

RESEARCH ARTICLE

Effectiveness of Hemophilia Educational Program on Parents' Knowledge of Children with Hemophilia

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ABSTRACT

Background: Mothers and fathers mentioned difficulty in identifying the proper structure of remedy for their child, anxiousness about illness of blood products, fear of the achievable long-term aspect consequences of prophylaxis, and a desire to avoid any unnecessary medications. It is clear from what has been noted above that mother appreciably want a health care program to help their hemophilic young people to limit the complications and bleeding episodes as much as viable so that their teenagers can live close to everyday life.

Objective(s): The aim of this study is to evaluate the effectiveness of hemophilia educational program on parents' knowledge of children with Hemophilia, And To find the relationship between the educational program and the demographic information of the parents (age, gender and educational level)

Method: A quasi-experimental design (Study and control group) is carried out through the use of questionnaire format for non-probability (purposive) sample of (40) patients who their children have hemophilia and treat in Blood Disease center in - AL_ Nasiriya City.

Results: The results showed that was statistically significance differences between two periods (pre and post-tests) of study sample in all items of the Knowledge of Parents' information for children with hemophilia of the Study Sample .This reflects that the Parents knowledge was affected by educational program when analyzed by (t-test).

Conclusion: The study concluded that the educational program was effective to improve to the participation parents for children with hemophilia.

Recommendations: Continuous educational program to health team to increase parent' knowledge about enhance self-care for patients with hemophilia. It is recommended to the Mistry of Health to increase educational program to patient with hemophilia and very important implication.

Keywords: Effectiveness, Hemophilia, Educational Program, Parents, Knowledge, Children with Hemophilia.



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INTRODUCTION

Lack of consciousness regarding the importance of early treatment of bleeding episodes is a common barrier. Current World Federation of Hemophilia tips advocate the cure of an acute bleed inside two hours of its initiation. Parents, in turn, may additionally no longer desire to infuse an uncooperative child with clotting element until they deem it absolutely necessary. Parents have suggested feeling uneasy about injecting their child, a lack of confidence in their potential to raise out the injection correctly, and concern of causing damage or ache to their infant as predominant challenges in home-based care. In regard to larger responsibility, mother and father mentioned difficulty in identifying the proper structure of remedy for their child, anxiousness about illness of blood products, fear of the achievable longterm aspect consequences of prophylaxis, and a desire to avoid any unnecessary medications (Saxena, 2013).

It is clear from what has been noted above that mothers appreciably want a health care program to help their hemophilic young people to limit the complications and bleeding episodes as much as viable so that their teenagers can live close to everyday life. (Hussein, 2013). In Egypt, Consanguineous marriage consequently frequent, recessive attribute coagulation ailment attain a greater incidence than in many different countries. (Tonbary et al, 2010).

Serious lifelong health trouble and is an inherited X linked coagulation disorder brought about via deficiencies of the clotting factor VIII or of aspect IX. It can lead to persistent ailment and lifelong disabilities, if now not appropriate managed when you consider that early infancy. Caregivers are regularly confronted with a disturbing life and are exposed to exaggerated worries related with the illness of the children, as nicely as to different associated stressors (Widayanti, 2011).

Home treatment of hemophilia is currently the standard of care for patients with severe hemophilia. Home treatment increases the responsibility of the patients for their own treatment and care. Therefore, it is of utmost importance to attain a high level of knowledge and practical skills. The aim of our study was to investigate whether or not an educational e-learning program improves knowledge and skills of adult patients with hemophilia on home treatment (Mulders et al., 2012).

Home-based management involve self-care patient to prevent complications of SCD and it is the only management of SCD that does not require the use of a health care facility or health care practitioner. Even palliative care and

comprehensive clinical care requires some form of self-care management by the patient. Compliance to self-care management resources continues to be a problem until now (Nolan, Nottage, Cole, Hankins, & Gurney, 2015).

The hemophilia nurse plays a major role in preparing the patient and parents/careers for home treatment as part of this, self-treatment initiation training and education are an integral part of the hemophilia nurse job. While the initiation of home treatment means more responsibility for the patient and career, close surveillance by hemophilia treatment centers (HTCs) is still very important. This also provides the opportunity to review the patient treatment diary and detect any medication problems. Hemophilia nurses may also play a part in the community, visiting patients in their home to help train them on effective treatment in the home (Mondorf et al., 2009). Thus, The aim of this study is to evaluate the effectiveness of hemophilia educational program on parents' knowledge of children with Hemophilia.

METHOD

Design: quasi-experimental design with two groups (Study and control group) is carried out to evaluate the effectiveness of hemophilia educational program on parents' knowledge of children with Hemophilia.

Objective(s): The aim of this study is to evaluate the effectiveness of hemophilia educational program on parents' knowledge of children with Hemophilia.

Setting of Study: The data collection process lasted for three months been done at Blood Disease center in - AL Nasiriya City

Sampling: A non-probability (purposive) sample of (40) parents who their children have hemophilia and treated in Blood Disease center.

Data collection: the questionnaire format was used to collect the data which is contain two parts, first part about demographic characteristic (age, gender, social status, level of education, occupation), the second part about knowledge of parents' information regarding hemophilia children.

RESULTS

Table (1): Statistical Associations between the Demographic Variables of Study Sample and Effectiveness of an Educational Program on Parents knowledge for Children with Hemophilia :

No	Demographic Variables Parents Knowledge	Statistics						
		S.O.V	Sum of Squares	df	Mean Square	F	P. value	Sig
1	Age	Between Groups	0.910	1	0.910	4.251	0.045	S
		Within Groups	10.277	38	0.214			
		Total	11.187	39				
2	Gender	Between Groups	0.750	4	0.750	3.449	0.049	S
		Within Groups	10.437	35	0.217			
		Total	11.187	39				
3	Educational Level	Between Groups	0.055	5	0.011	3.146	0.019	S
		Within Groups	0.118	34	0.003			
		Total	0.172	39				

S.O.V=Source of Variance F = Fisher test, d.f. = degree of freedom, P = probability value, , NS : Non Significant at $P \geq 0.05$, S : Significant at $P < 0.05$.

This table show their statistically significances differences between demographics variables (Parents age, gender, and educational level) and effectiveness of an educational program on parents' knowledge for children with hemophilia, when analyzed by ANOVA.

Table (2): Comparison Significant Identify the Knowledge of Parents information for children with hemophilia of the Study Sample (Study Group):

No.	Items Related to Parents knowledge*	Pre - test			Post-test			P-value	C.S.
		M.S.	S.D.	Ass.	M.S.	S.D.	Ass.		
3.1.1	Hereditary hemorrhagic disease or hemophilia	1.40	0.495	M	2.00	0.000	H	0.01	S
3.1.2.	There are many types and forms of hemophilia patients	1.38	0.530	M	1.96	0.198	H	0.09	S
3.1.3	The most dangerous of all types:	1.32	0.471	L	1.74	0.443	H	0.014	S
3.1.4	Among the main causes of hemophilia patients:	1.30	0.463	L	1.82	0.388	H	0.031	S
3.1.5	Symptoms associated with this disease	1.30	0.463	L	1.78	0.418	H	0.028	S
3.2.1	Among the unhealthy foods for hemophilia patients:	1.42	0.499		1.42	0.499	M	0.033	S
3.2.2	One of the foods that contain vitamin K, which contributes to the clotting process	1.34	0.479	M	1.66	0.443	M	0.020	S

3.2.3	Nutritional advice for patients with hemophilia:	1.24	0.431	L	1.68	0.454	H	0.012	S
3.2.4	It is recommended to stay away from foods except for one:	1.14	0.351	L	1.74	0.501	H	0.010	S
3.2.5	One of the following statements includes foods or drinks not recommended for the patient	1.26	0.443	L	1.46	0.503	M	0.022	S
3.3.1	We advise patients suffering from hemophilia about their medications:	1.24	0.431	L	2.00	0.000	H	0.016	S
3.3.2	Hemophiliacs should take folic acid to:	1.12	0.328	L	1.98	0.141	H	0.038	S
3.3.3	Among the medicines that are prohibited for use by patients with hemophilia:	1.22	0.418	L	1.92	0.274	H	0.010	S
3.3.4	Among the safe medications as analgesics during bleeding:	1.28	0.454	L	1.96	0.198	H	0.040	S
3.4.1	One of the following is a sign of excess fluid in the body:	1.30	0.463	L	1.80	0.404	H	0.034	S
3.5.1	The benefits of exercising for hemophilia patients are:	1.38	0.490	M	1.86	0.351	H	0.01	S

M.S. =Mean of score , S.D. = Standard, Eval.= Evaluation. , Comparison, Significant , No.= Number of domain , NS : Non Significant at $P \geq 0.05$, S : Significant at $P < 0.05$, Level of Evaluation:(1-1.33) = Low ;(1.34-1.67) = Moderate; (1.68-2.00) = High.

Table (2) shows that information of study sample were presented low level of knowledge at items (3.1.3, 3.1.4, 3.1.6, 3.2.3, 3.2.4, 3.2.5, 3.3.1, 3.3.2, 3.3.3, 3.3.4 and 3.4.1) at pre-test. While presents Moderate level of knowledge at items, So the results show high level of knowledge at post-test except (3.2.1, 3.2.2 and 3.2.5) were presented as moderate level of knowledge. That there are statistically significance differences between two periods (pre and post-tests) of study sample in all items of the Knowledge of Parents' information for children with hemophilia of the Study Sample .This reflects that the Parents knowledge was affected by educational program when analyzed by (t-test).

DISCUSSION

Parents patients' knowledge, show their statistically significances differences between demographics variables (parents age, gender and educational level) and effectiveness of an educational program on parents knowledge. This result compatible with Mohammed and hattab, (2013) his concluded, high significant relationship between (age and educational level) and knowledge of mothers with hemophilia.

Patient knowledge towards health prevention and self-care, show their statistically significances differences at parents' gender, while there is no

statistically significances differences between demographics variables (parents age and educational level) and effectiveness of an educational program on parents knowledge.

Parents' knowledge of self-monitoring, show their statistically significances differences between demographics variables (Parents age and gender), and effectiveness of an educational program on parents' knowledge while there is no statistically significances differences between educational level and level of education. This result compatible with Mohammed, (2013) his concluded significant relationship between age and practice of mothers with hemophilia but different at educational level is significant.

The parents knowledge regarding home care, shows that good information of the study and poor information of control and statistically significance differences between two periods (posttest for study group and posttest of control group) toward parents patients knowledge regarding home care.

This finding was congruent with Phadnis & Kar (2017) who conducted a study entitled "The Impact of Haemophilia Education Intervention on the Knowledge and Health related Quality of Life of Parents of Indian Children with Haemophilia and reported that there was improvement in knowledge scores immediately after intervention, which remained significantly after intervention.

The parent knowledge towards health prevention and self-care, shows that sometimes information of the study and control group and statistically significance differences between two periods (posttest for study group and posttest of control group) toward parent knowledge of health prevention and self-care.

In this respect, Solish and Perry (2008) stated that parents with higher self-efficacy showed more responsibility and attempt for developing appropriate behaviors in their children and, as a result, were more competent to take care of their children and has highlighted that there was a significant improvement of the total mean score.

The parents' knowledge of self-monitoring, shows that sometimes information at the study group and don't information at control group and statistically significance differences between two periods (posttest for study group and posttest of control group) toward parents' knowledge of self-monitoring.

Similarly, Poon and Card, (2012) his concluded that improving hemophilia care can best be met by comprehensive care program which designed to provide education to families had children with hemophilia. Also finding was in accordance with Hussein et al. (2013) who found that the mean scores of mothers' practices were higher in the study group at the post-test.

CONCLUSION

The study concluded that the education program was effective to improve to the participation parent for children with hemophilia.

RECOMMENDATIONS

Continuous educational program to health team to increase parent' knowledge about enhance self-care for patients with hemophilia. It is recommended to the Mistry of Health to increase educational program to patient with hemophilia and very important implication. It is recommending including the nursing team ' role in the process of enhancing home-care level of

patient ' in the blood disease center this will enhance a good communication between patient and nurse also will ease a healthy relationships guide the best outcome.

ETHICAL CONSIDERATIONS COMPLIANCE WITH ETHICAL GUIDELINES

This study was completed following obtaining consent from the University of Baghdad.

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AUTHOR'S CONTRIBUTIONS

Study concept, Writing, Reviewing the final edition by all authors.

DISCLOSURE STATEMENT:

The authors report no conflict of interest.

REFERENCES

- Hussein, K. A., Al-Azzawi, S., & Al-Khateeb, E. M. (2013). Impact of Education Program upon Mother's Knowledge and Practices of Haemophilic Children Type A. *Medical Journal of Babylon*, 10(1), 100-109.
- Mohammed AO, & hattab KM. Assessment of Mothers Knowledge and Practices with Hemophilic Children type A at Azadi Teaching Hospital in Kirkuk City. *Iraqi National Journal of Nursing Specialties*. 2013; 26 (2):35-48.
- Mohammed, A. O. (2013). Assessment of Mothers Knowledge and Practices with Hemophilic Children type A at Azadi Teaching Hospital in Kirkuk City. *Iraqi National Journal of Nursing Specialties*, 26(2).
- Mondorf, W., Siegmund, B., Mahnel, R., Richter, H., Westfeld, M., Galler, A., & Pollmann, H. (2009). Haemoassist™ - A hand-held electronic patient diary for haemophilia home care. *Haemophilia*, 15(2), 464-472. <https://doi.org/10.1111/j.1365-2516.2008.01941.x>
- Mulders, G., De Wee, E. M., Vahedi Nikbakht-van de Sande, M. C. V. M., Kruip, M. J. H. A., Elfrink, E. J., & Leebeek, F. W. G. (2012). E-learning improves knowledge and practical skills in haemophilia patients on home treatment: A randomized controlled trial. *Haemophilia*, 18(5), 693-698. <https://doi.org/10.1111/j.1365-2516.2012.02786.x>
- Nolan, V. G., Nottage, K. A., Cole, E. W., Hankins, J. S., & Gurney, J. G. (2015). Prevalence of Vitamin D deficiency in sickle cell disease: A systematic review. *PLoS ONE*, 10(3), 1-12.

<https://doi.org/10.1371/journal.pone.0119908>

- Phadnis, S., & Kar, A. (2017). The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. *Haemophilia*, 23(1), 82-88.
- Poon, M. C., & Card, R. (2012). Hemophilia management in transfusion medicine. *Transfusion and Apheresis Science*, 46(3), 299-307.
- Saxena. (2013). Barriers and perceived limitations to early treatment of hemophilia. *Journal of Blood Medicine*, 49. <https://doi.org/10.2147/jbm.s43734>
- Solish, A., & Perry, A. (2008). Parents' involvement in their children's behavioral intervention programs: Parent and therapist perspectives. *Research in Autism Spectrum Disorders*, 2(4), 728-738.
- Tonbary, Y. Al, Elashry, R., El, M., & Zaki, S. (2010). *Descriptive Epidemiology of o Hemophilia and nd Other Coagulation Disorders in.* 2(3). <https://doi.org/10.4084/MJHID.2010.025>