

Assess the Effect of Self Instructional Module on Care of Autistic Children among Parents Caring Child with Autism in a Selected Institution at Kanyakumari District, Tamil Nadu

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Abstract: Autism is a disorder of neural development characterized by impaired social interaction and communication, and by restricted and repetitive behavior. **Statement of the Problem:** A study to determine the Effect of self instructional module on knowledge of parents caring of child with autism in Santhi Nilayam at Kanyakumari district. **Objectives of the Study:** To assess the knowledge of parents caring of children with autism. To assess the effectiveness of self instructional module on care, autism among parents of autistic children. To determine the association between autism and demographic variables [Age, education, sex, standard of living]. **Assumptions:** There will be less knowledge regarding the care of autism among parents of autistic children. Autistic children may not have adequate skill to do their daily activities. **Limitation:** The study is limited to, Parents of autistic children. Limited period of one month. **Projected Outcome:** The study findings will help the researcher to determine the parent's knowledge regarding the care of autism. The study will help to promote knowledge regarding the care of autistic children. The study findings will help the nurse researchers to carry out the same study in a different setting to promote best care of the autistic children.

Keywords: Parents, autism, Self-Instructional Module, Autism, Knowledge

1. Introduction

Autism is a disorder of neural development characterized by impaired social interaction and communication, and by restricted and repetitive behavior. These signs all begin before a child is three years old. Autism affects information processing in the brain by altering how nerve cells and their synapses connect and organize; how this occurs is not well understood. It is one of three recognized disorders in the autism spectrum (ASDs), the other two being Asperger syndrome, which lacks delays in cognitive development and language, and Pervasive Developmental Disorder-Not Otherwise Specified (commonly abbreviated as PDD-NOS), which is diagnosed when the full set of criteria for autism or Asperger syndrome are not met.

Autism has a strong genetic basis, although the genetics of autism are complex and it is unclear whether ASD is explained more by rare mutations, or by rare combinations of common genetic variants. In rare cases, autism is strongly associated with agents that cause birth defects. Controversies surround other proposed environmental causes, such as heavy metals, pesticides or childhood vaccines; the vaccine hypotheses are biologically implausible and lack convincing scientific evidence. The prevalence of autism is about 1–2 per 1,000 people; the prevalence of ASD is about 6 per 1,000, with about four times as many males as females. The number of people diagnosed with autism has increased dramatically since the 1980s, partly due to changes in diagnostic practice; the question of whether actual prevalence has increased is unresolved.

Parents usually notice signs in the first two years of their child's life. The signs usually develop gradually, but some autistic children first develop more normally and then regress. Although early behavioral or cognitive

intervention can help autistic children gain self-care, social, and communication skills, there is no known cure. Not many children with autism live independently after reaching adulthood, though some become successful. An autistic culture has developed, with some individuals seeking a cure and others believing autism should be accepted as a difference and not treated as a disorder.

Autistic children often have difficult behaviors because they lack the ability to communicate their needs and wants in an appropriate way. To eliminate the unwanted behavior, the child needs to be helped to have their needs and wants met in a constructive way.

Raising a child with autism is one of the hardest things a parent will ever have to do. It is an overwhelming challenge physically and emotionally adding anxiety on the person caring for the child. Rearing a child with autism often contributes to marital problems, problems with other children, and job instability. Unfortunately, there are no reliable treatments for autism, and the responsibility of upbringing, developmental and behavioral problems of the autistic child falls largely on the family. Although there is nothing that we can do to change the origin of the problem, there are strategies which family members can do to reduce the level of abnormal behavior and increase the child's ability to cope.

Research indicates that parents of children with autism experience greater stress than parents of children with learning disabilities. An individual with autism may not express their basic wants or needs in a way that one would expect. Therefore, parents are left playing a guessing game. Is the child crying because he/she is thirsty, hungry, or sick? When a parent cannot determine their child's needs, both are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious

behaviors that threaten their safety and the safety of other family members (e.g. siblings).

Autism characteristics and compulsive behaviors concern parents since they seem odd and obstruct with performance and learning. More parents are raising children with a diagnosis of autism and families often find themselves dealing with financial and social challenges, as well. Daily care routine, economic problems, receiving appropriate help and education are the basic hardships of the parents of a disabled child. The additional stress can be significant, taking its toll on the whole family and even contributing to a high divorce rate. Fifteen years ago the incidence of autism was 1 in 5,000, compared to today's rate of 1 in 150, according to the Centers for Disease Control and Prevention. While an ASD diagnosis can alter parents' dreams for their children, they should be optimistic. Much has been learned about ADS in the last 15 years and research into causes and interventions continues to grow.

Recent estimates have placed the prevalence of autism in the U.S. at approximately 1 in 150 people. At India's current population, this means there are more than 2 million autistic persons in the country. Of course, this estimate assumes that there are no significant variations in this rate worldwide, which is a question that has not yet been addressed by epidemiologists outside the West. While the disorder is not rare, the majorities of autistic people in India have not been diagnosed and do not receive the services they need. This problem occurs in many countries, but is especially true in India where there is a tremendous lack of awareness and misunderstanding about autism among the medical professionals, who may either misdiagnose or under diagnose the condition. There has been a marked increase in the incidence of autism in the past few decades. In the USA it is said to be 1 in 166 (Cure Autism Now 2004) making it the third most prevalent developmental disorder in the world.

1.1 Need for the Study

There are many things parents can do to help children with autism overcome their challenges and get the most of life. From learning all can about autism spectrum disorders to getting child into treatment right away, can make a big difference.

It's also important to make sure get the support in need. When we're looking after a child with autism, taking care of our self is not an act of selfishness—it's a necessity. Being emotionally strong allows the mother to be the best parent that can be to the child in need.

Parents need to prepare, be creative, and have a sense of humor when caring for children with autism and other developmental disabilities. Parents of children with autism are often extremely knowledgeable and are an excellent resource for their child. Autistic children have absence of social skill. The parents should take the important role to develop this skill.

1.2 Statement of the problem

A study to determine the Effect of self instructional module on knowledge of parents caring of child with autism in Santhi Nilayam at Kanyakumari district.

1.3 Objectives of the Study

- To assess the knowledge of parents caring of child with autism
- To assess the effectiveness of self instructional module on care autism among parents of autistic children.
- To determine the association between autism and demographic variables [Age, education, sex, standard of living]

1.4 Operational Definitions

Parents

In this study parents refers to both father and mother of an autistic children who is attending regular classes from selected institute.

Self-Instructional Module

Self-Instructional Module refers to learning package which contains instructional material necessary for learning regarding care of autistic children

Autism

In this study autism refers to impairment in social skill, language and behavior.

Knowledge

In this study knowledge refers to awareness or familiarity regarding care of autistic children through experience, education or any other mass media programs.

1.5 Assumptions

- There will be less knowledge regarding care of autism among parents of autistic children.
- Autistic children may not have adequate skill to do their daily activities.

1.6 Limitation

The study is limited to,

- Parents of autistic children.
- Limited period of one month.

1.7 Projected Outcome

- The study findings will help the researcher to determine the parent's knowledge regarding care of autism
- The study will help to promote knowledge regarding care of autistic children.
- The study findings will help the nurse researchers to carry out the same study in a different setting to promote best care to the autistic children

2. Review of Literature

The review of literature is defined as broad comprehensive in depth, systematic and critical review of scholarly publications, unpublished scholarly print materials, audiovisual materials and personnel communications. It helps in identifying and searching for information of a topic and developing an understanding of the state of knowledge on that topic. (Basavanthappa B.T. 2003).

Bilgin H, Kucuk L. (2009) conducted a study on Raising an autistic child: Perspectives from Turkish mothers. Autism is an illness with severe deficits in reciprocal social interactions, imagination, communication, and restricted or unusual behavioral repertoires that affect all areas of a child's life such as daily living activities, home/school life, and relationships with family members and others. Yet there is much to be learned about the impact of this disorder on parent's experiences, and ways in which their lives are altered and ways that they can be assisted to better manage the home environment. The purpose of this study was to explore and categorize the experiences of mothers having an autistic child using a phenomenological design in the qualitative tradition. Semi structured interviews were conducted with 43 mothers regarding their experiences with their autistic children. Data were analyzed with deductive content analysis based on coding, and were grouped into categories based on common themes. The distributions of common responses in categories were presented as percentages. Based on this qualitative study, mothers expressed feelings of burden and stress because of their child's behaviors associated with autism, as well as their own role and future expectations, and the complexity of care needed by their children at home. This study provided new knowledge about the difficulties and experiences of mothers of autistic children in Turkey. The results underscored the needs of mothers who require support from family members, healthcare organizations, and society. The findings support the need for training programs for mothers and parents conducted by nurses and other healthcare professionals who have special knowledge and skill to provide education and modeling of therapeutic interventions.

J. Dev Behav. (2010) conducted a study on Autism, cognition, and parent counseling. Parents often have an inaccurate understanding of outcomes in autism, and development lists contribute to this when they omit consideration of cognitive functioning in their discussions with parents. Developmentalists need to incorporate information about cognitive levels (including intellectual disability, when present), in order to properly educate parents about prognosis for their child with autism.

An Pillay M, Alderson-Day B, Wright B, Williams C, Urwin B. (2010) conducted a study on enhancing nurture and development evaluation of intervention support groups for parents. There is relatively little evidence about the effectiveness of parent-training programmes for children with autism spectrum conditions. Here we evaluate a programme developed to fill a gap in the provision of parent interventions after EarlyBird, which is only

available for parents of pre-school ASC children. This programme has now been running for five years. Questionnaires were used to evaluate seven consecutive 11-session programs from 2004 to 2007, involving 79 parents representing 58 children. We measured satisfaction ratings in all seven groups; the latter five groups were given Developmental Behavior Checklists and parental knowledge questionnaires pre and post-course. Eighty-eight per cent of respondents found the course useful or very useful while parental knowledge and skills improved significantly across a range of learning outcomes. DBC scores showed significant changes post-course for total problem behaviors and disruptive/antisocial behavior's, with a trend towards reductions in anxiety as reported by parents. Changes in behavior scores moderately correlated with specific learning items relating to improved skills in behavior management. This preliminary evaluation suggests that the course produces positive outcomes in terms of parent satisfaction, parent learning and perceived changes in child behavior, although further independent analysis is required in the form of randomized controlled trial.

Farrugia D. (2009) conducted a study on medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder. This paper analyses 12 parent interviews to investigate the stigmatization of parents of children diagnosed with an autism spectrum disorder. Drawing on post structural accounts of the relationship between knowledge and subjectivity, the stigma concept is critically interrogated in order to address previous individualistic constructions of stigmatization and to place stigma within the power dynamics of social control. The results of the study indicate that a child's diagnosis with an autism spectrum disorder is critical for parents to resist stigmatization. Parents experienced considerable enacted stigma, but successfully resisted felt stigma by deploying medical knowledge to articulate unspoiled subject positions. The institutionalization of medical knowledge within the autism community was critical to this process. Resistance to enacted stigma was successful to the degree that medical constructions of deviance deployed by parents were accepted by others, notably those in power within institutions. It is concluded that post structural accounts of subjectivity and social control provide a useful way of conceptualizing stigmatization. An acceptance of the painful nature of stigma as lived experience co-exists with an emphasis on the constantly negotiated nature of embodied subjectivity as a contingent social process to illustrate the conditions for active resistance to stigmatization.

J. Genet Couns. (2009) conducted a study on parent's perceptions of autism spectrum disorder etiology and recurrence risk and affects of their perceptions on family planning: Recommendations for genetic counselors knowledge about the etiology of Autism Spectrum Disorders (ASDS) is increasing, but causes remain elusive for most cases. Genetic counselors are positioned to help families that have children with ASDS despite uncertainty regarding etiology. To determine how genetic counselors might best provide services, an anonymous survey was

conducted with 255 parents whose children were diagnosed on the autism spectrum. Questions concerned: 1) their perceptions of ASD causes and 2) recurrence risk, 3) whether perceived risk affected family planning decisions, 4) whether parents had received genetic services, and 5) how genetic counselors might assist families. The most prevalent perceived cause was genetic influences (72.6%). Most parent's recurrence risk perceptions were inaccurately high and significantly affected family planning. Only 10% had seen a genetic professional related to an ASD. Parents provided several suggestions for genetic counselor best practices. Findings indicate the importance of genetic counselor awareness of parent perceptions in order to best help families who have children with ASDs.

Chakrabarti S. (2009) conducted a study on early identification of autism. This study was carried out to determine the nature and timing of parents initial concerns and their subsequent help seeking behavior, so as to suggest ways to facilitate early identification of autism. The introductory part of the Autism Diagnostic Interview-Revised was used in a survey to elicit relevant information from parents of autistic children. Delayed/deviant speech and language development was the commonest early concern of parents. The mean age of parental recognition of any problem was 23.4 months. The mean time lag from first recognition of the problem to seeking professional help was 4 months and to diagnosis, 32 months. In 68% of cases, the first professional consulted was a child specialist.

Vernon M, Rhodes A. (2009) conducted a study on deafness and autistic spectrum disorders. An orientation to autistic spectrum disorders (ASD), also known as autism, is provided, and the specific syndrome of autism and deafness is addressed. The two conditions have in common a major problem: communication. Case histories are provided, the development of treatment for autism is discussed, and the separate disorders that make up ASD are defined. Important medical conditions often present in ASD are named, and their roles in treatment and diagnosis are described. Because autism is generally regarded as increasing in prevalence, some say to epidemic proportions, there is an increase in children who are both deaf and autistic. The resulting pressure on day and residential school programs for the deaf to accept and educate these difficult, multiply disabled children is increasing. The parents of autistic children are a sophisticated, politically active group who are demanding services through legal and legislative means, among others.

Inglese MD, Elder JH. (2009) conducted a study on carding for children with autism spectrum disorder. Autism spectrum disorder (ASD) affects 1 in 150 children and has been gaining national attention over the past decade. Given the prevalence of this disorder, there is a high probability that pediatric nurses will care for a child with ASD, regardless of the setting in which they work. Children with ASD traverse the primary care outpatient setting, schools, subspecialty clinics, and inpatient units. A basic understanding of the current issues regarding

prevalence and etiology, coupled with knowledge of the core features of ASD, will help pediatric nurses in all settings and at various practice levels better care for these children.

Woodgate RL, Ateah C, Secco L. (2008) conducted a study on the experience of parents who have a child with autism. In this study that sought to describe the experiences of parents who have a child with autism. Qualitative interviews were conducted with parents from 16 families of children with autism residing in a western Canadian province. "Living in a world of our own" emerged as the essence of the parents experiences. In "living in a world of our own," parents described a world of isolation. Three themes representing the essential challenging elements of the parent's experiences included vigilant parenting, sustaining the self and family, and fighting all the way. Although much is known about the fundamental importance of support to parents of children with chronic conditions and/or disabilities, findings from this study indicate that knowledge has not been adequately transferred to the care of children with autism.

Rhoades RA, Scarpa A, Salley B. (2007) conducted a study on the importance of physician knowledge of autism spectrum disorder results of a parents survey. Early diagnosis and referral to treatment prior to age 3-5 years improves the prognosis of children with Autism Spectrum Disorder (ASD). The average age of ASD diagnosis was later than optimal if children are to receive the most benefit from early intervention. Most professionals gave caregivers further information about ASDs, especially developmental pediatricians, but a sizeable minority did not. This may reflect a lack of training in the wide range of behaviors that occur across the autism spectrum. Parents turned to outside sources to learn more about ASD. We recommend that all physicians receive specialized training about ASDs to improve upon early screening and diagnosis, and then advise caregivers about empirically-supported services.

Whitelaw C, Flett P, Amor DJ. (2007) conducted a study on parental knowledge. To describe recurrence risk information currently being obtained by families affected by Autism Spectrum Disorder (ASD). Structured telephone interview of parents of 21 children who received a diagnosis of ASD at calvary health care Tasmania, Hobart, Australia between May 2005 and May 2006. Only one of the 21 parents knew their true recurrence risk. Many overestimated their risk substantially, and in four cases this had led to a decision against increasing family size. Eleven parents said they had received no information about recurrence risk, and only one cited medical practitioners as a source of information about recurrence risk. Current provision of information about recurrence risk to families affected by ASD is inadequate.

McConachie H, Diggle T. (2007) conducted a study on parent implemented early intervention young children with autism spectrum disorder. The review found very few studies that had adequate research design from which to draw conclusions about the effectiveness of parent-implemented early intervention. Both randomized and

controlled studies tended to suggest that parent training leads to improved child communicative behavior, increased maternal knowledge of autism, enhanced material communication style and parent child interaction, and reduced maternal depression. It seems that parent training can successfully contribute to intervention for your children with ASD. However, the review highlights the need for improved research in this area.

Renty J, Roeyers H. (2006) conducted a study on satisfaction with formal support and education for children with autism spectrum disorder. The aim of the present study was to identify and describe factors associated with variations in the level of parental satisfaction with formal support and education for children with autism spectrum disorder (ASD) in Flanders. Participants were recruited by a mailing from a diagnostic centre for pre-schoolers and by advertisements dispersed in the Flemish parent organization for ASD and in services and special schools. The sample consisted of 244 parents of children with ASD. The data were collected using a questionnaire on experiences with education and support, which was compiled for the purpose of this study. The data resulting from the questionnaire were supplemented with information obtained from semi-structured in-depth interviews with a stratified sample of 15 parents. The study revealed that parents experienced difficulties with the diagnostic process, with support and education provided by mainstream settings and with the accessibility of autism-specific service provisions. Conversely, parents reported to be satisfied with the quality of autism-specific support and education. Predictors of overall satisfaction were parental involvement in formal support, knowledge of available service provisions and time between first consultation and final diagnosis. Practical implications of the results are discussed.

Cullen LA, Barlow JH, Cushway D. (2005) conducted a study on positive touch the implications for parents and their children with autism: an exploratory study. The aims of this study were (1) to explore the experience of touch between parents and children with autism before, during, and after a Training and Support Programme (TSP), and (2) to develop a model of the process of touch therapy for this group of parents and children. Fourteen parents and their children agreed to take part in the study. Five of these parents withdrew. Reasons for withdrawal included personal circumstances and ill health. Data were collected by semi-structured interviews with parents before attending the TSP and Home Record Sheets completed by parents during the TSP. Results indicate that before the TSP touch was experienced as out of parent's control. During the TSP, the experience of touch appeared to change. A key benefit gained by parents was the feeling of closeness to children. The key benefits gained by children were perceived by the parents as improved sleep patterns, children were more relaxed after receiving the massage and appeared more amenable to touch. Of interest was children's request for massage at home. At 16-week follow-up both parents and children continue to enjoy giving and receiving touch therapy, respectively.

Luther EH, Canham DL, Young Cureton V. (2005) conducted a study on coping and social support for parents of children with autism. Autism in children has increased significantly in the past 15 years. The challenges and stressors associated with proving services and caring for a child with autism affect families, educators, and health professionals. This descriptive study used a survey to collect data on parent's perceptions of coping strategies and social support. Instruments included the social index and the family crisis oriented personal evaluation scales. One half of the families identified serious stressors in addition to autism. Acquiring social support and reframing were the most frequently used coping strategies. The school nurse is in a position to identify needs and refer families to local support groups and agencies, facilitating social support and development of coping strategies.

Pisula E. (2002) conducted a study on parents of children with autism: Pracowni Psychologii Rehabilitacy Jnej UW. The parents of autistic children have become objects of many controversial studies and theories. This is a review of the studies are combined into three categories: works on the broader phenotype, studies on the parental stress and the perception of the child, and finally, parents as therapists of their children. Although the idea of genetic determination of the cognitive, social and communication deficits, has been widely spread, it still has not been sufficiently proved. The research show that parents of children with autism experience profound stress. This stress response has specific profile the most difficult for parents are handicaps related with atypical child problems. But even though, the parents are handicaps related with atypical child behaviors, and the lack of knowledge about real development limitation and child problems. But even though, the parents supported by professionals may become the good teachers and therapists for their children. The partnership between parents and professionals is one of the conditions of the parent's success in these roles.

Chamak B, Bonniau B, Oudaya L, Ehrenberg A. (2010) conducted a study on the autism diagnostic experiences of French parents. This survey focused on French parents views of the diagnostic process relating to their child with autism. Data were collected on the age at diagnosis, the time taken to obtain a diagnosis and the difficulties encountered. Questionnaires filled in by the parents and in-depth interviews were analyzed in order to obtain quantitative and qualitative results. The ages of the children ranged from 4 to 45. This approach enabled us to compare the practices of professionals now and in the past. The mean age of diagnosis was 10 to 8 years from 1960 to 1990, 5 to 3 years from 1990 to 2005. The results showed that the mean delays between first consultation and diagnosis were reduced. Regarding the way the diagnosis was announced, 63% of the parents of children with autism and 93% of the parents of adults with autism were dissatisfied. We discuss the parents reactions and the changes in the diagnostic process.

Valentine K. (2010) conducted a study on a consideration of medicalisation: choice, engagement and other responsibilities of parents of children with autism spectrum disorder. Classic studies of medicalization point

to the 'rise of the experts' as disempowering patients and refusing to acknowledge their expertise in their own lives. More recently, medicalisation scholarship has taken a different turn, arguing that patient choice is both a responsibility imposed on patients, and a driver of medicalisation. To what extent does autism, a childhood developmental disorder in which parents are invited to take a close role, instantiate these different manifestations of medicalisation? This paper reports on a qualitative study of parent's experience of diagnosis and treatment, conducted in four states in Australia in 2008-2009. It draws on 49 interviews with parents of young children with autism, and with early intervention service providers and clinicians. Our study shows that the importance of choice in decisions around treatment cannot be subsumed under the single category of disenfranchisement or engagement. The diverse responses of parents to the diffuse, complex field of autism treatment illustrate an admixture of consumption, advocacy and education driving contemporary medicalisation.

Benjak T, Vuleti C, Mavrinac G, Pavi C, Simetin I. (2009) comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia. A total of 350 parents participated in the study: 178 parents of children with ASD and 172 parents of non-disabled children matched by age, education, and place of living. Parent's self-perceived health was assessed using the Croatian version of the health status questionnaire SF-36, while socio-demographic information, chronic medical conditions, and needs were assessed by a general questionnaire. Parents of children with ASD had poorer health than the control group in all components, except physical health. Because parents are the main providers of support for children with ASD, preserving parent's good health and well-being is a precondition for an optimal care for children. Therefore, current system for treating children with ASD in Croatia should also include permanent improvement.

Rao PA, Beidel DC. (2009) conducted a study on the impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. The study involves a sample of parents of 15 children with HFA and parents of 15 matched control children who completed questionnaires measuring the dependent variables. The results indicate parents of children with HFA experience significantly more parenting stress than parents of children with no psychological disorder, which was found to be directly related to characteristics of the children. The study further shows that the higher intellectual functioning in children with HFA does not compensate for the stress associated with parenting children with autism spectrum disorders. Because the intervention efforts directed at children with HFA will not eliminate the child's primary symptoms, treatment programs may need to address parental stress, which in turn will help optimize treatment outcome for the child and the family.

3. Conceptual Frame Work

Conceptual frame work is a brief explanation of a theory or those portions of a theory to be tested in a study. (Grove 2003)

The conceptual frame work of this study is based on the J.W. Kenny's open system model.

All living systems are opened, in that there is continuous exchange of matters, energy and information open system have varying degree of information with environment with a system receives input and gives back output in the form of matter, energy and information. For survival all system must receive varying types, amount of matter and information. The math concepts of the system theory are input, throughput, output and feedback.

This method of J.W. Kenny's open system is sorted to this study to determine the effectiveness on sim.

Input

Input refers to resources which are taken from the external environment.

In this study input refers to the assessment of knowledge of care of autistic children.

Throughput

Throughput refers to the process of conversion of transformation of resources within the system.

In this study throughput refers to the transformation of knowledge regarding care of autism which will occur within the system because of self-instructional module.

Output

Output is the whole of the system expected back into the environment.

In this study, output refers to the gain in the level of knowledge regarding care of autism among parents of autistic children.

Feedback

Feedback refers to a continuing source of information conceiving the relationship with the external environment used to make the necessary changes in order to survive and groups.

Feedback is essential to know that the given education was effective or not and hence cycle has to be repeated. Feedback emphasized to strengthen the input and throughput.

In this study feedback refers to the analysis of the post test.

The conceptual framework based on J.W. Kenny's open system model is presented in figure-1.

Conceptual Framework

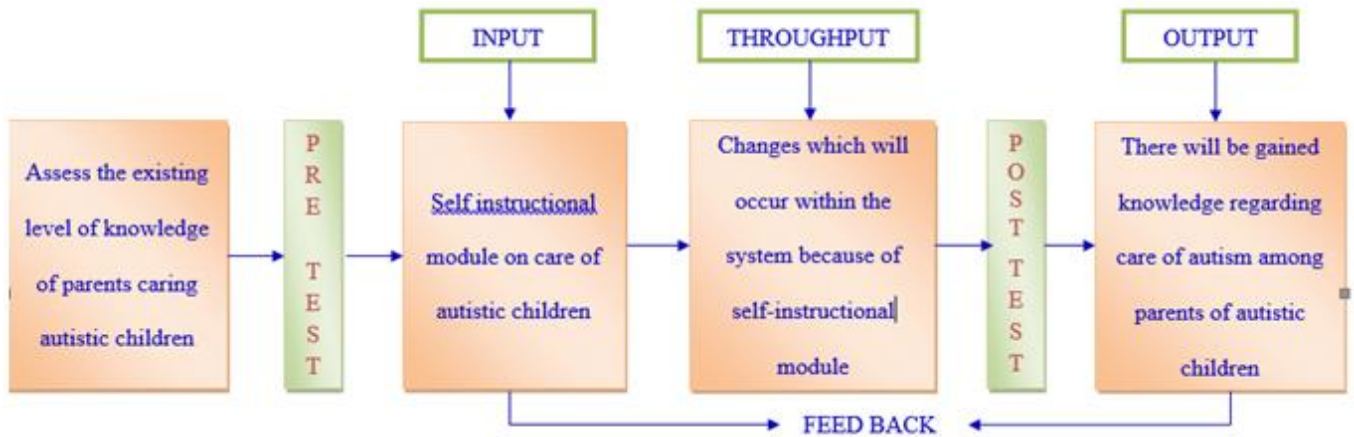


Figure 1: The conceptual Framework based on J. W. Kenny's Open System Model (2002)

4. Research Methodology

Methodology is the systematic approach of exploring facts with the application of the principles of reasoning to scientific and philosophical enquiry. It involves orderly procedures by which the researcher starts from an initial identification of a problem to its conclusion (Sharma, 1990). Methodology indicates the general pattern for organizing the procedure for gathering valid and reliable data. It includes research approach, research design, setting, sample size, sampling technique, criteria for sample selection, data collection tool, plan for data analysis and protection of human rights (Polit, 2000).

Research Approach

Quasi experimental approach is a powerful design for testing hypothesis of causal relationship among variables (Basavanthappa, 2005).

Research approach used for the study was Quantitative approach.

Research Design

The research design is the plan of how, when and where data are to be collected and analyzed (Parahoo, 2006). The research design selected for this study was quasi experimental design, under that one group pre-test post-test design was adopted. Here the pre-test measurement was made on the knowledge of care of autism among parents caring Autistic children and self-instructional module was given by semi structured interview schedule.

Diagrammatic representation of the design is given below.

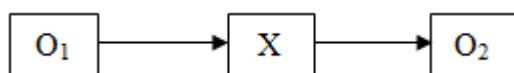


Figure 2

Research design

- O₁ - Pre-test
- X - Administration of self-instructional module
- O₂ - Post-test

Setting of the Study

Setting is the physical location and condition in which data collection takes place in study (Polit, 2008). The study was conducted at School for mentally challenged at Santhi Nilayam in Erumpukadu, which is situated about 35 kilometers away from Christian College of Nursing. The average census of students in this institution is 250. The average of 70 Autistic children studied in that institution.

Population

Entire set of individuals or objects having some common characteristics (Polit 2005). In this study population refers to those parents of autistic children attending special classes in school for mentally challenged in Santhi Nilayam.

Sample

A sample is a selected proportion of the defined population (Polit 2005).

In this study sample consisted of 30 parents of autistic children in school for mentally challenged in Santhi Nilayam.

Sample Technique

It refers to the process of selecting a portion of the population to represent the entire population (Polit, 2005). Purposive sampling technique was used in this study.

Variables

Variables are often inherent characteristics of research subject. In this study,

- a) Dependent variable -Care of autistic children
- b) Independent variable -Self-instructional module on care of autistic children
- c) Demographic variables -Age, sex, education, family income

Criteria for Sample Selection

Inclusion criteria

- Parents who are able to read the self-instructional module.
- Parents who are caring autistic children.

- Parents of autistic children of mentally challenged in Santhi Nilayam.

Exclusion criteria

- Parents who are not willing to participate in the study.

Research Tool and Technique

Preparation of the tool

After literature review and consultation with the experts, a semi-structured interview schedule was developed to assess the knowledge on care of autism among parents of autistic children. The semi structured interview schedule consisted of two section.

Section – I

Demographic data such as Age, sex, education, occupation, family income.

Section – II

Consisted of 20 questions to assess the knowledge of care of autism among parents of autistic children.

Self-Instructional Module On Care of Autistic Children

A self-instructional module was developed by review of literature and expert's opinion. The module was developed based on the care of autism.

Validity of the tool

Validity is the degree to which an instrument measures what is intended to measure (Polit, 2008). The content was submitted to five experts, one psychiatrist, one psychologist and three Nursing faculties. The tool was found to fulfill the objectives.

Reliability

The reliability of the tool was assessed by calculating the stability and internal consistency.

The stability of the tool was tested by the method of "test retest". The calculated co-efficient correlation of knowledge was $\gamma =$

The stability of the tool was significant since the γ was more than

The internal consistency between the questions of the knowledge was tested by the method of method knowledge alpha $\alpha =$

From the above calculation the tool is reliable.

Pilot Study

Pilot study is a small version or miniature of the main study (Polit, 2005).

The pilot study was conducted at Santhi Nilayam from to 3 parents of autistic children who met the inclusion criteria were selected consent was obtained from the sample after establishing good rapport. The knowledge on care of autism were assessed using a semi-structured interview schedule. After the interview, a self-instructional module on care of autistic children was administered.

Effectiveness of the self-instructional module was measured by the same interview schedule after two weeks. The data which was obtained were analyzed and the post-test knowledge score was significantly higher than the pre-test knowledge score. Hence it was found that the data collected were amenable for statistical analysis and thus the study was found to be feasible.

Data Collection Procedure

The participants of the study were parents of Autistic children in Santhi Nilayam. After establishing rapport with them, a pre-test was done using the semi-structured interview schedule and knowledge of care of autistic children were determined. On completion of interview, self-instructional module on care of autistic children was administered to them. After two weeks, their knowledge was found out using the same interview schedule.

Plan for Data Analysis

The data collected were analyzed using descriptive and inferential statistics. The knowledge scores obtained was graded as follows.

Grade	Percentage
Adequate	76 – 100
Moderately adequate	51 – 75
Inadequate	Below 50

Based on above scoring procedure, parent's knowledge was assessed.

Protection of Human Rights

The data was collected individually. Before collecting the data individual consent was obtained and the purpose of the study was explained. Formal written permission was got from the concern authority and the ethical committee. All participants were assured to maintain confidentiality.

5. Data Analysis and Interpretation

This chapter deals with the analysis and interpretation of data obtained from the study, which is intended to evaluate the effectiveness of self-instructional module on care of autistic children among parents caring child with autism.

The data collected were organized, tabulated, analyzed and interpreted using descriptive and inferential statistics.

Section I: Data on selected demographic variables.

Section II: Effectiveness of self-instructional module on knowledge of care of autistic children among parents caring children with autism.

Section III: Association between selected demographic variables and level of knowledge regarding care of autistic children among parents caring child with autism.

Section – I

This section deals with the distribution samples according to the selected demographic variable.

Table 1: Percentage Distribution of Demographic characteristics of study subjects

S. No	Demographic variables	Components of the variables	Parents n=30	
			Frequency	%
1.	Age (years)	20 – 29	7	23.3
		30 – 39	12	40
		40 – 49	8	26.7
		50 – 59	3	10.0
2.	Relationship	Father	9	30.0
		Mother	21	70.0
3.	Education	Degree	9	30.0
		Higher Secondary	13	43.3
		High school	8	26.7
4.	Family monthly income (Rs)	5000 – 10,000	7	23.3
		10,000 – 15,000	16	53.3
		15,000 – 20,000	2	6.7
		20,000 – 25,000	5	16.7
5.	Types of family	Joint	14	46.7
		Nuclear	16	53.3
6.	Occupation	Employed	12	40.0
		Unemployed	18	60.0

In the above table, the median age of the parents was 36 years and the mean age of them was 36.6 ± 8.9 . Among the 30 respondents 15 (50%) parents were less than 36 years and the remaining 15 (50%) parents were above 36 years of age 9 (30%) Fathers and 21 (70%) mothers had participated in the study. In respect of education status, 9 (30%) parents had acquired graduation, 13 (43.3%) had

studied Higher Secondary level and the remaining 8 (26.7%) had studied high school level. The median income of the family was Rs. 12,000/- per month and the mean income was $Rs.12900 \pm 5886$ per month. Out of 30 parents 14 (46.7%) were living jointly and the remaining 16 (53.3%) had nuclear family type. Majority 18 (60%) parents were unemployed and 12 (40%) were unemployed.

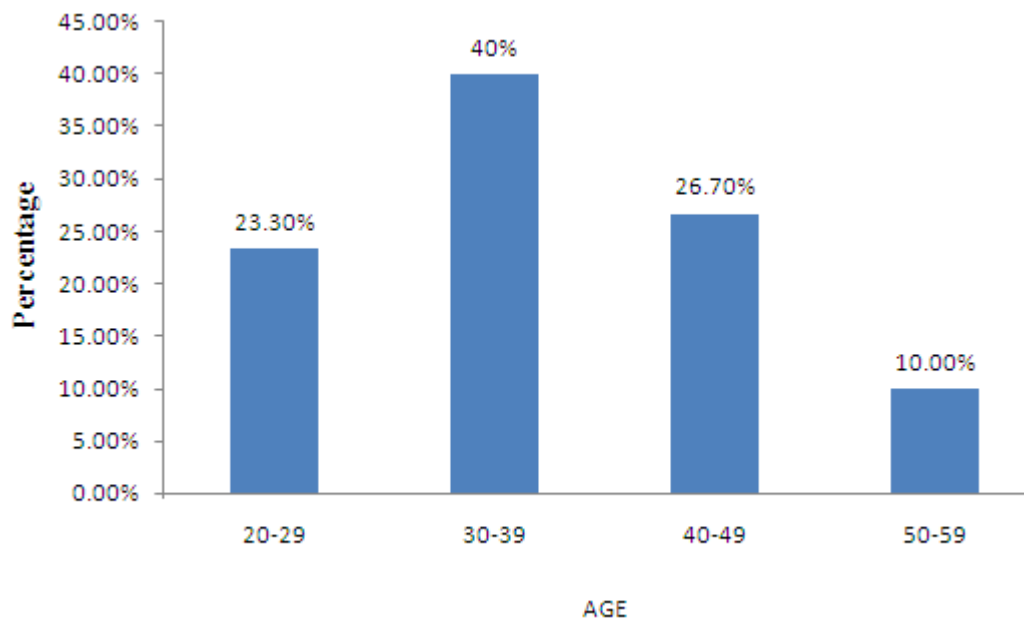


Figure 3

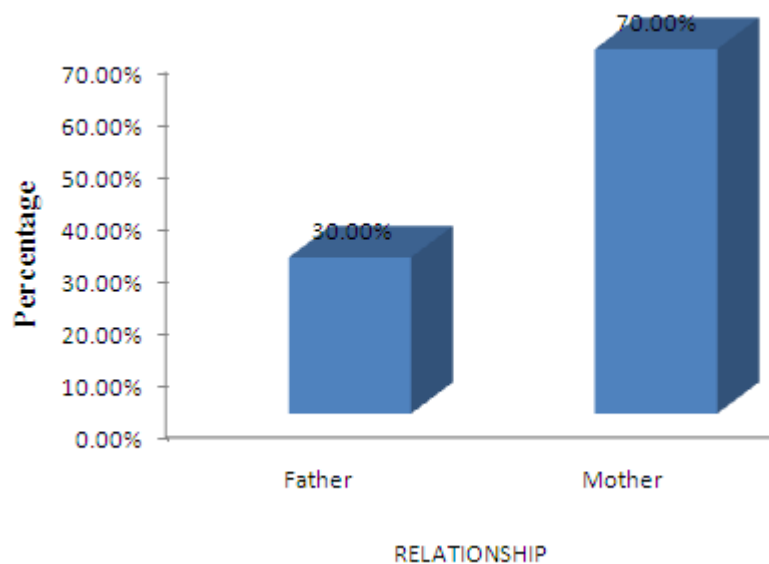


Figure 4

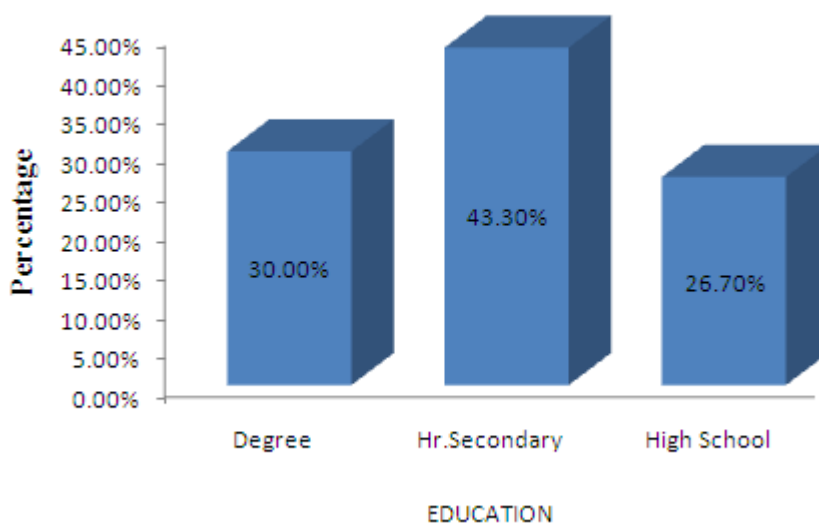


Figure 5

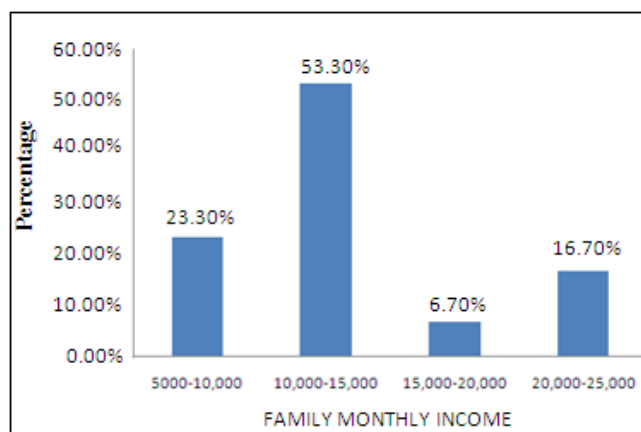


Figure 6

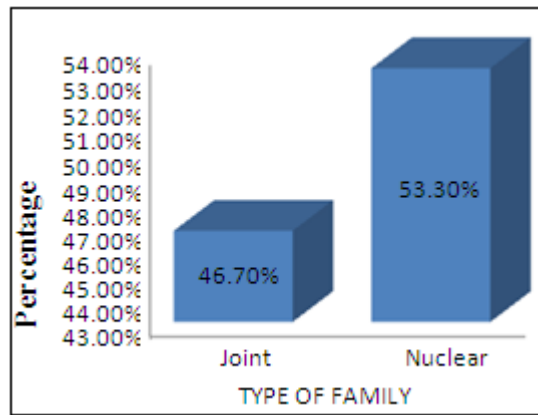


Figure 7

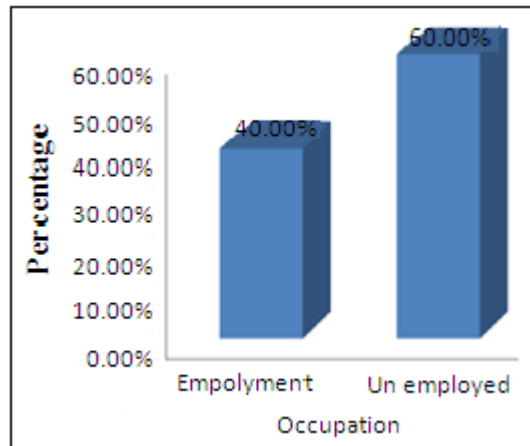


Figure 8

Section II

Effectiveness of self-instructional module

The effectiveness of the self-instruction module by comparing the pre and post knowledge scores and interpreted accordingly.

Table 2: Effectiveness of the self instructional module

	Pre test		Post test		Mean		d-f	t	significance
	Mean	S.D	Mean	S.D	Mean	S.D			
	Difference								
Self instructional module	11.8	2.6	19.1	0.8	7.3	2.4	29	16.847	P<0.001

The above table 2 evaluates the effectiveness of self-instructional module. The mean of the pre-test score was 11.8 ± 2.6 and the same of the post-test was 19.1 ± 0.8 scores. The increase of the scores from the pre to post test was 7.3 ± 2.4 . the above increase was statistically very highly significant ($t=16.847$ $d-f = 29$ and $P < 0.001$). the statistically very highly increased knowledge of parents on

care of autistic children was the effectiveness of self-instructional module.

Effectiveness of self-instructional module in terms of percentage

The effectiveness of self-instructional module was assessed in terms of the prevalence of total knowledge during pre and posttests.

Table 3: Percentage of distribution of pre and posttest of knowledge on care of autistic children.

Knowledge score	Percentage of score	Level of knowledge	Before		After	
			Parents		Parents	
			Frequency	%	Frequency	%
0 – 10	< 50.0	Inadequate	6	20.0	-	
10 – 15	50 – 75	Moderate	21	70.0	-	
15 – 20	75 – 100	Adequate	3	10.0	30	100.0
Total			30	100.0	100.0	

The above table 3 reveals the assessment of knowledge of parents. Before introduction of the model only 3 (10%) parents had adequate knowledge. The remaining 6 (20%) and 21 (70%) of parents had inadequate and moderate knowledge in care respectively. The above level of knowledge was increased after introduction of self-introduction module.

Section – III

Association between pre-test knowledge with demographic variables

The association between pre-test score with demographic profiles of parents were studied the variables namely age, relation, education, family income, family type and occupation.

Table 4: Association between knowledge with age of parents

Age group	Number of parents caring autistic children			Total	χ^2	df	Significance
	Inadequate	Moderate	Adequate				
20-29	2	3	2	7	6.271	6	P>0.05
30-39	3	8	1	12			
40-49	1	7	0	8			
50-59	0	3	0	3			
Total	6	21	3	30			

The above table 4 describes the association between knowledge on care of autistic children and the age of the parents. The result reveals that there was no significant association between the knowledge and age of parents.

Table 5: Association between knowledge with the relationship of autistic children

Relationship	Number of parents with autistic children				χ^2	df	Significance
	Inadequate	Moderate	Adequate	Total			
Father	2	7	0	9	1.429	2	P>0.05
Mother	4	14	3	21			

The association shown in the table 5 reveals that the knowledge did not associated with either mother or father of the autistic children.

Table 6: Education and educational status of parent’s association on care of autistic children

Education	Number of parents with autistic children				χ^2	df	Significance
	Inadequate	Moderate	Adequate	Total			
Degree	0	9	0	9	9.254	6	P>0.05
Hr.secondary	4	8	1	13			
High school	2	4	2	8			
Total	6	21	3	30			

Educational status of parents did not release any role in respect of the knowledge on care of autistic children vide table 6.

Table 7: Relation between to family income with knowledge of parents

Monthly income	Number of parents with autistic children				χ^2	df	Significance
	Inadequate	Moderate	Adequate	Total			
5000-10000	3	2	2	7	9.254	6	P>0.05
10000-15000	3	12	1	16			
15000-20000	0	2	0	2			
20000-25000	0	5	0	5			
Total	6	21	3	30			

The above table 7 states the relationship between the knowledge with family income. The family income had no association with knowledge of parents on care of autism children (P>0.05).

Table 8: Association between knowledge with the type of family.

Type of family	Number of parents with autistic children				χ^2	df	Significance
	Inadequate	Moderate	Adequate	Total			
Joint family	2	11	1	14	0.918	2	P>0.05
Nuclear family	4	10	2	16			
Total	6	21	3	30			

The family type and knowledge of parents regarding to association shown in to above table 8 reveals that there was no significant association between the two attributes (P>0.05).

Table 9: Parents of autistic children's occupations association with knowledge

Occupation	Number of parents with autistic children				χ^2	df	Significance
	Inadequate	Moderate	Adequate	Total			
Employed	2	9	1	12	0.238	2	P>0.05
Unemployed	4	12	2	18			
Total	6	21	3	30			

The association between the occupations of parents with their knowledge on care of autistic children was explained with above table 9. The result of the above interpretation reveals that occupation and knowledge of parents had no significant association between them (P>0.05).

6. Results and Discussions

The present study is to assess the effectiveness of self-instructional module on knowledge of care of autistic children among parents caring child with autism. A total number of 30 parents was selected for the study. The knowledge was assessed by structured questionnaires.

The objectives of the study are

- To assess the knowledge on care of autistic children among parents caring child with autism.
- To assess the effectiveness of self-instructional module on care of autistic children among parents caring child with autism.
- To find out the association between knowledge of care of autistic children and selected demographic variables (age, relationship, education, income, type of family, occupation).

Sample Characteristics

The parents caring child with autism were described according to their demographic socio and economic profiles like age, relationship, education, income, type of family and occupation. On analysis of data obtained from table 1 the mean age of the parents was 36.6 ± 8.9 years and the median age was 36 years. In the study 9 (30%) others and 21 (70%) mother were participated. In respect of education status, 9 (30%) parents had acquired graduation, 13 (43.3%) had studied Higher Secondary level and the remaining 8 (26.7%) had studied high school level. The median income of the family was Rs.12000/per month and the mean income was $Rs.12900 \pm 5886$ /per month. Out of 30 parents 14 (46.7%) were living jointly and the remaining 16 (53.3%) had nuclear family type. Majority 18 (60%) parents were unemployed and 12 (40%) were employed.

The first objective of the study was to assess the knowledge on care of autistic children among parents caring care of autism.

The data obtained from table reveals that the knowledge of the study subjects regarding care of autistic children before introduction was of module assessed as 11.8 ± 2.6 . 10% (3) of parents had adequate knowledge. The remaining 20% (6) and 70% (21) of parents had inadequate and moderate knowledge on care respectively.

The second objective of the study to assess the effectiveness of self instructional module on knowledge of care of autistic children among parents caring child with autism.

The data obtained from table reveals that the mean of the pre-test score was 11.8 ± 2.6 and the same of the post-test was 19.1 ± 0.8 scores. The increase of the scores from the pre to post test was 7.3 ± 2.4 . The above increase was statistically very highly significant ($t=16.847$ $df=29$ and $P<0.001$). The statistically very highly increased knowledge of parents on care of autistic children was the effectiveness of self-instructional module.

The third objective of the study was to find or the association between knowledge of care of autistic children and selected demographic variables.

The data obtained from table shows the association between the demographic variables of study subjects (age, relation, education, family income, family type and occupation) and the components of knowledge. The results reveal that there was no significant association between the demographic variables with almost all the knowledge components.

7. Summary and Recommendations

This chapter presents the summary, conclusions, recommendations for future research and implications of study in learning.

7.1 Summary

This study was undertaken to assess the effectiveness of self-instructional module on knowledge of care of autistic children among parents caring child with autism in school for mentally challenged at Santhi Nilayam. One group pre-test post-test quasi experimental design and purposive sampling technique was used on the basis of inclusion criteria. Conceptual frame work was formulated according to J.W. Kenny's open system model. Sample selected for the study was 30 parents of autistic children. The tool for the study consisted of two sections. Section A consisted of demographic variables, section B consisted of 25 questions to assess the knowledge of care of autistic children among parents caring child with autism. The data was analysed and interpreted in terms of objectives. Descriptive and inferential statistics were used for data analysis.

Objectives of the Study

- To assess the knowledge on care of autistic children among parents caring child with autism.
- To assess the effectiveness of self-instructions module on care of autistic children among parents caring child with autism.
- To find out the association between knowledge on care of autistic children and selected demographic variables.

Major Findings of the Study

- Among the parents caring child with autism who were selected for the study 50% of the parents were in the age group of 35 and above and the median age was 36 years.
- Majority (70%) of the subjects were females.
- Among the subjects 43.3% were having higher secondary school education.
- 60% of the study subjects were unemployed.
- The mean post-test knowledge (19.1) higher the mean pre-test knowledge (11.8).
- There was no significant association between the knowledge on care of autistic children among parents caring child with autism and selected demographic variables.

Nursing Implications

The findings of the study have shown implications in nursing practice, nursing education, nursing administration and nursing research.

Nursing Practice

- Providing information to parents caring child with autism regarding care of autistic children is an important professional responsibility of nurses as non-adherence to the care of autistic children may lead to fatal complications.
- The self-instructional module developed for the study can be utilized as a resource material for both professionals and parents. By using self-instructional

module, a large number of parents can be educated within less time.

- Self-instructional module also serves as a quick reference material at home.

Nursing Education

- Importance on care of autistic children should be given emphasis in the nursing curriculum from diploma to master degree and nursing students should be prepared for imparting knowledge on care of autistic children in their training period itself.
- Students can utilize the module for the clinical presentation; ward teaching more over for conducting seminars.
- Teachers and students can use it as reference material for preparing other visual aids like pamphlet, leaf let, handout, posters etc.

Nursing Administrations

- As nurse administrators are responsible for rendering psycho education to the parents, they have to develop standards and policies for the provision of care of autistic children.
- Adequate provision can be made to keep the self-instructional module in the psychiatric units and mentally challenged schools, so that the parents and relatives can go through it.
- Nurse administrators should also organize psycho education programmes to parents caring child with autism to them with current knowledge regaining care of autistic children.

Nursing Research

- As nurses are the health professionals who are in close contact with the autistic children and their parents, they can undertake the studies to identify the problems related to their daily activities.
- This study adds to the existing body of knowledge in nursing.
- The data obtained from the study can be used for further reference.

8. Recommendations

- 1) Similar study can be replicated with larger samples.
- 2) Comparative study can be conducted between male and female.
- 3) A self-instructional module can be developed in related areas like knowledge on care of mental retarded children, learning disability children and attention deficit hyper activity children's and effectiveness can be found out.
- 4) A descriptive study can be undertaken to assess the quality of life of parents caring child with autism.

9. Conclusion

Based on the study findings the following conclusions were made;

- 1) The knowledge on care of autistic children among parents caring child with autism was inadequate before the administration of self-instructional module.
- 2) The self-instructional module improved the knowledge of parents caring child with autism.
- 3) The mean post-test knowledge score was significantly higher than the mean pre-test knowledge score of parents caring child with autism.
- 4) It has been clearly revealed that there was no significant relationship between the knowledge on care of autistic children among parents caring child with autism and selected variables such as age, relation, education, family income, family type, and occupation. Hence the self-instructional module can be utilized for imparting knowledge on care of autistic children among parents caring child with autism irrespective of age, relation, education, family income, family type, and occupation.

References

Text Books

- [1] Ahuja Niraj, (2002). A short text book of Psychiatry. (5th ed). New Delhi: Jaypee Brothers Medical Publishers (P) Ltd.,
- [2] Boyd Ann Mary, (2008). Psychiatric Nursing. Contemporary Practice. (4th ed). New Delhi: Wolters Kluwer (P) Ltd,
- [3] Basavanthappa, B.T. (2007). Psychiatric Mental Health Nursing. (1st ed.). New Delhi: Jaypee Brothers Medical Publishers (P) Ltd,
- [4] Bimla Kapoor, (2008). Psychiatric Nursing. (1st ed). Vol-II. Delhi: Kumar Publishing House,
- [5] Basavanthappa, B.T. (1998). Nursing research (1st ed.). Mumbai: Jaypee Brothers Medical Publishers. .
- [6] Bhatia, M.S. (2004). Essentials of Psychiatry. New Delhi, CBS Publishers.,
- [7] Gail W. Stuart, Michale Lararia, (2005). Principles and Practice of Psychiatric Nursing, (8th ed). New Delhi: Elsevier Publications Ltd,
- [8] Lalitha, K. (2007). Mental Health and Psychiatric Nursing- An Indian perspective. (1st ed). Bangalore: VMB Book House,
- [9] Mary C. Townsend. (2005). Psychiatric Mental Health Nursing. (5th ed). New Delhi: Jaypee Brothers Medical Publishers (P) Ltd,
- [10] Mahajan, B.K. (1997). Methods in Biostatistics. (6th ed). Delhi: Jaypee Brothers Medical Publishers.
- [11] Neeraja, K.P. (2008). Essentials of Mental Health and Psychiatric Nursing. (1st ed). Vol-I. New Delhi: Jaypee Brothers Medical Publishers (P) Ltd,
- [12] Rao, P.S.S, Richard, J. (2002). Introduction to Biostatistics and Research Methods. (4th ed.). New Delhi: Prentice Hall of India Private Limited.
- [13] Sreevani, R. (2007). A Guide to Mental Health and Psychiatric Nursing. (2nd ed). New Delhi: Jaypee Brothers Medical Publishers (P) Ltd,
- [14] Fortinash, Holoday Worret. (2008). Psychiatric Mental Health Nursing. (4th ed). Missouri : Mosby Publications.

Part – I

Demographic Variables

Choose the correct Answer and put (✓) mark in the box

1. Age
2. Relationship with the Autistic Children
 - a) Father
 - b) Mother
3. Education
 - a) Middle School
 - b) High School
 - c) Higher Secondary School
 - d) Degree
 - e) Illiterate
4. Family Income
5. Type of Family
 - a) Joint Family
 - b) Nuclear Family
6. Occupation
 - a) Employed
 - b) Unemployed

Part – II

Tools for Assessing Knowledge of Parents Regarding Care of Autism

Choose the correct Answer and put (✓) mark in the box.

1. Which one is the following symptom of Autism?
 - a) Impairment of vision
 - b) Impairment of social skills
 - c) Impairment of hearing
2. Autism most commonly affects?
 - a) Girls
 - b) Boys
 - c) Boys and girls
3. Autism should identify the age
 - a) Of 10 years
 - b) Before 3 years of age
 - c) After 5 years
4. Which one of the following a predisposing causes for Autism?
 - a) Drug abuse during pregnancy
 - b) Fracture of leg
 - c) Poor nutrition
5. Signs and Symptoms of Autism except
 - a) Appears in different to surroundings
 - b) Displays lack of response to others
 - c) Like Cuddling
6. Autistic children can

- a) Easily study sign languages
- b) Have a hard time to learn sign languages
- c) Understand verbal languages
7. Autistic children may need,
- a) Reward for good behavior
- b) Punishment
- c) To know principles
8. Autistic children is beneficial, if
- a) Following schedule time
- b) Not following schedule time
- c) Disruptions of schedule
9. Autistic children are
- a) Take care of them self
- b) Caring of others
- c) Prone to get injuries
10. Approach to autistic children generally involves,
- a) Teaching all skills at a time
- b) Teaching skills step by step
- c) Teaching group of activities together
11. Autistic children understand
- a) Verbal language
- b) Sign language
- c) Written format
12. The friendship of autistic children is
- a) Peer group
- b) Family members
- c) Inanimate objects
13. Autistic children
- a) Can go to special school
- b) Can go to normal school
- c) Can go to any type of school
14. Most common activity for autistic child is
- a) Study
- b) Sleep
- c) Repetitive play
15. Important skill that is need for an autistic child is
- a) Social
- b) Psychological
- c) Physical
16. Autistic children have marked impairment except
- a) Eye to eye contact
- b) Language development / common
- c) Playing
17. Autistic children fail to develop, age appropriate
- a) Peer relationship
- b) Physical growth
- c) Verbal language
18. Autistic children look like as if
- a) Social
- b) Deaf or dumb
- c) Generous
19. Autistic children usually don't hare?
- a) Social smile
- b) Play activity
- c) Eating habits
20. Autistic children have
- a) Stereotyped and repetitive movements
- b) Normal eating habits
- c) Abnormal physical growth.