

NICU Graduates- Family And Societal Perceptions

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Abstract

Objective; Determine the Family and societal perceptions about NICU graduates [neonates surviving intensive care] with neuro developmental delay .

Study design; Observational study

Setting; Child Development centre, Institute Of Child Health,

Subjects Parents of 25 children who are attending child development centre

with neuro developmental delay. They had required ventilation for various reasons during the neonatal period

Methods; Parents of 25 children with neuro developmental delay were included in the study Baseline data about their family and index child, awareness and perception of the disability in their child, issues in extended family such as, financial, emotional and physical support and the stigma and discrimination felt in their social circle and by the health care providers were enquired about.

Results; Awareness about neurodevelopmental delay and the need for long term therapy should be emphasized to the family members because the support of the extended family and the society is very important in realizing the full potential of the child with Neuro developmental delay

INTRODUCTION

Every child is conceived with a million dreams in the minds of the parents. When the child has a difficult neonatal period which has resulted in neuro developmental disability, care giving becomes very stressful for the parents especially the mother .The financial burden faced by the parents towards medical treatment and other remedial measures is also considerable. In addition it is a drain on the time spent in taking care of the family and other children. There are also issues affecting their social life.[1,4] With more children surviving perinatal insults the burden on the community is enormous and the role of a doctor does not end with just salvaging these neonates. This study was performed with the aim of determining the Family and societal perceptions about NICU graduates with neuro developmental delay.

SUBJECTS AND METHODS

Parents of 25 children who had required ventilation for various causes and were attending child development centre

with neuro developmental delay were enrolled in the study after obtaining consent. They were informed that confidentiality of their information would be maintained. Baseline data about their family and index child like age, sex, religion, order of birth, rural/urban residence, age, educational qualification and occupation of parents was obtained. They were asked about the awareness and perception of the disability in their child, time of diagnosis, how their emotions were on knowing that the child had a neurological disability and how the disability was managed so far They were also asked about the level of the handicap and how dependent the children were in performing their daily activities .Issues in extended family such as, financial, emotional and physical support and the stigma and discrimination felt in their social circle and by the health care providers was enquired about. Regarding, the family dynamics they were asked about the perceptions of the immediate family members including how they cared for their normal children. Finally they were asked about how

they were coping with the problem and how they perceived their child's future to be.

RESULTS

There were 15 male and 10 female children in the study group ranging from 6 to 12 months of age. Majority of them were Hindus and of the 1st order of birth. While 16 children were from the city, 9 were from the rural suburbs.

17 children were part of a joint family, while 8 belonged to nuclear families. Most children were conceived of a non consanguinous marriage. 20 parents claimed that their child was the first one with a neuro developmental disability among their family members.

Only 13 parents said that they were informed about the risk of neurological handicap during ventilation. The other parents knew about the neurological impairment at the time of discharge or during their subsequent follow up visits.

Their response on knowing that their child was going to have a permanent neurological problem varied from acceptance in 6 parents, denial in 4 and extreme sadness and depression in 7 and anxiety in 6 parents. Only 2 mothers complained of feeling guilty about their child's condition.

Steps taken by the parents included taking the child to the rehabilitation centre in 21 cases. While 2 were giving physiotherapy at home, 2 stopped giving therapy when they did not notice any improvement.

Except for 6 children, 19 of them were reported to have improved with treatment. In all cases it was the mother who was taking the child for therapy. While 14 mothers claimed that their extended family was supportive, 6 said they were blamed for the baby's condition and 5 mothers felt that their in laws were indifferent.

3 families felt that their relationship with their spouses was strained while the others enjoyed a supportive environment at home. When the siblings were asked about the situation at home, some siblings resented the importance shown to the special child and the extra time spent on them

Except for 3 mothers all others felt the discrimination by their relatives. This had hampered their social activities. All mothers having other siblings claimed that they were giving equal attention to the other siblings. While 8 mothers who had only one child were planning on the next one, 9 others did not want another child till this child became better.

Since some mothers had to travel long distances to reach

their therapy centre, they felt the need for more rehabilitation centres in the vicinity of their place of residence.

DISCUSSION

The burden associated with the upbringing of children with special needs is enormous. Problems like disturbance of - routine, family health, social life, as well as the finances of the economically deprived family make it difficult for them to cope as well as give their best to the affected child.

There was no major difference in the upbringing of these special children whatever the background of the parents. But there was a difference in their attitude towards these children when societal pressures increased. One mother refused to take the baby off the ventilator despite knowing that her child will have a neurological impairment and despite family pressures. Her family accepted her and her child with special needs only after a year.

There was an impact on marriage as well as in house relationships as shown by Vidhya et al.[2] The more dependent the child, the more adverse was his effect on his siblings, The more the responsibility required by the normal siblings (particularly girls), the less likely the special child was welcomed into the fold by his brothers and sisters.[3]

All parents felt stigmatized by the society including the extended family members as shown by previous studies [3,4] It is therefore mandatory that grandparents be included during counselling sessions at discharge so that they would be aware of the magnitude of the problem and would also be supportive to the parents especially the mother who carries the entire burden most often.

The need for more rehabilitation centres cannot be overemphasized. It was heartening to know that in Block PHC'S Physiotherapists are available to cater to the population of that sector and transport is also made available for these children with special needs. This will certainly go a long way in reducing the impact of neurological impairment. It is important that decision-makers, health-insurers and healthcare providers are aware of the total clinical, financial and emotional burden borne by parents at this critical time in the parent-child relationship. At this moment evidence is missing to convince decision makers of the seriousness of parents' perspective [6] Providing holistic, family-centered, developmentally supportive care and open communication with parents in this stressful experience is essential.[7]

CONCLUSION

Awareness about neurodevelopmental delay and the need for long term therapy should be emphasized to the family members because the support of the extended family and the society is very important in realizing the full potential of the child with special needs

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