International Journal of Contemporary Pediatrics
Adhikari KM et al. Int J Contemp Pediatr. 2019 Sep;6(5):1782-1788
http://www.ijpediatrics.com
pISSN 2349-3283 | eISSN 2349-3291

DOI: http://dx.doi.org/10.18203/2349-3291.ijcp20193700

Original Research Article

Risk factors in relation to neurological morbidity in children: a study on perception of health professionals and parents

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Received: 07 August 2019
Accepted: 19 August 2019

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ABSTRACT

Background: Morbidity resulting from various neurological illnesses is a common reason for seeking regular help from health care facilities. There is increased requirement of awareness about neurological, psychiatric, physical, and developmental disorders in the community. Present study was undertaken to assess the community awareness and perception of risk factors for neurodevelopmental disabilities in children.
Methods: The study was conducted with an objective of finding out level of awareness of a group of young health professionals and parents regarding their perception of likely factors that contribute for the occurrence of neurodevelopmental disabilities. This was a cross sectional study with discussion between the participants of various groups by using the method of Focused Group Discussions. Perceived risk factors as emerged during the discussions were free-listed and categorized under Biological/Familial/Genetic factors, Environmental factors, Socio-cultural factors and Economic/ Financial factors.
Results: Lack of prenatal care, prematurity, unaffordability of care, low birth weight, malnutrition, infections and lack of maternal education emerged as important risk factors for neuromorbidity as perceived by the participants. Participants also enumerated insufficient knowledge on preventable risk factors, lack of trained manpower and neglect of female children as important contributors to occurrence of developmental disabilities.
Conclusions: It is of paramount importance to identify the community perception of the risk factors for developmental disability which gives us an estimate of awareness among people and caregivers. Interventions tailored to the needs based on the level of community awareness help us in better channelling of preventive programmes and strategies.

Keywords: Community perception, Developmental disability, Focussed group discussion, Health professionals, Neuromorbidity, Risk factors

INTRODUCTION

Morbidity resulting from various neurological illnesses is a common reason for seeking regular help from pediatric out-patient department (OPD) services. Most of these morbidities come to attention due to disability at various spheres of children's development. Many of these disabilities are amenable to identification and treatment at pre-natal and antenatal period, where as a host of them come to attention only after significant disability has already set in, making early screening and identification an important component of ambulatory pediatric care.

In children, static neurological disorders like Cerebral Palsy (CP) pose considerable diagnostic and therapeutic challenges to the caregivers. The degree of involvement may range from mild with minimal disability to severe, associated with many co- morbid conditions.[1] Epilepsy is probably the most common disorder seen by pediatric neurologist.[2] Acquired conditions like meningitis,

encephalitis and neurocysticercosis are the common cause of seizures in childhood. Morbidity after ever-increasing road traffic accident and other types of trauma pose additional and constant burden on existing plethora of diseases that result in permanent neurological disability. With availability of better facilities in relation to imaging and metabolic screening, more and more children are diagnosed with tumors, neurodegenerative conditions, neurometabolic disorders and vascular abnormalities.

In developing countries, regular OPD services catering only for neurology cases in pediatrics are very few. This may result in irregular follow-up. These children may not get the proper attention and management as most of them need detailed periodic evaluation to assess benefit of particular intervention. This is not only time consuming but may not be feasible in the absence of regular neurology services. With improvement in child survival, there is spurt in awareness of the widespread incidence of neurological, psychiatric, physical, and developmental disorders. Unfortunately, there is relatively limited understanding about burden of developmental disabilities and their causative factors in these children. Keeping these issues in mind the present study was undertaken to assess the community awareness and perception of risk factors for developmental disabilities in children.

METHODS

This study was conducted in the Pediatric Neurology OPD of a tertiary care center in the year 2007-2008 at Maharashtra, India. Main aim of this study was to assess the community perception of risk factors for the developmental disabilities in children. The study was conducted with an objective of finding out level of awareness of community regarding the risk factors and their perception of likely factors that contribute for the occurrence of developmental disabilities.

This was a cross sectional study with discussion between the participants of various groups by using the method of Focussed Group Discussions (FGD). The FGD was conducted on the topics related to risk factors for neurological morbidity in children.

Inclusion criteria

It was decided to have four sessions of FGD. The characteristics of the groups included for the four sessions of FGD are given in the Table 1.

Group 1 consisted of personnel who can be put under the category of health workers. These were the professional assistants who helped in day to day patient care of our hospital. Most of them had completed their graduation through correspondence course after joining the hospital. Group 2 involved students who were about to begin their internship. Authors selected them in place of practicing doctors to sensitise them on developmental disabilities and to judge their level of understanding on this subject. They were also very enthusiastic to participate in the FGD. Group 3 had ladies who work in the outreach program of this tertiary care center at an adopted village. This group had constant interaction with parents in the rural areas and they were likely to tell the feelings of the rural population whom they serve. Group 4 included parents of children who visited our Pediatric/ Pediatric neurology OPD and consisted of 05 mothers and two fathers.

Table 1: The characteristics of the groups selected for the four sessions of FGD.

Group characteristics	Total number of participants: included after consent
Health workers- professional assistants of the hospital	7
Doctors- students of the attached medical college who had finished their final exams and were doing internship	8
Peripheral level health assistants equivalent to anganwadi workers- personnel who work for an outreach programmed organized by the medical college at a nearby village	9
Parents who visited the pediatric neurology OPD of the hospital	7 (05 mothers, 02 fathers)

The counseling room of the Pediatric OPD in the hospital was used for the conduct of FGD. The room is spacious, has arrangements to seat 15 people at a time with facilities for recording and even for showing short video films. Profile of the participants was recorded before the commencement of the FGD. The participants were briefed about the objective of the study after giving a brief introduction on the topic. Participants were encouraged to discuss freely all the issues they felt contributory for the problem of neurodevelopmental morbidity. They were told that there are no right or wrong answers and each one's opinion was valuable. Two post graduate residents, one of whom knew local language recorded the proceedings of the discussions. Discussion was allowed to progress in correct perspective and was interrupted only on deviation. Each FGD was

conducted till repetition was noted and till no fresh points were forthcoming. Sociogram of the group for the duration of discussion was drawn. Participants were thanked and the same session was used to give a small health education lecture on prevention of neuromorbidity, particularly conditions like hypothyroidism, head injury, infections and role of periconceptional folic acid and multivitamin supplementation. After detailed analysis of the transcription, free listing of the responses was carried out. Appropriate code was assigned to free listed observations and logbook was prepared for easy summarization of the data. Important quotable quotes were recorded by free listing for inclusion during discussion (which appear within "quotes" in the discussion). Results were tabulated and risk factors brought out by the participants were assigned appropriate category. Ambiguous and inappropriate terminologies beyond the scope of the proposed study were dropped. The free listed items were further assigned into four major categories. The categories were Biological/Familial/Genetic factors, Environmental factors, Socio-cultural factors and Economic/ Financial factors.

RESULTS

The enthusiasm by the groups during FGD and the willingness to participate in the discussion was really praiseworthy. Few parents actually became quite emotional towards the latter part of discussion when they started highlighting the difficulty experienced by them in getting even the basic care that is due for their challenged children. There were total of 31 respondents and some respondents were able to describe multiple risk factors, while few others were able to tell only one or two risk factors. These were noted as mentioned in methodology. Important risk factors perceived by respondents under the biological, familial and genetic factor domain are given in Table 2. Out of many risk factors, premature birth, low birth weight and abnormal brain development were felt as top three causes of neurological morbidity.

Table 2: Sub-domains noted under biological and genetic factors.

Biological, familial and genetic factors	Total respondents (n=31)
Risk factor	**No of respondents**
Premature birth	12
Low-birth weight	11
Abnormal brain development	10
Newer infections like HIV/AIDS	9
Birth asphyxia	8
Some defect in one or both parents	8
Infections like polio, malaria and TB	5
Visual and hearing defects	5
Family member with disability	4

Important risk factors described by respondents under the environmental factor's domain are given in Table 3. Out of all these lack of supplements to mother, improper maternal nutrition and toxins in food, water and atmosphere were perceived as important risk factors.

Table 3: Sub-domains noted under environmental factors.

Environmental factors	Total respondents (n=31)
Risk Factor	**No of respondents**
Lack of supplements	14
Improper maternal nutrition	10
Toxins in food, water and atmosphere	8
Drugs consumed by mother	6
Lack of iodized salt	4
Lack of essential elements in the diet	4
Accidents/ Injury	3
Non-availability of safe water / sanitation	2

Table 4: Sub-domains noted under socio-cultural factors.

Socio-cultural factors	Total respondents (n=31)
Risk factor	**No of respondents**
Lack of access to health care	18
Lack of proper antenatal care	16
Lack of trained manpower	13
Unattended deliveries	12
Illiteracy among care givers	9
Lack of awareness of risk factors and preventive measures	9
Others(Lack of family support, psychological stress, neglect of female children and not feeding colostrum to babies)	11

Table 5: Sub-domains noted under financial and economic factors.

Financial and economic factors	Total respondents (n=31)
Risk Factor	**No of respondents**
Not able to afford care	18
Poverty	17
Apathy from the government	11
Lack of transport and other infrastructure	10
Maldistribution of resources	2

Risk factors brought out by respondents under the socio-cultural domain are given in Table 4. Lack of access to health care, lack of proper antenatal care and lack of

trained manpower were felt as important risk factors by the various groups of community. There were many other sociocultural risk factors were brought out during FGD.

Factors highlighted by the participants of these FGDs under the major domain of financial and economic issues are given in Table 5. Unaffordability, poverty and apathy of government were perceived as top three out of many risk factors.

DISCUSSION

The study brought out important components regarding perception on risk factors for neuromorbidity in children with most of the participants from all the four major groups bringing out issues needing intervention. Premature birth as one of the main risk factors was brought out by majority of the respondents. Neonatal insults and events around birth are considered to be one of the important factors that determines neuromorbidity with consequent developmental disability.[3] Respondents felt that "premature birth is almost invariably associated with some degree of disability which may come to notice later in life". Low birth weight babies are also at increased risk for various perinatal problems compared to babies with normal birth weight and respondents came up with this response very promptly. Consistent associations have been demonstrated between consanguinity and developmental disabilities.[4] Responses like abnormal brain development, some defect in one or both parents and family member with disability were voiced by few respondents, which links indirectly consanguinity with likely possibility of being born with some defect.

Nine participants came out with "infections like HIV" as important contributors to neuromorbidity. This is one of the most impressive and sound observation by the participants. Few children with HIV infection may survive up till school age and may be victims of developmental disabilities of various magnitude due to their predisposition for sepsis, CNS infection and degenerative processes and side effects of antiretroviral therapy.[5] HIV per se can cause neuro-cognitive decline and along with their susceptibility to a host of CNS infections, this could cause more havocs in low-income countries like ours.[6] Though maximum respondents who gave HIV/AIDS as a response were interns, it was encouraging to see few parents and health workers also addressing this issue.

Infections like polio, malaria and tuberculosis as risk factor for developmental disabilities were suitably brought out. "Many of these infections can kill the child and even if the child survives, he may be left with disability" as told by a parent whose baby was diagnosed as a case of sequelae to tubercular meningitis. Along with stroke due to sickle cell disease, cerebral malaria is one of the important causes of brain insult with disability in African countries.[7] Even in non-fatal cerebral malaria, morbidity with cognitive deficits are common findings.[8,9] Malaria during pregnancy can cause IUGR and low birth weight with increased risk for disability.[10,11] One Kenyan study even demonstrated speech and language disorder in children of cerebral malaria even after two years of illness.[12] Post-natal infections like measles, polio, acute bacterial meningitis, tubercular meningitis and encephalitis can result in significant disabilities.[13] Common infection like acute bacterial meningitis can result in cognitive deficit, deafness and motor disabilities which has significant bearing on the burden of developmental disabilities.[14] Participants may not be aware of these sound evidences; however, it was encouraging to note these factors addressed suitably during the FGDs.

Difficulties during birth, home deliveries and other factors that predispose to birth asphyxia are significant contributors to developmental disabilities.[15-17] "Failure to breathe or delayed breathing in newborns", as told by few participants implies the awareness of community on detrimental effects of birth asphyxia on subsequent child development. Defects of vision and hearing have significant bearing on overall development of every child. Any disease that affects these sense organs can result in considerable permanent disability.[12-14,18] "Though physically normal, children who are deaf and blind are not able to lead a normal life" was an important comment by two participants. Issue of congenital infections and sexually transmitted diseases as risk factor was mainly addressed by group of interns and evidence in literature are clear for the cause and effect relationship of congenital infection and developmental disabilities. [6,19,20]

It was very encouraging to note many respondents bringing up the issue of lack of supplements during pregnancy as one of the important risk factor for developmental disability. There are many countries in the world where problems related to vitamin A deficiency are well known.[21] Role of iron deficiency in the causation of cognitive deficits, even when subclinical, resulting in developmental disability is a well-established fact.[22] Relationship between folate deficiency and neural tube defects is a widely studied entity with worldwide practice of periconceptional folic acid supplementation.[23] There is no doubt that lack of few supplements during pregnancy could lead to many conditions that have significant bearing on the development of disability. Continued awareness of these and efforts to reduce their adverse impact can substantially lessen the burden of neuromorbidity that have developmental consequences.

"Insufficient and improper maternal food intake during pregnancy and lack of essential elements in the diet" was brought out as an important risk factor by participants. This translates into possible deficiency of essential factors in the diet that are described in the previous paragraph. "Dangerous substances in the food, water and atmosphere and maternal drug exposure" could also be considered to have considerable impact on fetus and baby with developmental consequences. Environmental toxins

like lead; even at low level can have huge impact on the overall development of the child.[24,25] Though industrialization and rapid economic progress has pollution and increased exposure to toxins as an in-built disadvantage, at least unnecessary drug exposure can be prevented by judicious use during pregnancy. Few participants, mainly the interns, addressed "Lack of iodised salt and various types of injury, particularly head injury". Cretinism resulting from reduced maternal iodine is an important cause of preventable mental retardation with developmental implication all over the world.[26] Increased dissemination of this information to prospective mothers in all the developing countries would go a long way in reducing the developmental disability in their offsprings. Non-fatal injury including minor head injury can result in significant neurological deficit with impact on development.[27,28] Injury prevention advice should be an integral part of all ambulatory pediatric care services.

"No country can hope to have improved medical outcome unless proper pregnancy health checkups and access to suitable health care facilities are provided to majority of these poor population" was a strongly conveyed statement by many participants and they went about stressing the importance of these factors repeatedly. There are enough evidences in literature also to support their feelings. Lack of prenatal care, birth difficulty, home deliveries and lack of maternal education were noted to be associated with developmental disabilities, with major impact on cognitive development.[15-18] Participants of all the FGD groups surprisingly and aptly enumerated illiteracy among caregivers at villages, insufficient knowledge on preventable risk factors, lack of trained manpower and neglect of female children as important contributors to occurrence of developmental disabilities.

"All the advanced facilities are concentrated in the cities and many cannot afford the cost there" was the emotionally charged statement given by various participants, particularly towards the end of FGD sessions. Socio-economic gradients in a country and their impact on developmental disability in the under privileged population is an established and it is quite logical even to presume this association.[16,19,24] Poverty can be the root cause of many other risk factors.[30] There has been little change in the death rates of children of manual labourers, despite scientific and economic advances in the developing countries.[31] These major areas brought out by the participants highlights the fact that strong political commitment to improve the overall living conditions of the resident population in a country is the need of the hour at global level.

It is obvious after the analysis of these risk factors that these population was quite aware of areas that need to be tackled to reduce the burden of neuro - morbidity even 10 years back. The major problem area is to bridge the gap between this awareness and implementation of preventive strategies based on the available knowledge. Some factors like poverty, illiteracy need commitment and effort from national leaders to common man alike. Few other areas like provision of basic antenatal care, provision of adequate supplements and prevention of infections and widespread coverage of vaccination can be easily attained by all with little motivation. Eradication of measles and malaria is another attractive avenue feasible. Iodisation of the salt with widespread usage of such product would reduce the mental retardation substantially in susceptible children. Vitamin A supplementation has proved its worth beyond doubt.[31] Drive to fortify food with folate have contributed to phenomenal decrease in neural tube defects and other congenital abnormalities.[32] Oral rehydration therapy has resulted in reduction of mortality and morbidity due to shock in children.[33] Low-cost, locally fabricated assist devices have reduced disability due to defective vision.[34] Opportunities to reduce the contributing risk factors and improve the outcome abound. There is strong need to translate the knowledge on these risk factors into easily implementable preventive strategies.

Main shortcoming of this study is that the three out of four groups were in medical profession with access to health education material during day-to-day work and periodic training sessions are taken for ambulance assistants and other health care workers. This could have influenced the outcome as most of the risk factors were aptly highlighted. Involving more numbers of parents and general OPD population would have been better determinant to assess the community perception of risk factors for developmental disabilities. Though the factors that emerged during the discussion date back to a decade earlier, they are relevant even today and re-emerging/emerging infections and toxin influences of modern industrialization are the proof for such relevance. Awareness and community perception of various risk factors appears to be quite sound; the daunting task is to address the issue of intervention strategies to reduce the developmental disabilities.

To conclude, morbidity resulting due to neurological illness or other diseases are common and residual effects of these can lead to various degrees of developmental disabilities. There are a host of risk factors that contribute to developmental disabilities in the society. It is of paramount importance to identify the community perception of the risk factors for developmental disability which gives us an estimate of awareness among people and caregivers. This will help us in better channelling of preventive programmes and strategies. Knowledge and awareness in the community help to welcome the preventive initiatives. Bridging the gap between the awareness and implementation of the preventive initiatives needs periodic assessment of clientele perception utilizing large community based approaches involving participants from all sections of society.

ACKNOWLEDGEMENTS

Authors would like to thank the efforts of Post graduate residents and OPD staff of our all the help in conducting the sessions of FGD and for record of observations and creating the sociograms for analysis after FGD.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Adhikari KM, Bhandari A. Risk factors in relation to neurological morbidity in children: a study on perception of health professionals and parents. Int J Contemp Pediatr 2019;6:1782-8.