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Knowledge of family caregivers on care of mentally challenged children at selected institution, Bangalore: A descriptive study

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Abstract
Background: There is an increasing number of children being diagnosed with Mental Retardation. Social, cultural and educational components in the society are helping to increase awareness of this disability, and subsequent to diagnosis, its acceptance by the affected family.
Objective: To assess the level of knowledge of family caregivers towards Mentally Challenged Children in selected Institution of Bangalore.
Research Design: descriptive research design.
Study setting: Nachiketa Manovikasa Kendra special school for mentally retarded, M.C. Layout Bangalore.
Tools: It consisted of two sections: Section A - Socio demographic Profile and Section B - Knowledge Questionnaire for family caregivers towards Mentally Challenged Children.
Results: The mean knowledge score was 11.8±4.611 and 78% of the family caregivers had inadequate knowledge.
Conclusion: The present study throws light on the importance of the need of empowerment of the family caregivers with adequate and appropriate information on the trend of development of the mentally challenged child and to know-how of managing developmental delays so that they could provide suitable environment for their care and development.

Keywords: Knowledge, awareness, mentally challenged children, family caregivers, mental retardation and descriptive study

1. Introduction
An analysis of ten Indian studies on psychiatric morbidity to estimate the median values for the prevalence rates was conducted in India. Prevalence rate for all mental disorders was observed to be 65.4 per 1000 population. Prevalence rate of Mental Retardation was found to be 4.2 per 1000 population [1]. There is an increasing number of children being diagnosed with Mental Retardation. Social, cultural and educational components in the society are helping to increase awareness of this disability, and subsequent to diagnosis, its acceptance by the affected family. Caregivers will need to identify the problem, obtain evaluation and handle the situation in such way that the Mentally Challenged Child as well as his family to adjust well in the society, and make optimum use of their abilities [2]. Not all caregivers of mentally challenged children have adequate knowledge regarding mental retardation. The presence of a disabled child in the family negatively influences the life pattern of all members was explored in a study conducted by H.I. Awadalla HI, Kamel EG, Mahfouz E M, Mohamed A.M and El-Sherbeeny AM, 2010 where caregivers of mentally challenge children reported that they did not know anything about the definition, etiology, manifestation, management and complications of the illness were for the most part negatively adapted.[3] Sikandar K, Pranati P and Sinmayee D 2015 revealed that 64% of the care givers of mentally challenged children had poor knowledge and 34% had average knowledge [4]. Khatib J M, Khadi P B & Naik R K 2014 recognised that around 88.33% of the mothers did not possess knowledge regarding Mental Retardation and also they did not have adequate knowledge regarding causes of problem behaviours and management of their children [5].

Similar findings were reported by El-Ganzory GS, Abo El Matty G M & El- Reheem M 2013 [6]. Lin L P *et al.* 2011 identified that "menstrual pain", "age at menarche", "masturbation", "diet during perimenopause", and "publicly available reproductive health services" were issues in which caregivers lacked adequate knowledge and required further instruction [7]. Thus the above reviews suggests that there is an existing lack of knowledge among the family caregivers on care of mentally challenged children in variety of areas such as the definition, etiology, condition of disability, management, medications, basic care, menstrual hygiene, handling behaviour problems, facilities and benefits available for mentally challenged. Family is the child's best resource. Supporting the family and ensuring its emotional and physical health is an extremely important aspect of overall management. Caregiver's knowledge regarding disability enables better care and development of behaviour and management. Hence, this study was directed to explore the caregivers knowledge regarding care of mentally challenged children in the selected institution in Bangalore [5].

2. Methods and materials

2.1 Statement of the problem: A study to evaluate the level of knowledge of family caregivers towards Mentally Challenged Children in selected Institution, Bangalore.

2.2 Objective: To assess the level of knowledge of family caregivers towards Mentally Challenged Children in selected Institution of Bangalore.

2.3 Research Design: Descriptive research design was adopted for the present study.

2.4 Study setting: Nachiketa Manovikasa Kendra special school for mentally retarded, M.C. Layout Bangalore.

2.5 Sampling: Nachiketa Manovikasa School was selected for the study. After obtaining permission from the special schools the data collection procedure was initiated. Family caregivers were first informed of the study by the school principal and then by the researcher during a parents meeting day. After obtaining the willingness of the caregivers who fulfilled the selection criteria, 50 family caregivers were selected for the study.

2.6 Tools: It consisted of two sections: Section A- Socio demographic Profile and Section B - Knowledge Questionnaire for family caregivers towards Mentally Challenged Children. The researcher developed the knowledge questionnaire. The questionnaire consisted of 30 multiple choice questions. Each question had 4 choices with one correct answer. There were 5 dimensions such Concept of mental retardation, assessment and management, basic child care, behaviour modification, sexual issues and prevention of sexual abuse and government concessions and benefits for mentally challenged. Each correct answer was given the score of one; and the wrong answer was given zero. The total score ranges from 0-30 and the following categories were made based on the score Scores <50%- Inadequate knowledge, Scores 50% -75%- Moderately adequate knowledge and Scores >75%- Adequate knowledge

3. Results

Section I: Sociodemographic data

Table 1: Frequency and percentage distribution of family caregivers in terms of age, gender, relationship with the child, level of Mental Retardation of the child and associated problems of the child.

n=50

S. No	Variable	F	%
1	Age		
	a.27 -32	7	14%
	b.33-38	17	34%
	c.39-44	17	34%
	d.45- 50	9	18%
2	Gender		
	a. Male	14	28%
	b. Female	36	72%
3	Relationship with the child		
	a. Father	14	28%
	b. Mother	36	72%
4	Degree of retardation		
	a. Mild	21	42%
	b. Moderate	29	58%
5	Associated problems		
	1.Epilepsy	17	34%
	2.Behvaiour Problem	14	28%
	3.Visual impairment	5	10%
	4.Physical impairment	6	12%
	5.Speech delay	2	4%
	6.Hyper active	2	4%
	7.Learning disability	1	2%
	8. Behaviour Problem, Visual & hearing impairment.	2	4%
	9. Nil	1	2%

The family caregivers were well distributed across the age spectrum. In the present study 14% of the family caregivers belonged to the age of 27-32, 34% of them were between 33yrs -38yrs, 34% of them belonged to the age group of 39-44yrs and 18% of them belonged to the age group of 45yrs – 50yrs. Majority of the caregivers were found in the age group of 33-38 (34%) and 39-44(34%). Among the family caregivers 28% were males and the remaining 72% were females. Among the family caregivers 28% were fathers and the remaining 72% were mothers. 42% of the children of the family caregivers belonged to mild Mental Retardation and 58% of the children belonged to moderate Mental Retardation. Majority of Mentally children of the family caregivers belonged to moderate Mental Retardation. the associated problems identified were Epilepsy (34%), Behaviour problem (28%),Visual impairment(10%), Physical impairment (18%), Speech delay (10%), Hyperactive (4%), learning disability (1%), Behaviour Problem, Visual impairment & hearing impairment (4%) and Nil (2%). Majority of the Mentally Challenged Children of the family caregivers are suffering from Epilepsy (34%) and behaviour problems (28%).

Section II: Level knowledge of family caregivers on the care of mentally

3.1 Challenged children: The objective of the present study was to assess the level of knowledge of family caregivers towards Mentally Challenged Children.

Table 2: Maximum score, mean scores, mean percentage and standard deviation of knowledge scores of the family caregivers N=50

S. No	Component	Maximum score	Mean knowledge scores	% of mean	Standard deviation
1.	Knowledge	30	11.8	39.33	4.611

Table 3: Level of knowledge of family caregivers on the care of Mentally Challenged Children

Group	Level of Knowledge					
	Inadequate Knowledge		Moderately adequate Knowledge		Adequate Knowledge	
	f	%	F	%	f	%
Experimental	39	78	10	20	1	2

The mean and mean percentages were calculated to assess the level of knowledge. The knowledge questionnaire had 30 items on multiple choice questions format. Each question had four distracters and among them only one was the correct answer. Each correct answer was given 'one' mark. Thus maximum score a subject could get on knowledge questionnaire was 'thirty'. The mean knowledge score was 11.8 and the mean percentage was 39.33%. The mean knowledge score (39.33%) showed that they had inadequate knowledge. Majority of 78% of the family caregivers had inadequate knowledge, 20% had moderately adequate knowledge and only 2% of the family caregivers had adequate knowledge.

4. Discussion

Approximately half of the family caregivers 34% participated in the study were between the age group of (33-38yrs). A higher percentage of the family caregivers were in the age group of 33-38yrs.A lesser percentage of family caregivers, 14% were in the age group of 27 -32years. These findings were consistent with study conducted by Radojichich D D 2014 where in the mean age of the mothers participated in the study was 35.6 years [8] and by Awadalla HI, Kamel EG, Mahfouz E M, Mohamed A.M and El-Sherbeeny AM, 2010 where the mean age was 39.2 (SD 5.3) years [3]. These study findings were contradicting to the study conducted by Jafta 2008 where a majority of 30.6% of the parent's age were above 50 years [9] and Chirwa, Esther 2009 [10]. Also dissimilar with Jacob D 2012 where in (68.33%) were in the age group of 39 years and above [11]. Also dissimilar with Sikandar K, Pranati P, Sinmayee D 2015 in which most 27(54%) of the caregivers were found in the age group 41–50 years [4].

Majority of the family caregivers around 72% who participated in the study were females. Whereas a less percentage of the family caregivers (28%) were males. The present study finding is consistent with a study conducted by Thengal N 2013 [12] where in a majority of 56% of the caregivers were females and with Radojichich D D 2014 where in a majority of 76% of the respondents were females [8].

A high percentage of the family caregivers (72%) participated in the study were mothers and 28% were fathers. This study finding was similar to the study finding conducted by Thengal N 2013 [12] where in a majority of 56% of the caregivers were mothers.

Majority of the Mentally Challenged Children (58%) of the family caregivers were having moderate Mental Retardation. This study finding is similar to a study conducted by Kuppusamy, Baskar BN, Narayan JN, Nair D 2012, where about half (48.5%) of the clients had a mild degree of retardation [13]. similar findings of 31 children (29.8%) had mild ID, 46 (44.2%) had moderate ID was reported by Lakhan R and Sharma M 2010 [14]. and by Prakash J, Sudarsanan S, and Prabhu H.R.A. 2007 where in majority 19 (79.2%) of the children participated in the study were having moderate Mental Retardation and Mild 11 (50%) [15]. Contradictory study was reported by Sahay A, Prakash J, Khaique A And Kumar P 2008 where majority participated in the study were having mild Mental Retardation [16].

The associated problems identified in the study are Epilepsy (34%, 28%), Behaviour problem (28%, 26%), Visual impairment (10%, 6%), Physical impairment (18%, 12%), Speech delay (10%, 4%), Hyperactive (4%, 2%) and learning disability (1%, 2%). This study shows that majority of the Mentally Challenged Children were suffering from epilepsy and behavioural disorder. This study finding is consistent by a study conducted by Kuppusamy, Baskar BN, Narayan JN, Nair D 2012 where epilepsy is identified as the associated problem (8.7%) next to cerebral palsy [13] Lin L P *et al.* 2011 revealed health issues for people with ID include respiratory problems, gastrointestinal disorders, challenging behavioural problems, and neurological conditions [7]. The presence of an additional disability along with ID, such as cerebral palsy, epilepsy, mental illness, or Down syndrome was present in 39 children (37.5%) was also reported consistently with Lakhan R and Sharma M 2010 [14]. Similar finding was reported by Ganesh K S 2008 in which most common type of disability among the disabled was mental disability (22/60) followed by loco motor (17/60), hearing (13/60), speech (12/60) and visual (10/60) disability. 80% (48) of the disabled had single disability and the rest 20% had multiple disabilities. Consistent finding was also reported by Raina, S. K., Razdan, S., & Nanda, R. (2012) 69% had other neurodevelopment disabilities including motor, seizure, vision and/or hearing disorders [17]. Also Singh T K, Indla V and Indla, R R 2008 reported that a majority of 59 (90.80%) of the caregivers reported comorbid conditions in their children [18].

The study finding is contrary to a study conducted by kumar S G *et al.* 2008, where in all the disabled subjects were previously diagnosed with one or the other mental ailment, viz., affective disorders (7), Mental Retardation (3), neurosis (9), schizophrenia (1), alcohol addiction (4) except for fits (3) [19]. Also Majority of the disabled had joint pain and backache (35, 58.3%). Hypertension was present in 30% (18) followed by asthma/COPD in 15% (9), diabetes mellitus and fits in 10% (6) and heart problems in 5% (3) of the disabled was reported by Ganesh KS 2008 [20].

Sikandar K, Pranati P and Sinmayee D 2015, reported similar finding in his study that the overall mean score in the pretest was (11.38±2.64) which is 37.93% of the total score revealing that the caregivers had poor knowledge regarding care of MR children. The level of knowledge of the caregivers reveals that in pre-test, 2% of the caregivers had very poor knowledge and 64% of them had poor knowledge

whereas only 34% had average knowledge [4]. Similar Studies were reported by Lakhan R, Sharma M. 2010. Both groups lack information and have misconceptions and misperceptions [21] and Jacob D 2012 where in (86.7%) mothers had inadequate knowledge and 13.3% had moderate knowledge [11].

This study findings are similar to a study conducted by John B 2012, In the pre-test, 8 (13.33%) had poor knowledge, 52(86.67%) had average knowledge and none had good knowledge scores on identification of signs and symptoms of mental retardation [22] Also supported by John B 2012 [22].There is a need for intense focus and drive towards creating awareness among families of mentally challenged children. Structured teaching programme can be conducted at the special schools to sensitize the family caregivers of the information. Various print and non-print modes are to be used for this purpose so that even illiterate persons will benefit from the information provided. The finding is contradictory to a study conducted by Khatib J M and Khadi, P B 2014, it was identified that 73.3 per cent mothers had high score on knowledge regarding mental retardation, 25 per cent medium and 1.67 per cent with low knowledge [5].

5. Conclusion

The present study throws light on the importance of empowerment of the family caregivers with adequate and appropriate information on the trend of development of the mentally challenged child and to know-how to manage developmental delays; so that they could provide suitable environment for their care and development.[5] Therefore caregivers of Mentally Challenged Children require a lot of help to acquire knowledge, and competence in building up the desirable behavior of their children and proper development in their children. Thus there is a need to educate family caregivers.

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