Effect of Stepwise Program on Mothers' Care of their Children with Beta Thalassemia

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Abstract

Background: Beta-thalassemia stands as a prevalent variant of thalassemia among the children, presenting a substantial healthcare challenge necessitating specialized attention for both the affected children and their families. Therefore, this study **aimed** to investigate the effect of a stepwise program on mothers' care of their children with beta thalassemia. A pre-experimental design was employed for this study at the hematology outpatient clinic affiliated to Assiut University Children Hospital. The study involved a purposive sample comprising 115 mothers of children diagnosed with beta-thalassemia. Data collection utilized a structured interview questionnaire comprising four tools: the first part the children's characteristics and medical history, while the second part focused on the mothers' personal information. The subsequent tools assessed the mothers' knowledge, practices, and attitudes towards the management of beta-thalassemia. **Findings:** Post the implementation of the program, there was a notable enhancement observed in the mothers' knowledge, practices, and attitudes, with scores shifting from 12.0522±1.76140 to 23.1304 ± 6.05461, 9.0696 ± 3.66281 to 13.4087 ± 4.48955, and 2.9826 ± 1.41411 to 4.0957 ± 1.20652, respectively. **Conclusion:** The findings underscore the considerable efficacy of a stepwise program in augmenting mothers' knowledge, practices, and attitudes concerning the beta-thalassemia. It is **recommended that** the adoption of a stepwise program for mothers of children with thalassemia be implemented across all healthcare facilities catering to such patient populations.

Keywords: Stepwise Program, Mothers, Children and Thalassemia

Introduction:

Thalassemia,is a widely distributed genetic disorder, encompasses over 200 mutations related to β-thalassemia, the majority of which are uncommon. Around 80% of thalassemia instances globally are linked to approximately 20 prevalent alleles. The prevalence of carriers of the β-thalassemia gene is estimated at 3% across the world, while in Southeast Asia, the prevalence of carriers of the α-thalassemia gene ranges from 5% to 10%. In Egypt, thalassemia represents the primary form of chronic hemolytic anemia, constituting about 85.1% of cases. Based on a sample of 1,000 randomly selected individuals from various regions of Egypt, the estimated carrier rate ranges from 9% to 10.2% (**Ferraresi et al., 2023).**

Thalassemia can be divided into alpha and beta types. In the Mediterranean area, β-thalassemia is the predominant form, further distinguished as thalassemia major, thalassemia intermedia, or thalassemia minor. Thalassemia major typically emerges in early childhood, characterized by severe anemia requiring frequent red blood cell transfusions. In contrast, thalassemia intermedia presents as moderate anemia later in life and does not mandate regular transfusions. While some children may exhibit signs of moderate anemia, thalassemia minor generally remains asymptomatic (**Xiang et al., 2021).**

Beta thalassemia results from either the total absence (B0) or partial reduction (B+) of beta globin chains. This deficiency prompts a compensatory rise in the synthesis of Hb A2 and Hb F. The clinical severity observed in children with beta thalassemia major is influenced by the surplus of alpha globin chains. Conversely, children carrying one abnormal beta thalassemia gene (beta thalassemia minor) usually display negligible or no anemia and remain without symptoms **(Xie, et al., 2019).**

Thalassemia imposes a range of physical health consequences on impacted children, encompassing physical abnormalities, stunted growth, and postponed onset of puberty. These

outcomes, exemplified by skeletal distortions and reduced height, contribute to adverse self-perception and can culminate in critical conditions such as heart failure, irregular heart rhythms, liver disorders, hormonal imbalances, and heightened vulnerability to infections among children affected by thalassemia **(Fouad, et al., 2019).**

Progress in treatment modalities focuses on rectifying inadequate red blood cell production and balancing globin levels. Despite these advances, traditional methods such as blood transfusions and standard iron-chelation therapy persist as prevalent treatment strategies for beta-thalassemia. The routine administration of blood transfusions, coupled with the developmental irregularities linked to thalassemia, significantly influences the holistic well-being of afflicted children **(Wang et al., 2022).**

The treatment of thalassemia requires a coordinated effort from an inclusive multidisciplinary group. Consistency in specialized care and fostering a compassionate bond with each patient are enabled through the retention of a consistent primary physician. Dedicated nursing staff, coupled with ongoing oversight by specialists spanning disciplines such as hematology, endocrinology, cardiology, orthopedics, nutrition, ophthalmology, neurology, and psychology, are vital for delivering optimal care. Furthermore, imparting health education to caregivers in the home setting is imperative (**Angastiniotis, 2019).**

The engagement of mothers plays a pivotal role in the management and nurturing of children afflicted with thalassemia. Elevating the well-being of thalassemic children hinges on enhancing the understanding, perspectives, and behaviors of mothers concerning the condition. While at home, mothers should be prepared and motivated to participate in routine activities like playtime, meals, hygiene routines, storytelling, and providing emotional encouragement. Consistent monitoring is essential to avert complications, as the mother's ability to oversee and nurture her child significantly influences the child's progress and growth **(Punaglom, et al., 2019) & (Husain, et al.,2018) &** (**Elhalfawy, et al., 2017).**

Nurses play a critical role in devising effective educational programs for children and their caregivers. Disseminating knowledge regarding the pathology of the disease, its hereditary transmission, the significance of adherence to treatment, the administration of desferal using a subcutaneous pump at home, potential adverse effects, and their mitigation form integral components of patient education. Furthermore, educating patients and caregivers about anemia, its symptoms, impacts, management techniques, the necessity of blood transfusions, and handling their associated complications is paramount. Moreover, providing education on dietary considerations is essential given that β-thalassemia can lead to heightened gastrointestinal absorption of iron and consequent iron overload. Patients should steer clear of iron-rich foods like liver, leafy greens, grains, spleen, molasses, legumes, and nuts **(Atshan& Aziz., 2022).**

Significance of the study

Thalassemia is a prevalent factor in causing long-lasting hemolytic anemia in Egypt, leading to significant illness and death. According to **Rahman et al. (2019),** the estimated prevalence of β thalassemia carriers in Egypt is around 9-10% of the population.

Parenting children with beta thalassemia presents multiple challenges that require dedication, knowledge, and ongoing support. A systematic approach has been developed to help mothers improve their conduct by providing them with instructions on how to effectively manage their own lives. Training is employed as a potent method to enhance performance by leveraging previous experiences, knowledge, and abilities. The program not only imparts new abilities and knowledge, but also functions as a mentor to facilitate the application of acquired knowledge and skills, leading to improved performance. Preliminary evidence supports the program's efficacy in improving mothers' performance. Moreover, empower mother to attain the desired levels of goal attainment.

Aim of the Study

The study aimed to evaluate the effect of stepwise program on mothers' care of their children with beta thalassemia

This aim was achieved through this objectives:

1. Enhance knowledge: The stepwise program aimed to improve the understanding of

mothers regarding beta thalassemia, its management, and implications for their children's health.

2. Foster positive attitudes: The program seeked to cultivate positive attitudes among mothers towards the care and treatment of children with beta thalassemia.
3. Encourage best practices: The program aimed to instill best practices in mothers, equipping them with the necessary skills and confidence to effectively manage and support their children with beta thalassemia in daily life.

Research hypothesis:

(H0): The the stepwise program does not improve the knowledge, attitude, and reported practices of mothers of children with beta thalassemia.

(H1): The stepwise program is anticipated to enhance the knowledge, attitude, and practices of mothers of children with beta thalassemia.

Operational Definition:

Stepwise Program: It refered to a measurable assessment of the impact of a structured, incremental intervention program on the knowledge, attitudes, and practices of mothers in managing and supporting their children diagnosed with beta thalassemia.

Methods

Research design

This study employed a pre-experimental design.

Setting

The research was conducted at the pediatric hematology out-patient clinic and unit situated in Assiut University Children Hospital.

Subjects

The study involved a purposive sample of 115 mothers. These mothers had children who received a medical diagnosis of beta thalassemia and did not have mental retardation, congenital defects, impairments, or any other chronic disorders. The sample size was calculated using power analysis, taking into account the population flow rate, a confidence range of 95%, a precision level of 5%, and a p-value of < 0.05.

Tools of data collection:

Tool I: A Structured interview Questionnaire

The researchers produced it after conducting a thorough study of pertinent literature and consulting with specialists. The questionnaire comprised two parts:

Part I: Children' characteristics and history including age, gender, birth order, residence and duration of disease.

Part II: Personal data of mothers including age,marital status,residence, education level, occupation,family size,family relation between husbands and previous history of having child suffering from beta thalassemia.

Tool II: Knowledge assessment form: This questionnaire adapt from **(Biswas, et al., 2021)**. This form consisted of 9 questions: Definition of beta thalaseemia, risk factors, causes, early signs and symptoms, examinations made for the diseased child, complications, medications, side effects of medications used in treatment and prevention against beta thalaseemia.

The researchers analyzed the responses made by the mothers using a sheet of proper responses that they had produced. A score of 2 was allocated for an accurate response, 1 for a partial answer, and 0 for an incorrect answer. The overall knowledge score varied between 0 and 18. The knowledge scores were classified into three categories: good knowledge (75% and above), average knowledge (50% to < 75%), and poor knowledge (less than 50% of the total score).

Tool III: Health-related practices form: This questionnaire adapt from **(Khresheh & Brair., 2020)** contained six questions as (maintain regular medical appointments , administer medications as iron chelation therapy and folic acid supplementation, promote healthy lifestyle which includes a balanced diet, regular exercise, and sufficient rest , measuring weight , taking vital signs and emotional support of the child).

Two scores were given for a reported practice that was fully completed, one score for an incomplete answer, and zero for a practice that was not done. The scoring system categorized mothers' practices as satisfactory (60% and above) or unsatisfactory (less than 60% of the total score).

Tool IV: Concerned with mothers' attitude regarding to thalassemia adapt from **(SHUKR ,etal.,2011)** contained six questions that covered the reported attitude as concern about their children's present status and future vision, and a relationship child with a thalassemic person. According to the responses obtained from the studied mothers, each question scored three (3) for agree answer, each not sure answer scored two (2) and each not agree answer scored one (1). The total score of the questionnaire equals 18 grads that classified into positive when mothers' attitude was 75 % and more and negative when mothers' attitudes scored was less than 75 % of total scores.

Ethical Considerations

Prior to commencing the experiment, the research proposal obtained approval from the local Ethics Committee at Assiut University's Faculty of Nursing, bearing the identification number (1120240766). Prior to commencing data collection, the researchers provided the participating mothers with a comprehensive explanation of the study's objectives and aims, and obtained their verbal consent. The entire study process was done with a guarantee of secrecy. The researchers provided the participants with a guarantee that all obtained information would be treated as confidential and utilized only for the study's objectives. The participants were notified that their involvement in the study was entirely voluntary and they had the autonomy to withdraw at any point, without the need for justification.

Validity:

In order to establish the content validity of the form, a group of five professional academics who specialize in pediatric nursing and pediatrics hematology evaluated the tool's thoroughness and appropriateness. The content validity index, which quantifies the degree to which the tool accurately represents the intended material, was found to be 0.91.

Reliability

The tool's reliability was evaluated using Cronbach's Alpha test, resulting in a coefficient of 0.82. This suggests a strong degree of internal consistency among the elements in the tool.

Pilot Study

A pilot research was done using a sample size that represented 10% of the total individuals.Modifications were implemented, which involved revising certain questionnaire items and removing superfluous questions. The pilot study lasted for around one month, and mothers who took part in the pilot study were not included in the final study population.

Field Work

The researchers built the instructional program using pertinent literature. The objective of this initiative was to enhance the knowledge, practices, and attitudes of mothers with children diagnosed with beta thalassemia. The program was executed in four distinct phases in the hematology outpatient clinic associated with Assiut University Children Hospital, as outlined below:

Phase 1: The researchers initiated the program by engaging in interviews with the mothers of thalassemic children. The researcher introduced herself and provided an orientation and explanation of the program to gain the mothers' collaboration. The aim and objectives of the study were explained, assuring the mothers that their answers would remain confidential and used solely for scientific research purposes.

Data collection involved individual interviews and observations with the mothers. Background information was gathered, and the mothers' knowledge, attitude, and practices were evaluated using checklists filled out by the researcher. Data collection took place for two days per week using an Arabic questionnaire format.

Phase 2: The stepwise program was conducted over eight weeks, with two sessions per week. A total of 16 sessions were sequenced, each lasting between 45 to 60 minutes, including discussion periods. The program began with an introduction in the first session, followed by immediate feedback on the previous session. Simple language was used to ensure the mothers' understanding.

Phase 3: Various educational methods were used, including lectures, demonstrations, and re-demonstrations. The researchers prepared appropriate teaching aids, such as real

equipment, posters, and pictures, to cover the program's content and enhance the mothers' knowledge about thalassemia. The content covered topics such as the definition of beta thalassemia, risk factors, causes, early signs and symptoms, examinations for the affected child, complications, medications, side effects, and prevention against beta thalassemia. Sessions also aimed to improve the mothers' attitudes and practices, including maintaining regular medical appointments, administering medications (iron chelation therapy and folic acid supplementation), promoting a healthy lifestyle (balanced diet, regular exercise, and sufficient rest), measuring weight, taking vital signs, and providing emotional support to the child. The questions in the sessions included a combination of open-ended and closed-ended formats, and the mothers took approximately 30 to 45 minutes to complete them.

Phase 4: The program was evaluated two weeks after its implementation using the same pre-programming tool.

Statistical design

The data analysis was conducted utilizing the SPSS 20 statistical program. Quantitative and qualitative characteristics were described using descriptive statistics, including frequency, percentages, range, mean, and standard deviation. The data analysis involved the application of Chi-square and McNemar tests, using a significance level of P-value < 0.05 to determine statistical significance.

Results

Table (1):-Showed the studied children' characterictis and history. Finding revealed that (47.8%) of children were in the age group(8 < 12 years) with mean age at diagnosis was 1.19 ± 1.05. Also about two thirds (53%) of children were males. Regarding residence, (60%) of children were from rural area. Finally (54.8%) of children the length of hospital stay were from 4-7 days.

Table (2): Presents the studied mothers' personal data. It was found that 40.0% of studied mothers his aged ranged from 31-40 years age. Regarding their marital status 85.7% were married as well as 74.8% place of his residence were from rural areas. Additionally, 64.3 were don't read and write and 82.6% were house wives. 91.3% of the studied mothers had a family relation with their husbands. As well, 80% of the studied mothers reported no previous history of having child suffering from beta thalassemia

Table (3): Displays the acquired knowledge of the mothers involved in the study on beta thalassemia before and after the stepwise program. Statistically significant differences were observed in mothers' knowledge beta thalassemia before and after the stepwise program. The program led to a considerable improvement in mothers' knowledge.

Figure (1): Presents that there was highly statistically significant difference among mothers' knowledge regarding beta thalassemia in pre and post stepwise program in which in which 58.3% of mothers had poor knowledge pre program compared to only 7% post program.

Table (4): Demonstrates the studied mothers' practice regarding beta thalassemia pre and post stepwise program. It was found that there were highly statistically significant differences between mothers' practice regarding beta thalassemia in pre and post stepwise program ($p < 0.001$).

Figure (2): Presents that mothers had unsatisfactory practice regarding beta thalassemia in pre program 73% which became satisfactory in post program76.5%.

Table (5): presents an overview of the attitudes of the mothers studied regarding beta thalassemia before and after the stepwise program. The analysis revealed highly significant statistical variances in the mothers' attitudes toward beta thalassemia before and after the stepwise program ($p < 0.001$).

Table (6): demonstrates a direct and significant correlation between the levels of total knowledge scores and both practice and attitude. This correlation indicates that sufficient knowledge directly influences the attitudes and practices of the mothers.

Table (1): Distribution of the studied children' characteristics and history (N=115).

Characteristics	No.	%
Child age: (years)		
1 - < 8	23	20
8 - < 12	55	47.8
12– 18	37	32.2
Mean ± SD	13.21 ± 1.71	
Age at diagnosis: (years) Mean ± SD	1.19 ± 1.05	
Child gender:		
Male	61	53
Female	54	47
Child birth order:		
First	35	30.4
Second	30	26.1
Third	39	33.9
Fourth or more	11	9.6
Residence:		
Urban	46	40
Rural	69	60
Length of hospital stay: (days)		
1 day	19	16.5
2 or more	33	28.7
4-7days	63	54.8
Duration of disease: (years) Mean ± SD	14.03 ± 2.13	

Table (2): Distribution of the studied mothers' personal data (N=115).

Characteristics	No.	%
Age in years		
- ≤ 20-30 years	43	37.4
- 31-40 years	46	40.0
- ≥ 41 years	26	22.6
Mean ± SD	33.15±8.412	
Marital status		
- Married	98	85.7
- Divorced/ widow	17	14.8
Residence		
- Rural	86	74.8
- Urban	29	25.2
Mother education		
- Don't read and write	74	64.3
- Primary	17	14.8
- Secondary	10	8.7
- University education	14	12.2
Mother job		
- House wife	95	82.6
- Employee	20	17.4
Family size		
- <5	89	77.4
- 6-7	21	18.3
- ≥8	5	4.3
Mean ± SD	1.27 ± 0.535	
Family relation between husbands		
- Yes	105	91.3
- No	10	8.7
Previous history of having child suffering from beta thalassemia		
- Yes	23	20
- No	92	80

Table (3): Distribution of the studied mothers' knowledge regarding beta thalassemia pre and post stepwise program (N=115).

Items	Pre-program			post –program			Paired t test	P. value
	Correct	Incomplete	Wrong	Correct	Incomplete	Wrong		
	%	%	%	%	%	%		
1. Definition	4.3	10.4	85.2	51.4	18.3	30.4	0.209	0.025*
2. Risk factors	0.9	12.2	87.0	34.8	35.7	29.6	0.522	0.000**
3. Causes	0.9	11.3	87.8	31.3	48.7	20.0	0.251	0.007**
4. Signs and symptoms	3.5	0.9	95.7	51.3	24.3	24.3	0.013	0.000**
5. Examinations made for the diseased child	25.0	47.5	27.5	65.3	22.2	12.5	0.206	0.022*
6. Complications	1.7	3.5	94.8	42.6	31.3	26.1	0.322	0.037*
7. Managements	0.0	0.9	99.1	41.7	24.3	33.9	0.257	0.05*
8. Side effects of medications	35.0	45.0	20.0	79.5	10	10.5	0.054	0.008**
9. Prevention	11.3	14.5	74.2	77.4	12.2	13.4	0.154	0.003**
10. Equipment used at home for thalassemic patient	4.3	7.0	88.7	29.6	33.0	37.4	0.154	0.007**
11. Methods used at home for infected thalassemic patient	0.0	7.8	92.2	36.5	23.5	40.0	0.130	0.003**
12. Home care measures	0.9	5.2	93.9	47.8	26.1	26.1	0.113	0.009**

***Significant level at P value < 0.05**
**** Highly Significant level at P value < 0.001**

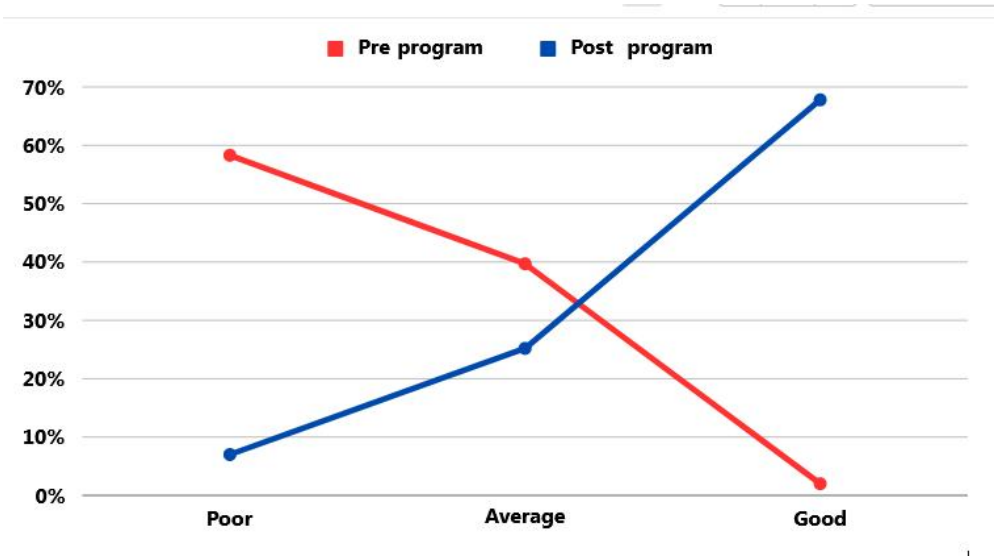

Figure (1): Total knowledge regarding beta thalassemia among studied children's mothers in pre and post program.

Table (4): Distribution of the studied mothers' practice regarding beta thalassemia pre and post stepwise program (N=115).

Items	Pre-program			post –program			Paired t test	P. value
	Done completely	Done incompletely	Not done	Done completely	Done incompletely	Not done		
	%	%	%	%	%	%		
1. Regular medical appointments	16.5	24.3	59.1	51.3	25.2	23.5	0.523	0.000**
2. Administer medications	22.6	13.0	64.3	44.3	26.1	29.6	0.695	0.000**
3. Promote healthy lifestyle	17.4	17.4	62.2	60.0	13.0	27.0	0.646	0.000**
4. Measuring weight	9.6	24.3	66.1	46.1	23.5	30.4	0.595	0.000**
5. Taking vital signs	7.0	26.1	67.0	42.6	30.4	27.0	0.533	0.000**
6. Emotional support of the child	12.2	33.0	54.8	60.9	12.2	27.0	0.724	0.000**

** Highly Significant level at P value < 0.001

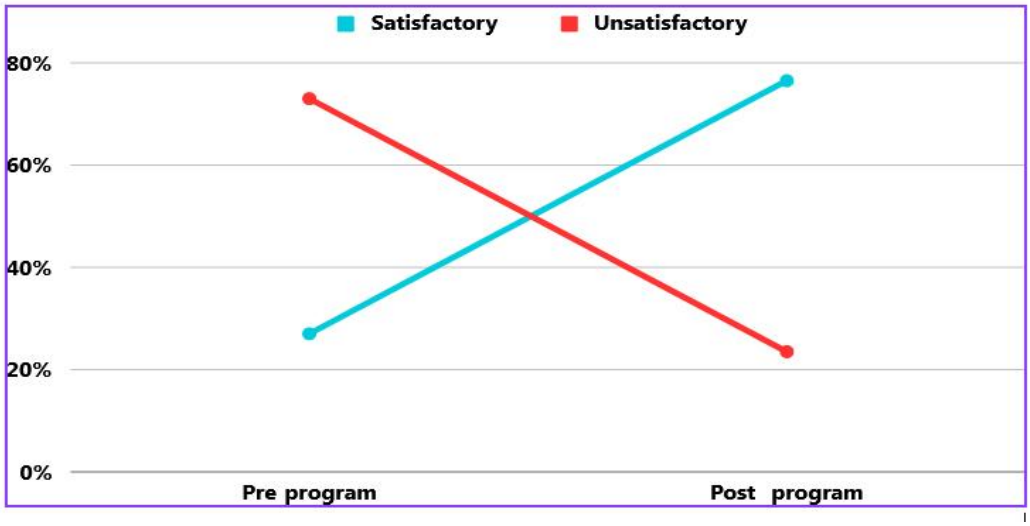

Figure (2): Total practice regarding beta thalassemia among studied children's mothers in pre and post program.

Table (5): Distribution of the studied mothers' attitude regarding beta thalassemia pre and post stepwise program (N=115).

Items	Pre-program			post -program			Paired t test	P value
	No Answer	Agree	Not Agree	No Answer	Agree	Not Agree		
	%	%	%	%	%	%		
1. Mothers concern about their children's present status and future vision	41.7	8.7	49.6	27.0	44.3	28.7	5.538	0.000**
2. Get children from affected person	24.3	29.6	46.1	12.2	29.6	58.3	0.2416	0.017*
3. Child relationship with a thalassemic person	31.3	27.8	40.9	3.5	47.0	49.6	4.012	0.000**
4. Consider thalassemic childe as financial difficulties	41.7	8.7	49.6	27.0	44.3	28.7	5.538	0.000**
5. Thalassemic childe need social and psychological support	31.3	27.8	40.9	3.5	47.0	49.6	4.012	0.000**
6. Thalassemic disease negatively impact their children quality of life	41.7	8.7	49.6	27.0	44.3	28.7	5.538	0.000**
Total scores of attitude Negative Positive	62.6% 37.4%			25.2% 74.8%			0.812	0.000**
Total Mean ±SD	2.9826±1.41411			4.0957± 1.20652			0.7129	0.000**

***Significant level at P value < 0.05**
**** Highly Significant level at P value < 0.001**

Table (6): Correlation between pre & post Program total score of Mothers' knowledge and their practice and attitude (N=115).

Item	Total scores of knowledge			
	Pre program		Post program	
	r.value	P value	r.value	P value
Practice	**0.248**	**0.007****	**0.231**	**0.013***
Attitude	**0.299**	**0.001****	**0.199**	**0.033***

***Significant level at P value < 0.05**
**** Highly Significant level at P value < 0.001**

Discussion

Beta thalassemia major, is a prevalent hereditary hemolytic disorder globally, arises from a disturbance in beta globin production. Symptoms in affected children vary widely, ranging from negligible to severe anemia requiring continuous blood transfusions**(Benz & Angeluci, 2018)**. Inadequate awareness and education about this condition are critical non-medical influencers leading to considerable social, economic, and psychological hurdles for affected children**(Ebrahim et al., 2019)**. Pediatric nursing care for children with beta thalassemia focuses on offering family education and support**(Ebrahim et al., 2019)**.

In this study, it was observed that a majority of the mothers exhibited insufficient knowledge, with over half displaying poor knowledge levels and more than a third possessing an average level of knowledge. Notably, none of the mothers demonstrated a good level of knowledge. These outcomes align with earlier research conducted by **Thakur et al. (2015),** which similarly highlighted the notably low levels of thalassemia knowledge within Sindhi families and **Karimzaei et al. (2015),** who reported that only a tenth of the sample had a satisfactory level of knowledge regarding thalassemia prevention. From the researcher's perspective, it is probable that mothers' interest in treatment is solely focused

on obtaining medical care rather than gaining knowledge about the disease. Additionally, it is likely that nearly two-thirds of the participants in the study had insufficient education.

This study revealed that a significant proportion of the mothers included in the study were unaware that thalassemia is a hereditary condition. Additionally, less than one third of them had knowledge regarding the causes of thalassemia prior to the implementation of the program. The findings align with a study conducted in Pakistan by **Ishfaq et al. (2016)** titled "The knowledge of parents having thalassemia child." The study reported that only fifty percent of the parents surveyed were aware that thalassemia is an inherited disease, while more than half of the parents were unaware of the causes of thalassemia.Also **Mostafa & Abd- Elaziz (2014)** in Zagazig reported that over half of the participants provided inaccurate answers regarding the meaning, occurrence, contributing causes, and complications of thalassemia in both thalassemia children and their mothers.

The current study revealed that most of the participants had a poor understanding of thalassemia before the stepwise program was introduced. Nevertheless, after the program was put into effect, there was a significant enhancement in their knowledge. The results align with a prior investigation conducted by **Mohammed et al. (2022),** which revealed that over half of participants exhibited insufficient understanding of thalassemia. In contrast to the results of a study conducted by **Ebrahim et al. (2019),** which indicated that over half of participants have adequate knowledge. The variation in these findings can be ascribed to individual variations and discrepancies in educational attainment, as evaluated by the researchers.Furthermore, this study's findings align with the research conducted by **Goyal et al. (2015),** which stated that over two-thirds of the mothers evaluated had inadequate understanding of the common symptoms of thalassemia.

Consistent with **Uddin et al. (2017)** in Pakistan, who investigated the frequency and awareness of thalassemia within families with cousin marriages, it was noted that the awareness levels among patients were inadequate. Conversely, in a study by **Aggarwal et al. (2016)** focusing on assessing parental knowledge concerning the management of thalassemia among children aged 2-7 years attending a thalassemic ward, the results indicated that parents possessed a moderate level of knowledge regarding thalassemia management.

Regarding mothers practices the current study showed that nearly three quarter of the mothers had unsatisfactory practices level while only more than fifth had satisfactory practices level and these results agree with the study performed by **Wahidiyat et al. (2021)** titled “cross-sectional study on knowledge, attitude and practices towards thalassemia among Indonesian youth” who said that more than half of studied mothers had poor practices. This study contradicts the findings of a study conducted by **Mohammed et al. (2022)** titled "Effect of Health Coaching Intervention on Mothers' Performance and Quality of Life of Their Children with Beta Thalassemia" in Egypt. The previous study claimed that the mothers who participated in their research exhibited satisfactory practices.

In the contrast the study conducted by **Saxena et al. (2017)** in Navi Mumbai, India, it was shown that most parents lacked sufficient knowledge and awareness regarding the disease, despite having good practices and a positive mindset. In a study conducted by **Basu (2015)** in Kolkata, the author examined the knowledge, attitude, and practice regarding thalassemia among the general population in an outpatient department at a tertiary care hospital. The findings revealed that over half of the participants had satisfactory knowledge about thalassemia, the majority had a positive attitude towards it, and only fourteen individuals demonstrated good practice in managing thalassemia.

The findings of the present study indicate a statistically significant enhancement in the total scores of mothers' knowledge, practices, and attitudes in the post-test compared to the pre-test, with a significance level of $P < 0.001$. This improvement may be attributed to the mothers' keen interest in acquiring knowledge and actively participating in patient care. Similar results were reported in a study conducted by

Mohammed et al. (2022) in Egypt, titled "Effect of health coaching intervention on mothers' performance and quality of life of their children with beta thalassemia," involving 70 participants, demonstrating a significant positive relationship between total knowledge and practices. This outcome may be attributed to individual variances among mothers. These findings are consistent with the research by **Wacharasin et al. (2015),** which highlighted that a family empowerment program led to increased family empowerment and functioning at one and three months follow-up compared to standard care. The observed influence could be attributed to the impact of the program on enhancing information dissemination, attitudes, and practices of mothers towards their affected children.

Similarly, a study by **Kargar et al. (2011)** conducted in Iran demonstrated a notable enhancement in the knowledge and attitudes of mothers with children affected by thalassemia following the introduction of the family-centered empowerment model. Furthermore, **Pordehkordi et al. (2008)** observed beneficial impacts on awareness and attitudes among parents of affected children through direct face-to-face educational sessions such as lectures. Another research conducted in Ahvaz illustrated a positive outcome in augmenting the knowledge and attitudes of parents with children having thalassemia subsequent to the establishment of a counseling center.

Consistently, a study by **Hussein and Qadir (2013)** conducted in Erbil City indicated an improvement in maternal knowledge following the implementation of a health education program in the study group in comparison to the control group. Additionally, **Cheng et al. (2018),** who investigated the impact of health education on the prevention and management of severe thalassemia within communities, reported a significant enhancement in knowledge and attitudes concerning the prevention and control of severe thalassemia among the intervention group.

Conclusion

The present study findings and research hypothesis indicate that the adoption of a systematic program for mothers to care for their children with beta-thalassemia is a very efficacious approach to improve mothers' knowledge, practices, and attitude. Furthermore, there was a statistically significant improvement in the mothers' overall scores of knowledge, practices, and attitude after the program compared to before the program. This highlights the significance of the stepwise program in enhancing mothers' development.

Recommendations

The research suggests that a comprehensive training program for mothers is essential for improving the care of children with beta thalassemia. It recommends providing Arabic pamphlets and brochures to mothers visiting pediatric outpatient clinics, raising public awareness about premarital screening and counseling, and conducting further research on beta thalassemia. Parents should also be encouraged to participate in training courses and specialized congresses to enhance their knowledge and expertise in providing care for their offspring. This will help improve the quality of care for these children.

Study Limitation:

One potential limitation of the study on the "Effect of Stepwise Program on Mothers' Care of their Children with Beta Thalassemia" could be the lack of a control group for comparison. Without a control group, it may be challenging to attribute changes solely to the stepwise program, as external factors or the passage of time could also influence the outcomes.To overcoming the limitation researchers using a pre-test and post-test design within the intervention group to track changes in knowledge, attitudes, and practices over time. This would allow for a more robust assessment of the program's impact on mothers' care of children with beta thalassemia.

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