Knowledge and practices among Mothers about Care of their children with Beta Thalassemia Major: A descriptive Study

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Abstract

Background: Thalassemia is a major health problem in Jordan that requires extensive attention and management. **Aim of the study:** to assess the current knowledge and care practices of mothers of thalassemia children about thalassemia. **Design:** A descriptive design was used. **Subjects**: A purposive sample of mothers with thalassemic children (45 mothers) was used. **Tools:** A structured questionnaire to assessed demographic data, knowledge, and care practices of mothers regarding thalassemia. **Results:**The majority of mothers had low levels of knowledge regarding thalassemia and the majority practiced the administration of Desferal tablets incorrectly. No significant association was found between knowledge and care practices of mothers and their socio-demographic characteristics. **Conclusion:** Jordanian mothers of thalassemic children do not have adequate knowledge on thalassemia and their practice towards their children in dealing with thalassemia was very poor. **Recommendations**: Health education programs on knowledge and care practices about thalassemia be introduced for mothers of thalassemic children in every public hospital in Jordan.

Keywords: Knowledge, Care Practices, Thalassemia**.**

Introduction

Thalassemia is the most common hereditary disease in the World. It is estimated to affect up to 270 million people Worldwide,15 to 25 million of them in the Mediterranean area (Kountouris et al., 2014; Ladis, Karagiorga-Lagana et al., 2013). Beta thalassemia accounts for 50,000 to 100,000 deaths per year of all deaths of children under 5 years in low or middle income countries (Agarwal et al., 2019). In Jordan, beta thalassemia is one of the major inherited disorders, with the carrier rate for the disease estimated at 24%. High consanguinity marriages are the most common contributing factor to the high incidence of beta thalassemia and other genetically determined recessive disorders in Jordan(Abdalla et al., 2011).

Since no effective treatment exists for beta thalassemia and affected individuals require continuous care including regular blood transfusion, this can represent a major financial and psychological load on the patients and their families, in addition to the challenges introduced onto the national healthcare system (Sadiq et al,2001). In Jordan, more than 1500 cases of beta thalassemia major were recorded in the year 2018 (JMOH,2018). The birth

incidence for beta thalassemia is about 1 in 2500 live birth and since the birth rate in Jordan is around 200,000 births annually, this would add around 80 new cases of beta thalassemia every year. The cost of treatment was estimated at around 4.5 million dollars every year (Hamamy and Al-Hait,2017).

In order to address the needs of patients with thalassemia and reduce the rate of affected individuals, Jordanian Ministry of Health has introduced a national obligatory premarital screening for beta thalassemia, in 2007. Once the couples are screened, they are offered genetic counseling, explaining the results of the test and the available options with more rigorous management in cases where both individuals might be carriers for beta thalassemia. Creating awareness and educating parents proved to be cost-effective in the prevention of the disease and improvement of quality of life of patients with thalassemia (Saxena et al,2017).

Previous studies revealed that mothers of children with thalassemia have demonstrated lack of knowledge about the occurrence of thalassemia, genetic issues, and caring for children living with thalassemia (Prasomsuk et al,2007). Ghazanfari et al,2010 also argued that parents of thalassemic children have poor knowledge about the nature of the disease and high educational needs. The knowledge gap about thalassemia was described by the parents as a major source of frustration (Liem et al,2011).

Nurses play a critical role in managing the quality of life of patients with thalasemia by helping to prevent unnecessary complications and providing treatment aimed at minimizing interference with the demands of the daily life. This includes e.g. instructing the patient and their family about the detection and reporting the serious symptoms such as fever or pain, clarifying the importance of cleanliness and encouraging interaction with other health professionals (Azize et al., 2015)

Significance of the study

Despite the fact that thalassemia is a major health problem in Jordan that challenges children, parents and health care system, no studies have addressed the need for knowledge and concerns raised by parents regarding their thalassemic children in Jordan. Since the incidence of this disease is increasing in Jordan, it requires extensive attention and management (Mrayyan et al, 2004; Hamamy and Al-Hait,2017).

Aim of the study

To assess knowledge and care practices of mothers of thalassemic children in Jordan

Research questions

1.What are the levels of mothers' knowledge about thalassemia?

2.What are the levels of mothers' care practices for their children with thalassemia?

3.Is there an association of the knowledge and care practices of mothers with their socio-demographic characteristics?

Subjects and Methods

Research Design:

A descriptive cross-sectional design was utilized in this study.

Setting:

The study was conducted in the main public hospitals located in the three regions of Jordan. Three public hospitals were selectively sampled based on presence of thalassemia center in each one.

Subjects:

The number of children with thalassemia who were registered and attended the selected centers was 4 child. All these children were approached and invited to participate in the study.

Tools of data collection:

1. A structured standardized questionnaire (Jordanian association of thalassemia, 2016).

The questionnaire consisted of two sections; the first section consisted of14 items exploring the demographic data of the participant mothers and their children. The second section consisted of 50 items that evaluated mother's knowledge regarding thalassemia disease.

Responses to knowledge questions include 'True', 'Not sure', and 'False'. The total knowledge score ranged from 0 to 50, higher scores indicated better thalassemia knowledge. Each correct response was given 1 point and added to the total knowledge score. The knowledge level was considered «poor» if the correct answers ranged between 0-16 points while it was considered «average» if the answers were between 17-33 points and «good» if answers ranged between 34-50 points.

Completed questionnaires were collected by research assistants in each hospital whom were previously trained on filling in the questionnaire and on communication with the patients.

2.Observatory checklist.

Mothers' care practices were assessed by an observation checklist(kozier,2008) that consisted of 11 steps to assess the practices related towards the care provided to their sick children including the method for administration of Desferal tablet. Each item in the observation checklist was classified into two points «done» and «not done», if the mother performed the steps correctly, it was scored one point, and it was scored zero if incorrectly done or not done at all. The total care practices scores ranged from 0 to 11. The higher the total practice score the better the thalassemia care practices. According to the actual practice for each study subject, it was categorized into unsatisfiable 0-3 points and satisfiable 8-11points.

Tools validity and reliability

To achieve the criteria of trustworthiness of the tools of data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability. Face and content validity are tested by five experts (faculty members in the field of nursing=3 and medicine =2) Mutah university and Jordan university science and technology.

- The questionnaire was read, explained and choices were recorded by the researcher. The consumed to fill out the questionnaire sheet ranged from10 to 15 minutes, so the collection of the data ranged from 4 to 6 caregivers weekly.

- Data collection lasted for six months, from 3September to 4 March 2018.
- Questionnaire and checklist was applied at 5 mothers with their children before assessment intervention study.

Field Work

Assessment data were collected from3September to 4 March 2018. The intervention of assessment for mothers of children with thalassemia who come for health care in three governmental hospitals, selectively sampled from the three regions of Jordan, South AL-karak Government hospital, Middle AL-Bashir Government hospital, and North, Rahma Teaching Hospital based on the availability of thalassemia management center in each one. The children and their mothers used to come to thalassemia center either for blood transfusion or hematological assessment of serum ferritin and hemoglobin level. During this visit they were interviewed in groups of 4-6 children and mothers. The needed information and explanations were provided to mothers by the assistant researchers, and then a written consent for participation was obtained from each mothers. Which included letter for the mothers therefore the purpose of this study is to introduce an assessment the knowledge and care practices for mothers of thalassemia children in Jordan this will allow mothers to participate in their children's care at home and during hospitalization. They were asked to fill out the two parts of the questionnaire or the researcher fills it for them if they can't write. Data was collected through interviews using a standardized structured questionnaire.

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.

Ethical considerations:

The study was approved by the AlNeelain Institutional Review Board (IRB) in Sudan and the Ministry of Health in Jordan. Research assistants consented the mothers before enrolling them in the study. Mothers were assured that participation is voluntary and they could withdraw from the study at any time without giving any reason. **Data analysis**

Data was analyzed by SPSS 16 software using descriptive analytic methods. Frequencies and percentages were used to describe the socio-demographic characteristics of participants. Chi-Square was used to test the association between demographic variables and the knowledge and practice domains.

Result:

Table (1): illustrates that 44.4% of mothers were between 30 to 39 years old with mean age of 35.7y, ±13.3, 88% were married, 53.3% had monthly income less than 400 JD, 62.3% had low level of education, 53% were not employed and 28.9% governmental employment. The mean age of the thalassemic children was 7.8y ±5.0, 53.3% of them were males, and 51.1% were between 6-10 years old.

Table (2): show poor knowledge level of thalassemia among participant mothers on the overall knowledge scale and subscales. The overall knowledge score ranged from 11 to 43 with a mean of 27.78.The average of correct score knowledge (15.6%)and subscale knowledge (21.50%). Mothers have poor

knowledge regarding causes, risk factors, signs, symptoms, complication, and management of thalassemia.

Table (3):show high percentages of mothers practicing the administration of the Desferal incorrectly .The majority (69%) did not check medication expired date, 98% did not clean their hands correctly, 93% did not check Creatinine level before and after medication, 71% did not observe side effect of medication example abdominal pain, diarrhea, nausea, vomiting, disturbance in hearing and vision, 98% did not give medication by 30 minutes before eating at empty stomach and should not crashed or swelled. 96% did not give medication at the same time daily.Results show that 71% of mothers had poor scores on the care practice scale.

Table (4): show no significant association between socio-demographic characteristics of mothers and the overall level of the knowledge scale about thalassemia (χ^2=70.8, *P*=0.61) or subscales (χ^2= 22.12,*P*=0.442), and no significant association between socio-demographic characteristics of mothers and the overall care practices score of Desferal tablets administration (χ^2=15.0,(*P*=0.81).

Table 1. Socio-demographic characteristics of mothers (n=45) and children (n=45)		
Variables	**N**	**%**
Age of mothers (years)		
20-30	11	24.4
30-40	20	44.4
40-50	12	26.7
50- <60	2	4.4
Marital status		
Married	40	88.9
Divorced	2	4.4
Widow	3	6.7
Place of living		
South of Jordan	15	33.3
North of Jordan	15	33.3
Middle of Jordan	15	33.3
Level of education		
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 occupation		
Employed	21	47
Not employed	24	53
Employment		
Governmental	13	28.9
Private	8	17.8
Self employed	3	6.7
Unemployed	21	46.7
Monthly income (Jordanian Dinar)		
below 200	9	20.0
200-300	11	24.4
300-400	6	13.3
400-500	7	15.6
500-1000	11	24.4
1000 <2000	1	2.2
Age of child (years)		
1-5	12	26.7
5-10	23	51.1
10-15	10	22.2

Table 2. Mothers' level of knowledge about thalassemia (n=45)			
	Poor 0-16	**Average 17-33**	**Good 34-50**
Overall scale	27(60%)	11(25%)	7(15%)
Subscales			
Causes and Risk factors	26(58%)	10(22%)	9(20%)
Signs, symptoms and complication	25(55%)	12(27%)	8(18%)
Diagnoses	23(51%)	7(16%)	15(33%)
Management	30(67%)	8(18%)	7(15%)

Prevention	29(64%)	4(9%)	12(27%)

Table 3. Mother's care practices about Desferal tablet administration (n=45)

Questions	Correct		Incorrect	
	N	%	N	%
1-Check medication and expired date	14	31	31	69
2-Perform hand hygiene	1	2	44	98
3-Check for serum Ferritin level before and after medication	36	80	9	20
4-Check for creatinine level before and after medication	3	7	42	93
5-Medication should be given when the serum ferritin levels is more than 1000mg/ml or after taken 20 packed cells of blood	29	64	16	36
6-Medication given only one tablet daily by doctor order (dose 125mg, 250mg, 500mg)	31	69	14	31
7-Observe side effect of medication example (abdominal pain, diarrhea, nausea, vomiting, disturbance in hearing and vision.	13	29	32	71
8-Medication given by 30 minutes before eating at empty stomach and should not crashed or swelled	1	2	44	98
9-Medication given at the same time daily	2	4	43	96
10-Medication dissolved in 100-200 ml of water or orange juice	40	89	5	11
11-Vitamin C and E should be given with medication	30	67	15	33

Table 4.Association between Socio-demographic characteristics and Knowledge and practice of mothers

Socio-demographic characteristics	Knowledge				Practice		
	Poor	Average	Good	X^2 (*P-value*)	Unsatisfied	Satisfied	X^2 (*P-value*)
Age				70.8			15.0
20-30	7	3	1	(0.61)	11	0	(0.81)
30-40	13	3	4		20	0	
40-50	5	5	2		11	1	
50-60	2	0	0		2	0	
Marital status				37.5			13.0
Married	23	10	7	(0.90)	39	1	(0.50)
Divorced	1	2	0		2	0	
Widow					3	0	
Region of living	4	7	4	58.0	15	0	19.2
South				(0.18)			(0.15)
North	15	1	0		16	0	
Middle	8	3	3		13	1	
Educational level				131.0			30.6
Primary				(0.86)			(0.90)
	6	3	1		10	0	
Secondary	4	3	1		8	0	
High school	6	2	2		10	0	
Diploma	4	0	2		6	0	
Bachelor	4	2	1		6	1	
Post diploma	1	0	0		1	0	
Master	2	1	0		3	0	
Occupation				51.0			6.8
Employed	12	6	3	(0.43)	21	0	(0.94)
Not employed	14	5	4		23	1	
Income				116.0			25.5
< 200	3	4	2	(0.69)	9	0	(0.87)
200-299	6	3	2		11	0	
300-399	6	0	0		6	0	
400-499	4	1	2		7	0	
500-1000	6	3	2		10	1	
Above 1000	1	0	0		1	0	
Sex of child				43.0			12.9
Male	12	6	6	(0.74)	24	0	(0.53)
Female	15	5	1		21	0	
Age (child) years		3	1	52.0	12	0	8.6
1-6	8			(0.38)			(0.85)
6-10	13	6	4		22	1	
10-15	6	2	2		10	0	

Discussion

The aim of this study was to assess the knowledge and care practices of mothers of thalassemic children in Jordan.

The finding of the present study showed that most of the mothers' age ranged from 30-39 years. These results were in line with findings of previous study about Thalassemia syndrome blood disease in

infancy and child hood (Benz et al,2003). Our results show that the Majority of the mothers (53.3%) had a monthly income of less than 400 JD which was considered as the low socio-economic class, 62.3% had low level of education, and 53% of them were not employed. These results were in line with a study about Chelation therapy for thalassemia, who also found that most mothers in his study were unemployed, belonged to the lower socioeconomic strata and had primary or secondary school which could explain the poor levels of knowledge among participant mothers (Picot,2007).

In the current study findings revealed poor levels of knowledge on thalassemia among mothers regarding causes, risk factors, signs and symptoms, complications, diagnosis and management of the disease. The average total score for knowledge among participants was15.6%. This poor knowledge could be explained due to the lack of health education programs dedicated to mothers of thalassemic children in the selected centers. Regarding causes and risk factors, the majority of mothers (77%) did not know that when both parents are carriers of thalassemia there is a 25% chance for the child to be thalassemic and (84%) did not know that if both parents are carriers of thalassemia, 50% of their babies will also carry gene but will not be thalassemic. This percentage seemed very high, in a study by(Arif et al, 2008) there was similar lack of knowledge among parents regarding transmission of thalassemia. On inquiring about antenatal screening, only 31% of mothers were aware of thalassemia being detected antenatally. This could be explained by the fact that in some countries much attention has been directed towards prevention of the disease and therefore people gained some knowledge on modes of transmission and detection. This result contradict the results of a study conducted by Ali et al in 2015 where it was found that 74% of parents were aware of antenatal detection of thalassemia.The importance of mothers' awareness regarding antenatal detection and prevention programs such as marriage counseling will decrease the number of thalassemic cases.

Regarding the findings related to signs, symptoms and complications of the disease, it was found that most mothers 55%poor knowledge and 18% good knowledge. Causes and Risk factors, it 58% of mothers poor knowledge where as 20% good knowledge. Diagnoses , 51% of mothers poor knowledge where as 33%good knowledge. Management,67% of mothers poor knowledge and 15%good knowledge. Prevention, 64% of mothers poor knowledge and 27%good knowledge These results are congruent with findings of a previous study in India (Saxena etal,2017). Saxena et al. found that the knowledge and awareness about thalassemia was inadequate among most participants in their study. They found that only 47.5% of parents were aware of thalassemia being a genetic disorder,45% of parents were aware of thalassemia being detected antenatally but many parents (55%) did not know any permanent cure for it.

Like previous studiesour findings revealed that more than half (62%) of mothers knew that blood transfusion should be given to thalassemic patients and only 78% knew the reason for Desferal tablet as a substance to get rid of excess serum ferritin and prevent complications of thalassemia. Saxena et al. in 2017 found that 57.5% of participants did not know the complications and side effects of chelation therapy. Arif et al. in 2008 also found that knowledge regarding Desferal

administration was present in 55% of the patient's parents but only 10.9% were receiving it adequately.

Results of the present study found inadequate knowledge (60%) and poor care practice (71.1%) among mothers of thalassemic children in Jordan. These findings are consistent with findings of other studies from developing countries that reported inadequate knowledge regarding beta thalassemia and its management among parents in general public which could negatively affect the health and safety of children with thalassemia (Saxena et al,2017; Arif et al, 2008; Basu, 2015). This could be explained as a result of the absence of structured educational programs for thalassemic patients and their guardians in Jordan. Basu in 2015 found only 14.02% had good practice towards thalassemia among participants and as a result and recommended awareness programs about management of thalassemia to be offered for general public (Basu,2015).

Study by Karimzaei et al,2015 investigated the knowledge of marring partners who were thalassmic genetic carriers in parents of birth of children with major thalassemia results shows that they believed knowledge increasing (40%),genetic counseling(33%) and premarital screening (27%) were the most important strategies for prevention of thalassemia. Current study regarding knowledge of prevention (64%) mothers answers located in the poor range scales. Mothers knowledge related thalassemia prevention very important mothers knowledge about strategies for prevention of thalassemia will decrease the number of thalassemia so that the important of conducted health educational program in the governmental hospital on the mother knowledge and care practices for thalassemic children in Jordan.

Conclusion

Parental awareness regarding various aspects of beta thalassemia is of great importance for the proper management of thalassemic children. It was obvious from the results obtained in this study that Jordanian mothers of thalassemic children did not have adequate knowledge on thalassemia and their practice was very poor towards the disease and more information was needed regarding the disease. The study highlighted the knowledge gap of Jordanian mothers about thalassemia. This could help in devising strategies to address these needs and help improve care practices of mothers for their thalassemic children at home and during hospitalization, an example of such strategies is to develop and implement a health education program for parents of thalassemic children in every public hospital in Jordan.

Recommendations

1. Introduce a health education programs on knowledge and care practices about thalassemia for mothers of thalassemic children in every public hospital in Jordan.

2. Further studies should be conducted with large sample in different settings to generalize the results

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Conflict of interest

No

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