

## Effectiveness of Parent Centered Education on Knowledge Regarding Homecare Management of Children with Spina Bifida in a Tertiary Care Hospital, Kochi



### Medical Science

**KEYWORDS :** SB: Spina bifida, parent centered education.

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### ABSTRACT

*Introduction: Spina bifida is a lifelong condition that is not curable. Some children born with spina bifida will require intensive treatment throughout their lives due to the range of complications associated with the defect.*

*Methods: The approach used was quantitative approach using quasi-experimental one group pre-test post-test research design, conducted among 25 parents of children who met with the eligibility criteria following non-probability total enumeration sampling technique.*

*Findings: Regarding homecare management of spina bifida, in the pretest 13(52%) had average knowledge, two (8%) had good knowledge, and 10(40%) had poor knowledge, and after the parent-centered education, post-test knowledge score showed that 20(80%) had good knowledge and five (20%) had average knowledge.*

*Conclusion: The study depicts the need and importance of implementing various interventions for parents / children with chronic illness, as it would help improve knowledge, follow healthy practices and build up a healthy generation.*

### Introduction

Spina bifida (SB) is a birth defect in which the tissues and the vertebrae, that normally cover the spinal cord, fail to close completely during the baby's development before the birth. The most commonly occurring spina bifida is myelomeningocele. Many complications can occur such as mobility problems, bowel and bladder complications, latex allergy due to exposure to medical equipment containing this substance, tendonitis, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, depression, social isolation and sexual issues. Management often focuses on preventing or minimizing deformities and maximizing the child's capabilities at home and in the community.

The caregiver plays a central role in long-term comprehensive care through collaborative comanagement with multiple medical and surgical specialists. It has long been recognized that the provider of care in the home must be knowledgeable about the unique medical issues of spina bifida and its developmental, educational, and social consequences. From the clinical experience of the researcher, it was found to be very much essential in providing education to the parents of children with spina bifida to enable them to promote the growth and development of the child to a normal extent with less complications.

### Material and Methods

Quantitative approach using quasi-experimental one group pre-test post-test research design was adopted for the present study. The setting was, Amrita Institute of Medical Sciences, a super specialty tertiary care health centre with an attached medical college, Kochi. The subjects for the study were parents of children with spina bifida, who were consulting Spina Bifida Clinic, Pediatric Neurosurgery Outpatient Department, AIMS hospital, Kochi. Non probability total enumeration sampling technique was used for the selection of subjects. Twenty five parents were selected from pediatric neurosurgery departments of AIMS who met with the inclusion criteria: parents of children aged between birth to 5 years who attend spina bifida clinic or OPD of Paediatric Neurosurgery, parents of children who were available at the time of data collection. Data collection period was 5 weeks from 13-11-2013 to 06-12-2013.

The data collection instrument include semi structured questionnaire to assess the socio-demographic and clinical data. Tool I: It includes two sections: Section A- Demographic profile includes age of parents, educational and employment status of

parents, and annual income of the family, significant events in antenatal period of the mother are those related to the sample. Section B: child characteristics like age and gender and clinical details of the child. Tool I totally comprise of 21 items. Tool II: It was a structured-knowledge questionnaire regarding homecare management of children with spina bifida with 35 questions. It includes questions on the following areas - basic information, spina bifida and its clinical manifestations, management of spina bifida, management of spina bifida child with hydrocephalus.

### Findings

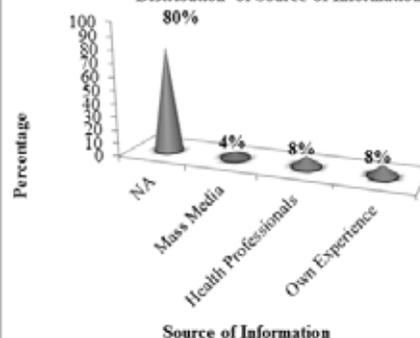
The first objective of the study was to evaluate the effectiveness of parent centered education on knowledge regarding homecare management of children with spina bifida.

Distribution of Previous Knowledge



The figure 1 reveals the distribution of sample based on previous knowledge obtained from various sources. While 20 (80%) of the parents claimed that they don't have previous knowledge regarding spina bifida, five (20%) had.

Distribution of Source of Information



The figure 2 represents the distribution of various sources from

which the parents obtained previous knowledge regarding spina bifida. Among them two (8%) each claimed that they obtained information from health professionals and own life experience and one (4%) from mass media.

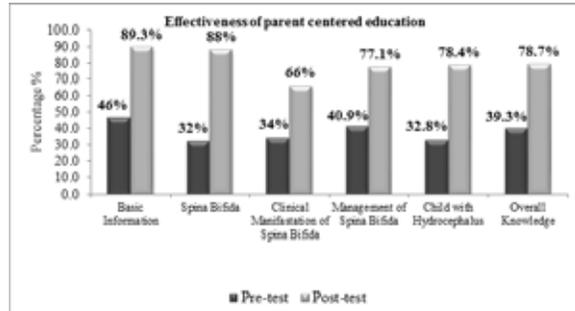


Figure 3 illustrates the overall mean pre-test knowledge score of the sample was 13.76 and the mean post-test score was 27.65. The mean difference of the knowledge score was calculated as 13.80 in order to compare the knowledge scores of the subjects before and after the administration of the parent-centered education on home-care management of children with spina bifida, the paired 't' test was done. The value of 't' obtained was 14.968 with 24 the degrees of freedom at the significance level of  $p < 0.001$ . The corresponding table value was 3.75. As the calculated test statistic value was higher than the table value, the null hypothesis was rejected and the alternative hypothesis was accepted, so the mean post-test knowledge score of the parent were significantly higher than the pre-test score.

**Table 1. Mean and standard deviation of pretest and post test knowledge n=25**

No.	Components of knowledge	Mean		SD		Difference
		Pretest	Post test	Pretest	Post test	
1	Basic Information	2.76	5.36	1.480	0.757	2.60
2	Spina Bifida	0.64	1.76	0.757	0.436	1.12
3	Clinical Manifestation of Spina Bifida	1.36	2.64	0.995	1.036	1.28
4	Management of Spina Bifida	7.36	13.88	3.187	1.965	6.52
5	Child with Hydrocephalus	1.64	3.92	1.350	0.862	2.28
6	Overall Knowledge	13.76	27.56	6.234	3.980	13.80

Table 1 represents the mean pre-test and post test knowledge for each components like basic information, spina bifida, clinical manifestation, management and child with hydrocephalus determined using the paired 't' test. The mean difference in the knowledge score was most for management of spina bifida, calculated as 6.52 with a 't' value 12.387 and 24 the degrees of freedom at the significance level of  $p < 0.001$ . The corresponding table value was 3.75. As the calculated test statistic value was higher than the table value for all the components, the null hypothesis was rejected and the alternative hypothesis was accepted, so the mean post-test knowledge score of parents are significantly higher than the pre-test score.

The findings of the present study were congruent with the study conducted by A descriptive study conducted by Mukherjee S, Boudos R on 'Preparing for Transition: Knowledge and Behavior Are Teens and Parents Saying the Same Thing?' (2009). Appropriate education can be provided to increase patient's knowledge and specific behaviors to increase self-management.

A descriptive study was conducted by Smith J, Swallow V,

Coyne I on 'Involving parents in managing their child's long-term condition-a concept synthesis of family-centered care and partnership-in-care' (2015). Fostering effective engagement, collaboration and empowerment are central to supporting parents caring for children with long-term conditions.

In the present study, an educational intervention was provided, which would help the parents to become more realistic about the future. Even though, the samples obtained information from various sources, they considered the information shared by the health professional were more valuable.

The second objective of the study was to find the association between knowledge and selected demographic and clinical variables.

**Table 2. Association between mean pretest knowledge of sample and previous knowledge n=25**

Previous Knowledge	Frequency	Knowledge pretest		
		Mean	SD	t- value
Yes	5	18.80	4.658	2.172
No	20	12.50	6.013	
Total	25	13.76	6.234	

df 23,  $p < 0.05$

The table 2 brings out using independent t test, the association between mean pre-test knowledge and previous knowledge of the parents. The calculated t - value for the pre-test was 2.172 at 23 the degrees of freedom and the corresponding table value was 2.07 with level of significance  $p < 0.05$ . As the computed t-value was higher than the table value for the pre-test knowledge, there was significant association between the mean knowledge and the previous knowledge of the parents.

The investigator could not include any study showing the association between level of knowledge and selected variables due to unavailability of selected study.

**Conclusion**

The study on the effectiveness of parent centered education on home-care management of children with spina bifida was a successful venture by the investigator. It was an initial step used to impart knowledge to the parents, which could improve the quality of life of the children. The study depicts the need and importance of implementing various interventions for parents / children with chronic illness, as it would help improve knowledge, follow healthy practices and build up a healthy generation.

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