

A Study to Assess the Knowledge and Attitude regarding Care of Autistic Children among Parents of Autistic Children in Selected Centers of Dehradun, Uttarakhand with a View to Develop Self Instructional Module

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Abstract: Autism is a complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. Because of the range of symptoms, this condition is now called autism spectrum disorder (ASD). Symptoms of autism typically appear during the first three years of life. Some children show signs from birth. Others seem to develop normally at first, only to slip suddenly into symptoms when they are 18 to 36 months old. Bringing up a child with autism can be challenging for parents, especially when other people do not understand the issues. The knowledge of the caregivers regarding the care of children with autism is highly important in rearing a child with autism. A descriptive study was conducted to assess the knowledge and attitude regarding care of autistic children among parents of autistic children in selected centers of Dehradun. A quantitative research approach was used for this study. The sample consisted of 50 parents in selected autism care centers of Dehradun. They were selected by Non Probability convenient sampling technique. A structured knowledge questionnaire and a likert scale was used for the data collection. Data was analyzed and interpreted by using descriptive and inferential statistics. It shows that majority (56 %) of parents had moderate knowledge with a mean knowledge percentage of 50.33 %. Also, majority (52 %) of parents had a positive attitude towards care of autistic children. Moreover, a moderately positive correlation was found between the knowledge level and attitude.

Keywords: Autism, knowledge, attitude, parents

1. Introduction

Autism is a complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. Because of the range of symptoms, this condition is now called autism spectrum disorder (ASD). Symptoms of autism typically appear during the first three years of life. Some children show signs from birth. Others seem to develop normally at first, only to slip suddenly into symptoms when they are 18 to 36 months old. Bringing up a child with autism can be challenging for parents, especially when other people do not understand the issues. The knowledge of the caregivers regarding the care of children with autism is highly important in rearing a child with autism. A descriptive study was conducted to assess the knowledge and attitude regarding care of autistic children among parents of autistic children in selected centers of Dehradun. A quantitative research approach was used for this study. The sample consisted of 50 parents in selected autism care centers of Dehradun. They were selected by Non Probability convenient sampling technique. A structured knowledge questionnaire and a likert scale was used for the data collection. Data was analyzed and interpreted by using descriptive and inferential statistics. It shows that majority (56%) of parents had moderate knowledge with a mean knowledge percentage of 50.33%. Also, majority (52%) of parents had a positive attitude towards care of autistic children. Moreover, a moderately positive correlation was found between the knowledge level and attitude.

2. Introduction

“Autism is the fastest growing developmental disability in our nation.” -Mary Bono

Children are innocent, trusting and full of hope. Their childhood should be joyful and loving. Their lives should mature gradually, as they gain new experiences. Each child is a unique, a person whose future will be affected for better or worse by the influences that mould his or her life during the early years. The future of any society depends on its children. Parents are laying the foundation for their child's lives. When a child is born with developmental disorder, parents often need assistance in promoting normal developmental skills. There is no way to predict when a child should be able to master self help skills. Parents must be supported, included as the primary caretaker and teacher of the child, and also give proper information about the care, disease condition and commercially available devices that can aid in achievement of independence of their children. – cry.org

The history of autism dates back to 1911, when Eugen Bleuler coined the term “autism” which means “living in self”. In 1943, the American child psychiatrist Leo Kanner described the children's common traits of impairments in social interaction, good memory, echolalia, over sensitivity to certain stimuli especially sound, food problems, limitations in spontaneous activity, good intellectual potential often coming from talented families. He called the children autistic. In 1944, Hans Asperger, a pediatrician

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independent of Kanner, wrote about a group of children he called 'autistic psychopaths'. In most aspects they resembled the children of Kanner's description. On December 18, 2007, the United Nations General Assembly declared April 2 as World Autism Awareness Day. -**SAGE, History of the Human Sciences, 2013**¹

Autism is a complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. Because of the range of symptoms, this condition is now called autism spectrum disorder (ASD). It covers a large spectrum of symptoms, skills, and levels of impairment. ASD ranges in severity from a handicap that somewhat limits an otherwise normal life to a devastating disability that may require institutional care. Symptoms of autism typically appears during the first three years of life. Some children show signs from birth. Others seem to develop normally at first, only to slip suddenly into symptoms when they are 18 to 36 months old. Autism is four times more common in boys than in girls. It knows no racial, ethnic, or social boundaries. Family income, lifestyle, or educational levels do not affect a child's chance of being autistic. - **Web Md**²

Children with autism sometimes may have physical symptoms, including digestive problems such as constipation and sleep problems. Children may have poor coordination of the large muscles used for running and climbing, or the smaller muscles of the hand. About a third of people with autism also have seizures. - **Web Md**²

Children with ASD may also experience sleep problems and irritability. ASD symptoms in older children and adolescents who attend school are often first recognized by parents and teachers. Parents may talk with the specialists about their child's social difficulties including problems with subtle communication. Older children and adolescents may have trouble understanding figures of speech, humor, or sarcasm. Parents may also find that their child has trouble forming friendships with peers. -**NIMH 2018**³

Autism also has links to other medical conditions, such as epilepsy. According to the National Institute of Neurological Disorders and Stroke (NINDS), an estimated 20 to 30 percent of people with ASD develop epilepsy by the time they reach childhood. People with autism thrive on routine, and the ability to predict the outcomes of certain behaviors and places. A break in routine or exposure to loud, overstimulating environments can overwhelm a person with ASD, leading to outbursts of anger, frustration, distress, or sadness. -**Medical news today.com Nov. 2018**⁴

In some children with ASD, medications and behavioral health interventions can improve the effects of the condition to enable a person to function independently in adulthood. For others, the symptoms and co-existing conditions, such as epilepsy, may require further management and assistance. A combination of education about ASD and earlier recognition means that people with autism can receive early assistance for the condition. Ideally, a person should receive treatments and therapies as early as possible to enhance their quality of life. **Medical News today.com, 2018**⁴

Children with autism spectrum disorder (ASD) may also have restrictive and ritualistic behaviors that affect their eating habits. Some of them limit what they eat, so severely that it results in nutritional deficiencies that lead to weight loss, malnutrition and inadequate growth. Dr. Olive said children with autism who have feeding problems fear new foods. Dr. Girolami said that while some children with autism may be selective with their diets due to compulsive behaviors, others may face motor and sensory challenges that restrict their ability to eat a variety of foods. A child with motor deficits may have trouble chewing and swallowing, which is why they may develop a preference for smooth foods that would not require much of either. -**Interactive Autism Network, Kennedy Krieger Institute, 2014**^{5,6}

Bringing up a child with autism can be challenging for parents, especially when other people do not understand the issues. Children with ASD experience the world differently from most people. They often have difficulty expressing themselves. Sensory issues can affect how they smell, hear, or see things. They may find it impossible to eat foods of a particular color, for example. Parents can find it difficult and embarrassing when their child demonstrates unusual behaviors in public. If parents feel stressed and unable to cope, their own health can be at risk. It is important for parents to address their own needs as well as those of their child. **Medical News today.com, 2016**

"The knowledge of the caregivers regarding the care of children with autism is highly important in rearing a child with autism. Knowledge of the caregivers can be crucial in assessing the signs and symptoms, current condition, recurrence risk, carrying out the instructions and interventions prescribed by the physician, identifying the side effects of medications and handling the common behaviour problems at home. But the knowledge of the caregivers regarding the care of children with autism is inadequate. Through education and knowledge people with autism can considerably improve their level of functioning and quality of life. The need for information for the caregivers on a variety of unexpected skills, and support, is immediate and urgent. - **International Journal of Pharmaceutical and Clinical Research March 25, 2018**

3. Objective of the Study

- 1) To assess the knowledge regarding care of autistic children among the parents of Autistic children in selected centers.
- 2) To assess the attitude regarding care of autistic children among the parents of Autistic children in selected centers.
- 3) To find out an association between knowledge of parents regarding Autism with selected demographic variables.
- 4) To find out an association between attitude of parents with selected demographic variables.
- 5) To find out the correlation between knowledge and attitude of parents.

Hypothesis

H₁:- There will be moderate knowledge among parents regarding care of autistic children.

H₂:- There will be a significant association between knowledge of parents and selected demographic variables.

H₃:- There will be a positive attitude among parents towards care of autistic children.

H₄:- There will be a significant association between attitude of parents and selected demographic variables.

H₅:- There will be a significant relationship between knowledge and attitude of parents.

4. Material and Methods

Research Approach

A quantitative research approach is used for this study. "A quantitative research is an applied form of research that involves finding out how well a program, practice and policy is working". The main goal is to assess or evaluate the success of the intervention.

Research Design

The research design adopted for the study is descriptive.

Variables

Two types of variables are used in this study. They are:

- 1) Research variable
- 2) Extraneous variables

1) Research variable

The research variable for this study is "The knowledge and attitude of parents of Autistic children regarding care of autistic children"

2) Extraneous variables:

Extraneous variables are the factors that are not the part of the study but may affect the measurement of the study variables. In this study, demographic variables refer to age of parents, parent literacy status, area of living, occupation of parent, socio economic status of family, age of autistic child, birth order of child, number of siblings, source of information and type of family.

Setting of the study

The study was conducted in selected autism centers of Dehradun. This setting was selected because of the availability of samples and feasibility of conducting the study.

Population

In the present study the population is parents of autistic children availing treatment in Dehradun.

Target Population

In the present study the target population is parents of autistic children coming for treatment to selected autistic centers of Dehradun.

Accessible Population

In the present study the accessible population will be those parents of autistic children who meet the designated criteria and are also available for research study.

Sample

In the present study the sample consists of parents of autistic children coming to selected autism centers of Dehradun.

Sample Size

In this study, sample comprises of 50 parents of autistic children.

Sampling Technique

In this study, a Non-probability Convenient sampling technique was used for sampling the parents of autistic children.

Data collection instrument:

Structured Questionnaire method and Attitude scale was used.

Section A

Demographic variables

Items on demographic variables like age of parents, parent literacy status, area of living, occupation, socio economic status of family, number of children, birth order of autistic child, age of autistic child, source of information and type of family.

Section B

Structured questionnaire

Structured questionnaire regarding care of autistic children. Various aspects of care are included like communication of child, social behavior, dietary problems, neurological problems, self care, achievement of milestones and relationship with family members. It consists of 30 multiple choice questions. Each correct answer was given a score of 1 and wrong answer, a score of 0.

Score interpretation

- Below 50%- Inadequate knowledge
- 51-75%- Moderate knowledge
- 76-100%- Adequate knowledge

Attitude Scale

Likert scale to assess the attitude of parents towards care of autistic child. Various aspects were included such as social stigma, dependence of child, anxiety and stress of parents, future concerns and prognosis of child. It consists of 25 items with a five point rating scale scored from 1-5. For all the positive items, maximum score given was 5 and for all the negative statements, 1-2 marks were given.

Score interpretation:

- <50%- Negative attitude
- >50%- Positive attitude

Reliability of the tool

The tool was administered on 5 samples and the reliability of the tool was found by using split half method. The reliability of the tool was found to be $r=0.90$ (for questionnaire) and $r=0.61$ (for likert scale). Hence the tool was found to be reliable when used in the pilot study.

Data collection procedure

The period of data collection was extended from 10.06.2019 to 06.07.2019. The purpose and nature of study was explained to the parents and their consent was obtained. A structured questionnaire was prepared and administered to assess the knowledge of parents regarding care of autistic

child. Also, likert scale was prepared and administered to assess their attitude towards care of autistic child.

Plan for data analysis

Master data sheet was prepared by the investigator to analyze the data. The data was analyzed in terms of descriptive (mean, percentage, standard deviation) and inferential statistics (chi-square test) as follows:

1) **Descriptive statistics**

Frequency, Percentage, Mean and Standard deviation were used for analysis of test scores.

2) **Inferential statistics**

- a) Chi-square test was used to determine the association between knowledge and attitude with demographic variables.
- b) Karl Pearson correlation coefficient was used to determine the correlation between knowledge and attitude.

Level of significance is set at 0.05 to interpret the hypothesis and finding.

5. Results

The major findings of the study were as follows:

Section-A: Distribution of respondents according to demographic variables

According to their demographic details the majority of the respondents 28 (56%) were in the age group of 25-34 years, 28 (56%) were graduates, 15(30%) were doing a private job, 39(78%) were living in urban area, 22(44%) belong to nuclear family, 22(44%) had an income of >6 lks annually, 27(54%) had 6-10 years old autistic child, 27(54%) of the autistic children were the first child of their parents, 24(48%) of autistic children had 1 sibling and 33 (66%) of parents received knowledge from their doctor.

Section-B: Knowledge scores of parents regarding care of autistic children

Table 1: Frequency and percentage distribution of knowledge scores

Level of knowledge	Score range	Frequency n=50	Percentage (%)
Inadequate	<50%	20	40
Moderate	50-75%	28	56
Adequate	76-100%	2	4

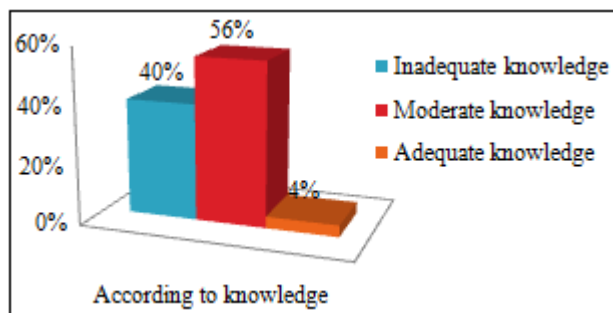


Figure 1: Bar diagram showing knowledge of parents regarding care of autistic children

Data in table 1 and fig-1 shows that 40% of the sample had inadequate knowledge, 56% of them had moderate knowledge and only 4% of the sample had adequate knowledge. It implies that majority of the sample had moderate knowledge regarding care of autistic children.

Table 2: Mean and standard deviation of the knowledge scores of parents (n=50)

Knowledge score value	Mean	SD
Questionnaire	15.1	3.41

Data shown in table 2 revealed that the mean knowledge score value among parents of autistic children was moderate. Hence the hypothesis (H1) is accepted.

Section C: Association of knowledge scores and demographic variables

The results of chi square analysis depict that the demographic variables such as Educational status, Occupation, Area of living, Type of family, Annual family income, Age of autistic child, Birth order of child, number of siblings and Source of knowledge show no significant association while Age of parents had a statistical significant association with the level of knowledge. The obtained chi square value of the variables such as Education ($\chi^2=3.82$, $P>0.05$), Occupation ($\chi^2=5.13$, $P>0.05$), Area of living ($\chi^2=1.64$, $P>0.05$), Type of family ($\chi^2=3.72$, $P>0.05$), Annual family income ($\chi^2=4.83$, $P>0.05$), Age of autistic child ($\chi^2=4.63$, $P>0.05$), Birth order of child ($\chi^2=0.22$, $P>0.05$), Number of siblings ($\chi^2=0.39$, $P>0.05$) and Source Of knowledge ($\chi^2=3.89$, $P>0.05$). Whereas Age of parent ($\chi^2=9.05$, $P<0.05$).

Hence research hypothesis (H₂) was rejected and null hypothesis was accepted.

Section D: Likert (attitude) scores of parents regarding care of autistic children

Table 3: Frequency and percentage distribution of Likert (attitude) scores

Attitude	Likert Score range	Frequency n=50	Percentage (%)
Negative	<50%	24	48
Positive	50-100%	26	52

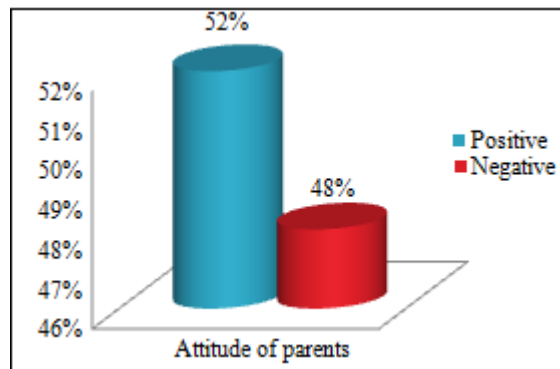


Figure 2: Cylindrical diagram showing attitude of parents regarding care of autistic children

Data in table-3 and fig- 2 shows that 48% of the sample had negative attitude and 52% of them had positive attitude. It

implies that majority of the sample had positive attitude towards care of autistic children.

Table 4: Mean and standard deviation of the likert scores of parents (n=50)

Attitude scale	Mean	SD
Likert score value	61.46	5.55

Data shown in table -4 revealed that the mean likert score value among parents of autistic children was 61.46 which shows that majority of them had a positive attitude towards care of autistic children. **Hence the research hypothesis (H3) was accepted and null hypothesis was rejected.**

Section E: Association of attitude of parents (Likert scores) with selected demographic variables

The results of chi square analysis depict that the demographic variables such as Age of parents, Occupation, Area of living, Type of family, Annual family income, Age of autistic child, Birth order of child, number of siblings and Source of knowledge show no significant association while Educational status had a statistical significant association with the attitude of parents. The obtained chi square value of the variables such as Age of parent ($\chi^2=0.84$, $P>0.05$), Occupation ($\chi^2=3.19$, $P>0.05$), Area of living ($\chi^2=0.21$, $P>0.05$), Type of family ($\chi^2=4.34$, $P>0.05$), Annual family income ($\chi^2=0.99$, $P>0.05$), Age of autistic child ($\chi^2=2.81$, $P>0.05$), Birth order of child ($\chi^2=1.25$, $P>0.05$), Number of siblings ($\chi^2=2.29$, $P>0.05$) and Source Of knowledge ($\chi^2=7.45$, $P>0.05$). Whereas Education ($\chi^2=7.46$, $P<0.05$). Hence research hypothesis (H_4) was rejected and null hypothesis was accepted.

Section F: Correlation between knowledge scores of parents with their attitude towards care of autistic children.

Table 5: Relationship between knowledge and attitude of parents regarding care of autistic children

S.No.	Knowledge score (mean)	Attitude (likert) score (mean)	Karl Pearson's correlation coefficient (γ)	Correlation
1	15.1	61.46	0.31	Moderately positive

Data shown in table 5 revealed that the mean knowledge score among parents of autistic children was 15.1 and the mean likert score value was 61.46. The Karl Pearson's correlation coefficient was calculated to be 0.31. Since $0 < \gamma < 1$, it shows a moderately positive correlation between the knowledge level of parents and their attitude regarding care of autistic children. **Hence the research hypothesis (H5) is accepted and null hypothesis is rejected.**

6. Conclusion

Majority of parents had moderate knowledge about care of autistic children. At the same time, quite a large number of parents had inadequate knowledge while just a few had adequate knowledge. Parents' attitude towards care of autistic children was majorly found to be positive while a good number of parents also had a negative attitude. There was a moderately positive correlation between knowledge

level of parents and their attitude towards care of autistic children.

Nursing Implications

The findings of this study have implication for nursing education, nursing practice, nursing administration and nursing research and it also gives insight to the future studies.

Nursing Education

It is important that the nurses and all health personnel should be given the responsibility to teach the parents of children coming to paediatric OPD regarding screening of children for autism. Nurse educator should provide all necessary knowledge to parents about autism and the care of autistic child.

Nursing Practice

Nursing professionals should render services according to the changing needs of the society. There is need for the health personnels to take active part in providing health education to parents of autistic children regarding their care, providing adequate training to enable them in taking care of the child at home, providing referral services and conducting counseling sessions for the parents.

Nursing Administration

The administrators can organize conferences, workshops and seminars for nurses regarding care of autistic child. Nurse administrator should encourage the nurses to teach the parents about screening their child for autism and other developmental disabilities. Promote opportunity for nurses to attend training programs to update their knowledge and skill.

Recommendations are given to the management for allocation of funds for conducting teaching programs, audiovisual aids etc.

Nursing Research

The study will provide a valuable reference and material for further researchers. The findings need to be disseminated through conference, seminars and published to journals. The findings of the research study will help in building and strengthening body of knowledge in the discipline of nursing.

7. Recommendations

- A similar study can be done on a large population.
- Parents should actively participate in awareness programs about developmental disabilities to initiate treatment and therapies in early stages of the disease.
- Government should take actual steps to sponsor/ fund more similar studies to improve the adaptation of families to autism.
- A comparative study can be undertaken to see the improvement in knowledge of parents after providing them a structured teaching program.
- Regular health education programs should be conducted by the health professionals in the hospital and community centers to help the parents in early identification of developmental disabilities like autism.

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