Assessment of Mothers' Knowledge about Their Children with Sickle Cell Anemia and Non-Pharmacological Approaches to Pain Management in Basra Center for Hereditary Blood Diseases

تقييم معارف الأمهات حول أطفالهن المصابين بفقر الدم المنجلي والأساليب غير الدوائية لمعالجة الألم في مركز البصـــرة لأمـــراض الـــدم الوراثيـــة

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المستخلص

الأهداف: تهدف الدراسة الحالية إلى تقييم معارف الأمهات حول أطفالهن المصابين بفقر الدم المنجلي حول الأساليب غير الدوائية لمعالجة الألم ولإيجاد أي علاقة بين معرفه الام وبياناتها الديموغرافية مثل العمر والمستوى التعليمي والمهنة.

منهجية البحث : تصميم وصفي. للفترة من ١٩ ايلول (٢٠٢٠) الى ٣٠ من يناير(٢٠٢١). أجريت الدراسة على العينة غير محتملة (قصدية) تم اختيار عينة غير احتمالية تتكون من (٣٠) الامهات لدى اطفالهن فقر دم منجلي في مركز البصره لامراض الدم الوراثية. وتم اعتماد و تعديل اداة البحث لغرض هذه الدراسة . تم تحليل البيانات من خلال تطبيق الاساليب الاحصائية الوصفية و الاستدلالية التي تم تطبيقها بأستخدام الحزمة الاحصائية للعلوم الاجتماعية، الأصدار ٢٤,٠ .

النتائج أشارت نتائج الدراسة إلى وجود مستويات معتدلة من المعارف تجاه أطفالهن المصابين بفقر الدم المنجلي حول الأساليب غير الدوائية لإدارة الألم. لا توجد علاقة ذات دلالة إحصائية بين معارف الأمهات بجميع المعلومات الديموغرافيه عند القيمة $p = 0.05$ باستثناء وجود علاقة بين معارف الأمهات والتعليم، بالإضافة إلى وجود علاقة بين معارف الأمهات والوظيفة عند قيمة $p = 0.05$.

التوصيات: أوصت هذه الدراسة بضرورة أن يكون هناك برنامج تعليمي غير دوائي لمعالجة الألم لتحسين وتعزيز مستوى معارف الأم. هناك حاجة حقيقية للتنسيق مع وسائل الإعلام من أجل زيادة معرفة الأمهات حول معالجة الألم غير الدوائية.

الكلمات المفتاحية: تقييم معارف الأمهات، الأساليب غير الدوائية، معالجة الألم، فقر الدم المنجلي

Abstract

Objective(s): To assess mothers' knowledge about their children with sickle cell anemia and non-Pharmacological approaches to pain management and found some relationship between mothers knowledge and their demographic data of age, level of education, and occupation.

Methodology: A descriptive design used in the present study established was for a period from September 19th, 2020 to March 30th, 2021. The study was conducted on a non-probability (purposive) sample of (30) mother their children with sickle cell anemia was chosen. The data were analyzed through the application of descriptive and inferential statistical approaches which are applied by using SPSS version 22.0.

Results: The findings of the study indicated that moderate levels of knowledge toward their children with sickle cell anemia about non-pharmacological approaches to pain management. No significant relationship among mothers' knowledge with all demographic at p-value= 0.05 except, there are relationship between mothers' knowledge and Education, as well as there are relationship between mothers' knowledge and Occupation at p-value= 0.05.

Recommendations: The researcher recommends that need to educational program about non pharmacological to pain management to improve and enhance level of mother's knowledge. There is a real need for coordination with the media in order to increase mothers' knowledge about non-pharmacological to pain management.

Keywords: Assessing of Mothers' Knowledge, Non-Pharmacological Approaches, Pain Management, Sickle Cell Anemia

Introduction

Sickle cell anemia is an inherited disorder that occurs in the sixth amino acid locus in the beta chain of the hemoglobin molecule. As a result, neither the hemoglobin molecule nor the red blood cells form sickle cell erythrocytes, take the form of a crescent [(1)]. As they develop, during childhood and adolescence, they have increased susceptibility to infection, and multi-organ problems [(2)].

The most distinctive feature and aspects of sickle cell anemia are periodic episodes of pain, called crises. Pain occurs when sickle-colored red blood vessels become hard and sticky in the various vital organs of the body in the chest and abdomen, as well as in the joints and bones, trapped in small vessels and blocking blood flow to these vessels [(3)].

Many therapies are available that decrease the number of crises. There is no treatment for most persons with sickle cell anemia to avoid complications and alleviate pain. With a bone marrow transplant, certain people may be treated. For seizures that cause extreme pain, an effective medication called hydroxyurea is now available and is treated with pain relievers, intravenous fluids, and oxygen. If infection is suspected, antibiotics are given [(4)].

Pain is an experience that is both emotional and physical. For this purpose, to provide qualitative and quantitative information about pain, many different assessment techniques are required, qualitative evaluation is a summary of the location, duration and characteristics of the pain, as well as factors influencing the pain, quantitative evaluation measures the severity of the pain using a pain scale, it is important in the clinical evaluation of pain [(5)].

Non-pharmacological methods are categorized as drug-free pain management. More precisely, non-drug therapies apply to the non-medical methods that doctor's use in routine practice. Non-drug therapies can complement pharmacokinetics and may provide alternative treatment options in managing symptoms, including pain [(6)]. There are many non-pharmacological approaches to pain management related to sickle cell anemia as, behavioral-cognitive interventions [(7)], relaxation training focuses [(8)] deep breathing [(9)], distraction themselves from frightening stimuli [(10)] ,emotional Support[(11)]

Methodology

A descriptive design study was carried out at Basra Center for Hereditary Blood Diseases in order to assess Mother's Knowledge toward their children with Sickle Cell Anemia about Non-Pharmacological Approaches to Pain Management in Basra Center for Hereditary Blood Diseases from19 September 2020 to 30 March 2021.

The setting of the study includes mother who visit Basra Center for hereditary blood diseases in Basra governorate which receive child with blood diseases for investigation and treatment.

The sample of the study is non-probability (purposive) sample which is chosen for the current study. The sample involves (30) mother are selected for the study and (10) Mother are selected for the initial need assessment and (5) mothers are selected for pilot study.

Ethical Considerations

Scientific Research Ethical Committee at the University of Baghdad, College of Nursing has approved the study to be conducted. All mothers who have participated in the study have signed consent form for the human subjects' rights.

The Study Instrument

A questionnaire is constructed and introduced to the mother to evaluate the questionnaire of the program upon mother's demographic information, child demographic information, knowledge which is composed of 2 parts each part is divided to items.

Each item contains 17th question in knowledge about sickle cell anemia and 25th questions in knowledge about non-pharmacological approaches to pain management and presented

Validity of the Study Instrument

Content validity of the program and the study tools are determined by the panel of (10) experts in different nursing and medical fields. The experts were asked to analyze the questionnaire to clarify the validity and appropriateness of the content. Their responses are taken and some changes are made according to their opinion.

Reliability of the Study Instrument

The reliability of the instrument is determined through the computation of Spearman Correlation Coefficient; test-retest method is used for determining the reliability. The Spearman Correlation Coefficient is applied to determine the reliability of the present study instrument by application of Statistical Package for Social Science Program (IBM SPSS) version 24.0.The result of the reliability for the questionnaire (0.79) is statistically acceptable which means that the questionnaire is adequately stable measure.

Data Collection

Data are collected through the use of the study instrument.

Data Analysis

Data are analyzed through the application of the descriptive and inferential statistical data analysis approaches.

Results

Table (1): Distribution of the Mothers According to their Socio-demographic Characteristics

Characteristics		f	%
Age: (M±SD= 37±7 years)	20 – 29 years	5	16.7
	30 – 39 years	15	50
	40 – 49 years	10	33.3
Level of education	Doesn't read & write	4	13.3
	Read & write	1	3.3
	Primary school	11	36.7
	Secondary school	10	33.4
	Institute (Diploma)	0	0
	College (Bachelor)	4	13.3
Occupation	Working	3	10
	Does not working	27	90
Marital status	Married	27	90
	Divorced	3	10
Number of children in family	1 – 3	13	43.3
	4 – 6	15	50
	7 ≤	2	6.7
Is there a patient with sickle cell anemia in the family	No	6	20
	Yes	24	80

f: Frequency, %: Percentage, M: Mean, SD: Standard Deviation

This table shows that half mothers are young adult with age group 30-39 years (50%) with average (37±7). The level of education refers that the highest percentage of mothers are graduated from primary school (36.7%) and 33.4% are graduated from secondary school. The occupational status indicates that only 10% of mothers are working while the remaining are doesn't (90%). Most of mothers are living with normal marital status in which 90% of them are married and only 10% are divorced. Half of mothers are reported that they have 4-6 children in their families (50%) and more of them are reported that they have patient inflicted with sickle cell anemia in family (80%).

Table (2): Distribution of Children According to their Socio-demographic Characteristics

Characteristics		f	%
Age (M±SD= 7±3 years)	3 – 5 years	10	33.3
	6 – 8 years	6	30
	9 -11 year	9	30
	12 – 15 year	5	16.7
Gender	Male	16	53.3
	Female	14	46.7
Birth order	First	8	26.7
	Second	7	23.3
	Third	3	10
	Fourth +	12	40
Age at diagnosis	< 1 year	14	46.7
	1 – 3 years	13	43.3
	4 – 5 years	3	10
Number of pain severity/ month	1	5	16.7
	2	14	46.7
	3	9	30
	4	2	6.7

f: Frequency, %: Percentage, M: Mean, SD: Standard Deviation

This table presents the descriptive analysis of socio demographic characteristic of children with sickle cell anemia; the table reveals that 33.3% of children are with age 3-5 years (average=7±3). 53.3% of them are male children who are fourth or more among his family (40%). The highest percentage among children are referring to 46.7% that children are diagnosed at age less than one year and 43.3% are diagnosed at age of 1-3 years. The number of pain severity is referring that occurs two times per month as reported by their mothers (46.7%).

Table (3): Levels of Mothers' Knowledge about Sickle Cell Anemia and Non-Pharmacological Approaches to Pain Management

Levels of Knowledge Non-Pharmacological Approaches to Pain Management	Overall Assessment	
	F.	%
Low	5	16.7
Moderate	21	66.7
Good	4	16.7
***Mean*+ SD**	٥٢١.+١.٩٣	
%: Percentage, M: Mean, SD Standard deviation, Poor= 0-8, Fair= 9-17, Good=18-25		

Levels of Knowledge Sickle Cell Anemia	Overall Assessment	
	F	%
Low	5	١٦.٧
Moderate	20	٧٣.٣
Good	5	١٠
Total	*30*	١٠٠
SD *+Mean*	٥٨٧.±٢.٠٠	
Percentage, M: Mean, SD Standard deviation, Poor= 0-5, Fair= 6-11, Good=12-17 :%		

This table depicts that mothers are showing moderate level of knowledge about non-pharmacological approach management for sickle cell anemia of study (73.3%), and showing moderate level of knowledge about sickle cell anemia of study (66.7%),

Table (4): Relationship between Mothers' Knowledge and their age, education and occupation

Knowledge Age	Value	df	P-value	Sig.
Knowledge about sickle cell anemia	17.817[a]	20	0.599	N.S
Knowledge about pain management	34.364[a]	38	0.638	N.S
Knowledge Education	**Value**	**df**	**P. value**	**Sig.**
Knowledge about sickle cell anemia	40.884[a]	40	0.431	N.S
Knowledge about pain management	19.838[a]	8	.011	S
Knowledge Occupation	**Value**	**df**	**P. value**	**Sig.**
Knowledge about sickle cell anemia	6.111[a]	2	.047	S
Knowledge about pain management	11.987[a]	2	.002	S

This table reports that there is no significant relationship among mothers' knowledge with all demographic at p-value= 0.05 except, there are relationship between mothers' knowledge and education, as well as there are relationship between mothers' knowledge and their occupation at p-value = 0.05.

Discussion

Part I: Discussion of Mothers' Socio-Demographic Characteristics

In regard to mothers' age, half of mothers are young adults with age group (30-39) years (50%) with average (37±7). This finding agrees with that of a study which finds that (56%) of mothers age from (30-39) years, with mean age (38.2±.8.1) [(12)]. The age group (30-39) years are the most among the age groups that reply and participate in the program. So, their percentage is the highest as being compared to other age groups, while those who are

twenty-year-old could not commit to attend because their spouses do not accept their participation in the program, so their percentage is small in the sample. Also, the older age group is not in the mood to participate in the program, so their percentage is low.

Regarding to mothers' level of education, the study refers that the highest percentage of mothers are graduated from primary school (36.7%) and (33.4%) are graduated from secondary school. This finding is close to the percentages of a study indicates that primary (14%), secondary (36%), and university (46%) [13].

This is due to mothers who have a university education and more and they have good knowledge of sickle cell anemia through the initial need assessment for the education program construction. So, their participation rate is low compared to mothers with primary and secondary education who do not have sufficient knowledge of the disease and their participation rate in the educational program is high.

Relative to their occupational status, the study indicates that only (10%) of mothers are working while the remaining are do not (90%). While a study finds that (64%) are not working and (36%) are working [14].

The reason for this is that mothers who work because of their commitment to work were not able to join and participate in the educational program, so their percentage was small compared to mothers who did not work who had time to participate in the program.

With respect to their marital status; most of mothers are living with normal marital status in which 90% of them are married and only 10% are divorced. This result is match with the result of a study that finds that the highest percentage of mothers (94%) who are married and only (4%) are divorced [15].

The percentage of divorced women is very small, due to their inability to participate, as most of them had an excuse. I could not participate in the study and commitment because I could not go out on my own.

In relation to number of children, half of mothers have reported that they have (4-6) children in their families (50%) and more of them are reported that they have patient inflicted with sickle cell anemia in family (80%). On the other hand, a study finds that the number of children in family (1- 3) (62.2%) while (37.8%) have more than three children, (44.4%) have a history of sickle cell anemia and (55%) without a family history [16].

This could be explained by the fact that, couples with sickle cell trait will have each of their pregnancy having (25%) chance of giving birth to a child affected by sickle cell disease.

The largest percentage is among the Arabs in the extreme south, where (6.48%) of Basra's population carries the sickle cell trait.

With regard to child age, (33.3%) of children are with age (3-5) years (average=7±3). (53.3%) of them are male children who are fourth or more among his family (40%). While study is done in Egypt finds that, the mean age of the children is 12.0., 3.15 years; more than half of them (55.0%) are males [14].

Relative to child age at diagnosis, the present study shows that the highest percentage among children are referring to (46.7%) that children are diagnosed at age less than one year and (43.3%) are diagnosed at age of (1-3) years. While the study has been done in Iraq has revealed that the onset of illness is one year for (88%) of children, while it is two years for (12%) only of them [17].

The age groups through which signs and symptoms of the disease begin to appear are the age group from (6) month to (5) years.

In relation to number of pain severity, the present study is referring that is occurred two times per month as reported by their mothers (46.7%). While a study that is done in Iraq which shows that more than three quarters of children (78%) had severe pain and (22%) of them only had moderate pain. while, none of them had mild pain[17].

Because most of them take an hydroxide that works to reduce the attacks of pain, while before giving the child this treatment the pain attacks were from 4 to 5 times during the month.

Regarding to the assessment of mothers' knowledge about behavioral, emotional strategies and biophysical interventions of non-pharmacological approach to pain management; the present study shows that mothers are presenting moderate level of knowledge about sickle cell anemia. This is consistent with findings of a study that is done in which reports that the mothers have poor knowledge about sickle cell anemia [18].

A study shows that (95.1%) of the adolescents and early adulthood with Sickle cell disease (SCD) had unsatisfactory knowledge about knowledge toward SCD before carried out of the program. While after the carried out the program the 100% of the adolescents and early adulthood with SCD had a good knowledge about SCD. The difference is statistical significant, P-value = 0.02 [19].

This result may be due to the increase of mothers' education due to empowering them to be more knowledgeable and act effectively.

In regard to relation between mother's knowledge their age and education; the present study shows that there is no significant relationship among mothers' knowledge with regard to their age at p-value= 0.05; however, there is significant relationship between mothers' knowledge about non-pharmacological approach to pain management with regard to their educational level evidence by significant difference at p-value= 0.029 respectively. This does not match that of a study which is done in Egypt that indicates an increase in satisfactory knowledge of mothers age from 30:39 years were (12%) in pretest and increase to (50%) in posttest, satisfactory knowledge of mothers who have secondary school education in pretest is (12%) and increase to (42%) in posttest. However, this increase reached statistically significant difference between the mothers' age and formal education their knowledge (P $\leq$ 0.01 and 0.01); respectively [12].

This can be illustrated that mothers, regardless of their age, as soon as one of her children is diagnosed with sickle cell disease, she works hard on how to take care of her child in a healthy way and acquire the correct information that helps her with that. Also the level of education of mother is helps to understand the information being given during the program teaching session.

Regarding the association between mothers' knowledge and their occupation, the present study reveals that there is a significant relationship between overall mothers' knowledge with regard to their occupational status particularly their knowledge about pain management approach as seen by significant differences in knowledge with regard to working mothers at p-value= .014. This finding is inconsistent with a study which is done in India which has stated that occupational status of the husband is statistically not associated with their knowledge score [(20)].While the findings of the present study agree with finding of a study which is done in New Valley which indicates that mothers have significantly higher frequencies of satisfactory score (44.4%) or good score (37.0%) in comparison to housewife mothers [(16)].

The employed mother is more knowledgably than the unemployed mother.

Recommendations

1. The researcher recommends that need to educational program about non pharmacological to pain management to improve and enhance level of mother's knowledge.
2. There is a real need for coordination with the media in order to increase mothers' knowledge about non-pharmacological to pain management. the study recommended to establish further studies to measure a large population, so that, results can be generalized.

References

1. Obeagu, E. I., Ochei, K. C., Nwachukwu, B. N., & Nchuma, B. O. (2015). Sickle cell anaemia: a review. Scholars Journal of Applied Medical Sciences, 3(6B), 2244-2252.
2. Costa, F. F., & Conran, N. (2016). *Sickle cell anemia: From basic science to clinical practice*. New York: Springer International Publishing.
3. Inati-Khoriaty, A. (2008).*Sickle cell disease*. Nicosia: Thalassemia International Federation.
4. Komaroff, A. L. (2005). *Harvard medical school family health guide*. New York: Simon and Schuster.
5. Harding, M. M., Kwong, J., Roberts, D., Hagler, D., & Reinisch, C. (2019). *Lewis's Medical-Surgical Nursing E-Book: Assessment and Management of Clinical Problems, Single Volume*.11th edition . Canada: Elsevier Health Sciences.
6. Gélinas, C., Arbour, C., Michaud, C., Robar, L., & Côté, J. (2013). Patients and ICU nurses' perspectives of non-pharmacological interventions for pain management.
7. Efe, E., Özcan, D., Dikmen, Ş., & Altaş, N. (2017). Turkish pediatric nurses use of nonpharmacological methods for postoperative pain relief in 6 to 12-year-old children. *The Open Pain Journal*, *10* (1), *56*-64.
8. Kerns, R. D., Sellinger, J., & Goodin, B. R. (2011). Psychological treatment of chronic pain. *Annual Review of Clinical Psychology*, *7*, 411–434.
9. Coco, M. (2018). Nonpharmacologic treatment of pain in sickle cell disease. *Topics in Pain Management*, *34*(5), 1–8.
10. Prasai, K &Gaire, S. (2020*). Non-pharmacological pain management of child from 1 to 10 years*(Bachelor's Thesis) .
11. Perry, A. G., Potter, P. A., & Ostendorf, W. (2016). *Nursing interventions & clinical skills-E-Book*. United States of America: Elsevier Health Sciences.
12. Abolwafa, N. F., & Ali, A. S.(2019). Educational Program for Empowering Mothers of

Fewer Than Five Children to Overcome Sickle Cell Crisis .*International Journal of Nursing Didactics*,*9(04)*.doi:https://doi.org/10.15520/ijnd.v9i04.2513.

13. El-Adham, N. A. E.-, Said, D. A., & Awad, H. (2020). Effect of an Educational Program for Parents of Children with Sickle Cell Anemia. *Journal of Nursing and Health Science*, *9*(3), 21–30. https://doi.org/10.9790/1959-0903062130.
14. Abd Elaziz, S. M., & Mohamed, R. A. E. (2019). Effect of self care management program on pain and fatigue in sickle cell children. *International Journal of Novel Research in Healthcare and Nursing*. *6*(3), 747-761
15. Awd, R. A. E. M., Abdel-Sadik, B. R., & El-AAsar, H. N. (2018). Mother's knowledge and practice regarding care of their children with sickle cell anemia. *Menoufia Nursing Journal*, *2*(2)
16. Abed al Fatah, S. M., Mobarak, A. A., & Edien, Z. M. M. (2016). Mothers' knowledge and practices for their children with sickle cell anemia at new valley governorate hospitals. *Assiut Scientific Nursing Journal*, *4*(9), 144–155. https://doi.org/10.21608/asnj.2016.60346.
17. Essawy, M. A., El Sharkawy, A., Al Shabbani, Z., & Aziz, A. R. (2018). Quality of life of children with sickle cell anemia. IOSR J Nurs Health Sci, 7, 29-39.
18. Abd El-Gawad, S.M. (2017). Empowering Mothers to overcome sickle cell crisis in their children through engagement and education. *American Journal of Nursing Research*, *5*(5), 182–190.
19. Hassan, K., & Qalawa, S. A. (2021). Impact of Educational Program for Adolescents and Young Adults with Sickle Cell diseases on their knowledge, Perception, and Self-Care. *Indian Journal of Public Health Research & Development*, *12*(1). 19
20. Rakshale, N., Sebastian, T., Hatwar, K., Bhoyar, P., Bhute, K., Bhusari, P., ... & Kambdi, P. (2020). Knowledge regarding sickle cell anaemia among newly married couples: A qualitative study. *Intern J Cur Res Rev*, *12*(19), 128-133.