

Delays in diagnosis and rehabilitation among children with cerebral palsy: A retrospective study from a tertiary care centre in Sri Lanka

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ABSTRACT

Introduction: Early identification of cerebral palsy is essential in receiving appropriate interventions, better patient outcomes, reducing the cost of rehabilitation. The aim of the study was to identify the delay in diagnosis and wait time for rehabilitation and factors associated with it.

Methods: A retrospective descriptive cross-sectional study was conducted among 100 children with cerebral palsy attending rehabilitation services and neurology clinics at a leading tertiary children's hospital in Sri Lanka. Consecutive eligible children were recruited using convenience sampling until the required sample size was achieved. Data were collected from parents or guardians using a pre-tested interviewer-administered questionnaire, supplemented by review of clinic records and clinical examination.

Results: Majority of the children were male (66%), had spastic (78%) and quadriplegic (55%) CP, belonging mainly to GMFCS IV and V. In this study, 25% were born below 32 weeks. The most common associated factors were birth asphyxia (45%), neonatal jaundice (41%) and hypoglycaemia (24%). Maternal risk factors for sepsis was below 10%. The most common clinical presentation was developmental delay (82%), diagnosed mostly (58%) by general paediatricians. Mean age at diagnosis, at referral for physiotherapy, occupational therapy, speech and language therapy and cortical visual stimulation were 16 months, 20 months, 8.4 months and 8.0 months respectively. Financial status, appointment delay and missed dates were the common factors associated with delayed referral.

Conclusions: In this sample of children with cerebral palsy in Sri Lanka, diagnosis was made generally after infancy, and delays were particularly evident in referral to and commencement of specialised rehabilitation services such as speech and language therapy and cortical visual stimulation. Financial constraints, appointment delays, and missed clinic dates were frequently reported barriers to timely rehabilitation. These findings highlight the need for strengthened early identification pathways, clearer referral systems, and improved access to multidisciplinary rehabilitation services for children with cerebral palsy.

Keywords: *Cerebral palsy, Delay, Diagnosis, Rehabilitation, Risk factors.*

Introduction

Cerebral palsy (CP) is a term used to describe a group of conditions caused by injury to the developing brain in the prenatal, perinatal, or postnatal period that leads to disorder of movement, tone, and/ or posture (1). It is a motor disorder in children with a prevalence of 1.5 per 1000 live births in most population-based registries (2, 3).

With recent development in diagnostic modalities such as in neuro-imaging, the cause for CP can be readily delineated (4). CP also has a wide spectrum of severity, ranging from a mild increase in “tightness” in tendon Achilles to full blown spastic quadriplegic CP (5).

There may also be specific social and cultural factors that influence health-seeking behaviour leading to a delay in presentation (6). Furthermore, health professionals’ ability to identify cerebral palsy has a wide variability; their exposure and training determining the ease of diagnosing CP and subsequently making timely referrals (7).

Early identification of children with physical and developmental disabilities is essential to ensure they receive appropriate interventions as soon as possible. This helps children develop their full potential, maximise their functional abilities, and prevent further disabilities (8, 9, 10). However, factors that limit access to rehabilitation services, such as long waiting times, can significantly impact a child’s functional outcome and health. Early referral and initiation of rehabilitation have proven benefits (8, 9). Despite the importance of this issue, there is limited information on low- and middle-income countries (LMICs), with most current literature focusing on high-income countries (HICs) (11). Even in studies conducted in LMICs, many children do not benefit from available services due to various challenges (11). The current study explores these details.

The aim of the study was to identify the delays in diagnosis and barriers of early rehabilitation resulting in more meaningful care, better patient outcomes, quality of life and minimise the time invested in rehabilitation.

Methods

This retrospective descriptive cross-sectional study was conducted among children with cerebral palsy attending rehabilitation services and neurology clinics at Lady Ridgeway Hospital for Children, Colombo, Sri Lanka. Children older than 2 years who fulfilled the clinical criteria for cerebral palsy were eligible for inclusion. Children with progressive neurological disorders, familial neurological diseases, non-cerebral palsy neurological diagnoses, major congenital anomalies, or severe systemic illnesses that could independently affect neurodevelopment or access to rehabilitation were excluded. The minimum sample size was calculated using the formula for estimating a single population proportion, $n = Z^2 p(1 - p)/d^2$.

As local data on delays in diagnosis and rehabilitation among children with cerebral palsy were limited, a prevalence estimate of 50% was used to obtain the maximum sample size. With a 95% confidence level and a margin of error of 10%, the minimum required sample size was 96 participants. Allowing for incomplete data, the target sample size was set at 100 children. Consecutive eligible children were recruited over a 3-month period using convenience sampling until the target sample size was achieved (Figure 1).

An interviewer-administered questionnaire was provided to mothers of eligible candidates at the time of the clinic visit. The questionnaire on clinical details was completed by both direct questioning as well as by perusal of clinic records to avoid recall bias and investigator/ participant biases. The latter was done to both gather essential clinical information, which parents might not remember, and to cross-check the reliability of information given. Subsequently, the child was physically examined by an investigator (paediatrician) to ensure that the case definition for CP was fulfilled (18) and to record the motor disabilities the child had during the time of examination. Only the principal investigator administered the questionnaire and undertook the physical examination to make sure that uniformity is maintained. The questionnaire was developed by the investigators and pretested with 10 nonparticipants (who are excluded from this study) fulfilling the inclusion criteria. The following categories were included in the questionnaire.

- Characteristics of participants: gender, age, CP type by anatomical distribution (Diplegic

Hemiplegic, Quadriplegic), Physiological distribution (Spastic, Dystonic, Athetoid) and Gross Motor Functional Classification System (GMFCS).

- Risk factors of CP in this sample:

- **Antenatal Risks:** These refer to factors that occur before birth, which can affect the developing brain and increase the risk of CP

- Co-morbidities, (gestational diabetes, pregnancy induced hypertension etc.)
- Risk factors for sepsis (premature rupture of membranes, maternal fever, urinary tract infection in 3rd trimester, positive high vaginal swab etc.)

- **Perinatal Risks:** These are factors that occur during the time of birth

- Birth asphyxia requiring resuscitation, fever during labor, meconium-stained liquor etc.

- **Postnatal Risks:** These involve factors that occur after birth, particularly in the first few years of life.

- Hypoglycaemia, meningitis, neonatal jaundice etc.

For data analysis, the *Statistical Package for Social Sciences (SPSS)* software version 24 was used. Descriptive statistics were used to describe the data through frequency tables with measures of central tendency included where relevant.

Ethical clearance for the study was granted through the Ethics Review Committee of Lady Ridgeway Hospital for Children, Colombo, Sri Lanka. Participants were informed about the purpose of the study and informed written consent was obtained prior to data collection.

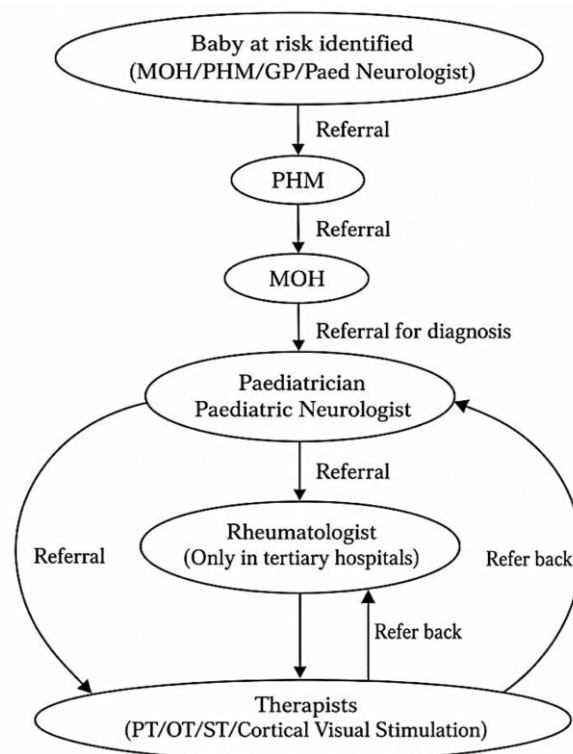


Figure 1: Referral pathway for children with suspected cerebral palsy accessing tertiary paediatric neurology and rehabilitation services in Sri Lanka.

Author-created schematic showing the usual referral pathway at the time of study from early identification to diagnostic assessment and rehabilitation services, including physiotherapy, occupational therapy, speech and language therapy, and cortical visual stimulation.

Results

Sociodemographic details

The sample consists of 100 children with CP, where majority were males (66%) and the male : female ratio was 1.94 : 1. Of the sample, 29% were between the age group of 2 - 4 years. The majority (78%) of participants were spastic and quadriplegic (66%). Almost one third (32%) of the children belonged to GMFCS (Gross Motor Functional Classification System) category IV (Table 1).

Table 1: Characteristics of children with cerebral palsy

Characteristics	Percentage (%)
Sex	
Male	66
Female	34
Age group (years)	
2 - 4	29
4 - 6	28
6 - 8	20
8 - 10	12
>10	11
CP subtype	
Anatomical distribution	
Diplegic	12
Hemiplegic	22
Quadriplegic	66
Physiological distribution	
Spastic	78
Dystonic	17
Athetoid	5
GMFCS ^a level	
I	4
II	16
III	21
IV	32
V	27

^a Gross Motor Functional Classification System

The study sample included a representation from all provinces of the country. Most mothers (54%) were educated up to Ordinary Level, 26% completed up to Advanced Level and 12% only received primary education. Majority (47%) of the participants earned a monthly income less than LKR 20,000/-.

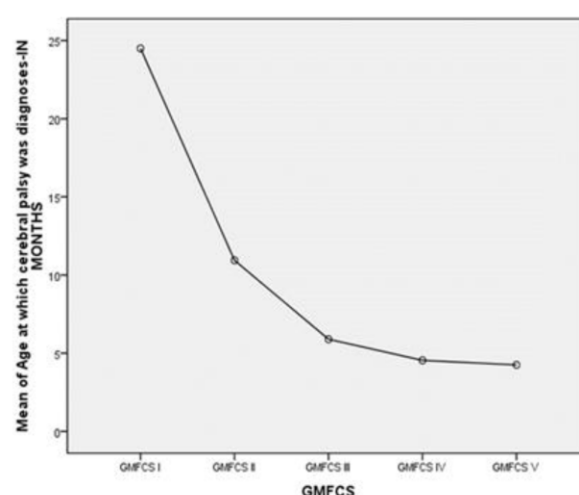
Associated factors for CP

Table 2 shows the contribution of associated factors identified in the sample.

Table 2: Associated factors for cerebral palsy

Characteristics	Percentage out of total sample (%)
Antenatal	
Co-morbidities	
Gestational Diabetes	11
Pregnancy induced hypertension	21
Risk factors for sepsis	
PROM ^a	9
Maternal Fever	7
UTI ^b in 3 rd Trimester	2
Positive high vaginal swab	2
Perinatal	
Birth asphyxia requiring resuscitation	45
Fever during labor	2
Meconium-stained liquor	10
Postnatal	
Hypoglycemia < 40 mg/dL	24
Clinical hypoglycemia	9
NNJ ^c requiring phototherapy	41
NNJ requiring exchange transfusion	3
Meningitis	15

^a Premature Rupture of Membranes, ^b Urinary Tract Infection, ^c Neonatal Jaundice

**Figure 2:** Mean age at diagnosis of CP according to GMFCS

GMFCS I, II, III, IV and V were diagnosed at 2 years, 10.2 months, 5.4 months, 4.1 months and 4 months, respectively

The major proportion (58%) of the sample was term infants. One quarter was less than 32 weeks. The need for resuscitation was a common factor in all gestational groups. Nonetheless, children with CP who were preterm showed a much higher proportion (62%) to undergo resuscitation than the term group (36%).

Diagnosis of CP

The mean age at which CP was diagnosed among these children was 1 year and 4 months (SD 1.03). Figure 2 shows the mean age of diagnosis with GMFCS, with higher GMFCS categories being diagnosed before lower categories.

Table 3: Presenting features that led to suspicion of cerebral palsy

Presenting feature	n (%)
Developmental delay	82 (82.0)
Stiffness	16 (16.0)
Other presenting features	2 (2.0)

Most children were diagnosed by general paediatricians (58.0%), followed by medical officers (20.5%) and paediatric neurologists (20.0%). General practitioners diagnosed only 1.5% of cases.

The most common presenting feature that raised suspicion of cerebral palsy was developmental delay, reported in 82% of children, followed by stiffness in 16% (Table 3).

Rehabilitation of children with CP

Table 4 shows those children who were referred to and subsequently commenced under relevant rehabilitation services.

Both clinicians and parents were found to be almost equally responsible for the delay in referral with 82% and 84% taking responsibility, respectively. Barriers to timely rehabilitation were reported at both the referral and service-initiation stages. Financial difficulty was reported as a reason for delayed referral by 25% of caregivers. Delayed commencement of rehabilitation after referral was most commonly attributed to appointment delays (25%), financial constraints (19%), and missed scheduled clinic or therapy dates (18%).

Table 4: Age at referral and commencement of rehabilitation services

Rehabilitation service	Number of children with CP at each stage	Mean age (SD) of referral/ start of service in years
Physiotherapy		
Referred	100	1.84 (0.32)
Commenced	100	1.92 (0.12)
Occupational therapy		
Referred	100	1.84 (0.32)
Commenced	100	2.01 (0.55)
Speech and Language therapy (SLT)		
Referred	87	3.51 (0.66)
Commenced	85	4.21 (0.21)
Cortical visual Stimulation		
Referred	21	4.69 (0.34)
Commenced	20	5.36 (0.21)

Discussion

This study describes delays in diagnosis and access to rehabilitation among children with cerebral palsy attending a tertiary paediatric centre in Sri Lanka. As this was a tertiary-care clinic-based sample, the cohort may include a high proportion of children with severe motor impairment, particularly GMFCS levels IV and V. Therefore, the findings should be interpreted as reflecting children accessing specialised tertiary services rather than the wider population of children with cerebral palsy in Sri Lanka. Most children were male and belonged to the 2 - 4 year age group, which is broadly consistent with the sex and age distributions reported in previous studies (13 - 20). The majority of mothers had an education level up to secondary school, and nearly half of the families reported a monthly income below LKR 20,000/-, indicating a high representation of families from lower socio-economic backgrounds.

In our study, 59% of children had severe motor impairments, classified as GMFCS IV and V, which contrasts with a Swedish study where only 22% were non-ambulatory (21). Unlike the Swedish study, which found similar GMFCS distributions between males and females, our sample showed differences potentially due to the more focused geographical area. Most of our population had spastic (78%) and quadriplegic (66%) motor types, consistent with other studies (19, 22, 23). Birth asphyxia (45%), was the leading cause of CP in our study similar to an Indian study (52.2%) (19). Postnatal seizures and neonatal jaundice requiring phototherapy were also common causes, aligning with findings from other Indian studies [24, 25]. Pregnancy-induced hypertension was present in 21% of cases, which is lower than in Moldova (20), while gestational diabetes emerged as a potential risk factor, which has been less explored in previous studies. A systematic review of children with CP in developed countries identified birth asphyxia, low birth weight, and hypoglycaemia as key risk factors, which were also found in our study (26). CP was diagnosed at a mean age of 1 year and 4 months in our population, later than in Danish (27) and Australian studies (28), but earlier than in LMICs like Bangladesh, where the mean diagnostic age was 5 years (29).

Developmental delay and stiffness were the main presenting features that raised suspicion of cerebral palsy in this cohort. This finding suggests that many children were identified only after motor developmental concerns became clinically apparent. Other early features, such as feeding difficulties, irritability, abnormal general movements, or sleep-related concerns, have also been described in the literature and may provide additional opportunities for earlier recognition in high-risk infants (30).

Most diagnoses were made by general paediatricians, while paediatric neurologists diagnosed 20.0% of cases and general practitioners diagnosed only 1.5%. This pattern may reflect the tertiary-care setting of the study, where children are more likely to be assessed by paediatric specialists than by primary-care practitioners. However, the low proportion diagnosed by general practitioners is important in the Sri Lankan context, as primary-care and first-contact clinicians may play a key role in recognising early developmental concerns and initiating timely referral.

Delayed diagnosis not only worsens health outcomes for children with CP but also contributes to increased parental stress and emotional burden (31).

Although the General Movements Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE) were not assessed in the present study, these validated tools have been shown to support earlier identification of infants at high risk of cerebral palsy. Their integration into high-risk infant follow-up pathways may be particularly useful in resource-limited settings, where access to advanced neuro-imaging and specialist developmental assessment may be constrained.

In another study examining wait times for therapy services in children with CP, there were similar patterns observed regarding delayed access to specialised therapies. For instance, Novak *et al.*, (2012) found that while physiotherapy (PT) and occupational therapy (OT) were typically initiated relatively early following diagnosis, there were significant delays in referrals and access to services such as speech and language therapy (SLT) and vision-related interventions (32). This mirrors the findings of the current study, where PT and OT

services were initiated promptly, with mean referral ages of around 20 months, closely following the mean age of diagnosis at 16 months. In contrast, SLT and cortical visual stimulation were delayed, with referrals occurring at 3 years and 5 months and 4 years and 6 months, respectively.

These consistent findings across studies highlight the challenge in ensuring timely access to specialised therapies beyond PT and OT for children with cerebral palsy, underlining a gap in service delivery that requires attention. The delays in diagnosis and the start of rehabilitation services in children with CP have serious consequences for patient outcomes and strain the healthcare system. Early diagnosis and timely intervention are vital, especially in resource-limited settings like Sri Lanka. Prolonged wait times for services, such as speech-language therapy and cortical visual stimulation, worsen the situation by delaying intervention and increasing the financial burden on families. To address these issues, targeted strategies such as training for general practitioners, expanding early intervention programs, and improving referral systems are needed. These efforts are crucial for reducing long-term costs and enhancing the quality of life for children with CP and their families. A study across several LMICs, including Bangladesh, Indonesia, Nepal, and Ghana, found that the mean age of commencing rehabilitation services for children with CP ranged from 2 years and 9 months to 3 years and 9 months, though it did not specify particular types of services (33). Similar to our findings, children with visual impairments in these countries were less likely to access rehabilitation services compared to those with speech and motor impairments. Common causes for delayed service initiation included appointment delays, financial issues, and missed appointments. Parental education and financial status were linked to earlier service use in both LMICs (34) and high-income countries (35), though the burden remains higher for children in LMICs. Additionally, factors such as female gender and intellectual impairment contributed to delays in specific countries (34).

This study has several limitations. As it was conducted in a single tertiary paediatric centre using convenience sampling, the findings may not be generalisable to all children with cerebral palsy

in Sri Lanka, particularly those who do not access specialised neurology or rehabilitation services. The retrospective nature of data collection may have introduced recall bias, although clinic records were reviewed to improve the reliability of reported clinical details. The study was primarily descriptive and was not designed to establish causal relationships or independent predictors of delayed diagnosis or rehabilitation. Further multi-centre studies, including community-based and primary-care populations, are recommended to better characterise diagnostic and rehabilitation delays among children with cerebral palsy in Sri Lanka.

Conclusions

This study identified key factors linked to cerebral palsy and highlighted significant delays in diagnosis and rehabilitation. To mitigate preventable risks and improve early detection, stakeholders should implement educational programs for healthcare workers and parents on early CP markers. Addressing referral and service delays is essential to reduce morbidity and improve the quality of life for children with CP. These actions can lead to more timely interventions and better long-term outcomes.

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