Public Health Research 2019, 9(4): 77-86
DOI: 10.5923/j.phr.20190904.02

Socioeconomic, Demographic and Disease-Related Determinants of Quality of Life among Thalassemia Patients in Gaza Strip - Palestine

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Abstract Thalassemia is the most common hemoglobin disorder in the world and thalassemia major and intermedia stand among the most severe forms. Quality of Life (QOL) and its determinants has emerged as an important parameter for assessing the quality of health care of patients with thalassemia disease. The QOL of thalassemia patients in the Gaza Strip has not previously been studied. This study aimed to determine the socio-demographic and disease-related determinants of QOL among patients with thalassemia disease in Gaza Strip, using the Short Form-36 (SF-36) questionnaire. Descriptive, analytical, cross-sectional study has been performed on 200 eligible thalassemia patients at two hematology centers in Gaza in 2014. After collecting the participants' socioeconomics, demographics and disease characteristics, they filled out the SF-36 questionnaire. T-test and ANOVA were used to determine the relationship between various variables and the QOL score. The results showed that study participants had a medium perception level of QOL (mean score was 41.98, SD=19.24). The overall mean percentage for SF-36 domains scores ranged from 24.68% to 53.85%. The general health domain got the highest score (53.85%) while the lowest domain was physical role limitation (24.68%). Finding showed that males had poorer QOL than female (40.93% compared with 43.02%). QOL was better at the older age (26-85 years) participants (45.66%), compared with the younger age (18-25 years) participants (40.80%). In addition, married participants (47.51%) had better QOL compared with unmarried (41.45%). Moreover, employed participants with high income had better QOL (44.23%) than those with low income (40.94%). In addition, findings showed that, patient with university educational level had significantly better scores than those with secondary educational level or less (p=0.046). For disease related variables, finding showed patients with thalassemia major (41.62%) had poorer QOL than patients with thalassemia intermedia (45.03%). The association between the previous variables did not reach significant level. Finally, comorbidities did not have any significant effect on QOL scores. The findings concluded that male, younger age, unmarried, low income, unemployment, low education and thalassemia major were the most prominent determinants of lower QOL among thalassemia patients. Psychosocial, social and financial support may help patients to cope better with their chronic disease. Designing and implementing educational programs for nurses and physicians who work in hematology units would reduce the negative impact of thalassemia on the patients' QOL.

Keywords Quality of life, Thalassemia, Socioeconomic, Demographic, Disease-Related, Determinants

1. Introduction

Thalassemia - as the most common hereditary disorder over the world - is regarded as a serious problem in public health issues in the Mediterranean area [1]. Thalassemia refers to a heterogeneous group of inherited disorders of hemoglobin synthesis characterized by a disturbance of globin chains' production, leading to anemia, ineffective erythropoiesis and destruction of erythroblast in the bone marrow and blood cells in the peripheral blood [2].

It is a life-limiting and potentially life-threatening condition that causes substantial disruption in education and social activities. Patients and their families are conscious of the disabling nature of the condition and chronic therapy is a constant reminder that they are "different", making it practically impossible to lead a normal life. Generally, the psychosocial burden affects many aspects of the patient's life, such as education, free-time, physical activities, skills, capabilities and family adjustment, the effects of which, often result in anxiety, isolation and depression and poor quality of life (QOL).

QOL is defined as perception of individuals of life, values, goals, standards, and interests in the context of culture. There

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Published online at http://journal.sapub.org/phr
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are a number of factors related to the diseases and related to the social context that can affect QOL. Ages, gender, level of education, the amount of symptoms and distress experienced by individuals with thalassemia have been related to QOL [3].

In Gaza Strip (GS) - Palestine, thalassemia is considered an exhausting, lifelong-suffering disease from two aspects; the chronic nature of the disease itself in terms of frequent hospital visits, drug unavailability, side effects of drugs, disease complications and socioeconomic hardships in GS, and implications of the disease on the quality of life of patient regarding the physical, psychological, emotional, and social aspects.

Unfortunately, factors influencing QOL of thalassemia patients in GS are not well known. The researcher tries to bridge this gap through exploring the socio-demographic and disease-related determinants of quality of life among thalassemia patients in Gaza strip for the first time in Palestine generally and in GS specifically.

2. Methodology

2.1. Design

Descriptive analytical cross sectional study has been conducted at the only two main centers providing care for hematology patients. The first center is located at Al-Shifa Hospital in Gaza city while the second center is located at European Gaza Hospital (EGH) in Rafah city. The time allocated for data collection was from 01 August 2014 to 31 October 2014.

2.2. Sample

The study sample included 200 patients with thalassemia; of them, 137 patients were treated at Al-Shifa Hospital and 68 patients were treated at EGH.

2.3. Inclusion and Exclusion Criteria

Eligible participants were aged 18 years or older, suffered from beta thalassemia major or beta thalassemia intermedia, agreed to give consent and were able to respond to the questionnaire. Any patient who did not meet the inclusion criteria or were seriously ill were excluded from the study.

2.4. Study Instrument for Assessment of QOL

The Short-form Health Survey (SF-36) item has been used in this study to assess QOL. The SF-36 survey is a well-recognized, self-administered QOL scoring system. It consists of eight independent scales and two major dimensions. The eight multi-item scales include physical functioning, physical roles, bodily pain, general health, vitality, social functioning, emotional roles and mental health. The first four scales are summarized into the physical health dimension and the last four scales into the mental health dimension [4,5]. It also includes a single item that provides an indication of perceived change in health.

SF-36 survey is widely used in many countries and has been translated into many languages and proved to be valid and reliable. The Arabic version is being used in Arabic speaking countries where certain items were modified in order to fit more closely into the Arabic context, and consist with the inherent norms of Arabic societies, which share almost the same socio-cultural norms [6,7].

The SF-36 was scored according to the recommendation by McHorney [4]. The SF-36 items describing the eight health concepts were transformed into a score of 0-100 and the items scale averaged to obtain a subscale score. Physical component summary and mental component summary were computed by averaging the values of the respective subscales. A higher score indicated higher levels of function and better health.

2.5. Ethical and Administrative Approvals

The ethical approval from Helsinki Committee in Gaza and an administrative approval from the Ministry of Health were taken to conduct the study.

Before initiation of the data collection a brief introduction on the aim and objectives of the study was presented to the patients. They were informed about their full right to participate or refuse to participate in the study. Moreover the researcher assured the respondents that there would be no invasive procedure included in the study and all the findings of the study would be used to guide the service providers and policy makers to improve QOL for thalassemia patients. A complete assurance was given to participants that all information provided would be kept confidential and their names or anything which could identify them would not be published or exposed anywhere. Their participation and contribution would be acknowledged with due respect. The researcher explained the purpose of the questionnaire to the patients before obtaining consent. Moreover participants were informed that the study results will be used for scientific purposes and no personal data would be revealed. Questionnaires were only distributed to those who had consented to participate in the study.

2.6. Pilot Testing

Data collection instruments (demographic sheet and the SF-36 item health questionnaire) were tested by 20 participants. The goals of the pilot study were to assess the adequacy of the data collection plan, to explore whether respondents understand the questions in the same way, to minimize the problems which may rise during data collection, to identify all domains and components of instruments, and to estimate the interview duration. The pilot participants were included in the study. Results from the pilot study pointed out that the questionnaire would provide the needed data to meet the purpose of the study.

2.7. Data Collection

Data were collected through face-to-face SF-36 questionnaire interview and from patients' files. At the start,

all questionnaire forms were prepared, organized, and classified with serial numbers to ensure the availability of the needed information.

The patients were contacted personally and informed about the aims of the study and that the participation was voluntary. The researcher gave the patients enough time to answer the questions and encouraged them to be open and virtuous, while assuring them that information given in the interview would remain confidential and just used for the purpose of the study. During the interview any vague information were simplified by the researcher to ensure exact and real answer by the responder.

2.8. Response Rate

According to the eligibility criteria, the researcher selected 200 patients whose age was more than 18 years to participate in the study. A total number of 161 patients agreed, which represented (80.5%) of the study population while 39 patients refused, which represented (19.5%) of the population.

2.9. Statistical Analysis

Statistical analysis had been done using the Statistical Package for Social Sciences Software (SPSS) version 20.0. The results were expressed as mean values ± standard deviations and proportions, as appropriate. We conducted univariate analysis to determine the correlations between clinical and demographic factors and the QOL score. The independent samples t-test was used to compare scores between pairs of subgroups of patients in relation to each of the variables of gender, age, type of thalassemia and comorbidity. The analysis of variance (ANOVA) test was used to make comparisons between the scores in different categories of patients in relation to educational level and economic class. Two-tailed p-values less than 0.05 were considered statistically significant.

3. Results and Discussion

3.1. Socioeconomic and Demographic Variables

Of the 200 eligible patients with thalassemia, 161 (80.5%) participated in the study and completed SF-36 questionnaire by interview. Table (1) showed that 81 (50.3%) were females and 80 (49.7%) were males. The average age of participants was 22.59 (range: 18–58 years, SD=5.57). The highest percentage was aged 18-25 years which represented (75.8%) while the lowest was aged more than 26 years which represented (24.2%). Level of education of 66.5% was secondary school whereas (31.0%) had higher education. Concerning the marital status, 91.3% were unmarried while only 8.7% were married patients. About 140 (87.0%) were unemployed while 21 (13.0%) of them were employed. Most of the participants had an income of less 300 US$ (n=110; 68.3%) while 31.7% had an income of more than 300 US$.

Table (1). Distribution of study participants according to socioeconomic and demographic related data

Variables		Respondents (n=161)	
Characteristics	**Categories**	**Frequency**	**Percent**
Gender	Male	80	49.7
	Female	81	50.3
Age group	Mean ± SD* 22.59±5.57		
	18-25 years	122	75.8
	26-58 years	39	24.2
Educational level	Primary and less	21	13.0
	Secondary	107	66.5
	University	33	20.5
Marital status	Not-married	147	91.3
	Married	14	8.7
Governorate	North Gaza	37	23.0
	Gaza City	52	32.2
	Mid-Zone	19	11.8
	Khan Younis	22	13.7
	Rafah	31	19.3
Employment status	Working	21	13.0
	Not-working	140	87.0
Monthly family income (US$)	≤ 300	110	68.3
	> 300	51	31.7
Total		161	100%

*SD: standard deviation.

3.2. Disease Related Variables

3.2.1. Thalassemia Type

Of the 161 participants in the study, 144 (89.4%) were diagnosed as thalassemia major while 17 (10.6%) diagnosed as intermedia (Table 2).

3.2.2. Comorbidities

Concerning history of chronic disease, the study revealed that (39.2%) of participants had a history of chronic diseases; of them, (20.5%) had a history of hepatitis B or C, (8.7%) had a history of cardiologic disorders, (6.2%) diabetes mellitus and (4.3%) had other diseases.

Table 2. Distribution of participants by disease-related variables

Variables		Respondents (n=161)	
Disease-related variable	**Categories**	**Frequency**	**Percent**
Diagnosis	Beta-thalassemia major	144	89.4
	Intermedia	17	10.6
Comorbidities	Cardiologic disorders	14	8.7
	Diabetes mellitus	10	6.2
	Hepatitis B or C	33	20.5
	Others	7	4.3
	No comorbidity	97	60.2
Total		161	100%

3.3. The Effect of Thalassemia on the QOL Domains

The Physical Component Summary (PCS) consists from physical function, role limitation due to physical health, bodily pain, and general health. The Mental Component Summary (MCS) consists of vitality, social functioning, role limitation due to emotional problems, and mental health. The researcher considered the median of QOL scores as the referent point. The median was 37.71, so categories were as follows: 25.92 or less (very poor level of QOL); 26.0-37.71 (poor level); 37.8-53.75 (medium level) and 53.76-100 (good level of QOL).

Table (3) showed that the mean scores for the SF-36 subscales ranged from 53.85 (SD=19.81) for general health to 24.68 for role limitation due to physical function. Most of the respondents had a medium level (46.35 ± 20.26) of QOL for Physical Component Summary (PCS). The results showed that the lowest domain in PCS was role limitation due to physical function with a mean of 24.68; mean score of bodily pain domain was 49.90; physical function domain was 50.62 (SD=21.65). The results also showed that the general health domain got the highest score (mean=53.85, SD=19.81).

For Mental Component Summary (MCS), the results showed that the lowest domain was role limitation due to an emotional problem (31.88); the vitality domain got the second lowest score with a mean of 32.70; mental health domain had a mean of 33.19. The social function domain got the highest score in MCS with a mean of 51.78. This indicates that thalassemia patients were satisfied with their social activity justifying that they were interacting significantly with others, such as family members, friends, neighbours and involved in other social relations. For MCS, the finding showed a mean score of 35.24 (SD=20.26) implying that most of the respondents had a poor level of QOL for MCS. However, the total mean score of SF-36 was 41.98 (SD=19.24) indicating that most of the respondents had a medium level of QOL.

Table 3. SF-36 QOL domains among thalassemia patients (n=161)

SF-36 Domains	QOL among thalassemia patients (n=161)				Rank
	No. of Items	Sum of score	Mean	S.D.	
General Health	5	8670	53.85	19.81	1
Social Functioning	2	8337	51.78	29.31	2
Physical Functioning	10	8150	50.62	21.65	3
Bodily Pain	2	8035	49.90	28.25	4
Mental Health	5	5344	33.19	19.74	5
Vitality	4	5256	32.70	19.00	6
Role Limitation-Emotional	3	5133	31.88	40.19	7
Role Limitation-Physical	4	3975	24.68	37.28	8
Physical Component Summary	21	7462	46.35	20.26	
Mental Component Summary	14	5703	35.42	20.27	
Total SF-36	**36**	**6759**	**41.98**	**19.24**	

Table 4. Differences in QOL scores of patients with thalassemia disease according to gender

SF-36 Domains	Male (n=80)*	Female (n=81)*	t-test	p-value
Physical Functioning	49.25±20.14	51.97±23.09	0.797	0.426
Role Limitation-Physical	23.12±35.52	26.23±39.11	0.523	0.598
General Health	53.81±19.49	53.88±20.24	0.024	0.981
Bodily Pain	52.34±29.46	47.50±26.96	1.088	0.278
Vitality	32.25±18.45	33.14±19.64	0.299	0.765
Social Functioning	50.93±28.11	52.62±30.60	0.364	0.716
Role Limitation-Emotional	28.75±39.59	34.97±40.79	0.983	0.327
Mental Health	31.35±19.72	35.01±19.71	1.178	0.240
Physical Component Summery	45.65±19.01	47.04±21.71	0.433	0.665
Mental Component Summery	33.84±19.81	36.98±20.71	0.983	0.327
Total SF-36	**40.93±18.54**	**43.02±19.98**	**0.687**	**0.493**

*Values are presented as mean ± standard deviation

3.4. QOL and Socioeconomic Demographic Variables

3.4.1. Differences in QOL According to Gender

To differentiate between the scores of QOL of males and females, independent t-test was used (table 4). It showed that, female patients had better QOL than male on seven of the eight subscales (physical functioning, physical role, general health, vitality, mental health, social functioning, and emotional role) and on both summary scales PCS and MCS. However, the differences between overall QOL perception did not reached statistically significant differences (p=0.493). This result is consistent with Safizadeh et al. (2012) who found that female participants had a higher scores in all domains except for bodily pain, when compared to the male participants, such a difference was only significant in physical function and general health domains ($p < 0.05$) [8]. In addition, results were consistent with Montazeri et al. (2005) who conducted a large population-based study in Iran, and found that women and older age had lower scores on bodily pain domain and role limitation due to emotional problems [9].

On the other hand, the results here are not consistent with other studies. Haghpanah et al. (2013) conducted a cross sectional study by using a SF-36 questionnaire to investigate QOL and its determinants among patients with beta thalassemia in southern Iran. They found that women had significantly lower scores than the men on two scales, pain (p=0.041) and emotional role (p=0.009) [10]. Moreover, Sobota et al. (2011) conducted a longitudinal cohort study to assess QOL among thalassemia patients aged over 14 years which found that women with thalassemia reported worse QOL than the United States population [11]. A cross-sectional study of Tajvar et al. (2008) to predict QOL determinants among Tehran residents aged over 65 years using univariate analysis indicated that women reported significantly poorer QOL [12].

Possible explanation could be that most of women in Palestine and other Arabic countries are homemakers who play a major role in raising children and taking care of the house, with less contact with their outside environment, with no major change in their QOL after the impact of disease such as thalassemia, while men are usually the breadwinner of the family and working all day out of home, and face problems while they are out of home environment, so, their QOL could be deteriorated. Other explanations include biological factors and biases in the provision of care according to gender [13], and differences in the clinicians' attitudes towards female patients [14].

3.4.2. Differences in QOL According to Age

Table 5 showed that, patients whose age was more than 26 years had better QOL than patients whose age was less than 25 years on seven of the eight subscales (physical functioning, general health, vitality, mental health, social functioning, and emotional role) and on both summary scales PCS and MCS. The differences between the means of the seven QOL domains due to the age group have not reached statistically significant level ($p>0.05$). Here the researcher noticed that QOL was worse in patients younger than twenty-five years which means that they were incompatible with their disease-related conditions. In addition, disease restricts patients' natural life, which gives them a sense of the weakness in their QOL.

For the role limitation due to physical function domain, table (5) shows that there were statistically significant differences between the thalassemia patients (p=0.042) due to age. The differences were in favor of patients whose age was more than 26 years. This means that the mean score of QOL among older patients was higher than among younger age. This might be explained as the elderly may have adapted with the disease and with the reality in which they live, while young thalassemia patients have poor QOL because they look at the healthy people who are of the same age who play, love and get married. These factors may affect QOL in young age patients.

Table 5. Differences in QOL scores of patients with thalassemia according to age

SF-36 Domains	18-25 years (n=122)*	26-58 years (n=39)*	t-test	p-value
Physical Functioning	49.22±20.40	55.00±24.94	1.456	0.147
Role Limitation-Physical	21.31±34.56	35.25±43.57	2.053	0.042**
General Health	54.22±19.93	52.69±19.62	0.418	0.676
Bodily Pain	49.69±28.62	50.57±27.40	0.170	0.866
Vitality	31.96±19.26	35.00±18.20	0.867	0.387
Social Functioning	50.20±28.61	56.73±31.26	1,212	0.227
Role Limitation-Emotional	28.68±39.11	32.71±20.88	1.796	0.074
Mental Health	33.34±19.45	32.71±20.88	0.172	0.864
Physical Component Summery	45.10±19.15	50.26±23.24	1.390	0.166
Mental Component Summery	34.36±19.72	38.76±21.82	1.182	0.239
Total SF-36	**40.80±18.20**	**45.66±22.05**	**1.377**	**0.171**

*All values are presented as mean ± standard deviation. **Statistically significant

Results were consistent with Haghpanah et al. (2013) who conducted studies to investigate QOL and its determinants among patients with beta thalassemia in southern Iran regarding the physical health, mental health. The total SF-36 scores demonstrated that there were no statistically significant relationships (p>0.05) between the scores and age groups [10]. Sobota et al. (2011) found that adolescents and adults with thalassemia reported worse QOL than that in the United States population [11]. However, Tajvar et al. (2008) revealed that for both the physical and mental components summary scores of the SF-36, the gender, education and economic status were significant determinants of poorer physical QOL, while for the mental component summary score only gender, education and economic status were significant determinants of poorer mental QOL [12]. In Thailand, patients younger than eighteen years were evaluated. It was found that compatibility with the disease-retated conditions has not been formed in younger ages. Patients better accept such a state by the passage of time [1].

This compatibility and incompatibility between studies could originate from the differences in the age of the samples, methodological approaches and designs.

3.4.3. Differences in QOL According to Educational Level

One-way ANOVA test was used to investigate differences between the scores of QOL domains of thalassemia patients regarding educational level as illustrated in table 6. Finding showed that thalassemia patients at university level had better mean scores in all of QOL domains (physical functioning, physical role, general health, vitality, mental health, social functioning, and emotional role) and on both summary scales PCS and MCS than other educational categories.

University-level patients had statistically significant higher scores in the physical function domain and role limitation due to physical function than other educational groups (F=6.109; p=0.003; F=3.869; p=0.023) respectively. Highly educated patients may have more privileges as work, better housing type and financial support. Moreover, they have better accessibility to health services and drug availability, fulfilling their leisure time and participating in social and physical activities. Additionally, these patients can interlace better with their condition relying on better understanding of the chronic nature of the disease, its complications, and how to cope with it.

This explains the role of education in enhancing better understanding the nature of the disease and its complications, and coping with the hard chronic health condition.

These findings were consistent with earlier study done by Carod-Artal (2003) [15] which showed that educational level influenced scoring of QOL assessed by SF-36, but inconsistent with Haghpanah et al. (2013) and Safizadeh et al. (2012) who disseminated that there was no significant difference regarding different age groups and educational levels in any of the SF-36 domains [8,10].

3.4.4. Differences in QOL According to Marital Status

Table (7) showed that there were no statistically significant differences between overall QOL scores according to marital status (p=0.262), despite the fact that married patients had slightly higher scores in the following domains: physical functioning, physical role, general health, vitality, mental health, social functioning, and emotional role, and on both summary scales PCS and MCS than married patients.

However, in vitality domain, married patients had a statistically significant higher mean scores than the non-married (t=2.57, p=0.011). On the contrary, the non-married patients had reported higher -but not significant- scores than the married in the bodily pain domain. These results were consistent with Haghpanah et al. (2013) who demonstrated that there were no statistically significant relationships (p>0.05) between the QOL scores and marital status [10].

Table 6. Differences in QOL scores according to educational level

SF-36 Domains	Primary and less (n=21)*	Secondary (n=107)*	University (n=33)	F-test	p-value
Physical Functioning	46.42±18.85	47.94±20.84	61.96±22.70	6.109	0.003**
Role Limitation-Physical	25.00±37.91	19.85±33.42	40.15±45.04	3.869	0.023**
General Health	50.00±15.57	54.15±20.84	55.30±18.95	0.495	0.610
Bodily Pain	40.71±23.62	50.72±28.38	53.10±30.07	1.375	0.256
Vitality	27.38±16.62	32.42±18.95	36.96±20.15	1.680	0.190
Social Functioning	40.47±23.68	52.10±29.31	57.95±31.22	2.229	0.100
Role Limitation-Emotional	25.39±36.36	30.84±39.04	39.39±45.98	0.884	0.415
Mental Health	31.42±22.42	33.00±19.09	34.90±20.52	0.211	0.810
Physical Component Summery	42.65±16.32	44.29±19.72	55.38±22.13	4.353	0.014**
Mental Component Summery	30.27±19.17	35.10±19.35	39.75±23.38	1.451	0.237
Total SF-36	**37.70±16.34**	**40.61±18.47**	**49.12±22.00**	**3.145**	**0.046****

*All values are presented as mean ± standard deviation. **Statistically significant

Table 7. Differences in QOL scores according to marital status

SF-36 Domains	Not-married (n=147)*	Married (n=14)*	t-test	p-value
Physical Functioning	50.57±21.64	51.05±22.54	0.081	0.935
Role Limitation-Physical	23.45±37.15	37.50±37.65	1.349	0.179
General Health	53.26±20.23	60.00±13.72	1.217	0.225
Bodily Pain	50.13±28.64	47.50±24.49	0.333	0.740
Vitality	31.53±18.36	45.00±21.92	2.578	0.011**
Social Functioning	51.27±29.86	57.14±22.84	0.715	0.476
Role Limitation-Emotional	31.06±39.72	40.47±45.62	0.863	0.404
Mental Health	32.70±19.93	38.28±17.45	1.010	0.314
Physical Component Summery	45.97±20.45	50.27±18.36	0.756	0.451
Mental Component Summery	34.67±20.24	43.36±19.51	1.540	0.125
Total SF-36	**41.45±19.30**	**47.51±18.34**	**1.125**	**0.262**

*All values are presented as mean ± standard deviation. **Statistically significant

Table 8. Differences in QOL scores of patients with thalassemia according to employment

SF-36 Domains	Working (n=12) *	Not working (n=140) *	t-test	p-value
Physical Functioning	61.42±23.08	49.00±21.04	2.492	0.014**
Role Limitation-Physical	44.04±41.00	21.78±35.96	2.597	0.010**
General Health	60.71±22.09	52.82±19.32	1.713	0.089
Bodily Pain	54.04±27.50	49.28±28.40	0.719	0.473
Vitality	39.52±21.55	31.67±18.46	1.776	0.078
Social Functioning	66.66±29.93	49.55±28.66	2.537	0.012**
Role Limitation-Emotional	42.85±44.89	30.23±39.35	1.345	0.181
Mental Health	44.38±18.92	31.51±19.37	2.846	0.005**
Physical Component Summery	57.24±22.50	44.71±19.47	2.692	0.008**
Mental Component Summery	45.85±22.02	33.86±19.60	2.571	0.001**
Total SF-36	**52.68±21.67**	**40.37±18.41**	**2.790**	**0.006****

*All values are presented as mean ± standard deviation. **Statistically significant

3.4.5. Differences in QOL Scores According to Employment

Findings show that employed thalassemia patients had statistically significant higher scores in the following QOL domains: physical function, physical role limitation, social function and mental health and on both summary scales PCS and MCS than the unemployed (t=2.49, 2.59, 2.53, 2.84; p=0.014, 0.010, 0.012, 0.005) respectively (table 8).

This might be due to several reasons; they are financially more secured, feel calm and peaceful, have better communications and fulfill their leisure time. On the other hand, the unemployed patients suffer from financial dependence, lack of resources and insufficient income to meet basic needs. All of these factors led to hard socioeconomic state and dissatisfaction among the not-working patients.

Elayyan (2007) and Eljedi (2010) found that patients who are employed with higher monthly income had higher scores of QOL in comparison with other categories [16,17].

3.5. Disease Related Variables

3.5.1. Differences in QOL According to Thalassemia Type

Table (9) revealed that patients with thalassemia intermedia had better levels of QOL than thalassemia major on the following subscales: physical functioning, physical role, general health, vitality, mental health, social functioning and emotional role, and on both summary scales PCS and MCS. The differences between patients with thalassemia major and thalassemia intermedia were not statistically significant (p>0.05).

Patients with thalassemia major require periodic, lifelong blood transfusion every 2-3 weeks to maintain a hemoglobin level higher than 9.5 gm/dl and sustain normal growth. This procedure needs a nurse to insert a cannula to patients with very thin and week veins leading the nurse to try more than once to find a vein. Secondly, most of thalassemia major patients suffer from fatigue, vertigo and general weakness due to low hemoglobin level. These factors lead to lower QOL among thalassemia major patients. These results were consistent with Safizadeh et al. (2012) who found that QOL of patients with thalassemia intermedia was better than that of patients with thalassemia major [8].

3.5.2. Differences in QOL Scores According to Comorbidities

Table (10) indicated that thalassemia patients without

comorbidities had slightly higher total QOL scores compared with thalassemia patients with comorbidities (cardiologic disorders, diabetes or hepatitis). However, there were no statistically significant differences ($p>0.05$) between the means of the all of QOL domains and history of chronic disease.

These findings were congruent with the earlier study done by Nichols-Larsen (2005) which found that poorer QOL scores were associated with diabetes mellitus, and concluded that comorbidities in thalassemia were important contributors to QOL [18]. In addition, these findings were consistent with Al-Garni (2006) who concluded that comorbidity had an effect on QOL scores as there were differences in QOL between patients who had diabetes mellitus and those who did not. Comorbidity factors accompanied by other health problems affect individual's function and QOL [19].

Particular attention deserves to be paid to decreasing these comorbidities and their complications through regular periodic examination, follow-up and appropriate management of disease complications in thalassemia patients.

3.6. Univariate Analysis of Clinical and Demographic Factors and QOL Scores

Table 11 demonstrates the results from the univariate analysis on covariates in relation to the physical health, mental health and total SF-36 scores. There were no statistically significant relationships between the scores and gender, age, marital status, household income, thalassemia type and comorbidities ($p>0.05$). The patients with higher education level had significantly higher scores for physical health, mental health and total scores, in comparison with patients with primary and secondary levels ($p=0.046$). Moreover, the patients who work had higher scores than shown by patients who do not work, in all of these three evaluated scores ($p<0.001$).

Table 9. Differences in perceptions about QOL scores of patients with thalassemia disease according to thalassemia type

SF-36 Domains	Major (n=144)*	Intermedia (n=17)*	t.test	p-value
Physical Functioning	50.06±21.99	55.29±18.41	0.940	0.348
Role Limitation-Physical	23.43±37.07	35.29±38.58	1.242	0.216
General Health	51.76±19.03	54.02±19.95	0.458	0.648
Bodily Pain	49.94±28.68	49.55±25.08	0.054	0.957
Vitality	32.36±19.63	35.58±12.48	0.661	0.510
Social Functioning	48.52±20.19	52.17±30.23	0.483	0.630
Role Limitation-Emotional	31.94±40.37	32.61±19.97	0.055	0.956
Mental Health	32.61±19.97	38.11±17.38	1.088	0.278
Physical Component Summery	45.91±20.44	50.09±18.77	0.805	0.422
Mental Component Summery	35.19±20.68	37.43±16.69	0.431	0.667
Total SF-36	**41.62±19.49**	**45.03±17.27**	**0.690**	**0.491**

*All values are presented as mean ± standard deviation.

Table 10. Differences in QOL scores according to comorbidities

SF-36 Domains	Yes (n=64)	No (n=97)	t-test	p-value
Physical Functioning	49.84±22.81	51.13±13	0.369	0.713
Role Limitation-Physical	24.21±36.72	25±37.84	0.130	0.897
General Health	54.60±20.06	53.35±19.73	0.393	0.694
Bodily Pain	41.40±26.32	55.51±28.20	3.189	0.002
Vitality	33.75±19.98	32.01±18.49	0.567	0.571
Social Functioning	53.71±28.92	50.51±29.64	0.676	0.500
Role Limitation-Emotional	30.72±40.84	32.64±39.95	0.295	0.768
Mental Health	36.12±19.68	31.25±19.64	1.537	0.126
Physical Component Summery	45.29±20.81	47.05±19.96	0.538	0.592
Mental Component Summery	36.80±19.85	34.52±20.59	0.698	0.486
Total SF-36	**41.89±19.52**	**42.03±19.16**	**0.046**	**0.964**

All values are presented as mean ± standard deviation. *Statistically significant

Table 11. Univariate analysis of covariates with Short Form-36 QOL scores

Variables	Physical health mean ±SD	p-value	Mental health mean ±SD	p-value	SF-36 scores mean ±SD	p-value
Gender						
Male (n=80)	45.65±19.01	0.665	47.04±21.71	0.327	40.93±18.54	0.493
Female (n=81)	33.84±19.81		36.98±20.71		43.02±19.98	
Age (years)						
≤ 25 (n=122)	45.10±19.15	0.166	34.36±19.72	0.239	40.80±18.20	0.171
> 25 (n=39)	50.26±23.24		38.76±21.82		45.66±22.05	
Educational level						
Primary-less (n=21)	42.65±16.32	0.014*	30.27±19.17	0.237	37.70±16.34	0.046*
Secondary (n=107)	44.29±19.72		35.10±19.35		40.61±18.47	
University (n=33)	55.38±22.13		39.75±23.38		49.12±22.00	
Marital status						
Not-married (n=147)	45.97±20.45	0.451	34.67±20.24	0.125	41.45±19.30	0.262
Married (n=14)	50.27±18.36		43.36±19.51		47.51±18.34	
Employment						
Working (n=12)	57.24±22.50	0.008*	45.85±22.02	0.001*	52.68±21.67	0.006*
Not working (n=140)	44.71±19.47		33.86±19.60		40.37±18.41	
House hold income						
< 1000 NIS	45.37±20.23	0.369	34.29±19.45	0.298	40.94±18.97	0.315
≥ 1000 NIS	48.46±20.36		37.87±21.92		44.23±19.83	
Thalassemia type						
Major (n=144)	45.91±20.44	0.422	35.19±20.68	0.667	41.62±19.49	0.491
Intermedia (n=17)	50.09±18.77		37.43±16.69		45.03±17.27	
Comorbidities						
Yes (n=40)	45.29±20.81	0.592	36.80±19.85	0.486	41.89±19.52	0.964
No (n=121)	47.05±19.96		34.52±20.59		42.03±19.16	

*Statistically significant. SD: standard deviation

4. Conclusions

The overall mean scores of SF-36 domain were at a medium level and ranged from (24.68%) to (53.85%). Significant differences were found concerning socio-demographic and disease-related variables. Patient with university educational level had significantly better scores than patients with secondary educational level or less. Regarding the gender, there were no statistically significant differences between male and female patients in all of QOL domains.

Concerning the age of patients, patients aged 26 years and more had better QOL domains such as physical functioning, general health, vitality, mental health, social functioning, emotional role, PCS and MCS in comparison with other age groups. The results also revealed that married patients had better scores than non-married in most of QOL domains. Moreover, employed patients with high income got better scores especially in mental health domain. According to health profile, patients with thalassemia intermedia have better status compared to those with thalassemia major in physical functioning, physical role, vitality, mental health, and emotional role and on both summary scales PCS and MCS. Finally, comorbidities did not have any significant effect on QOL scores.

5. Recommendations

Based on the findings of the study, the following recommendations would be considered:

1) Psychosocial support sessions should be scheduled regularly for patients and their families.
2) Availability of social workers and psychologists in the centers are crucial to improve QOL.
3) Policy makers and stakeholders should provide social and monetary support for patients and family members that in turn comprehensively reduce the disease burden and the improve QOL of thalassemia patients.
4) Training and educating physicians and nurses how to communicate effectively with thalasemia patients to help them cope with their disease.

ACKNOWLEDGEMENTS

I would like to express my gratitude to all patients who participated in the study. Many thanks also go to the administrations of Gaza European Hospital, and Al-Shifa hospital for their cooperation during the study period. Their sincere contributions made this research possible and fruitful.

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