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Research Protocol

Nursing Section

Effectiveness of Telenursing Intervention Program Focusing on Social Communication Skills and Behavioural Challenges in Parents of Children with Autism: A Research Protocol

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ABSTRACT

Introduction: Telenursing is the use of technological resources and communication systems such as computers and mobile phones to encourage the development of nursing from a remote setting. It has recently been employed to enhance access to healthcare. Through telenursing, nursing and healthcare, in general, can be accelerated. Telenursing can assist parents of children with autism by creating a bridge between the treatment and support systems.

Need of the study: Children with autism often exhibit challenging behaviour and poor social communication skills, which can lead to anxiety for their parents. Despite many advances in improving the quality of life for children with autism, many parents still struggle with unresolved issues.

Aim: To assess the effectiveness of the Telenursing Intervention Programme (TNIP) for parents of children with autism, in terms of their knowledge, attitude and self-efficacy regarding social communication skills and challenging behaviour.

Materials and Methods: A quasi-experimental pre- and postintervention study will be conducted at the autism Intervention Clinic of DEIC- Early Intervention Centre of the Department of Paediatrics, Safdarjung Hospital, Delhi, India, from March 2024 onwards until May 2025 (tentative). The target population will be parents of children with autism, with a sample size of 156 parents. A purposive sampling technique will be used. Socio-demographic variables, including age, relationship with the child, mother's education, father's education, type of family, child's gender, age of the child at the time of autism diagnosis and whether parents have attended any sessions on autism before, will be recorded through a questionnaire. The Telenursing Intervention Program (TNIP) will consist of a 60-minute video conference session divided into two sessions of 30 minutes each, conducted over two days. The session will include a 20-minute didactic lecture on social communication skills and challenging behaviour in children with autism, followed by a 10-minute discussion. The TNIP session will be held online via an online video platform. After the TNIP, parents will be reassessed for their knowledge, attitude and self-efficacy through a Google Form. Data will be collected using a structured knowledge questionnaire, an attitude questionnaire and the General Self-Efficacy (GSE) tool in both pretest and post-test formats.

Keywords: Attitude, Quasi-experimental study, Self-efficacy

INTRODUCTION

Autism, also referred to as Autism Spectrum Disorder (ASD), constitutes a diverse group of neurodevelopmental conditions that affect how people interact with others, communicate, learn and behave [1]. The prevalence of ASD is estimated to be approximately 1 in 100 children [2]. The exact aetiology of ASD remains unknown, but strong genetic and environmental influences appear to play a role in brain development. Identical twins have a higher prevalence of ASD. Other risk factors include children born to older parents, preterm babies (<35 weeks' gestation), or those with low birth weight (<2500 grams), who are at increased risk [3].

Nurses can play an active role in supporting parents of children with ASD by providing assistance in early detection, relaying knowledge regarding evidence-based interventions, educating families and coordinating care. By actively listening to the individuals with ASD and their family members, nurses can devise a plan that facilitates effective communication and avoids sensory overload [3]. With the expansion of technology and the emergence of new technological advancements, nursing personnel can now adapt and apply these tools to enhance the efficiency and effectiveness of nursing care for such patients. One such advancement is Telenursing, which involves the use of telecommunications, such as computers and mobile phones, to provide health education and nursing care remotely [4].

Early diagnosis and treatment, primarily involving non pharmacological interventions based on behavioural modification strategies, the use of medication when indicated, and regular counselling sessions can significantly improve quality of life [5].

This study aims to determine the effectiveness of the Telenursing Intervention Program (TNIP) for parents of children with autism in terms of their knowledge, attitude, and self-efficacy regarding social communication skills and challenging behaviours.

Based on the objectives, the following research hypotheses have been formulated:

H1: There will be a significant association between the TNIP and the knowledge of parents.

H2: There will be a significant association between the TNIP and the attitude of parents.

H3: There will be a significant association between the TNIP and the self-efficacy of parents.

REVIEW OF THE LITERATURE

In children with ASD, verbal communication can be challenging. In such cases, parents often struggle to understand their child's needs, which increases their stress and anxiety. Children with ASD typically communicate using language that reflects their intellectual or social development [6].

A study was conducted to explore the sources of stress and the variables/predictors affecting parents of children with ASD, particularly concerning language skills. The study involved 80 parents, and a questionnaire was used for data collection. The most common source of stress was related to concerns about the child's future and difficulties in understanding their speech and language. A multiple regression analysis revealed that child communication and language skills were valid predictors of parental stress, with significant results [6].

A meta-analysis included 17 controlled trials and found that parent implementation fidelity and self-efficacy significantly increased, while parental stress and children's problem behaviours significantly decreased in the telehealth group compared to the control group [7]. Another study investigated the effectiveness of a 6-month parent-mediated early intervention telehealth programme for children with ASD. The findings revealed that early intervention helps parents become more aware of how to benefit from interactions with their children, promoting their empowerment and reducing parenting stress [8].

Through the TNIP, parents can learn about current information related to autism. Group video calls allow parents to discuss common struggles, which enhances their access to better information and services. The Telenursing programme, providing 24-hour specialist nurse contact, can serve as an immediate support source for families facing challenges with poor social communication skills and behavioural issues, potentially improving coping strategies by building self-efficacy. To date, there is limited evidence regarding the effectiveness of such interactions, particularly in relation to parents from different socio-economic backgrounds.

MATERIALS AND METHODS

A quasi-experimental pre-post study will be conducted at the Autism Intervention Clinic of DEIC- Early Intervention Centre of the Paediatric Department at Safdarjung Hospital, Delhi, India, from March 2024 until May 2025. Institutional ethical committee clearance has been obtained (IEC- SGTDCHRI/FNUR-Ph.D/2024/07).

Inclusion criteria: All parents willing to participate, who own a mobile device and have an internet connection and are able to read and understand English and Hindi, will be included in the study.

Exclusion criteria: Parents who refused to participate in the online sessions and parents whose children had any concomitant history of neurological disorder will be excluded from the study.

Sample size calculation: Statistical software programs such as G*Power were used to calculate the sample size. To the best of our knowledge, no previous studies have utilised the tool we are proposing in our current study. Hence, for sample size calculation, benchmark values were obtained from a pilot study involving 10 respondents assessed on various parameters before and after the test. One of the important parameters of present study was efficacy, which was assessed using scores ranging from 1 to 4 across 10 different questions. The total of these scores was then used for further data analysis. The mean total efficacy score was calculated as 30.9±6.95 pretest, which increased to 32.6±4.19 post-test. Based on these reference values, the minimum required sample size at a 5% level of significance and 95% power is determined to be 148 participants. Sample size needed for Wilcoxon test would be 1.053 times as needed for a t-test. Hence minimum sample required for present study is rounded to 156 respondents. A purposive sampling technique will be employed to select 156 parents of children with autism. The study will proceed after obtaining consent from the parents, who will be provided with an explanation of the purpose and methods of the study, along with the data collection procedure.

Data will be collected in a step-wise manner:

Step 1: Preparation and validation of TNIP.

This involves preparing information materials and PowerPoint slides related to social communication skills and behavioural challenges in children with autism, which will be validated by experts in paediatrics, child psychiatry and nursing education. The Telenursing programme will be tailored for parents of children with autism, with a focus on information regarding social communication skills and behavioural challenges in children, as well as the role of parents.

Step 2: Development and Validation of Study Tool [Appendix]

To ensure the content validity of the tools, they will be submitted to experts, including specialists in paediatrics, child psychiatry, nursing education and clinical psychology. Suggestions provided by the experts will be incorporated.

Section A of the tool will consist of a total of 10 items to collect information on socio-demographic details, including age, relationship with the child, mother's education, father's education, type of family, child's gender, age of diagnosis for autism and previous sessions on autism attended (if any) [Appendix].

Section B will comprise 32 items in a structured knowledge questionnaire, including 12 multiple-choice questions and 20 dichotomous questions (true/false) [Appendix].

Section C will contain 13 attitude-based items. Scoring will be done on a Likert scale of 1-4 [9]. Section D will involve a GSE tool, which is a self-administered questionnaire. The GSE scale, a prevalidated tool, will be used. The total score is calculated by summing all items. For the GSE, the total score ranges between 10 and 40, with a higher score indicating greater self-efficacy [Appendix] [10].

Step 3: Conducting TNIP

The intervention programme for a total of n=156 parents will consist of a 60-minute video conference session, divided into two sessions of 30 minutes each, conducted over two days. On Day 1, there will be a didactic lecture on social communication skills and behavioural challenges in children with autism for 20 minutes, followed by a 10-minute discussion. Day 2 will focus on strategies for teaching and developing social skills, common challenges of parenting a child with autism, and the role of parents in supporting their child. The TNIP will include:

i. A discussion on information provided about autism;
ii. Time for parents to reflect on whether their newly acquired knowledge and experience can aid in managing their child's condition.

The TNIP sessions/discussions will be held online via a video platform. After TNIP, parents will be assessed again for their knowledge, attitude and self-efficacy through a Google Form. Data will be collected using the structured knowledge questionnaire, attitude questionnaire and GSE tool in both pretest and post-test formats.

Step 4: Data Collection

Socio-demographic variables will be recorded. A pretest will be conducted before TNIP. Following the intervention, parents will again be assessed for their knowledge, attitude, and self-efficacy, and a post-test will be conducted. Data will be gathered through the structured knowledge questionnaire, attitude scale, and GSE tool in both pretest and post-test formats.

STATISTICAL ANALYSIS

The data will be stored in an MS Excel spreadsheet, and statistical analysis will be performed using IBM Statistical Package for the Social Sciences (SPSS) version 20.0. Continuous variables will be expressed as Mean±SD, while categorical variables will be presented in terms of frequency and percentages. As the primary outcome may have a non normal distribution, a non parametric test will be used for analysis. A p-value <0.05 will be considered statistically significant.

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APPENDIX

Tools Description

Instructions

a. Read each statement carefully
b. Select answer option which most closely indicates your estimate for each statement by using tick mark [√]
c. Respond to every statement
d. Do not spend too much time on any one statement, but give the answer which seems to describe your knowledge and understanding of the topic. Your Answers Will Be Confidential!

Section A

I. Sociodemographic details (10 items)

1. Age in years
   a. 20-29 years
   b. 30-39 years
   c. 40-49 years
   d. Above 50 years
2. Relationship with child
   2.1) Mother
   2.2) Father
3. Mother's education
   a. Primary education (1-10th standard)
   b. Higher secondary (11-12 th standard)
   c. Graduation
   d. Post-graduation and above
4) Father's education
   a. Primary education (1-10 th standard)
   b. Higher secondary (11-12 th standard)
   c. Graduation
   d. Post-graduation and above
5) Type of family
   a. Nuclear
   b. Joint
6) Age of the child when autism was diagnosed
   a. Less than 2 year
   b. 2-4 years
   c. 5-7 years
   d. After 7 years
7) Child's gender
   a. Male
   b. Female
   c. Others
8) Have you attended any session on Autism before?
   a. Yes
   b. No
9) Is there any behavioural challenge being faced by the child?
   a. Yes
   b. No
10) Is there any social communication skill affected in your child?
   a. Yes
   b. No

Section B

II. Knowledge-based questions multiple choice questions (12 items)

1. What is Autism Spectrum Disorder (ASD)?
   A) A physical disability
   B) A neuro-developmental disorder
   C) A mental illness
   D) A learning disability
2. At what age are symptoms of autism generally first observed?
   A) At birth
   B) In the first 2 years of life
   C) During teenage years
   D) In adulthood

3. Identify a behaviour that is often seen in individuals with autism.
   A) Spontaneous play with others
   B) Repetitive movements and behaviours
   C) Flexible attachment to interests
   D) Immediate response to name calling
4. By what age should a child typically respond to their name?
   A) 6 months
   B) 9 months
   C) 12 months
   D) 15 months
5. Which of the following is a social-communication deficit associated with autism?
   A) Excellent eye to eye contact
   B) Absence of social smiling
   C) Good understanding of personal boundaries
   D) Fluent and typical language use
6. What is a common impairment in social interaction for individuals with autism?
   A) High levels of eye contact
   B) Frequent social smiles
   C) Remaining aloof
   D) Strong interpersonal relationships
7. What social behaviour might be missing in toddlers with autism?
   A) Lack of attachment to significant adults
   B) Strong cooperative play
   C) Frequent imaginative play
   D) Active friendships
8. Which type of communication is affected in autism?
   A) Only verbal skills
   B) Only non verbal skills
   C) Both verbal and non verbal skills
   D) Neither verbal nor non verbal skills
9. What is a common stressor for parents of autistic children?
   A) Excessive free time
   B) Lack of child care duties
   C) Balancing multiple responsibilities with limited time for self-care
   D) Uninterrupted personal time
10 What is a key strategy for parents to support their autistic child?
   A) Ignoring positive behaviours
   B) Scolding the child
   C) Rewarding the child
   D) Consistent punishment
11. Why is it important for parents to stay consistent and on schedule?
   A) It reduces structure for the child
   B) It creates unpredictability
   C) It helps the child feel more secure and understand expectations
   D) It increases the child's anxiety
12. What is a beneficial way for parents to manage their own stress?
   A) Avoiding exercise
   B) Maintaining isolation
   C) Creating balance in life
   D) Ignoring personal hobbies

True/False Questions (20 Items)

1. Children with autism often exhibit developmental learning delays.
   - True
   - False
2. Toddlers with autism often show strong interest in group activities.
   - True
   - False
3. Play Therapy uses play to help children with autism engage with therapists.
   - True
   - False
4. Consistent schedules and routines are beneficial for children with autism.
   - True
   - False
5. Peer-led support groups for Autism are typically run by professionals like doctors and therapists.
   - True
   - False
6. Educational support groups provide valuable data on autism and treatment approaches.
   - True
   - False
7. Online support groups offer flexibility for parents who cannot attend in-person meetings.
   - True
   - False
8. Whole-family support groups focus solely on the autistic child.
   - True
   - False
9. Can parental neglect be attributed as a cause for autism?
   - True
   - False
10. Symptoms of autism may vary from one child to another.
   - True
   - False
11. Autistic children use gestures to communicate?
   - True
   - False
12. Autism is related to the use of electronics
   - True
   - False
13. Autism tends to run in families
   - True
   - False
14. Advanced paternal (father) age is a risk factor for Autism Spectrum Disorder (ASD).
   - True
   - False

15. Children with autism tend to perform better when tasks are presented visually than verbally.
    - True
    - False
16. Children with autism have difficulty in maintaining social relationships?
    - True
    - False
    - I don't know
17. Autism can be permanently cured.
    - True
    - False
18. Autism can be controlled through diet modifications?
    - True
    - False
19. Medications are useful in the management of behavioural aspects of Autistic children
    - True
    - False
20. Is some type of intervention required for the improvement in the autistic condition?
    - True
    - False

Section C

Attitude of Parents Regarding Autism

S. No.	Statements	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1.	I believe that autism is a condition that can be managed effectively with proper support and intervention.					
2.	I am comfortable with the idea of my child interacting with children who DO NOT have autism.					
3.	Children with autism should be educated in the same classrooms as other normal children.					
4.	It is important for society to promote the inclusion of individuals with autism in all aspects of life.					
5.	I believe that certain factors (e.g., genetics, environment) are the main causes of autism.					
6.	I think early intervention programs are effective in improving outcomes for children with autism.					
7.	I support the use of alternative therapies (e.g., dietary changes, supplements) in addition to traditional treatments for autism.					
8.	I believe the current educational system adequately supports children with autism.					
9.	Community resources and services for families of children with autism are easily accessible.					
10.	It is essential for parents to receive training and education on how to support their child with autism.					
11.	Having a child with autism significantly impacts family dynamics and relationships.					
12.	I feel confident in my ability to support the social and emotional needs of a child with autism.					
13.	A child's autism diagnosis greatly affects their future opportunities (e.g., education, employment, independence).					

Section D

General Self Efficacy (GSE) Scale: Self-Administered Tool

Instruction to Parents

Following is the questionnaire designed to determine how confident you are at this point that you can perform each of the following behaviours. Please consider the following behaviours.

Read each behaviour and then circle the number to the right of the behaviour to indicate how confident you are that you can perform the behaviour.

S. No.	Items	Not at all true	Hardly true	Moderately true	Exactly true
		1	2	3	4
1.	I can always manage to solve difficult problems if I try hard enough.				
2.	If someone opposes me, I can find the means and ways to get what I want.				
3.	It is easy for me to stick to my aims and accomplish my goals.				
4.	I am confident that I could deal efficiently with unexpected events.				
5.	Thanks to my resourcefulness, I know how to handle unexpected situations.				
6.	I can solve most problems if I invest the necessary effort.				
7.	I can remain calm when facing difficulties because I can rely on my coping abilities.				
8.	When I am confronted with a problem, I can usually find several solutions.				
9.	If I am in trouble, I can usually think of a solution.				
10.	I can usually handle whatever comes my way.				

The total score is calculated by finding the sum of the all items. For the GSE, the total score ranges between 10 and 40, with a higher score indicating more self-efficacy.