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Effective of STP on Knowledge Regarding the Management of Hemophilia

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Abstract

Aim: A study to assess the effectiveness of structured teaching programme on knowledge regarding the management of haemophilia among mothers of children with haemophilia.

Objectives: The objective of the study to identify the knowledge of mothers. Mothers regarding the management of haemophilia. To determine the association between post-test knowledge score and demographic variables.

Method: The research approach used for the study was one group pre-test post-tests design. The setting was Alkai hospital and Ashwini hospital .Sample for the major study included 50 mothers on the basis of convenient sampling technique method. A structured questionnaire was used to evaluate the knowledge of mothers of children with haemophilia. The reliability of the tool was established by split half technique and the reliability co-efficient were calculated to be 0.95.

Result: The findings revealed that knowledge scores of mothers were inadequate before the administration of STP on management of haemophilia among mothers of children with haemophilia. i.e. mean percentage of pre-test was 39%. The STP helped them to update their knowledge on management of haemophilia among mothers of children with haemophilia. The mean percentage of post-test knowledge of sample significantly increased about nearly 79.95% after administration of STP. The data was analysed by applying Descriptive and Inferential statistics. The results of the study indicated that mothers do not have adequate knowledge regarding management of haemophilia.

Conclusion: The conclusion drawn on the basis of following findings of the study. assessment project has helped the investigator to develop an STP to improve the knowledge on management of haemophilia among mothers of children with haemophilia. The results have also shown that various demographic variable have significant association with respect to the knowledge of mothers regarding management of haemophilia.

Keywords: Effectiveness; Knowledge; Management; Hemophilia.

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INTRODUCTION

Today's children are the citizens of tomorrow, and they are the treasures of nation. Healthy children are the greatest resources and pride of any nation. There is no task more important, so investment in the children development is an investment in the future of the nation. Thus, their health and development must be monitored at every step of their life.[1]

Hemophilia is a rare genetic disorder where

blood does not clot normally. The term hemophilia has Greek roots; the two parts are hemo, meaning blood and philia, meaning a tendency towards. Thus, people with hemophilia have a tendency to bleed. The blood disorder manifests itself in three forms, Hemophilia A, Hemophilia B, and Hemophilia C.[2]

Hemophilia is the blood clotting disorder caused by mutation of the factor VIII and factor IX genes respectively, which lead to defective synthesis or synthesis of dysfunctional factor VIII or IX. Hemophilia A is more common than hemophilia B. Inheritance is X-linked recessive; hence, males are affected while females are carriers. A hemophilic pseudotumor is an encapsulated, chronic, slowly expanding hematoma, due to recurrent hemorrhage; and is seen in 1−2% patients with severe coagulate disorder (less than 1% of normal factor VIII activity). It usually occurs in soft tissues, muscles, tendons and sub periosteal part of bones. The tumor enlarges slowly, develops a fibrous capsule, and can destroy underlying tissues by progressive necrosis.[3]

Hemophilia has been indirectly known about since the second century AD. During those times families did not have to get their baby boys circumcised if they already had two sons die after the procedure. A Philadelphia doctor, Dr. John Otto, wrote about a "haemorrhagic disposition in certain families'. Otto saw that the bleeding disorder was genetic and that males were significantly more likely to have the condition. After some research, he determined that a woman who settled in Plymouth in 1720 was the likely source of the disorder. In 1828, Hoff was the first to use the term haemophilia when he was describing its symptoms and the conditions. In England, hemophilia plagued the royal family because Queen Victoria (1837-1901) was a carrier of the disorder. She passed haemophilia on to one of her sons, and two of her daughters became carriers. When her daughters married royalty from other countries, haemophilia was then passed into the ruling families of Russia, Spain and Germany.[4]

A person who has hemophilia is lacking a sufficient amount of a certain protein, also known as clotting factor. In order for proper blood coagulation to occur, the body's clotting factors work to form a blood clot. When a blood vessel is injured a blood clot is needed to stop the vessel from bleeding. Blood platelets form the clot and the clotting factors help the platelets clump and stick together to cover the injury and stop the bleeding. When the clotting protein is not present, clotting occurs at a much slower rate and sometimes will not happen at all. A seemingly minor or small injury to a person with hemophilia can take much more time to heal because of the slower rate of coagulation. Fortunately, there are injections that people with hemophilia can take to normalize the clotting process.[5]

Though Hemophilia is a hereditary disorder, without proper treatment it will leads to serious damage to limb and joints function within the first one to two decades of life. This isdue to joint mobility, contractures, muscle atrophy and chronic pain. Certain serious complications can further complicate the management of Hemophilia. Between 10-20% of people with Hemophilia A. and 2-3% ofthose with Haemophilia. develop inhibitors deficient factor. Such patients do not respond to usual replacement therapy.[5]

As the mothers are in close interaction with their children and they are in better position to identify the health problems of the children. As a part of this, mothers have to be given adequate orientation in early diagnosis of common health problems of children. Thus, they will be a dynamic force, instrumental and indispensable to health team for promoting health and preventing diseases. This can play a major role in the early detection and treatment of disease.

Need for the Study

Usually, mothers are more involved than fathers in the daily care of a chronically ill child. This is also the case in parents of children with hemophilia. Majority of fathers accompanied their child to clinical consultations regularly. Deeper involvement in home based care might result in different coping and higher levels of illness related stresses and strains for mothers. Mothers of children with hemophilia are more depressed and anxious than fathers.

About 80% of hemophilia patients have hemophilia A, which is caused by a deficiency in clotting factor VIII. The other 20% have hemophilia B, caused by a deficiency in factor IX. Hemophilia leads to improper clotting, thus causing patients to suffer from frequent spontaneous bleeding episodes.[6]

Here presents the data on survival and morbidity of people with Hemophilia in India. India has a factor Vlll usage rate of 0.01 international units per capita. While the USA has a factor Vlll usage of 3.4 IU per capita. Nearly 12,000 persons with hemophilia were nationwide registered in India, with 1,800 patients were identified in Karnataka, 44% were under 15 yrs of age, 35% were between

15 and 30 yrs, 16% were between 30 and 50 yrs and only 5% were above 50 yrs of age.[7]

Signs and symptoms of hemophilia vary depending on how deficient are in clot-forming proteins called clotting factors. If levels of deficient clotting factor are very low, will experience spontaneous bleeding. If levels of deficient clotting factor are slightly to moderately low, will bleed only after surgery or trauma. Excessive unexplained bleeding or bleeding easily can be caused by numerous diseases including bleeding disorders and several severe diseases (e.g. Leukemia). Any type of bleeding is a severe symptom that needs prompt professional medical diagnosis.[8]

When modern medicine finds a way to treat a medical condition, people often think that the problem is solved. But it is necessary to find ways to get that treatment into the hands of those who need it. For example, new research from North Carolina State University shows that much more needs to be done to help get existing treatment to hemophilia patients in the developing world. So, there is a need for implementing actions to assist the patient and family members of the same disease.[9]

Quality of life in parents of children suffering from Hemophilia may be diminished by the illness burden experienced in daily life and by non-adaptive ways of coping. A study was conducted to examine the relation between parent's quality of life, their perceived psychosocial strains and ways of coping, and to compare parent's outcome to other pediatric illness groups. The parents are concerning with the quality of life, psychosocial, coping strategies, needs and illness parameters.

This study includes comparison groups such as parents of children with Juvenile idiopathic arthritis (n=161) and parents of children with type 1 Diabetes (n=69). Compared to parents from other pediatric illness, the parents of children with Hemophilia experience more impact on their quality of life and psychological strains. Quality of life was predicted by the coping strategy, improving marital relationship, emotional strains and worries concerning future. Parents reported a pronounced need for further information on comprehensive management on Hemophilia. In psychological care of families with a child suffering from Hemophilia, reducing psychological strains and strengthening adaptive coping strategies may be preventive intervention for improving the quality of life.[10]

Mathews V, Nair SC, founds that data are limited on inhibitors in people with hemophilia in developing countries. There is a perception that the overall prevalence of inhibitors, ranging from 7 to 19% in different reports, may be lower in these countries as compared with that reported from developed countries. The genetic or other environmental factors also contribute to this need for further study. There is a need to develop laboratory infrastructure and establish quality control programs for laboratory tests for inhibitors in developing countries. Significant individualization of approach to management is therefore required depending on the available resources, particularly with regard to the use of bypassing agents. The limited data on immune tolerance induction with some low dose regimens deserve further study. Even in resource constrained environments, education and a policy of systematic screening of patients associated with judicious use of bypassing agents.[11]

As the demographical variables shows the emerging need for conducting a serious study to find the prevalence of hemophilic cases and to implement actions to improve the knowledge of mothers to assist their children to meet the daily activities in challenging life.[12]

Thus the researcher found that it is a importance for providing knowledge and contributing to the individual and for their family who faces the secondary problems of Hemophilia.

Objectives

The main objectives of the present study are mentioned here.

Objectives of the Study

- To assess the existing knowledge of mothers regarding management of Hemophilia in selected hospitals at Akluj.
- To assess the post-test knowledge score regarding the management of Hemophilia.
- To evaluate the effectiveness of structured teaching programme regarding management of Hemophilia by comparing pre- test and post-tests knowledge score.
- To find out the association between the post-test knowledge score with the Demographic variables.

Operational Definitions

- *Evaluate:* In this study evaluate refers to determine the knowledge gained by the mothers regarding management of Hemophilia after structure teaching programme.
- *Effectiveness:* In this study it refers to

significant gain in knowledge as determined by significant difference in pre and post-test scores of mothers regarding management of Hemophilia.

- *Structured Teaching Programme (STP):* In this study STP means a well prepared teaching programme designed to provide information to mothers regarding management of Hemophilia in selected hospitals
- *Knowledge:* In this studyknowledge refers to the correct responses of mothers to the items in the self-structured interview regarding management of Hemophilia.
- *Hemophilia:* It is a congenital bleeding disorder caused by the genetic lack of factor Vlll (antihaemophilic factor) and factor lX (Christmas factor).

Delimitations

- This study will be limited to only mothers of children with hemophilia.
- Data collection is limited to mothers who are willing to participate in the study.
- The mothers who will be present during data collection.

Hypotheses

H_1: There is a significant difference between the pre and post-test knowledge scores of the mothers regarding management of Hemophilia.

H_2: There is a significant association between the post-test knowledge scores of the mothers and the selected demographic variables.

Research Methodology

Research Approach: The approach adopted for this study is Evaluative research.

Research Design: In the present study "one group pre-test, post–test design" was selected which is a pre-experimental design were selected.

Variables Under Study

Dependent Variable: In this study knowledge of mothers on management of hemophilia is the dependent variable.

Independent Variable: In this study independent variable was structured teaching program regarding management of hemophilia.

Research Settings: This study was conducted at Alkai nursing home and Ashwini Hospital, Akluj.

Population: In the present study population includes mothers of children with hemophilia at the time of data collection in selected settings at Alkai nursing home and Aswini Hospital.

Sample: The sample comprised of 50 mothers of children with AlkaiNursing home and Aswini Hospital.

Sample Size: Study includes A sample of 50 mothers of children with hemophilia.

Sampling Technique: Convenient non-probability sampling technique which was found appropriate for this study.

Sampling Criteria

Inclusion Criteria:

- Selected mothers of children with Hemophilia admitted in selected hospitals.
- Mothers who are willing to participate in the study.
- Mothers who are available at the time of data collection.

Exclusion Criteria:

- Mothers who are not co-operative.
- Mothers who are not available during the study.
- Mothers of children not suffering from hemophilia.

Method of Data Collection:

Data Collction Tool: The purpose of the study was to assess the level of knowledge of mothers regarding management of hemophilia, a structured knowledge questionnaire was found appropriate for collection of the data.

Development of Tool: In this study the researcher used structured knowledge questionnaire. The tools were prepared on the basis of the objectives of the study.

Description of the Tool

The structured interview schedule consists of two parts.

Part I: Demographic Performa

The characteristics included; Age, Gender, Education, Residential Area, Family Income, Familial Hemophilic History, Type of Family and Source of Information of mothers of children with hemophilia cases.

Part II: Structured knowledge questionnaire.

It consists of 44 items divided into 5 areas

All the items were multiple choice questions, which has 3 alternative responses. A Score value of (1) was allotted to each correct response. The total knowledge score was 50 in positively stated items the score for yes is 1 and for No is 0. In negatively stated items the score for Yes is 0 and for No is 1.

Data Collection Procedure

Prior written permission was obtained from the medical superintendent and Nursing Superintendent of Alkai nursing home and Ashwini Hospital. The samples were selected by convenient sampling. The purpose of the study was explained to them and informed consent was obtained. The structured knowledge questionnaire was administered for 5 mothers in first day, 10 mothers in second day, 10 mothers in fourth day, 8 mothers in fifth day at Alkainursing home and on the same day for each group STP was administered. The next day structured knowledge questionnaire was administered in Ashwini Hospital 6 mothers in first day and 5 mothers in second day, 6 mothers in third day on the same day from which the data was collected. On the same day STP was administrated for those mothers, and then 10 minutes was allotted for discussion. After 7 days of STP, post-test was conducted with the same questionnaire for the same group of mothers of children with haemophilia at both Alkai nursing home as well as Ashwini hospital to assess the effectiveness of STP.

Plan For Data Analysis

The data collected in the present study was analyzed by computing the standard deviation, mean and mean percentage.

Protection of Human Rights

1. Permission for the study was obtained from the Medical and Nursing Superintendent of a Selected Hospital
2. An Informed consent was also obtained from the respondents after proper explanation about the purpose, usefulness of the study and assurance given about the confidentiality of their responses.

RESULTS

The data has been analyzed and interpreted in the light of objectives and hypothesis of the study.

Organization of Findings:

The data collected from the mothers were organized, analyzed and presented under the following headings:

- Section I: Description of sample characteristics.
- Section II: Assess the level of knowledge.
- Section III: Evaluate effectiveness of structured teaching program.
- Section IV: Association between the demographic variables and knowledge of mothers.

Section I: Description of sample char-acteristics.

The age distribution of mothers who had participated in the study. 15 mothers are in the age group of 21-25 yrs. 20 mothers are in the age group of 26-30 yrs. remaining 15 are in the age group of above 30yrs. The maximum participants are from the age group of above 26-30 years and the least number of participants are in the age group of 21-25 and >31 years.The gender of participants in the study. About 35 responded as yes and 15 responded as no were participated in the research study. Education distribution of mothers.[35] mothers are primary education holders. 6 mothers are matriculation holders. Remaining 9 are graduate holders. The residential area distribution of mothers.[20] mothers are vegetarian and 30 mothers are non-vegetarian.The family income distribution of mothers. 30% mothers has got primary health centre, 20% mothers have got private hospitals and 50% mothers has got government hospital services. Familial homophilic history distribution of mothers.[10] mothers shows no history of haemophilia and 40 mother's shows history of hemophilia.20% mothers are from urban and 80% mothers are from rural areas. Source of information distribution. 30 sources got from newspaper and magazine and 20 sources from radio and television.

Section III: Evaluate Effectiveness of Structured Teaching Programme by Comparing Pre and Post-Test Knowledge Score

Comparison between pre-test and post-test scores of mother'slevel of knowledge before and after administration of STP. In pre-test 86% mothers had inadequate knowledge on management of haemophilia, 14% had moderate level of knowledge and none of them had adequate level of knowledge. But in the post-test, none of the mothers are inadequate knowledge, 6% mothers are moderate level of knowledge, 94% mothers are adequate level of knowledge regarding management of

Section II: Assessment of knowledge on management of hemophilia among mothers of children with hemophilia before administering STP.

Table 1: Mean, Standard deviation, range and mean score percentage of knowledge of children before administering structured teaching program.

Knowledge	Max Possible Score	Mean	SD	Range	Mean Score%
Management of hemophilia	44	17.16	2.37	15-23	39.00 %

Table 2: Overall knowledge of mothers regarding knowledge on management of hemophilia before administration of structured teaching programme.

Over all level of knowledge	Frequency	%
Inadequate	43	86%
Moderately adequate	7	14%
Adequate	0	0%

Table 3: Mean standard deviation; mean score percentage of knowledge score after the administration of STP.

Knowledge	Max Possible Score	Mean	SD	Range	Mean Score %
Management of haemophilia	44	35.18	2.01	34-39	79.95 %

hemophilia.

Section IV: Association between the demographic variables and knowledge of mothers regarding management of hemophilia.

Association between the Age and the knowledge of mothers:

A total of 21 mothers were below median and 29 mothers were above median. Calculated $\chi 2$ Value was found to be 2.8, which is less than table value with p-value > 0.05. Hence accept null hypothesis i.e. there is a no significant association between age and post-test knowledge of mothers of children with hemophilia.

Association between previous knowledge and the Knowledge of mothers:

A total of 70% were yes and 30% were no. A total of 27 mothers were below median and 23 mothers were above median. Calculated $\chi 2$ Value was found to be 7.81 which is less than table value, DF = 1 with p-value > 0.05. There is a statistical association between previous knowledge and post-test knowledge of mothers.

Association betweenEducational Qualification and the knowledge of mothers:

The chi-square test was resulted to be no significant at 0.09 (i.e., p< 0.05). Hence accept null hypothesis. There is no association between educational qualification and post-test knowledge of mothers.

Association between availability of health care service and the Knowledge of mothers:

The result of availability of health care service and knowledge. The chi-square test was resulted to be significant at 0.01 (i.e., p< 0.05). So there is a statistical association between availability of health care service and post-test knowledge of the mothers.

Association between dietary pattern and the Knowledge of mothers:

The chi-square test was resulted to be non-significant at 0.01 (i.e., p< 0.05). So there is no statistical association between dietary pattern and post-test knowledge of mothers.

Association between family hemophilic history and the Knowledge of mothers:

The chi-square test was resulted to be significant at 0.04 (i.e., p< 0.05). So there is a statistical association between family hemophilic history and

post-test knowledge mothers.

Association between residential area and knowledge of mothers:

The chi-square test was resulted to be non-significant at 0.04 (i.e., p< 0.05). So there is no statistical association between residential area and post-test knowledge.

Association between source of information and knowledge of children:

Chi-square test was resulted to be significant at 0.09 (i.e., p< 0.05). Hence accept H2 hypotheses. There is an association between source of information and post-test knowledge of mothers.

CONCLUSION

On the basis of the findings of the studyto evaluate the effectiveness of Structured Teaching Program on knowledge regarding management of hemophilia. The pre-test showed that knowledge of mothers regarding management of hemophilia was inadequate in all areas. STP tested in this study was found to be effective in improving the knowledge of mothers participated in the study.The structured teaching programme is an effective method in improving the knowledge of mothers.It indicates the importance of frequent education programs to update the knowledge regarding management of hemophilia.

The findings of the study can be used by nurse educator to educate the student nurses, which help them to provide an effective nursing care and to practice the management of hemophilia while caring a hemophilia patient.

Limitations

The limitations of the present study were

1. The study was confined to small number of subjects about 50 mothers of children with hemophilia and was conducted on a convenient sampling, in a selected hospital, which limits the generalization of findings.
2. A structured knowledge questionnaire was prepared for data collection, which restricts the amount of information that can be obtained from the respondents.
3. No attempt was made to do follow up of mothers.
4. The study lacked control group that did not receive any specific teaching to allow the researcher to test the increase on mother's knowledge without STP.

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