

Effect of an Educational Program regarding Thalassemia on the Knowledge and Care Practices of Mothers of Thalassemic Children in Jordan

Seirin Mohammad Khresheh¹ and Sara Lavinia Brair²

¹Department of Community Health Nursing, Faculty of Nursing, Mutah University, Jordan

²Department of Community Medicine, Faculty of Medicine, Al Neelain University

المستخلص

المقدمة : الثلاسيميا هي واحدة من أكثر الأمراض الموروثة في الأردن . كان الهدف من هذه الدراسة هو تقييم فعالية برنامج تعليمي حول مرض الثلاسيميا وحول ممارسات المعرفة والرعاية لأمهات أطفال مرضى الثلاسيميا في الأردن.

الطريقة: تم استخدام دراسة التجريبية مع الاختبار القبلي والاختبار البعدي لجمع البيانات. تم الحصول على عينة ملائمة 45 من الامهات اللواتي لديهن اطفال مرض الثلاسيميا من ثلاثة مستشفيات حكومية في الاردن. وتم استخدام استبيان منظم موحد لجمع البيانات من خلال المقابلات. تم تحليل البيانات باستخدام الاصدار 16 من SPSS.

النتائج: بلغ متوسط عمر الأمهات (35.7) ، 88 ٪ منهن متزوجات، 37.7٪ لديهن مستوى تعليم عالي.

53٪ لا يعملن، 53.3٪ لديهن مالدخل شهري أكثر من 300 دينار. و متوسط عمر الأطفال المصابين بمرض الثلاسيميا (7.8) ٪، 53.3٪ منهم ذكور ، و 51.1٪ ما بين اعمار 6-10 سنوات. أظهرت النتائج أن المستوى العام للمعرفة لدى الامهات قد زاد بشكل كبير بعد ادخال البرنامج . مقارنة ما قبل ادخال البرنامج . لوحظ تحسن كبير في درجات معرفة الامهات في جميع مقاييس المعرفة للثلاسيميا $t=96.75$ ، $P=0.000$. كما تحسنت ممارسات الرعاية للأمهات بشكل ملحوظ بعد اعطاء البرنامج التعليمي $t=104.99$ $P=0.000$ مقارنة مع نتائج ما قبل اعطاء البرنامج . تشير هذه التحسينات الكبيرة في نتائج ممارسات الرعاية الشاملة للأمهات أن البرنامج التعليمي كان فعالاً. **الخلاصة:** أظهر البرنامج التعليمي تأثيراً كبيراً ويشكل زيادة ملحوظة في مستوى معرفة وممارسة الأمهات . يوصى بتنفيذ برنامج تعليمي صحي مماثل في مراكز الثلاسيميا الاخرى في الأردن لجميع أمهات الأطفال المصابين بمرض الثلاسيميا .

Abstract:

Introduction: Thalassemia is one of the most common inherited diseases in Jordan. The aim of this study was to evaluate the effectiveness of an educational program about thalassemia on knowledge and care practices of mothers of thalassemic children in Jordan.

Methods: An experimental design with a pre and post-test was used. A convenient sample of mothers with thalassemic children (n=45) was obtained from three governmental hospitals in Jordan. A standardized structured questionnaire was used to collect data through an interview and data was analyzed using SPSS version 16.

Results: The mean age of mothers was (35.7 years, SD=13.3), 88% were married, 37.7% had high level of education, 53% were not employed, 53.3% had monthly income more than 300 Jordanian Dinars (JD). The mean age of thalassemic children was (7.8 years, SD=5.0), 53.3% of them were males, and 51.1% were between 6-10 years old. Results showed that, the mothers' overall level of knowledge had significantly increased post intervention compared with the pre-intervention. Significant improvements in mothers' knowledge scores were observed on all subscales of the knowledge scale ($t= 96.75$, $P=0.000$). The care practices of mothers have also improved significantly post intervention ($t= 104.99$, $P=0.000$) compared with the pre-intervention results.

These significant improvements in mothers' overall care practices scores indicate that the educational program was effective. Results showed no significant association of mothers' overall level of knowledge and care practices with their socio-demographic characteristics at pre-test or post-test.

Conclusion: The educational program showed a significant impact in the form of a remarkable increase in the mothers' level of knowledge and care practice. It is recommended to implement a similar health educational program at the other thalassemia center in Jordan for all mothers' of thalassemic children.

Keywords: Educational program; Knowledge; Care practices; Thalassemia

Introduction

Thalassemia is an autosomal recessive disorder. The genetic defect results in reduced rate of synthesis of one of the globin chains that produce hemoglobin. Thalassemia is categorized into Alpha thalassemia and Beta thalassemia depending upon the globin chain affected. According to the WHO data, there are 269 million carriers of thalassemia worldwide alone, of which 25 million are in Mediterranean region.¹⁻² It is recognized that 300,000 infants are born with major hemoglobinopathies worldwide, each year 60,000 to 70,000 are born with β -thalassemia major cases. Severe β -thalassemia accounts for 50,000 to 100,000 deaths per year or 0.5% to 0.9% of all deaths of children under 5 years in low or middle income countries.³ In Jordan, β -thalassemia is one of the major inherited disorders, the incidence was estimated at 3.3% and 3.5%.⁴⁻⁵ More than 1500 patients live with β -thalassemia major as was recorded in the year 2018.⁶ The high prevalence of β -thalassemia in Jordan can be attributed to the high consanguinity marriages, with the carrier rate for the disease estimated at 24%.⁵ It was estimated that the cost for treating β -thalassemia in Jordan about 4.5 million dollar.⁷

Thalassemic population is mainly young (under 15 years old) and family plays a very important role in providing care for them. Previous studies demonstrated that it is the responsibility of the family to administer iron chelating therapy to children, the follow-up of taking regular blood transfusion and checking of hemoglobin level.⁸ Considering the chronic nature of thalassemia, it is necessary for patients and their families to have adequate information on the disease process and related therapeutic measures. The introduction of educational programs about thalassemia for mothers of thalassemic children in Jordan will allow mothers to participate in their children's care at home and during hospitalization correctly. Health education programs regarding thalassemia will also assist in raising community awareness, improve mothers' knowledge, attitudes and care practices when dealing with their thalassemic children. Knowing more information about the nature of the disease, complications, prevention and treatment will help decrease the incidence, mortality and morbidity rate of thalassemia.

There are no educational programs for mothers with thalassemia children in Jordan. Therefore, the purpose of this study was to introduce an educational program about thalassemia for mothers of children with thalassemia in Jordan and evaluate the effectiveness on knowledge and care practices of mothers of thalassemic children.

Methods

This was an experimental design with a pre and post-test done for the interventional program for mothers of children with thalassemia. The intervention consisted of an educational program for mothers of children with thalassemia who come for health care in three governmental hospitals, selectively sampled from the three regions of Jordan, South, Middle, and North based on the availability of thalassemia management center in each one. The educational program consisted of six sessions; four theoretical sessions that focused on providing mothers with information regarding the causes of thalassemia, risk factors, signs and symptoms, diagnoses, management and prevention in addition to two practical sessions to demonstrate care practices for mothers. The duration of each session ranged between 30-45 minutes and consisted of a power-point presentation and demonstration session. The sessions were designed and scheduled for approximately (4 hours/day) for five days in each thalassemia center. A pre-test was done for mothers before implementing the health education program and the post-test was done one month after the implementation of the program in the three selected thalassemia centers.

Mothers of children with β -thalassemia who attended the selected hospitals for health care were selected based on the inclusion criteria that included: 1) Jordanian biological mother able to communicate in either Arabic or English, 2) with at least one child diagnosed with β -thalassemia major for at least one year, and free from any other chronic and hematological disorder. Non-Jordanian mothers; step-mothers or any other care giver and mothers who had communication problems (such as deafness or any verbal communication) were excluded from the study. Mothers of children with β -thalassemia major but had other concomitant chronic disorders, for example physical or mental disease, cerebral palsy or diabetes mellitus and other types of thalassemia including 'alpha' thalassemia and thalassemia 'intermedia' or any other hematological disorder were also excluded.

Data was collected through interviews using a standardized structured questionnaire. The questionnaire consisted of two sections, the first section consisted of 14 items that explored the demographic characteristics of participant mothers and their thalassemic children. The second section consisted of 50 items that evaluated mother's knowledge and care practices regarding thalassemia disease. Mothers' knowledge was assessed using questions regarding the causes of thalassemia, risk factors, signs and symptoms, diagnoses, management and prevention. Responses

included 'True', 'Not sure', and 'False'. Regarding mother's knowledge about thalassemia, higher score results indicated better knowledge on thalassemia. The total knowledge score ranged from 0 to 50. Each correct response was given 1 point and added to the total knowledge score. The knowledge level was considered «poor» if the correct answers was 0-16 points while it was considered «average» if the answer was between 17-33 points and was considered «good» if the answer was 34-50 points.

The mothers' care practice was assessed using a checklist that demonstrated the mother's ability to care for the thalassemic child including ability to administer Desferal tablets. The checklist was developed based on the guidelines given by the Fundamentals of Nursing Care Patients Process and Practices⁹ and consisted of 11 steps that should be followed for ideal thalassemic patient care. The evaluation checklist was classified into two criteria «done» and «not done», if the mother performed the steps correctly, one point was given, if incorrectly done or not done at all, a zero was given, therefore the total care practice scores ranged from 0 to 11. The higher the practice score the better the thalassemia care practice, for the care to be satisfiable, the mother should have performed at least 8 out of 11 steps correctly. Therefore, the care practice was categorized into "unsatisfiable" with 0-3 points "average" practices with 4-7 points and "satisfiable" with 8-11 points. Face and content validity of the questionnaire were assessed by five health experts in the area of thalassemia of whom two were physicians and three were nurses.

Data was collected over a period of 6 months by research assistants in each hospital, those mothers who attended the center with their thalassemic children for either blood transfusion or hematological assessment of serum ferritin and hemoglobin level were interviewed in groups of 4-6 mothers using a questionnaire for the pre-test and each interview took at least 25-35 minutes. Post intervention data were collected after one month of the end of the intervention using the same questionnaire. The effectiveness of the educational intervention was assessed by comparing the pre and post test results. Mothers who answered more than 34-50 points with percentage $\geq 70\%$ of the items correctly in the knowledge domain questions were considered knowledgeable. Mothers who practiced more than 8-11 points with percentage $\geq 70\%$ of the checklist correctly were considered to have satisfiable practice. Comparison of mothers' ability before, immediately after implementing the program was used to evaluate the quality of the educational program and after

one month to assess the efficiency of mothers' practices, and after three months to assess the retained knowledge and proficiency in the practice.

Data was analyzed by SPSS 16 software. Chi-Square was used to test the association between demographic variables and the knowledge and practice scores. Paired t – test was used to test the effectiveness of the educational program on knowledge and care practices of mothers' of thalassemic children.

The study was approved by the Al Neelain Institutional Review Board (IRB) in Sudan and another approval was obtained from the Ministry of Health in Jordan. The needed information and explanations were provided to mothers by the assistant researchers, and then a written consent for participation was obtained from each mother.

Results

Results show that the mean age of mothers was (35.7, SD=13.3) years, 44.4% of them were between 30 to 39 years old, 88% were married, 53.3% had monthly income more than 300 JD, 37.7% were highly educated, 53% were not employed and 28.9% had a governmental job. The mean age of the thalassemic children was (7.8, SD=5.0), 53.3% of them were males, and 51.1% were between 6-10 years old, Table 1.

Table 1. Socio-demographic characteristics of mothers (n=45) and children (n=45)

| Variables | Frequency N | Percentage % |
|----------------------------------|----------------|-----------------|
| Age of mothers (years) | | |
| 20-29 | 11 | 24.4 |
| 30-39 | 20 | 44.4 |
| 40-49 | 12 | 26.7 |
| 50-60 | 2 | 4.4 |
| Marital status of mothers | | |
| Married | 40 | 88.9 |
| Divorced | 2 | 4.4 |

| | | |
|--|----|------|
| Widowed | 3 | 6.7 |
| Place of living of mothers | | |
| South of Jordan | 15 | 33.3 |
| North of Jordan | 15 | 33.3 |
| Middle of Jordan | 15 | 33.3 |
| Level of education of mothers | | |
| Primary school | 10 | 22.2 |
| Secondary school | 8 | 17.8 |
| High school | 10 | 22.2 |
| Diploma | 6 | 13.3 |
| Bachelor | 7 | 15.6 |
| Post diploma | 1 | 2.2 |
| Master degree | 3 | 6.7 |
| Current mother occupation | | |
| Employed | 21 | 47 |
| Not employed | 24 | 53 |
| Employment | | |
| Governmental | 13 | 28.9 |
| Private | 8 | 17.8 |
| Self employed | 3 | 6.7 |
| Nothing | 21 | 46.7 |
| Family monthly income (Jordanian Dinar) | | |
| below 200 | 9 | 20.0 |
| 200-299 | 11 | 24.4 |
| 300-399 | 6 | 13.3 |
| 400-499 | 7 | 15.6 |
| 500-1000 | 11 | 24.4 |
| above 1000 | 1 | 2.2 |
| Gender(child) | | |
| Male | 24 | 53.3 |
| Female | 21 | 46.7 |

| Age of child (years) | | |
|----------------------|----|------|
| 1-5 | 12 | 26.7 |
| 6-10 | 23 | 51.1 |
| 11-15 | 10 | 22.2 |

Results showed that mothers' overall level of knowledge about thalassemia had significantly increased post intervention ($t=96.75$, $P=0.000$) compared with the pre-intervention results. The overall knowledge score ranged from 34 to 49 with a mean of 45.11 points. The average of correct scores overall knowledge pre-test was 7(15%) and post-test 40 (89%). Significant improvements in mothers' knowledge scores were observed on all subscales of the knowledge scale. These included: the "Causes and risk factors" ($t=91.83$, $P=0.000$) the average of correct scores pretest 9 (20%) and post-test 36(80%). Regarding results of the subscale "Signs, symptoms and complication of thalassemia" it was ($t=85.34$, $P=0.000$); the average correct scores pre-test was 8 (18%) and post-test 38 (84%). The subscale "Diagnoses of thalassemia" ($t=12.73$, $P=0.000$), the average of correct scores pre-test was 15 (33%) and post-test 39 (87%). The management of thalassemia" subscale had ($t=38.62$, $P=0.000$); the average of correct scores pre-test 7 (15%) and post-test 34 (76%). "The prevention of thalassemia" subscale had ($t=35.46$, $P=0.000$) the average of correct scores pre-test 12 (27%) and post-test 39 (87%).

Results of all subscales regarding mothers' knowledge after the post-test was in the good range scales which ranged between 34-50 points. Results showed that care practices of mothers have also improved significantly post intervention ($t=104.99$, $P=0.000$) compared with the pre-intervention results. The overall care practice scores ranged from 8 to 11 with a mean of 9.91. The average of correct scores in the pre-test was 5 (11%) and in the post-test was 39 (87%). Results of the mothers' care practices after post-test located in the good range scales 8-11 points. Table 2-

Table (2) Mothers' knowledge and care practices regarding thalassemia pre/post program implementation (n=45)

| Items | Pre-program Mean \pm SD | Post-program Mean \pm SD | Paired t-test | P-value |
|--------------------------------------|------------------------------|-------------------------------|------------------|---------|
| Total knowledge | 27.78 \pm 8.079 | 45.11 \pm 3.128 | 96.75 | 0.000 |
| Knowledge on Thalassemia | | | | |
| Causes and Risk factors | 9.40 \pm 2.973 | 15.58 \pm 1.138 | 91.83 | 0.000 |
| Signs, symptoms and complication | 5.244 \pm 2.2978 | 7.42 \pm 0.583 | 85.34 | 0.000 |
| Diagnoses | 1.73 \pm 0.809 | 3.76 \pm 1.979 | 12.73 | 0.000 |
| Management | 9.31 \pm 2.898 | 14.04 \pm 2.440 | 38.62 | 0.000 |
| Prevention methods | 2.36 \pm 1.384 | 4.44 \pm 0.841 | 35.46 | 0.000 |
| Care practice (overall score) | 4.36 \pm 1.667 | 9.91 \pm 0.63325 | 104.99 | 0.000 |

Results showed no significant association of mothers' levels of knowledge or care practices with their socio-demographic characteristics, Table 3 and Table 4.

| Table 3. Association between Socio-demographic Characteristics and Mothers' Knowledge at pre and post test | | | | | | |
|--|-------------|---------|------|-------------|---------|------|
| Socio-demographic characteristics | Knowledge | | | | | |
| | Pretest | | | Posttest | | |
| | Poor | Average | Good | Poor | Average | Good |
| Age | | | | | | |
| 20-29 | 7 | 3 | 1 | 0 | 0 | 11 |
| 30-39 | 13 | 3 | 4 | 0 | 2 | 18 |
| 40-49 | 5 | 5 | 2 | 0 | 0 | 12 |
| 50-60 | 2 | 0 | 0 | 0 | 0 | 2 |
| $X^2(P\text{-value})$ | 70.8 (0.61) | | | 23.3 (0.89) | | |
| Marital status | | | | | | |
| Married | 23 | 10 | 7 | 0 | 2 | 38 |
| Divorced | 0 | 2 | 0 | 0 | 0 | 2 |
| Widow | 3 | 0 | 0 | 0 | 0 | 3 |
| $X^2(P\text{-value})$ | 37.5 (0.90) | | | 20.2 (0.57) | | |
| Region of living | | | | | | |
| South | 4 | 7 | 4 | 0 | 2 | 13 |
| North | 15 | 1 | 0 | 0 | 0 | 16 |
| Middle | 8 | 3 | 3 | 0 | 0 | 14 |
| $X^2(P\text{-value})$ | 58.0(0.18) | | | 27.7 (0.18) | | |

| | | | | | | |
|--------------------------|--------------|---|---|-------------|---|----|
| Educational level | | | | | | |
| Primary | 6 | 3 | 1 | 0 | 1 | 9 |
| Secondary | 4 | 3 | 1 | 0 | 1 | 7 |
| High school Certificate | 6 | 2 | 2 | 0 | 0 | 10 |
| Diploma degree | 4 | 0 | 2 | 0 | 0 | 6 |
| Bachelor degree | 4 | 2 | 1 | 0 | 0 | 7 |
| Post-graduate Diploma | 1 | 0 | 0 | 0 | 0 | 1 |
| Master | 2 | 1 | 0 | 0 | 0 | 3 |
| $X^2(P\text{-value})$ | 131.0 (0.86) | | | 66.3 (0.46) | | |
| Occupation | | | | | | |
| Employed | 12 | 6 | 3 | 0 | 0 | 21 |
| Not employed | 14 | 5 | 4 | 0 | 2 | 22 |
| $X^2(P\text{-value})$ | 51.0 (0.43) | | | 22.0 (0.45) | | |
| Income | | | | | | |
| < 200 | 3 | 4 | 2 | 0 | 1 | 8 |
| 200-299 | 6 | 3 | 2 | 0 | 1 | 10 |
| 300-399 | 6 | 0 | 0 | 0 | 0 | 6 |
| 400-499 | 4 | 1 | 2 | 0 | 0 | 7 |
| 500-1000 | 6 | 3 | 2 | 0 | 0 | 11 |
| Above 1000 | 1 | 0 | 0 | 0 | 0 | 1 |
| $(P\text{-value}) X^2$ | (0.69) 116.0 | | | 46.5 (0.78) | | |
| Sex of child | | | | | | |
| Male | 12 | 6 | 6 | 0 | 2 | 22 |
| Female | 15 | 5 | 1 | 0 | 0 | 21 |
| $X^2(P\text{-value})$ | 43.0 (0.74) | | | 10.8 (0.97) | | |
| Age (child) years | | | | | | |
| 1-5 | 8 | 3 | 1 | 0 | 0 | 12 |
| 6-10 | 13 | 6 | 4 | 0 | 2 | 21 |
| 11-15 | 6 | 2 | 2 | 0 | 0 | 10 |
| $X^2 (P\text{-value})$ | 52.0 (0.38) | | | 20.9 (0.52) | | |

| Table 4. Association between Socio-Demographic Characteristics and Mothers' Practice at pre and post test | | | | |
|---|-------------|-----------|-------------|-----------|
| Socio-demographic characteristics | Practice | | | |
| | Pre-test | | Post-test | |
| | Unsatisfied | Satisfied | Unsatisfied | Satisfied |
| Age | | | | |
| 20-29 | 11 | 0 | 0 | 11 |
| 30-39 | 20 | 0 | 0 | 20 |

| | | | | |
|--------------------------|-------------|---|-------------|----|
| 40-49 | 11 | 1 | 0 | 12 |
| 50-60 | 2 | 0 | 0 | 2 |
| $X^2 (P\text{-value})$ | 15.0 (0.81) | | 15.9 (0.06) | |
| Marital status | | | | |
| Married | 39 | 1 | 0 | 40 |
| Divorced | 2 | 0 | 0 | 2 |
| Widow | 3 | 0 | 0 | 3 |
| $X^2 (P\text{-value})$ | 13.0 (0.50) | | 5.7 (0.45) | |
| Region of living | | | | |
| South | 15 | 0 | 0 | 15 |
| North | 16 | 0 | 0 | 16 |
| Middle | 13 | 1 | 0 | 14 |
| $X^2 (P\text{-value})$ | 19.2(0.15) | | 6.7 (0.34) | |
| Educational level | | | | |
| Primary | 10 | 0 | 0 | 10 |
| Secondary | 8 | 0 | 0 | 8 |
| High School Certificate | 10 | 0 | 0 | 10 |
| Diploma | 6 | 0 | 0 | 6 |
| Bachelor | 6 | 1 | 0 | 7 |
| Post Graduate Diploma | 1 | 0 | 0 | 1 |
| Master | 3 | 0 | 0 | 3 |
| $X^2 (P\text{-value})$ | 30.6 (0.90) | | 19.2 (0.37) | |
| Occupation | | | | |
| Employed | 21 | 0 | 0 | 21 |
| Not employed | 23 | 1 | 0 | 24 |
| $X^2 (P\text{-value})$ | 6.8 (0.94) | | 7.0 (0.32) | |
| Income | | | | |
| < 200 | 9 | 0 | 0 | 9 |
| 200-299 | 11 | 0 | 0 | 11 |
| 300-399 | 6 | 0 | 0 | 6 |
| 400-499 | 7 | 0 | 0 | 7 |
| 500-1000 | 10 | 1 | 0 | 11 |
| Above 1000 | 1 | 0 | 0 | 1 |
| $X^2 (P\text{-value})$ | 25.5(0.87) | | 19.5 (0.19) | |
| Sex of child | | | | |
| Male | 24 | 0 | 0 | 24 |
| Female | 21 | 0 | 0 | 21 |
| $X^2 (P\text{-value})$ | 12.9 (0.53) | | 8.3 (0.21) | |
| Age (child) years | | | | |
| 1-5 | 12 | 0 | 0 | 12 |
| 6-10 | 22 | 1 | 0 | 23 |
| 11-15 | 10 | 0 | 0 | 10 |
| $X^2 (P\text{-value})$ | 8.6 (0.85) | | 8.7 (0.19) | |

Scale of overall knowledge level among mothers:

| | Poor 0 – 16 points | Average 17 - 33 | Good 34 - 50 |
|------------------------------------|-------------------------------------|----------------------------------|-------------------------------|
| Number of mothers per-test | 27 (60%) | 11 (25%) | 7 (15%) |
| Number of mothers post-test | 3 (7%) | 2 (4%) | 40 (89%) |

Scale of subscales knowledge level among mothers

| | Poor 0-16 | | Average 17-33 | | Good 34-50 | |
|---|----------------------------|------------------|--------------------------------|-----------------|-----------------------------|-----------------|
| Number of mothers (45) | Pre test | Post test | Pretest | Posttest | pretest | Posttest |
| Causes and Risk factors | 26 (58%) | 3 (7%) | 10 (22%) | 6 (13%) | 9 (20%) | 36 (80%) |
| Signs, symptoms and complication | 25 (55%) | 4 (9%) | 12 (27%) | 3 (7%) | 8 (18%) | 38 (84%) |
| Diagnoses | 23 (51%) | 4 (9%) | 7 (16%) | 2 (4%) | 15 (33%) | 39 (87%) |
| Management | 30 (67%) | 9 (20%) | 8 (18%) | 2 (4%) | 7 (15%) | 34 (76%) |
| Prevention | 29 (64%) | 2 (4%) | 4 (9%) | 4 (9%) | 12 (27%) | 39 (87%) |

Scale of practices level among mothers

| | Poor 0 – 3 points | Average 4 - 7 | Good 8 – 11 |
|----------------------------------|------------------------------------|--------------------------------|------------------------------|
| Mothers' pre test scores | 32 (71%) | 8 (18%) | 5 (11%) |
| Mothers' post test scores | 2 (4%) | 4 (9%) | 39 (87%) |

The above scales showed that the overall knowledge of mothers and subscales regarding thalassemia during the pretest was located in the poor range according to knowledge scales test 0-16 points, and the majority of mothers' care practices was located in the poor range according to practices scales test of 0-3 points. In the post-test, the majority of mothers' overall knowledge and subscales regarding thalassemia was located in the good range according to knowledge scales test 0-16 points and the majority of mothers' care practices are located in the good range according to the practice's scales test of 0-3 points.

Discussion

The aim of this study was to evaluate the effectiveness of an educational program regarding thalassemia in Jordan. Participants' characteristics, age distribution in the current study showed that 51.1% of children were between 6-10 years with a mean age of 7.8 ± 5.0 years. There was a slight male predominance to females (53.3% vs. 46.7%). These results were in line with studies done by Al-Kherbash et al and Qadir et al who found that most of children in their studies were between the ages of 6-10 years with male predominance to females.^{10,11} These results could also be explained by the high number of male children who participated in the current study.

Findings of our study identified significant improvements in the mothers' knowledge scores on all subscales of the knowledge scale post implementation. The overall knowledge ($t=96.751$, $P=0.000$) and the average of correct scores in the post-test were in the good zone range 40 (89%). Regarding the knowledge in the subscales; the "Causes and risk factors" ($t=91.83$, $P=0.000$); 36 (80%) of mothers fell in the good zone in the post-test. "Signs, symptoms and complications of thalassemia" ($t=85.34$, $P=0.000$); 38 (84%) of mothers' knowledge regarding symptoms and complications responded correctly with scores that fell in the good range zone. Post-implementation results also showed significant improvement in the mean scores of thalassemia knowledge among mothers regarding causes and risk factors, signs, symptoms and complications. These results were in line with Qadir and Hussein (2012) who reported improvements in mothers knowledge about meaning of thalassemia, causes; signs symptoms and complications; and iron complications after face to face education, which achieved positive effects on awareness of mothers regarding knowledge of thalassemia.¹¹ Current study showed significant improvement post implementation of program ($p=0.00$) $P\text{-value} \leq 0.05$. "Diagnoses of thalassemia" ($t=12.73$, $P=0.000$); the average of correct scores in the post-test that fell in the good range zone were 39

(87%) compared to only 15 (33%) of mothers were in the good range zone in the pre-test. "The management of thalassemia" ($t=38.62$, $P=0.000$); the average of correct scores in the post-test in the good range zone were 34 (76%) compared to 7 (15%) in the pre-test. Regarding the subscale "The prevention of thalassemia", 39 (87%) of females answered correctly and their scores fell in the good range zone, and an association of ($t=35.46$, $P=0.000$). Results also showed significant improvement in the mean scores of thalassemia knowledge among mothers regarding diagnosis of thalassemia post implementation of the educational program. These findings are consistent with findings of a study done by Qadir and Hussein (2012) which reveals that mean scores for knowledge of diagnosis and management among mothers in their study improved pre/post program ($X=9.06/15.7$). Current study ($P=0.00$) $P\text{-value} \leq 0.05$ significant improvement post implementation of educational program.

According to mothers' care practices of their thalassemic children, the current study revealed a significant improvement in the level of the mothers' care practice after the conduction of the educational program. The total average practices percentage score pre-test 32(71%) located in the poor range scales 0-3 points. While post-test 39 (87%) it is located in a good range scales 8-11 points. These findings are consistent with findings of other studies from developing countries that also reported improvement in knowledge and care practice of thalassemic children.^{8,11} A study conducted in Iraq to improve mothers' knowledge and practices of thalassemic children using Desferal therapy on the importance of Desferal administration after blood transportation, its complications and side effects, the study revealed that mothers' knowledge and practices regarding Desferal therapy in the study group improved post intervention.¹¹ Elsayed and Hussein conducted a study in Egypt to evaluate the effectiveness of an educational intervention on maternal management of children with β -thalassemia regarding mothers' knowledge, maternal management of Desferal, serum ferritin level and length of hospitalization; their findings revealed that after the program implementation, a remarkable improvement in mothers' level of knowledge and practice was observed. They found mothers' knowledge improve after one month in 78%, and 68.4% retained it after three months of the education program. For example, knowledge in the area of causes and prognosis of the disease has improved from 36.84 % at the pretest to 94.74% immediately and after three months. Post intervention, mother's knowledge regarding the amount of iron in the body has improved significantly to 97.4% and the administration of Desferal improved to 97.4%. The authors conclude β -thalassemia requires prolonged regimen of

management and care. For the care to be effective, mothers and children need continuous support, understanding, and frequent interview to reinforce the positive behavior and keep refining their knowledge through educational intervention. Premarital counseling is highly needed, social and professional support is highly recommended.⁸

Results showed no significant association between mothers' levels of knowledge and care practices and their socio-demographic characteristics. These results indicated that the health education program about the disease of thalassemia should target all mothers of thalassemic children in Jordan regardless of their different socio-demographic characteristics.

Conclusion and recommendations

This was the first study that introduced and implemented an educational program on thalassemia for mothers of thalassemic children in Jordan. The health education program regarding knowledge and care practice that was conducted in the three thalassemia centers showed a significant impact in the form of a remarkable increase in the mothers' level of knowledge and care practices. It is therefore highly recommended that we implement similar health education programs at the other thalassemia centers in Jordan for mothers of thalassemic children. It is also recommended to advocate for this health education program to be broad casted through social and mass media. This study recommends that health care professionals need to support and empower mothers and provide them with the appropriate and effective options to make their own decisions regarding the care practices of their children with thalassemia.

Acknowledgements

We would like to thank all the associated personnel in any reference that contributed in the research. Special thanks to the Department of Community Health Nursing and all the patients who participated in the study.

Conflict of interest: None declared

References

- Sharma S, Seth B, Jawade P, Ingale M, Setia M. Quality of life in children with thalassemia and their care givers in India. *Indian J Pediatr*. 2017;84(3):188-194. 1.
- Bernadette Modell a MDa. Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*. 2008; 86(6):417-496. 2.
- Abolghasemi H, Amid A, Zeinali S, et al. Thalassemia in Iran Epidemiology, Prevention, and Management *J Pediatr Hematol Oncology*. 2007;29(4):233-238. 3.
- Bashir N, Barkawi M, Sharif L, Momani A, Gharaibeh N. Prevalence of hemoglobinopathies in north Jordan. *Trop Geogr Med* 1992;44(1-2):122-125. 4.
- Hamamy H, Al-Hait S, Alwan A, Ajlouni K. Jordan: communities and community genetics. *Community Genetic journal* 2007;10(1):52-60 ,35, 99, 267-273. 5.
- Jordanian Ministry of Health. Number of thalassemia in Jordan. [Online] Available at <http://www.moh.gov.jo/MOH> [Accessed 18th August 2018]. 2018. 6.
- Mrayyan M, Al-Omary O, Saber A. Jordanian families' attitudes toward thalassaemia and genetic counseling. *The Medical and Biologic Journal*. 2004;31(1):67-73. 7.
- Elsayed E, Hussein A. The Effectiveness of An Educational Intervention on Maternal Management of Children With Beta Thalassemia *Alexandria Journal of Pediatrics*. 2002;16(2):251-258. 8.
- Kozier., Erb's. Fundamental of nursing care patients process and practices. *Upper Saddle River New Jersey: Julie Levin Alxandar*. 2008. 9.
- Al-Kherbash HA, Al-Awdi A, Hasan NS. Pattern and clinical profile of thalassemia among pediatric patients attending the Yemeni Society Centers for Thalassemia and Genetic Blood Disorders in Yemen *Hala The Scientific Journal of Al-zhar Medical Faculty, Girls*. 2018;1(2):43-56. 10.
- Qadir K, Hussein K. Effectiveness of an educational health programme on mothers' knowledge and practices of thalassaemic children receive desferal therapy in Hawler thalassemia center therapy center//Erbil City Erbil City. *Zanco J Med Sci*. 2013;17(1): 357-362. 11.
- 12 Saxena, A., M. Sharif, et al. (2017). "Knowledge, practice and experiences of parents with a thalassemic child." *International Journal of Contemporary Pediatrics* 4(5): 1630-1633.