Parental Perceptions Influencing the Utilization of Early Intervention Services in Children with Developmental Delay

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Abstract

Introduction: Early intervention services play a pivotal role in the management of children with developmental delays but the utilization of these is quite low. This study aims to explore the influence of parental perceptions on the utilization of these services. **Material and Methods:** This is a hospital based qualitative study of 31 parents having children with developmental delay in 2 or more domains who presented for the first time for diagnostic evaluation. A semi-structured questionnaire was used in the interviews, exploring various aspects of parental perceptions regarding the child's disability and the services required for them. **Results:** Apart from factors like educational and socioeconomic status of parents, accessibility of the services there are other factors involved at the level of parents which influence their readiness and motivation to utilize a service, viz understanding of the total spectrum of a child's disability by parents and how well their child care needs are fulfilled. **Conclusion:** The parents' long term motivation for utilizing the services depends upon how well their idea of a futuristic goal for their child is being addressed.

Key words: developmental neurosciences, rehabilitation, paediatric neurology, growth, development, child health.

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Introduction

Developmental delay occurs when a child exhibits a significant delay in the acquisition of milestones or skills, in one or more domains of development (i.e., gross motor, fine motor, speech/language, cognitive, personal/social, or activities of daily living). Global developmental delay (GDD) is defined as a delay in two or more developmental domains. In India, sources have found prevalence of 1.5-2.5% of developmental delay in children under 2 years of age[1].

As regards the management of these children with developmental delay, the importance and the benefits of early intervention services cannot be underscored. Early intervention services involve a multidisciplinary approach consisting of a psychiatrist, clinical psychologist, physio-occupational therapist, speech therapist, social worker and a special educator to promote greater achievement of functional potential in all activities in these children[2,3]. But the real benefit lies in the full and appropriate utilization of the available services. In our country where basic intervention services like childhood immunization programs are underutilized[4], ensuring utilization of early intervention services for developmental delay is a big challenge. More so over, the success of these programs depends upon their acceptance by the parents or family members (decision makers).

Till date, studies done on the utilization of rehabilitation services in children with disability in 1 domain in India have shown high rates of non-utilization with poor perceptions about disability[5,6]. Situation gets much more complicated with less specific disorders like global developmental delays where multiple interventions are required to enhance skills across multiple domains as an ongoing process individualized for each child[3].

As a part of the management of children with disability, many steps have been taken by Ministry of Social Justice and Empowerment and Ministry Of Health and Family Welfare. In 1992, Rehabilitation Council of India was formed. In 1995, the Persons' with Disability Act was passed and then BIWAKO Millennium Framework was adopted to make provisions for early interventions in cases with developmental delay[7]. Since 2013, RBSK (Rashtriya Bal Swasthya Karyakram) has been endorsed by the Government of India as a comprehensive observation scheme for early identification of developmental delays. DEICs (District Early Intervention Centre) have been set up in order to provide referral support to children detected with these health conditions up to 6 years of age[8].

But the effectiveness of any program that is conducted within a community is influenced by numerous variables. Low participation rates are a frequent dilemma of the intervention programs causing diminished effectiveness of the benefits intended[9,10,11].

In order to make any intervention service a success, it is very essential to understand the perceptions of the population to whom they are intended, their individualized requirements and expectations as well as their limitations which can act as barriers to the utilization of such services. Challenges involving the utilization of early intervention services are unique in the sense that multiple interventions are intended towards the population which is different from the population that finally decides the utilization of services recommended.

There are many factors working at the level of child (benefit receivers), parent (decision makers) and service delivery that influence the utilization of services. At the level of the child, the age at presentation and the characteristics of his/ her impairments; at the level of the parents, their education and socioeconomic status; at the level of service delivery, the accessibility play a very important role.

In India, there is a paucity of evidence on the utilization pattern of early intervention services for children with developmental delay. The objectives of this study were to assess the utilization pattern and the factors influencing the utilization plan of early intervention services at the level of parents.

Material and Methods

This study was conducted on the parents/family members of a consecutive cohort of 31 children less than six years of age with developmental delay in various domains who visited the Paediatric O.P.D. of a Postgraduate Teaching and Research Institute for the first time for diagnostic evaluation between Jan - Dec 2016. The study was approved by the institutional ethical committee. The assessment of all the children, diagnosis making, and plan of management and interview of the parents/family members was conducted by the same Paediatrician to prevent any bias.

Initially, after detailed history taking, the paediatrician assessed for growth and development and conducted a detailed general, systemic and neurological examination of every child and categorized the child as (1) GDD with predominant motor involvement; (2) GDD with multiple disabilities and; (3) GDD with co morbidities viz seizures, ADHD. For final diagnosis making, screening procedures and investigations were planned along with initiating Early Intervention which included: a) treatment of any medical illness at the time of presentation, b) nutritional care plan, c) initiating child specific intervention in the form of making Referrals for Physiotherapy, Hearing &Speech Intervention, Child psychologist, Special Education. All the services were available in the Institute itself except for special education service for which referral was made to a private facility about 25 kms from the institute.

Once the plan was made, the Paediatrician conducted an in-depth interview of the parents/ family members with the help of a semi-structured questionnaire with open- ended questions in two phases: (1) The first phase was conducted right after the initial workup; (2) The second phase was conducted on the scheduled visit 1 month after the initial contact. Apart from collecting the socio-demographic data, interview focused on these research areas: 1) Parental interpretation of the child's disability and its influence on the utilization pattern of professional recommendations. 2) Parental perceptions regarding the services recommended and their benefits.

3) Parental Needs and Challenges that influence the utilization of services.

Each interview was recorded on paper. The language of the interview was Hindi.

Results

The first phase of the interview had 31 participants whereas the second phase had 22 parents as participants who came for scheduled follow up.

Socio-demographic characteristics of the parents: (Table 1)

Of the 31 participants, 90% were parents and rest (10%) were relatives. The mean age of the participants was 29.29±7.59 years. The participants included 21 mothers, seven fathers, one grandfather and two maternal uncles. Nearly 70% of the mothers were illiterate and majority were housewives with only one being a skilled worker. Only two fathers had proper jobs. Rest of them was either unemployed or labourers or farmers by occupation. 84% of participants belonged to joint families. 54.8% parents had ≤2 children; rest had at least ≥3 children.

Characteristics of the children in the study: (Table 2)

The mean age of the children at the time of presentation was 30.48±18.32 months. Parents of all these children perceived that their children were having profound weakness that can be treated by medicines alone. Eleven subjects had problem detected since birth with six having the history suggestive of birth asphyxia and two were premature deliveries. 36.7% respondents could not tell the exact onset of problems in their children.

The utilization of massage, drugs and health supplements was maximum (nearly 100%) and that of special education services was nil. Physiotherapy was utilized more in children with predominant locomotor involvement as compared to children with multiple disabilities. Speech therapy and hearing assessment services were utilized only in the children >3 years of age in whom the parental concern was regarding the child's inability to speak properly. Early stimulation therapy was utilized by around 30% of children with multiple disabilities and 57% of children with predominant locomotor involvement. Counselling services were mainly utilised by parents of children who had presented with co morbidities.

Perception of Parents: (Table 4)

1) Parental interpretation of the child's disability and its influence on the utilization pattern of professional recommendation:

About 87% believed that the disability in the child was due to some biomedical cause and out of them, around two-third believed it to be due to weakness in muscles and bones. The rest thought it to be due to some problem with the mother or brain fever or due to birth complications. Although all the children enrolled in the study had developmental delay in multiple domains, the parental concern at the time of presentation generally belonged to only one domain depending on their area of maximum concern. Maximum parents were of the opinion, "My child is weak. Massage will make him strong and health supplements will improve his appetite". Regarding the acceptance of professional opinion, more than one third of the participants had either ambivalent feelings or they straightaway refused to accept the professional opinion regarding the child. Rest of the parents were ready to at least listen to the professional opinion.

2) *Parental Needs and Challenges that influence the utilization of services:*

Child care needs at home:

These needs fell in two categories: a) Taking care of the disabled child and b) Taking care of other children.

Mothers, who had only one child and with disability more readily accepted the management protocols as they had no other liability. Also in Mothers who had 2-3 grown up children, especially daughters, who could take care on their own and also could assist her in daily household routines, the acceptance was better. The real challenge lay with mothers who had only two children and one of them disabled. "I am always busy with either the household work or taking care of my disabled child. My other child is getting very aggressive and does not behave with me properly."

Socioeconomic needs: The need of financial assistance was definitely there which included the need of money for various investigations, devices in the form of hearing aids or orthotics etc., transportation costs.
Challenges faced by the parents:

a. Family support: Though two-thirds of the children belonged to joint families, the caregivers had mixed responses. For some, being in a joint family acted as a support as there was always at least someone to look after their other children. But for others it meant that the decision making was not completely in their own control.
b. Inability to accept the futuristic goal: The aim of intervention service is to achieve maximum functional ability possible but that may not fulfil the expectations of the parents. When counselled

regarding the need of special education in a female child with Down's syndrome, her mother replied, "What's the use of spending money now if she cannot be married in a good family. Her father says that we shall marry her to some poor man, so that both of them will stay with us only."

c. Physical and emotional stress: The immediate caregivers were mostly the mothers who were responsible for everything, right from managing whole of household to sometimes waking up throughout the night. If the fathers were unemployed or self employed, they were able to support their wives. But in case they were daily wages labourers or were doing some job, most of them used to leave their homes early in the morning and came back from work late in the night with minimal or no leave option.

3) *Parental perceptions regarding the services recommended and their benefits:*

   a. Type of service recommended: The type of service utilized depended upon the parent's perceived utility of the service for their child. Physiotherapy was more widely accepted as compared to speech therapy in children with GDD as the parents perceived that the child should first start using his limbs and with increasing age, he may start talking on his own. Most of the parents failed to perceive the need for special education or counselling services and this reflected in the dismal rate of utilization of these services.

   b. Frequency of visits scheduled/Site where the services were provided: The compliance was better when the frequency of planned visits were less and when all the recommended services were available in one single institute. The parents visited all the units in the institute at least once. None of the parents went to avail the special education service.

Parents who did not turn up for follow up were those whose predominant complaint was either regarding speech defect or cognitive involvement or profound locomotor defect. Dissatisfaction with the rate of improvement was considered as one of the reasons for leaving the services. The mother of a 5 month old female infant, who had presented with no social smile, no neck holding and seizures, did come for follow up but complained, "I have been following every advice given but even after one month, and my baby is not showing any signs of improvement. For how long will I suffer like this?"

Table 1: Personal Characteristics of the parents of children included in the study:

Variables	Characteristics of Parents	Number (n=31)	Percentage (%)
Age (years)	**18-30**	**21**	**67.7%**
	>30	**10**	**32.3%**
Education of Mother	Illiterate	22	70.96%
	Informally educated upto 5th	4	12.9%
	6-9th	2	6.45%
	10-12th	3	9.67%
Education of Father	Illiterate	14	45.16%
	Informally Educated/ upto 5th	2	6.45%
	6-9th	8	25.8%
	10-12th	4	12.9%
	Degree	2	6.45%
Religion	Hindu	15	48.4%
	Muslim	16	51.6%
Type of family	Joint	26	83.87%
	Nuclear	5	16.13%
Household size	≤6	12	38.70%
	≥7	19	61.3%
Number of children	≤2	17	54.8%
	≥3	14	45.2%

Table 2: Profile of the children included in the study:

Variables	Characteristics of Children (n=31)	Number (%)
Sex	Male	24(77.4%)
	Female	7(22.6%)
Age at presentation(years)	≤3 years	20(64.5%)
	>3 years	11(35.5%)
Parental concern regarding the child		
≤3 years(n=20)	Visual impairment	2(10%)
	Seizures	5(25%)
	Is not sitting or walking as per age	13(65%)
>3 years(n=11)	Is unable to walk / clumsy	5(27.3%)
	Inability to speak properly	3(27.3%)
	Does not understand anything	1(9.09%)
	Hyperactivity	2(18.2%)
Onset of Disability	Since birth	11 (35.5%)
	0-6 months	2 (6.45%)
	6-12months	4 (12.9%)
	1-5 yrs	3 (9.67%)
	Cannot tell	11(35.5%)
Type of Disability	GDD with multiple disabilities	20(64.5%)
	GDD with pred. locomotor inv.	7(22.6%)
	GDD with co morbidities	7(22.6%)

Table 3: Early intervention services recommended according to the need of the child and their utilization pattern:

Services Recommended	GDD with Multiple Disabilities (n=20)		GDD with Co morbidities (n=7)		GDD with predominant locomotor involvement (n=7)	
	Rec.	Uti.	Rec.	Uti.	Rec.	Uti.
Physiotherapy	20	5(25%)	7	0	7	4(57%)
Hearing assessment & Speech therapy	20	3(15%)	7	0	7	0%
Early stimulation therapy	20	6 (30%)	7	0	7	4(57%)
Nutritional care	20	19(95%)	7	6(85%)	7	4(57%)
Massage	20	20(100%)	7	1(14.3%)	7	7(100%)
Health Supplements	20	20(100%)	7	7(100%)	7	7(100%)
Drug therapy	0	-	7	7(100%)	0	
Counselling services	20	2(10%)	7	5(71.42%)	7	0%
Special Education	20	0%	7	0%	7	0%

Abbreviations: Rec-Recommended Uti-Utilized

Table 4: Categories and subcategories of Parental Perceptions, needs and challenges:

Categories	Subcategories
Perceptions on the causes of disability	*Biomedical causes* Weak bones and muscles Brain fever Birth complications Tongue tie *Hereditary*
Parental interpretation of the disability in the child	Inability to use the limbs Visual problem Inability to speak Inability to understand anything Hyperactivity Seizures

Table 4 cont ...

Categories	Subcategories
Perceptions on the treatment options	Traditional Primary Care Referral to other specialties Specialized care Early Intervention Services
Parent's response to specialist opinion	Ambivalence Refusal Willing to know more Relief
Parental readiness for further diagnostic workup	Want a diagnosis Shall consult family members Give medicines, my child will be relieved Start treatment, Investigations can wait Financial Issues
Parent perceptions regarding the services recommended	Type of service recommended Number of services recommended Site where the services were provided. Benefit of the services
Needs of the parents	Child care needs at home Socioeconomic needs
Challenges faced by parents	Lack of family support Lack of a real futuristic goal

Discussion

The results show that recommending early intervention services and their appropriate utilization is not a one way affair. Since taking care of a disabled child is an ongoing process, marked by changing needs with the growth of the child[12], the acceptance of these services heavily relies on the caregivers, their wellbeing, their unique needs and challenges which must be acknowledged[13].

In our country, mostly mothers are responsible for child raising as reported in other studies[14]. The present study also found that majority of immediate caregivers were mothers but some fathers were highly motivated to shoulder their responsibility. One of the factors that limited their participation was their job profile. Fathers, who were farmers and living in joint families, were able to take care of their child as compared to those who were either labourers or had proper jobs. This evolving role of fathers in the care of their disabled children has also been reflected in studies from Western India[15,16].

The study shows that disparity exists among parental and professional opinion regarding disability and this acts as one of the most important barriers in convincing the parents to accept the treatment protocols. Study by Kochanak et al also reported that the mothers who believed that service decisions should be made by professionals, evidenced higher utilization rates[17]. Like in past, the present study indicates that the acceptability of recommendations not only rests on the financial issues but also to a great extent on the parental acceptance of professional opinion, their willingness, their coping strategies, their information seeking behaviour and knowledge regarding the disability.

Studies[19,20] have expressed a great need to establish a parent-professional rapport for increasing the parents' faith and level of satisfaction which will ultimately lead to better utilization of services.

The parents' perceptions regarding the treatment options clearly reflected the level of awareness regarding the services available for disabled children which is similar to other studies[5,6]. No parent was aware of the early intervention services. Some had a slight idea regarding specialized services like Physiotherapy, speech therapy, hearing aids since someone in their acquaintance had been advised or was receiving one of those services.

Another issue was the perception of the parents regarding the service itself. The parent receptivity of the services recommended, number of visits scheduled, the availability of all services at one place and more importantly, the parent perception of the benefit to the child determined the regular follow ups. Similar results have been shown by past studies[3,21]. Some studies also support this view point that Parent's over-expect from the centre and failure in early results may be responsible for poor follow-ups[22]. The acceptance of counselling services, which basically deal with making the parents understand the condition of their child and to accept it, was found to be quite dismal. This may be because most of the parents tend to live in denial. Dalwai et al[23] in their study showed that changing the counselling methodology from behaviour modification approach to goal-driven outcome-oriented approach, led to better acceptance and adherence to counselling advice.

Overall these results reflect that the understanding of the parents about why a particular service has been advised and why multiple interventions and multiple visits are required and their participation in the treatment process are crucial to the proper utilization of services. Intervention models in cases of Autism Spectrum Disorders report parent participation to be the most effective contributor to the level of improvement in the child[24].

Even if the issues regarding the parental perceptions, hindering the acceptance of services, are addressed, there are certain very practical issues which have surfaced during these interviews. The most important among them is the amount of time a mother can spare from her household routines. Lack of support as well as difficulty in balancing the basic needs of her disabled child with that of her other normal children greatly influenced her regular adherence to appointment schedules. Also, a disabled child needs 24-hr nursing care which is obviously provided by the mother. The facility-based early intervention services never address this issue as also supported by past study[25]. The parents face a dilemma in properly allocating their already limited financial resources between the needs of their normal children whose future they can visualize and the needs of their disabled child. Lack of a real futuristic goal regarding the child and the acceptance of the goal of achievement of fullest functional potential instead of full cure, was the most important issue which influenced the utilization of services in the present study.

Conclusion

Utilization pattern of the Early Interventional services was skewed towards the predominant usage of massage, drugs and health supplements instead of the Special Educational Services. The pattern depended upon the parental interpretation of the child’s disability. This understanding of the utilization of resources by parents in management of children with developmental delay in developing country would help to find the gaps and motivating parents to seek such services

Limitations of the study

It is an institutional based study of the utilization of services which may be different from community based service utilization pattern. Also because of the small sample size, the results cannot be extrapolated on the community at large. The Questionnaire used was not validated. But still, some very logical points were discovered during the whole process which may help in a better delivery of services to increase the utilization rate.

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