Parents of Children with Intellectual Developmental Disorder (IDD): A Study of Informal Caregivers in Kerala and Maharashtra

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Abstract

The struggles and hardships that parents undergo in their life while exercising their parental duty to a child with intellectual disability is immense. Parents referred in this paper as primary caregivers and informal caregivers. This paper highlights the role that parents perform in their life as informal caregivers of children with IDD. The challenges they face while they execute their role as caregivers varies different aspects like physical, psychological, social, relational and economical. It was a descriptive study with quantitative research methodology by using standardized scale and semi-structured interview schedule. The study found that financial crisis was crucial among parents because in many cases bread winner of the family was single. Even though there were challenges, all the participants were satisfied in doing their service. A humanitarian approach and altruistic attitude towards children with IDD are more visible in this study.

Key Words: *Intellectual Disability, Informal Caregivers, Humanitarian Approach, Altruistic Attitude.*

Introduction

Intellectual developmental Disorder (IDD) is a neurological disorder which is based on IQ of a person, and it appears by birth and its severity expands throughout the ages unless he/she gets proper training. Caring a child is not a simple task in the current scenario. Caring a child with disability, especially Intellectual disability demands more attention, time, patience and adjustability to their own life and lifestyle. Caring is simply helping a person or assist to perform his/her personal needs, sustainability or well-functioning of an organism. We understand this concept caring as paid or non-paid. For example, a mother or father who cares children function their role of caring not in a formal manner as paid job but in an informal manner and they carry their responsibility as primary caregivers to their children with ID. This paper mainly focusses on the role of parents as informal caregivers to their children with ID and the challenges they face in their life while they execute their parental duties.

Review of Literature

There are many studies that emphasise the care giving role of NGOs and parents towards children with Intellectual Developmental Disorder (IDD). Here I am going to narrate certain studies and their finding related to this topic for the study. Sukant Chhotaray (2020) studied both mother and father of 30 children with intellectual disability by using NIMH Disability Impact Scale. The study came up with the result that both the parents affected by their disabled child and mothers considerably affected more than fathers. The study found that cultural influences and maternal role of caring causes higher disability impact and stress in mothers of the children with ID. The result of the study revealed that the impact of having a child with ID on parents were both negative and positive. The negative impacts were embarrassment and negative thoughts towards self on mothers. More sensitivity, tolerant and empathic towards the situation were the positive impacts on mothers (Sukant, 2020). The study by Adithyan G.S et.al., discussed thoroughly positive and negative impacts among caregivers of children with intellectual disability. They used National Institute for the Mentally Handicapped Disability Impact Scale (NIMH, 2000) and focused group discussions (FGDs) to achieve this task. The major positive impacts they found in their study were self-esteem among parents, strengthening of family ties and social responsibilities. The negative impacts they summarized in personal and health impact, financial impact and social impact. (Adithyan, Sivakami, and Jacob, 2017).

A cross-sectional study on children with Intellectual Disability and its impact on caregivers by Divya Bunga et.al., assessed 100 parents of ID children. They assessed level of ID child with developmental screening test and the ICD-10 and impact it’s on parents studied by using the modified National Institute of Mentally Handicapped Disability Impact Scale (DIS). The study came up with the result that physical care of the child with disability impacted

56.63% parents of the study. Other major impact was on financial problems (58.87%), social restriction (36.75%) due to domains of disability. Caring an ID child didn’t make any kind of feeling of embarrassment on parents (71.72%). Positive impacts like tolerance, patience, self-efficacy, general satisfaction with life were increased (67.3%) (Bunga, Manchala, Ravindranath, and Shankar, 2020).

A study by Sanne A. H. Giesbers et.al., based on social capital theoretical perspective examined perceptions of people with mild intellectual disability about their family support in comparison with their family members. The major finding of the study was that participants with mild intellectual disability had a denser family network than what their family members expected or perceived. The study concluded with the statement that perceptions of people with mild intellectual disability and their family were different on several aspects of the family support network (Giesbers, et al., 2021).

Anna Gutowska had made a study on informal (Family) caregivers’ perspectives on care of adults with Intellectual Disabilities (ID). She interviewed 12 caregivers from the age between 51 to 82 and who were caring individuals between the age of 20 to 49. These informal caregivers were parents who were supporting and assisting to everyday activities of their adult children. The support and assistance they provided both physically and emotionally was constant and regular in nature. The major finding of the study was that majority of respondents had a negative effect on their well-being due to their caregiving role of adults with ID. They performed their caregiver’s role at the expense of their own lifestyle (Gutowska, 2022).

Giesbers et.al., made a comparative study on students with and without intellectual disability. The study came up with the result that participants with mild intellectual disability had fewer family networks and relationships with family members in which support was received (Giesbers S. A., Hendriks, Hastings, Jahoda, and Tournier, 2020). Cognitive impairment and the negative effect of ID and psychiatric disorders regulate individuals with ID from many connections existing among their significant family members. They may have a lower centrality in the family dynamics. The reason for that may be because of the relational withdrawal from patients and thus their relative isolation and feelings of dissatisfaction and incompetence of parents and siblings (Widmer, Constantin, Tissot, Lanzi, and Galli, 2008).

The concept like parents as single sources of support for adolescents and young adults with intellectual disabilities should be reconsidered. Larger configurations of family ties are important when we deal with the interrelation between family support and the psychological adjustment of individuals with intellectual disabilities. As a result, young adults with ID are embedded in various family configurations that lead them to distinct types of social capital and which have an effect on their psychological adjustment (Widmer, Kempf, Sapin, and Carminati, 2013).

Objectives of the Study

1. To describe the socio-economic conditions of the informal caregivers/ Parents with IDD children.
2. To analyze the Social, psychological, health, relationship, financial burden and challenges of the Parents with IDD children.

Research Design

The current study adopted a descriptive research design to meet the above objectives. The researcher has opted two provinces in India based on highest incidences of IDD. Kottayam, district from Kerala and Satara, from Maharashtra has the highest number of IDD incidents. The researcher interviewed 27 respondents with a semi-structured interview schedule with the help of eight special schools running by NGOs in the district of Kottayam, Kerala and Satara, Maharashtra. All these NGOs were providing services in the form of special education, therapeutic interventions, early interventions, counselling and vocational training to the children and adults with intellectual disability. The study was looking at the role of NGOs and parents as caregivers. It covers the duties, responsibilities and services they are providing and the challenges they face in their personal life, family life and in NGO while they are assisting with their caring responsibility and services to the children with Intellectual disability.

Methodology

The study follows quantitative methodology.

Variables: The informal caregivers/Parents with IDD children. The data analyzed through the statistical tools. Quantitative data entered in SPSS and interpreted with statistical tests like cross tabulation, correlation, descriptive statistics, mean, standard deviation and other statistical tools. Researcher used purposive sampling method for data collection.

Participants: Researcher interviewed parents/ informal caregivers with a semi-structured interview schedule with an open-ended and close-ended**.**

Materials and Procedure: Researcher also used Zarit Caregiver burden Scale to assess the challenges and burden that parents face in their life while they perform their parental role towards their children with IDD.

Reliability Statistics of the Zarit Caregiver burden Scale

Scale

Cronbach's Alpha	N of Items
.855	21

(Table-1)

Data Analysis and Discussion

Informal caregivers participated in this study were both male and female parents as father and mother. Female participation was dominant with 59% and whereas male participation was 41%. They were educated with degree, higher secondary, postgraduate and school respectively according to their ascending order. The following table demonstrate crosstabulation of gender and education.

Gender * Education Crosstabulation

Count

		Education					
		Primary	HSC	Degree	PG	No School	Total
Gender	Male	3	4	1	3	0	11
	Female	1	5	7	2	1	16
Total		4	9	8	5	1	27

(Table-2)

The participants among study, majority (22/27) have completed higher education with higher percentage from HSC (33%) followed by Degree (30%), PG (18%). A small proportionate studied primary school (15%) and one participant was illiterate. The higher number of participants were studied HSC and participant with graduation was higher than participants with post-graduation and school education. There was one participant who had not gone to the school. The number of female participants graduated with degree were higher in comparison with male participants in the study. The participant who had not gone to the school was a female participant. Age of the participants pictured in the below descriptive statistical table.

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Age	27	30	59	44.70	8.995
Valid N (listwise)	27				

(Table -3)

The participants of the study were from the age of 30 to 59. The mean age of the study participants is 44.7 years with a range of 30-59 years and standard deviation of ~9 years. There were only two parents who were working in the government sector whereas majority were working in private sector (41%). Parents who were not working due to their care giving responsibility was in the second position (33%) among the participants of the study. There were five parents who were self-employed. Marital status and mode of family also accessed in the study. All the respondents were married and one of them was widowed. Seventy-five percentage of respondents had nuclear family with one or two children. The extended families with grandparents were 19% and joint families were only 7%.

Financial status of the family was also an important factor in the study. ‘Father’ was engaged in money earning job in many cases (70%) whereas in some cases both ‘father and mother’ were earning (11%). Majority of them belonged to BPL category (42%) and respondents earned above one lakh twenty thousand annually were 22%. The number of respondents who were earning below sixty thousand was also same. It means that parents below poverty line and near to poverty line together comprise majority (67%) of the respondents. The following table shows crosstabulation of IQ of the child and sex of the child.

Sex of Child * IQ level Crosstabulation

Count

		IQ level				
		0-20/25 (Profound)	20/25-35/40 (Severe)	35/40-50/55 (Moderate)	50/55-70 (Mild)	Total
Sex of Child	Male	0	4	9	3	16
	Female	2	0	5	4	11
Total		2	4	14	7	27

(Table -4)

Children with intellectual disability were the care recipient in the study. Basic information of care recipient also mentioned in the study. IQ level of the child was decisive factor of parental challenges. Majority of parents in the study were having moderate (52%) and mild (26%) IQ level children. Parents having severe ID children were higher in the study compared to profound category (15% and 7% respectively). Majority of parents in the study were having male child with IDD (63%) and their age range was from 3 to 17. Parents in the study had only one child with IDD and no other siblings were in the state of IDD. Duration of caregiving in most of the cases were from 12 to 24 hours of a day. One child was totally independent in the study.

Parents were doing the role of primary caregivers, especially, husband, wife and grandparents. Among the participants of the study 58 % were mothers and 42 % were fathers. Majority of the respondents replied that they are getting support from family always in caregiving (73%). But 15% of parents responded that they were not getting support from anyone. Majority of children referred in the study were regular to the school (82%) and only a few children (18%) were irregular to school study because of health issues and financial problems. Health issue was the major reason behind irregularity. Majority of children used school bus (73%) for the transportation to the school. Some children were coming to the school by own vehicles (19%) and others were coming by private vehicles (8%). In most of the cases NGOs were providing school bus facility to the children. It was really a great support for majority of parents. It makes their travel more comfortable to the school and back to home.

The minimum and maximum commuting time to school from home and vice versa was 10 minutes to one hour. Even though, the majority of the respondents were taking one hour to reach in school. Children were getting scholarship and pension amount from state government (66%) and central government (15%). The children who were not getting any kind of scholarship were 19%. They were connected to the NGOs from one to fifteen years. Many of them enrolled in the NGOs within 5-year span. 81% of children were regular to NGO and 19 % were not regular because of their health issues and in one case the reason was financial problem. Number of children who were sharing and not sharing their school experience at home was 54% and 46% respectively. The children were getting home assignments from special schools (81%) and all the parents whose children were getting home assignments from school were happy to get home assignments (81%). All the children involved in the study had Aadhar card, Disability certificate, UDID card and ration card. All the children except two had bank accounts jointly with their parents and only two children were having pan card. NGO helped them to obtain these documents (85%).

Parents were undergoing mild to severe burden on the following items: lost control of life (54%), uncertain about relative (54%), sense of strain (85%), anger (73%), uncomfortable over friends (52%), social life (71%), other relationships (76%), excessive help requests (71%), and fear not able to continue caring (65%). Parental burden was mild to extreme on certain items like: no time for them (81%), overtaxed with responsibilities (85%), should do more to relative (77%), could do better job of caring (77%), health (81%) and privacy (78%), responsibility on one caregiver (62%), future regarding relative (89%), fear not having enough money (71%), fear not able to continue caring (65%), depend on you as caregiver (63%).

Majority of respondents felt that they were not losing their control of life due to their caregiving role. Majority were not felt embarrassment or uncomfortable about having friends over. But many of them felt moderate to severe burden on their social life and other relationship with family and friends. There was moderate to severe burden on sense of strain and anger. The highest number of participants expressed that they were not at wish to leave care to someone else and also, they were not felt embarrassment. They were ready to take care their child with IDD till their time. But about their future was a thought that created a fear in them and some of them had financial problems to manage the situations. Parental burden is accessed in more details in the following categorizations. Zarit burden scale score is pictured below.

Zarit Caregiver burden scale Score

Question Item	**Never-(0) No burden**			**Extremely Rare (1) Mild burden**			**Very Rarely (2) Moderate burden**			**Rarely (3) Severe burden**			**Nearly Always (4) Extreme burden**		
	Freq	**%**	**Score**	**Freq**	**%**	**Score**	**Freq**	**%**	**Score**	**Freq**	**%**	**Score**	**Freq**	**%**	**Score**
No time for you care giver	5	19	0	4	15	4	12	46	24	3	11	9	3	9	12
Overtaxed with responsibilities	4	15	0	4	15	4	10	39	20	7	23	21	2	8	8
Lost control of life	12	46	0	3	11	3	8	28	16	4	15	12	0	0	0
Uncertain about relative	12	46	0	4	15	4	4	15	8	7	24	21	0	0	0
Should do more to relative	6	23	0	6	23	6	8	28	16	5	19	15	2	7	8
Could do better job of caring	6	23	0	1	4	1	11	42	22	7	24	21	2	7	8
Sense of strain	4	15	0	6	23	6	10	39	20	6	23	18	0	0	0
Anger	8	27	0	5	19	5	10	39	20	4	15	12	0	0	0
Embarrassment	14	53	0	6	23	6	3	10	6	3	10	9	1	4	4
Uncomfortable friends over	13	48	0	4	15	4	4	15	8	6	22	18	0	0	0
Social life	8	29	0	2	8	2	13	48	26	4	15	12	0	0	0
Other relationships	7	24	0	5	19	5	10	38	20	5	19	15	0	0	0
Health	5	19	0	1	4	1	8	28	16	12	45	36	1	0	4
Privacy	6	22	0	2	8	2	9	35	18	8	29	24	2	4	8
Excessive help requests	8	29	0	6	23	6	8	29	16	5	19	15	0	0	0
Responsibility one caregiver	10	38	0	8	29	8	7	25	14	1	4	3	1	4	4
Future regarding relative	3	11	0	4	15	4	3	11	6	10	38	30	7	25	28
Fear not having enough money	8	29	0	8	29	8	4	15	8	5	19	15	2	8	8

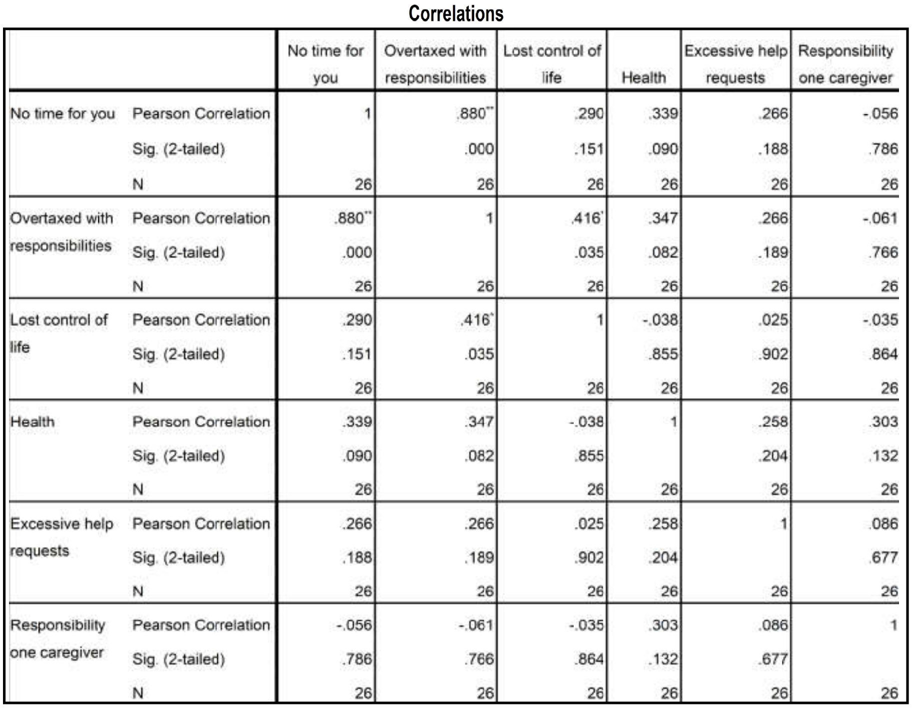
Fear not able to continue caring	9	35	0	7	23	7	10	38	20	1	4	3	0	0	0
Wish to leave care to someone	14	53	0	8	29	8	1	4	2	3	10	9	1	4	4
Depend on you as caregiver	8	27	0	9	35	9	4	15	8	4	15	12	2	8	8

(Table-5)

The Zarit Burden Interview (ZBI) consists of 22 items rated on a 5-point Likert scale that ranges from 0 (never/ no burden) to 4 (nearly always/ extreme burden) with the sum of scores ranging between 0 to 88. These 22 items divided into five domains or five areas of burden. The above depicted chart shows the scoring of each item in the current study. Health burden consists of 6 items which maximum can be scored 24 totally scored 256 for 27 participants. So, the present study found mild to near moderate burden on health with the score of 9.48. Psychological burden combined 5 items with the maximum score 20 obtained 188 for 27 respondents. Psychological burden was also clear in the study with 6.96 having mild to moderate burden. Financial burden accessed with 4 items can totally be scored 16 scored 160 for 27 respondents in the current study. It clearly states in the study that their financial burden was from mild to moderate (score 5.92). Social burden comprises 3 items can totally be scored 12 scored 110 for 27 respondents. Social burden was also from mild to moderate with the score 4.07. Relationship burden includes 4 items can totally be scored 20 scored 170 from 27 respondents. The current study observed a mild to moderate burden in relationship with the score of 6.29. The following correlation matrix will explain these burdens in detail.

Health Burden

Health burden of the participants was accessed with zarit burden scale items. No time for you, overtaxed with responsibilities, lost control of life, health, excessive help requests, responsibility on one caregiver was the items come under health burden. The following correlation table will explain its relevance on this study.



Correlations

		No time for you	Overtaxed with responsibilities	Lost control of life	Health	Excessive help requests	Responsibility one caregiver
No time for you	Pearson Correlation	1	.880**	.290	.339	.266	-.056
	Sig. (2-tailed)		.000	.151	.090	.188	.786
	N	26	26	26	26	26	26
Overtaxed with responsibilities	Pearson Correlation	.880**	1	.416*	.347	.266	-.061
	Sig. (2-tailed)	.000		.035	.082	.189	.766
	N	26	26	26	26	26	26
Lost control of life	Pearson Correlation	.290	.416*	1	-.038	.025	-.035
	Sig. (2-tailed)	.151	.035		.855	.902	.864
	N	26	26	26	26	26	26
Health	Pearson Correlation	.339	.347	-.038	1	.258	.303
	Sig. (2-tailed)	.090	.082	.855		.204	.132
	N	26	26	26	26	26	26
Excessive help requests	Pearson Correlation	.266	.266	.025	.258	1	.086
	Sig. (2-tailed)	.188	.189	.902	.204		.677
	N	26	26	26	26	26	26
Responsibility one caregiver	Pearson Correlation	-.056	-.061	-.035	.303	.086	1
	Sig. (2-tailed)	.786	.766	.864	.132	.677	
	N	26	26	26	26	26	26

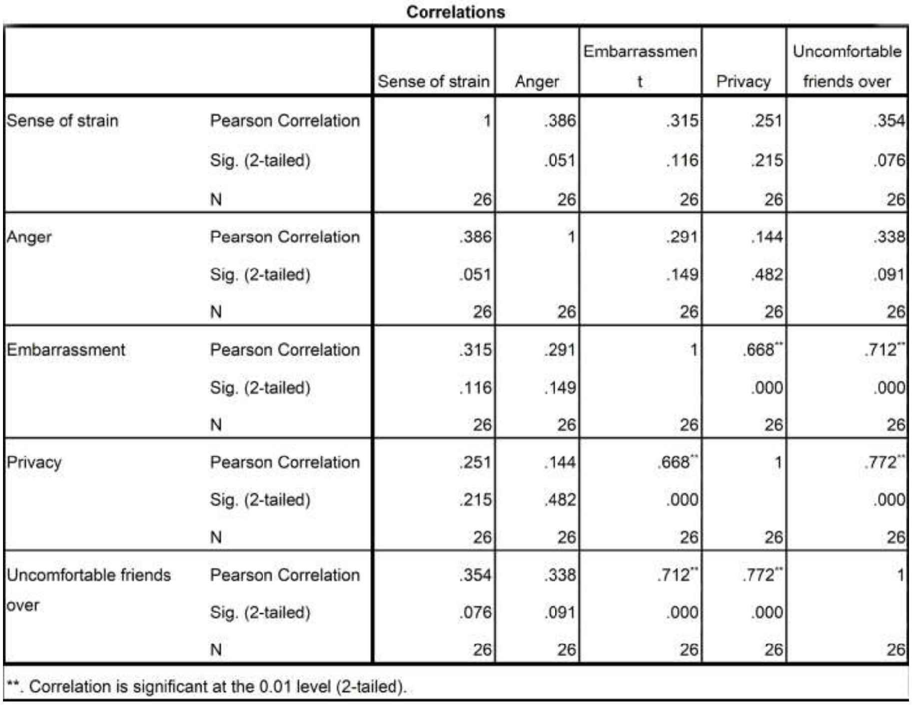
(Table-6)

Parents as primary caregivers were affected with mild to moderate health burden on many of the aspects. Statistical analysis of their physical burden had significant correlation in certain aspects. There was a strong positive significant correlation between 'overtaxed with responsibilities and no time for you (r = .880**, P= .000 < .05). The study clearly showed that majority were not overtaxed with responsibilities, and they did not feel that they were not getting time for themselves. Health and overtaxed with responsibilities also had a moderate positive significant correlation (r = .416*, P= .035 < .05). It is visible in the study that their health burden was moderate. Responsibility on one caregiver had a negative strong correlation with 'no time for you, overtaxed with responsibilities and lost control of life. (r = -.056, -.061, -.035, .207; P= .788, .766, .864, > .05). Responsibility on one caregiver had a positive week correlation with health (r = .303, P= .132 > .05). Parents' caregiving role and other responsibilities of their life didn't create any uncontrolled situations in their life. They could manage their life with their responsibilities. Excessive help requests from care recipient had week positive correlation with 'no time for you, overtaxed with responsibilities, lost control of life, health, responsibility on one caregiver (r = .266, .266, .025, .258, .086; P= .188, .189, .902, .204, .677 > .05). This is not a significant correlation.

Health had moderate positive correlation with 'no time for you and overtaxed with responsibilities and responsibility on one caregiver (r = .339, .347,.303, P= .090, .082,.132 >.05). Health had a positive week correlation with excessive help requests (r = .258, P= .204 > .05). Health had a negative week correlation with 'lost control of life' (r = -.038, P= .855 >.05). None of these correlations are significant. 'Lost control of life' had a week positive correlation with 'no time for you' and excessive help requests (r = .290, .025, P= .151, .902 >.05) and negative week correlation with health and responsibility on one caregiver (r = -.038, -.035, P= .855, .864 >.05). Lost control of life had a positive significant moderate correlation with overtaxed with responsibilities (r = .416*, P= .035< .05). The only significant correlation of 'lost control of life' is this only. Overtaxed with responsibilities had significant positive strong correlation with 'no time for you' (r = .880**, P= .000 < .05), moderate positive correlation with 'lost control of life' (r = .416* P= .035 < .05). and week positive correlation with 'health and excessive help requests' (r = .347,.266, P= .082, .189 > .05). There was a negative week correlation with 'overtaxed with responsibilities' and 'responsibility on one care giver' (r = -.061 P= .766 >.05). No time for you had significant positive strong correlation with 'overtaxed with responsibilities (r = .880** P= .000 < .05), week positive correlation with 'excessive help requests,' 'health' and 'lost control of life' (r = .266,.339,.290 P= .188,.090,.151>.05), and negative week correlation with 'responsibility on one caregiver' (r = -.056, P= .786 > .05).

Psychological Burden

Their psychological burden was accessed with five items. There was some significant correlation between certain items. Their overall psychological burden was mild to moderate and majority had moderate to severe burden on privacy. The following correlation table demonstrate psychological burden clearly.



Correlations

		Sense of strain	Anger	Embarrassment	Privacy	Uncomfortable friends over
Sense of strain	Pearson Correlation	1	.386	.315	.251	.354
	Sig. (2-tailed)		.051	.116	.215	.076
	N	26	26	26	26	26
Anger	Pearson Correlation	.386	1	.291	.144	.338
	Sig. (2-tailed)	.051		.149	.482	.091
	N	26	26	26	26	26
Embarrassment	Pearson Correlation	.315	.291	1	.668**	.712**
	Sig. (2-tailed)	.116	.149		.000	.000
	N	26	26	26	26	26
Privacy	Pearson Correlation	.251	.144	.668**	1	.772**
	Sig. (2-tailed)	.215	.482	.000		.000
	N	26	26	26	26	26
Uncomfortable friends over	Pearson Correlation	.354	.338	.712**	.772**	1
	Sig. (2-tailed)	.076	.091	.000	.000	
	N	26	26	26	26	26

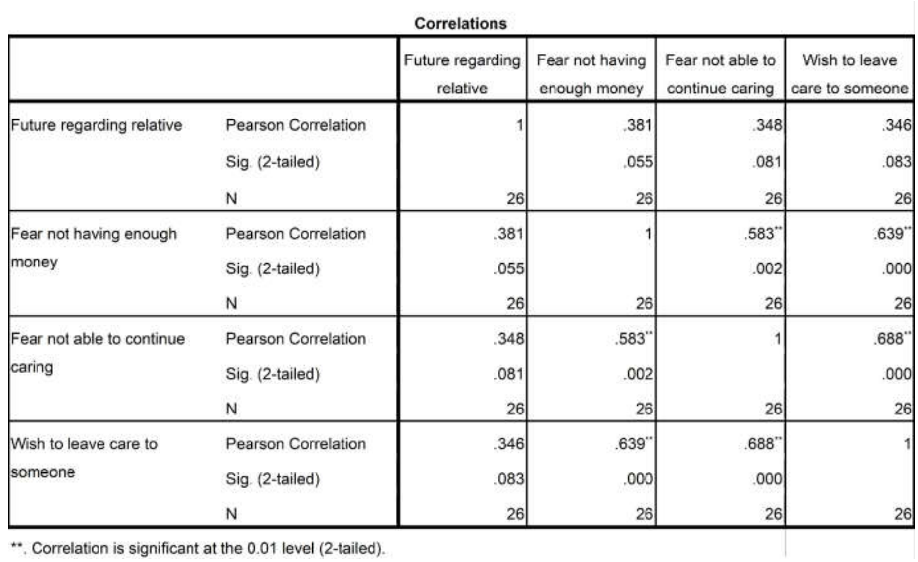
**. Correlation is significant at the 0.01 level (2-tailed).

(Table-7)

The study observed a positive strong correlation of ‘embarrassment’ with ‘privacy and uncomfortable about having friends over’ (r = .668**, .712** P= .000, .000 <.05). ‘Embarrassment’ with ‘anger and sense of strain’ had a positive week correlation (r = .291, .315 P= .149,.116 > .05). Feeling uncomfortable about having friends over had a significant positive strong correlation with embarrassment and privacy (r = .712**, .772** P= .000, .000 <.05). A positive moderate correlation observed between ‘uncomfortable over friends’ with ‘sense of strain and anger’ (r = .354, .338 P= .076, .091 > .05). Privacy also had a significant positive strong correlation with ‘embarrassment and uncomfortable friends over’ (r = .668**, .772** P= .000, .000 <.05). Correlation of privacy with sense of strain and anger is positive moderate correlation anger’ (r = .251, .144 P= .215, .482 > .05). They had a positive week correlation between ‘sense of strain with ‘Anger, embarrassment, privacy and feeling uncomfortable about having friends over’ (r = .386, .315, .251, .354 P= .051, .116, .215, .076 >.05). Correlation between 'Anger' and 'sense of strain, embarrassment, privacy and uncomfortable friends over' also had a positive week correlation (r = .388, .291, .144, .388 P= .051, .149, .482, .091 > .05). Both of these correlations are not significant.

Financial Burden

Financial burden of primary caregivers evaluated with four items in the scale. Statistical correlation revealed that their 'fear of not able to continue caring' and fear of not having enough money significantly related to the 'wish to leave care to someone.' Following correlation table depict it clearly. The following table showcase correlational statistics in financial burden.



Correlations

		Future regarding relative	Fear not having enough money	Fear not able to continue caring	Wish to leave care to someone
Future regarding relative	Pearson Correlation	1	.381	.348	.346
	Sig. (2-tailed)		.055	.081	.083
	N	26	26	26	26
Fear not having enough money	Pearson Correlation	.381	1	.583**	.639**
	Sig. (2-tailed)	.055		.002	.000
	N	26	26	26	26
Fear not able to continue caring	Pearson Correlation	.348	.583**	1	.688**
	Sig. (2-tailed)	.081	.002		.000
	N	26	26	26	26
Wish to leave care to someone	Pearson Correlation	.346	.639**	.688**	1
	Sig. (2-tailed)	.083	.000	.000	
	N	26	26	26	26

**. Correlation is significant at the 0.01 level (2-tailed).

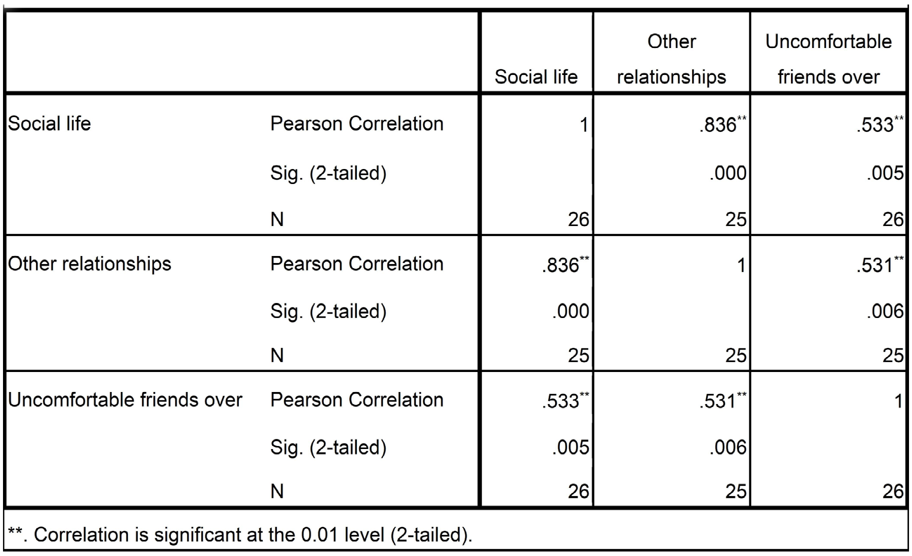
(Table- 8)

Fear of future regarding their child with IDD observed a moderate positive correlation with fear not having enough money, fear not able to continue caring and wish to leave care to someone (r = .381, .348, .346 P= .055, .081, .083 >.05). Their fear of not having enough money stated a positive moderate correlation with fear of future regarding their child, fear that not able to continue caring and wish to leave care to someone (r = .381, .583**, .688** P= .002, .000 >.05). A significant positive moderate correlation noted with fear not having enough money with fear not able to continue caring and wish to leave care to someone else. 'Fear not able to continue caring' have a positive moderate correlation with 'future regarding relative, fear not having enough money, wish to leave care to someone' (r = .348, .583**, .688** P= .081, .002, .000 >.05). (r = .696**, P= .006 <.05). Their wish to leave care to someone had a significant positive moderate correlation with fear not having enough money and fear that they were not able to continue caring (r = .639**, .688** P= .000, .000 >.05).

Social Burden

Social burden was evaluated with 'social life, other relationships and uncomfortable friends over'. The study perceived a significant positive strong correlation with social life and other relationships. The table pictured below shows statistical analysis of social burden.

Correlations



		Social life	Other relationships	Uncomfortable friends over
Social life	Pearson Correlation	1	.836**	.533**
	Sig. (2-tailed)		.000	.005
	N	26	25	26
Other relationships	Pearson Correlation	.836**	1	.531**
	Sig. (2-tailed)	.000		.006
	N	25	25	25
Uncomfortable friends over	Pearson Correlation	.533**	.531**	1
	Sig. (2-tailed)	.005	.006	
	N	26	25	26

**. Correlation is significant at the 0.01 level (2-tailed).

(Table-9)

The table shown above describe social life had significant positive strong correlation with 'other relationships and uncomfortable friends over' (r = .836**, .533** P= .000, .005 <.05). All these three items are inter-connected. Comfortability over friends and other relationships are decisive factors of social life. Majority in the study were feeling moderate to severe burden on their 'social life' and both 'other relationships and uncomfortable having friends over'.

Relationship Burden

Relationship burden is assessed with four items in the scale. A significant correlation observed only between 'could do better job of caring and uncertain about relative.' Participants in the study related to the child as father and mother and their parental relationship entrusted them duties of taking care their children with IDD. The following table describes the correlational statistics of relationship burden.

Correlations

		Depend on you as caregiver	Should do more to relative	Could do better job of caring	Uncertain about relative
Depend on you as caregiver	Pearson Correlation	1	-.080	.017	-.096
	Sig. (2-tailed)		.699	.935	.641
	N	26	26	26	26
Should do more to relative	Pearson Correlation	-.080	1	.188	.192
	Sig. (2-tailed)	.699		.358	.347
	N	26	26	26	26
Could do better job of caring	Pearson Correlation	.017	.188	1	.715**
	Sig. (2-tailed)	.935	.358		.000
	N	26	26	26	26
Uncertain about relative	Pearson Correlation	-.096	.192	.715**	1
	Sig. (2-tailed)	.641	.347	.000	
	N	26	26	26	26

**. Correlation is significant at the 0.01 level (2-tailed).

(Table-10)

The above table depicts a positive significant strong correlation was observed between 'could do better job of caring' with 'uncertain about what to do to the child' (r = .715**, P= .000 >.05). The correlation between 'could do better job of caring' with 'depend on you as caregiver and should do more to relative' was positive week correlation. It was explicitly clear in the study that uncertainty and their wish to do more to the child led them to feel that they could do better job of caring. There is a negative week correlation with 'depend on you as caregiver' with 'should do more to relative and uncertain about relative' (r = -.080, -.096 P= .699, .641 >.05). The role was shared in the family and this relationship and sharing of role reduced their burden.

Major findings of the study

1. Parents were getting scholarship and pension amount for their child with ID from state and central government. State government was not considering special educators with the pay scale of normal school teachers and many of the NGOs were running with the donations they were collecting through different means.
2. The ratio of boys was higher than girls by almost 20% in NGO
3. Children with moderate IDD and mild IDD were higher whereas profound category children were less in number. One reason for that may be, majority of NGOs were mainly concentrating on special education and in many cases severe and profound category children were having multiple forms of disabilities and therefore educating them instead of supporting them with care and protection was not an easy task. The major support that NGOs provide for them was therapeutic interventions for life support and ADL (Activities of Daily Living) training. The internal consistency of different categories in NGO were also significant. In all the NGOs moderate children were high in number and mild, severe and profound simultaneously.
4. Primary caregivers' role in the family was taken up by mothers than fathers. Majority of them were not able to be engaged in any income earning job because of their caregiving duties. Number of moderate and severe children were higher in comparison with number of children having mild and profound intellectual development. It clearly underlines the fact that NGOs services through special education mainly focused on mild to severe IDD children.
5. The study perceived mild to moderate burden on many of their caregiving role by parents. Their fear regarding future of their IDD child was the extreme burden they felt in their life. Majority of respondents expressed

that they could lead a balanced life without losing their control on life. They were not getting embarrassment but many of them felt their social life and other relationship with family and friends negatively affected because of their caregiving role.

Limitations

The study is limited to a small sample size, but it covers a quantitative data and analysis with open ended questions. The study is also limited to two districts of Kerala and Maharashtra.

Conclusion

Since the study was based on a limited data, its vision was also little narrow downed. So, it has a weightage problem to affirm major challenges described in this study. But it shed light to the different aspects of care giving role of informal caregivers. It opened up many challenging roles that parents undertaking through their noble service to the child with IDD.

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