

ACCESS TO POST-NATAL CARE AMONG CHILDREN WITH ATHETOID CEREBRAL PALSY: STUDY IN REHABILITATIVE CENTER PESHAWAR

Aymen Imtiaz¹, Eemaz Nathaniel¹, Aimen James¹

ABSTRACT:

Objective: To determine the frequency of access to postnatal care among children with athetoid cerebral palsy and to determine the factors influencing access to postnatal care.

Methodology: It was a cross-sectional study conducted from 1st April 2018 to 31st May 2018 on 100 mothers of children with Athetoid Cerebral Palsy who came for follow-up to Akbar Kare Institute. Data were collected using a consecutive sampling approach through an interview-based questionnaire, which included questions related to access to postnatal care and reasons, including mothers' awareness regarding the importance of early post-natal care, for not accessing postnatal care on time. Descriptive statistics were obtained using SPSS 20.0.

Results: A total of 100 subjects visited Akbar Kare Institute for follow-up. Mothers of patients who have cerebral palsy took part in the study. Mean age of the study population at the time of marriage was 18.6 ± 2.6 years, with a range of 15-25 years. Fifty eight percent of mothers had received education till primary level (class 1-5) while 93% of mothers were living in a joint family system. The decision maker in the family on health matters such as visit to the hospital was not the mother of the child alone but 51% of the time it was the child's paternal grandmother. Fifty-six families had a total monthly income less than Rs.20,000. Among the study participants, 54% did not receive post-natal care. Most of the mothers (89%) reported that they were not aware that the increased bilirubin levels would eventually cause permanent damage to their children.

Conclusion: Women who participated in the study showed insufficient knowledge of and misunderstandings regarding neonatal jaundice, which should be addressed to significantly decrease the harmful outcomes of this common condition.

Keywords: Cerebral Palsy; Rehabilitation center; Mothers; Post-natal care; Kernicterus.

INTRODUCTION

Cerebral palsy (CP) is a group of irreversible or permanent disorders of the maturing of movement and posture causing activity limitation that are caused by no disturbances that occurred in the developing fetal or infant brain¹. The term used to describe the yellow staining of the deep nuclei of the brain is Kernicterus.

It is currently used to describe the neuropathology of bilirubin-induced brain injury and its associated clinical findings. The term bilirubin encephalopathy is designated to the clinical condition associated with an elevated serum bilirubin². Kernicterus is an important cause of athetoid cp.

Early recognition, preventative measures and therapy of hyperbilirubinemia makes athetoid cerebral palsy due to kernicterus a preventable disease. A structured approach to the proper handling and therapeutic management of newborn jaundice is very important. The need for additional measures for its anticipation and prevention has become uncustomary because of increased screening for and prevention of Rh incompatibility which remained a historically significant cause of kernicterus³. However, in Pakistan Rh compatibility and screening for hyperbilirubinemia is still a major cause of kernicterus.

1. Rehman Medical Institute, Peshawar

Address for correspondence:

Eemaz Nathaniel

House Officer, Rehman Medical Institute,
Peshawar

eemazoo64@gmail.com

The American academy of paediatricians or AAP guidelines for the management of neonate jaundice was expected to eliminate severe hyperbilirubinemia. In Pakistan and other developing countries little to no data is available regarding the incidence and prevalence of kernicterus.

It is very important to understand why the incidence of kernicterus causing CP is so high in our country and what can be done to reduce it.

Because it is a burden on parents and the community and poses a public health concern, there is a need for development of strategies and additional protocol for its prevention.

Research on this subject will further emphasize the need for surveillance to describe a population that is at risk, much like identifying a population with diabetes, and generation of reliable data on the prevalence of severe neonatal hyperbilirubinemia which will help to create simpler ways that it can be prevented and controlled simply by screening and or creating awareness among mothers.

It will also allow us to understand how we can apply AAP recommended universal systemic approach to management of newborn jaundice in our developing country in the most efficient way.

This will reduce incidence of severe hyperbilirubinemia using different methods to create awareness and encourage mothers to seek post-natal care on time.

The generation of reliable data on the incidence and prevalence of severe neonatal hyperbilirubinemia and its disastrous outcomes are essential to organization, execution and evaluation of intervention including public policy and educational programs to help create awareness and prevent adverse outcomes.

A study in Denmark from 1994-2002 showed that only 8 cases of kernicterus were reported

for those years, whereas no cases had been reported 20 years prior. After the report, from 2002-2005, a more attentive attitude was used to approach the management of newborn jaundice and no more cases were reported in Denmark ever since⁴.

The objectives of this study are to determine the frequency of access to postnatal care services, the factors influencing it and to establish the knowledge of mothers about the benefits of seeking postnatal care early.

MATERIALS & METHODS

It was a cross-sectional study conducted at a pediatric rehabilitative center Akbar Kare institute (AKI) in Hayatabad, Peshawar, Khyber Pakhtunkhwa. The duration of the study was 2 months, from 1st April to 31st May 2018. The population was children with Athetoid Cerebral Palsy whose mothers gave informed consent to participate in the study. An interview-based questionnaire was used. The questionnaire contained 21 questions including both open ended and close ended questions. A verbal consent was taken from all the respondents before the interview began and they were informed of the professional secrecy that would be maintained. Postnatal care was defined as the care given to the newborn baby after the birth and for the first six weeks of life.

Consecutive sampling technique was used to gather data. Data were collected from those mothers who visited AKI during the study period and consented to take part in the study. SPSS version 20.0 was used for data analysis. Frequencies were determined in terms of percentages and presented in the form of table and graph.

Results:

A total of 100 subjects visited AKI for follow-up. Table 1 shows the demographic parameters of the study population (n=100).

Table 1: Demographics parameters of study population (n=100)

Mother age when married, Mean±SD	18.6 ± 2.6
Mother age when 1 st baby was born, Mean±SD	19.9
Educational Status of Mother, No. (%)	
Primary Education	58 (58%)
Higher Secondary Education	32 (32%)
University	10 (10%)
Gender of the affected Child, No. (%)	

Male	42 (42%)
Female	58 (58%)
Family System	
Joint	93 (93%)
Single	07 (07%)
Decision maker, No. (%)	
Mother	2 (2%)
Father	41 (41%)
Paternal Grandfather	6 (6%)
Paternal Grandmother	51 (51%)
Total monthly income, No. (%)	
10,000 - 20,000/-	56 (56%)
> 21,000/-	44 (44%)
Post Natal Care received, No. (%)	
Yes	46 (46%)
No	54 (54%)

A total of 54 mothers did not visit any hospital facility for any post-natal care. Most (89%) mothers said that they were not aware about the effects of jaundice on neurological development of the baby. Unavailability of the post-natal care services in the area they are living was the reason in 6% cases. The remaining had financial problems.

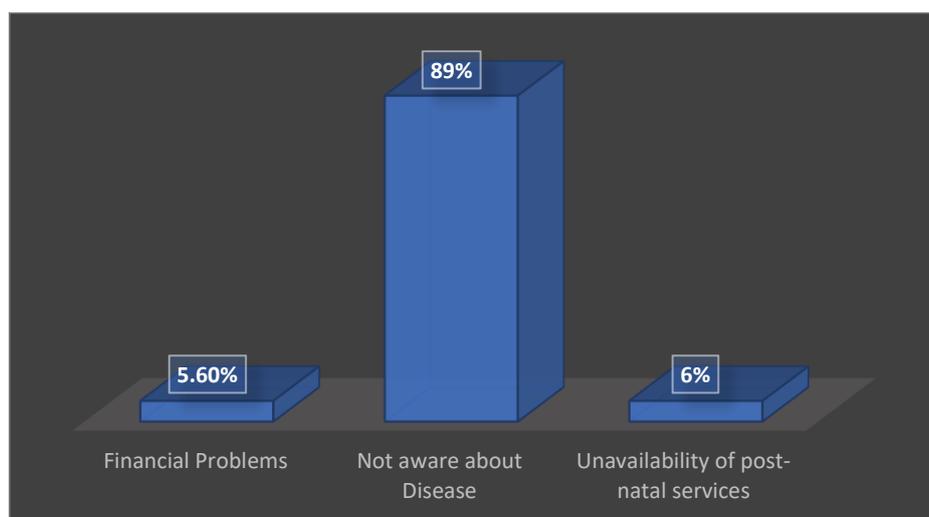


Figure 1: Comparison of the causes for not visiting any hospital facility.

Of the 46 mothers who visited hospital to avail post-natal care services, majority received health care advise from Lady Health Visitor (84.8%). Gynecologist and mid-wife also provided post-natal care to 8.7% and 6.5 percent children, respectively.

DISCUSSION

This study was done to determine the frequency of post-natal care, the factors influencing postnatal care services and to establish the knowledge of mothers about the

benefits of seeking postnatal. To our knowledge this is the first study done in Pakistan that focused on athetoid cerebral palsy in rehabilitative centers in Peshawar. While other countries have researched on athetosis as a

preventable disease no proper study has been done in Pakistan regarding this.

A total number of 100 subjects visited AKI during the study period. Most (54%) of children did not receive post-natal care. The mean age of the study population at the time of marriage was 18.6 ± 2.6 years, with a range of 15-25 years. Consanguineous marriage and early marriage were found to be the significant risk factors in a study conducted amongst Turkish children with CP⁵.

Fifty eight percent of mothers had received education till primary level (class 1-5). A study in India found that knowledge amongst parents about cerebral palsy was grossly insufficient and inadequate. A single public health session or educational lecture can significantly increase parental knowledge about multiple basic knowledge points about cerebral palsy⁶.

Our study found that 93% of mothers were living in a joint family system and only 7% lived as a separate family unit. The decision maker in the family on health matters such as visit to the hospital was not the mother of the child alone but 51% of the time it was the child's paternal grandmother. The mother did not have a say in her child's health, and this may have led to the delay in seeking post-natal care on time, eventually leading to the development of athetoid cerebral palsy.

Majority of the families (56%) had a total monthly income less than Rs.20,000. A study in Bangladesh showed that significantly greater stress levels were found in rural rather than in urban mothers of children with cerebral palsy. To further highlight this, a significant association with land ownership was also found. Those who had at a maximum half an acre of land were more stressed than those who had more land⁷. This points out that rich families could afford a follow up after birth of child and poor families could not.

When asked if mothers knew prolonged jaundice could lead to brain damage, a striking 89% of mothers answered that they were not aware. A study in Lagos, Nigeria showed that only 25.6% participants gave a correct definition of neonatal jaundice⁸. Many of those who did not give a correct definition were from a lower socioeconomic background. In order to reduce significantly the devastating consequences of this common condition, the problem of insufficient and inadequate

knowledge about neonatal jaundice must be addressed

Standard guidelines for evaluating and effectively treating jaundice in term babies include follow-up of all babies for jaundice, monitoring several laboratory tests in which it is discovered to have early jaundice or bilirubin levels more than 12-13 mg/dL, using phototherapy to try to maintain serum bilirubin levels below 20 mg/dL, and exchange transfusions in babies in whom phototherapy fails, irrespective of the cause of the jaundice. When followed these guidelines are highly likely to lead to complete recovery and treatment of majority of jaundiced term infants because most jaundiced infants have no underlying illness or pathology⁹.

CONCLUSION

The frequency of post-natal care was only 54%. Most of the mothers who did not avail post-natal care were not aware of the consequences of prolonged jaundice. We recommend improvement in female literacy and mass health education programs to scale back significantly the complications of this common and easily cured condition. If parent friendly policies and new guidelines with mandatory follow-up early after childbirth are implemented, there will be a significant decline in children suffering from athetoid cerebral palsy.

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