



The Level of Social Support Perceived by the Parents of Children with Intellectually Disabled in Kozhikode District of Kerala, India

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Abstract

Background: Intellectual disability was recognised in ancient Indian literature, but organised services have a history of just five decades. India shares many features of low- and middle-income (LAMI) countries regarding intellectual disability. **Objectives:** This study attempts to analyze the social support available among parents of children with intellectual disabilities and compare the perceived social support level between fathers and mothers of children with intellectual disabilities in the Kozhikode district of Kerala. **Methodology:** Primary data was gathered through a field survey, which was conducted during December 2019 to February 2020, and secondary data was collected from research papers, books, and internet websites etc. The interview schedule was used for the study prepared by the research scholar and supervisor. Both, the qualitative and quantitative method has been used during the data collection. Out of 370 respondents, 148 were selected through the purposive sampling technique. **Results:** The result shows that the majority of the respondents (37.2%) perceived a higher level of social support. In the study area, the majority of the respondents were found to have perceived informal social support from family members, neighbours, through awareness programmes, guidance and other form of support from parents of same children. The study also reveals that the mothers and fathers perceived the same level of social support. **Conclusion:** So, the parents' perceived social support in their environment is satisfied and makes it easy to manage stress. **Suggestion:** The parents should need to perceive formal social support also.

Keywords: Children, Intellectual Disability, Parents, Social Support

I. INTRODUCTION

Social support is the perception and actuality that one is cared for, has assistance available from other people, and most popularly, that one is part of a supportive social network. These supportive resources can be emotional (e.g., nurturance), informational (e.g., advice), or companionship (e.g., sense of belonging); tangible (e.g., financial assistance) or intangible (e.g., personal advice). Social support can be measured as the perception that one has assistance available, the actual received assistance, or the degree to which a person is integrated in a social network. Support can come from many sources, such as family, friends, pets, neighbors, coworkers, organizations, etc.

Societal support is a relief given to us by our family, friends, and others. The comfort provided to us from side to side these resources is support for us. Social support can be significant, materialistic, emotional and informational (Zimet et al., 1988 & Edwards, 2004). Sociologist Emile Durkheim primarily gave the concept of social support in 1894 as social ties, which were further divided into 2 aspects; perceived and received social support. Perceived support is getting categorical acceptance from society, being positive and satisfied with one's life, and living a meaningful life. Support works as a buffer in an individual's life and permits constructive sense that predicts well-being, development and positive growth (Ho et al., 2008).

Social support patterns for families children with a developmental disability are divided into 2 supports; formal and informal. Formal social support is perceived as to be given by professionals, and informal support is perceived as family members, social groups, and friends integrated into the family's daily lives. Formal support resources can be family therapists, family education professionals etc. Informal support provided by family members, family support groups, neighbours and friends (Dunst et al., 1986).

Informal support is more competent than formal support for protecting stress's negative effects (Boyd, 2002). Researchers reported that although relatives, friends, and neighbours are willing to provide emotional support to the family with a developmental disability having Child, the support level towards practice is low (Werner et al., 2009).

As the social support level of families with a developmental disability having child increases, it is seen that parents behave more positively towards a child, interact with the child more positively while playing games and behaviour development of the disabled child is more positive. Also, children have less physical limitations, behavioural problems, and more social acknowledgement and personality traits if their parents have a more supportive social network (Dunst et al., 1986). Limited social support causes withdrawal from stress-reducing social activities, negatively affecting (Meral & Cavkaytar; 2012).

II. REVIEW OF LITERATURE

This literature review aims to identify some key documents reflecting a range of social support perspectives available to parents of children with intellectual disability. The general idea of the relevant literature works has helped the researcher determine the research objectives, outline the research design, and decide the overall methodological parameters.

Habib, H. A. et al., (2016) examined the relationship between satisfaction with life and perceived social support of parents of children with Intellectual Disabilities in Karachi. For this purpose, 66 parents were approached. Results indicated that satisfaction, which is a person's evaluation of self is related to the support that they perceive from others. Support gives us relief and works as an asset when someone is in a stipulation of dissatisfaction.

Felizardo. S. et; al (2016) highlighted the differences in parental stress and social support among groups of parents whose children have different disabilities in the context of parental adjustment to disability. The selected 152 parents of children with different disabilities by using a convenience sample, (82 with intellectual disability, 37 with motor problems and 33 with autism) supported by schools and institutions in Viseu. The tools used were: a Portuguese version of the Parenting Stress Index (Abidin; 1995), the Social Support Questionnaire – short version (Pinheiro & Ferreira; 2001), and a Parental Questionnaire (demographic and family data). Data were gathered in schools and institutions that support people with disabilities located in the Municipality of Viseu (Portugal). Based on social support dimensions shows the significant differences between parents in the extent and availability of the social support network (SSQN).

Pandey & Dubey (2019) conducted a study to determine the effect of socio-economic demographics and social support on parents' perceived stress with intellectual disability. The selected 100 parents of children with intellectual disability in Chhattisgarh, India. The perceived stress scale and Social support scale were the tools used in the study for data collection. The result indicated that socio-demographic variables income, education, and gender significantly contributed to stress variation and showed a negative association with stress. The result of the mediating effect of social support showed a significant association between income and stress.

Hermansyah (2017) focused on the relationship between gratitude and perceived social support in parents of children with intellectual disability at Makassar. There were 40 respondents selected using purposive random sampling. The criteria for selecting respondents are parents of children with moderate or severe intellectual disability who are educated in informal/non-formal education. Based on Rank Spearman correlation, the result showed a significant positive correlation between gratitude and perceived social support.

Most studies focused on social support regarding stress and formal and informal type of social support received by parents of children with intellectual disability. Some of the studies highlighted that the parents who have perceived sufficient social support in their environment are more satisfied than those who have less perceived support of their surroundings. Hence the researchers want to analysis the available social support in the study area and compare based on gender are as given below:

Objectives

1. To analyze the social support available for parents of children with intellectual disability in the study area.
2. To compare the social support among the fathers and mothers of children with intellectual disability in the study area.

Research Design

In the present study, the descriptive research design was adopted. It enables the analysis of the various dimensions of social support facilities available for parents of children with intellectual disability in Kerala's, Kozhikode district. Following a systematic way to compare the social support available between fathers and mothers of children with intellectual disability.

Sampling Design

The present study was undertaken in the Kozhikode district, a north part of Kerala State. The study aims to analyze the social support available for parents of children with intellectual disability in the study area. In the study area, 38 special schools (Multiple forms of disabled schools) are running, and among them, 12 special schools are found in which different forms of intellectually disabled children were enrolled. To achieve the targeted objectives, the researcher selected 4 out of 12 special schools by using a random sampling technique. The details of all these special schools were gathered from the District Social Justice Office Kozhikode-20.

The researcher gathered information from 148 respondents in the age range of 25 to above 40 years by using random sampling, when parents day was conducted by these institutions. The sample includes 10 out of 25 from "Smile", 44 out of 110 from "Abhayam", 46 out of 115 from "Karunyatheeram" and 48 out of 120 from "Prasanthi". From each school, 40 per cent of the parents of children with intellectual disability in the age range of their children below 18 years admitted in these schools were selected. The study's eligible population was all fathers and mother of children with intellectual disability were interviewed with a brief description of demographic information. The data was gathered from respondents during December 2019 –February 2020.

Criteria for Sample Selection

The study sample was selected by the following inclusion and exclusion criteria

Inclusion Criteria

1. Parents of children only with intellectual disability
2. Fathers and mothers were biologically parents of children.
3. Parents only registered children in the institutes.
4. Parents of children with intellectual disability, who can understand either Malayalam or English language.
5. Those who gave their consent for the study.

Exclusion Criteria

1. Parents of children in the age range of above 18 years.
2. Parents of children who are not enrolled in the institutions.
3. Parents of children who have Autism, ADHD, Cerebral Palsy, Hearing loss were omitted.
4. The parents, who have more than one intellectually disabled children.

Interview Schedule

The researcher and her supervisor developed this Interview Schedule. This questionnaire consists of 20 statements. The item statements are rated for agreement by parents using "Yes" or "No".

Reliability Test

Table. 1: Reliability Test

Variables	Item	Reliability
Social Support	20	0.92

Table 2: Correlation Validity

Variables	Items	Table Value	Calculated Value	Result
Social Support	20	0.273	0.371 to 0.723	Valid

$$\text{Lawshe (1975): Content Validity Ratio (CVR)} = \frac{N_e - \frac{N}{2}}{\frac{N}{2}}$$

Where

N – Number of Experts

N_e – Number of Experts opined yes

$$\text{CVR}_1 = \frac{8 - 8/2}{8/2}$$

$$\text{CVR}_2 = \frac{7 - 8/2}{8/2}$$

$$\text{CVR}_1 = \frac{8 - 4}{4}$$

$$\text{CVR}_2 = \frac{7 - 4}{4}$$

$$\text{CVR}_1 = \frac{4}{4}$$

$$\text{CVR}_2 = \frac{3}{4}$$

$$\text{CVR}_1 = 1$$

$$\text{CVR}_2 = 0.75$$

Three-point scale (Not necessary, Useful and Essential) questionnaire was distributed to eight experts. All the experts said 'Useful and Essential' accounting to the calculation of CVR. Even 7 referrals are sufficient, but the whole recommendation of 'Useful and Essential' was considered for the study. The item range was from 0.75 to 1.

Table 3: Mean and Standard Deviation of Social Support available among Parents of Children with Intellectual Disability

S.No.	Items	N	Mean		SD
1	I get emotional support from immediate family members.	148	2.7770	1	0.41765
2	My other family members understand my child's conditions and they cooperate with me.	148	2.7297	2	0.44561
3	In crucial time, I am getting support from my close friends.	148	2.5000	9	0.74231
4	My neighbors understand my child's condition and they support me when I need.	148	2.6892	3	0.46440
5	I am getting guidance and support from other parents of children with special needs when I am in distress.	148	2.6622	4	0.47458
6	Regularly contact with other parents who experienced the same situation.	148	2.5473	6	0.49945
7	I am participating in an organized parents support group.	148	2.4189	12	0.49506
8	Receiving support from religious institutions for my child care.	148	2.1486	17	0.35695
9	Special teachers provide guidance and assistance for upliftment of children.	148	2.5946	5	0.73621
10	Hospitals provide free medical checkup and treatment.	148	2.5405	7	0.50005
11	Public transport system shows cooperative attitude with special equipments to meet my child's needs.	148	2.3041	14	0.46157
12	Educational institutions conduct recreation and fun activities are helpful for behavioural modification of disabled child(ren).	148	2.5000	9	0.74231

13	Educational institutions provide free transport facilities to the child.	148	2.4932	10	0.50165
14	I am getting information from special therapists and counsellors about how I can help my child(ren).	148	2.5270	8	0.74181
15	Educational institutions and NGO's conduct vocational training programmes for children.	148	2.4865	10	0.74218
16	Through awareness programmes I get information about my child's condition/disability.	148	2.5878	5	0.73706
17	Receiving financial support from well-wishers/self-help group.	148	2.2973	15	0.45862
18	Receiving financial assistance from the Government.	148	2.3919	13	0.73434
19	I am getting information through mass media about my child problem.	148	2.4392	11	0.73980
20	I am getting counseling from professional persons.	148	2.2635	16	0.70336
Overall		148	2.4949		0.37470

Source: Primary data

Table 3 demonstrated the mean and standard deviations of social support statements perceiving respondents of children with intellectual disability. The table consists of twenty statements based on "Yes" and "No" structured by the research scholar and supervisor. The mean value ranges from 2.78 to 2.15. The mean value shows that there is a minor variation among the statements. The calculated standard deviation lies between 0.74 to 0.36. It is observed that the statement "I get emotional support from immediate family members" has secured highest mean value (2.78) followed by the statement "My other family members understand my child's conditions and they cooperate with me" comes second in order (2.73), the statements "My neighbors understand my child's condition and they support me when I need" comes third (2.69), followed "I am getting guidance and support from other parents of children with special needs when I am in distress" (2.66). After that comes "Special teachers provide guidance and assistance for upliftment of children" and "Through awareness programmes I get information about my child's condition/disability" both got same mean value of (2.59), "Regularly contact with other parents who experienced the same situation" (2.55) and "Hospitals provide free medical checkup and treatment" secured (2.54). Further comes "I am getting information from special therapists and counsellors about how I can help my child(ren) (2.53), "Educational institutions conduct recreation and fun activities are helpful for behavioural modification of disabled child(ren)" and "In crucial time, I am getting support from my close friends" got same mean value (2.50), then follows "Educational institutions provide free transport facilities to the child" and "Educational institutions and NGO's conduct vocational training programmes for children" both got same mean value of (2.49). Furthermore the statements, "I am getting information through mass media about my child problem" (2.44), followed by "I am participating in an organized parents support group" (2.42), "Receiving financial assistance from the Government" (2.39), "Public transport system shows cooperative attitude with special equipments to meet my child's needs" and "Receiving financial support from well-wishers/self-help group" both got the same mean value (2.30). Finally, the last statements, "I am getting counseling from professional persons" (2.26), and "Receiving support from religious institutions for my child care," secured a mean value of (2.15). Based on mean value, the data shows that parents are receiving informal social support than formal social support.

The value is inferred from the standard deviation that there is a minor variation among social support dimensions regarding respondents of children with intellectual disability.

Felizardo found similar findings. S. et al (2016) show that there significant differences between parents in the extent and availability of the social support network (SSQN). Formal social support are perceived as being given by professionals, and informal support is perceived as family members being a member of social groups and friends that are integrated into family's daily life. Formal support perceived by family therapists, family education professionals etc. Informal support provided by family members, neighbours, friends, family support groups (Dunst et al., 1986).

Table 4: Distribution of the respondents by the Social Support

Variable		Frequency	Per cent
Social Support	Low	42	28.3
	Moderate	51	34.5
	High	55	37.2
	Total	148	100.0

Using K-mean cluster analysis divided social support into three levels: low, moderate, and high. The above table shows that the majority (37.2%) of the respondents whose children are intellectually disabled perceived a high level of social support, 34.5 per cent of the respondents perceived a moderate level of social support, and 28.3 per cent of the respondents perceived a low level of social support.

It could be concluded that the majority (37.2%) of the respondents perceived a high level of social support.

The above literature supported the present study indicated in their study that satisfaction is a person's evaluation of self-related to the support they perceive from others. Support gives us relief and works as an asset when someone is in a stipulation of dissatisfaction (Habib et al; 2016). Further reported that although relatives, neighbours, friends are willing to provide emotional support to the family having a developmental disability child, the support level of them towards practice is low (Werner et al; 2009) and also Hermansyah (2017) highlighted that Rank Spearman correlation illustrated that there existed a significant positive correlation between gratitude and perceived social support.

Table 5: Mean Difference in the Social Support of the Parents of Children with Intellectual Disability based on Gender

	Gender	N	Mean	SD	t	p
Social Support	Father	60	2.4833	0.43286	-0.545	0.587
	Mother	88	2.5180	0.33924		

Source: primary data

H₁: There is a significant difference between mothers and fathers with regard to social support.

To test the hypothesis, "there is a significant difference between fathers and mothers with regard to social support", the significance of the difference between the mean scores of fathers and mothers in social support of the respondents of children with an intellectual disability considered in the present study was found out. The results are summarized in Table 5.

Out of the total of 148 respondents, 88 respondents were mothers and 60 respondents were fathers. The mean value reveals that the respondents who are mothers secured a mean value of 2.52 and the respondents who are fathers secured a mean value of 2.48. So the above mean value highlights that fathers perceived higher social support than mothers. But this difference is not statistically significant. The t-value is -0.545 of the Independent Simple t-test is not significant at a p-value of 0.587. Hence, the above formulated alternative hypothesis is rejected. So, it is concluded that there is no significant difference between mothers and fathers with regard to social support.

During the data collection process, it was observed that both fathers and mothers were taking care of their children very well. Because of the high literacy rate in the study area, the common people were ready to help and support them, and most parents also were found to be educated among them. So they were not facing any discrimination in perceiving equal social support from their family members, friends, relatives, educational institutions, and government institutions. The goal of the parents was to make a smooth and comfortable future for their children.

III. CONCLUSION

The overall studies evaluated that the parents of children with intellectual disability are managing their stress by social support availability. Similarly, the present study found that the parents of children with intellectual disability perceived informal social support more than informal like support from family members, neighbours, awareness programmes, guidance and support from other parents of same children. So the parents' perceived social support in their environment is satisfied and makes it easy to manage their stress. However, the parents should need to perceive formal social support.

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