Professional help Seeking Behavior Patterns in Parents of Children with Developmental Disabilities

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Abstract

When parents discover that their child has developmental delay, they undergo an emotionally shattering experience. This grim situation predisposes them to shop for professional advice, drugs or other palliatives to overcome their predicament. While there is justification in seeking a professional second opinion on their child's condition; for some parents, the shopping spree for seeking professional help becomes an endless and futile exercise. This results in loss of precious time that could otherwise be profitably utilized in implementation of early infant stimulation program to optimally benefit their child. This paper attempts to discover the nature, frequency and duration of professional consultations sought by parents of children with developmental delays. The results show that parents go through a long drawn out itinerary of shopping for professional help. This is influenced by variables like severity, sex, age, diagnostic condition of the child as well as allied socio-demographic variables. The details are presented and discussed in the light of the need and importance to curb such treatment seeking practices in parents of children at risk or those with development al delays.

Key words: Developmental Delays – Professional Help Seeking – Parents/Caregivers

Upon discovering that their child has developmental delay (DD), parents experience a wide range of emotional reactions including shock, denial, anger, depression, overprotection, blame, guilt and shame until eventually, they learnt to accept the inevitable condition (Akhtar and Verma, 1972; Peshawaria et al, 1994; Venkatesan, 2007). During the early emotionally shattering experience, many parents shop for professional advice with an ardent hope to derive drugs or other palliatives to overcome their predicament.

While there maybe justification for seeking a second opinion from professionals about their child's condition; for some parents, the shopping spree itself becomes an ever elusive camouflaged pilgrimage in search of a wonder drug or panacea for all their problems. Indeed, there are variations in the specific pattern of treatment search of these parents. In an earlier longitudinal follow up study on treatment seeking behaviors of parents of mentally retarded children, Chaturvedi and Malhotra (1982) reported that nearly half of their sample did not seek second help from professionals within that year. They found more shopping behaviors in parents from higher educational and socioeconomic levels.

It was the aim of this study to discover the nature, frequency and duration of professional consultation sought by parents of children with developmental delays in relation to child variables like sex, severity, chronological age and diagnostic status as well as allied variables like type or size of family, socioeconomic status and informants' education.

Method

Sample

The present study was conducted by drawing the required sample (N: 97) from Diagnostic Services at All India Institute of Speech and Hearing (AIISH), an autonomous agency under Ministry of Health and Family Welfare, Government of India, located at Mysore, India. Among many other activities, the AIISH provides clinic based services, home based training program, preschool services, and other support services like diagnosis, certification for social security schemes, etc., for individuals with mental handicaps. Upon initial registration, each child is screened, diagnosed and intervened by multidisciplinary team comprising of specialists like speech and language specialists, audiologists, otolaryngologists, clinical psychologists, pediatrician, special educator, physiotherapists, occupational therapists, etc. Only cases of children with DDs below six years were considered for inclusion in this study. This was to obviate the possibility of retrospective falsification and recall bias that would likely contaminate reports of parents of older children.

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Procedure

Data collection involved use of a semi structured interview schedule to elicit information on each child's list of previous consultations in a chronological sequence. Wherever possible, the derived information was corroborated by pursuing actual evidence from available prescriptions and medical records about the child. The raw data from this study included the nature, type, duration and frequency of consultations sought for overall and sub samples of children with DDs (Table One).

SNo	Variables	N	Levels of Consultation (+)								Total	Mean	Chi Square
			I	II	III	IV	V	VI	VII	VIII			
A	Overall	97	97	88	63	43	27	15	7	2	342	3.53	-
B	SEVERITY:												
	Borderline DD	8	8	6	4	3	-	-	-	-	21	2.63	2.727
	Mild DD	54	54	52	35	25	15	7	4	1	193	3.57	Df: 4
	Moderate DD	24	24	22	18	12	10	6	3	1	96	4.00	
	Severe-Profound DD	11	11	8	6	3	2	2	-	-	32	2.91	
C	SEX:												
	Male	58	58	51	35	28	16	8	2	1	199	3.43	1.777
	Female	39	39	37	28	15	11	7	5	1	143	3.67	Df:4
D	CHILD'S AGE:												
	0-24	46	42	38	27	18	11	4	1	-	141	3.07	3.249
	25-48	32	32	29	20	13	10	8	6	2	120	3.75	Df: 6
	49-72	19	19	18	14	11	5	3	-	-	70	3.68	
E	DIAGNOSTIC STATUS												
	Single Diagnosis	11	11	9	3	2	1	1	-	-	27	2.46	10.703
	Dual Diagnosis	33	33	29	19	10	5	2	2	-	100	3.03	Df: 3*
	Triple/Multiple Diagnosis	53	47	44	35	26	18	11	5	2	188	3.55	
F	TYPE OF FAMILY												
	Nuclear	70	70	66	50	39	24	15	7	2	273	3.90	14.260
	Non Nuclear	27	27	22	13	4	3	-	-	-	69	2.56	Df: 3**
G	SIZE OF FAMILY												
	<= 5 members0	73	73	67	51	38	23	13	5	1	271	3.71	3.695
	>= 6 members	24	24	27	12	5	4	2	2	1	77	3.21	Df: 3
H	SES												
	Level One	54	54	46	32	19	8	5	2	-	166	3.07	11.044
	Level Two	28	28	27	21	17	15	8	4	2	122	4.36	Df: 6
	Level Three	15	15	15	10	7	4	2	1	-	54	3.60	
I	INFORMANTS EDUCATION												
	Under Graduates	57	57	50	33	20	8	4	-	-	172	3.02	14.318
	Graduates	33	33	31	24	19	17	10	7	2	143	4.33	Df: 3*
	Post Graduates	7	7	7	6	4	2	1	-	-	27	3.86	

(*p: <0.05; **p: <0.01; ***p: <0.001); (+): indicates the sequential level of consultation ranging from first to eighth;

Table 1. Distribution of Frequency of Consultations in relation to various variables

In order to determine the time gap between consultations, the mean number of consultations sought by parents for a given child was divided by his/hr chronological age. For example, if a 24 month child had three consultations, his mean time gap between consultations was computed as 8.00 months. The combined mean and SDs was then determined for overall sample and sub samples (Table Two).

Variables	N	Mean	SD	T Value	Df	Probability
A. Overall	97	11.09	9.50			
B. SEVERITY:						
(i) Borderline DD	8	10.96	7.26	1.128	68	>0.05
(ii) Mild DD	54	9.77	7.95			
(i) Borderline DD	8	10.96	7.26	0.368	30	>0.05
(iii) Moderate DD	24	10.47	9.86			
(i) Borderline DD	8	10.96	7.26	4.756	17	<0.001
(iv) Severe-Profound DD	11	20.58	11.66			
(ii) Mild DD	54	9.77	7.95	1.249	73	>0.05
(iii) Moderate DD	24	10.47	9.86			
(ii) Mild DD	54	9.77	7.95	8.884	63	<0.001
(iv) Severe-Profound DD	11	20.58	11.66			
(iii) Moderate DD	24	10.47	9.86	6.854	33	<0.001
(iv) Severe-Profound DD	11	20.58	11.66			
C. SEX:						
(i) Male DD	58	11.86	10.47	3.859	95	
(ii) Female DD	39	10.38	7.75			<0.001
D. CHILD'S AGE						
(i) 0-24 months	46	5.71	4.68	21.559	76	<0.001
(ii) 25-48 months	32	14.18	8.83			
(i) 25-48 months	32	14.18	8.83	6.671	45	<0.001
(ii) 49-72 months	19	19.80	10.70			
(i) 0-24 months	46	5.71	4.68	20.268	63	<0.001
(ii) 49-72 months	19	19.80	10.70			
E. DIAGNOSTIC STATUS						
(i) Single Diagnosis	11	16.74	14.46	4.075	42	<0.001
(ii) Dual Diagnosis	33	10.19	8.72			
(i) Single Diagnosis	11	16.74	14.46	3.981	62	>0.05
(iii) Triple/Multiple Diagnosis	53	10.80	8.20			
(ii) Dual Diagnosis	33	10.19	8.72	0.770	84	>0.05
(iii) Triple/Multiple Diagnosis	53	10.80	8.20			
F. TYPES OF FAMILY						
(i) Nuclear	70	10.28	8.86	2.975	95	<0.01
(ii) Non Nuclear	27	13.82	10.56			
G. SIZE OF FAMILY						
(i) <= 5 Members	73	10.10	7.97	2.729	95	<0.01
(ii) >= 6 Members	24	14.80	12.44			
Variables	**N**	**Mean**	**SD**	**T Value**	**Df**	**Probability**
H. SES:						
(i) Level One	54	13.26	10.90	4.586	80	<0.001
(ii) Level Two	28	8.90	7.26			
(i) Level One	54	13.26	10.90	4.226	67	<0.001
(ii) Level Three	15	8.49	5.00			
(ii) Level Two	28	8.90	7.26	0.361	41	>0.05
(ii) Level Three	15	8.49	5.00			
I. INFORMANT'S EDUCATION						
(i) Under Graduates	57	12.33	8.95	2.484	88	<0.05
(ii) Graduates	33	9.66	10.76			
(i) Graduates	33	9.66	10.76	0.150	38	>0.05
(ii) Post Graduates	7	10.14	5.41			
(i) Under Graduates	57	12.33	8.95	0.979	62	>0.05
(ii) Post Graduates	7	10.14	5.41			

Table 2. Mean Number of Consultations sought by Parents in Relation to Various Variables

Data was also compiled on specific type of specialists consulted by parents at various points of their treatment seeking. There were four classes of such consultations, viz., pediatricians, individual or institutional services and the AIISH respectively. Invariably, all cases had consulted AIISH since it was the last point of their contact at the time of this study. The distribution of frequency and types of specialists/institutional services approached by parents at various points of their treatment seeking was calculated for overall sample as well as sub samples (Table Three).

SNo	Type of Consultation	Levels of Consultation (*)								Total
		I	II	III	IV	V	VI	VII	VIII	
1	Pediatrician	61	28	13	10	6	3	-	-	121
2	AIISH	9	25	20	16	12	8	5	2	97
3	Institutional	15	23	16	9	6	3	1	-	73
4	Individual	12	12	14	8	3	1	1	-	51
	TOTAL	97	88	63	43	27	15	7	2	342
	Percentages	100	91	65	44	28	16	7	2	

(*): indicates the sequential level of consultation ranging from first to eighth;(Chi Square: 63.15; df: 12; p: <0.001; VHS)

Table 3: Distribution of Frequency and Types of Specialists Consulted by Parents of Children with Developmental Delays

The mean chronological ages of children at various points of their treatment seeking until their last consultation at AIISH in relation to various variables for overall and sub-samples was computed. Data was coded and compiled in Microsoft Excel format before subjecting them to statistical analysis by using freely downloadable statistical software/calculators on the web.

Results and Discussion

The results are presented and discussed under the following headings:

(i) Frequency of Consultations:

For the overall sample (N: 97), parents have sought 342 (Mean: 3.53) consultations from various specialists or service delivery institutions for their children with DDs (Table 1). In terms of severity, parents of children with moderate DDs (Mean: 4.00) have sought more frequent consultations than parents of children with mild DDs (Mean: 3.57) or Borderline DDs (Mean: 2.63). Probably, the parents of children with severe-profound DDs have sought lesser consultations (Mean: 2.91) owing to a subjective resignation that nothing can be done for these children. There is greater frequency of treatment seeking for females (Mean: 3.67) than males with DDs (Mean: 2.43). The parents of children with multiple diagnostic complaints and those from nuclear family backgrounds (Mean: 3.90) seek more consultations than children with singular diagnostic conditions or those from non-nuclear family backgrounds (Mean: 2.56). This may be explained by the palliative advice, supports and assurance that 'children will eventually grow into normalcy' often given in Indian joint or extended families. The influence of other associated socio demographic variables like SES, size of family and informant's education appears to be insignificant on the frequency of treatment seeking behaviors of parents in this sample.

(ii) Mean Time Lag between Consultations:

For the overall sample, parents seek at least one consultation per child in 11.09 months (SD: 9.50) for their children with DDs (Table 2). The time gap for consultations for children with severe-profound DDs (N: 11; Mean: 20.58; SD: 11.66) is greater than for children with mild DDs (N: 54; Mean: 9.77; SD: 7.95) or moderate DDs (N: 24; Mean: 10.47; SD: 9.86). Probably, parents of children with mild and moderate DDs still see a positive hope for improvement in their children (p: <0.001). The temporal proximity of consultation sought by parents of female children (N: 39; Mean: 10.38; SD: 7.75) is closer than for males (N: 58; Mean: 11.86; SD: 10.47) with DDs.

There appears to be a progressive linear relationship between chronological age of the DD children and mean time lag between consultations sought by parents. The older children above 49 months (N: 19; Mean: 19.80; SD: 10.70) are not taken as frequently for consultations as children below 24 months (N: 46; Mean: 5.71; SD: 4.68). The children with dual/multiple diagnostic labels (N: 33; Mean: 10.19; SD: 8.72) seek consultations with greater rapidity than those with single diagnosis (N: 11; Mean: 16.74; SD: 14.46). The parents from non-nuclear family backgrounds (N: 27; Mean: 13.82; SD: 10.56) and with small family sizes

(N: 24; Mean: 14.80; SD: 12.44) seek consultations with shorter time lag than parents from nuclear family (N: 70; Mean: 10.28; SD: 8.86) and large size families (N: 24; Mean: 14.80; SD: 14.44) (p: <0.01). Further, children with DDs from higher SES (N: 54; Mean: 13.26; SD: 10.90) and those with lower educational backgrounds (N: 57; Mean: 12.33; SD: 8.95) show greater time lag between consultations than parents from lower classes and higher educational backgrounds (p: <0.05).

(iii) Type of Services or Specialists Consulted:

Parents show a range of one to eight consultations for their children with a progressive decrement, both, in number and percentages of treatment seeking behaviors over various levels/points of consultations. The trend analysis reveals a gradual decrement to around 2 % of the cases seeking consultations by the eighth round from a base index of 97 cases (100 %) at first consultation (Table 3). Further, most consultations in this sample have been with pediatricians (N: 121; 35.38 %) followed by consultations at AIISH (N: 97; 28.36 %), other institutional services (like general or specialist hospitals) (N: 73; 21.35 %) and individual physicians/specialists (like orthopedics, ophthalmologists, psychiatrists, etc) (N: 51; 14.91 %) respectively (p: <0.001).

(iv) Mean Time Points for Consultation:

A series analysis of mean temporal points of consultation by parents for overall sample shows the mean age for first consultation at 12.52 (SD: 10.88) months. Gradually, this progresses at regular intervals to culminate at mean age for eighth consultation at 40 (SD: 4.00) months. The mean age for first and last consultation for children with borderline DDs is much earlier (9.50; SD: 7.79) than cases for severe-profound DDs (21.00; SD: 10.96). The mean age of first consultation is similar for males (12.66; SD: 11.92) and females (12.31; SD: 9.11). But, parents of males begin with more frequent and rapid consultations followed by a period of slackening, which is rather caught up in case of females with DDs. The mean age of last consultation for males halt much earlier to females (p: <0.01). The children with dual/multiple diagnosis have significantly more early and prolonged first to last consultation than children with singular diagnosis. The plurality of their problems may be the reason for parents to seek repeat consultations (p: <0.001).

There is apparently no difference in the age of consultation for children from nuclear families (Mean: 12.36; SD: 11.13) and/or non nuclear families (Mean: 12.96; SD: 10.18). However, children from nuclear families attrition rapidly by their fifth consultation in comparison to those from nuclear family backgrounds, who continue to seek treatment up to their eighth consultation. Further, children from small families seek their first consultation early and move rapidly to their last consultation in contrast to children from large families (p: <0.001). The children form higher social class seek their first consultation much later than children from lower class as also they continue to go for their last consultation at comparatively later date. Likewise, parents with higher educational levels seek their first consultation much later than parents with lower educational qualifications.

Conclusion

In sum, the present study highlights that parents have sought 342 (Mean: 3.53) consultation for their children with DDs. The frequency of treatment seeking behaviors is influenced by variables like sex, diagnosis or severity of their child's condition; financial variables like type or size of family, parents education, etc. On an average, parents seek at least one consultation per child in 11.09 months with a progressive decrease in their number and percentages of their treatment seeking behaviors over time. The mean age of first consultation for the children is 12.52 (SD: 10.88), which progresses at regular intervals to culminate at mean age for their eighth consultation at 40 months (SD: 4.00).

These findings appraise the importance and need to restrict the superfluous shopping sprees of parents having children with DDs. Rather, the emphasis must be on improving quality of services so that parents are weaned away from the tendency to waste the precious and early years of their children. They may have to be guided to concentrate on the

implementation of home based early infant stimulation programs. This study also throws the need to investigate the mean age of authentic consultation even for older children with communication disorders and mental disabilities.

References

Akhtar, S., and Verma, V.K. (1972). Guidelines for Parents of Mentally Retarded Children. Indian Journal of Mental Retardation. 5. 1 & 2. 75-88.

Chaturvedi, S.K., and Malhotra, S. (1982). Treatment Seeking Behaviors of Parents of Mentally Retarded Children. Indian Journal of Clinical Psychology. 9. 2. 211-216.

Peshawaria, R., Menon, D.K., Ganguly, R., Roy, S., Pillay, R.P.R.S., Gupta, A., and Hora, R.K. (1994). Moving Forward: An Information Guide for Parents of Children with Mental Retardation. Secunderabad: National Institute for he Mentally Handicapped.

Venkatesan, S. (2007). Children with Developmental Disabilities: A Training Guide for Parents, Teachers and Caregivers.4th Print. New Delhi: Sage Publications.