

Cognitive facet and paradigm of the caregivers of children with developmental problems in Eastern India

Partha De¹, Nandita Chatterjee², Ranabir Pal³, Amrita Ghosh⁴

¹Associate Scientist, Population Studies Unit, Indian Statistical Institute, Kolkata, West Bengal, India, ²Department of Paediatrics, MGM Medical College and LSK Hospital, Kishanganj, Bihar, India, ³Department of Community Medicine, MGM Medical College and LSK Hospital, Kishanganj, Bihar, India, ⁴Department of Biochemistry, Midnapore Medical College, Paschim Medinipur, West Bengal, India

ABSTRACT

Background: The role of caregivers in grooming the neuro-developmental outcome of high-risk newborns and developmental challenges in children needs to be explored. **Objectives:** To find the knowledge and perception among parents regarding the neuro-developmental outcome of high-risk newborns, methods adopted to address these problems, and to identify areas on which awareness generation needs to focus. **Materials and Methods:** A questionnaire-based awareness survey was conducted to understand the knowledge, attitude, and practices of families of children with developmental challenges. **Results:** The study revealed that more than 70 percent of families lack information about child development, developmental challenges, and means to deal with them. They are unaware of the available health care services and other resources. One in three families has misconceptions on developmental disabilities; consider them as curse or jinx and consequently neglected. Female children with developmental problems are further ostracized due to gender inequity in families. About 10 percent of families have shown great openness toward acquiring new skills and knowledge for handling their children with developmental delays. **Conclusions:** This study is based on the précis research findings of our grass-root level fieldwork conducted in remote rural Bengal areas. The observation will be of interest and learning materials for general primary care practitioners, family physicians, and stakeholders to initiate appropriate intervention strategies for properly rehabilitating children with developmental delay at grass-root levels of primary health care.

Keywords: Awareness, developmental delay, disability, family medicine, primary care

Introduction

The term “disability” refers to a loss of health, where health means having full functional capacity in such domains as mobility, cognition, hearing, and vision related to participation restrictions.^[1,2] Over 150 million children in the world live with a disability, and 80% of them live in developing countries. According to UN Enable, women and children with disabilities

are particularly at a greater risk of abuse. Children with disabilities are at a 1.7 times greater risk of being subjected to some form of violence.^[3] Nine out of ten of these children do not attend school.^[4] The British Department for International Development (DFID) has recognized that “disability is a major cause of social exclusion and it is both the cause and consequence of poverty.”^[5] In India, 2.21% of the population has a disability, which is slightly higher than in the previous census year of 2001 (2.13%). The data show 207.8 lakh households have disabled persons in the country, constituting 8.3 percent of the total households. In children, 1.14% of the 0-4 age group, 1.54% of the 5-9 age group, and 1.82% of the 10-19 age group population have a disability.^[6] 1.7 million babies are born with birth defects, and one million newborns are discharged each year from Special

Address for correspondence: Dr. Amrita Ghosh, Department of Biochemistry, Midnapore Medical College, Paschim Medinipur, West Bengal, India.
E-mail: amritaghosh1973@yahoo.com

Received: 05-11-2023

Revised: 01-01-2024

Accepted: 04-01-2024

Published: 24-05-2024

Access this article online

Quick Response Code:



Website:
<http://journals.lww.com/JFMPC>

DOI:
10.4103/jfmpe.jfmpe_1780_23

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How to cite this article: De P, Chatterjee N, Pal R, Ghosh A. Cognitive facet and paradigm of the caregivers of children with developmental problems in Eastern India. J Family Med Prim Care 2024;13:2006-14.

Newborn Care Units (SNCUs), who are at risk of developmental delay and growth retardation.^[7] A study on the role of caregivers on their children with neuro-developmental challenges is of great help to the practitioners of Family Medicine and Primary Care in India. Against this backdrop, this study was conducted in the primary care settings among family members and parents with the objectives (a) to discern the knowledge and perception regarding neuro-developmental outcome of high-risk newborns, (b) to identify methods adopted to address these problems, (c) to identify areas on which awareness generation need to focus.

Method

Study area: This case-control study was performed on 152 families with a child (0-6 years) with developmental challenges in the Purulia district of West Bengal, India.

Study period: January 1, 2016, to December 31, 2017.

Inclusion criteria: a. Families having a child (0-6 years) with developmental challenges. B. Family members and parents who were willing to participate wholeheartedly.

Exclusion criteria: a. Children and/or their caregivers were seriously ill during the study period. B. Families with more than one child affected or absence of both parents.

Study population: 461 at-risk children discharged from the SNCU over a 2-year period from across the district were screened by a team of specialists for developmental delays/challenges, viz. cerebral palsy, speech and communication problems, intellectual disability, autism spectrum disorders, and behavioral disorders. One hundred seventy-one children were screened positive (11 families refused). Families with more than one child affected or with the absence of both parents were excluded (total 8). The data collected in this study was collected from 152 families with at least one child with a challenge – “Study group.” Another 152 families with typically developing children were identified by picking a family of similar demographic profile from the neighborhood of each family in the study population – “Control group.”

Data collection tool: Standardized and validated tools like Trivandrum Development Screening Chart (TDSC),^[8] Denver Development Screening Test (DDST II)^[9] M-CHAT-R (Modified Checklist for Autism in Toddlers, Revised) M-CHAT,^[10] Language Evaluation Scale Trivandrum (LEST 3-6 years)^[11] were used for the screening by trained and dedicated personnel under direct supervision of the investigators. A questionnaire with 37 items comprising of major components related to medical, educational, economic, social, and behavioral was used for the study. The predesigned, pre-tested questionnaire was prepared by the experts based on the literature. It was administered to collect data from the study participants using the interview technique to elicit socio-demographic background, precise perception, and experiences, including objective and subjective findings.

Data collection procedure: Divisional Committee of Scientific Workers (DCSW) and Technical Advisory Committee (TAC) of the Institute approved the study. Each participant was individually counseled before the study that no potential risk was involved and they would have full autonomy to leave the study at any point. It was ensured that the data would only be used for research purposes. Strict confidentiality was maintained while gathering information and was ensured about the sanctity and strict confidentiality of data. All the collected data were kept confidential with the investigators and were not disclosed for any type of assessment, management or intervention. The data collection procedure was undertaken by the principal investigator and co-principal investigators with necessary follow-up. All the data were reported, and missing data was rectified. The study and control groups were compared on their differences in perception, attitude, and practices regarding developmental problems and disability in children. A total of 304 parents (152 parents of challenged children and 152 parents of normal children) from 20 blocks of the Purulia district were interviewed in their own languages to understand their knowledge, attitude, and practice toward their children.

Data analysis: Data were entered into a Microsoft Excel sheet by an independent person, and analysis was performed using STATA Version 10.0 (StataCorp LLC, Texas, USA). Odds ratios (OR) in this analysis [Tables 1 and 2] are the measures of odds of occurrence of the dependent variable (developmental delay) as a crude or adjusted effect of independent variables (e.g, age group of child, gender, birth weight, mother’s education, etc.). Chi-square test score analysis was performed with an alpha level of 5 percent and compared between groups. Approval from Divisional Committee of Scientific Workers (DCSW) and Technical Advisory Committee (TAC) of the Institute was obtained for the study in a meeting held on 11.06.2014.

Results

This study was conducted in Purulia district, a primarily rural (88.93% population), marginalized district in West Bengal, India, 43.65% of families under the BPL category, overall literacy 65.38%, and female literacy alarmingly low (37.15%). Among developmental challenges, the majority had a motor delay (74.34%), speech delay (69.08%), hearing (34.21%) and behavioral problems (30.92%), cognitive delay (29.60%), visual impairment (16.45); the majority had multiple issues, no age group bias, generally brought to a health care facility after 2 years age and a higher proportion of male children. The incidence of very low birth weight and low birth weight was higher (32.2%) in the study group than in controls (25.7%). Incidence of prematurity (gestational period <37 weeks) was significantly higher (36.8%) for challenged children than controls (18.4%). Twin babies were more prone to developmental delay than singletons and significantly higher (17.1%) for the study group than controls (9.2%). Mother’s age (<18 years) was an important contributing factor for developmental delay [Table 1].

Table 1: Distribution of number of children according to developmental status by demographic characteristics (Purulia, West Bengal)

Characteristics	Category	Developmental delay		Normal development		Total no. of children	Crude OR [95% CI]	P	Adjusted OR [95% CI]	P	Chi-square
		No.	Col %	No.	Col %						
Age group of child	Upto 2 years	14	9.2	11	7.2	25	RC				0.73 (df=2, P=0.69)
	> 2 years to 4 years	54	35.5	60	39.5	114	1.41 (0.592-3.379)	0.436	1.15 (0.456-2.931)	0.761	
	Above 4 years	84	55.3	81	53.3	165	1.22 (0.526-2.862)	0.635	1.11 (0.446-2.781)	0.817	
Sex of the child	Male	95	62.5	79	52.0	174	RC		RC		3.44 (df=1, P=0.06)
	Female	57	37.5	73	48.0	130	1.54 (0.975-2.433)	0.064	1.45 (0.882-2.397)	0.142	
Type of baby	Twin	26	17.1	14	9.2	40	2.03 (1.017-4.068)	0.045	1.85 (0.903-3.804)	0.09	4.14 (df=1, P=0.04)
	Single	126	82.9	138	90.8	264	RC		RC		1.60 (df=1, P=0.20)
Birth weight	Low birth weight	49	32.2	39	25.7	88	RC		RC		12.8 (df=1, P=0.00)
	Normal weight	103	67.8	113	74.3	216	1.07 (0.838-2.268)	0.207	0.82 (0.444-1.532)	0.543	
Gestation type	Term (37 weeks and above)	96	63.2	124	81.6	220	RC		RC		5.27 (df=1, P=0.02)
	Preterm (<37 weeks)	56	36.8	28	18.4	84	2.58 (1.526-4.372)	0.001	2.45 (1.299-4.653)	0.006	
Mother's age at first birth	Below 18 years	18	11.8	7	4.6	25	2.78 (1.127-6.872)	0.027	2.31 (0.877-6.126)	0.09	
	18 years and above	134	88.2	145	95.4	279	RC		RC		4.54 (df=1, P=0.03)
Any history of disability in the family	Yes	14	9.2	5	3.3	19	6.42 (1.414-29.233)	0.016	6.80 (1.433-32.300)	0.016	
	No	138	90.8	147	96.7	285	RC		RC		
Total		152	100.0	152	100.0	304					

Note: RC=Reference Category for Logistic Regression, CI=Confidence Interval

Table 2: Distribution of children according to developmental status by Mother's education and occupation (Purulia, West Bengal)

Characteristics	Category	Developmental delay		Normal development		Total no. of children	Crude OR [CI 95%]	P	Adjusted OR [CI 95%]	P	Chi-square
		No.	Col %	No.	Col %						
Mother's education	Illiterate	63	41.4	59	38.8	122	1.71 (0.781-3.775)	0.109	1.79 (0.804-3.990)	0.153	7.28 (df=3, P=0.05)
	Upto primary	39	25.7	58	38.2	97	2.72 (1.210-6.142)	0.015	2.872 (1.256-6.567)	0.012	
	Class eight pass	28	18.4	23	15.1	51	1.51 (0.616-3.681)	0.369	1.58 (0.635-3.949)	0.324	
	Secondary and above	22	14.5	12	7.9	34	RC		RC		
Mother's occupation	HH work	143	94.1	137	90.1	280	0.57 (0.243-1.357)	0.106	0.51 (0.210-1.247)	0.141	1.62 (df=1, P=0.20)
	Working outside HH	9	5.9	15	9.9	24	RC		RC		
Total		152	100.00	152	100.00	304					

Note: RC=Reference Category for Logistic Regression, CI=Confidence Interval

With the increase in the mother's educational level, the incidence of developmental delay in the offspring decreases, while the mother's occupation has no significant impact [Table 2].

In the awareness survey, the first part was on "parents' knowledge," the second part on "attitude of parents," and the third part on "practices of parents" for developmental problems; responses were compared with the control group at each level. Knowledge of child development, disability, and available services were similar in both groups; equally poor among the general population with lots of misconceptions and misperceptions. In the study group, 64.5% of parents believe their children became disabled due to god's decree, 35.5% attributed to different causes, viz., age of mother and harmful self-medication, disease suffered by the child after birth, and heredity. Knowledge on the impact of parental consanguinity was totally lacking, and consanguineous marriages were very common locally. Maternal undernutrition and prematurity were not considered as probable causes for delayed development by 55.9 and 55.3%, respectively. Chi-square analysis between the two groups indicated significant differences in belief regarding illness in the neonatal period and early infancy. Both groups were unaware of the available services at the local health facilities and were oblivious of their rights and entitlements; 40% were unaware of services by the field level workers (ASHA, ANM, and AWW) at sub-centers and ICDS centers; 77% aware of the disability certification system, yet did not know about the procedure to collect; hence very few children possess such certificates [Table 3a].

Developmental delays were noted mostly within 1-2 years of age; the mother usually first noticed (79.6%). On the future of their children, responses were similar in both groups: one-thirds wanted regular treatment, attention, and school; 15% vocational training; two-thirds of both groups believed that these children could not be admitted to normal school; few had no hope for child's future (16%); deeply concerned on their future life in their absence (32%) [Table 3b].

Regarding attitudes toward differently abled kids, responses varied, ranging from dissatisfaction and remorse (39%) to accepting the challenge with full effort to rehabilitate to normal life (52%) and expressing concern about financial burden (9.2%).

Regarding gender bias, one-fifth showed a clear preference toward the male child; 39.1% of families denied offering the same status for a differently abled child with normal with evident negligence; less eagerness to take special care (28.3%); half (47%) with special children agreed to give equal attention to all the children (typical and special). Regarding the involvement of other family members and the community at large, the majority (66.4%) showed a willingness to explore more scope and social opportunities. Sadly, one-fourth (23.4%) considered the issue as the sole responsibility of affected parents, ignoring other's role. Regarding the proper time to bring kids to the nearest health care facility, parents agreed to intervention therapy but were unaware of the importance of early intervention; half (47%) had taken the initiative for treatment only after 3 years of age [Table 4].

The extra burden of treatment costs was shared by other family members or neighbors to reduce the suffering of the families; one in four (26%) received such financial help; 43.9% shared their saga with similar families; 87.8% parents were not receiving any financial help for assistive devices or for treatment from any NGO or government; the major problem for the drop out for various reasons. Initially, parents started treatment; the majority discontinued for various reasons, which was a major hindrance to early intervention evident in 74.3%; half (50%) discontinued due to financial constraints, 38% due to lack of time and loss of workdays; long and difficult to commute on rough terrain was other important causes for irregularity [Table 5].

Discussion

Children with disabilities lead to long-term physical, mental, intellectual, or sensory impairments with various barriers that may hinder their full and effective social participation. In most parts of the world, people with disabilities are subject to multiple deprivations with limited access to basic services, including medical, education, employment, and rehabilitation facilities. The purpose of this study was to conduct a survey of knowledge, attitudes, and practices of parents of children with developmental delay and disability, comparing that with parents of typically developing children. In many parts of rural India, with limited access to health care resources and poor literacy levels, the incidence of developmental challenges in children

Table 3a: Distribution of response by parents of children according to developmental status by knowledge about the reasons for occurrence of developmental problems (Purulia, West Bengal)

Knowledge of parents about the occurrence of developmental problem among children	Category	Developmental delay (DD)		Normal development (ND)		Total no. of children	% of total no. of children	Chi-sq	P
		no.	Col %	no.	Col %				
DD by GOD's decree	Yes	98	64.5	93	61.2	191	62.8	0.352	0.55
	No	54	35.5	59	38.8	113	37.2		
DD due to problem of mother during pregnancy	Yes	76	50.0	74	48.7	150	49.3	0.053	0.82
	No	76	50.0	78	51.3	154	50.7		
DD due to undernutrition of moth. During pregnancy	Yes	67	44.1	76	50.0	143	47.0	1.07	0.30
	No	85	55.9	76	50.0	161	53.0		
DD due to under age of pregnancy of mother	Yes	73	48.0	87	57.2	160	52.6	2.59	0.10
	No	79	52.0	65	42.8	144	47.4		
DD due to harmful self-medication during pregnancy	Yes	89	58.6	104	68.4	193	63.5	3.193	0.07
	No	63	41.4	48	31.6	111	36.5		
DD due to receiving tobacco, alcohol during pregnancy	Yes	61	40.1	60	39.5	121	39.8	0.014	0.91
	No	91	59.9	92	60.5	183	60.2		
DD due to premature delivery of child	Yes	68	44.7	60	39.5	128	42.1	0.864	0.35
	No	84	55.3	92	60.5	176	57.9		
DD due to disease suffered by the children after birth	Yes	89	58.6	71	46.7	160	52.6	4.275	0.04
	No	63	41.4	81	53.3	144	47.4		
DD due to child grown up in at unhealthy environment	Yes	20	13.2	26	17.1	46	15.1	0.922	0.34
	No	132	86.8	126	82.9	258	84.9		
DD due to negligence of kid during childhood	Yes	32	21.1	27	17.8	59	19.4	0.526	0.47
	No	120	78.9	125	82.2	245	80.6		
DD problem may be generated from heredity	Yes	86	56.6	104	68.4	190	62.5	4.547	0.03
	No	66	43.4	48	31.6	114	37.5		
DD probability is high in kin marriage	Yes	31	20.4	28	18.4	59	19.4	0.189	0.66
	No	121	79.6	124	81.6	245	80.6		
Total		152	100.0	152	100.0	304	100.0		

is disproportionately high and mostly goes unattended. Thus, awareness among parents is of paramount importance to improve the state of affairs. Rashtriya Bal Swasthya Karyakram (RBSK) has initiated child health screening and early intervention services under the National Health Mission, Ministry of Health and Family Welfare, Government of India.^[12]

In our study population in the developmental status, no specific distribution was noted by demographic characteristics. Globally, low birthweight, prematurity, multiple births, and infection during pregnancy were associated with increased risk for developmental disabilities.^[13] In a study conducted among intellectually disabled children attending special schools in South India, the research group observed that Health-related quality of life was quite low.^[14]

Awareness

In our study, awareness level was similar in both groups, though attitudes to the problem differed. Overall, awareness about disability was poor in this region of our country. Both groups lack information about services available in the locality and the rights and entitlement due to a person with a disability. The majority of the respondents were unaware of the various "Disability Acts" and the provisions there and had minimum knowledge about methods to claim their rights. Literature supports our findings that three things: knowledge, attitudes, and practices in amalgamation govern all aspects of life in human societies which

supports.^[15] A South Indian study assessed structural therapeutic factors to predict intensive, parent-mediated, multi-component, early intervention outcomes in autistic children.^[16]

Knowledge

Kuppusamy's study pointed out that "there is a need for intense focus and drive toward creating awareness of legislation among families of persons with intellectual disability."^[17] In our study, more than 70 percent of families did not know about the facility of free compulsory education, and in spite of all such provisions, the majority of the identified children were not enrolled in the schools. Union Government aligned Sarva Shiksha Abhiyan (SSA) norms with the Right of Children to Free and Compulsory Education Act, 2009. SSA ensures every child with special needs, irrespective of the kind, category, and degree of disability, provides meaningful quality education and adopts a zero rejection policy.^[18]

It was observed in our study population that misconceptions about developmental challenges such as considering it a curse or jinx were widely prevalent. The afflicted children were kept hidden away from society for fear of being unaccepted and ostracized. Developmental challenges were not considered to be diseases that might be treatable. Negligence toward disabled children in the family was commonly evident, as parents accept the disability as an ill fate and see no hope of respite. They were unaware

Table 3b: Distribution of response by parents of children according to developmental status by knowledge about the developmental problem (Purulia, West Bengal)

Knowledge of parents about developmental problem among children	Category	Developmental delay		Normal development		Total no. of children	% of total no. of children	Chi-sq	Sig. (0.05)
		no.	col %	no.	col %				
The problem was first noticed by parents at age	Within 6 months	47	30.9					---	---
	>= 7 to <=12 months	66	43.4						
	>= 13 to <=24 months	34	22.4						
	>= 25 months	5	3.3						
Developmental problem first noticed by whom	Mother	121	79.6					---	---
	Father	11	7.2						
	Other family members	12	7.9						
	Neighbor	0	0.0						
	Others	8	5.3						
Any idea about ASHA/ANM those who can help with the treatment/education of DD child	Yes I know	89	58.6	85	55.9	174	57.2	1.378	0.502
	Don't know	60	39.5	66	43.4	126	41.4		
	any other comment	3	2.0	1	0.7	4	1.3		
Do you know the government provides certificates for DD children? Using that, you can get different social/economic benefits for him/her	Yes	117	77.0	120	78.9	237	78.0	0.172	0.678
	No	35	23.0	32	21.1	67	22.0		
Knowledge about the availability of free compulsory education for DD children	Yes	42	27.6	47	30.9	89	29.3	0.397	0.529
	No	110	72.4	105	69.1	215	70.7		
Future of developmentally challenged children	Need regular treatment, attention, and education to secure a smooth life	60	39.5	53	34.9	113	37.2	0.215	0.978
	In the absence of parents, it will be difficult to continue a secure life	45	29.6	52	34.2	97	31.9		
	Vocational training can help them for smooth functioning of life	20	13.2	25	16.4	45	14.8		
	They have no future and find it really difficult to continue life	27	17.8	22	14.5	49	16.1		
Do you think that developmentally challenged children can be admitted to normal school	Yes	46	30.3	52	34.2	98	32.2	0.487	0.721
	No	106	69.7	100	65.8	206	67.8		
Total		152	100.0	152	100.0	304			

of the scope of prevention, recovery, or rehabilitation in most cases. Other research groups reported closer observations.^[19] In our study, more males reported with developmental disorders, and females were more deprived. Gender inequity may be due to a more care-seeking attitude for males while affected girls are neglected. Parents may be more concerned about the survival and well-being of male children than females. Other research groups also reported comparable findings.^[20,21] The level of education of the mother always had some impact on better care in the family of developmental delay, though her occupation had no such. Other researchers observed analogous findings.^[22]

Attitude and practice

The afflicted parents were eager to learn about their child's problems and how to handle them. In both groups, families showed openness toward change in knowledge and attitude toward childhood disability. However, parents with typically developing children showed a more humane approach to the problem, probably because they are not directly affected by the

problem, which generally creates bitterness and alienation, as experienced by the study group.

Social support

Worldwide professionals and policymakers are now interested in community-based approaches for contributing services to differently able people. Undoubtedly, community-based rehabilitation (CBR) is cost-effective and has a wider impact on the benefited people.^[23] In the case of Institutional Based Rehabilitation (IBR), it cannot reach people living in remote and rural areas of our big country. Since a majority of developmentally challenged children live in rural areas, it is necessary to promote CBR effectively^[24] with parental involvement and community participation. For this, it is essential to sensitize parents and citizens regarding the detection of early markers of developmental delay and early intervention measures so that they may be involved in home-based early intervention therapy and management. Much of the disability burden can be reduced if the developmental delays are detected early and

Table 4: Distribution of responses by parents of children according to developmental status by attitude about the developmental problem (Purulia, West Bengal)

Attitude of parents about developmental problems among children	Category	Developmental delay		Normal development		Total no. of children	% of total no. of children	Chi-sq	Sig. (0.05)
		No.	Col %	No.	Col %				
Parent's first feelings about Developmental Delay or disability of their child	Child future is uncertain and in dark	59	38.8			59			
	Give full effort to rehabilitate the child into a normal life	79	52.0			79			
	Worried about to bear the cost of living for the child	14	9.2			14			
Sex biases about the treatment of Developmental Delay or disability	Boy child should get first preference for treatment	27	17.8	34	22.4	61	20.1	1.367	0.505
	Girl child should get first preference for treatment	9	5.9	11	7.2	20	6.6		
	Both the child should get the opportunity of treatment equally	116	76.3	107	70.4	223	73.4		
Acceptance of Developmental Delay or disabled child in the family	Not considered as the same status as a normal child	60	39.5	59	38.8	119	39.1	5.258	0.072
	Treat equally to the normal and disabled child	35	23.0	51	33.6	86	28.3		
	Take special care of DD's child and give more importance than a normal child	57	37.5	42	27.6	99	32.6		
Apart from parents, the duty of other members of the family to a disabled child	This problem is solely for the parents of disabled children, and others have nothing to do with that	34	22.4	37	24.3	71	23.4	0.179	0.914
	Other members of the family should try to explore more scope and social opportunities for the child	102	67.1	100	65.8	202	66.4		
	Should help the child for socialization and be equally treated like other normal children	16	10.5	15	9.9	31	10.2		
In a family, who should receive more attention—normal or a disabled child?	Attention more to normal child	13	8.6	11	7.2	24	7.9	5.399	0.067
	Attention more to challenged child	67	44.0	49	32.2	116	38.2		
	Give attention equally to both the child	72	47.4	92	60.6	164	53.9		
Total		152	100.0	152	100.0	304			

Table 5: Distribution of response by parents of children having developmental problem

Practices of parents about developmental problems in their children (n=148)	Category	Developmental delay	
		No.	col %
Time of early intervention	Just after the detection of Developmental Delay	40	27.0
	Doing treatment according to personal convenience	6	4.1
	After 2 years, when it becomes prominent	37	25.0
	After 3 years when people came to me and advised me to treatment	69	46.6
Whether other family members or friends have come forward to help financially for the treatment or education of the child	Yes	38	25.7
	No	114	77.0
Sharing of problems with other parents of the disabled child	Yes	65	43.9
	No	87	58.8
Receive any help for purchasing any assistive devices or for treatment from Govt or any NGO for your child	Yes	22	14.9
	No	130	87.8
Does the child receive any treatment on a regular basis from a doctor or hospital	Yes	38	25.7
	No	110	74.3
Reasons behind irregular or no treatment for the child having disability/developmental problem (multiple response questions) (n=152)			
Type of problems	No. of children	Percent of children	
Financial stringency	76	50.0	
Treatment is useless	17	11.2	
Long distance of hospital or treatment place from residence	43	28.3	
Paucity of time for treatment due to workload	58	38.2	
Scarcity of manpower in the home	31	20.4	
Feel uneasy about bringing the child in front of common people	1	0.7	
Other reasons	4	2.6	

“Early Intervention” is initiated, thereby averting a permanent disability with developmental problems have very low rates of initial school enrollment and are most likely to drop out very early without going to secondary level even^[25] and they are also at increased risk of school violence and harassment.^[26]

The most important Acts relating to disabilities in India are (i) the Rehabilitation Council of India Act (1992) (RCI Act), (ii) the Persons with Disabilities (Equal Opportunities, Protection of Rights and full participation) Act (1995) (PWD Act), (iii) the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental retardation and Multiples Disabilities Act (1999) (NT Act), and (iv) the Rights of PWD Act, 2016 (RPWD Act, 2016) which was passed in both houses of Parliament. The RCI Act regulates training policies and programs in the field of disability rehabilitation for human resource development. The PWD Act ensures the rights of persons with disabilities. However, the NT Act focuses on providing responsibility to persons with disabilities. The principle of the RPWD Act reflects a total shift in thoughts about disability from a social welfare perspective to a human rights issue. Though all these Acts are in vogue, emphasizing rights and entitlements for persons with disabilities, awareness about these issues is very much limited among parents and families.^[27] A Western Indian study noted that the quality of life of caregivers of kids with a developmental disability was below par and varied based on the type of disability. Teaching coping strategies with rehabilitation programs notably eased the burden through collaboration.^[28]

Strengths of the study

We felt the need for a systematic and organized community-based survey to identify the knowledge, attitude, and practices among parents having developmentally challenged young children for which we took up the present study in the Purulia district of West Bengal.

Limitations of the study

Data analysis after a gap could result in change in the situation at the ground level. Further, the data of the two groups (developmental problem and normal) is small. Therefore, it is not possible to generalize outcomes at a higher level. Much more intensive studies are needed to generate interventional plans to mainstream these children.

Future Directions of the Study

In our next phase of studies, we will try to cover three tier levels of health system, that is, primary, secondary, and tertiary levels involving other districts as a multicentric study; if possible, quaternary special care hospitals should also be included.

Conclusion

This study reveals scarcity of awareness in the community regarding developmental delays and disabilities with a lack of

positive attitudes toward specially abled children. Rigorous efforts to ensure legal rights in terms of acquiring disability certificates and legal guardianship under the National Trust Act (1999) of the government are essential. Attempts should be made to create greater awareness among parents about various aspects of child developmental problems, starting from early intervention at home, education, and rehabilitation, thereby promoting CBR. Remoteness and poor communication facilities, coupled with poor resources, pose a great hindrance to proper follow-up of these children. Decentralization of Early intervention facilities through District Early Intervention Centres and home-based management must be focused on to cater to the needs of these vulnerable children of rural communities.

What this research study adds to knowledge

Understanding the levels of knowledge, attitudes, and practices among the study participants enabled us to address the needs of the community and generate customized awareness programs and appropriate intervention strategies to help stakeholders plan ahead. This study was conducted in the remote rural district of Bengal. The study findings will be of enormous help for the practitioners of Family Medicine and Primary Care.

Acknowledgment

The authors acknowledge the logistic help from Nanritam, a voluntary welfare organization working in the Purulia district on childhood disability; we are thankful to the specialist team from Udbhaas-Nanritam, who carried out screening of developmental challenges.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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