suitable equipment remains paramount for effective treatment, a reality underscored by the contrasting healthcare landscapes between the US and Pakistan. While the US boasts a comprehensive array of treatments and rehabilitation programs, Pakistan faces significant challenges in infrastructure, resources, and awareness, resulting in limited access to CP therapies. Through qualitative interviews with healthcare professionals from both countries, this study aims to illuminate the stark differences in CP treatment availability, shedding light on the pressing need for equitable access to care worldwide.

Background

When translated, CP means weakness with using the muscles as a result of developmental brain damage. CP is a congenital disease that affects the development of motor and balance

skills, affecting one in 345 children in the United States (Centers for Disease Control and Prevention, n.d.). The symptoms of CP range from patient to patient, however, they commonly include difficulty with movement and maintaining posture (National Library of Medicine, n.d.).

Prior to treating a child with CP, they must first be assessed to confirm their diagnosis and severity. This typically starts with the parents' assessment for developmental delays in their own child. The earliest delayed milestones include not being able to sit without support. The next most apparent one is delayed/ impaired walking. Other common, yet lesser known delays include trouble chewing foods, speech delays, and other mouth motor disabilities. Each of these are correlated to a lack of control in motor ability, thus causing delays in development.

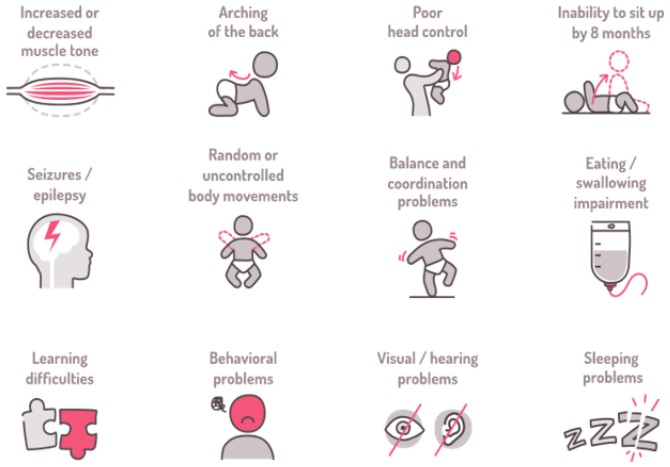

Figure 1: A diagram by the National Library of Medicine showing early onset CP symptoms

A child is typically diagnosed by the age of two following a series of imaging tests. Since CP exists on quite a large scale of symptoms, numerous examinations are performed on the child to grasp the severity of the symptoms and create a suitable treatment plan. Some children may only have trouble supporting their posture which may be aided with physical therapy, while others may not be able to walk, requiring assistive devices.

Regardless of severity, the treatment depends entirely on access to technology and appropriate equipment. Such treatments in the United States include botox, physical therapy, assistive devices, and corrective surgery. Each of these requires an essential understanding of a

patient's muscle tones and muscular anatomy. To do so, ultrasounds, MRIs, and physical examinations are performed. Currently no cure exists for CP, thus making availability of treatments far more important. Here in the United States there are numerous rehabilitation programs to aid them in having a slightly easier childhood.

Unfortunately, such a range of treatments does not exist in Pakistan, a third world country located in southern Asia. According to a study conducted in the Khyber Pakhtun region of Pakistan in 2017, the prevalence of CP in Pakistan is 1.22/1000 live births. This number is much lower than that stated for the US however can be explained for a couple of reasons. The first being that the number previously stated is for live births. Meaning that is the number for children diagnosed with CP as soon as they are born. CP, however, can be diagnosed anytime between the ages of 0-8, especially as a result of diseases that cause damage to the brain such as meningitis or typhoid (Tharwani, n.d.). These diseases are typically extremely rare in the United States as there is a high availability of vaccinations to prevent them. In a third world country, such as Pakistan, there is a higher prevalence of such diseases as there are fewer vaccines available and less hygienic environments- i.e. access to clean water (Tharwani, n.d.). The reason neurological disorders can often lead to CP being developed despite being born healthy is since there is a risk of damage occurring in the spinal cord, such as an infection or damaging of nerves in the brain stem, connected to the spinal cord (Globalwaters, n.d.). Despite the cause of CP being diagnosed after birth, most of these cases are likely not reported in the earlier statistic.

Another reason for the statistic appearing lower is that it represents reported cases of CP. While some of the more modern cities in Pakistan (including Lahore, Islamabad, and Karachi) may mirror technologies relatively similar to those in the United States, some of the rural areas (such as Hunza valley, Gujranwala, and many other smaller villages) do not have an updated

system yet. Due to this, most of their records are not updated digitally, rather kept as paper forms (Refworld). Since they are not available digitally, they likely were not accounted for when the survey for the study was sent out. Limited awareness on diagnosis of CP has a direct correlation with lack of treatment, or less available therapies for the children. CP as a whole represents an under represented and under researched community in Pakistan. With there being limited knowledge on the prevalence of CP, the therapies available also become a question of focus.

Methods

A qualitative method was used to conduct a study to compare the therapies available for CP in the United States and in Pakistan from the perspective of the doctors. This was done through constructive interviews with practicing doctors offering treatments for CP. Due to the complex nature of the disease being discussed, it is important to give the clinicians, the primary source in this field of research, the opportunity to openly explain the thought process to their treatment approaches. Interviews are beneficial because they also allow for in depth exploration and elaboration. Doing so will hopefully raise awareness on the privilege, and lack thereof, of availability of treatments and therapies for individuals with cerebral palsy.

Since CP affects an extensive range of bodily systems, it therefore requires a team of doctors in order to treat it effectively. As a result there is quite a bit of jargon and niche topics when considering treatment options. The interviews were designed to follow a general question framework which asks about the diagnostic process and treatments which that specific physician provides. Using this further questions were asked to build upon what previous physicians have said and their own experience. Conducting a one on one interview allows for a personal and in depth explanation of their experience in treating CP.

More specifically, CP is treated by orthopedists, neurologists, physical therapists, pharmacists, and pediatricians. At least one physician from each of these fields were interviewed. In total, from both countries, 10 interviews were conducted, lasting 30 minutes to an hour each. The interviews were conducted either via Zoom or Whatsapp. The physicians from the United States were currently practicing at John Hopkins Hospital and the University of Virginia Medical Center. The physicians from Pakistan practiced at various local clinics and larger hospitals in Lahore, Pakistan. This included King Edwards Hospital, Lahore General Hospital, and Punjab Institute of Neuroscience.

Literature Review

Access to Healthcare Systems in the United States and Pakistan

Access to healthcare systems is a critical determinant of health outcomes and disparities. Therefore it is important to consider the equity in availability prior to examining the contents which are available. Aside from the quality of treatment, the financial burden of them must be analyzed. Several times that is the determining factor when seeking further treatment.

In order to afford healthcare treatments several civilians in the United States rely on health insurance to lower the cost. In 2020, The U.S. Census Bureau reported that approximately 91.4 percent of the population had health insurance coverage. Medical insurance promotes health equity by ensuring that everyone, regardless of socioeconomic status, has access to necessary healthcare services (Institute of Medicine, 2010). Studies have consistently shown that individuals with medical insurance have better health outcomes, as they are more likely to receive regular medical care, preventive screenings, and recommended treatments (National Institute of Health, 2018). By reducing financial barriers to care, medical insurance enables

individuals to access medical services promptly, leading to improved health outcomes and overall well-being.

When considering Pakistan, research indicates that access to healthcare services is influenced by various factors, including socioeconomic status, geographic location, infrastructure limitations, and cultural barriers (Nishtar, 2010). Rural populations, in particular, face significant challenges in accessing healthcare due to limited healthcare facilities and healthcare workforce shortages (Jooma & Khan, 2011). As is the case with the United States, financial barriers, such as out-of-pocket expenses, can hinder access to care, especially for low-income individuals and marginalized communities. Additionally, cultural beliefs and gender norms may restrict women's access to healthcare services, particularly in conservative regions (Sarwar et al., 2016). Initiatives such as the Sehat Sahulat Program, which provides health insurance coverage to vulnerable populations, have been created in recent years (Government of Pakistan, 2019). The issue with this is lack of continuous, consistent funding, causing the program- similar to many others of its type- to fade over after a few years. Due to these inconsistencies, access to affordable healthcare remains a pressing issue in Pakistan.

CP Treatments in the US:

Knowledge of CP is obtained through a variety of methods including research strategies and clinical studies. Research on CP treatments in the US has investigated various interventions across the lifespan, including early intervention services, rehabilitation therapies, medications, surgical procedures, assistive devices, and multidisciplinary care approaches (American Academy of Pediatrics, 2016). Clinical studies evaluate the effectiveness of physical therapy interventions, occupational therapy, speech therapy, and other rehabilitative modalities in improving motor function, mobility, communication, and quality of life for individuals with CP

(American Academy of Orthopaedic Surgeons, 2018). It is crucial to note that since CP affects a vulnerable population, in this case children, research efforts are limited and highly regulated to ensure safety of these children.

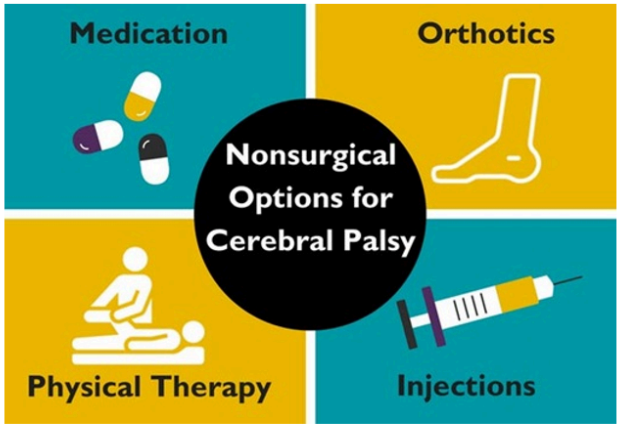

Figure 2: A diagram obtained from Johns Hopkins University Hospital showing the range of CP treatments they offer

Additional research has examined the efficacy and safety of surgical interventions such as selective dorsal rhizotomy, orthopedic surgeries, botulinum toxin injections, and orthotic management for managing spasticity, contractures, and orthopedic issues associated with CP (American Academy of Orthopaedic Surgeons, 2018). Technological innovations, such as assistive technologies, mobility aids, communication devices, and orthotic devices, play an increasingly important role in supporting individuals with CP in daily activities and participation. The typical process for this research involves first conducting research computationally in a lab to and based on prior to hypothesizing beneficial results. Once enough evidence is grounded for this, clinical studies begin in which qualified patients are brought to the trial to determine the extent to which the treatment is effective for them.

CP Treatments in Pakistan

In Pakistan, CP treatments are relatively limited compared to other countries, reflecting challenges in healthcare infrastructure, research capacity, and resources. However, existing research has begun to explore various aspects of CP treatments in Pakistan, including rehabilitation interventions, healthcare utilization patterns, barriers to care, and outcomes of CP

management in diverse settings. Studies have investigated the effectiveness of physical therapy interventions, occupational therapy, and speech therapy in improving motor function, mobility, communication, and activities of daily living for individuals with CP in Pakistan (Khan, Amjad, Tabasum, & Yousafzai, 2019). This research also examined the availability and accessibility of healthcare services for individuals with CP, highlighting disparities in access to the treatments listed previously. Since research in this area is a relatively developing topic, the researchers concluded that their most effective take away was the gaps addressed in the Pakistan healthcare system.

Challenges in CP management in Pakistan include limited healthcare infrastructure, shortage of trained healthcare professionals, financial constraints, cultural beliefs, and lack of awareness. Despite these challenges, efforts are underway to improve CP care in Pakistan through initiatives such as capacity-building programs, community-based rehabilitation services, and advocacy for increased funding and resources for CP treatment and support services (Government of Pakistan, 2019).

Results and Discussion

Diagnosis of CP

Despite the location of practice, all physicians agreed that their sole duty was to provide the most effective treatment available to their knowledge. The comprehension of CP for the physicians was no different depending on whether they were in Pakistan or the States, since they all received their medical license and degrees from education supplemented by standardized textbooks. Drawing from this, all physicians agreed that due to CP's wide range in symptoms it required numerous doctors to beneficially treat them. A family physician from King Edwards

Medical College describes the process of diagnosis in the following excerpt translated from his interview.

> Researcher: Can you please tell me the standard procedure in which the children are diagnosed?
>
> Interviewee: Yes, typically a parent will bring a child to their ped with concerns on delayed milestones. Sometimes as young as six months they are not able to hold up their head and sometimes after a year if they are unable to walk.
>
> Researcher: What is the oldest age a child typically presents symptoms?
>
> Interviewee: Usually a child is diagnosed by the age of 3-5, the latest symptoms show around 2 years of age.
>
> Researcher: If the pediatrician also notices the delays observed by the parent what are next steps?
>
> Interviewee: Depending on the age of the child, the pediatrician will monitor for gait changes and posture imbalance, if this is strongly present the pediatrician will refer the child to a neurologist. The neurologist confirms diagnosis with scans.

This can be compared to the diagnostic procedure as described by a neurosurgeon at Johns Hopkins children's center.

> Researcher: What is the diagnosis procedure typically followed here at this institution?

Interviewee: As a neurosurgeon, the child typically arrives to us already diagnosed. They are here mainly to seek treatment. The pediatrician deals with all things like getting scans and confirming diagnosis and beginning initial treatments.

Researcher: What do early treatments consist of?

Interviewee: Initial treatments are really specified since every case we see is so different. So it can be anything from medicine to therapy. We want to avoid invasive procedures until it can be beneficial. So, we start with light physical therapy and then it gets more intense. After a time at therapy depending on their condition, we will prescribe assistive devices or a rhizotomy. For the procedure to get diagnosed there are several check ups that occur in the child's first year. Typically, the pediatrician will note any recurring delays the child presents, repetition and worsening of these over time is typically when an official diagnosis will be made.

From these it is notable that presentation of symptoms and process in diagnosis are relatively similar. One discrete difference is where the concern for diagnosis originates. In the United States, for a child's first year of life they are required to have a doctor's appointment once a month. These check for routine development as well as immunization fulfillments. Therefore, the pediatrician is typically able to note early symptoms of CP. For Pakistan, regular appointments are a suggestion not a requirement. Meaning, the parents will usually bring their child after noticing irregular symptoms. One physician from the University of Virginia stated that is "not the optimal" procedure as it can prevent early diagnosis, the prime way to get an effective treatment plan for CP before symptoms risk worsening.

The drastic differences begin to arise when treatments are brought into question.The following subsections will detail treatments, ranging from most to least similarities between the two countries.

Physical Therapy

All physicians spoken to agreed that the first step in treating CP is prescribing physical therapy (PT). For the physical therapists spoken to in the United States, first muscle tones are examined. One physical therapist from the University of Virginia stated that muscle tone is essentially any resistance to motion in the arms and legs. In CP there are higher levels of muscle tones so exercises performed during PT, such as light stretches, range of motions, and strengthening, aims to decrease these muscle tones. PT is typically performed once or twice a week with a physical therapist. During the weekly PT sessions, the children work with various instruments and independently to aid in bodily movements. The instruments include rubber bands, to control strength required to stretch, light weights, to increase strength, and cardio, to increase endurance. In addition to this, simpler exercises are taught to conduct at home. This helps to increase consistent ranges of motion in patients to avoid overexertion and allow for faster improvement.

In Pakistan, physical therapy is typically also performed weekly. However, the patients are seldom given exercises to perform at home. A physical therapist from Lahore General hospital stated that physical therapy starts with light stretches and expands to more intense exercises. The exercises performed are similar to those performed in the United States, however, typically do not require the use of tools which require electronics or battery powers. In order to ensure consistent treatment options, electronics are avoided in therapeutics as their upkeep is not

always regulated. Nonetheless, despite the country, the goals of PT remain the same: to increase mobility and voluntary movements of muscles in patients.

Medications

Alongside PT, medications may also be administered to alleviate some of the tension created in the muscles. As described by another surgeon at Johns Hopkins University, an oral medication by the name of Baclofen is prescribed after some time at therapy. The goal of Baclofen is to reduce muscle spasms, cramping, and tightening of muscles. Which, again, is to decrease the side effects of CP. Baclofen is also available upon prescription in Pakistan. In Pakistan, it is regarded as more of a muscle relaxant to treat CP, rather than an aid in conjunction with PT.

Medication wise, muscle relaxants are typically the only treatment given to patients. At certain research centers in the United States- such as Johns Hopkins- botulism toxin is administered to patients to decrease muscle spasms. This was stated to be a rarer form of treatment as the results for it last around 12 weeks and is painful for children. Additionally, being injected with botulinum toxin limits additional treatment options like surgery.

Surgery

A pediatric neurosurgeon at Johns Hopkins Children's Hospital in Florida conducts Selective Dorsal Rhizotomy procedures on children with CP. This procedure aims to reduce spasticity by cutting sensory nerve fibers in the spinal cord. According to this neurosurgeon, the procedure has been evolved to be minorly invasive, meaning a smaller incision is made however a short hospital stay is required for recovery. His success rate for the procedure was around 90 percent. Prior to the surgery, intense physical therapy is required to achieve maximum capacity

of muscles in the children. This surgeon also stated that a rhizotomy is a readily available procedure performed by the majority of pediatric neurosurgeons in the nation.

Rhizotomy is also performed in major cities in Pakistan. A pediatric neurologist from Punjab Institute of Neuroscience stated that the procedure is commonly performed in neuro-specialized clinics in Rawalpindi, Lahore, and Karachi. This places those in rural areas at a disadvantage as they do not have immediate access to treatments. Distance often sways patients from seeking treatments as well since it is an inconvenience to travel further and endure a larger financial burden.

General Trends

The two noticeable differences in treatments include reduced use of technology and limited access to treatments. The treatments in the United States and in Pakistan are nearly identical due to the knowledge coming from the same literature. Lack of awareness about CP in Pakistan creates a divide in access to treatment. Since less individuals are being diagnosed in a timely manner, simply from not having access to adequate clinics in proximity to them, there are fewer effective treatment options available to them. This, thus, causes a decrease in interest in to expand, at a rate similar to the United States, on possible treatments options.

Conclusion

In conclusion, the research presented in this paper underscores the profound impact of socioeconomic, cultural, and infrastructural factors on the availability and quality of CP treatments in the United States and Pakistan. Disparities in access to healthcare services, compounded by limited resources and awareness, pose significant challenges for individuals with CP, particularly in regions with underdeveloped healthcare systems. While the US boasts a comprehensive framework of interventions, including physical therapy, medications, and surgical

procedures, Pakistan grapples with barriers ranging from financial constraints to a shortage of trained healthcare professionals. However, amidst these challenges, efforts to improve CP care in Pakistan are underway, driven by initiatives aimed at capacity-building, community-based rehabilitation services, and advocacy for increased funding. By illuminating the contrasting landscapes of CP treatment between these two countries, this research underscores the urgent need for global collaboration and resource allocation to ensure equitable access to care for all individuals living with CP, irrespective of geographic location or socioeconomic status. Only through concerted efforts can we strive towards a future where every individual with CP receives the support and treatment they need to thrive.

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