

Knowledge, Attitude and Awareness Among Parents Regarding Developmental Disability and Early Intervention

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Abstract

Background: Developmental disability due to neurodevelopmental disorders (NDD) are major public health problems globally. Developmental delay can be an early indicator in identification of children who may experience a disability. Early intervention (EI) programmes support these young children who are at risk of developmental delay. Early diagnosis and early intervention, becomes very important measure in preventing disability among these children hence parent's awareness regarding the developmental disability and early intervention becomes the prime indicator towards seeking timely healthcare service. So this study aimed to check the level of awareness and knowledge among parents regarding developmental disability and early intervention.

Materials and methods: Seventyseven parents and caregivers of infants and children who were either at risk of developmental disability or diagnosed with developmental disability were interviewed through a structured questionnaire to understand their knowledge, attitude and level of awareness regarding developmental disability and early intervention.

Results- This study observed very poor level of knowledge about the developmental disability (26%) and limited awareness regarding early intervention (8%) among parents. knowledge among healthcare professional regarding role of early intervention was also scarce.

Conclusion: Overall knowledge and awareness regarding developmental disability and early intervention was very poor among parents. Incidental finding of limited level of awareness among the healthcare professionals was also noted influencing timely referral and health seeking behavior among the parents for early intervention.

Keywords: Developmental disability, Early intervention, Developmental delay, Awareness

Introduction

Neurodevelopmental disorders (NDDs) causing developmental disabilities are significant global public health issues, especially in lower and middle-income countries (LMICs)¹. One to three percent of children worldwide are said to have developmental delays². A recent community-based multicentric study carried out in India in 2018 found that among children aged 2 to 9 years, the average prevalence of neurodevelopmental disabilities was 12%³. Nearly 2.3 million Indian children under the age of six are thought to suffer from a developmental disability of impairment.⁴

Poor birth outcomes, insufficient stimulation, starvation, persistent illness and other organic issues, familial and psychological circumstances, and other environmental factors can all contribute to developmental delays. Even though developmental delays are not always permanent, they can be used as a basis to identify kids who might have disabilities¹.

Developmental surveillance is a systematic approach to identify and keep an eye on infants and children who pose a high risk. Absence of screening results in worse prognosis, more health service utilization, increased morbidity and parental distress, delayed detection, and early intervention initiation. The American Academy of Pediatrics (AAP) advises routine screening of low-risk children at 9, 18, and 24/30 months or earlier if concerns are raised, and developmental surveillance of high-risk children at every health visit from birth to three years.⁴

Programs known as early childhood intervention (ECI) or early intervention (EI) are intended to assist children who have been diagnosed with developmental delays or disabilities or who are at risk

of developing later than expected. To guarantee and improve children's personal development and to encourage families and kids to be socially included, early childhood inclusion (ECI) offers a variety of services and supports. It includes specialized services that can be provided at an early intervention center or rehabilitation center, like physical habilitation (like developmental therapy and assistive devices) and family-focused support (like training and counseling). Understanding the importance of early diagnosis and intervention, parental/ caregivers knowledge becomes the major indication of obtaining timely healthcare services for screening, diagnosing, and intervening in the prevention of developmental impairment.

The purpose of this study is to assess parents' awareness and understanding about developmental disabilities and early intervention.

Study Method

This was a cross-sectional research conducted on parents and caregivers of newborns and children who were either at risk for developmental impairment or had been diagnosed with developmental disability. All the parents who visited the early intervention unit at the study center first time either referred by pediatrician, neonatologist or parents who came directly to the study center without reference were included in the study. The parents who were already visiting on regular basis for therapy of their children prior to initiation of study were excluded from the study because the study centre incorporates parents education regarding the developmental disability and need of intervention on regular basis as the first line of management. So, including those parents might

influence the study outcome. The study lasted for one year, and the sampling approach used was a thorough enumeration of all parents of children with developmental delays who visited our early intervention program for the first time throughout the study. After describing the goal of the study and obtaining informed consent, all participants were questioned using a structured questionnaire that had been designed and verified for its content and face by a team of ten professionals including a pediatrician and a physiotherapist. The questionnaire consisted of question related to demographic data of the parents/caregivers, basic formal educational status of respondents, probable reasons for developmental delay through various events during and after birth indicating risk for developmental delay, few leading questions related to knowledge of developmental disability, their attitude towards disability, awareness about early intervention, role of physiotherapy professionals in early intervention, and few questions related to their interest in being part of awareness program towards prevention of disability.

Ethical clearance and considerations

Research Ethic Committee of Study Institute granted ethical permission. The participants attested to their desire to engage in the study by signing a written informed consent form. Through cultural awareness and respect for the participants' ideas, the interviewing writers made sure that the participants suffered no emotional or social harm. Transparency was always maintained by making sure there was honest and open communication with the participants.

Analytical Statistics

Version 15 of the SPSS statistical program was used to analyze the data. A summary of the variables was obtained using descriptive statistics. Every categorical variable was summarized using frequency and percentage.

Results and discussion

The purpose of this study was to assess the level of awareness, of knowledge, and attitude toward developmental disability and early intervention among parents and caregivers of children with neurodevelopment issues.

Total 77 parents and caregivers participated in the study. The study centre was located at a semi-urban area which included the mixed population of educated as well as uneducated community with predominance of villagers from nearby areas of 60 km radius. The mean age of the respondents was 30.14 years, with a standard deviation of 7.8years. The majority of participants were young, indicating an early stage of parenthood. Median age of child was 9 months with IQR ranging from 7 to 17 months. This indicates that child was hardly exposed to therapy at very early of 0-3 months which could be indirect indicator of lower level of awareness. Ideally, risk factors are identified as early as during birth indicating need for neurodevelopment therapy within 3 months of birth to get better outcome. If we look at the educational status of the participants, it was observed that 11.7 % were educated till primary school, 22% of the participants were educated till high standard. 44.2% were educated till graduation. 18.2% underwent professional education. We observed in our study that irrespective of higher percentage of participants with graduate level of education, the awareness status about neurodevelopmental problem was poor indicating the need to educate the community. The lesser number of participants with professional education could be due to location of study centre which was semi urban with majority flow of patients from rural area.

Among the distribution of participants it was observed that majority were mothers (49.4%), 45% were fathers and only 3.9% were grandparents of the child. Most of the study participants were homemakers (46.8%) and 33% were in some form of job. This

indicates the need to educate the females regarding neurodevelopmental disorder and disability. Also, they are ones who spends maximal time with the child so they would be the best person to identify any deviation from normal development if trained and educated for the same.

The main etiological factor behind the developmental issues in our study was birth asphyxia (51.9%) other etiological factors like seizures, postnatal sepsis, LBW and respiratory distress in combination or alone contributed to 16.9%. In our study, 74% of the respondents were not aware that the problems mentioned above during or immediately after birth can affect child development in terms of gross motor, fine motor, social milestone etc. This could be related to poor knowledge and understanding about disability. Educational status can also effect awareness level⁵. This could be attributed to the respondents' average educational level, as the majority of them finished pre-university. Majority of the Participants (68.8%) in our study were also not aware that above problems can cause disability in their child.

When participants were asked about early intervention, 92.2% were not aware about early intervention or physiotherapy intervention in the children for above issues or role of physiotherapy in preventing risk of disability. The first line of contact for any illness or development milestone among children is pediatrician. Many of the participants were never directed by pediatrician to consult a physiotherapist; also the concept of early intervention in the nearby areas of selected study centre was surprisingly new. We also observed during our study that the knowledge among healthcare professional regarding role of early intervention was scarce. This was the indirect observation based on the respondents reply saying "Doctor has told that child will be absolutely alright with age and just gave calcium supplements/multivitamins" inspite of clear history of birth asphyxia and clinically presenting as severe spastic or hypotonic with poor gross motor function as per age. During our study it was noted that few parents (30%) were directed for physiotherapy treatment timely however due to majority of under qualified and un-experienced professionals in the nearby rural and semi-urban area of selected population the parents were deceived and precious time were lost where many components of motor/sensory development could have been targeted and achieved.

It was surprising to know that people were ignorant about physiotherapy profession. 92.2 % of participants heard about physiotherapy for the first time when they were referred or directed. Many of them came across the professionals first time during the course of the treatment of their child. In order to understand their readiness and concern for treatment options, we enquired about their willingness to participate in education program. Almost all the participants showed their interest in knowing further about the profession and the problem their child is facing so that they can educate their relatives and neighbors about the same.

In our research, we attempted to study the attitude of respondents too. Despite of the study location at semi-urban area it was observed that 90.9% of the respondents were not feeling embarrassed or tried to hide the child to avoid people labeling their child as disabled which shows that social stigma is not prevailing among the population. This is very positive and motivating factor and we can anticipate a successful education program if conducted in future. It can be presumed that if sufficient education is given regarding timely identification of the neurodevelopmental issue, early intervention can be initiated and disability can be prevented.

Limitation

Despite this is the first study about evaluation of awareness, knowledge and attitude among parents regarding developmental disability there are few limitations. Firstly, Though the study centre

is a super-specialty centre the study has been delimited to one centre. Conducting such research in different sections of the state/country would assist to clarify the legitimate picture of insight and perception. Second, we need to survey a huge population to understand the need for rehabilitation services and contribute to successful policymaking

Conclusion

This study highlights that the overall awareness and knowledge regarding developmental disability and early intervention is very poor among parents. Present study also reported incidental finding of limited level of awareness among the healthcare professionals which influenced the timely referral and health seeking behavior for early intervention. This research supports the necessity for the sensitization and advocacy strategy to address physiotherapy as an early intervention possibility for high –risk neonates.

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