



## EFFECTIVENESS OF SELF-INSTRUCTIONAL MODULE (SIM) ON KNOWLEDGE REGARDING CARE OF CHILDREN WITH BETA THALASSEMIA AMONG CARETAKERS AT SELECTED HEALTHCARE FACILITY, BENGALURU

Medical Science

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### ABSTRACT

Worldwide, approximately 15 million people are estimated to suffer from thalassemia disorders. Reportedly, there are about 240 million carriers of  $\beta$ -thalassemia worldwide, i.e. 1.5% of world population, and in India alone, the number is approximately 30 million. The burden is of hemoglobinopathies in India is high with nearly 12,000 infants being born every year with a severe disorder. The present study is, "Evaluate the effectiveness of Self-instructional module (SIM) on knowledge regarding care of children with beta thalassemia among caretakers at selected healthcare facility, Bengaluru.

**Method:** A Pre-experimental study with one group pre-test and post-test design was used to assess the effectiveness of self-instructional module (SIM) on knowledge regarding care of children with beta thalassemia among caretakers at selected healthcare facility, Bengaluru. Purposive sampling technique was used to collect data from 30 subjects attending Samraksha "The thalassemia day care centre" Keshavashilpa, Kempagowda Nagar Bengaluru-19 and the data was collected and interpreted to assess the effectiveness self-instructional module (SIM) on knowledge regarding care of children with beta thalassemia among caretakers.

**Results:** The finding of the study with regard to pre-test knowledge assessment revealed that the mean percentage was 21.87% with standard deviation 8.07. In pretest knowledge level 90% had inadequate knowledge. In posttest, significant increase in knowledge was found. However, in posttest the mean percentage of knowledge was 90.34% with 6.17 standard deviation. In posttest knowledge level, 80% had adequate knowledge.

**Interpretation & Conclusion:** The overall knowledge mean score of the pretest was 21.87% with standard deviation 8.07 and overall posttest score of knowledge was 90.34% with 6.17 standard deviation.

The enhancement in the respondent's knowledge is by 68.47%. The statistical paired, "t" test indicate that enhancement in the mean knowledge scores was found to be significant with "t" value 12.48 level for all aspects under study which indicates there is a significant increase in knowledge after administration of self-instructional module.

There is significance relationship between post test score and the demographic variables.

### KEYWORDS

Beta thalassemia, SIM, Knowledge, caretakers.

#### Introduction

Children in the age group of 0-14 years constitute 40% of the population. The well-being of these children is the responsibility of parents as well as health personnel. As they are the most vulnerable section which undergo various types of health problems. The risk is connected to growth, development and survival. The primary health care in children aims at prevention and promotion of health. Among all the childhood diseases, hematological and hereditary diseases are most life threatening disease conditions which affects in their early life. It affects upon birth, severely affecting their ability to survive on their own due to chronic anemia resulting from an inherited hemoglobin disorders.<sup>1</sup>

The term Thalassemia originated from Greek word "thalassa" meaning sea. It is more common among people living in near the Mediterranean Sea, Middle Eastern, African and Asian descent are at higher risk of carrying the genes for thalassemia. This is a condition of importance in developing countries, where it increases the burden of health care delivery system. In India it came with Alexander during his invasion with Greeks and Egyptians who settled in India. It is more common among north Indian. Wide geographical distribution probably as a result of genetic migration through intermarriage made thalassemia to spread to south India. Thalassemia is a disease characterized by deficiency in the rate of production of specific globulin chain in the hemoglobin.<sup>2</sup>

Thalassemia has an autosomal recessive pattern of inheritance it arises from mutation or deletion in one or more globin genes which leads to a reduction in the production of hemoglobin. In children with beta thalassemia symptoms appear in the first two years of life and include paleness, headache, fatigue, irritability, growth failure, shortness of breath, jaundice, splenomegaly, hepatomegaly etc.<sup>3</sup> They usually come to medical attention within the first two years of life. Without treatment, affected children have severe failure to thrive and shortened life expectancy. Treatment with a regular transfusion program and chelation therapy, aimed at reducing transfusion iron overload, allows for normal growth and development and may improve the overall prognosis.<sup>4</sup>

They occur at their highest frequency in countries of where their control and management is hampered by a lack of knowledge of their

true prevalence, adequate services for their management and control, and support by their governments and international health agencies. However, there has been some progress recently in addressing these problems and there are several ways in which the lot of children with thalassemia in poor countries could be improved in the future. Over the last 20 years there has been considerable improvement in the control and management of the thalassemia in the richer countries of the world. Unfortunately, however, this is not the case for many of the developing countries, where there have been few improvements in the control of the numbers of births of babies with thalassemia or in the care of thalassemic children since the frequency of the problem started to become evident in the 1960s. Thus the researcher tries to assess the current situation in these countries and examine some of the potential approaches for improving the current situation.<sup>5</sup>

Studies have proved that improvement of the quality of patient care, reinforcement of medical education and enhanced efforts by clinical staff to provide practical knowledge to caretakers of children with thalassemia major will significantly improve the adherence to treatment.

#### Material and method

Evaluative approach with Pre-experimental one group pre and post-test design was used. 30 Caretakers of children with beta thalassemia attending the Samraksha "The thalassemia day care centre" Keshavashilpa, Kempagowda Nagar Bengaluru-19 were selected by purposive sampling method. The pretest (O1) was carried out to determine the level of knowledge among caretakers followed by Self-instructional module (SIM). Post-test (O2) was conducted on the 7th day following the pre-test.

#### Results

##### Frequency and percentage distribution of subjects (Caretakers of beta thalassemia) according to their baseline characteristics

Majority 60.0% of subjects belong to 20-25 years, 20.0% belongs to 26-30 years, 20% belong to 31-35 age group. Majority 80% of subjects were female subjects and 20% were male subjects. Majority 40% of subjects were matriculate, 26.6% had primary education, 20% were post graduate and remaining 13.3% were graduates. Majority 66.7% of subjects had income of less than 10,000 INR and remaining 33.3% had income more than 10,001 INR. All the subjects under study are Indian

while none of them is a foreigner. Majority 63.3% of the subjects are Hindus, 20% Islam and remaining 16.7% were Christians. Thus, it is observed that most of the subjects were Indian so majority of them were Hindu. Majority 100% of the subjects are married none of the subjects is widow, single or separated. Majority 93.3% of the subjects are married non consanguineously and 6.7% are married consanguineously. Majority 83.3% of subjects had no family history of beta thalassemia and 16.7% had a family history of beta thalassemia. Majority 66.7% of the subjects are from nuclear family and remaining 33.3% are from joint family. Majority 100% of the subjects had not been exposed to ant educational programme on care of children with beta thalassemia. Majority 70% of the subjects had information from friends, 20% had printed media and 10% had electronic media.

**Table 01: Mean, mean percentage and standard deviation for pretest knowledge of subjects regarding care of children with beta thalassemia among caretakers.**

Knowledge	No. of questions	Min –Max score	Knowledge score		
			Mean	±SD	%
Introduction	2	0-2	0.42	± 0.78	21.00
Causes and Risk factors	5	0-5	1.02	± 1.56	20.40
Signs/symptoms, complications and diagnosis	7	0-7	1.80	± 1.98	25.71
Medical management and Home care	18	0-18	3.76	± 3.75	20.88
<b>Total</b>	<b>32</b>	<b>0-32</b>	<b>7.00</b>	<b>8.07</b>	<b>21.87</b>

The overall pre-test knowledge scores of subjects was found to be 21.87% with standard deviation 8.07.

**Table 02: Mean, mean percentage and standard deviation for post-test knowledge regarding care of children with beta thalassemia among caretakers.**

Knowledge	No. of questions	Min –Max score	Knowledge score		
			Mean	±SD	%
Introduction	2	0-2	1.78	± 0.78	89.00
Causes and Risk factors	5	0-5	4.12	± 1.26	82.40
Signs/symptoms, complications and diagnosis	7	0-7	6.23	± 1.38	89.00
Medical management and Home care	18	0-18	16.78	± 2.75	93.22
<b>Total</b>	<b>32</b>	<b>0-32</b>	<b>28.91</b>	<b>±6.17</b>	<b>90.34</b>

The overall knowledge scores of subjects were found to be 90.34% with standard deviation 6.17 in post-test.

**Table 03: Distribution of subjects by level of knowledge (pretest and posttest) on care of children with beta thalassemia.**

Aspects	No. of Subjects	Pre-test Mean±SD	Post-test Mean±SD	Student's paired t-test
Overall Knowledge Score	30	7.00±8.07	28.91 ±6.17	t=12.48 P=0.01 significant

\* significant at  $P \leq 0.05$ , \*\* highly significant at  $P \leq 0.01$  \*\*\* very high significant at  $P \leq 0.001$

From the above table no. 17 it is evident that the obtained "t" value for overall knowledge score is 12.48 which is greater than the table value at 0.05 level of significance. Therefore, "t" value is found to be significant. It means there is gain in knowledge level of subjects. This supports the effectiveness of Self-instructional module (SIM) on knowledge regarding care of children with beta thalassemia among caretakers.

#### Association between Posttest Level of Knowledge score and Demographic Variables

There was significant association between posttest knowledge score and following demographic variables Age ( $\chi^2=2.41$   $P=0.01$ \*\* df 4), gender ( $\chi^2=.87$ ,  $P=0.025$ \*df 2), income ( $\chi^2=0.99$   $P=0.03$ , df 2), nationality, ( $\chi^2=1.36$   $P=0.04$ , df 2), religion ( $\chi^2=1.64$   $P=0.02$ , df 4),

marital status ( $\chi^2=1.526$   $P=0.004$ , df 1), family history of thalassemia ( $\chi^2=2.065$   $P=0.01$ , df 2), type of family ( $\chi^2=1.85$   $P=0.04$ , df 2), educational programme ( $\chi^2=0.76$   $P=0.01$ , df 1), information ( $\chi^2=1.65$   $P=0.01$ , df 4). There is no significant association between posttest knowledge and educational status ( $\chi^2=241$   $P=0.41$  df 6), type of marriage ( $\chi^2=1.83$   $P=0.05$ , df 2).

#### Conclusion

The study concludes that the Self-Instructional Module (SIM) will be effective in terms of gaining knowledge among caretakers of children with beta thalassemia.

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