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ORIGINAL ARTICLE

Analysis of the Relationship between Quality of Life and Fatigue in Individuals with Thalassemia Major

Talasemia Majörlü Bireylerde Yaşam Kalitesi ile Yorgunluk Arasındaki İlişkinin İncelenmesi

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Abstract

Objective: Thalassemia major is a chronic blood disease that causes severe anemia. This causes individuals to feel fatigued and decreases their quality of life. This study aims to analyse the relationship between the QOL and fatigue in individuals with thalassemia major.

Method: This study is a descriptive correlational study. This research was conducted in Nicosia, North Cyprus, with 78 individuals with thalassemia major. Data were collected using the personal information form, Nottingham health profile, and visual analogue fatigue scale.

Results: The researcher calculated the average age of the participants as 38.9±7.23. The sub-dimension of the Nottingham Health Profile scale showed that emotional reaction, pain, and levels of energy were the lowest in the QOL of the participants with scores of 53.2, 52.6, and 51.2, respectively. The average score of the participants was 4.5 in the visual analog fatigue scale. There was a weak negative correlation (r=-0.241, p<0.034) between the visual analog fatigue scale scores and the total scores in the QOL scale, and a moderately negative correlation between the visual analog fatigue scale and the pain subscale scores (r=-0.475, p<0.01).

Conclusion: The results of the study reveal the importance of planning health services to reduce fatigue and improve the QOL of patients with thalassemia major, as well as monitoring their fatigue levels and QOL.

Keywords: Thalassemia major, fatigue, quality of life

Öz

Amaç: Talasemi majör, ciddi anemiye neden olan kronik bir kan hastalığıdır. Bu durum bireylerin kendilerini yorgun hissetmelerine ve yaşam kalitesinin düşmesine neden olmaktadır. Bu çalışmanın amacı talasemi majörlü bireylerde yaşam kalitesi ile yorgunluk arasındaki ilişkiyi analiz etmektir.

Yöntem: Bu makale tanımlayıcı korelasyonel bir çalışmadır. Araştırma Kuzey Kıbrıs Lefkoşa'da, 78 talasemi majör hastası ile gerçekleştirildi. Veriler, kişisel bilgi formu, Nottingham Sağlık profilini ve görsel analog yorgunluk ölçeği ile toplandı.

Bulgular: Katılımcıların ortalama yaşı 38,9±7,23 olarak saptandı. Nottingham sağlık profili ölçeğinin emosyonel reaksiyonlar, ağrı ve enerji alt boyut puanları, (sırasıyla 53,2, 52,6 ve 51,2), katılımcıların yaşam kalitelerinin en düşük olduğu alanlar olarak saptandı. Katılımcıların görsel analog yorgunluk ölçeğinden aldıkları ortalama puan 4,5 olarak saptandı. Görsel analog yorgunluk ölçeği puanı ile yaşam kalitesi ölçeği toplam puanı arasında zayıf negatif korelasyon (r=-0,241, p<0,034), görsel analog yorgunluk ölçeği ile ağrı alt ölçeği arasında ise orta derecede negatif korelasyon saptandı (r=-0,475, p<0,01).

Sonuç: Çalışmanın sonuçları, talasemi majörlü hastaların yorgunluğunu azaltmaya ve yaşam kalitesini iyileştirmeye yönelik sağlık hizmetlerinin planlanmasının ve hastaların yaşam kalitelerinin ve yorgunluk düzeylerinin takibinin önemini ortaya koymaktadır.

Anahtar Kelimeler: Talasemi majör, yorgunluk, yaşam

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Introduction

Thalassemia major can be seen in any part of the world; however, it is more common in individuals originating from the Mediterranean, Africa, South Asia, and South China regions (1,2). In the 1980s, the Thalassemia Prevention Program started in North Cyprus and has achieved good success rates to the extent that thalassemia almost does not exist among new-born babies (3). Although thalassemia prevention and treatment programs became an important part of the previously mentioned countries' health policies, 350,000 babies were born with haemoglobinopathetic in the world (4). Individuals with beta-thalassemia live with symptoms like fatigue, paleness, loss of appetite, and restlessness. Thanks to developments in thalassemia treatments, collaborations and partnerships between centres for the exchange of expertise and resources, the quality of life (QOL) and life span of patients showed a substantial increase (5). Despite these improvements, there are still complications in treatments that negatively affect the QOL score. The clinical manifestations of beta-thalassaemia and treatment-related complications may also affect the QOL negatively (6-8). Individuals with Beta-thalassemia major (β-TM) receiving blood transfusion and individuals with beta-thalassemia intermedia patients who are not transfused are exposed to symptoms such as decreased muscle strength and flexibility, and bone pain due to the effects of the disease on muscles and bones. This affects their QOL (9,10).

The treatment process for Beta-thalassemia major (β-TM) is arduous. Individuals face severe anemia attacks and various health problems, especially fatigue, which may negatively affect their daily activities and QOL. Thalassemia major and severe hypochromic microcytic anemia cause severe fatigue (11). The current studies show that there is a relationship between fatigue seen in patients with thalassemia major and the QOL. A study conducted by Nanas et al. (12) found that patients with thalassemia major have lower exercise capacities and lower peripheral muscle functions; therefore, they should avoid high intensity activities and activities over prolonged periods. Nurses take an active role in the treatment and care of patients with thalassemia major. Due to their constant blood transfusion needs, patients are frequently followed up in health centers, which creates an opportunity for nurses to identify their needs and problems. To plan nursing interventions that will contribute to increasing patients' QOL, reducing complications, and improving care outcomes, it is necessary to first determine the current QOL and fatigue levels of patients.

Main Points

- The results of the study show that fatigue and the quality of life of patients with thalassemia major are moderate.
- According to the Nottingham health profile scale, patients' emotional reaction, pain, and level of energy scores were low, while sleep scores were high.
- There was a weak negative correlation between the visual analogue fatigue score and the total score of the quality of life scale, and a moderate negative correlation with the pain subscale scores.

The recent literature has many studies on the QOL of patients with thalassemia and their self-care (13-16). However, there is no study to the best of our knowledge that shows the QOL and fatigue levels together in adults. Therefore, this study aims to analyse the relationship between fatigue and the QOL of patients with thalassemia major. The study raises awareness about fatigue and the QOL of thalassemia major patients. Furthermore, it is thought that the results of this study will contribute to the efforts made on decreasing the fatigue of patients with β-TM, and will increase their QOL.

Material and Method

Study Design

This research is a descriptive correlational study that analyzes the relationship between the QOL and fatigue levels in patients with β-TM.

Setting and Participants

The study was conducted between January and May 2017 at the Thalassemia Centre in Nicosia, North Cyprus. The population of the study consists of 106 individuals with β-TM who are registered at the Thalassemia Centre. The inclusion criteria consisted of living in Northern Cyprus continuously, being 18 years of age and over, speaking Turkish, and participating in regular follow-ups and treatments at the Centre where the study was conducted. Patients who did not want to participate in the study, nor were they under treatment at the same centre, were excluded. Of the participants, 21 live and receive treatment abroad. In addition, among the remaining 85 patients living in Northern Cyprus and whose follow-ups and treatments were conducted at the Centre, 78 of the voluntary individuals with β-TM were included in the study because seven refused to participate . In this study, 88.0% (n=78) of the participants were reached with a 95% confidence interval, 0.5% error, and 80% power.

Instruments

The data collection form used in the study included three parts. The first part consisted of a personal information form that included information about demographic and disease characteristics. The second part of the data collection form applied the Nottingham health profile (NHP). The third part utilized the "visual analog fatigue scale (VAFS)".

Nottingham Health Profile:

NHP defines emotional, social, and physical problems perceived by individuals. The scale consists of 38 items and six subscales. Subscales of the scale consist of energy level (3 items), pain (8 items), physical activity (8 items), sleep (5 items), emotional reactions (9 items) and social isolation (5 items). The highest score that can be obtained from each subscale is "100" and the lowest score is "0". A score of 0 represents the best health status, and 100 indicates the worst health status. The total score is between 0 and 600, with a higher score indicating a lower perception of health-

related QOL. The higher the score, the greater the number and severity of problems. In the Turkish validity and reliability study of the scale, Cronbach's alpha coefficients ranged between 0.56 and 0.83 (17). In this study, Cronbach's alpha coefficient values of the scale vary between 0.52 and 0.73.

Visual Analog Fatigue Scale:

The visual analog scale is a self-reported measurement tool that is often used to measure subjective experiences such as fatigue and pain (18). In this study, VAFS was used to quantify a participant's fatigue levels based on participants' self-reports. Numbers between 0 and 10 were defined on a line, and the participants were asked to indicate their level of fatigue intensity on this line. Participants with no fatigue scored 0 and extremely tired participants scored 10.

Data Collection

The data of the study were collected by a researcher at the Thalassemia Centre. The researcher used the face-to-face method with the patients. The duration of data collection for each patient ranged between 10 and 20 minutes.

Ethical Issues

The study was approved by the Girne American University ethics committee of the university where the study was conducted (no: 6.1/17, date: 27.01.2017). They were also informed that their participation was voluntary. The participants gave their written and verbal consent to participate in the study.

Statistical Analysis

The statistical analysis of the results was conducted using the IBM SPSS 20.0 software. The Kolmogorov-Smirnov test was used to make sure that the data were not consistent with the normal distribution. Then, the researchers used the non-parametric tests of Mann-Whitney U and Kruskal-Wallis to compare the groups. The relationships between QOL and fatigue were analysed using Spearman's rank correlation.

Results

Table 1 shows the distribution of some of the introductory and disease-related characteristics of the participants. The average age was 38.9. Of the participants, 56.4% were female. Furthermore, 50.0% of the participants reported having a family member with thalassemia major. Table 2 shows the distribution of the NHP and VAFS points. The average fatigue of the participants was 4.5 on a scale of 1 to 10. Total NHP scale mean scores of the participants were determined to be 299.1. When the NHP subscale scores were used for the participants, the scores were ranked from high to low, with emotional reaction (53.2) listed as first; pain (52.6) listed as second. The mean score of the VAFS of the participants in the study was determined at 4.5.

Table 3 shows the comparison of the QOL scores. The emotional reaction sub-dimension of the QOL score was found to be lower in the younger age group. The difference between the two groups was statistically significant

Table 1.
Patient Characteristics (n=78)

	n	**%**
Age	Mean (SD) 38.9 (7.23)	Min-Max 20 - 56
Gender		
Female	44	56.4
Male	34	43.6
Marital status		
Married	38	48.7
Single	40	51.3
Education		
Secondary school and below	32	41.0
High school and above	46	59.0
Health insurance		
Yes	31	39.7
No	47	60.3
Children		
Yes	14	17.9
No	64	82.1
Smoking		
Yes	50	64.1
No	28	35.9
Using alcohol		
Yes	46	59.0
No	32	41.0
Employment status		
Unemployed	34	43.6
Employed	44	56.4
Exercising		
Yes	34	43.6
No	44	56.4
β-TM History in the Family		
Yes	39	50.0
No	39	50.0
Other chronic diseases		
Yes	6	7.7
No	72	92.3
Frequency of blood transfusion		
Once in two weeks	14	17.9
Once in three weeks	42	53.9
Once in four weeks	22	28.2

β-TM=beta thalassemia major, SD=standard deviation

(p<0.05). While the average emotional reaction of unemployed individuals was low (44.7), their average sleep was high (52.4) (p<0.05). The physical activity average score of the unemployed individuals (52.8) was also found to be significantly higher (p<0.05) compared to another group. The average emotional reaction score of individuals with health insurance was higher, at 63.4 (p<0.05), than those without insurance. In addition, the results showed that the physical activity mean score of the individuals with children (60.9) was higher than that of individuals without children. In addition, those individuals with children had a lower emotional reaction score (p<0.05).

The average scores for sleep and physical activity of smokers were 49.2 and 54.5, respectively, and they were found to be high (p<0.05). When exercising was analyzed, the average sleep scores varied significantly. Those whose exercise activity was found to have an average sleep score of 40.0 had a lower score than those who do not exercise, who had an average of 49.1 (p<0.05). Finally, those who did exercise tended to have higher average physical activity scores (p<0.05).

The researchers also examined the energy levels of the participants. The results showed that the number of participants who didn't have another chronic disease was significantly higher (p<0.05). Regarding the average pain and social isolation scores of participants who received a blood transfusion once every three weeks, the scores were higher than those of participants who received a transfusion once every four weeks (p<0.05). When comparing the blood transfusion status with patients' sleeping and physical activities, the results showed that those who had a transfusion once in four weeks had a sleep average score of 61.8 and a physical activity average score of 63.8, which were higher than those who had a transfusion once in three weeks, with a sleep average score 42.4 and a physical activity average score 42.0 (p<0.05).

Table 2.
Distribution of Points of Participant in NHP and VAFS (n=78)

Scales	M	SD
Nottingham health profile		
Emotional reaction	53.2	19.2
Pain	52.6	21.2
Level of energy	51.2	35.6
Physical activity	49.0	17.4
Social isolation	47.9	20.2
Sleep	45.1	24.4
Total	299.1	50.6
VAFS	4.5	2.2

M=mean, SD=standard deviation, NHP=Nottingham health profile; VAFS=visual analog fatigue scale

Table 4 shows the comparison of the VAFS mean scores according to the characteristics of the participants. The difference in fatigue scores between smokers (5.6±1.8) and non-smokers (3.8±2.1) was found to be statistically significant (p<0.05). In addition, fatigue scores of the participants who didn't exercise (5.0±1.9) were found to be significantly higher than those who exercised (3.6±2.1) (p<0.05).

Table 5 shows the correlation between the QOL and fatigue scores of participants. The highest correlation is between sleep and physical activity [r=0.452. n=78. p<0.01]. On the other hand, there is a negative and moderate level of correlation between sleep and emotional reactions [r=-0.387, n=78, p<0.01]. A moderately negative correlation was determined (r=-0.587, p<0.001) between the total scores of the NHP and the level of the energy sub-dimension. In addition, there was a negative weak correlation between the NHP score and pain (r=-0.262, p<0.020), physical activity (r=-0.318, p<0.005), sleep (r=-0.358, p<0.001) and social isolation (r=-0.251, p<0.027). There was a moderately negative correlation between the VAFS score and the pain subscale scores (r=-0.475, p<0.01).

Discussion

This study focused on individuals with thalassemia major in North Cyprus and the relationship between their QOL and fatigue levels. One of the areas that most affected the QOL of the participants was their emotional reaction. The results showed that the emotional reaction sub-dimension scores are low for participants who are employed and those who are 39 years old and above. The scores were also lower for those who have health insurance, and children. A study conducted on 164 individuals with β-TM aged between 15 and 24 years to evaluate their mental health showed that 50.8% of the patients had indications of psychiatric disorders. The research indicated that 11.6% of the individuals had depression, 8.5% had anxiety, and 4.3% had a social dysfunction (19). In another study, findings showed that patients with β-TM have a tendency psychiatric diseases and moderate levels of pain (20). The following study results indicated that the areas that most affected the QOL were depression, fatigue, dyspnea, physical function, and psychological distress. In addition, the study stated that as long as patients stay in the hospital, the QOL will continue to decrease (21).

According to the study of Sobota et al., (22) the QOL of the patients with β-TM was low in 5 out of 8 subscales (physical functionality, role-physical, overall health, social functionality and role-emotional). In addition, the QOL of the patients with β-TM was analysed in 2001 and 2009 by Gollo et al. (23). The results showed that after the second analysis, the overall health of the patients had improved. The study also showed that the subscale of mental health resulted in better recovery outcomes compared to other aspects (23). In another study examining the QOL of individuals with thalassemia, it was determined that the scores of

Table 3.
Comparison of Average Points of Quality of Life of Participants In Accordance with Their Characteristics (n=78)

	Level of energy		**Pain**		**Emotional reactions**		**Social isolation**		**Sleep**		**Physical activity**	
	M (SD)	**Test* / p**	**M (SD)**	**Test* / p**	**M (SD)**	**Test* / p**	**M (SD)**	**Test* / p**	**M (SD)**	**Test* / p**	**M (SD)**	**Test* / p**
Age												
38 and below	56.4 (38.4)	-1.259 / 0.208	54.2 (19)	-0.519 / 0.604	49.2 (17.8)	-2.15 / **0.032**	46.7 (20.7)	-0.766 / 0.444	49.2 (23.3)	-1.625 / 0.104	49.3 (17.4)	-0.182 / 0.855
39 and above	46.1 (32.2)		50.9 (23.3)		57.3 (19.9)		49.2 (19.9)		41 (25.1)		48.7 (17.6)	
Employment status												
Unemployed	53.8 (38.6)	-0.483 / 0.629	52.9 (24)	-0.405 / 0.685	44.7 (18.9)	-3.36 / **0.001**	47.1 (16.2)	-0.474 / 0.635	52.4 (26.1)	-2.237 / **0.025**	52.8 (16.8)	-2.28 / **0.023**
Employed	49.2 (33.4)		52.3 (19)		59.8 (16.9)		48.6 (23)		39.5 (21.8)		46.1 (17.5)	
Health insurance												
Yes	51.5 (29.8)	-0.117 / 0.907	53.9 (22.8)	-0.4 / 0.689	63.4 (22.7)	-3.567 / **<0.001**	49.7 (20.6)	-0.491 / 0.623	40 (24.2)	-1.091 / **0.275**	51.1 (16)	-0.543 / 0.587
No	51 (39.3)		51.6 (20.2)		46.5 (12.9)		46.8 (20.1)		48.5 (24.2)		47.6 (18.3)	
Children												
Yes	35.6 (20.7)	-1.762 / 0.078	40.6 (23.7)	-1.758 / 0.079	43.5 (17.4)	-2.228 / **0.026**	54.3 (9.4)	-1.211 / 0.226	35.7 (17.9)	-1.600 / 0.110	60.9 (20.2)	-2.674 / **0.007**
No	54.7 (37.3)		55.2 (19.8)		55.4 (19)		46.6 (21.7)		47.2 (25.3)		46.4 (15.8)	
Smoking												
No	42.8 (40.5)	-1.681 / 0.093	54.7 (19.9)	-0.472 / 0.637	52.4 (12.7)	-0.261 / 0.794	45 (20.8)	-0.606 / 0.545	37.9 (19.9)	-2.410 / **0.016**	39.2 (14.4)	-3.578 / **<0.001**
Yes	56 (32)		51.4 (21.9)		53.7 (22.1)		49.6 (19.9)		49.2 (25.9)		54.5 (16.6)	
Exercising												
None	52.3 (35.6)	-0.315 / 0.753	48.7 (23.5)	-1.658 / 0.097	54 (18.6)	-0.248 / 0.804	46.8 (19.3)	-0.629 / 0.530	49.1 (24.6)	-1.883 / 0.060	56.2 (17.3)	-4.108 / **<0.001**
Occasionally	49.9 (36.1)		57.6 (16.7)		52.3 (20.2)		49.4 (21.6)		40 (23.6)		39.7 (12.6)	
History of thalassemia in family												
No	44.4 (38.5)	-1.789 / 0.074	56.1 (21.8)	-2.067 / **0.039**	52.6 (16.9)	-0.548 / 0.584	44.1 (15.3)	-2.187 / **0.029**	43.6 (25.9)	-0.186 / 0.853	46.1 (10.4)	-0.979 / 0.327
Yes	58.1 (31.4)		49 (20.2)		53.9 (21.5)		51.8 (23.7)		46.7 (23.1)		51.9 (22.1)	
Other chronic diseases												
No	54.6 (34.7)	-2.928 / **0.003**	51.4 (21.4)	-1.872 / 0.061	53.1 (19.4)	-0.115 / 0.908	48.1 (20.3)	-0.059 / 0.953	46.1 (25)	-1.414 / 0.157	49.3 (18)	-0.117 / 0.907
Yes	11 (17.0)		66.7 (12.9)		55.3 (17.6)		46.7 (20.7)		33.3 (10.3)		46 (6.2)	
Frequency of blood transfusion												
Once in two weeks	57 (35.8)	7.364 / **0.025**	51.3 (16.8)	23.565 / **<0.001**	53.3 (13.5)	0.141 / 0.932	45.7 (12.2)	11.538 / **0.003**	27.1 (12.7)	20.273 / **<0.001**	46.6 (10.1)	27.087 / **<0.001**
Once in three weeks	41.2 (30.3)		62.7 (16.4)		53.6 (21.6)		53.8 (21.9)		42.4 (24.3)		42.0 (16.7)	
Once in four weeks	66.7 (39.9)		33.9 (19.3)		52.6 (18.1)		38.2 (17.4)		61.8 (20.4)		63.8 (13.3)	

**=Mann Whitney U test was applied to groups that have two variants and Kruskal Wallis test was applied to groups with more than two variants. M=mean, SD=standard deviation*

Table 4.
Distrubition of VAFS Points in Accordance with Participant's Characteristics (n=78)

Characteristics	VAFS		
	M	SD	z* / p
Gender			
Women	4.5	1.8	-0.01/ 0.992
Men	4.4	2.6	
Marital status			
Married	4.1	2.5	-1.39/ 0.163
Single/Divorced	4.8	1.8	
Employment status			
No	4.2	1.9	-0.73/ 0.463
Yes	4.7	2.3	
Smoking			
Yes	5.6	1.8	-3.51/ <0.001
No	3.8	2.1	
Exercising			
Yes	3.8	2.3	**-2.47/0.014**
No	5.0	1.9	

**=Mann Whitney U test for groups with two variants, M=mean, SD=standard deviation, VAFS=visual analog fatigue scale*

the participants in the domain of mental health were low (15). The researchers also claimed that by using the latest developments in treatment along with better management of complications, this approach can result in improved patient outcomes (23,24).

As thalassemia is a chronic physical disease, symptoms may include emotional and behavioural problems (25). During treatments, a nurse caring for patients with β-TM should evaluate them physically, socially, and psychologically. Research suggests that it would be beneficial to identify psychologically risky groups and to counsel them on seeking professional help.

In the current study, the participants scored lower in the sub-dimensions of pain and energy levels in the NHP at the second and third levels. A positive correlation is observed between the NHP total score average, and the patients' level of energy and pain sub-dimensions. The previous results are due to the available developments in thalassemia treatments, and the increased life span of the patients. This, in turn, introduces emerging issues such as chronic pain into the literature.

Healthcare professionals frequently face patients with severe and persistent chronic pain problems. A systematic review indicates that the frequency and severity of chronic pain increases over time with age (26). Chronic pain negatively affects the quality of patients' lives. Some

Table 5.
Corelation Between Quality of Life and VAFS of Participants (n=78)

		Emotional reactions	**Level of energy**	**Pain**	**Physical activity**	**Sleep**	**Social isolation**	**Total NHP**	**VAFS**
Emotional reactions	R								
	P								
Level of energy	R	0.006							
	P	0.958							
Pain	R	-0.003	-0.115						
	P	0.982	0.315						
Physical activity	R	-0.219	0.053	-0.203					
	P	0.054	0.642	0.075					
Sleep	R	-0.387**	0.018	-0.280*	0.452**				
	P	**<0.001**	0.877	0.013	**<0.001**				
Social isolation	R	-0.145	-0.252*	0.241*	-0.049	-0.023			
	P	0.205	0.026	0.034	0.671	0.844			
Total NHP	R	0.060	0.587**	0.262*	0.318**	0.358**	0.251*		
	P	0.604	**<0.001**	**0.020**	**0.005**	**0.001**	**0.027**		
VAFS	R	-0.067	-0.014	-0.241**	-0.054	0.103	-0.191	-0.241*	
	P	0.557	0.905	**<0.001**	0.641	0.369	0.094	**0.034**	

**=Spearman Corelation is meaningful at 0.05 level, **=Spearman Correlation is meaningful at the 0.01 level, NHP=Nottingham health profile, VAFS=visual analog fatigue scale*

adults experience severe pain as a result of the decrease in their hemoglobin levels during the final periods of their transfusion cycles. Interdisciplinary control of their pain is obligatory, but using painkillers, even at safe levels, can be harmful. Therefore, there are many approaches to managing pain without relying on painkillers, such as physiotherapy, psychological consultations, and occupational therapies. Other effective methods for pain management include maintaining optimal bone density and having an active lifestyle. The results of this study highlight the importance of health care providers needing to implement effective pain management strategies, provide continual assessment, and utilize evaluation measurement methods for patients with β-TM.

Individuals with thalassemia frequently have problems such as fatigue, bone pain, and muscle weakness. In the current paper, the VAFS score of the participants is moderate. In addition, it was observed that the VAFS score of the individuals who participated in the study had a negative correlation with the total scores of the NHP scale and the pain subscale scores . In a qualitative study conducted with adolescents with thalassemia, the researchers claim that fatigue and pain are among the physical problems experienced by the participants (27).

In another qualitative study, it was indicated the most important factor that negatively affected their life was fatigue. The participants indicated that if they did not have thalassemia, they would have achieved their life goals. The participants said that fatigue and stigma negatively affected their daily routines, social life, and hobbies (28). It is frequently stressed in the literature that chronic diseases, QOL, and fatigue are related (29). In the research, it is stated that thalassemia major negatively affects the physical and mental health of individuals (30-33). The results obtained from our study are similar to findings in literature. Fatigue along with a chronic disease causes a decrease in physical functions and therefore decreases overall QOL.

Furthermore, the current study found that the fatigue scores of individuals who smoke and do not exercise are higher than those who do engage in these behaviors. Individuals with thalassemia, which causes anemia, resulting in hemoconcentration , experience low exercise capacity and frequently experience fatigue. In a systematic review of literature, the effect of non-pharmacological approaches on fatigue is seen in patients undergoing hemodialysis treatment (34). According to this review, some studies indicated that increasing physical activities like exercise programs can foster a sense of well-being, positively affecting fatigue levels. This study also reveals a positive relationship among physical activity, sleep levels, social isolation, and QOL.

In a study that examines the relationship between sleep, fatigue, and QOL in cancer patients, the researcher found that feeling sleepy during the daytime can negatively affect the QOL. The same study shows that fatigue, daytime sleepiness and quality of sleep are important predictors of mental and physical areas (35). Quality of sleep directly affects the QOL. Patients with thalassemia should be informed about behaviors that will improve their quality of sleep. In the research, individuals with thalassemia said that fatigue and pain negatively affected their daily activities, and socialization (36). The results obtained in our study are similar to the findings literature. The current research, suggests that an effective approach for well-being, is for individuals with thalassemia and their relatives to express their feelings about how their daily life affects them. In addition, they should create support groups that will enable them to discuss their concerns and successes.

Study Limitations

One limitation of this study is that it was conducted at one healthcare centre. Thus, the results do not represent all patients with thalassemia major. The other limitation of this study is that it is cross-sectional, so how fatigue levels affect patients' lives and their methods of coping were not revealed. For future research, qualitative studies should be conducted to determine how the QOL and fatigue levels of thalassemia patients affect their daily lives.

Conclusion

The results of this study show that the QOL of patients with β-TM is at a moderate level. It is found that participants are worse when experiencing emotional reactions and pain as defined in the sub-dimensions of the NHP. It also shows that experiences of fatigue by the participants are at a moderate level. In the study, a negative correlation was found between VAFS scores and the NHP's total scale and pain subscale scores. The results of the study prove the importance of educating patients about developing healthy lifestyles that are effective for treating fatigue (e.g., good nutrition, the importance of exercise, organizing activities and rest periods), as well as educating their relatives. Finally, it is important for health care providers to regularly check the level of fatigue and the QOL of patients with beta-thalassemia.

The results of this research are important for health professionals working in the treatment and maintenance of individuals with β-TM, as it helps them understand factors related to the QOL and fatigue. To prevent overlooking other health problems that can develop, such as β-TM chronic disease, healthcare professionals should use integrative methods that address the physical, social, and psychological aspects of life when evaluating their patients. In addition, healthcare professionals should be aware of factors related to the QOL of patients with β-TM and actively participate in developing health policies at the national level to improve the QOL for patients.

Ethics Committee Approval: The study was approved by the Girne American University ethics committee of the university where the study was conducted (no: 6.1/17, date: 27.01.2017).

Informed Consent: The participants gave their written and verbal consent to participate in the study.

Footnotes

Authorship Contributions: Concept –M.U., S.T.; Design – M.U., S.T.; Data Collection and/or Processing – M.U.; Analysis and/or Interpretation – M.U., S.T.; Literature Review –M.U., S.T.; Writing –M.U., S.T.

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