

A Comparative Study of Pathways to Care for Children with Specific Learning Disability and Mental Retardation

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ABSTRACT

Context: Early intervention in specific learning disability (SpLD) results in better outcome and prevents comorbidity. Understanding the pathways is therefore important. **Aims:** To study and compare the pathways to care for children with SpLD and mental retardation (MR) before reaching a tertiary care center. **Settings and Design, Material and Methods:** A cross-sectional study was conducted for pathways to care of two groups: SpLD and MR with 50 children in each group from 8 to 16 years. MINI-KID for comorbidity and Goldberg's pathway to care instrument was used. The groups were divided into early contact (up to three carers) and late contact (more than three carers) and compared. **Statistical Analysis:** Data were analyzed using Statistical Packages for Social Sciences (SPSS) version 10.0 software. **Results:** Majority ($n = 24$ or 48%) of SpLD children visited "others" (teachers, neighbors, relatives, and guardians of fellow classmates) as first carer. Allopathic practitioners were the first choice for MR children ($n = 31$ or 62%). Six children (12%) in SpLD group and 10 of MR (20%) group have seen either traditional practitioner or healer as first carer. Maximum referral to the tertiary center in both groups was done by others (62% in SpLD and 56% in MR group). Early contacts in SpLD group belonged to younger age group ($P = 0.01$). While comparing both groups on the basis of early and late contact, mother's education was found to be significant in early contact group ($P = 0.036$) and having comorbidity was significant among late contacts ($P = 0.038$). **Conclusions:** The pathways to care for SpLD children are more or less similar to MR children whose parents recognize MR late. Both the groups visit multiple carers including traditional healers substantiating the strong belief for supernatural causation of developmental disorders in India.

Key words: Care, mental retardation, pathways, specific learning disability

INTRODUCTION

Specific learning disability (SpLD) is a hidden disability. Untreated SpLD can lead to school refusal, conduct, and substance abuse disorder.^[1] The earlier the children

with SpLD were identified and intervened, the less severe their problems are likely to be.^[2] Phonologically mediated reading intervention has shown improvement in reading fluency.^[3] Mental retardation (MR) is usually recognized by delaying development milestones or abnormal facial features.^[4] However, mild MR may go unnoticed.^[5]

The present study was undertaken to understand the pathways and barriers. Taking minimum age criteria of 8 years, it also attempted to identify sources of delay for children with MR who fail to seek early care. We compared the two pathways to detect any significant difference between the two.

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MATERIALS AND METHODS

The study was conducted in a tertiary care hospital for mental health and neurological ailments in India. The subjects for the study were selected by purposive sampling method. The children who were worked up in detail for SpLD and MR and then referred to Clinical Psychology Department for LD and intelligent quotient (IQ) assessment and those who fulfilled the selection criteria formed the subject group. National Institute of Mental Health and Neuro Sciences (NIMHANS) index of SpLDs was used for LD assessment, while IQ was measured using various standard scales. The study was approved by the ethical committee of the institute. Informed consent and assent (wherever possible) was taken.

Two groups were created for the purpose of study: 1) SpLD Group and 2) MR Group. Each group consists of 50 subjects of both sexes with chronological age from 8 to 16 years. We took minimum age criteria as 8 years because SpLD cannot be conclusively diagnosed before 8.^[6] Children with at least one reliable guardian were selected, as our study was based on history taken from the past. Children with overt neurological illness were excluded as this might contribute to bring them early for tertiary care. For MR group, children with IQ less than 70 were included as per International Classification of Diseases (ICD)-10 criteria.^[7] Comorbid autism was excluded. A detailed history and sociodemographic data were taken. The children were then interviewed using MINI-KID for presence of any comorbid axis I disorder.^[8] To understand the pathways, we have used Pathways to Care Instrument devised by Goldberg and Huxley.^[9] For our study, we have modified and excluded certain questionnaires which were not relevant in developmental disorders. The data were analyzed using the Statistical Packages for Social Sciences (SPSS) version 10.0 software.^[10] A *P*-value of <0.05 was considered statistically significant.

RESULTS

Table 1 shows the sociodemographic pattern of both SpLD and MR groups. Both the groups did not differ significantly except mother's education which was less in MR group (*P* = 0.004).

The pathways followed by the SpLD and MR children have been depicted in Figures 1 and 2, respectively. Most of SpLD children's parents (*n* = 24 or 48%) consulted "others" (which include teachers, neighbors, relatives, and guardians of fellow classmates) as first contact and this group referred the maximum cases to our tertiary center (*n* = 31 or 62%). Next source of referral were the allopathic practitioners whom 20

Table 1: Sociodemographic characteristics

Sociodemographic variables	SpLD		MR		Chi-square value	<i>P</i> -value
	<i>n</i> =50	<i>n</i> (%)	<i>n</i> =50	<i>n</i> (%)		
Gender						
Male	38	76	31	62	2.29	0.13
Female	12	24	19	38		
Age (years)						
8-10	22	44	21	42	0.2	0.90
11-13	13	26	15	30		
14-16	15	30	14	28		
Religion						
Hindu	37	74	40	80	2.84	0.24
Muslim	8	16	9	18		
Christian	5	10	1	2		
Background						
Urban	28	56	28	56	3.27	0.20
Semiurban	14	28	8	16		
Rural	8	16	14	28		
Guardian						
Father/mother	4	8	5	10	0.12	0.73
Both parents	46	92	45	90		
Others				0		
Education of father						
Illiterate	6	12	13	26	6.32	0.18
Primary	9	18	12	24		
Up to tenth standard	18	36	17	34		
Up to graduation	12	24	6	12		
Postgraduate	5	10	2	4		
Education of mother						
Illiterate	5	10	16	32	15.52	0.004
Primary	8	16	13	26		
Up to tenth standard	22	44	17	34		
Up to graduation	9	18	4	8		
Postgraduate	6	12	0	0		
Occupation of father						
Not working	1	2	2	4	2.86	0.58
Agriculturist	5	10	8	16		
Private employee	19	38	13	26		
Government employee	8	16	6	12		
Self-employed	17	34	21	42		
Occupation of mother						
Not working	28	56	30	60	2.97	0.56
Agriculturist	4	8	5	10		
Private employee	9	18	4	8		
Government employee	2	4	1	2		
Self-employed	7	14	10	20		
Monthly income						
Up to 3,000	14	28	18	36	5.20	0.07
3,000-10,000	18	36	24	48		
10,000 and above	18	36	8	16		
Positive family history	6	12	7	14	0.09	0.77
Comorbidity present	11	22	14	28	0.48	0.49

(40%) children contacted first. Traditional healers (religious and faith healers) were favorites for four (8%) children and nine (18%) children consulted them after seeing others. For two children (4%), traditional

practitioners (which include homeopathic, ayurvedic or unani practitioner) were the first carer. Fourteen children (28%) sought consultation from others after visiting allopathic practitioners while nine (18%) did the opposite [Figure 1].

For MR children, allopathic practitioners were the first choice for 31(62%). However, they constitute 44% ($n = 22$) of source of referral as 56% ($n = 28$) were referred by others. Fifteen children (30%) went to “others” from allopathic doctors, while eight children (16%) did the opposite. Parents of six children (12%) favored traditional healer, while four children (8%) preferred traditional practitioner as primary carer [Figure 2].

Table 2 shows the comparison between early and late contact to the tertiary center for SpLD group. Early contact was defined as those who came to our tertiary care center after visiting less than or equal to three carers. For more than three carers, it is late contact. This cut-off point of three carers was decided taking the median value. Twenty-six (52%) SpLD children contacted early, while 24 (48%) came late. Children in the age group of 8-10 years were brought to the

Table 2: SpLD correlation between sociodemographic data and pathways to care

Sociodemographic variables	Early contact to center	Late contact to center	Chi-square value	P-value
Total children	26	24		
Gender				
Male	19	19	0.25	0.61
Female	7	5		
Age (years)				
8-10 years	15	7	8.94	0.012
11-13 years	8	5		
14-16 years	3	12		
Religion				
Hindu	16	21	5.30	0.07
Muslim	7	1		
Christian	3	2		
Background				
Urban	17	11	3.21	0.20
Semiurban	7	7		
Rural	2	6		
Primary caregiver				
Father/mother	2	2	0.007	0.93
Both parents	24	22		
Education of father				
Illiterate	1	5	7.40	0.12
Primary	6	3		
Up to tenth standard	12	6		
Up to graduation	6	6		
Postgraduate	1	4		
Education of mother				
Illiterate	4	1	3.73	0.44
Primary	3	5		
Up to tenth standard	13	9		
Up to graduation	4	5		
Postgraduate	2	4		
Occupation of father				
Not working	0	1	3.47	0.48
Agriculturist	2	3		
Private employee	12	7		
Government employee	5	3		
Self-employed	7	10		
Occupation of mother				
Not working	17	11	6.28	0.18
Agriculturist	1	3		
Private employee	2	7		
Government employee	1	1		
Self-employed	5	2		
Monthly income				
Up to 3,000	6	8	2.43	0.30
3,000-10,000	12	6		
10,000 and above	8	10		
Positive family history	4	2	0.59	0.44
Comorbidity present	6	5	0.04	0.85

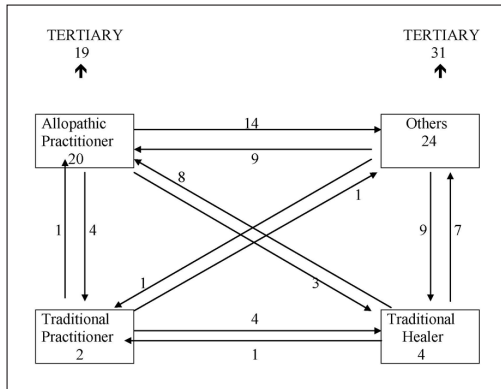


Figure 1: Specific learning disability (SpLD) pathways

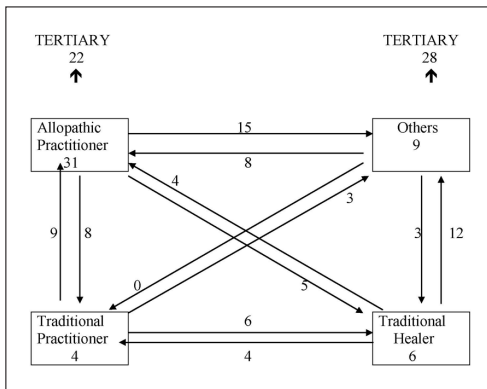


Figure 2: Mental retardation (MR) pathways

$P < 0.05$ = Significant, SpLD — Specific learning disability

center early, while those belonging to 14-16 years age group came late. The difference is statistically significant ($P = 0.01$). There is no significant difference between the two groups on background, education and occupation of parents, monthly income, positive family history, or comorbidity ($P > 0.05$).

Tables 3 and 4 shows the comparison between SpLD and MR group on the basis of early and late contact. Twenty-six children in SpLD group and 28 in MR group had early contact, while 24 SpLD children and 22 MR children came late. The early contact group differed significantly on education of mother, where six out of 26 mothers in SpLD group had minimal graduate qualification and none had such in MR group ($P = 0.036$). The late contact group had statistically significant difference on psychiatric comorbidity as 11 out of 22 in MR group had a psychiatric comorbidity compared to five out of 24 in SpLD ($P = 0.038$).

We also observed other interesting findings (not shown in the tables). Majority of the SpLD children were in fourth standard (24%) followed by ninth standard (18%) when they contacted us. The mean time to see the first carer and tertiary carer was 1.08 and 3.39 years, respectively. For majority (74%), curriculum was state syllabus and medium of instruction was English. Majority (64%) of SpLD children presented with poor academics, while 14% with symptoms of comorbidity. Parents of 23 (46%) children were not aware of the facility available in this tertiary care hospital, 15 (30%) were hoping for spontaneous resolution, eight (16%) had lack of faith in allopathic system, and four (8%) mentioned stigma as the reason for coming late. In the MR group, 43(86%) had mild MR and main presenting feature was poor intelligence (32%) followed by symptoms of comorbidity (22%).

DISCUSSION

The pathways followed by SpLD children matches with mentally retarded children of older age group. Both visit multiple carers which include traditional practitioner, healers, and allopathic practitioner. Teachers, friends, neighbors, relatives, and guardians of other children (included under "others") play a crucial role in guiding to the right center. Role of teachers assumes significance as they form the majority of the "others" group. SpLD children who come early for care are of younger age group. Having a positive family history or comorbidity does not bring them early to the proper carer. SpLD children seek help early when their mothers are well-educated. Older children with MR seek help when comorbid symptoms start appearing.

Table 3: Comparative chart of children who get early contact: SpLD vs MR

Sociodemographic variables	SpLD	MR	Chi-square test	P-value
No. of children	26	28	0.16	0.69
Gender				
Male	19	18	0.48	0.49
Female	7	10		
Age (years)				
8-10	15	14	0.33	0.85
11-13	8	10		
14-16	3	4		
Religion				
Hindu	16	21	1.68	0.43
Muslim	7	6		
Christian	3	1		
Background				
Urban	17	13	4.07	0.13
Semiurban	7	7		
Rural	2	8		
Primary caregiver				
Father/mother	2	3	0.15	0.70
Both parents	24	25		
Education of father				
Illiterate	1	8	6.66	0.16
Primary	6	7		
Up to tenth standard	12	8		
Up to graduation	6	4		
Postgraduate	1	1		
Education of mother				
Illiterate	4	9	10.30	0.036
Primary	3	8		
Up to tenth standard	13	11		
Up to graduation	4	0		
Postgraduate	2	0		
Occupation of father				
Not working	0	2	6.97	0.14
Agriculturist	2	3		
Business	12	6		
Government employee	5	3		
Self-employed	7	14		
Occupation of mother				
Not working	17	15	1.08	0.90
Agriculturist	1	2		
Business	2	2		
Government employee	1	1		
Self-employed	5	8		
Monthly income				
Up to 3000	6	11	2.77	0.25
3,000-10,000	12	13		
10,000 and above	8	4		
Positive family history	4	5	0.06	0.81
Negative family history	22	23		
Comorbidity present	6	3	1.48	0.22
Comorbidity absent	20	25		

$P < 0.05$ = Significant. SpLD — Specific learning disability, MR — Mental retardation

Table 4: Comparative chart of children who get late contact: SpLD vs MR

Sociodemographic variables	SpLD	MR	Chi-square test	P-value
No. of children	24	22	0.05	0.83
Gender				
Male	19	13	2.18	0.14
Female	5	9		
Age (years)				
8-10	7	7	0.1	0.95
11-13	5	5		
14-16	12	10		
Religion				
Hindu	21	19	3.02	0.22
Muslim	1	3		
Christian	2	0		
Background				
Urban	11	15	5.04	0.08
Semiurban	7	1		
Rural	6	6		
Primary caregiver				
Father/mother	2	2	0.008	0.93
Both parents	22	20		
Education of father				
Illiterate	5	5	4.82	0.31
Primary	3	5		
Up to tenth standard	6	9		
Up to graduation	6	2		
Postgraduate	4	1		
Education of mother				
Illiterate	1	7	9.14	0.06
Primary	5	5		
Up to tenth standard	9	6		
Up to graduation	5	4		
Postgraduate	4	0		
Occupation of father				
Not working	1	0	6.97	0.14
Agriculturist	3	5		
Business	7	7		
Government employee	3	3		
Self-employed	10	7		
Occupation of mother				
Not working	11	15	4.31	0.37
Agriculturist	3	3		
Business	7	2		
Government employee	1	0		
Self-employed	2	2		
Monthly income				
Up to 3,000	8	7	4.03	0.13
3,000-10,000	6	11		
10,000 and above	10	4		
Positive family history	2	2	0.008	0.93
Negative family history	22	20		
Comorbidity present	5	11	4.31	0.038
Comorbidity absent	19	11		

$P < 0.05$ = Significant. SpLD — Specific learning disability, MR — Mental retardation

Majority of SpLD children's parents preferred "others" of which teachers were the major constituent. The role of teachers is crucial in pathways to care for child and adolescent psychopathology.^[11] Altogether 46 out of 50 children (92%) took other's support before reaching the tertiary center. They referred the maximum children to the center. Several pathways of care studies in adults have reported this group to be major referring agency.^[12] We found similar pattern of referral in children also. Many parents revealed about awareness being created by television (TV) programs. The fact that 14 children (28%) came to "others" after seeing allopathic practitioner highlights their significance in help seeking.

In MR group, it is again "others" who did the maximum referral (56%). A similar trend to see "others" after consulting allopathic doctors was seen. This is not an unexpected finding since we included MR children from 8 years onwards and majority (86%) of them were of mild category. Parents seemed to be confused about nature of problem and whom to approach.

Six children in SpLD group and 10 of MR group have seen either traditional practitioner or healer as first carer [Figures 1 and 2]. While 22 SpLD children met them as subsequent carer, 26 did so in MR group. This is an important finding of our study which shows that there is not much difference in pattern of seeking help between the groups. Many parents of SpLD children perceived the problem as poor intelligence and opted for alternative care. Parents of SpLD children took their children to temples where priests touched the tongue with divinely blessed rice grains as a mode of cure. The sprinkling/ingestion of holy water and chanting mantra was also reported. Help seeking pattern in developmental disorders depend on the cultural model of illness prevailing in that region.^[13] A belief regarding supernatural causation of illness will promote help seeking from traditional means, and biological causation about psychiatric disorder will favor help seeking behavior from a professional.^[14] An earlier Indian study found that parents failed to understand the biological basis of SpLD even after exposure to educational intervention.^[15]

The SpLD children who made early contact were of younger age group. Interestingly, we did not find any significant correlation between positive family history, comorbidity, and urgency of seeking care in contrast to other care pathways studies in children.^[16]

While comparing the two groups (SpLD and MR) on early and late contact, mother's education was found to be a significant factor in seeking help early. Our finding

is in accordance with a 10-year follow-up study of learning disabled students in USA.^[17] Also, MR children who came late had more psychological comorbidity. In our study, majority was mild MR and main presenting features were poor intelligence and symptoms of comorbidity. It is apparent that parents sought specialized care only when these children developed behavioral problem and were difficult to manage. This matches the views expressed by authors of an earlier study done in India.^[18] Finally, factors like unawareness of facility, hope for spontaneous resolution, stigma of coming to a psychiatric hospital, and more faith in traditional cure methods dithered them from seeking intervention from tertiary care center.

Majority of SpLD children were in fourth and ninth standard at the time of contact. The bimodal peak could be because it is during fourth standard period when children “read to learn” and deficit becomes apparent. The second peak at ninth standard is when pressure to perform in the first board examination makes parents to bring the children for proper care. There was also a considerable time lag between problem perceived by parents and care sought. However, the mean delay in diagnosis in our study (3.39 years) is better than an earlier Indian study which found the delay to be 5.8 years.^[19]

To our knowledge, this study is the first of its kind on help seeking pattern of children with SpLD in Indian context. The strength of our study is that it has taken subjects as SpLD or MR diagnosed on standard scales by qualified psychologists. The limitation is that it was conducted in a tertiary level center and the findings may not reflect the attitude of general population.

Findings from our study substantiate the role of teachers as gatekeepers. It implicates that teachers should be trained about presenting features of learning disability, when to suspect it. Our second suggestion is to create awareness through electronic and print media. Films like “Tare Zameen Par” were successful in conveying these messages. Topics on SpLD can be discussed during parent-teacher meetings. Finally, strengthening collaboration between traditional practitioners, general practitioners (GPs), pediatricians, neurologists, and mental health professionals would help in removing the unnecessary delay in referral.

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