Effect of Educational Program Based on the Precede-Proceed Planning Model on Quality of Life of Children with Thalassemia

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Abstract

Background: Thalassemia is an inherited blood disorder affecting hemoglobin synthesis that can negatively affect the quality of life of children as a result of the disease and it's provided treatment. **Aim of the study** was to evaluate the effect of educational program based on the precede-proceed planning model on quality of life of children with thalassemia. **Design:** A quasi-experimental design was used. **Setting:** This study was conducted at Pediatric Hematology Unit and Pediatric Hematology out-Patient Clinic at Benha Specialized Pediatric Hospital affiliated to Egyptian Ministry of Health and Population and Secretory of Specialized Medical Centers at Benha City. **Subjects:** A purposive sample of 125 children. **Tools of data collection:** Two tools were used; **Tool I**: A structured interviewing questionnaire based on precede-proceed planning model involving five parts; Part (1) Characteristics of the studied children, Part (2) Medical history of the studied children, Part (3) Predisposing factors assessment questionnaire, Part (4) Reinforcement factors assessment questionnaire and Part (5) Enabling factors assessment questionnaire, **Tool II:** Pediatric Quality of Life Inventory Generic core scale. **Results**: Less than one quarter and less than three quarters of studied children had high quality of life at pre-and post-intervention phases respectively. While, less than one quarter and 12.8% of them had low quality of life pre and post intervention respectively. **Conclusion:** Children with thalassemia had higher quality of life scores after implementation of the program based on the precede–proceed planning model. **Recommendations:** Integrating of the precede-proceed planning model in designing intervention programs in pediatric hematology units.

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Keywords: Children, Educational Program, Precede-Proceed Planning Model, Quality of Life, Thalassemia

Introduction

Thalassemias encompass a class of hereditary blood disorders in which the body fails to produce enough adult hemoglobin. The cause of thalassemia is decreased or defective synthesis of hemoglobin polypeptide chains, which forms abnormal and fragile red blood cells. This, subsequently, results in hemolysis and chronic anemia. Thalassemia is considered a monogenic disorder inherited as autosomal recessive disease from parents **(Leifer, 2023 & Kliegman et al., 2020).**

Thalassemia, as any chronic diseases, affects quality of life (QOL) of children physically and psychologically in a negative way. Physical deformities, retarded growth, and delayed hemolysis are consequences of thalassemia on physical development of children. Short stature and a bulged abdomen as a result of splenomegaly may impact the self-esteem of an affected child. The psychological aspects of thalassemia involve feeling bored, saturated and hopeless, limited

activities, low academic performance and decreased self-confidence. Besides increasing the morbidity rate among children, thalassemia's complications malfunction the physical, mental and social aspects of children, and hence, lowering their overall quality of life (**Biswas et al., 2023**).

Quality of life is a multi-facet concept that highlights to what extent the disease and its treatment contribute to health of children. QOL is subjective perception of a person's position in life, in the cultural environment, the value system in which they live and their relation to life destinations, expectations, norms and other relevant dimensions that include a very broad and complex QOL, involving physical problems, psychological status, freedom, social relationships and the environment to which they belong (**Akcal et al., 2019**).

The therapeutic intervention of thalassemia is complicated, prolonged and inconvenient, requiring frequent hospitalization and blood transfusion, which adversely affects the physical and mental health of children. The life expectancy of children with thalassemia has been increased due to modern advancements in transfusion and iron chelation therapy. Unfortunately, their QOL stills low if compared with healthy peers. Lifelong therapeutic management prescribed to decrease complications has an effect on the children's quality of life (**Sharma et al., 2017**).

The precede-proceed planning model is described as a planning, participatory and community-based model that is broadly applied to plan and change behaviour. It was introduced by **Green and Kreuter, 2015** and is particularly used to guide health promotion strategies among different categories, with

advantage of implementing theoretical frameworks, interventions and evaluations. This model has successfully been used to assess the quality of life in children having various diseases (**Zareban et al., 2018**). The precede section of the model refers to predisposing, reinforcing and enabling constructs in educational diagnosis and evaluation. The proceed part concentrates on health promotion dimensions, involving polices, regulations, and organizations in environmental and educational development (**Kim et al., 2022**).

The model introduces a framework for determining variables that have a direct influence on behaviours comprising; predisposing factors, reinforcing factors and enabling factors. The predisposing factors stands for factors which provide a motivation or rational to undertake that behaviour including knowledge, attitude, beliefs, preferences and self-efficacy beliefs. Reinforcing factors refers to those factors which strengthen and reward for repetition of the desired behaviour. These factors involve social support, peer influence and alternative reinforcement. Enabling factors are described as antecedents that facilitate health behavioural and environmental change such as resources and skills (**Maheri et al., 2020 & Soedirham, 2018**).

The precede-proceed planning model is a multi-step approach for developing and conducting health promotion programs that depend on realistic nursing led interventions. It consists of eight phases; social assessment, epidemiological and behavioural assessment, educational and ecological assessment, administrative/ policy and intervention planning, implementation, process evaluation, impact evaluation and finally outcome evaluation. Furthermore, implementation of the precede-proceed planning model is categorized into three stages which are planning (four

phases), implementation (one phase) and evaluation (three phases) **(Kim et al., 2022)**

Significant progress in treatment manners and improved clinical management achieved an ultimately higher life expectancy of those pediatric patients. Unlike healthy peers, children with chronic illness such as thalassemia are vulnerable to emotional and behavioral problems causing poor quality of life. Thalassemia causes a sense of stigmatization in children causing feeling of shame and rejection. Additionally, social relations, school interactions, and self-esteem are violated **(Jajhara et al., 2021).**

Health education can enhance child's knowledge concerning the disease and its remedy that lead to treatment adherence and engaging in their health management in a more positive way. Raising health awareness plays an essential part in managing chronic disease. The primary purpose is to improve the behavior of individuals, groups and societies **(Bazpour et al., 2019).** Pediatric nurse has a pivotal role in provision of care for children with thalassemia. Nursing care should be directed toward following therapeutic regimen to promote their QOL. Furthermore, pediatric nurse should support and provide those children with education regarding the general standards of care. Also, the nurse should reassure parents with especial confirmation on possible health problems that may have a great effect on QOL of children. Measuring QOL includes assessment of the impact of disease process and its management modalities in well-being of children too **(Elsayed & Mahmoud, 2015)**

Significance of the study:

Thalassemia is one of the most widespread genetic disorders worldwide. It was estimated that there are 270 million carriers in the world and, 300000 up to 400000 are annually born with thalassemia in the world. Therefore, children afflicted with thalassemia suffer from a considerable range of developmental disorders with slow growth speed and poor body mass index that could occur as a result of low hemoglobin, anemia and increased levels of body ferritin **(Shahraki, et al., 2020).** In Egypt, occurrence of thalassemia disorders is growing whereas 1000 children out of 1.5 million live births are born with thalassemia yearly and about 10,000 registered thalassemia cases and more than 20,000 non-registered cases. The carrier rate in Egypt ranges from 5.3 to $\geq$ 9% and a gene frequency of 0.03 **(Bahnasawy et al., 2017).**

For chronic diseases like thalassemia, where a cure is unaffordable to most children and management may be lifelong, quality of life is likely to be a fundamental consequence when considering substitutes of management. Assessment of quality of life in children is significant for providing appropriate care, as it assists in determining the impact of the disease and treatment from children's perspective. A better understanding of the factors related to QOL among children with thalassemia could have a direct effect on developing more appropriate clinical, counseling and social support programs to improve results of treatment **(Sharma et al., 2017).**

The precede-proceed model is prominent in health education that concentrates on providing guidance in planning health programs. Taking into consideration the significance of planning and its part in the efficiency of intervention programs, it is proposed that participatory planning manners such as the precede-proceed model should be utilized for designing intervention programs **(Ghaffari et al., 2021).** Hence, the study aimed to evaluate the effect of educational program based on the precede-

proceed planning model on quality of life of children with thalassemia.

Aim of the study:

The study aimed to evaluate the effect of educational program based on the precede-proceed planning model on quality of life of children with thalassemia.

Research objectives:

- Assess children's knowledge about thalassemia.
- Assess attitudes of thalassemic children toward healthy life style.
- Identify the predisposing, reinforcing and enabling factors that promote the behavioral change in order to enhance quality of life of children with thalassemia.
- Determine polices, resources, organizational barriers and facilitators that are needed to improve quality of life of children with thalassemia
- Evaluate the effect of educational program based on the precede-proceed planning model on quality of life of children with thalassemia.

Research hypotheses:

H.1- Children's knowledge about thalassemia will be improved after implementation of the program based on the precede-proceed planning model.

H.2- Children will have positive attitude toward healthy life style after applying the program based on the precede-proceed planning model.

H.3- Children with thalassemia will have higher quality of life scores after implementation of the program based on the precede-proceed planning model than before.

Subjects and Method
Research Design:

A Quasi- experimental research design was used to conduct this study (pre and post-tests).

Research Setting:

The current study was carried out at Pediatric Hematology Unit and Pediatric Hematology Out-Patient Clinic at Benha Specialized Pediatric Hospital affiliated to Egyptian Ministry of Health and Population and Secretory of Specialized Medical Centers at Benha City. The Pediatric Hematology Unit is located in the fourth floor in the medical building of the hospital and consists of 4 rooms, two rooms of them are large rooms and contain 12 beds in each one while the other two rooms are small rooms and contain 4 beds in each one of them. While the Pediatric Hematology Out-Patient Clinic is located in the ground floor and consisted of 3 rooms, two of them were dedicated for examining sick children where they can receive medical care and treatment from healthcare professionals, the third big room are a waiting room for sick children until they are examined.

Sample size equation:

The number of subjects enrolled in this study was estimated according to the following equation:

$$n = t2 \times p (1- p)/m2$$

Where: n = is the sample size

t = confidence level at 95% (standard value 1.96)

P = is estimated prevalence in the study area = .089

m= margin of error at 5% (standard value of 0.05)

* By applying the previous figures to the equation the sample size is:

$$N = \frac{(1.96)^2 \times 0.089 (1-0.089)}{(0.05)^2} = 124.59 \sim 125$$

Sample type:

A purposive sampling of 125 children (one group pre and post); suffering from thalassemia and regularly visit the previously mentioned settings during the period of collecting data to

receive their medical management and nursing care, met the following inclusion and exclusion criteria and agree to take part in the study.

Inclusion criteria:
- Children aged from $8 \leq 18$ years.
- Children with thalassemia
- Both genders.

Exclusion criteria:

Children suffering from other chronic illness, developmental disorders, neurological, sensory, or motor disorders.

Tools of data collection:

Two tools were utilized to gather data pertained to the study as follows:

Tool (I): A structured interviewing questionnaire based on the precede-proceed planning model.

It was designed by the researchers after reviewing the recent and relevant literatures (**Kliegman et al., 2020, Lissauer & Carroll, 2022 and Soedirham, 2018**). It included five parts:

Part 1: Characteristics of the studied children: It included data about the studied children as age, gender, birth order, educational level, place of residence.

Part 2: Medical history of the studied children: It included data pertained to the medical history of the children under study as time at diagnosis of thalassemia, duration of illness, family history and consanguinity.

Part 3: Predisposing factors assessment questionnaire. It is subdivided into two parts:

A- Children's knowledge about thalassemia disease. It consisted of 11 closed-ended questions regarding definition, causes, risk factors, manifestations, types, diagnosis, prevention, treatment, nutrition, activities and complications of thalassemia.

Scoring System of children's knowledge

The scoring system was designed as follows: (1) score was granted for correct answer and (0) for the incorrect. The total level of children's knowledge was classified as follows:
- Poor knowledge: for $< 50\%$
- Average knowledge: for 50% to $< 75\%$
- Good knowledge: for $\geq 75\%$

B- Attitude toward healthy life style: It was adopted from **Bazpour et al., (2019).** It composed of 28 items regarding healthy food (8 items such as; taking regular meals, taking high calories fruits, taking products containing vitamin D, taking food containing vitamin A source …..etc.), dental care (6 items such as; brushing teeth at least twice daily, visiting the dentist in case of teeth pain or dental inflammation, decreasing sweet intake, using fluoride rich tooth paste, …..etc.), sleep (4 items as; sleeping at least 8 hours at night, suffering from insomnia at night…..etc.), activities (5 items as; practicing exercise, avoid hard sports, avoid practicing sports during the time of pain onset …..etc.), healthcare follow up (3 items such as; maintaining a regular follow up, following the medication guidelines…..etc.) and self-actualization (2 items such as; the child can perform by his own what is needed and the disease doesn't stop me from self-fulfilling).

Scoring System

Children's attitude was scored based on 3-points Likert scale: disagree (1), uncertain (2) and agree (3). The total score ranged from 28-84. The total scoring levels were categorized as:
- Negative attitude: for $< 50\%$
- Fair attitude: for 50% to $< 75\%$
- Positive attitude: for $\geq 75\%$

Part 4: Reinforcement factors assessment questionnaire. It consisted of 5 questions concerning social support, influence of peers, familial encouragement and support of health

care staff who reinforce children toward positive behavior as (friends' support, satisfaction with friends' support, familial encouragement, and providing appropriate care).

Part 5: Enabling factors assessment questionnaire. It involved 10 items regarding the existence and accessibility of resources and skills that could modify child's behavior (such as managing stress, interpersonal relations, self-awareness and making use of available information resources, educational programs or counseling center to enhance children's knowledge regarding thalassemia).

Scoring system

Every item on the enabling and reinforcement factors was scored as the following: (0) score for child's response with (No) and (1) score for child's response with (Yes). The total scoring levels were arranged as follows:

- Weak: for <50%
- Moderate: for 50% < 75%
- Strong: for ≥ 75%

Tool (II): Pediatric Quality of Life Inventory (PedsQL) Generic core scale

It was adopted from **Varni et al., (1998)** to assess health related quality of life (HRQOL) of children and adolescents in acute and chronic health conditions. Pediatrics QOL Thalassemic Module Version 4.0 was utilized to assess QOL of children. It consists of 23 items classified into four basic domain; namely, physical functioning (8 items such as finding difficulty in walking, running, making activities, lifting something, feeling Pain in all body, getting tired of least effort…..etc.), emotional functioning (5 items such as being afraid, feeling sad, having sleep troubles, being worried while waiting for medical examination ...etc.), social functioning (5 items

as feeling a lone with other kids, teasing from other kids, difficulty when playing with kids…..etc.), school functioning (5 items as being distracted in class, having problems in school work, missing school due to illness, obtaining lower scholastic achievement level than before….etc.).

Scoring system:

A 5-point Likert scale from never (0), almost never (1), sometimes (2), often (3) and almost always (4) was employed for scoring responses. The total score was 92. It was grouped into 32 scores for physical functioning, 20 scores for emotional functioning, 20 scores for social functioning and 20 scores for school functioning. The total scores of QOL were categorized into:

- High quality of life: for 75%- 100%.
- Moderate quality of life: for 50% to less than 75%.
- Low quality of life: foe less than 50%

Tools validity and reliability:

Tools of collecting data were designed in Arabic language and submitted to a jury of three professors in the field of pediatric nursing from the Faculty of Nursing/ Benha University, to test the content validity of the instruments and judge clarity, comprehensiveness, relevance, simplicity, and accuracy of tools. **Reliability**: The internal consistency of the developed and validated tools for knowledge sheet, attitude toward healthy life style, reinforcement factors assessment questionnaire, enabling factors assessment questionnaire and pediatric quality of life inventory were tested using Cronbach's alpha coefficient. Test retest results reflected that all items were significantly differ and has a correlation above the threshold of significance (r=0.85, 0.93, 0.75, 0.91 & 0.88) respectively.

Ethical considerations:

An official letter illustrating the aim of the study was sent to the hospital director before starting the practical work to conduct the study and gather the required data. Written consent was taken from the participants after clarifying the aim and nature of the study. They were informed that the gathered data will be used only for the purpose research of and they have the right to take part, refuse or withdraw at any time. Total confidentiality of the collected data was secured. The study doesn't cause any harmful effects on children.

Pilot Study:

A pilot study was conducted on 10% (12 children) of the sample size to evaluate the feasibility, applicability of the used tools and time required to collect data. After obtaining the results of the pilot study, the needed adjustments were made according to the study participants' responses, and the final form was created. Participants in the pilot study were excluded from the actual study.

Field work:

Taking into consideration the planning essence of the precede-proceed planning model, the subsequent phases are applied to accomplish the aim of the present study. The phases were conducted from the beginning of July 2022 to the end of April 2023 covering ten months. The researchers introduced themselves to the studied children and illustrated the aim of the study. Written approvals were taken from children to participate in the study before collecting and

after explanation of the aim and nature of the study.

Precede steps (four phases of needs assessment):

Phase 1: Social assessment: The researchers assessed characteristics of children (Tool 1, part 1 & 2) and quality of life for children with thalassemia (Tool 2) using face to face interviews (pretest).

Phase 2: Epidemiological, behavioral and environmental assessment: In this phase, the researchers identified the health priorities and their behavioral and environmental determinants. Also, attitudes of children towards healthy life style were assessed by tool 1, part 3.

Phase 3: Educational and ecological assessment: It identifies the predisposing, reinforcing and enabling factors that initiate or sustain the behavioral change in order to enhance QOL of children with thalassemia by using tool 1.

Phase 4: Administrative, policy assessment and intervention alignment: The purpose of this phase of needs assessment was to identify polices, resources, organizational obstacles and facilitators that were required to implement and sustain the program.

Based on the previous four phases of assessment, the researchers determined the actual needs of children. Then, the educational contents and materials were developed and the program is ready to be applied. The program was developed by the researchers in the light of children's understanding using simplified Arabic language. The booklet was given to all children to be considered as a reference value.
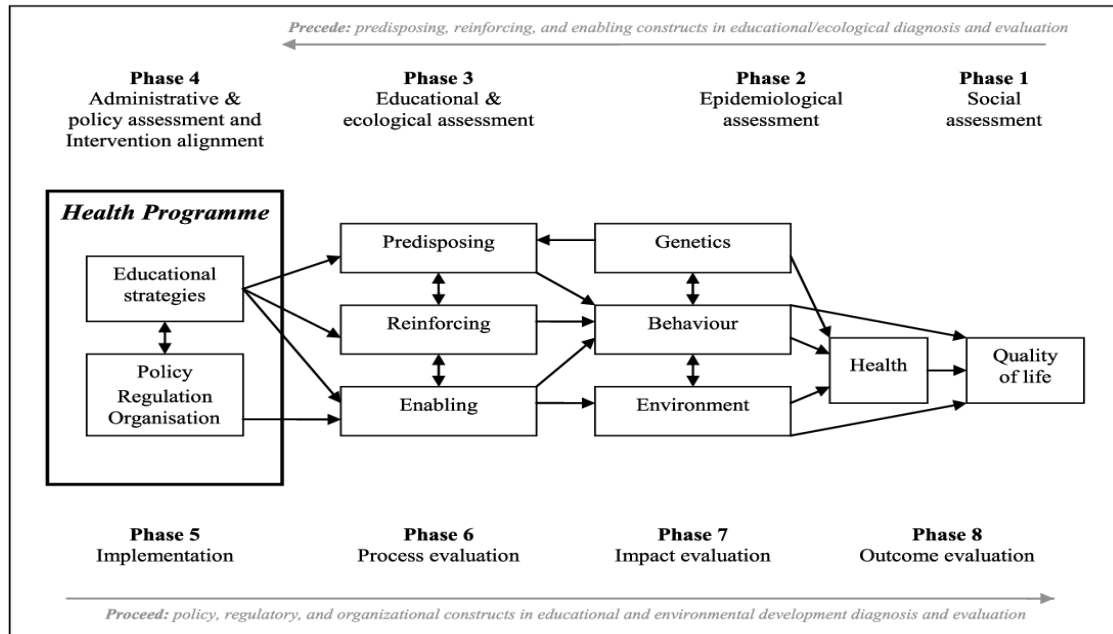
Figure (1): The Precede–Proceed Model
Green L. W. and Kreuter M. W., (2015): Precede-Proceed. P.3.Available at:
www.lgreen.net/precede.htm, accessed: 15/8/2022.

Proceed phases (the last four steps of the model):

Phase 5: Implementation phase: An educational program was implemented for children based on the findings from previous planning phases. The main objective of the program was to enhance the predisposing factors, reinforcing factors, and enabling factors in order to improve QOL for children with thalassemia. The study sample included 125 children; one group pre and post which divided internally into 16 subgroups and each subgroup consisted of 7-8 children to facilitate contact with children and ease implementing the study' phases. The researchers existed in study setting during the morning three days weekly for 4 hours/day.

The program was conducted through four sessions. Each one began with a summary of the previous session and the objectives of the current session. Motivation and reinforcement were used to encourage children to share in the study. Each session ranged from 30 -45 minutes. The sessions were repeated for different subgroups with the same content. Methods of teaching were booklet, pamphlets, lectures, face to face discussion, questions and answers, in addition to educational media such as videos and posters to assist children better understanding content.

Session I: It concentrated on providing adequate knowledge about thalassemia (Predisposing factors) such as definition, causes, risk factors, manifestations, types, diagnosis, prevention, treatment, nutrition, activities and complications of thalassemia.

Session II: It concerned with changing children's' attitudes towards healthy life style (predisposing factors) through informing them about healthy food, dental care, sleeping, activities**,** healthcare follow-up and self-actualization.

Session III: It focused on modifying reinforcing factors such as; encouraging children to be familiar with children suffering from thalassemia and health care staff,

participating in collaborative activities and advising parents to re-enforce their children in adherence to health behaviors positively

Session IV: The aim of this session was to enhance enabling factors via providing information on preventing crises, managing stress, relaxation techniques and providing educational sources such as pamphlets and booklet.

Evaluation based on the precede-proceed planning model.

Phase 6: Process evaluation: It determined to what extent the program was applied based on what had been designed in order to evaluate the operation process of the intervention.

Phase 7: Impact Evaluation: This phase consisted of reassessment of changes in predisposing, reinforcing, enabling factors among children, in addition to the behavioral and environmental factors after program implementation via analyzing questionnaires and meeting children (Post-test using tool 1)

Phase 8: Outcome evaluation: This phase determined the effect of the program on quality of life of children (Post-test using tool 2).

Statistical analysis:

The collected data, revised, organized, coded, tabulated, and analyzed using Statistical Package for Social Sciences (SPSS) version 20. Quantitative data were expressed as mean ($\overline{X}$) and standard deviation (SD). Qualitative data were expressed in form of frequency distribution tables, numbers and percentages. Qualitative variables were analyzed using Chi-Square test (x^2) & correlation coefficient (r) to determine the relation between variables of the study. The observed differences were considered as follows: Non- significant at $P > 0.05$, significant at $P < 0.05$ and highly significant at $P < 0.001$.

Results:

Table (1) reveals characteristics of the studied children. It is clear from this table that, more than half (55.2%) of children were in age group 12 - 18 years, with a mean age of 12.40±3.45 years. Regarding the gender, more than half (52%) of them were females. In relation to birth order, this table revealed that, more than two-thirds (67.2%) of them were the first child. As regards the educational level, more than two-fifths (44.8%) of them had primary education. Moreover, concerning place of residence, less than two-thirds (64.8%) of them were from rural areas.

Table (2) reflects distribution of the studied children according to their medical history. It is noticed from this table that, the majority (86.4%) of children were diagnosed with thalassemia within the first year of life, more than one third (36%) of them suffering from thalassemia 5- < 10 years ago. Moreover, this table represents that, less than one-third (32%) of children had family history of thalassemia and consanguinity was found among more than one quarter (28.8%) of children.

Table (3) shows that, there was a highly statistical significant difference between the results of post-intervention phase compared to pre-intervention phase in favor of post- intervention regarding all items of studied children's knowledge regarding thalassemia (P≤0.001).

Figure (2) displays that, 15.2% and more than three quarters (76%) of studied children had good knowledge about thalassemia pre and post intervention respectively. While, more than half (58.4%) and 13.68% of the studied children had poor knowledge about thalassemia pre and post intervention respectively.

Apparently **table (4)** reveals that, children had lower total mean scores for all domains of attitude toward healthy lifestyle pre-intervention. While, the total mean scores for all domains of attitude toward healthy lifestyle were higher post-intervention implementation (79.7±5.86 versus 51.84±5.65). Additionally, there was marked improvement with a highly statistical significant difference between the results of post intervention compared with pre intervention in favor of post intervention concerning all domains of children's attitude toward healthy lifestyle (P≤0.001).

It is observed from **fig. (3)** that, less than one quarter (24%) and the majority (82.4%) of studied children had positive attitude toward healthy lifestyle at pre & post intervention respectively. While, more than one third (35.2%) and only 9.6% of studied children had negative attitude toward healthy lifestyle pre & post intervention respectively.

Table (5) illustrates that, there was a highly statistical significant difference between the results of post intervention compared to pre intervention in favor of post intervention regarding all items of studied children's reinforcement factors, with p≤0.001.

Table (6) indicates that, there was a highly statistical significant difference between the results of post intervention compared to pre intervention in favor of post intervention regarding all items of studied children's enabling factors, with p≤0.001.

Figure (4): displays that, more than one quarter (28%) and more than two thirds (68.8%) of children had strong reinforcement and enabling factors at pre & post intervention respectively. While, less than one quarter (22.4%) and 15.2% of studied children had weak reinforcement and enabling factors at pre & post intervention respectively.

It is evident from **table (7)** that, children had lower total mean scores for all quality of life domains pre-intervention implementation. Meanwhile, the total mean scores for all quality of life domains were higher post-intervention implementation (75.13±5.916 versus 51.15±5.65). So, there were highly statistical differences between their mean scores pre-intervention as comparing to post-intervention (p ≤ 0.001).

It is evident from **fig. (5)** that, nearly one quarter (24.8%) and less than three quarters (72%) of studied children had high quality of life at pre & post-intervention phases respectively. While, less than one quarter (23.2%) and 12.8% of them had low quality of life pre and post intervention respectively.

Table (8) illustrates that, there was a highly significant statistical positive correlation between total knowledge and total attitude & total quality of life regarding thalassemia at pre-intervention and post-intervention phase (P≤ 0.001).

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Table (1) Distribution of the studied children according to their characteristics (n=125).

Characteristics of the studied children	No.	%
Age (years):		
8- > 12	56	44.8
12 – 18	69	**55.2**
Mean ± SD 12.40±3.45		
Gender:		
Male	60	48.0
Female	65	**52.0**
Birth order:		
The first	84	**67.2**
The second	30	24.0
The third or other	11	8.8
Level of education:		
Primary education	56	**44.8**
Preparatory education	42	33.6
Secondary education	27	21.6
Place of residence:		
Urban	44	35.2
Rural	81	**64.8**

Table (2) Distribution of the studied children according to their medical history (n=125).

Medical history of the studied children	No.	%
Time at diagnosis of thalassemia:		
Within the first year	108	**86.4**
Within the second year	17	13.6
Duration of illness (years):		
< 5	35	28.0
5- < 10	45	**36.0**
10- < 15	29	23.2
15 or more	16	12.8
Family history of thalassemia:		
Yes	40	**32.0**
No	85	68.0
Consanguinity		
Yes	36	**28.8**
No	89	71.2

Table (3): Distribution of the studied children regarding their knowledge about thalassemia at pre/ post-intervention phases (n= 125)

Knowledge items	Pre-intervention				post-intervention				X^2	P-value
	Correct answer		Incorrect Answer		Correct answer		Incorrect answer			
	No.	%	No.	%	No.	%	No.	%		
Definition of thalassemia	81	64.8	44	35.2	111	88.8	14	11.2	29.33	0.000**
Manifestations of thalassemia	100	80.0	25	20.0	120	96.0	5	4.0	15.15	0.000**
Causes of thalassemia	44	35.2	81	64.8	113	90.4	12	9.6	71.82	0.000**
Types of thalassemia	34	27.2	91	72.8	87	69.6	38	30.4	44.99	0.000**
Risk factors of thalassemia	74	59.2	51	40.8	108	86.4	17	13.6	23.35	0.000**
Complications of thalassemia	80	64.0	45	36.0	112	89.6	13	10.4	22.98	0.000**
Diagnosis of thalassemia	60	48.0	65	52.0	110	88.0	15	12.0	45.95	0.000**
Prevention of thalassemia	30	24.0	95	76.0	80	64.0	45	36.0	40.58	0.000**
Appropriate nutrition	55	44.0	70	56.0	115	92.0	10	8.0	70.51	0.000**
Activities	75	60.0	50	40.0	120	96.0	5	4.0	72.42	0.000**
Treatment of thalassemia	40	32.0	85	68.0	92	73.6	33	26.4	43.40	0.000**

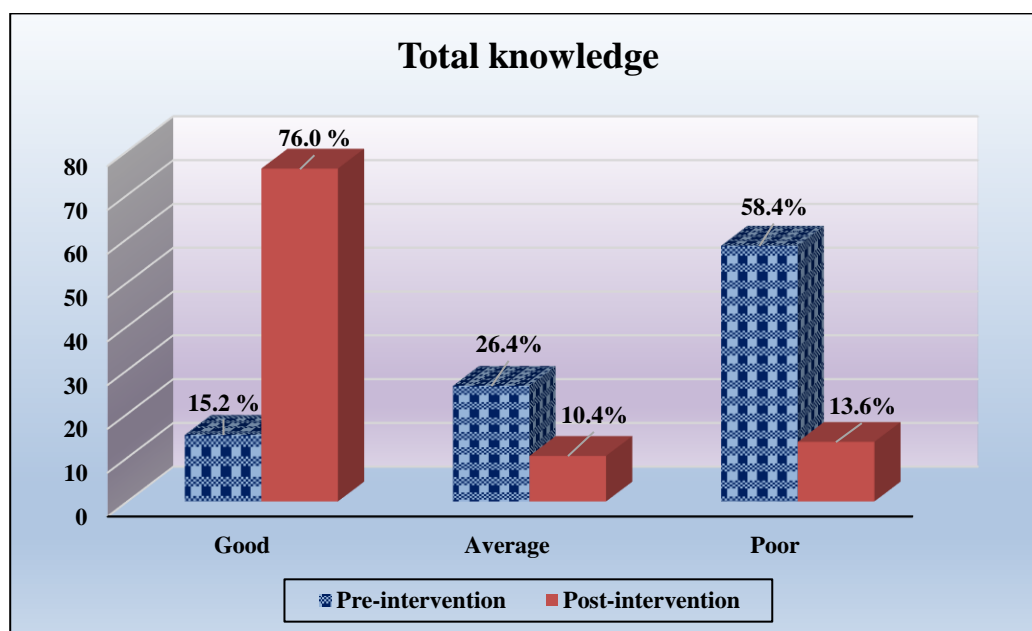**A Highly Statistical significant p $\leq$ 0.001

Figure (2): Percentage distribution of the studied children regarding their total knowledge score about thalassemia at pre/post- intervention phases (n = 125).

Table (4): Mean score of the studied children's attitude toward healthy lifestyle at pre/ post-intervention phases (n = 125).

Attitude domains	Maximum score	Pre-intervention	Post-intervention	Paired t-test	P-value
		Mean ± SD	Mean ± SD		
Healthy food	28	16.92±2.52	22.67±4.18	**13.05**	**0.000****
Dental care	20	7.24±1.83	15.29±2.05	**35.76**	**0.000****
Sleeping	12	6.85±1.34	9.65±1.81	**13.95**	**0.000****
Activities	20	9.87±2.69	15.77±2.72	**17.28**	**0.000****
Healthcare follow up	12	6.13±1.80	9.92±1.39	**17.09**	**0.000****
Self-actualization	8	4.83±1.39	6.38±1.05	**9.79**	**0.000****
Total score:	**100**	**51.84±5.65**	**79.7±5.86**	**36.04**	**0.000****

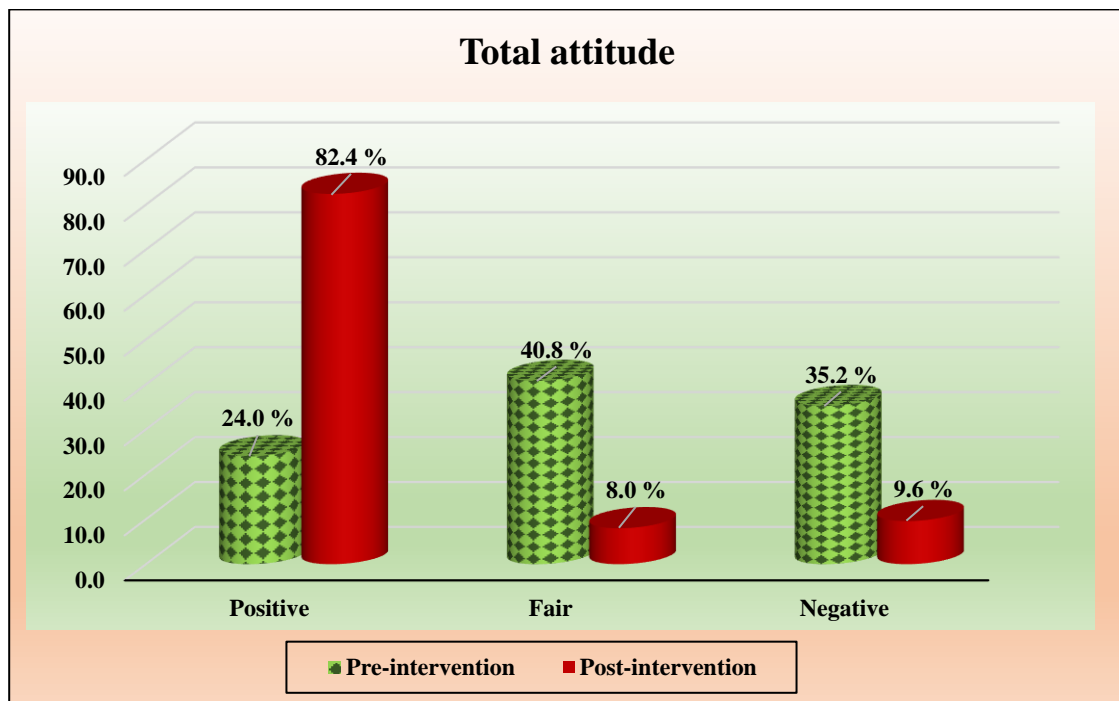**A Highly Statistical significant $p \leq 0.001$

Figure (3): Percentage distribution of the studied children regarding their total attitude score toward healthy lifestyle at pre/ post intervention (n = 125).

Table (5): Distribution of the studied children regarding reinforcement factors at pre/ post-intervention phases (n= 125).

Reinforcement factors	Pre-intervention				Post-intervention				X^2	P-value
	Yes		No		Yes		No			
	No.	%	No.	%	No.	%	No.	%		
I have supportive friends who support me when I need	65	52.0	60	48.0	108	86.4	17	13.6	**34.70**	**0.000****
I am satisfied with my friends support	55	44.0	70	56.0	110	88.0	15	12.0	**53.92**	**0.000****
My family encourage me to take the medication	90	72.0	35	28.0	113	90.4	12	9.6	**13.86**	**0.000****
My family encourage me to follow up with the treating physician	43	34.4	82	65.6	98	78.4	27	21.6	**49.20**	**0.000****
Appropriate care is available at the treatment facility	59	47.2	66	52.8	86	68.8	39	31.2	**11.97**	**0.001****

**A Highly Statistical significant p ≤ 0.001

Table (6): Distribution of the studied children regarding enabling factors at pre/ post-intervention phases (n = 125).

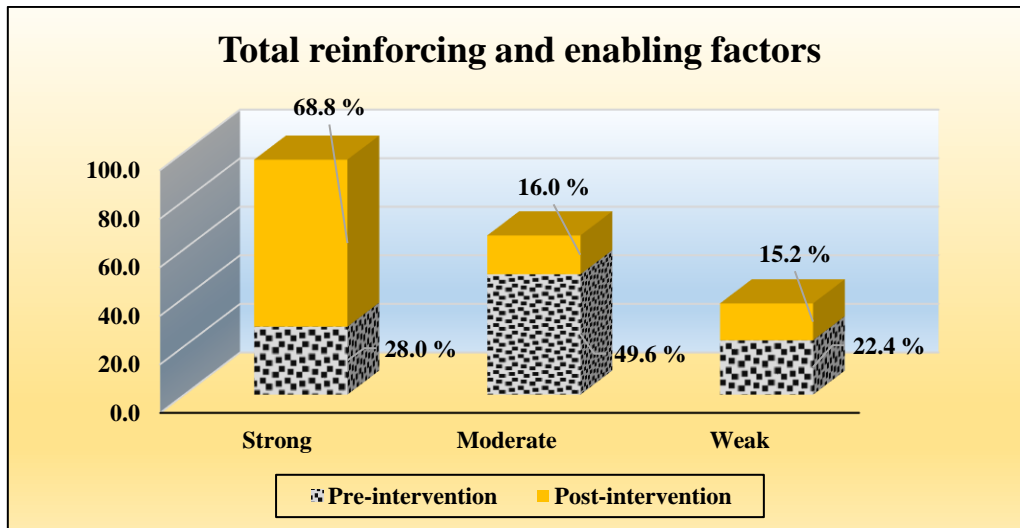| Enabling factors	Pre-intervention				Post-intervention				X^2	P-value
	Yes		No		Yes		No			
	No.	%	No.	%	No.	%	No.	%		
I can prevent the onset of thalassemia pain	58	46.4	67	53.6	112	89.6	12	9.6	**53.60**	**0.000****
Pain onset can be prevented by avoiding stressful activities	94	75.2	26	20.8	118	94.4	7	5.6	**17.87**	**0.000****
Pain onset can be prevented by avoiding sources of infection	54	43.2	71	56.8	90	72.0	35	28.0	**21.22**	**0.000****
I can get rid of stress resulting from thalassemia disease	48	38.4	77	61.6	107	85.6	18	14.4	**59.10**	**0.000****
Thalassemia doesn't affect my relations with others	31	24.8	94	75.2	111	88.8	14	11.2	**104.33**	**0.000****
Thalassemia doesn't lead me to self-isolation	42	33.6	83	66.4	100	80.0	25	20.0	**54.83**	**0.000****
I am not bullied by others when symptoms of thalassemia appear	54	43.2	71	56.8	102	81.6	23	18.4	**39.28**	**0.000****
I participate on thalassemia awareness group	39	31.2	86	68.8	94	75.2	31	24.8	**48.59**	**0.000****
I participate on thalassemia psychological support group	29	23.2	96	76.8	87	69.6	38	30.4	**54.10**	**0.000****
I have the access to the healthcare when necessary	74	59.2	51	40.8	109	87.2	16	12.8	**24.97**	**0.000****

**A Highly Statistical significant p ≤ 0.001

Figure (4): Percentage distribution of the studied children regarding their total reinforcement and enabling factors scores at pre/ post- intervention phases (n = 125).

Table (7): Mean score of the studied children's quality of life inventory (PedsQL) generic core at pre/ post- intervention phases (n = 125).

Quality of life domains	Maximum score	Pre-intervention Mean ± SD	Post-intervention Mean ± SD	Paired t-test	p-value
Physical functioning	32	22.48±4.52	25.04±4.51	**4.16**	**0.000****
Emotional functioning	20	9.98±1.69	16.80±2.46	**26.13**	**0.000****
Social functioning	20	10.64±1.93	17.43±2.41	**25.39**	**0.000****
School functioning	20	8.06±1.95	15.84±2.15	**30.85**	**0.000****
Total score:	**92**	**51.15±5.65**	**75.13±5.916**	**29.93**	**0.000****

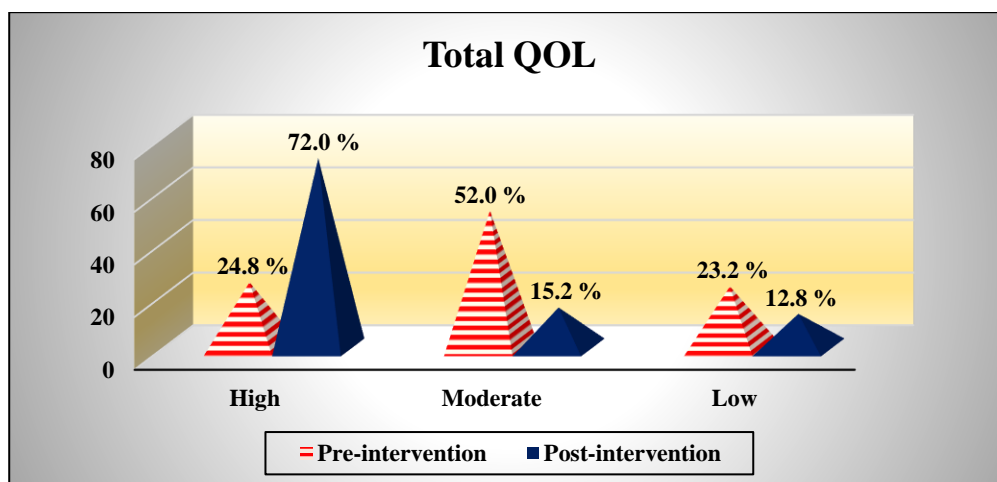**A Highly Statistical significant $p \leq 0.001$

Figure (5): Percentage distribution of the studied children regarding their total quality of life inventory (PedsQL) generic core scores at pre/ post- intervention phases (n= 125).

Table (8): Correlation between total knowledge and total attitude & total quality of life scores of the studied children regarding thalassemia at pre/ post intervention phases (n= 125).

Variables	Total knowledge			
	Pre		Post	
	r	P-value	r	P-value
Total attitude	0.559	**0.000****	0.513	**0.000****
Total quality of life	0.614	**0.000****	0.667	**0.000****

**A Highly Statistical significant p ≤ 0.001

Discussion

Thalassemia is considered the utmost popular hereditary chronic anemia disorder worldwide, and it has become a prime global issue as it affects life expectancy and QOL. So, the necessity for improvement in QOL remains a central accountability of the health care providers. Taking into consideration the improved survival rates, and respecting the value of QOL improvement as an essence target of healthcare provision, closer interest should be paid to the accurate determination of factors influencing QOL in pediatric patients with thalassemia. The efficiency of health education programs victoriously based on the selection of the proper health behavior model as it provides an obvious conception of strategies and intervention aims. Thus, applying the precede-proceed planning model as a conceptual scope to set apart factors affecting QOL in thalassemic pediatric patients is an advantage (**Maheri et al., 2020**).

Regarding characteristics of the studied children (table 1), the findings of this study reflected that, more than half of children were in age group 12 - 18 years, with a mean age of 12.40±3.45 years, more than half of

them were females, more than two-thirds were the first child and more than two-fifths of them had primary education. Moreover, in relation to place of residence, less than two-thirds of them were from rural areas. The results of the current study are in the same context with **Khalil et al., (2019)** who assessed quality of children with beta thalassemia major and showed that, the age of more than one third of children ranged from 6<10 and 10<14 years, while rest of them aged from 14 <18 years, with a mean age of 10.73±3.01 years, more than half of children were females and the highest percentage of them were in primary schools.

Similarly, these findings agree with **Abdel Aziz et al., (2021)** who conducted a study entitled "Impact of life style modification module on adherence to therapeutic regimen of children and adolescents with beta thalassemia major" and found that, more than two fifth of the studied children aged from 13 to <16 years with a mean age 14.25±2.84 years, more than half of them were females, and less than two of them were from rural areas. Moreover, these results agree with **Mahmoud et al., (2019)** in a study entitled "Quality of life of children in

Alexandria" and illustrated that, female gender constituted more than half of studied children, more than three quarters of them had primary education and two fifths of children ranked as the first birth order.

Concerning the medical history of the studied children (table 2), the results of the current study demonstrated that, the majority of children were diagnosed with thalassemia within the first year of life, more than one third of them suffering from thalassemia 5- < 10 years ago, less than one-third of children had family history of thalassemia and consanguinity was found among more than one quarter of children. These results are corresponding with **Biswas et al., (2023),** who studied "An Epidemiological Study of the Quality of Life of Children With Beta-Thalassemia Major and Its Correlates" who pointed that, less than three quarters of children were from rural areas, and more than half of them were diagnosed within the first year of life, and less than one quarter of children had family history of thalassemia.

In contrast, these results disagree with **Kafl & El-shahat, (2020)** who evaluated the "Effect of an Educational program on Nursing Care Practices regarding Pediatric Transfusion-Dependent β -Thalassemia Major" and found that, less than one third of the studied children were diagnosed as thalassemia for less than 5 years.

Additionally, **Jajhara et al., (2021)** who studied "Quality of life among thalassemic children aged 8 to 18 years", reflected that, less than three quarters of children were diagnosed as beta thalassemia by the first year of life, more than two-fifths of them had similar conditions in the family and consanguinity was present among one fifth of the parents. Likewise, **Ankush et al.,**

(2019) carried out a study entitled "Quality of life in children with thalassemia major following up at a tertiary care center in India" and noted that, more than one fifth of children had a positive family history and also, more than one fifth born out of consanguineous marriage.

Regarding knowledge of the studied children about thalassemia (table 3 & fig. 2), the current study clarified that, there was a highly statistical significant difference between the findings of post intervention phase compared to pre-intervention phase in relation to all items of children's knowledge about thalassemia (p≤0.001). Whereas, 15.2% and more than three quarters of children had good knowledge about thalassemia at pre & post intervention respectively. However, more than half and 13.68% of them had poor knowledge about thalassemia at pre & post intervention respectively. This could be interpreted due to applying simple methods of teaching and illustrative media to facilitate communication with children. This confirmed the effectiveness of the educational program based on the precede-proceed model in improving knowledge of children regarding thalassemia, taking into consideration that knowledge is of high significance in building positive attitudes and behaviors.

On the same scope, these results agree with **Abdel Aziz et al., (2021)** who found that, more than three quarter of the studied subjects had satisfactory knowledge regarding beta thalassemia after application of lifestyle modification module compared to pre intervention, with statistical significant difference between pre and post module implementation P <0.001. Similarly, the findings of the current study are in concurrence with **Bazpour et al., (2019)** who evaluated "The effect of a training program based on the

precede-proceed model on lifestyle of adolescents with beta thalassemia" and found that, the mean score of knowledge was weak in the two groups before intervention, however post intervention it became good in the study group, without any change in the control group.

Furthermore, these results agree with **Kim et al., (2022)** who evaluated "Effect of the precede-proceed model on health care programs" and concluded that, knowledge could be effectively improved when the program is implemented based on this model and added that, it will be beneficial to integrate the precede-proceed model in conducting programs for managing disease and promoting health.

Regarding attitudes of children's toward healthy lifestyle (table 4 & fig. 3), the results of present study represented that, there was marked improvement with a highly statistical significant difference between the results of post intervention compared to pre intervention in favor of post intervention in relation to all domains of children's attitudes toward healthy lifestyle (P≤0.001). Whereas, less than one quarter and the majority of children had positive attitude towards healthy lifestyle at pre & post intervention respectively. While, one third and 9.6% of them had negative attitude toward healthy lifestyle at pre & post-intervention phases respectively. This emphasized the effectiveness of the precede-proceed planning model in enhancing children's attitude toward healthy lifestyle. Moreover, the improvement of children's knowledge affects their attitudes toward healthy lifestyle positively.

The findings of the current study are supported by **Elkholy et al., (2022)** who evaluate the effect of application of precede-proceed planning model on quality of life

among children with sickle cell anemia" and stated that, half of studied children had negative attitudes pre intervention, while the majority of them had positive attitudes post intervention. Also, there was highly statistical significant difference between attitudes of children pre and post intervention (P <0.001). Similarly, **Bazpour et al., (2019)** emphasized that, there were no differences over time regarding the mean attitude score in control group; however it reached to the moderate level immediately post- intervention in the study group.

As regards children's reinforcement and enabling factors (table 5, 6 & fig. 4), the current study illustrates that, there was a highly statistical significant difference between the findings of post intervention compared to pre intervention as regards all items of studied children's reinforcement and enabling factors, with p≤0.001. Whereas, more than one quarter and more than two thirds of children had strong reinforcement and enabling factors pre & post intervention respectively. Meanwhile, less than one quarter and 15.2% of them had weak reinforcement and enabling factors pre & post-intervention respectively. This could be contributed to the effectiveness of the precede–proceed planning model as a conceptual framework in identifying and enhancing reinforcement and enabling factors which in turn affect QOL of children

The finding of the present study is compatible with **Bazpour et al., (2019)** who reported that, children in both groups had weak enabling and reinforcing factors at baseline, however post-intervention these factors reached the high level in the study group, with no change in the control group. Furthermore, the precede-proceed model is considered a suitable model for planning and

applying the training programs for enhancing healthier lifestyle. Likewise, these findings coincide with **Ghaffari et al., (2021)** who conducted a study entitled "Design, implementation and evaluation of a precede-proceed model-based intervention for oral and dental health among primary school students" and concluded that, intervention program based on the precede-proceed planning model was effective in enhancing behavior, as well as predisposing, enabling, and reinforcing factors.

Concerning quality of life of the studied children (table 7 & fig. 5), the results of the present study reflected that, children had lower total mean scores for all quality of life domains pre-program implementation. Meanwhile, the total mean scores for all quality of life domains were higher post-program implementation (75.13±5.916 versus 51.15±5.65). And, there were highly statistical differences between their mean scores pre-intervention compared with post-intervention (p ≤ 0.001). Whereas, nearly one quarter and less than three quarters of children had high quality of life pre- and post-intervention phases respectively. Meanwhile, less than one quarter and 12.8% of them had low quality of life before and after implementation of the program respectively.

This result is in the same context with **Mahmoud et al., (2019)** who reported that, the level of quality of life for children was low for the vast majority. This may be attributed to repeated hospital visits for prolonged treatment which in turn results in low school achievement, physical pain affecting their activities of daily life, low self-esteem due to physical changes and feeling of stigmatization leading to social isolation. On the same scope, **Bazpour et al., (2019)** indicated that, the overall score and the scores of dimensions of

the lifestyle were increased post-intervention in the study group.

Likewise, **Jajhara et al., (2021)** clarified that, less than one third of children had good QOL score, while less than two-thirds of them had fair score and concluded that, thalassemia like other chronic diseases had many negative impacts on perceived physical, emotional, social and school functioning that can lead to impaired quality of life among thalassemic children. **Elkholy et al., (2022)** demonstrated the majority of children had poor QOL in pre-test. However, two-thirds of them had moderate QOL on post-test. It reflects the impact of the educational program based on the precede-proceed planning model in improving children's knowledge and attitude towards healthy life style. Additionally, the precede-proceed planning model is considered successful in modifying reinforcing and enabling factors resulting in positive effects on children which in turn improve their quality of life.

Regarding correlation between total knowledge and total attitude & total quality of life scores of the studied children regarding thalassemia (table 8), the results of current study showed that, there was a highly significant statistical positive correlation between total knowledge and total attitude & total quality of life regarding thalassemia at pre-and post-intervention phase (P≤ 0.001). This result is in harmony with **Mardhiyah et al., (2023)** who carried out a study entitled "Nursing interventions to improve quality of life among children and adolescents with thalassemia" and stated that, there was a relation between knowledge and QOL in children with thalassemia. This could be interpreted as good knowledge regarding thalassemia can increase confidence of children in caring for themselves which in turn improve QOL. In contrast, this results

disagree with **Khalil et al., (2019)** who found that, there was a negative correlation between QOL of children and their knowledge (P=.024).

Conclusion:

The educational program based on the precede–proceed planning model was effective in improving children's knowledge about thalassemia and enhancing their attitudes toward healthy lifestyle. Moreover, children with thalassemia had higher quality of life scores after implementation of the program based on the precede–proceed planning model.

Recommendations:
- Integrating of precede-proceed planning model in designing intervention programs in pediatric hematology units.
- Providing updated guidelines and manual booklets for children concerning enhancing quality of life in the pediatric hematology units.
- Conducting the study in different settings of hematological units to generalize the results and raise the level of awareness about improving quality of life.

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تأثير برنامج تعليمى مبنى على نموذج التخطيط المسبق على جودة حياة الأطفال المصابين بأنيميا البحر المتوسط

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تعتبر أنيميا البحر المتوسط من اضطرابات الدم الوراثية التى تؤثر على تكوين الهيموجلوبين, مما يؤثر على جودة حياة الأطفال بسبب المرض والعلاج المقدم للأطفال. لذا هدفت هذه الدراسة الي تقييم تأثير برنامج تعليمى مبنى على نموذج التخطيط المسبق على جودة حياة الأطفال المصابين بأنيميا البحر المتوسط. حيث تم استخدام تصميم شبه تجريبي. و تم إجراء هذه الدراسة فى وحدة دم الأطفال وعيادة دم الأطفال الخارجية بمستشفى الأطفال التخصصى ببنها على عينة غرضية مكونة من 125 طفل. واظهرت نتائج الدراسة بأن أقل من ربع الأطفال و أقل من ثلاثة أرباع الأطفال كان لديهم مستوى جودة حياة عالي قبل وبعد تنفيذ البرنامج على التوالى. بينما أقل من ربع الأطفال و 12.8% من الأطفال كان لديهم مستوى جودة حياة قليل قبل وبعد تنفيذ البرنامج على التوالى. كما ان الأطفال المصابين بأنيميا البحر المتوسط كان لديهم مستوى جودة حياة عالي بعد تنفيذ البرنامج المبنى على نموذج التخطيط المسبق. واوصت الدراسة بدمج واستخدام نموذج التخطيط المسبق فى تصميم البرامج التعليمية فى وحدات دم الأطفال.