

A Study to Assess Effectiveness of Self-Instructional Module Regarding Knowledge On Angelman Syndrome Among Mothers of Under Five Year Children in Selected Areas At Bharatpur City

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Abstract :

Introduction: The first scientific paper reporting children with angelman syndrome was written by Dr. Harry Angelman, an English Physician at Warrington General Hospital. Based on Dr. Angelman's previous discoveries, Angelman syndrome is another name for happy puppet syndrome, was initially seen by Dr. Charles William and University of Florida Colleges of Medicine's Dr. Jaime Frias. Hyperactivity, a short attention span, and a strong. All of these traits are common in people who are fascinated by water. Most of the youngsters who are afflicted also have more difficulties sleeping than usual.

Materials & Methods: A pre-experimental one-group pre-test–post-test design was used to assess the effectiveness of a Self-Instructional Module (SIM) on knowledge regarding Angelman syndrome among mothers of under-5-year-old children. The study was conducted among 60 mothers from selected areas of Bharatpur city using a purposive sampling technique. The independent variable was the Self-Instructional Module, while the dependent variable was the mothers' knowledge regarding Angelman syndrome. Data were collected using a structured knowledge questionnaire consisting of 30 questions covering the meaning, incidence, causes, clinical features, diagnosis, and management of Angelman syndrome, along with five demographic items. Knowledge was assessed before and after administration of the SIM. The tool was developed through literature review, preparation of a blueprint, expert consultation, statistical consultation, and reliability testing through a pilot study. Mothers who were willing to participate and able to read and write were included in the study.

Results: Among 60 mothers, 35% were aged 20–25 years, 31.67% had high-school education, and 41.67% had a monthly family income of ₹15,001–₹20,000. Pre-test findings showed inadequate knowledge in 45%, while post-test findings showed adequate knowledge in 56.67%. The mean knowledge score increased from 58% to 71.67%, with a significant *t* value of 4.84, indicating that the Self-Instructional Module was effective in improving knowledge regarding Angelman syndrome.

Discussion: The study findings showed a significant improvement in mothers' knowledge regarding Angelman syndrome after administration of the Self-Instructional Module. The mean knowledge score increased from 58% in the pre-test to 71.67% in the post-test, indicating the effectiveness of the intervention. Significant associations were found with family income, number of under-five children, and previous knowledge regarding Angelman syndrome.

Keyword: Assess; Effectiveness; Self-Instructional Module; Knowledge; Angelman Syndrome; Under Five Year Children

INTRODUCTION

Pharmacological aspect: There's no remedy for Angelman condition. Exploration is zeroing in on focusing on explicit qualities for treatment. Current therapy centers around dealing with the clinical and formative issues. A multidisciplinary group of medical care experts will probably work with you to deal with your kid's condition. Contingent upon your kid's signs and indications, treatment

for Angelman condition might include. Anti-seizure drug to control seizures. Exercise based recuperation to assist with strolling and development tissues. Correspondence gesture-based communication and picture correspondence. Conduct treatment to assist with beating hyperactivity and a limited capacity to focus and to support improvement.²

Angelman syndrome. At the Oregon Health Science Center, he is a physician, in the form of a missing genetic coding on

chromosome 15. Angelman syndrome affects both men and women equally in India.³

Angelman syndrome is projected to impact 88,755 persons out of a population of 1,065,070,607 people. It includes developmental delays, intellectual disabilities, significant movement and balance difficulties, as well as speech impairment. Children with epilepsy frequently have recurrent seizures and have tiny heads. Between the ages of 6 and 12 months, there is a notable delay in development, as well as other early childhood signs and symptoms.⁴

Angelman syndrome (AS) is a rare neurogenetic disorder present in approximately 1/12,000 individuals and characterized by developmental delay, cognitive impairment, motor dysfunction, seizures, gastrointestinal concerns, and abnormal electroencephalographic background. AS is caused by absent expression of the paternally imprinted gene UBE3A in the central nervous system. Disparities in the management of AS are a major problem in preparing for precision therapies and occur even in patients with access to experts and recognized clinics. AS patients receive care based on collective provider experience due to limited evidence-based literature. We present a consensus statement and comprehensive literature review that proposes a standard of care practices for the management of AS at a critical time when therapeutics to alter the natural history of the disease are on the horizon.⁵

Angelman syndrome (AS) is a rare neuro-genetic disorder that occurs in one in 15,000 live births or 500,000 people worldwide. It is caused by a loss of function of the UBE3A gene in the 15th chromosome derived from the mother.⁶

Angelman syndrome shares symptoms and characteristics with other disorders including autism, cerebral palsy and Prader-Willi syndrome. Due to the common characteristics, misdiagnosis occurs often.⁷

People with Angelman syndrome have developmental problems that become noticeable by the age of 6 – 12 months. Other common signs and symptoms usually appear in early childhood like walking and balance disorders, gastrointestinal issues, seizures and little to no speech. Despite these symptoms, people with Angelman syndrome have an overall happy and excitable demeanor. An individual with AS will light up a room with their smile and laughter.⁸

Some symptoms of Angelman syndrome improve as individuals get older. Sleep issues and seizures tend to become less severe or infrequent. Because of mobility issues, obesity and scoliosis can develop in adolescence.⁹

The life expectancy of people with Angelman syndrome is normal. Angelman syndrome itself does not cause death. However, there can be severe complications due to some of the symptoms of the syndrome, such as seizures and aspiration pneumonia. There is also the possibility of accidents due to walking and balance issues and attraction to water that can cause severe injury.¹⁰

OBJECTIVES OF THE STUDY

1. To assess the pre-test knowledge regarding Angelman syndrome among mothers of under 5 year children.
2. To assess the post-test knowledge regarding Angelman

syndrome among mothers of under 5 year children.

3. To compare pre-test and post-test knowledge score among mothers of under 5 year children.

4. To find out association of post-test knowledge scores with selected demographic variables.

HYPOTHESIS:

H1: The mean post-test knowledge score will be significantly higher than the mean pretest knowledge score

H2: There will be a significant association between post-test knowledge scores of under five year children with their selected demographic variables.

METHODOLOGY

Research methodology is a way to solve the research problems systematically. It involves a carries of procedures in which researcher starts from initial identification of the problems to its conclusion.

Research approach:

The research approach used for the study is quasi-experimental in nature. According to Polit and Hungler, the purpose of quasi-experimental study is to explore aspects of a situation. The researcher planned to describe the knowledge of mothers of under 5-years children regarding Angelman syndrome.

Research Design:

The research design provided an overall (or) blueprints to carry out the study. Pre-experimental research design was used for assessing effectiveness of SIM for mothers of under 5-years children regarding Angelman syndrome.

Grove	Pre-Assessment	International	Post Assessment
Experimental	^o 1	X	^o 2

Key:

O1 = Pre-Assessment of knowledge of mothers of under 5-years children
O2 = Post Assessment of knowledge of mothers of under 5-years children.

X - Self Instructional module

VARIABLE:

The variables included in this study are dependent variables, extraneous variables and independent variable.

Independent variables:

Self - instructional module on Angelman syndrome of mothers of under 5-years children.

Dependent variable:

According to Polit and Hungler, in these study dependent variables refers to the knowledge of mothers of under 5-years children regarding Angelman syndrome.

Extraneous Variable:

Extraneous variables in this study are age, sex, educational qualifications, and years of experience, marital status and child psychology in the curriculum. In service education

and experience in mothers and Angelman syndrome with children.

SETTINGS:

Setting → Mothers of under 5-years children of Selected areas of Bharatpur city.

POPULATION:

The requirement of defining a population for a research project arises from the need to specify the group to which the study can be performed. The population for the present study is mothers of under 5-years children of Selected areas at bharatpur.

SAMPLE AND SAMPLING TECHNIQUE:

Sample: Mothers of under 5-years children selected areas at bharatpur of who met the selection criteria.

Sampling Techniques: Purposive sampling technique was used in the data collection of samples.

Sample size: The sample is used for the study 60 (sixty) mothers of under 5-years children.

CRITERIA FOR SELECTION OF SAMPLE:

Inclusion criteria:

- Mothers of under 5-years children of selected areas at Bharatpur.
- Mothers of under 5-years children who are willing to participate in the study.
- Mothers of under 5-years children who can read and write

Exclusion criteria:

- Mothers of under 5-years children who are not available on the day.
- Mothers of under 5-years children who are not willing to participate in the study.

SELECTION AND DEVELOPMENT OF INSTRUMENT:

Treece and Treece emphasized that the instrument selected in research should be as far as possible between the vehicles that would the best to obtain data for drawing conclusions pertinent to the study.

Selection of the instrument:

Structured questionnaire for knowledge assessment was used as the research tool because topic is relatively a new one for the mothers and is considered to be the most appropriate instrument to elicit responses from illness subjects.

Development of the tool:

The following steps were carried out in formulating the tool.

1. Related literatures were reviewed.
2. Blue print was prepared.
3. Guidance and consultation of the subject experts were taken and alterations made accordingly.
4. Consultation with statistician was done for the preparation of the plan for statistical data analysis.
5. Reliability was checked by doing Pilot study.

Descriptive of the tool:

The tool was organized into 2 sections. Section I & Section II.

Section I- Demographic data consists of 5 items seeking information about age, educational statues, mother qualification, No. of children, source of information regarding Angelman syndrome.

Section II – Consists of 30 questions related to meaning, incidences, causes clinical features, diagnosis and management. Each question has one correct answer that carries one mark and wrong answer carries 0 mark.

RELIABILITY OF THE TOOL:

The reliability of the tool in measuring the knowledge of mothers of under 5-years children regarding Angelman syndrome is estimated by following split half method and spearman's Brown prophecy formula. It is reliable.

PILOT STUDY:

The Pilot study was conducted on 05/10/23 to 11/10/23 in selected areas at bharatpur. Sample size is six of mothers.

DATA COLLECTION PROCEDURE:

1. A prior written permission was obtained from the leader of selected areas for study.
2. The feasibility of conducting the research study was ensured.
3. Data collection was started from 12/11/23 to 10/11/23.
4. The information pertaining to demographic data was collected.
5. Tool was distributed to mothers of under 5-years children.
6. Assessed the knowledge of mothers of under 5-years children pretest score was assessed.
7. Self-Instructional Module was administered after the pretest to all the mothers of under 5-years children of the experimental group.
8. All the mothers of under 5-years children took an active participation in the program.
9. The posttest knowledge was assessed after 7 days of administering self - instructional module to the mothers of under 5-years children of experimental group.

PLAN FOR STATISTICAL ANALYSIS:

Data was collected and checked with mothers of under 5-years children knowledge in selected areas at Bharatpur. The collected data was summarized and tabulated by utilizing descriptive statistics which includes mean percentage, standard deviation and inferential statistics include student 't' test, independent 't' test chi-square test etc.

RESULT

Analysis is a detailed examination of the elements or structure of something. In research, analysis means commutation of certain measures along with searching for patterns of relationship that exist among data group.

1. Age years	Frequency	Percentage
a) 20-25 Years	21	35.0
b) 26-31 Years	16	26.67
c) 32-37 Years	12	20.0
d) Above 40 Years	11	18.33
Total	60	100.0

Table – 2: Distribution of Mothers of under 5 year children by their Educational qualification

2. Educational qualification	Frequency	Percentage
a) Illiterate	13	21.67
b) Primary school	13	21.67
c) High school	19	31.67
d) Graduation and above	15	25.0
Total	60	100.0

Table – 3: Distribution of Mothers of under 5 year children by their. Monthly income of the family

3. Monthly income of the family	Frequency	Percentage
a) Less than Rs.10000	12	20
b) Rs.10001-Rs.15000	10	16.67
c) Rs.15001 to Rs.20000	25	41.67
d) Rs.20001 and above	13	21.67
Total	60	100.0

Table – 4: Distribution of Mothers of under 5 year children by Number of under-five year children in the family

4. Number of under-five year children in the family	Frequency	Percentage
a) One	34	56.67
b) Two	18	30
c) Three	5	8.33
d) Four and above	3	5.0
Total	60	100.0

Table – 5: Distribution of Mothers of under 5 year children by their previous knowledge regarding Angelman Syndrome

5. Mothers previous knowledge regarding Angelman Syndrome	Frequency	Percentage
a) Previous Exposure to Angelman Syndrome	4	6.67
b) Books	17	28.33
c) Internet	19	31.67
d) Information from others	20	33.33
Total	60	100.0

TABLE – 6: Knowledge level of Mothers of under 5 year children in pre -test and post-test regarding Angelman syndrome

Knowledge level	Pre Test		Post Test	
	Frequency	Percent	Frequency	Percent
a. Inadequate knowledge	27	45.0	11	18.33
b. Moderate knowledge	25	41.67	15	25
c. Adequate knowledge	8	13.33	34	56.67
Total	60	100	60	100

Table – 7: Mean, Mean percentage and standard deviation for pre -test knowledge of Mothers of under 5 year children

Sl. No.	Knowledge Aspect	No. of Items	Max Score	Mean	Mean %	Median	SD
1.	Questionnaire On Knowledge Related To Angelman Syndrome	5	5	3.45	69	4	1.24
2.	Questionnaire Related To Disability	18	18	9.78	54.33	9	3.45
3.	Questionnaire Related To Management	7	7	4.17	59.57	4	1.46
Overall Knowledge		30	30	17.40	58	17	4.51

Table – 8: Mean, Mean percentage and standard deviation for post-test knowledge of Mothers of under 5 year children

Sl. No.	Knowledge Aspect	No. of Items	Max Score	Mean	Mean %	Median	SD
1.	Questionnaire On Knowledge Related To Angelman Syndrome	5	5	4.0	80.0	4	1.1
2.	Questionnaire Related To Disability	18	18	12.35	68.61	13	3.32
3.	Questionnaire Related To Management	7	7	5.15	73.57	5	1.27
Overall Knowledge		30	30	21.50	71.67	24	4.76

Table – 9: Comparison of pre-test and post-test knowledge score of Mothers of under 5 year children regarding Angelman syndrome

Sl. No.	Knowledge Aspect	PRE TEST		POST TEST		Mean difference	t Value	Df	Inference
		Mean	SD	Mean	SD				
1.	Questionnaire On Knowledge Related To Angelman Syndrome	3.45	1.24	4	1.1	0.55	2.57	59	S
2.	Questionnaire Related To Disability	9.78	3.45	12.35	3.32	2.57	4.16	59	S
3.	Questionnaire Related To Management	4.17	1.46	5.15	1.27	0.98	3.92	59	S
Overall Knowledge		17.40	4.51	21.5	4.76	4.1	4.84	59	S

Among 60 mothers, 35% were aged 20–25 years, 31.67% had high-school education, and 41.67% had a monthly family income of ₹15,001–₹20,000. Most mothers (56.67%) had one under-five child, and 33.33% received information from others. In the pre-test, 45% had inadequate knowledge, while in the post-test 56.67% had adequate knowledge. The overall mean knowledge score increased from 17.40 (58%) to 21.50 (71.67%), with a significant mean difference of 4.10 and $t = 4.84$ ($df=59$), indicating that the Self-Instructional Module was effective in improving knowledge regarding Angelman syndrome.

DISCUSSION

The study assessed the effectiveness of a Self-Instructional Module (SIM) on knowledge regarding Angelman syndrome among 60 mothers of under-5-year-old children in selected areas of Bharatpur city. Data were collected using a structured questionnaire and analysed using the paired t -test and chi-square test. In the pre-test, 45% had moderate, 41.67% inadequate, and 13.33% adequate knowledge, whereas in the post-test, 56.67% had adequate knowledge. The mean knowledge score increased from 17.53 ± 4.44 (58%) to 20.91 ± 4.64 (71.67%), showing a significant improvement after the intervention. Significant associations were found with family income, number of under-five children, and previous knowledge, while age and educational qualification were not significant. Overall, the findings indicated that the SIM was effective in improving mothers' knowledge regarding Angelman syndrome.

CONCLUSION

The study concluded that most mothers had moderate knowledge (45%) in the pre-test, which improved to 56.67% adequate knowledge in the post-test. The mean knowledge score increased from 58% to 71.67%, with a statistically significant difference between pre-test and post-test scores, indicating that the Self-Instructional Module was effective in improving knowledge regarding Angelman syndrome. Significant associations were found with family income, number of under-five children, and previous knowledge

regarding Angelman syndrome.

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