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Assessment of the Quality of Life Among Thalassemia Patients in the Gaza Strip

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Abstract

Background: 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) 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. Objective: The objective of this study is to assess QOL among patients with thalassemia disease in Gaza Strip, using the Short Form-36 (SF-36) questionnaire. Design and Setting: Descriptive, analytical, cross-sectional study has been performed on 200 thalassemia patients aged 18 years or more on follow-up at two hematology centers; Al-Shifa Hospital and European Gaza Hospital, in 2014. After the participants' socioeconomics, demographics and disease characteristics had been recorded, they filled out the SF-36 questionnaire and the relationship between various variables and the QOL score was evaluated. Results: 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 with relative weight equaled 53.85%, the social function domain: 51.78%, the physical function domain: 50.62%, the bodily pain domain: 49.90%, the mental health domain: 33.19%, the vitality domain: 32.70%, the emotional role limitation: 31.88% and the lowest domain was physical role limitation with relative weight of 24.68%. Conclusion: The findings demonstrated that, patients with thalassemia disease had a medium perception level about their QOL. The lowest perception was observed in role limitation due to physical function, which led to restriction of work capacity. However, most of patients were satisfied with their general health, which led to buffering effect on their psychological status and QOL. Promoting psychosocial, social and financial support may help them to cope better with their chronic disease. Designing and implementing educational programs for nurses who work in hematology units might be positively reflected on patients' QOL.

Keywords

Quality of Life, Thalassemia, Gaza Strip

1. Introduction

Thalassemia is a chronic disease that poses a range of clinical and psychological challenges. Thalassemia implications on physical health can lead to physical deformity, under development and delayed puberty [1]. Heart failure, cardiac arrhythmia, liver disease, endocrine disease, and infections are common complications among thalassemia patients [2]. Quality of Life (QOL) is defined as perception of individuals of life, values, goals, standards, and interests in the context of culture [3]. Despite thalassemia is identified as a hereditary blood disorder that can be fatal if proper treatment is not received, over the past decades the development of new treatments and clinical management have significantly enhanced the prognosis as well as the survival rates of the patients [4]. However, the positive effect of these treatments is likely to be diminished, especially in terms of QOL, if they interfere with daily activities or are less tolerable. The life expectancy and survival of thalassemia patients have increased dramatically over past decade through introduction of regular blood transfusion and iron-chelating therapies. Despite the patients' survival has improved, their QOL is believed to be lower than that of the

normal population because of a variety of issues that these patients encounter during their life. These issues comprise the presence of comorbid chronic conditions, treatment components such as periodic, regular hospital visits for regular transfusions and painful injections, appearance, infertility, inability to raise their own family, disease complications, uncertainties about the future, psychiatric disorders, and difficulties in employment and playing a role within society. Because of these factors, patients with thalassemia experience many physical, psychological, mental and social problems that lead to decreased QOL [4-8]. In Gaza Strip (GS), the number of thalassemia patients treated at MOH in 2014 has reached 311 adult patients in addition to 75 thalassemia children aged 12 years or less [9].

Within the chronic uncertainty condition in GS and recurrent shortage of drugs at Ministry of Health (MOH) hospitals, 200 patients live under sustained psychological pressure and varying degrees of physical symptoms. Many medical problems that result from thalassemia lead to a reduction in physical functioning and medical complications such as cardiovascular and neurological complications. Furthermore, assessment of QOL in thalassemia patients has not been previously studied in GS. In GS there is an increasing number of thalassemia cases among unmarried individuals on account of several reasons, including the nature of the Palestinian society, which refuses to marry a thalassemia patient for fear of giving birth to babies carrying the disease. This is in addition to the Palestinian laws which prohibit marriage between patients carrying the genetic recipe of the disease until the blood test for thalassemia shows that the couples are free from the disease. Bearing that in mind, the impact of thalassemia on QOL was not fully acknowledged and it should bring attention and consideration of health care providers and decision makers. Therefore, the researcher became motivated to conduct this study to determine the QOL among thalassemia patients in Gaza strip. The findings and recommendations of this study will be presented to the stakeholders, in order to contribute to the improvement of the QOL of the thalassemia patients.

2. Methodology

2.1. Study Design

Descriptive analytical cross sectional study has been used to assess QOL among thalassemia patients in Gaza Strip. This cross sectional study has been conducted at two main centers providing care for hematology patients. The first center is located at Al-Shifa Hospital in the north and the second center is located at European Gaza Hospital (EGH) in the south. The time allocated for data collection by course coordinator was from 01 August 2014 to 31 October 2014.

2.2. Study Population

The study population included 200 patients with thalassemia disease. Of them; 137 patients were treated at Al-Shifa Hospital and 68 patients were treated at EGH.

2.3. Inclusion criteria

Eligible participants should be 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.

2.4. Exclusion Criteria

Patients who did not meet the inclusion criteria or were seriously ill were excluded from the study.

2.5. 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 [10, 11]. 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 [12, 13].

2.6. Scoring the SF 36-Item

The SF-36 was scored according to the recommendation by Ware (1993) [14]. 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.

Scoring the SF-36 questionnaire is a two-step process. In the first step, preceded numeric values are recoded per the scoring key given in. All items are scored so that a high score defines a more favorable health state. In addition, each item is scored on a 0 to 100 range so that the lowest and highest possible scores are zero and 100 respectively. Scores represent the percentage of total possible score achieved.

In step 2, items in the same scale are averaged together to create the 8 scale scores. Items that are left blank (missing data) are not taken into account when calculating the scale scores. Hence, scale scores represent the average for all items in the scale that the respondent answered [14]. The score given to QOL in each domain varies between zero and 100; a score close to zero implies a worse QOL

while the one close to 100 shows a better QOL [15].

2.7. Ethical and Administrative Approvals

Prior to initiation of the study an academic approval has been obtained from the School of Public Health at Al-Quds University, an ethical approval from Helsinki Committee in Gaza and an administrative approval from the director general of the Ministry of Health (MOH) hospitals 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. After completion of these procedures the interview was started.

2.8. 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.

2.9. 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. Great care has been taken to ensure privacy and confidentiality. 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. The researcher explained the purpose of the questionnaire to the patients before obtaining consent. During the interview any vague information were simplified by the researcher to ensure exact and real answer by the responder. Moreover participants were informed that the study results will be used for publication and no personal data would be revealed. Questionnaires were only distributed to those who had consented to participate in the study.

2.10. 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.

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, percentages and proportions, as appropriate.

3. Results and discussion

3.1. Characteristics of the Participants

Of the 200 eligible patients with thalassemia, 161 (80.5%) participated in the study and completed SF-36 questionnaire. Results indicated 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). 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. About 140 (87.0%) were unemployed while 21 (13.0%) 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$. About 144 (89.4%) were diagnosed as thalassemia major while 17 (10.6%) diagnosed as intermedia. Concerning history of chronic disease, 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%) DM and (4.3%) had other diseases.

3.2. Effect of Thalassemia Disease on SF-36 Quality of Life Domains

SF-36 QOL consists of eight core domains involving 35 items. The final (36th) item is a supplementary question related to changes in health status during the past years. The results of the analysis of SF-36 questionnaire were divided into eight domains. These include: general health, physical functioning, mental health, physical role limitation, emotional role limitation, bodily pain, vitality (energy/tiredness), and social functioning. The eight domains are hypothesized to form two distinct higher-ordered clusters due to the physical and mental health variance that they have in common. 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. Based on the median and percentiles for interpretation QOL scores, 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 1 showed that the mean scores for the SF-36 subscales ranged from 53.85 (SD=19.81) for general health to 24.68 (SD=37.28) for role limitation due to physical function. The lowest domain in PCS was role limitation due to physical function with a mean of 24.68 (SD=37.28). Additionally, the mean score of bodily pain domain was 49.90 (SD=28.25). Pain in patients with thalassemia disease is a problem of high importance as it may affect the physical activity of the patient leading him to stop the continuation of his normal life. Moreover, the results showed that the mean of the 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). This means that thalassemia patients shared in the study were satisfied with their general health condition. For PCS the findings showed a mean score of 46.35 (SD=20.26), meaning that most of the respondents had a medium level of QOL for PCS.

Table 1. *Scores of SF-36 domains of patients with thalassemia disease.*

SF-36 Domains	QOL among thalassemia patients (n=161)				Rank
	No. of Items	Sum of score	Mean	SD	
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 Summery	21	7462	46.35	20.26	
Mental Component Summery	14	5703	35.42	20.27	
Total SF-36	36	6759	41.98	19.24	

For MCS, the results showed that the lowest domain was role limitation due to an emotional problem with a mean of 31.88 (SD=40.19). The researcher found that thalassemia mainly affected the emotional health of patients. Results also revealed that the vitality domain got the second lowest score with a mean of 32.70 (SD=19.00). The researcher believes that vitality in patients with thalassemia disease is a very important problem as it may limit the patient activity and may have a negative impact on his social relations. In addition, the results showed that mental health domain had a mean of 33.19 (SD=19.74). For the social function domain, the results showed that this domain got the highest score in MCS with a mean of 51.78 (SD=29.13). This indicates that thalassemia patients participated in the study 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. The researcher generalized that for total SF-36, the finding showed a mean score of 41.98 (SD=19.24) indicating that most of the respondents had a medium level of QOL.

3.3. Effect of Thalassemia on General Health Domain and Physical Function

Table 2 indicated that 57.8% rated their general as good, (13.7%) as very good (11.2%) as excellent, 5.6% as poor, and (11.8%) rated their QOL as fair. Finding also showed that (32.9%) of the study sample expected good health in the future. By combining the weighted mean of each question related to general health, the researcher found that thalassemia patients (53.85%) had a good level of QOL for general health. Although, thalassemia patients got good level of general health but the percentage was low in comparison with other studies, for example, Eljedi (2010) [16] who conducted a descriptive, analytical cross-sectional study in Gaza governorate to assess the QOL among breast cancer patients which found that (80%) of breast cancer patients revealed positively about their QOL.

Table 2. *Distribution of responses to "General Health domain".*

Categories	Subcategories n (%)				
	Excellent	Very Good	Good	Fair	Poor
General health	18 (11.2)	22 (13.7)	93 (57.8)	19 (11.8)	9 (5.6)

Categories	Subcategories n (%)				
	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
Get sick easier than the other	50 (31.1)	9 (5.6)	37 (23.0)	12 (7.5)	53 (32.9)
Healthy as anybody I know	55 (34.2)	19 (11.8)	20 (12.4)	9 (5.6)	58 (36.0)
Exception health to get worse	6 (3.7)	6 (3.7)	96 (59.6)	15 (9.3)	38 (23.6)
Health is excellent	53 (32.9)	14 (8.7)	8 (5.0)	35 (21.7)	51 (31.7)

In addition, Luzon (2008) [17] conducted a cross sectional study to examine the QOL and to identify most common

factors influencing the QOL in long-term rehabilitated stroke survivors in Gaza governorate, by using Short Form-36 (SF-36). The researcher found that (77.77%) of stroke patients revealed positive about their general health. The researcher attributes the low general health scores of patients with thalassemia, compared to other patients with other diseases, to the difference in nature between thalassemia disease and other diseases. Thalassemia is chronic genetic disease and usually discovered at the beginning of life and continues until the patient dies, while other diseases such as cancer and stroke occur at a later age.

Physical functioning indicates the extent to which the respondents are capable to perform vigorous activities such as running, lifting heavy objects, participating in strenuous sports, climbing several flights of stairs and walking more than a kilometre. The scores on the physical functioning domain scale refer to the extent to which the participant's perceptions of their QOL are affected by their physical condition. As shown in the table 3, the higher percentage of the study sample were

"limited a lot" to perform activities that required physical endurance and capacity (vigorous and moderate activities, lifting or carrying, climbing several flights of stairs, walking for 1.5 km and more).

Approximately ninety nine percent of the participants also were unlimited performing walking for 100 meters. This means that some patients need assistance in doing light work, despite most of them reported no limitation at all to perform activities that require less physical endurance and capacity such as bathing or dressing. By combining the weighted mean of each question related to physical function, the researcher found that (50.62%) of thalassemia patients had a medium level of QOL related to physical functioning that occupied the second highest score.

Results disagreed with Luzon (2008) [17] who conducted a study to examine the QOL among stroke patient by using SF-36 questionnaire that found (40.89%) of them revealed negatively about their QOL. In addition, results were inconsistent with (Eljedi, 2010) [16] where the lowest domain was a physically one with relative weight of (61.3%). The researcher explains the difference in physical function scores between thalassemia and other diseases such as stroke, for example, as: stroke causes malfunction of the nervous system which affects the physical function.

Table 3. *Distribution of responses in reference to physical function related item "Physical Function domain".*

Categories	Subcategories n (%)		
	Yes, limited a lot (1)	Yes, limited a little (2)	No, not limited (3)
Vigorous activities	109 (67.8)	26 (16.1)	26 (16.1)
Moderate activities	90 (55.9)	38 (23.6)	33 (20.5)
Lifting or carrying groceries	64 (39.7)	50 (31.1)	47 (29.2)
Climbing several flights of stairs	97 (60.3)	29 (18.0)	35 (21.7)
Climbing one flight of stairs	21 (13.0)	99 (61.5)	41 (25.5)
Bending, kneeling, or stooping	26 (16.1)	84 (52.2)	51 (51.7)
Walking for more than 1.5	100 (62.1)	27 (16.8)	34 (21.1)
Walking for 1.5 km	49 (30.5)	78 (48.4)	34 (21.1)
Walking for 100 m	1 (0.6)	34 (21.1)	126 (78.3)
Bathing or dressing	3 (1.9)	5 (3.1)	153 (95.0)

3.4. Effect of Thalassemia on Role Limitation Due to Physical Health

This dimension attributes to the extent to which respondents' performance of their roles in daily activities hindered by their physical state of health; for example, their ability to perform vigorous activities such as lifting heavy objects or to perform moderate activities such as moving a table. The following table presents the study results regarding this domain. Table 4 showed that two-third of study sample (75.25%) had limited role due to their physical health. There was a cut down on the length of time spent on work or other activities, accomplished less than they would like to, were limited in the kind of work or other daily living activities, and had difficulty performing the work or other daily living activities. That means the higher percentage of the study sample complained of weakness in motor functioning that limited them to perform these activities like work or other daily activities that require good physical health. As a result, they had limitations in their usual role. By combining the weighted mean of each question related to role limitation due to physical health, the researcher found that (24.68%) of patients had very poor level of QOL related to role limitation due to physical health, which occupied the lowest score.

Table 4. *Distribution of responses to "Role Limitation" due to Physical problems.*

Categories	Subcategories n (%)	
	Yes = (1)	No = (2)
Cut down on the length of time you spent on work or other activities	119 (73.9)	42 (26.1)
Accomplished less than you would like to	123 (76.4)	38 (23.6)
You are limited in the kind of work or other activities	117 (72.7)	44 (27.3)
Had difficulty performing the work or other	126 (78.3)	35 (21.7)

The physical limitations and disability of thalassemia patient occur because of the effects of the disease itself and co-morbid disease, the treatment regimen and psychosocial problems. These findings were consistent with (Luzon, 2008)

[17] who mentioned that the poorer QOL domain was role limitation due to physical health (28.05%). Moreover, it was similar to (Eljedi, 2010) [16] which found the lowest domain was physically one with relative weight (61.3%).

3.5. Effect of Thalassemia on Role Limitation Due to Emotional Problems

This dimension assesses the extent to which the emotional condition of the participant, e.g. feeling depressed or anxious, limits his/her daily functioning and ability to perform roles, such as cutting down the length of time spent on work or other activities and accomplishing less than he/she would like to. As shown in table 5, more than half of the study sample (68.1%) reported limited role due to their emotional problems, this means they had problems with work or other daily living activities because of emotional problems that led to role limitation. The researcher combined the weighted mean of each question related to role limitations due to emotional problems, and found that (31.88%) of thalassemia patients had a poor level of QOL related to role limitations due to emotional health that occupied the second lowest QOL score.

Table 5. *Distribution of responses to role limitation due to emotional problems.*

Categories	Subcategories n (%)	
	Yes = (1)	No = (2)
Cut down the length of time you spent on work or other activities	113 (70.2)	48 (29.8)
Accomplished less than you would like	109 (67.7)	52 (32.3)
Didn't do work or other activities as carefully as usual	107 (66.5)	54 (33.5)

Finding were similar to [17] (Luzon, 2008) who concluded that role limitation due to emotional problem domain got the third lowest QOL score (42.97%).

3.6. Effect of Thalassemia on Vitality

This dimension points to what extent the respondents feel energetic and full of life, or feel worn out and tired. Table 6 shows the effect of thalassemia on vitality. Only (8.1%)

of the study sample felt full of life all of the time or at least most of their time, but the number increased among those having energy and feeling tired, and those who got worn out most of the time. By combining the weighted mean of each question related to vitality, the researcher found that (32.70%) of thalassemia patients had poor level of QOL related to vitality, which occupied the third lowest QOL score. Results were inconsistent with Luzon (2008) [17] who showed that (71.6%) of stroke patients revealed positively about vitality.

Table 6. *Distribution of responses in reference to vitality domain.*

Categories	Subcategories n (%)					
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Feel full of life	13 (8.1)	16 (9.9)	4 (2.5)	23 (14.3)	90 (55.5)	15 (9.3)
Have a lot of energy	14 (8.7)	17 (10.6)	7 (4.3)	21 (13.0)	82 (50.9)	20 (12.4)
Feel worn out	15 (9.3)	81 (50.3)	25 (15.5)	14 (8.7)	19 (11.8)	7 (4.3)
Feel tired	43 (26.7)	73 (45.3)	13 (8.1)	20 (12.4)	10 (6.2)	2 (1.2)

The researcher explains the low score of vitality (energy) among thalassemia patients compared to other patients with other diseases in view of the difference in nature of thalassemia disease, where thalassemia

patients suffer from low hemoglobin level, which leads to fatigue, decreased body movement and inability to carry out the normal activities.

3.7. Effect of Thalassemia on Mental Health

This dimension of the respondent is measured in terms of the extent to which he/she is entirely feeling livelily, happy, calm and peaceful, very nervous, or feeling worn out and tired. Table 7 shows the higher percent of the study sample felt downhearted and blue, felt so down in the dump that nothing could cheer you up and were nervous most of the time and they were not feeling happy and clam in a little of the time felt so. By combining the weighted mean of each question related to mental health, the researcher found that thalassemia patients had (33.19%) poor level of QOL related to mental health.

Table 7. *Distribution of responses to "Mental Health domain".*

Categories	Subcategoriesn (%)					
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have been a very nervous person	57 (35.4)	44 (27.3)	12 (7.5)	16 (9.9)	13 (8.1)	19 (11.8)
Have felt so down in the dumps that nothing could cheer you up	16 (9.9)	67 (41.6)	31 (19.3)	13 (8.1)	19 (11.8)	15 (9.3)
Have felt calm and peaceful	4 (2.5)	13 (8.1)	6 (3.7)	29 (18.0)	91 (56.5)	18 (11.2)
Have felt downhearted and blue	20 (12.4)	68 (42.2)	25 (15.5)	18 (11.2)	19 (11.8)	11 (6.8)
Have you been a happy person	5 (3.1)	8 (5.0)	11 (6.8)	16 (9.9)	90 (55.9)	31 (19.3)

The researcher explains the low QOL in mental health domain as: thalassemia patients feel they are less than others

in practicing a lot of tasks and they cannot keep up with their peers in a lot of activities. The findings were inconsistent with [17] (Luzon, 2008) who found that mental health was the best QOL domain (81.28%).

3.8. Effect of Thalassemia on Social Functioning

This dimension refers to social activities and interaction significantly with others, such as family members, friends, neighbours and other social relations. The components of the social domain (normal social activities with family, friends, neighbors or groups and visiting friends and relatives), were interfered with by thalassemia disease. By combining the weighted mean of each question related to social function, the researcher found that (51.78%) of thalassemia patients had a good level of QOL related to social functioning, which occupied the third highest score (table 8). These results were inconsistent with results of social domain scores among breast cancer patients (Eljedi, 2010) [16], stroke patients (Luzon, 2008) [17] and hypertensive patients (Elayyan, 2007) [18], where the social domain got the best scores in these studies. The researcher believes that Palestinian people, as other developing countries, prefer social relationships in-between them and family, friends, neighbors or groups, and visiting friends and relatives. Family and relatives provide support and help to their patients. Bart and other researchers revealed that the family was the place to talk about patients' feelings for most of patients. The family support was essential for them (Bart et al., 2002) [19]. Moreover, other studies showed thalassemia major had a negative impact on psychological, emotional and social functioning of patients [20, 21].

Table 8. *Distribution of responses to "Social Function domain".*

Categories	Subcategoriesn (%)				
	Not at all	Slightly	Moderately	Quite a bit	Extremely
Physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups	42 (26.1)	18 (11.2)	31 (19.3)	59 (36.6)	11 (6.8)

Categories	Subcategoriesn (%)				
	All of time	Most of time	Some of time	A little of time	None of time
Physical health or emotional problems interfered with your social activities (like visiting friends, relatives)	9 (5.6)	69 (42.9)	29 (18.0)	19 (11.8)	35 (21.7)

3.9. Effect of Thalassemia on Bodily Pain

The scores on this dimension indicate to what extent the participant's experience of bodily pain inhibits their performance of daily activities, including work-related duties in the public domain and tasks within the home environment. Most of thalassemia patients suffer from pain which can interfere with their normal work and activities of daily living. By combining the weighted mean of each question related to bodily pain, the researcher found that (49.90%) of thalassemia patients had a medium level of QOL related to bodily pain (table 9).

Table 9. *Distribution of responses to "Bodily Pain domain".*

Categories	Subcategories n (%)					
	None	Very limit	Mild	Moderate	Severe	Very severe
How much physical pain have you had during the past 4 weeks?	37 (23.0)	22 (13.7)	17 (10.6)	20 (12.4)	52 (32.3)	13 (8.1)

Categories	Subcategories n (%)				
	Not at all	Slightly	Moderately	Quite a bit	Extremely
How much did pain interfere with your normal work?	32 (19.9)	10 (6.2)	43 (26.7)	66 (41.0)	10 (6.2)

The result was inconsistent with (17) who examined the QOL to identify the most common factors influencing the QOL in long-term rehabilitated stroke survivors in Gaza governorate and found that bodily pain got the highest third score (76.24%). Yasmeen (2018) found that pain was significantly associated with low QoL scores [22]. The researcher explains the low bodily pain domain among thalassemia patients compared to other patients with other diseases as: the presence of pain makes patients live under tension which is reflected negatively on their other performances.

3.10. Health Compared to One Year Earlier

Table 10 shows the patients' evaluation of their health in comparison to one year earlier. About half of the study sample (52.8%) evaluated personal health as worse compared to one year earlier. By combining the weighted mean of each question related to health compared to one year earlier, the researcher found that (31.83%) of thalassemia patients had a poorer QOL. The researcher concludes that the effect of the disease is progressive over time, which worsens the QOL level.

Table 10. *Distribution of responses to health assessment one year earlier.*

Categories	Subcategories n (%)				
	Much better now	**Somewhat better now**	**About the same**	**Somewhat worse now**	**Much worse now**
Health compared to one year earlier	5 (3.1)	12 (7.5)	32 (19.9)	85 (52.8)	27 (16.8)

4. Conclusion

The findings demonstrated that, patients with thalassemia disease had a medium perception level about their QOL. The lowest perception was observed in role limitation due to physical function, which led to restriction of work capacity. However, most of patients were satisfied with their general health, which led to buffering effect on their psychological status and QOL. Promoting psychosocial, social and financial support may help them to cope better with their chronic disease. Designing and implementing educational programs for nurses who work in hematology units might be positively reflected on patients' QOL.

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