


Dysfunction among Families of Children with Intellectual Disability in India Using Systems Model: Prevalence, Pattern, and Severity of Impairment

Pastin Pushpa Rani, Helen Charles, Paul Swamidhas Sudhakar Russell¹, K. G. Selvaraj², Priya Mary Mammen¹, Sushila Russell¹, Muttathu K. C. Nair³

ABSTRACT

Objectives: Family dysfunction is observed in families with children with intellectual disability (ID). We study the prevalence, pattern of dysfunction, and severity of impairment in these special families using Systems approach. **Methods:** Sixty-two special families (a child with ID) and 62 typical families (all children with typical development) were included in the present study. The presence of ID was confirmed and quantified with the Binet–Kamat Scale of intelligence or Gesell’s Developmental Schedule and Vineland Social Maturity Scales among the special families. In the typical families, brief ID scale was used to rule out ID. Prevalence, pattern, and severity of family dysfunction were assessed using Family Apgar Scale, Chicago Youth Development Study Family Assessment Scale and Global Assessment of Relational Functioning Scale, respectively. Appropriate bivariate analyses were used. **Results:** About 53% of special families and 19% of typical families had family dysfunction. About 21% of special families and 71% of typical families had the satisfactory relational unit. Areas of adaptability, partnership, growth, affection, resolve, beliefs about family, beliefs about development, beliefs about purpose, cohesion, deviant beliefs, support, organization, and communication were significantly different between special and typical families. The functional impairment was significantly more in the special families. **Conclusion:** Family dysfunction is more prevalent among special families in India using systems approach. These families should be screened for dysfunction, and family therapy be prescribed when required.

Key words: Family dysfunction, impairment, India, intellectual disability, prevalence, systems model

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Department of Psychiatric Nursing, College of Nursing, Christian Medical College, ¹Department of Psychiatry, Child and Adolescent Psychiatry Unit, Christian Medical College, ²Department of Biostatistics, Christian Medical College, Vellore, Tamil Nadu, ³Child Development Centre, Thiruvananthapuram Medical College, Thiruvananthapuram, Kerala, India

Address for correspondence: Prof. Paul Swamidhas Sudhakar Russell
Child and Adolescent Psychiatry Unit, Christian Medical College, Vellore - 632 001, Tamil Nadu, India.
E-mail: russell@cmcvellore.ac.in

INTRODUCTION

The families of children with intellectual disability (ID) function differently than those with typically developing children.^[1] This difference in functioning can be either adaptive or maladaptive in nature and thus more functional or dysfunctional.^[2,3] In the Indian context, the presence of challenging behaviors in the children with ID, gender of the child and perceived burden makes the family dysfunctional functioning.^[4-6] Maladaptive family functioning results in poor psychological and physical health of the family members.^[7] Understanding the nature and development of such maladaptive family functioning is critical to formulating effective intervention in these families.^[8]

Systems approach for family functioning as proposed by the Circumplex Model focuses on the three dimensions of cohesion, flexibility, and communication and these components are often impaired in children with developmental disabilities. However, as the construct family dysfunction is laden with cultural undertones and hence, we compared the prevalence, pattern, and severity of the family dysfunction among families with children with ID with generally developing children in India using the systems model.

METHODS

Setting and sample

This prospective study was conducted at the facility for children with ID, Child and Adolescent Psychiatry Unit of Christian Medical College, Vellore, a teaching hospital in South India. As per the *a priori* sample size calculation, 124 family members (62 from the special need family [with an ID child] and typical family [all children with a typical development]) were recruited into the study if the family member had a working knowledge of Tamil or English. Families were excluded if they were unwilling to participate, if the child with ID was adopted, or the child/participating family member had a mental illness (as they confound family dysfunction in this culture). Data were collected from the families enrolled for either therapy program or drop-in outpatient clinic. While the members from special families were recruited using nonprobability purposive sampling, members of typical families were recruited by simple random sampling, using a computer-generated random table and door-to-door survey in the community around the Facility. ID in these children in the community was ruled out using a brief measure for ID.

Measures and Assessment

The Binet–Kamat Scale of intelligence^[9] or Gesell's Developmental Schedule^[10] was used to confirm the diagnosis of ID and further quantify. Vineland

Social Maturity Scale (VSMS)^[11] was administered for profiling and quantifying the social skills. Both these measures were administered to the child with ID in the special families. The different components of the Circumplex Model were assessed using the Family Apgar, Chicago Youth Development Study Family Assessment Scale (CYDS-FAS) and Global Assessment of Relational Functioning (GARF) Scale. Family Apgar Scale^[12] was administered to evaluate adaptability, partnership, growth, affection, and resolve in the family. A score of <6 was used in this study to define family dysfunction. CYDS-FAS^[13] was used to assess the family adaptability, cohesion, religious values, and somatization tendencies. This measure was used to identify the family dysfunction. GARF Scale^[14] was used as an overall measure of the impairment caused on a hypothetical continuum ranging from competent, optimal relational functioning to a disrupted, dysfunctional relationship. These three measures were given to the primary caregiving parent in the special and typical families. Brief ID Scale^[15] is 10-item measure, which was administered to all the children in the typical families in the community, to rule-out ID. A screening score of ≥ 5 has sensitivity and specificity of 71% and 81%, respectively, for identifying ID.

The diagnosis of ID was established for all children attending the Facility by a team of experienced psychologist with Binet–Kamat test or Gesell Developmental Schedules and VSMS. Another researcher independent to the psychologists' findings administered, in a face-to-face interview, the (CYDS-FAS), Family Apgar Scale and GARF Scale to the parents. Written informed consent was obtained for all the participants before the researcher collected the data. The local Institutional Review Board had reviewed the protocol and gave permission for the study.

Data-analysis

Only the assessments with the primary care-giving parent were used in the analysis, to avoid pseudo-replication of data. Descriptive statistics (mean with standard deviation [SD]) was used to assess the level of family functioning. Independent *t*-test and Chi-square test were used to compare the continuous and categorical variables, respectively, between special and typical families. $P < 0.05$ (two-tailed) was considered statistically significant. Data were analyzed using SPSS (version 19) IBM SPSS (version 19).

RESULTS

Participant characteristics

Of the 124 study parents, 84.7% belonged to the 26–45-year age group. Mothers (88.7%) outnumbered

the fathers (11.3%), equal number of parents from urban (50.8%) and rural (49.2%) residential area were noted in the study. About 41.4% of the parents were from low, 54.8% from middle and another 4.0% were from high socioeconomic status. Of the 124 children, 25.4% were aged between 4 and 6 years, 52.4% between 7 and 12 years, and 22.6% were between 13 and 16 years. Boys and girls were 51.6% and 48.4%, respectively. Of 62 children with ID, 38.8% of them had mild, 35.4% had moderate, 17.8% had severe, and 8.0% had profound disability. None of the children from typical families had an ID.

Family and relational dysfunction

The mean (SD) of the Family Apgar Score for special families and typical families was 4.90 and 7.19, respectively, which was a significantly different ($P = 0.0001$). Nearly half (53.23%) of the special families were found to be dysfunctional, whereas 80.65% of typical families were identified to be satisfactory. There was a statistically significant difference in the family functioning between the family members of special families and typical families in regard to adaptability ($P = 0.05$), partnership ($P = 0.0001$), growth ($P = 0.01$), affection ($P = 0.004$), and resolve ($P = 0.0001$) [Table 1].

There was a statistically significant difference in the family functioning between the special and typical families in the areas of beliefs about family ($P = 0.001$),

beliefs about development ($P = 0.01$), beliefs about purpose ($P = 0.001$), cohesion ($P = 0.04$), deviant beliefs ($P = 0.004$), support ($P = 0.03$), organization ($P = 0.04$), and communication ($P = 0.003$) in the CYDS-FAS [Table 2].

Impairment of relational functioning

There was a significant difference in the relational functioning ($P = 0.0001$) as assessed by GARF between the special and typical families. Only a small proportion of participants (20.97%) from special families reported satisfactory relational functioning while the majority of the participants (70.97%) from typical families reported satisfactory relational functioning [Table 2].

DISCUSSION

This study documents that family dysfunction is much prevalent in the families with a special child using the broad framework of systems approach. The patterns of dysfunction are different between families with special and typical child and such dysfunctions result in significant impairment among family members.

Our finding that a significant number of special families were dysfunctional had been noted in India in the past,^[16] who reported dysfunction in 48.2% of families in the areas of emotional status, role functions, support and social functions. Despite the above finding, surprisingly the majority of parents from

Table 1: Family dysfunction based on family Apgar

Relational dysfunction	Family Apgar		Statistics.(t)	P
	Special family (n=62), n (%)	Typical family (n=62), n (%)		
Total				
Dysfunctional family	33 (53.23)	12 (19.35)	-6.66	0.0001
Satisfied family	29 (46.77)	56 (80.65)		
Adaptability				
Hardly ever	16 (25.8)	10 (16.2)	-1.96	0.05
Sometimes	37 (59.6)	35 (56.4)		
Almost always	9 (14.6)	17 (27.4)		
Good partnership				
Hardly ever	17 (27.4)	4 (6.4)	-4.64	0.0001
Sometimes	25 (40.4)	15 (24.2)		
Almost always	20 (32.2)	43 (69.4)		
Growth				
Hardly ever	22 (35.4)	9 (14.6)	-2.88	0.01
Sometimes	20 (32.3)	21 (33.8)		
Almost always	20 (32.3)	32 (51.6)		
Affection				
Hardly ever	14 (22.6)	4 (6.4)	-2.94	0.004
Sometimes	23 (37.0)	20 (32.2)		
Almost always	25 (40.4)	38 (61.4)		
Resolve				
Hardly ever	25 (40.4)	5 (8.0)	-5.52	0.0001
Sometimes	23 (37.0)	19 (30.7)		
Almost always	14 (22.6)	38 (61.3)		

Table 2: Different areas of family dysfunction based on Chicago Youth Development Study Family Assessment Scale and impairment based on the Global Assessment of Relational Functioning scale

	Special family (n = 62), n (%)	Typical family (n = 62), n (%)	Statistics (t)	P
CYDS-FAS subscales				
Beliefs about the family				
Positive	51 (82.2)	56 (90.4)	-3.491	0.001
Neutral	10 (16.2)	6 (9.6)		
Negative	1 (1.6)	0		
Beliefs about the development				
Positive	51 (82.2)	56 (90.4)	-2.546	0.01
Neutral	10 (16.2)	6 (9.6)		
Negative	1 (1.6)	0		
Beliefs about purpose				
Positive	52 (83.8)	57 (92.0)	-3.396	0.001
Neutral	10 (16.2)	5 (8.0)		
Negative	0	0		
Cohesion				
Highly cohesive	33 (53.2)	43 (69.4)	-2.103	0.04
Fairly cohesive	28 (45.2)	19 (30.6)		
Poorly cohesive	1 (1.6)	0		
Deviant beliefs				
More deviant beliefs	3 (4.8)	8 (13.0)	-2.955	0.004
Some deviant beliefs	38 (71.2)	46 (74.2)		
No deviant beliefs	21 (33.8)	8 (13.0)		
Support				
Good family support	43 (69.4)	46 (74.2)	-2.272	0.03
Fair family support	17 (27.4)	15 (24.2)		
Poor family support	2 (3.2)	1 (1.6)		
Organization				
Well organized	33 (53.2)	45 (72.6)	-2.137	0.04
Fairly organized	28 (45.2)	17 (27.4)		
Poorly organized	1 (1.6)	0		
Communication				
Good communication	30 (48.4)	48 (77.4)	-3.046	0.003
Fair communication	21 (33.8)	10 (16.2)		
Poor communication	11 (17.8)	4 (6.4)		
GARF				
Impairment				
Satisfactory	13 (20.97)	44 (70.97)	-6.66	0.0001
Unsatisfactory	25 (40.33)	13 (20.97)		
Clearly dysfunctional	11 (17.74)	4 (6.45)		
Seriously dysfunctional	4 (6.45)	1 (1.61)		
Too dysfunctional	9 (14.51)	0		

CYDS-FAS – Chicago Youth Development Study Family Assessment Scale; GARF – Global Assessment of Relational Functioning

special families expressed positive beliefs, high family cohesion, and good support from the family. These findings are in congruence with a previous study,^[17] which has speculated to happen due to the need to form new identities, attempts to derive existential meaning from the situation and the development of a sense of personal control.

The reason for family dysfunction was poor adaptability, poor partnership, lack of growth, lack of affection, and poor resolve. Such findings have been recorded in the past in similar family contexts.^[18] Our finding of poor relational functioning also has been documented in the past.^[3]

The limitations of the study are that the special families were recruited from a tertiary facility and hence have compromised generalizability and the family dysfunction measures were not adapted to the culture. The strengths of the study were that the measures to quantify intelligence quotient/adaptive skills of children and measure to rule out ID were validated for the Indian culture. Moreover, we used specific measures to quantify each component of family functioning, using independent raters for family dysfunction and risk factors. We conclude that family dysfunction is noted in half the special families, only a handful of special families have a satisfactory relationship unit, their dysfunctional

profile is different from typical families as well as with more severe impairments. For future direction, we suggest the Circumplex Model (Olsen, 1999) be studied in depth as family psychopathology has been documented among special families now in India and other cultures as well.^[19] These families with significant dysfunction should be identified, and family therapy should be provided. Family therapy models have to be designed based on the psychopathologies we have documented in the special families.

CONCLUSION

Family dysfunction is more prevalent, in many areas of the family functioning, among special families in India using systems approach. These families should be screened for dysfunction, and family therapy be prescribed when required.

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Conflicts of interest

There are no conflicts of interest.

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