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| RESEARCH ARTICLE

Evaluation of A designed Program to Improve Quality of Life among β-Thalassemia Major Patients in Gaza Strip, Palestine

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| ABSTRACT

β-thalassemia (β-TM) is a global public health problem that affect populations from different parts of the world. Purpose: The purpose of the study was to evaluate the effectiveness of a designed program to improve the quality of life among thalassemia patients in Gaza Strip. Material & methods: The study used quazi-experimental design (pre-test, intervention, post-test). In this study 50 thalassemic patients (aged 16 years and more) attended an educational program to improve their quality of life (QoL). The researcher used the short form of QoL questionnaire (WHOQoL-BREF) designed by WHO (1997). Reliability of the questionnaire was tested and alpha coefficient was 0.88. Results: the mean age of the participants was 21.74 (16 – 30 years), 56% male and 44% female patients. The mean QoL score was 2.82 (56.4%) before intervention, increased to 3.32 (66.4%) after intervention. The mean score of satisfaction with health was 2.84 (56.8%) before intervention, increased to 3.08 (61.6%) after intervention. The mean score of physical health was 2.65 before intervention increased to 3.23 after intervention. The mean score of psychological health was 2.83 before intervention increased to 3.39 after intervention. The mean score of social relations was 3.00 before intervention increased to 3.52 after intervention. The mean score of satisfaction with environment was 2.66 before intervention increased to 3.35 after intervention. The overall mean score of QoL was 2.75 before intervention increased to 3.33 after intervention with 21.09% change. Participants aged 20 years and less expressed significant higher QoL after intervention compared to younger patients. There were no significant differences in QoL scores related to gender, level of education, and work status. Conclusion: The study concluded that the education program was effective and improved the level of QoL significantly.

| KEYWORDS

Thalassemia major, Quality of life, Education program, Gaza Strip, Palestine

| ARTICLE INFORMATION

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Introduction

Beta-thalassemia (β-TM) is considered as a major public health problem in the Mediterranean region and Southeast Asia (Baraz et al., 2016), especially in the Middle East and North Africa where a high percentage of β-TM patients and carriers has been reported. This is attributed to consanguineous marriage in these areas, as there was a strong relationship between consanguineous marriage and prevalence of β-thalassemia (Masih et al., 2023). Individuals with β-TM usually present with failure to thrive and progressive pallor requiring regular blood transfusions to survive, abdominal enlargement, caused by splenomegaly and the risk of developing iron overload related complications.

It is estimated that about 4.5% of the population in Egypt have β-TM (Hamdy et al., 2021). In Iran the prevalence of β-TM ranged between 1 to 10% in different regions of Iran (Dehaghi et al., 2016), estimated at 2.8% in Sri Lanka (Premawardhena et al., 2017), while 3.22% of the screened population are carriers and around 0.7% had thalassemia in Saudi Arabia (Alqahtani et al., 2024).

According to reports of Ministry of Health (MoH), the total number of thalassemia patients in the Palestinian territories (West Bank and Gaza Strip) is 866, of whom 309 are in the GS (170 males and 139 females). The impact can range from mild to severe and life-threatening, where patients depend on blood transfusion to survive.

Complications include jaundice and gall stones due to hyperbilirubinemia, cortical thinning and distortion of bones due to extramedullary hematopoiesis, high output cardiac failure due to severe anemia, cardiomyopathies, and arrhythmias - cardiac involvement is the major cause of mortality in thalassemia patients, hepatosplenomegaly due to extramedullary hematopoiesis and excess iron deposition due to repeated blood transfusions, excess iron can lead to findings of primary hemochromatosis such as endocrine abnormalities, joint problems, skin discoloration, neurological complications such as peripheral neuropathies, slow growth rate and delayed puberty, and increased risk of parvovirus B19 infection (Benites et al., 2019; Paul et al., 2019).

For such chronic conditions, not only patient survival is important but also their quality of life; psychological and social functioning are particular constraints. In addition, bio-psycho-social sequelae and accompanying depression lead to further deterioration in health-related quality of life (HRQoL) (Bahall & Bailey, 2022). The complications of thalassemia major are known to affect quality of life (QoL).

Although, morbidity and mortality of the β-TM has been reduced significantly in the light of modern medical treatment, however, it could influence diverse aspects of patients' lives. Some aspects of thalassemia major and its associated complications are expected to impact on the QoL.

Patients with β-TM come to the hospital to receive treatment and blood transfusion, but no follow up at home regarding their psychosocial life and educational opportunities as a consequence to this chronic disease. The QoL of patients with β-TM have been assessed in very few studies (Hamdy et al., 2021; Arian et al., 2020; Hakeem et al., 2018; Dehaghi et al., 2016), but no studies assessed the QoL of those patients in the Palestinian community, therefore, we do not have accurate information about the QoL of β-TM patients in Gaza Strip (GS).

This study focused on assessing the QoL in order to gain better understanding of their specific needs, then designing and implementing a training program to improve the QoL for β-TM patients in GS.

Methodology

Study design

The researcher used one group, Quazi-experimental design. The participants were selected from the registration files in the Turkish Friendship Hospital specialized for oncology and blood disease. The intervention program was implemented in a private center (Al Aqsa Center for Language Teaching) in Khanyounis.

Population and sample of the study

The population of the study consisted of all the thalassemia patients in Gaza Strip. The estimated number of registered patients diagnosed with thalassemia in governmental hospitals in Gaza Strip is about 309 patients. The sample of the study consisted of 50 patients who met inclusion criteria. They were recruited and invited to attend the educational program about QoL. The study was conducted during the period from September 2021 to August 2023. The intervention program commenced on January to March 2023.

Instruments of the study

The researcher used one instruments: The Quality of Life questionnaire. The researcher used the short form of QoL questionnaire (WHOQoL-BREF) designed by WHO (US version, 1997). Attached to each questionnaire a consent form to obtain acceptance of participants to be included in the study. The questionnaire was translated to Arabic to ease understanding by participants. The first part includes the sociodemographic characteristics of the participants, and the questionnaire consisted of the following domains and items: 1) Overall quality of life and general health (2 items); 2) Physical health: consisted of (7 items); 3) Psychological health: consisted of (6 items); 4) Social relationships: consisted of (3 items); and 5) Environment: consisted of (8 items).

Responses to the questionnaire items were measured using a 5-point Likert scale. For quality of life items, response options ranged from (5) an extreme amount, (4) very much, (3) a moderate amount, (2) a little, to (1) not at all. Satisfaction with health was assessed using a similar 5-point scale, with responses ranging from (5) very satisfied, (4) satisfied, (3) neutral, (2) unsatisfied, to (1) absolutely unsatisfied.

Description and components of the education program to improve QoL

The educational program was developed based on the findings of a pilot study, which identified participants' strengths and areas requiring improvement. Insights from the pilot analysis guided the structure and content of the program. The program consisted of four educational sessions delivered using interactive teaching strategies, including PowerPoint presentations, case scenarios, and educational videos. The Quality of Life (QoL) education program (Annex 4) was designed to enhance participants' overall well-being by addressing multiple dimensions of life beyond physical health. Core components included goal setting and planning, adoption of a holistic approach encompassing physical, psychological, social, and spiritual aspects, development of self-awareness and essential life skills, resilience building, and the application of positive psychology principles. The program also emphasized strengthening social support networks, promoting healthy lifestyle behaviors, fostering cultural competence, enhancing environmental awareness, and incorporating continuous evaluation and participant feedback to ensure relevance and effectiveness.

Data collection

The researcher collected data by himself. The researcher recruited the eligible patients to participate in the study. The patients were invited to fill the questionnaire before the intervention program (pre-test). They received instructions about filling the questionnaire and about the study as a whole. Also, after completion of the training program, the participants filled the questionnaire (post-test).

Data management and statistical analysis

The questionnaires had been coded, then the researcher entered the questionnaires to the computer. The researcher used SPSS program (version 25) for data entry and statistical analysis. Statistical analysis included frequencies, means, percentage, independent sample (t) test, and One-way ANOVA test, and paired sample (t) test.

Ethical and administrative considerations

Before conducting the study, the researcher obtained agreement to carry out the study from Albutana University in Sudan. In addition, a consent form had been attached to each questionnaire explaining the purpose of the study, and participants were assured about confidentiality of the collected information.

Results

Sociodemographic characteristics of study participants

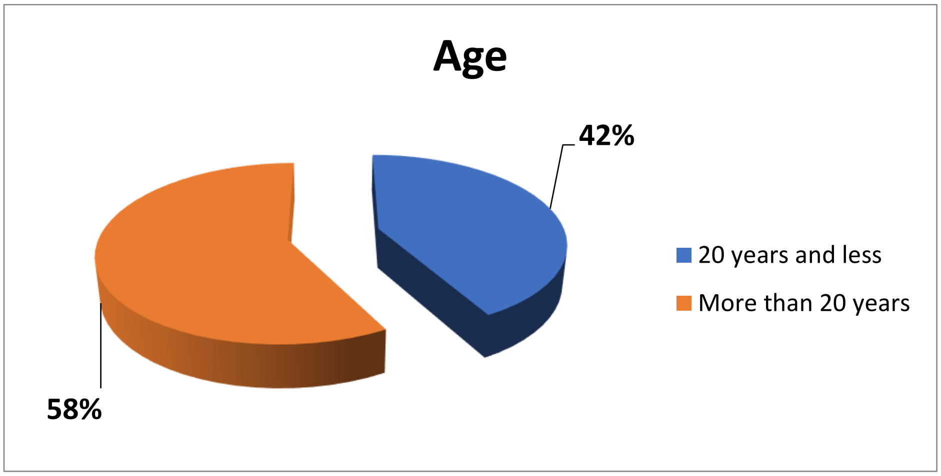

Figure (1): Distribution of study participants by age

The study participants consisted of 50 patients, their age ranged between 16 – 30 years, 21 (42%) of study participants aged 20 years and less, and 29 (58%) aged more than 20 years old. Their mean age was 21.74±3.445 years.

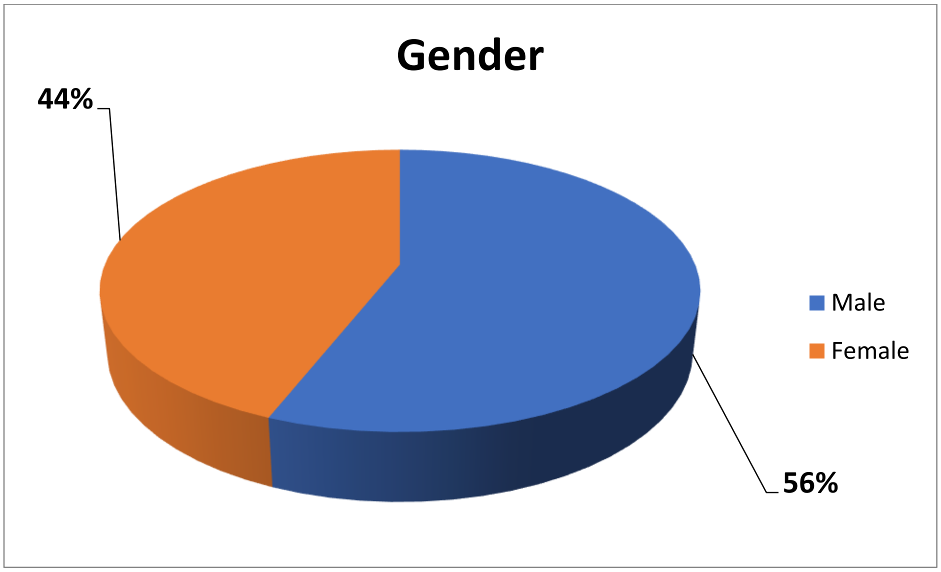

Figure (2): Distribution of study participants by gender

Figure (2) showed that 28 (56%) of study participants were male patients and 22 (44%) were female patients.

Table (1): Sociodemographic characteristics of study participants

Variable	**Number**	**Percentage (%)**
Level of education		
Secondary school and less	30	60.0
University	20	40.0
Total	50	100.0
Working status		
Working	13	26.0
Not working	37	74.
Total	50	100.0

Table (1) showed that 30 (60%) of study participants completed secondary school or less and 20 (40%) had university education.

Quality of life and health

Table (2): Overall quality of life and general health

How would you rate your quality of life?		Very bad	Bad	Some how	Good	Very good	Mean	SD	%
	Pre	6.0	24.0	52.0	18.0	0	2.82	0.800	56.4
	Post	0	10.0	52.0	34.4	4.0	3.32	0.712	66.4
How satisfied are you with your health?		Absolutely unsatisfied	Unsatisfied	Neutral	Satisfied	Very satisfied	Mean	SD	%

	Pre	4.0	40.0	24.0	32.0	0	2.84	0.934	56.8
	Post	0	34.0	24.0	42.0	0	3.08	0.876	61.6

Before the intervention program, the participants rated their QoL on a scale from "very bad" to "very good". The majority (52.0%) rated it as somehow, followed by 24.0% as bad, 18.0% as good, and no respondents in the extreme categories. The mean QoL score was 2.82, with a standard deviation of 0.800. After the intervention, there was a noticeable improvement. No participants rated their QoL very bad, and 34.4% rated it as very good.

Also, participants were asked to rate their satisfaction with health on a scale from "absolutely unsatisfied" to "very satisfied". The largest proportion (40.0%) were unsatisfied, followed by 32.0% as satisfied, and no respondents were absolutely unsatisfied or very satisfied. After the intervention, there was an overall improvement in satisfaction with health. The percentage of participants who were satisfied increased from 32.0% to 42.0%, and no respondents were absolutely unsatisfied.

As presented in table (2), the mean score of quality of life was 2.82 (56.4%) before the educational program increased to 3.32 (66.4%) after the educational program. Furthermore, the mean score for satisfaction with health was 2.84 (56.8%) before the educational program, increased to 3.08 (61.6%) after the educational program.

Table (3): Response of study participants about physical health

Physical health items		Pre-test		Post-test		t	P value
		Mean	SD	Mean	SD		
1	To what extent do you feel that physical pain prevents you from doing what you need to do? ®	3.06	0.890	3.38	0.805	-2.850	0.006*
2	How much do you need any medical treatment to function in your daily life? ®	2.70	0.931	3.060	0.890	-3.174	0.003*
3	Do you have enough energy for everyday life?	2.20	0.728	3.140	0.947	-5.309	0.000*
4	How well are you able to get around?	2.90	0.814	3.46	0.885	-3.832	0.000*
5	How satisfied are you with your sleep?	2.68	0.868	3.280	1.088	-4.041	0.000*
6	How satisfied are you with your ability to perform your daily living activities?	2.56	0.907	3.120	1.002	-4.478	0.000*
7	How satisfied are you with your capacity for work?	2.48	1.092	3.200	1.160	-4.086	0.000*
Total		**2.65**	**0.555**	**3.23**	**0.430**	**-7.023**	**0.000***

® reverse sentence Paired sample t-test *Significant at 0.05

Table (3) presented pre-test and post-test results for various physical health items, with mean scores and standard deviations. A t-test was conducted to assess the significance of changes, and the resulting t-values and p-values are provided.

To what extent do you feel that physical pain prevents you from doing what you need to do? There is a significant increase from a mean of 3.06 to 3.38 (t = -2.850, p = 0.006), indicating that participants felt more hindered by physical pain after the intervention.

How much do you need any medical treatment to function in your daily life? The mean score increased from 2.70 to 3.06 (t = -3.174, p = 0.003), suggesting an increased perceived need for medical treatment to maintain daily functioning.

Do you have enough energy for everyday life? A substantial improvement is observed from 2.20 to 3.14 (t = -5.309, p = 0.000), indicating an increase in perceived energy levels for daily activities.

How well are you able to get around? Participants reported better mobility, with the mean score increasing from 2.90 to 3.46 (t = -3.832, p = 0.000).

How satisfied are you with your sleep? Satisfaction with sleep significantly improved from 2.68 to 3.28 (t = -4.041, p = 0.000).

How satisfied are you with your ability to perform your daily living activities? Participants reported increased satisfaction with their ability to perform daily activities, as the mean score rose from 2.56 to 3.12 (t = -4.478, p = 0.000).

How satisfied are you with your capacity for work? Similar to the other measures, there was a significant improvement in satisfaction with work capacity, with the mean increasing from 2.48 to 3.20 (t = -4.086, p = 0.000).

In general, The overall mean increased from 2.65 to 3.23, reflecting a comprehensive improvement in participants' physical health (t = -7.023, p = 0.000).

Table (4): Response of study participants about psychological health

Psychological health items		Pre-test		Post-test		t	P value
		Mean	SD	Mean	SD		
1	How much do you enjoy life?	2.76	0.894	3.06	0.842	-2.605	0.012*
2	To what extent do you feel your life to be meaningful?	3.02	0.892	3.54	0.908	-3.487	0.001*
3	How well are you able to concentrate?	2.88	1.043	3.22	0.953	-2.621	0.012*
4	Are you able to accept your bodily appearance?	2.70	0.789	3.22	0.789	-3.949	0.000*
5	How satisfied are you with yourself?	2.92	1.007	3.64	0.984	-4.598	0.000*
6	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	2.74	1.026	3.70	0.839	-5.943	0.000*
Total		**2.83**	**0.542**	**3.39**	**0.456**	**-8.448**	**0.000***

Paired sample t-test *Significant at 0.05

Table (4) presented the results of a psychological health assessment with pre-test and post-test scores on various dimensions. Here's a breakdown of the information:

The study assessed psychological health using a set of six items and a total score. Pre-test scores represent participants' responses before intervention. Post-test scores indicate participants' responses after intervention.

Participants reported a significant increase in enjoyment of life (t = -2.605, p = 0.012), a significant increase in the meaningfulness of their lives (t = -3.487, p = 0.001), a significant improvement in concentration abilities (t = -2.621, p = 0.012), a significant improvement in accepting their bodily appearance (t = -3.949, p = 0.000), a significant increase in self-satisfaction (t = -4.598, p = 0.000), and a significant decrease in negative feelings like blue mood, despair, anxiety, and depression (t = -5.943, p = 0.000).

The total psychological health score also showed a significant improvement (t = -8.448, p = 0.000).

Table (5): Response of study participants about social relationships

Social relations items		Pre-test		Post-test		t	P value
		Mean	SD	Mean	SD		
1	How satisfied are you with your personal relationships?	3.42	1.052	3.82	0.940	-3.130	0.003*
2	How satisfied are you with your sex life?	2.26	1.006	3.140	0.969	-4.892	0.000*
3	How satisfied are with the support you get from your friends?	3.32	0.978	3.60	1.010	-3.259	0.002*
Total		**3.00**	**0.743**	**3.52**	**0.677**	**-5.511**	**0.000***

Paired sample t-test *Significant at 0.05

Table (5) presented results from a social relations assessment with pre-test and post-test scores on different dimensions. Analysis of the information about response to social relations items as follows:

How satisfied are you with your personal relationship? The increase in mean satisfaction from pre-test (3.42±1.052) to post-test (3.82±0.940) is statistically significant, as indicated by the p-value (0.003). Participants reported a higher level of satisfaction with their personal relationships after the intervention.

How satisfied are you with your sex life? The increase in mean satisfaction from pre-test (2.26±1.006) to post-test (3.140±0.969) is statistically significant, as indicated by the p-value (0.000). Participants reported a higher level of satisfaction with their personal relationships after the intervention. The significant increase in mean satisfaction with sex life suggests that the intervention or time period had a positive impact on participants' satisfaction levels in this aspect.

How satisfied are you with the support you get from your friends? The increase in mean satisfaction from pre-test (3.32±0.978) to post-test (3.60±1.010) is statistically significant, as indicated by the p-value (0.002). Participants reported a higher level of satisfaction with the support they received after the intervention, which suggests that the intervention had a positive impact on participants' satisfaction levels in this aspect. Similar to personal relationships, there is a statistically significant increase in satisfaction with the support from friends. Participants reported higher levels of satisfaction with the support they received from friends after the intervention.

The total score of satisfaction with social relationship showed a significant increase in mean score from pre-test (3.00±0.743) to post-test (3.52±0.677), suggesting an overall improvement in social relations satisfaction among participants.

Table (6): Response of study participants about environment

Perception of environment items		Pre-test		Post-test		t	P value
		Mean	SD	Mean	SD		
1	How safe do you feel in your daily life?	2.66	0.872	3.22	0.995	-3.694	0.001*
2	How healthy is your physical environment?	2.78	1.075	3.42	0.905	-3.975	0.000*
3	Have you enough money to meet your needs?	2.30	1.074	3.24	0.938	-5.692	0.000*
4	How available to you is the information that you need in your daily-to-day life?	2.62	0.967	3.20	0.903	-4.225	0.000*
5	To what extent do you have the opportunity for leisure activities?	2.34	0.895	3.34	1.002	-5.337	0.000*
6	How satisfied are you with the condition of your living place?	2.72	1.089	3.32	0.957	-4.379	0.000*
7	How satisfied are you with your access to health services?	2.98	0.961	3.60	0.832	-4.265	0.000*
8	How satisfied are you with your transport?	2.88	0.961	3.46	0.908	-4.910	0.000*
Total		**2.66**	**0.553**	**3.35**	**0.368**	**-8.629**	**0.000***

Paired sample t-test *Significant at 0.05

Table (6) provided data pertains to pre-test and post-test assessments related to perception of environment.

How safe do you feel in your daily life? Participants reported feeling significantly safer in their daily lives after the intervention as indicated by the increase in mean score (pre-test 2.66±0.872 increased to 3.22±0.995 post-test) and the low p-value (0.001).

How healthy is your physical environment? There is a statistically significant improvement in participants' perception of the healthiness of their physical environment as indicated by the increase in mean score (pre-test 2.78±1.075 increased to 3.42±0.905 post-test) and the low p-value (0.000), suggesting a positive impact from the intervention.

Have you enough money to meet your needs? Participants reported a significant increase in their perceived ability to meet their financial needs as indicated by the increase in mean score (pre-test 2.30±1.074 increased to 3.24±0.938 post-test) and the low p-value (0.000), indicating an improvement in their financial situation after the intervention.

How available to you is the information that you need in your day-to-day life? There is a statistically significant improvement in the availability of information needed in daily life as reported by the increase in mean score (pre-test 2.62±0.967 increased to 3.20±0.903 post-test) and the low p-value (0.000), suggesting better access to relevant information.

To what extent do you have the opportunity for leisure activities? Participants reported a significant increase in the opportunity for leisure activities as evidenced by the increase in mean score (pre-test 2.34±0.895 increased to 3.34±1.002 post-test) and the low p-value (0.000), indicating a positive impact on their quality of life.

How satisfied are you with the condition of your living place? There is a significant improvement in participants' satisfaction with the condition of their living place as indicated by the increase in mean score (pre-test 2.72±1.089 increased to 3.32±0.957 post-test) and the low p-value (0.000), suggesting an enhancement in their living environment.

How satisfied are you with your access to health services? Participants reported a significant increase in satisfaction with their access to health services as evidenced by the increase in mean score (pre-test 2.98±0.961 increased to 3.60±0.832 post-test) and the low p-value (0.000), revealing improved accessibility to healthcare.

How satisfied are you with your transport? There is a significant improvement in participants' satisfaction with their transport as evidenced by the increase in mean score (pre-test 2.88±0.961 increased to 3.46±0.908 post-test) and the low p-value (0.000), suggesting enhanced transportation services.

The total score of satisfaction with environment indicated a substantial overall improvement in participants' environmental satisfaction as indicated by the increase in mean score (pre-test 2.66±0.553 increased to 3.35±0.368 post-test), with a highly significant p-value (0.000).

Table (7): Overall changes in quality of life

Variable	Pre-test	Post-test	Mean Diff. (95% CI) (Pre - Post)	t- (df)	p value	Change %
	m(SD)	m(SD)				
Physical health	2.65(0.555)	3.23(0.430)	-0.580 (-0.745, -0.410)	-7.023 (49)	<0.001*	21.88
Psychological health	2.83(0.542)	3.39(0.456)	-0.560 (-0.693, -0.426)	-8.448 (49)	<0.001*	19.78
Social relations	3.00(0.743)	3.52(0.677)	-0.520 (-0.709, -0.330)	-5.511 (49)	<0.001*	17.33
Perception of environment	2.66(0.553)	3.35(0.368)	-0.690 (-0.850, -0.0.529)	-8.629 (49)	<0.001*	25.93
Overall QoL	**2.75(0.444)**	**3.33(0.307)**	**-0.586** **(0.-0.695, -0.476)**	**-10.777** **(49)**	**<0.001***	**21.09**

Paired sample t-test *Significant at 0.05

Table (7) presented the results of a pre-test and post-test assessment across various domains, including physical health, psychological health, social relations, environment, and overall QoL.

Physical health: Participants experienced a significant improvement in physical health, with a substantial increase in mean scores from pre-test (2.65±0.555) to post-test (3.23±0.430). The negative mean difference and the p-value (<0.001) indicate that this change is statistically significant.

Psychological health: There is a significant improvement in psychological health, with participants reporting higher mean scores post-test (3.39±0.456) compared to pre-test (2.83±0.542). The negative mean difference and low p-value (<0.001) indicate the statistical significance of this improvement.

Social relations: This domain also shows a significant improvement, with participants reporting higher satisfaction in this domain after the intervention (pre-test 3.00±0.743, post-test 3.52±0.677). The negative mean difference and low p-value (<0.001) confirm the statistical significance.

Environment: Participants' perceptions of their environment improved significantly, as indicated by the substantial increase in mean scores from pre-test (2.66±0.553) to post-test (3.35±0.368). The negative mean difference and low p-value (<0.001) highlight the statistical significance of this domain.

Overall QoL: Generally, the results showed a significant improvement, with participants reporting higher satisfaction in various life domains as the average mean score at pre-test was (2.75±0.444) increased to (3.33±0.307) at post-test. The negative mean difference and low p-value (<0.001) confirm the statistical significance of this improvement.

Quality of life and selected sociodemographic variables

- Participants from the age group 20 years and less expressed significant improvement in overall QoL after the intervention program (p= 0.019).
- There were statistically no significant differences in overall QoL before intervention (p= 0.998) and after intervention (p= 0.783) between male and female patients.
- There were statistically no significant differences in overall QoL before intervention (p= 0.952) and after intervention (p= 0.284).
- There were statistically no significant differences in overall QoL before intervention (p= 0.425) and after intervention (p= 0.187).

Discussion

Having day-to-day normal life is a big challenge for patients with chronic disease such as Thalassemia which requires frequent visits to the hospitals for blood transfusion, iron chelation, and complications that may encounter such as hepatitis, cardiomyopathy, diabetes, and other comorbidities. In addition, some patients may have weak compliance with treatment regimes, which will impact their QoL.

General QoL and satisfaction with health

The mean QoL score increased to 3.32, with a standard deviation of 0.712. The overall percentage of respondents with a positive QoL increased from 56.4% to 66.4%. The mean satisfaction with health score increased to 3.08, with a standard deviation of 0.876. The overall percentage of respondents with positive satisfaction with health increased from 56.8% to 61.6%.

This result was similar to the results of Dehaghi et al. (2016) which indicated that the total QoL of participants was 68.06, also, the mean general health was 57.48%, 7.5% stated that their general health was excellent, 32.5% felt very good, 30% felt good, 22.5% felt fair, and 7.5% felt bad..

In contrary, the result of this study was higher than the result of Hamdy et al. (2021) which indicated that the mean total score of QoL was low (44.9%), and the general health perception was the most affected domain by the disease. Moreover, the results of Safizadeh et al. (2012) reflected low QoL among thalassemic patients, and the results of Haghpanah et al. (2013) revealed low mean score of QoL among patients with β-TM.

Overall, it is clear that there was an improvement in both QoL and satisfaction with health after the intervention. The mean values indicated a positive shift in perceptions of QoL and health satisfaction. The percentage of participants with a good or very good QoL and satisfaction with health increased post-intervention.

Concerning physical health, the results indicated improvement in all the items of this domain. Also, the overall mean score indicated a comprehensive significant improvement in participants' physical health (m= 2.65 at pre-test, increased to 3.23 at post-test, p = 0.000).

The results of Dehaghi et al. (2016) indicated higher physical health (80.5) with good physical functions and activities such as walking, bathing, dressing, and climbing stairs. Whereas, the results of Hakeem et al. (2018) indicated low physical health among thalassemic patients.

These results proved that the intervention have positively impacted various aspects of physical health, including energy levels, mobility, sleep satisfaction, and overall daily functioning. The statistical significance (low p-values) suggests that these improvements are unlikely to be due to random chance. However, it's essential to consider the context of the study, the nature of the intervention, and potential limitations in drawing conclusions from the results.

Regarding the psychological health, the results indicated improvement in all the items of this domain. Also, the total mean score indicated a significant improvement in participants' psychological health (m= 2.83 at pre-test, increased to 3.39 at post-test, p = 0.000). The results of Hakeem et al. (2018) indicated low psychological health among thalassemic patients.

These results suggest a positive impact of the intervention or treatment on various aspects of psychological health. The statistical significance of the changes indicates that the improvements are likely not due to random chance. These findings may be relevant for interventions aimed at enhancing psychological well-being in similar populations.

In regard to social relations, the results reflected that the total score of satisfaction with social relationship showed a significant increase in mean score from pre-test to post-test (3.00 and 3.52 respectively). This result agreed with the results of Dehaghi et al. (2016) which reflected moderate social functioning (m= 68.94), among the participants 35% said that their emotional problems do not interfere with their normal social activities with family, friends, and neighbors, while 17.5% stated that it interferes severely.

The results of Hakeem et al. (2018) indicated low satisfaction with personal relationships among thalassemic patients.

These results indicated positive changes in participants' satisfaction with personal relationships, sex life, support from friends, and overall social relations. The negative t-values and low p-values suggest that these changes are statistically significant. The intervention seems to have had a beneficial impact on participants' social well-being.

Concerning perception of environment, the results indicated a significant overall improvement in participants' environmental satisfaction as indicated by the increase in mean score (pre-test 2.66 increased to 3.35 post-test, 0.000).

These results indicated positive changes in participants' perceptions of safety, physical environment, financial situation, information availability, leisure opportunities, living conditions, access to health services, and satisfaction with transport. The negative t-values and low p-values indicated that these changes are statistically significant, reflecting an overall positive impact on perception of environmental well-being.

Generally, the results showed that the overall QoL was low at pre-test (2.75) increased to (3.33) at post-test. Research has shown that males with thalassemia tend to have more severe symptoms and require more frequent transfusions than females. This could lead to a more significant impact on their physical health and QoL. The results of this study reflected a positive impact of the intervention on participants' physical health, psychological health, social relations, perception of environment, and overall QoL. The improvements are statistically significant, indicating positive changes (21.09%) across multiple aspects of participants' QoL.

Quality of life and sociodemographic factors

In this study, participants from the age group 20 years and less expressed significant better improvement in overall QoL after the intervention program. Whereas, there were statistically no significant differences in overall QoL related to gender, level of education, and working status.

Comparing our results with previous studies reflected variability in results as some studies reported similar or approximate results while other studies reflected different results. Approximate results obtained by Hamdy et al. (2021) which reported significant positive correlation between age of the patients and physical functioning, bodily pain, and mental health domain, but there were no significant differences in QoL between male and female patients. Other studies found no significant differences between male and female patients in all the aspects of QoL (Baraz et al., 2016; Dehaghi et al., 016). Also, the results of Haghpanah et al. (2013) reported no significant differences in physical health, mental health, general health, social functioning, and overall QoL between male and female patients. Moreover, the results of Hossain et al. (2023) showed that there were no significant differences between male and female patients regarding their general health, physical functioning, role physical vitality, mental health, role emotional, social functioning, and mental health summary.

Moreover, the results of Ansari et al. (2014) indicated that lower age and higher education level were associated with better physical health and social relationships, while higher education level was associated with better psychological HRQoL and environmental health, whereas, patients with higher education, and female patients had better overall QoL. Whereas, the results of Adam (2019) indicated that patients aged more than 14 years old had significantly lower scores for physical functioning and role limitations compared to younger age patients. Also, female patients and employed patients showed worse physical health and mental health.

In addition, the results of Hakeem et al. (2018) showed significant higher scores in psychological, social, emotional scores, and total HRQoL among younger age patients (8 – 12 years vs. 13 – 18 years).

From the above results, we can extract that one of the most powerful parameters which associated with many aspects of QoL was age. In my opinion, the reasons that younger age patients exhibited better QoL than older age patients attributed to fact that younger age patients have less complications of the disease. Older age patients have a longer period of exposure to the circumstances of repeated blood transfusion, longer exposure to iron metabolites which affect physical fitness. As the patients grow (becoming older) they recognize the nature of the disease, having more visits to the hospitals, having more days of being absent from the school, changes in the shape and appearance of patients, which will have negative impact on their self-image and self-esteem, and that will result in deterioration of their school achievement, psychological health and social relations.

The results of this study (before intervention) and the results of previous studies demonestrated that thalassemia causes severe clinical, physical, social, and psychological complications (Mazzone et al., 2009). In view of the findings of the study, it is worth to say that these patients are in need for psychosocial support to avoid impairment, and enhance their QoL. The findings extracted from the study are important for future establishment of national strategy to provide adequate support to these patients and improve their QoL. In addition, the study raised the need for national action plan to guarantee the holistic wellbeing of thalassemia patients.

Conclusion

- This study aimed to evaluate the effectiveness of an education program about QoL, 50 patients with thalassemia attended the program. The results showed that:
- The participants rated their general QoL as low 56.4% at pre-test, increased to 66.4% at post-test. Also, they rated their satisfaction with their health as low 56.8% at pre-test, increased to 61.6% at post-test.
- The mean score of physical health was 2.65 at pretest increased to 3.23, with change percent 21.88%.
- The mean score of psychological health was 2.83 at pretest increased to 3.39, with change percent 19.78%.
- The mean score of social relations was 3.00 at pretest increased to 3.52, with change percent 17.33%.
- The mean score of perception of environment was 2.66 at pretest increased to 3.35, with change percent 25.93%.
- The mean score of overall QoL was 2.75 at pretest increased to 3.33, with change percent 21.09%.
- The study concluded that there was a significant improvement in all aspects of QoL after the education program.

Recommendations

In the light of the study results, the researcher recommends the following:

- To establish a national strategy to provide adequate psychosocial support to thalassemic patients and their families.
- To assess the parents' knowledge and awareness about etiology, symptoms, and treatment of thalassemia.
- To enhance patients' compliance with scheduled blood transfusions to avoid the development of anemia and other complications.
- To activate the role of in-service training department at the hospital to increase nurses' attention and competency in caring for patients with thalassemia.

Suggestion for further studies

- To conduct a study to assess the psychosocial impact of thalassemia on patients and their families.
- To carry out a study to determine the barriers to compliance of patients with the long-term treatment regime.

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Annexes

Quality of Life Questionnaire -Short Form (English version)

Sociodemographic factors

Age:	.... Years
Gender:	⇒ Male ⇒ Female
Level of education:	⇒ Secondary school and less ⇒ University
Work:	⇒ Working ⇒ Not working

Overall quality of life and general health

How would you rate your quality of life?	**Very bad**	**Bad**	**Some how**	**Good**	**Very good**
How satisfied are you with your health?	**Absolutely unsatisfied**	**Unsatisfied**	**Neutral**	**Satisfied**	**Very satisfied**

Physical health

No.	Item	N ot	A lit	M od er at	Ve ry	An ex tre
1	To what extent do you feel that physical pain prevents you from doing what you need to do? ®					
2	How much do you need any medical treatment to function in your daily life? ®					
3	Do you have enough energy for everyday life?					
4	How well are you able to get around?					
5	How satisfied are you with your sleep?					
6	How satisfied are you with your ability to perform your daily living activities?					
7	How satisfied are you with your capacity for work?					

Psychological health

No.	Item	N ot	A lit	M od	Ve ry	An ex
1	How much do you enjoy life?					
2	To what extent do you feel your life to be meaningful?					
3	How well are you able to concentrate?					
4	Are you able to accept your bodily appearance?					
5	How satisfied are you with yourself?					
6	How often do you have negative feelings such as blue mood, despair, anxiety, depression?					

Social relationships

No.	Item	Ve ry	Di ss ati	N eit	Sa tis	Ve ry
1	How satisfied are you with your personal relationships?					
2	How satisfied are you with your sex life?					
3	How satisfied are with the support you get from your friends?					

Satisfaction with environment

No.	Item	Not	A little	Mod	Very	An ex
1	How safe do you feel in your daily life?					
2	How healthy is your physical environment?					
3	Have you enough money to meet your needs?					
4	How available to you is the information that you need in your daily-to-day life?					
5	To what extent do you have the opportunity for leisure activities?					
6	How satisfied are you with the condition of your living place?					
7	How satisfied are you with your access to health services?					
8	How satisfied are you with your transport?					

Thank you for your cooperation

The educational program

تم تقسيم اللقاء للبرنامج التعليمي على النحو التالي:

الوقت	العنوان	ملاحظات
اليوم الأول		
9:30 – 9:00	تسجيل وترحيب وتعارف	
10:30 – 9:30	مقدمة	تعريف بالبرنامج والهدف منه، ما هي جودة الحياة، عجلة الحياة
11:00 – 10:30	معرفة الذات	نقاط القوة، القيم والمعتقدات
11:30 – 11:00	نشاط تفاعلي	يقوم كل مشارك بالتفكير في نقطة قوة والتحدث عنها
12:00 – 11:30	استراحة	تقديم ضيافة (مشروبات باردة وساخنة، بسكويت)
13:30 – 12:30	المهارات الحياتية الأساسية	التواصل، حل المشكلات، إدارة الوقت، إدارة التوتر
15:00 – 13:30	استراتيجيات لتعزيز المرونة	إعادة صياغة التحديات، الرحمة بالذات، ممارسة الامتنان، إيجاد المعنى
15:30 – 15:00	مناقشة	الاستماع إلى أراء الحاضرين
اليوم الثاني		
9:15 – 9:00	تسجيل	
10:15 – 9:15	قوة الدعم الاجتماعي	ارسم خريطة دعمك .. الدائرة الداخلية، الدائرة الوسطى، الدائرة الخارجية
11:30 – 10:15	الاهتمام بالذات: نظرة شمولية	الجسدية، العقلية، العاطفية، الاجتماعية، الروحية
12:00 – 11:30	استراحة	تقديم ضيافة (مشروبات باردة وساخنة، بسكويت)
13:00 – 12:00	تحديد الأهداف التي تلهمك	ماذا؟ كيف؟ نعم أستطيع
13:30 – 13:00	رحلتك وثقافتك	العادات والمعتقدات الثقافية التي تدعم رفاهيتك
14:00 – 13:30	التحدي والأمل	قصص نجاح من واقع حياة المرضى
15:00 – 14:00	رسائل ختامية	ابراز نقاط القوة الفردية، ملاحظات
15:30 – 15:00	اختتام البرنامج	مناقشة، مراجعة عامة، الاستماع إلى الآراء والملاحظات