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Effect of a Health Education Program for Caregivers Having Children with Thalassemia on Their Burnouts

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Abstract: Background Thalassemia is a genetic blood disorder causes major physical and psychological problems for children leading to caregivers' burnout. **Purpose**: To evaluate effect of a health Education program for caregivers having children with thalassemia on their burnouts. **Research design**: A quasi-experimental research design was used to conduct this study. **Setting**: The study was carried out at hematology out-patient clinic in Mustafa Hassan University Hospital for pediatric, Al-Fayoum. **Sampling**: A purposive sample of 116 caregivers was used to achieve the purpose of the study. **Instruments**: Two instruments were used for data collection in the present study (knowledge about thalassemia structured interviewing questionnaire and caregivers` burnout instrument for thalassemia): **Results**: The findings revealed that there was an improvement in total knowledge, attitude, reported practice and reduced burnout as (8.6% Vs 82.7%), (13.8% Vs 87.9%), (15.5% Vs 87.1%) and (74.2% Vs 10.3%) respectively versus posttest. **Conclusion**: Health educational program about caring for children with thalassemia, improving knowledge, attitude, practices and reduce burnout.

Keywords*: Burnout, caregivers, thalassemia*

Introduction:

Thalassemia is a genetic disorder that manifest as the production of reduced hemoglobin. Symptoms depend on the type of thalassemia and can vary from none to severe, including death. Thalassemia can affect the production of red blood cells and also affect how long the red blood cells live. The incidence of it is increasing worldwide and is high among people living in areas of Mediterranean countries, the Middle East, Africa and Southeast Asia. There are two main types of thalassemia, alpha and beta thalassemia (Tan et al., 2024).

Children with thalassemia had several signs and symptoms depend on the type of thalassemia and severity of it. Signs and symptoms include mild or moderate anemia, pallor face, difficult of breathing, fatigue, yellowish discoloration of skin and sclera, poor growth and development, poor nutrition, poor weight, bone deformity in the face and leg, growth retardation and abdominal enlargement due to hepato-splenomegaly. These signs and symptoms lead to negative effect on emotional, social and self-esteem development of the children and their caregivers (Gupta, 2024).

There are two main types of thalassemia, alpha thalassemia and beta thalassemia. Alpha thalassemia is caused by absent or deficient synthesis of alpha-globin chains has many subtypes, type 1 called silent carrier (one gene affected), type 2 called alpha thalassemia trait (two genes affected), type 3 called Hemoglobin H disease (three genes affected). Type 4 called alpha thalassemia major or hydrops fetalis, (four genes affected). Beta thalassemia caused by mutations in the hemoglobin beta globin gene, classified into β-thalassemia minor, β-thalassemia intermedia and β-thalassemia major (Musallam et al., 2023).

Treatments for thalassemia include lifelong blood transfusions and iron chelation therapy. The period of blood transfusion vary from weeks to months according to type of thalassemia and degree of anemia but the most effective treatment and the only treatment that can cure thalassemia is bone marrow and stem cell transplantation from a compatible related donor. Nutritional supplements are very important of management of thalassemia as folic acid supplements and vitamin (B12) because of these nutritional supplements are key components to making healthy blood cells (Begum et al., 2024).

Complications associated with untreated thalassemia include splenomegaly, osteoporosis, heart failure due to severe anemia, growth retardation, failure of sexual maturation, failure of endocrine glands resulting in diabetes mellitus and insufficiency of the parathyroid, thyroid, pituitary and adrenal glands resulting in hypothyroidism and hypo-parathyroidism. Other complication include iron overload or iron deposition and blood transfusion-transmitted infections (TTIs) including hepatitis C and B virus and antibody formation (alloimmunization) (Tan et al., 2024).

Caregivers' burnout is defined as a state of physical, emotional and mental exhaustion accomplish by change in attitude from positive to negative attitude. It can happen when caregivers give much time and energy to manage the health and safety of others. It can also happen when try to do more than able to do emotionally, physically or financially. Signs and symptoms of caregivers' burnout include anxiety, stress, depression, fatigue, loss of appetite and headache from over thinking of the future of thalassemic children (Blom et al., 2023).

Community Health Nurse (CHN) has important role in prevention of thalassemia by giving health education to people about preventive strategies of thalassemia as premarital screening, genetic screening and counseling before marriage. CHN gives health education about causes and risk factors of thalassemia through awareness program and awareness campaigns in health care places. Also, CHN gives health education about importance of regular blood transfusion and iron chelation therapy to treat thalassemia and gives advices for importance of follow up to prevent complications (Krishnapradeep& Mudiyanse, 2024).

Significance of the study:

In Egypt it has been estimated that one thousand children from 1.5 million live births are born each year suffering from thalassemia disease. It is reported that the carriers' rate of thalassemia in Egypt is between 9 to 10% of the total population. In Egypt, despite the high prevalence of thalassemia carriers and the growing number of children born each year of thalassemia, there is no national thalassemia prevention program (Elsoudy et al., 2022).

Thalassemia is one of the most prevalent genetic disorders among the 60 countries in the world with annually about 100,000 babies being born with it. Consanguineous marriages, high fertility rate, high birth rate and low educational level are combined with an unawareness of the thalassemia disease and make developing countries to have a higher number of thalassemic children (Nabavian et al., 2022). Almost 70,000 infants are born with beta thalassemia worldwide each year while 5% of alpha-Thalassemia affects the world’s population (El-Shanshory et al., 2021).

Thalassemia is common in Mediterranean countries and has various signs and symptoms as general weakness, jaundice, facial and leg bone deformities and abdominal enlargement. Complications that result from iron deposition due to multiple transfusions are ulcerations in legs, arrhythmias, heart failure, slowness of child's growth and development, defect in thyroid gland and these had negative impact on the psychological, social health, self-esteem and quality of life of these children and their caregivers and has burden on the chilgren, caregivers and the healthcare system. (Musallam et al., 2023). Therefore, this study was conducted to evaluate the effect of a health educational program on reducing caregivers' burnout of their children with thalassemia.

Purpose:

To evaluate effect of a health Education program for caregivers having children with thalassemia on their burnouts.

Research Hypothesis:

Caregivers who receive health education program are expected to have fewer burnouts than caregivers who did not receive the educational program.

Methods:

Research design:

A quasi-experimental research design (pre-posttest) was used.

Setting:

The study was conducted at the Hematology Out-patient clinic at Al-Fayoum University Hospital in Al-Fayoum City, Egypt.

Type of Sample:

A purposive sample of 116 caregivers having children diagnosed with thalassemia.

Instruments:

Two instruments were used for data collection in the present study

Instrument one: Structured Interviewing Questionnaire:

Was designed based on literature review and approved by supervisors. It was written in simple Arabic language and consists of four parts.

- **Part 1:**

A. Demographic characteristics of the caregivers: includes data about caregiver's age, gender, educational level, marital status, occupation, monthly income, place of residence and number family of members.

B. Demographic characteristics of children: includes data about child age, child gender and child order in the family.

C. Past and present medical history of children and their family: includes data about blood relation between mother and father, kinship of relationship, family history of thalassemia and family member who suffer from thalassemia.

- **Part 2: Caregivers' knowledge questionnaire regarding thalassemia:**

(pre and post program): concerned with caregivers` knowledge about thalassemia. It contains of 10 items e.g. meaning, causes, signs and symptoms…….

Scoring system:

knowledge of caregivers regarding thalassemia was classified as correct was scored 1 and incorrect answer was scored zero.

Total scores equal 12 grades for 12 questions.

- Good knowledge ≥ 75% (10-12).
- Fair knowledge 50 - <75% (6-10)
- Poor knowledge <50 % (<6).

- **Part 3: Caregivers' attitude questionnaire regarding thalassemia:**

(pre and post program): it was concerned with caregivers' attitude regarding thalassemia and consisted of 14 items e.g. premarital screening reduces genetic diseases as thalassemia, consanguineous marriage increase the risk for having thalassemia, thalassemia is a hereditary disease…

Scoring system:

attitude of caregivers regarding thalassemia was classified as "Agree" that was scored 3, "Neutral" that was scored 2 and "Disagree" that was scored 1.

Total scores equal 42 grades for 13 questions. The score of each item stumped up and then was converted into percent scores as:

- Positive attitude ≥ 60% (26-42 grades).
- Negative attitude <60 % (14- <26 grades).

- **Part 4: Caregivers' reported practice regarding their children with thalassemia,**

(pre and post program): caregivers' reported practice regarding their children with thalassemia and consisted of 16 items including role of caregivers about giving medication contains 5 items such as perform blood transfusion and iron chelation therapy regularly for thalassemic child….

Scoring system:

scoring used for caregivers' reported practice regarding their children with thalassemia was scored by done (equals one score) and not done (equals zero score).

Total scores equal 16 grades for 16 items.

- Adequate practices ≥ 60% (>9.6-16 grades).
- In adequate practices <60% (<9.6 grades).

Instrument two: Caregivers' burnout tool for thalassemia:

adopted from adopted from (Maslach, & Jackson. 1981) and (Awad, 2013) and modified by researcher. It consists of 4 dimensions (45 items).

- **Emotional exhaustion**: it contains 20 items that include feel stress since taking care of my thalassemic child, feel worry and anxiety about my child's future, find difficulty to sleep and fatigue easily...
- **Social exhaustion**: It contains 18 items e.g. surround my child with more care than other siblings, spend more time with my child than i spend with other siblings...
- **Depersonalization**: It contains 4 items such as become more worried, anxious, nervous and angry since I took this care, feel with self-dispraising, deny and guilt due to affected child, feel my child blame me for some of his problems and worry that caring for my thalassemic child is hardening me emotionally.
- **Involvement**: it contains 3 items such as feel personally involved with my child`s problems, feel similar to my child's emotional problems and feel uncomfortable about the way I have treated some of my child's problems.

Scoring system for burnout:

The scale contained 45 items, divided into 4 subscales (emotional exhaustion which consisted of 20 items, social exhaustion subscale which consisted of 18 items, depersonalization subscale which contain 4 items and Involvement subscale which involved 3 items). The scale using a 3-point scale that ranges from 3 "agree", 2 "neutral" to 1 "disagree". The total scores of the scale were 135 grades. These scores were summed and converted into a percent score. It was classified into 2 categories:

- High if score ≥ 75% (101.2-135 grades).
- Moderate if score from 50-<75% (67.5-<101.3 grades).

- Low if score <50% (45-<67.5 grades).

Validity:

The validity of developed instruments was tested through a panel of experts in Community Health Nursing at Faculty of Nursing, Helwan University to review relevance of the instruments for comprehensiveness, accuracy, understanding and applicability.

Reliability:

Testing the reliability of the instruments was tested through Alpha Cronbach.

Instruments	Alpha Cronbach
Caregivers' knowledge questionnaire	0.946
Caregivers' attitude questionnaire	0.981
Caregivers' reported practice questionnaire	0.908
Caregivers' burnout for thalassemia	0.985

Ethical consideration:

An official permission to conduct the proposed study was being obtained from the Scientific Research Ethics Committee at Faculty of Nursing, Helwan University. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it was not be accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs were respected.

Pilot Study:

The pilot study was conducted to test clarity of questions, applicability and efficiency of tool. It also aimed to ensure simplicity, relevance and feasibility of conduction of the study instruments. It has been conducted on 10 % (12) of caregivers. The results of the pilot study helped in refining the interview questionnaire and to schedule the time framework. No modifications were done so. Participants of pilot were included in the main study sample.

Procedure:

Before conducting the study, an official letter was sent from the Dean of Faculty of Nursing, Helwan University to the manager of hematology out-patient clinic at Al-Fayoum University Hospital in Al-Fayoum City. The researcher met the caregivers and explained the purpose of the study and components of the instruments to them. The researcher collected data 2 days-week (Sunday and Wednesday) from 9 am - 2 pm in the study setting till completion of the questionnaire. The questionnaires were distributed and completed by the researcher from the studied caregivers to assess their knowledge, attitudes, reported practices and burnout regarding thalassemia.

The educational program was developed based on the results obtained from the pre-test questionnaire. The plan of educational program was prepared, implemented and the degree of improvement was assessed in the study group. The educational methods used in the study were lecture, active group discussion, brain storming, demonstration, re-demonstration and role play.

The researcher used a variety of supportive materials such as papers, colored posters, power point, handouts and booklet prepared by researcher. By the end of each session the researcher told the caregivers about the time and content of the next session. Data was collected during six months from the beginning of March 2024 to the end of the August 2024. At the end of the educational program, it was assessed at post program phase by using the same tools at the pre-program.

The health educational program was conducted throughout four phases: preparatory, assessment, planning and implementation and evaluation phase.

Preparatory phase

Assessment phase:

Before starting the designed educational program, the study instruments were applied to assess caregivers' knowledge, attitudes, reported practices and burnout regarding thalassemia.

Planning and implementation phase:

By developing a health education program content, purpose was to reduce caregivers' burnout of their children with thalassemia, it was explained to all participants from caregivers. Content of the program was developed and included meaning, causes, risk factors, signs and symptoms, types, diagnostic tests, complications, methods of prevention, methods of treatment, healthy life style for children with thalassemia, causes of burnout and advices to reduce it. The program tailored to suit caregivers` needs. The researcher developed pamphlet which guided caregivers about thalassemia.

- The studied caregivers were divided into 6 groups, each group contained 20 caregivers except the last group contain 16 caregivers. The program was applied through 5 sessions, each session took about 25-35 minutes. The program was carried out in the Hematology Out-patient Clinic at Al-Fayoum University Hospital. At the beginning of the first session, the researcher welcomes and introduces self to caregivers, an orientation to objectives of the program was given, take oral informed consent of caregivers, set an agreement on the time and duration of sessions. The researcher provides trust, warm and secure atmosphere between caregivers group to relieve anxiety and increase motivation to participate in all sessions of the health educational program. Caregivers were oriented about program sessions (time, duration, place and content).
- Also, the researcher stressed on the importance of continuous attendance and active participation. Different teaching and learning methods were used during the sessions, which included interactive lecture, group discussion, demonstration, redemonstration, instructional media included pictures and printed handout. Simple and clear Arabic language was used to suite the level of caregivers without ignoring motivation and reinforcement techniques to enhance learning.

Each session was started by a summary about the previous session and objectives of new session. The program was presented in a clear and concise form to be used as memorial reference. Direct reinforcement in the form of a copy from the booklet pamphlet was given as a reward for each caregiver to use it as a future reference. Caregivers were allowed to ask any interpretation or explanation of any item included in the sessions. At the end of every session, the caregivers were discussed to correct any misunderstanding.

Evaluation Phase:

After implementation of the educational program, post-test was done at the fifth sessions to evaluate the effect of the program on caregivers' knowledge, attitude, reported practices and level of burnout. The post test was done immediately at the end of the sessions using the same tools of pretest evaluation.

Ethical considerations:

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee, (25-7-2023) Faculty of Nursing, Helwan University. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations were include explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it not be accessed by any other party without taking permission of the participants. Informed consent was taken from caregivers to conduct the study. Objectives, tools and study technique were illustrated to gain their cooperation. Ethics, values, culture and beliefs were respected.

Statistical analysis:

All data were organized, tabulated and analyzed using appropriate statistical test. The data were analyzed by using the computer software of Microsoft Excel Program and Statistical Package for Social Science (SPSS) version 25. Data were presented using descriptive statistics in the form of frequencies and percentage for categorical data, the arithmetic mean (X) and standard deviation (SD) for quantitative data. Qualitative variables were compared using chi square test (X2). Differences between the groups during visits were assessed by paired t test. In addition, r-test were used to identify the correlation between the study variables for.

Significance of the results: -

- Statistically significant $p < 0.05$
- Highly statistically significant $p < 0.001$
- Not significant $P > 0.05$

Results:

Table 1: shows that 51.7% of the studied caregivers were between 20-<30 years old, the mean SD of age was 29.66±5.24 years. While, 86.2% and 85.3% of them were females and married, respectively. Furthermore, 33.6% of them had basic education. Furthermore, 54.3% of them reside at

rural areas. In addition, 44.0% of them had more than four family members.

Table 2: shows that 49.2% of the studied children were in the age group 3 - <5 years old, the mean SD of age was 5.33±2.01 years. While, 51.7% of them were males.

Figure 1: shows that there was a significant improvement in total caregivers' knowledge about thalassemia at post implementation of health educational program with a highly statistically significant difference at (P= < 0.01). As evidence, 8.6% of the studied caregivers had good level of total knowledge about thalassemia at pre implementation of health educational program which improved to 82.7% after implementation of health educational program.

Figure 2: shows that there was a statistical significant improvement in total caregivers' attitudes regarding thalassemia post implementation of health educational program (P= < 0.01). As evidence, 13.8% of the studied caregivers had positive attitude towards thalassemia at pre implementation of health education program. However, it improved to 87.9% after implementation of health educational program.

Figure 3: displays that 15.5% of the studied caregivers had adequate level of total reported practices regarding thalassemia pre implementation of health educational program and improved to 87.1% post implementation of health educational program.

Figure 4: shows that 74.2% of the studied caregivers had high level of burnout pre implementation of health educational program which decreased to 10.3% after implementation of health educational program.

Table 3: reveals that there was high significant statistical positive correlation between total caregivers' knowledge scores, total attitude scores and total reported practices scores at post implementation of health educational program at $p < 0.01$. While, there was high significant statistical negative correlation between total caregivers' knowledge scores, total attitude scores, total reported practices scores and total burnout scores regarding thalassemia at post implementation of health educational program at $p < 0.01$.

Table (1): Frequency distribution of the studied caregivers according to their demographic data (n=116).

Demographic data	**No.**	**%**
Age (years)		
20 -< 30	**60**	**51.7**
30- < 40	45	38.8
≥40	11	9.5
Mean SD	**29.66±5.24**	
Gender		
Male	16	13.8
Female	**100**	**86.2**
Educational level		
Don’t read and write	7	6.0
Read and write	17	14.7
Basic education	**39**	**33.6**
Secondary education	34	29.3
University education and more	19	16.4
Marital status		
Single	1	0.9
Married	**99**	**85.3**
Divorced	7	6.0
Widow	9	7.8
Occupation		
Employee	6	5.2
Free business	10	8.6
Crafts man	12	10.3
Housewife	**88**	**75.9**
Monthly income		
Save and enough	5	4.3
Not enough	33	28.5
Enough	**78**	**67.2**
Place of residence		
Urban	53	45.7
Rural	**63**	**54.3**
Number of family members		
Three	20	17.2
Four	45	38.8
More than four	**51**	**44.0**

Table (2): Distribution of the Studied Children according to their Demographic Characteristics (n=116).

Demographic characteristics of studied children	No.	%
Age (years)		
3 - <5	**57**	**49.2**
5 - ≤8	31	26.7
8- 12	28	24.1
Mean ± SD	**5.33±2.01**	
Gender		
Male	**60**	**51.7**
Female	56	48.3
Child's ranking among family the member		
First	36	31.0
Second	34	29.4
Third or more	**46**	**39.6**

Figure (1): Distribution of Caregivers' according to Their Knowledge about Thalassemia at pre and Post implementation of Health Educational Program (n=116).

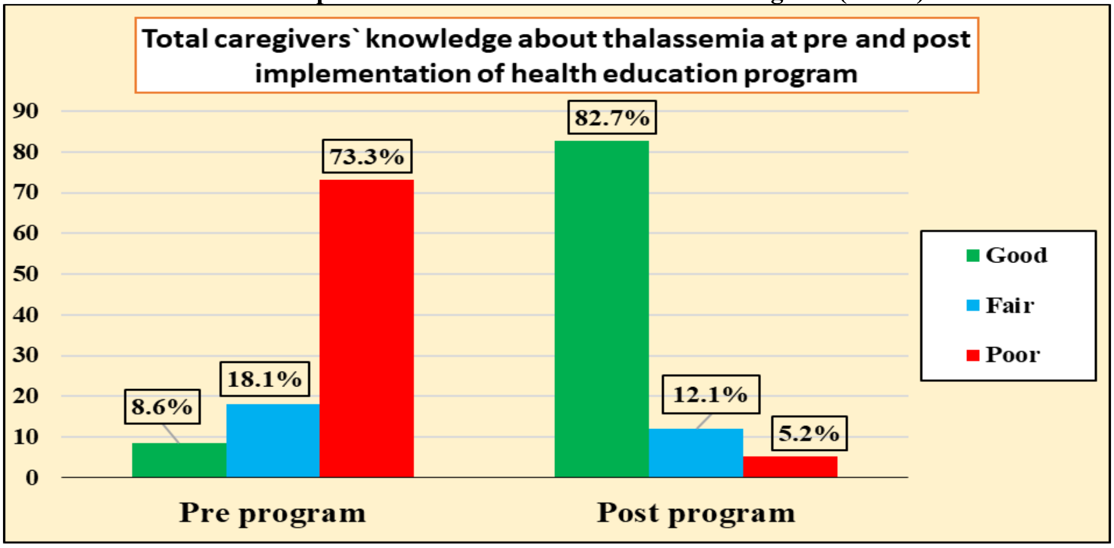

Figure (2): Distribution of Caregivers' According to Attitudes toward Thalassemia Pre and Post Implementation of Health Education Program (n=116).

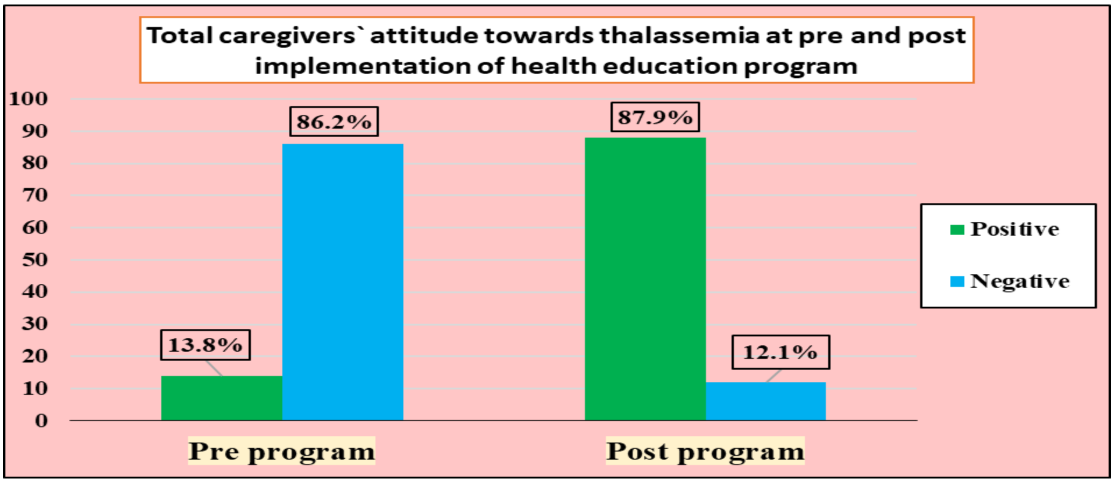

Figure (3): Distribution of Caregivers' according to Their Reported Practices about Care of Thalassemia Pre and Post Implementation of Health Educational Program (n=116).

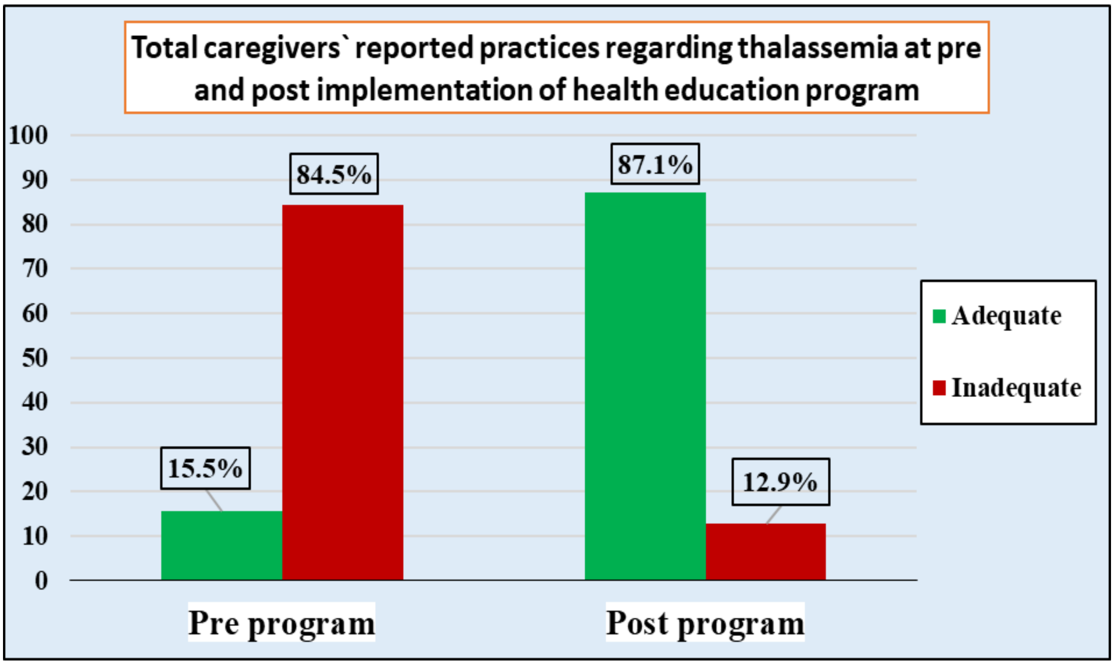

Figure (4): Distribution of Caregivers' according to Their Burnout Pre and Post Implementation of Health Educational Program (n=116).

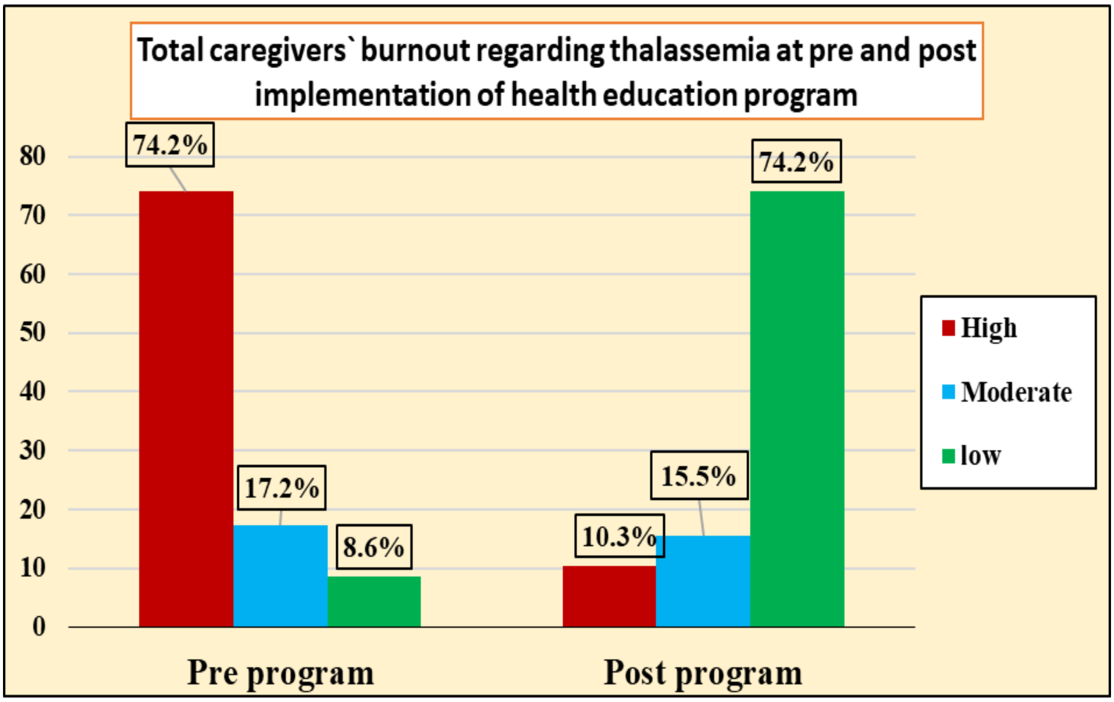

Table (3): Correlation between total caregivers' knowledge scores, total attitude scores, total reported practices scores and total burnout scores post implementation of health educational program (n=116).

Variables		Total knowledge score	Total attitude score	Total reported practices score	Total burnout score
Total knowledge score	r				
	p				
Total attitude score	r	0.836			
	p	0.000**			
Total reported practices score	r	0.861	0.906		
	p	0.000**	0.000**		
Total burnout score	r	-0.621-	-0.651-	-0.685-	
	p	0.000**	0.000**	0.000**	

R= Pearson correlation coefficient test. P= p-value. (-): Negative correlation.
(**) highly Statistically significant at p <0.01

Discussion:

Thalassemia is a genetic disorder due to a decreased or absent production of normal globin chains. Thalassemia has a negative influence on emotional and social life of caregivers as it is associated with significant social disruption, emotional or psychological stress and highly involved with children's psychological problems (Paramore et al., 2021). Most of caregivers of thalassemia children haven't sufficient knowledge and proper attitude and practices in facing the process of their child's disease. One of the ways to reduce the problems of thalassemia children is to improve knowledge, attitude and practices of their caregivers to manage preventable problems through educational programs (Lotfi et al., 2023). Therefore, the current study aims to evaluate the effect of a health educational program on reducing caregivers' burnout of their children with thalassemia.

Regarding to total caregivers' knowledge level about thalassemia at pre and post implementation of health educational program, the current study revealed that there was a statistical significant improvement in total caregivers' knowledge about thalassemia post-education program. As evidence, less than one tenth of them had good level of total knowledge about thalassemia pre-program which improved to the majority of them (82.7%) of them had good level of total knowledge about thalassemia after implementation of health educational program. These findings were supported by a study done by Abdolreza et al., (2022), in Iran entitled as "The Effect of Empowerment Program on the Knowledge and Performance of Mothers of Children with Thalassemia Major".

From the researcher point of view, this may be due to the effectiveness of the health educational program in addressing the caregivers’ knowledge gaps about thalassemia, enhancing awareness and equipping them with the necessary knowledge to care for their children with thalassemia effectively.

Concerning to caregivers' attitudes toward thalassemia at pre and post implementation of health education program, the present study showed that there was a statistical significant improvement in total caregivers' attitudes at post education program. As evidence, less than one fifth of studied caregivers had positive attitude towards thalassemia at pre-program. Whereas, the majority of them (87.9%) of them had positive attitude after education program.

These findings were consistent with a study by Zareban et al., (2024), in Iran entitled as "Effectiveness of the application of an educational program based on the Theory of Planned Behavior (TPB) in adopting preventive behaviors among mothers who have thalassemia children". From the researcher point of view these results may be due to the effectiveness of the health education program in enhancing caregivers' understanding of thalassemia, addressing misconceptions and equipping them with accurate information and practical strategies for managing the condition.

Regarding to total reported practices level, the current study highlighted that less than one fifth (13.8%) of the studied caregivers had adequate level of practices regarding thalassemia at pre implementation of health educational program, while improved to the majority (82.7%) of them had adequate practices at post-program. This result matched with a study done by Zareban et al., (2024), who affirmed that improvement of total reported practices at post intervention as, total reported practices at pre-intervention stage was 9.1 ± 21.32, which increased to 11.51 ± 0.59 in the post-intervention stage and the difference of the mean scores within two stages was significant (P value < 0.0001).

From the researcher's point of view, education and raising the level of caregivers’ care practices are the main pillars for empowering families, and empowerment programs develop the learner's skills. The significant improvement observed post-program may because of the effectiveness of the health educational program in enhancing caregivers’ competencies.

Concerning total burnout score, the present study indicated that less than three quarters (74.2%) of the studied caregivers have high level of burnout of their children with thalassemia at pre implementation of health educational program, which decreased to about one tenth (10.3%) of them post-program. In the same line, a study carried out on 70 mothers, by Biabani et al., (2020), entitled as “The effect of group education on adaptive behaviors and caregivers burden in mothers of children with thalassemia major" suggesting the positive impact of group education on mitigating caregiver burden (P < 0.001).

From the researcher point of view these results may be due to the significant impact of the health educational program in providing caregivers with practical strategies, emotional support and enhanced confidence in their caregiving abilities leading to a marked reduction in burnout levels post-implementation.

As for correlation between total caregivers' knowledge scores, total attitude scores, total reported practices scores and total burnout scores regarding children with thalassemia, the present study portrayed that there was high significant statistical positive correlation between total caregivers' knowledge scores, total attitude scores and total reported practices scores at pre and post implementation of health educational program and negative correlation between total caregivers' knowledge scores, total attitude scores, total reported practices scores and total burnout level at pre and post implementation of health educational program

The results of the present study were similar to Lotfi et al., (2023), who stated that Increasing awareness positively correlates with improving the attitude and performance of parents. In the same line, Biabani et al., (2020) affirmed that correct knowledge can lead to appropriate attitude, healthy behavior and these lead reduce in burnout level. From the researcher point of view these results may be due to the influence of correct knowledge and understanding on caring for children with thalassemia which could reduce burnout.

Conclusion:

Caregivers who received health education program acquired higher level of knowledge, self-reported practices, more positive attitudes towards thalassemia and fewer burnouts than caregivers who did not receive the educational program.

Recommendations:

From the previous findings, the following recommendations are suggested:

- Continuous implementing of health educational program should be provided to caregivers of their children with thalassemia.
- Booklet and posters about thalassemia should be distributed between caregivers.
- This research needs to be applied on a large sample and at another setting to ensure the generalizability of results.

References:

Abdolreza Gharebagh, Z., & Children with Moezifar, Z. (2022): The Effect of Empowerment Program on the Knowledge and Performance of Mothers of Thalassemia Major. Iranian Journal of Rehabilitation Research, 8(3), 66-74.

Awad, (2013): Social and emotional problems among parents of children with thalassemia.

Begum, R., Suryanarayana, G., Rama, B. S., & Swapna, N. (2024): An overview of thalassemia: A review work. Artificial Intelligence, Blockchain, Computing and Security Volume 1, 796-804.

Biabani, A., Kermansaravi, F., & Navidian, A. (2020): The effect of group education on adaptive behaviors and caregiver burden in mothers of children with thalassemia major: a trial clinical study. Medical-Surgical Nursing Journal, 9(1).

Blom, C., Reis, A., & Lencastre, L. (2023): Caregiver quality of life: satisfaction and burnout. International Journal of Environmental Research and Public Health, 20(16), 6577.

Chandra, A., Mallik, S., Chakrabarti, S., & Bhattacharyya, N. (2022): Health-related quality of life of parents of children with beta-thalassemia major attending a tertiary care institution in Eastern India. Muller Journal of Medical Sciences and Research, 13(2), 76-80.

Choudhary, D., Rakholia, R., & Agarwal, P. A. (2023): Cross Sectional Study for Growth and Quality of Life Assessment among Multitransfused Thalassemia Patients and Factors Affecting it in Kumaon Region of Uttarakhand, India. prevalence, 4(17), 4-6.

El-Shanshory, M. R., Sherief, L. M., Hassab, H. M., Ragab, S. M., Yahia, S., Mansour, A. K., & Saied, S. M. ,(2021): Prevalence of iron deficiency anemia and beta thalassemia carriers among relatives of beta thalassemia patients in Nile Delta region, Egypt: a multicenter study. Journal of the Egyptian Public Health Association, 96(1), 1-8.

Elsoudy, S. F., Madinay, N., & Yonis Mahrous, E. S. ,(2022): Compliance of Children with Thalassemia to Their Therapeutic Regimen. International Egyptian Journal of Nursing Sciences and Research, 2(2), 168-182.

Gupta, A. (2024): Thalassemia Major. In Decision Making Through Problem Based Learning in Hematology: A Step-by-Step Approach in patients with Anemia (pp. 35-51). Singapore: Springer Nature Singapore.

Hossain, M. S., Mahbub Hasan, M., Petrou, M., Telfer, P., & Mosabbir, A. A. (2021): The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret, and barriers. Orphanet journal of rare diseases, 16, 1-10.

Ibrahim, E. S., Al Nagar, M. A., Eita, L. H., & Alam, F. H.,(2021): Relationship between Quality of Life and Social Support among Mothers of Children with Thalassemia. Ibrahim, E. S., Al Nagar, M. A., Eita, L. H., & Alam, F. H. Relationship between Quality of Life and Social Support among Mothers of Children with Thalassemia,8, (2), 75-87.

Krishnapradeep, S., & Mudiyanse, R. M. (2024): Chronicles of Change: Thalassaemia Prevention Across Time.

Lotfi, M., Rahnama, M., Asadi-Bidmeshki, E., Abdollahimohammad, A., & Naderifar, M. (2023): Educational program effects on knowledge, attitude and performance of parents of thalassemia children: A quasi-experimental study. Medical Science, 27, e250ms3033.

Maslach, C., & Jackson, S. E. ,(1981): The measurement of experienced burnout. Journal of organizational behavior, 2(2), 99-113.

Musallam, K. M., Lombard, L., Kistler, K. D., Arregui, M., Gilroy, K. S., Chamberlain, C., ... & Taher, A. T. (2023): Epidemiology of clinically significant forms of alpha-and beta-thalassemia: A global map of evidence and gaps. American journal of hematology, 98(9), 1436-1451.

Nasif, A. M., Abd El-Aal, E. M., El-Sayed, D. M. S., & Shedeed, W. K. K. (2024): Caregivers' Empowerment regarding Care of their Children with Thalassemia.

Paramore, C., Levine, L., Bagshaw, E., Ouyang, C., Kudlac, A., & Larkin, M. ,(2021): Patient-and caregiver-reported burden of transfusion-dependent β-thalassemia measured using a digital application. The Patient-Patient-Centered Outcomes Research, 14(2), 197-208.

Puttagunta, V. (2023): HEALTH RELATED QUALITY OF LIFE AND ECONOMIC BURDEN IN CHILDREN WITH BETA THALASSAEMIA MAJOR AGED 2-18YEARS. Int J Acad Med Pharm, 5(4), 1237-1241.

Tan, J. Y., Yeo, Y. H., Chan, K. H., Shaaban, H. S., & Guron, G. (2024): Causes of Death and Mortality Trends in Individuals with Thalassemia in the United States, 1999-2020. Journal of Blood Medicine, 331-339.

Zareban, I., Oudi-Akbari, Z., Jadgal, M. S., Ansari, H., & Hosseinzehi Zamani, J. (2024): Effectiveness of the application of an educational program based on the Theory of Planned Behavior (TPB) in adopting preventive behaviors among mothers who have thalassemia children in Iran: A randomized controlled trial. Egyptian Journal of Medical Human Genetics, 25(1), 45.