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Quality of life and fatigue in patients with beta-thalassemia following different iron therapy treatments

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OBJECTIVE **To investigate the quality of life and fatigue in adult patients with β-thalassemia, their correlation, as well as their relationship with the socio-demographic and nosological characteristics of the patients.** METHOD **The sample of this cross-sectional study consisted of 100 patients, while data were collected using self-report questionnaires in the transfusions unit of the Provincial General Hospital of Larissa, Greece. The survey was carried out from November 2019 to January 2020 by applying the SF-36 and Multidimensional Fatigue Inventory (MFI-20) questionnaires to determine patients' quality of life and fatigue levels, respectively. Data analysis was performed with the Statistical Package for Social Sciences (IBM SPSS), version 22.0.** RESULTS **Most participants were women (57%), up to 45 years old (71%), married (50%), with no children (55%), and university graduates (56%). Seventy four percent of the participants had begun transfusions when they were less than 5 years old, with co-morbidity reaching 25% and the familial incidence of the disease being around 24%. Social functionality, physical pain and general health were the quality of life areas that were most addressed by those who reported having serious illness, while primary school graduates presented with a worse quality of life and significantly higher fatigue levels. Men demonstrated higher fatigue levels than women, whereas women demonstrated marginally better overall health. Oral chelation therapy, emotional role, and vitality were identified as independent predictors of fatigue.** CONCLUSIONS **Thalassemic patients manifest severe deficits in life quality and increased fatigue. Adequate nursing care and targeted socio-political interventions are required to assist them enjoy the highest level of life quality possible, while they continue to exercise their social and vocational activities easily.**

Ποιότητα ζωής και κόπωση των ασθενών με β-θαλασσαιμία που ακολουθούν διαφορετικές θεραπείες αποσιδήρωσης

Περίληψη στο τέλος του άρθρου

Key words

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Thalassemia consists of genetic syndromes of autosomal remanent disorders that are roughly distinguished in alpha and beta types. In alpha-thalassemia, a reduced synthesis of hemoglobin's alpha chains is observed, while in Mediterranean or beta-thalassemia the reduction concerns the beta chains.[1] The main symptom of beta-thalassemia is severe anemia due to ineffective erythropoiesis and hemolysis, which leads to the appearance of hemolytic anemia and hepatosplenomegaly.[2,3]

Beta-thalassemia is detected in approximately 4.4/10,000 births around the world and follows an autosomal pattern of inheritance with no gender preference. About 5% of the world's population carries a variant in the alpha or beta portion of the hemoglobin molecule, without necessarily manifesting any symptoms, a condition known as the "silent carrier." In fact, only in 1.7% of the world's population it presents with clinical signs as a result of gene mutations, that are commonly acknowledged as thalassemic charac-

teristics, while in countries with high prevalence solely 1% of the population is suffering from the disease.[4] In Greece, beta-thalassemia or thalassemia has an uneven distribution ranging from 5 to 20% with an average frequency of 5.5–8%. It is estimated that 3,500 people suffer from thalassemia, while 8% of the Greek population acts as disease carriers, with an incidence of over 15% in the areas of Karditsa, Biotia, Ilia, and the Ionian Islands.[3]

Thalassemia, along with its treatment, has a high socio-economic impact on both the patients and the healthcare system. Besides, posing a severe economic burden to patients, its treatment alone impedes their professional development through its additional requirements. Transfusions and chelation treatments represent 90% of total care costs, which corresponds to 1,000 €/patient/month.[5]

The main causes of morbidity and mortality among beta-thalassemia patients are cardiac complications, primarily caused from iron overload in the heart.[6] Heart disease treatment in thalassemia encompasses mainly chelation therapy to achieve toxicity reduction and safe iron levels.[7]

Regarding the quality of life in thalassemic patients that undergo chelation treatments, research supports its negative impact on their mental state. In particular, it is noted that chelation treatment creates feelings of anxiety and depression to patients, attributing a decrease in their quality of life levels, given the effect of the disease on their life stability and family dynamics, emerging form the difficulty of living with a chronic disease, the systematic transfusions, as well as the problems associated with the therapy itself.[5,8–11]

Chronic fatigue is rather common among thalassemic patients, affecting their lives gravely. Chronic fatigue differs from sleepiness, a term that describes the need for sleep. Besides drowsiness, shortness of breath, decreased activity, and muscle weakness can be associated with fatigue, with the symptoms occurring simultaneously.[12]

With chelation treatment being a mentally challenging process, as it does not cure the disease but treats its main complication, it functions as a reminder of the disease, causing emotional distress to patients who experience anxiety, stress, depression and low self-esteem, as they cannot manage their daily life and lifestyle with ease. Their physical health, level of function, personal relationships and socio-economic status are severely affected, as secondary factors associated with fatigue that have a significant effect on their quality of life.[13] The aim of the present study was to investigate the quality of life, fatigue levels, the correlation between them, as well as with the socio-demographic and nosological characteristics of adult thalassemic patients.

MATERIAL AND METHOD

One hundred and twenty-two thalassemic patients have visited the Mediterranean Anemia Unit of "Koutlibaneio and Triantafyleio" General Hospital of Larissa, a hundred of whom took part in this cross-sectional study (response rate 81.9%). The study was carried out through the implementation of a self-reported questionnaire from November 2019 to January 2020, after having received the required written approval of the Scientific Council of the Hospital. The research population resided in Thessaly, in Central Greece, and was monitored and transfused at regular time intervals, every 15–20 days, in the Unit. Adult patients diagnosed with thalassemia were included in the study sample, regardless of the severity of their condition, that were undergoing regularly transfusions in the Mediterranean Anemia Unit for at least one year prior to the beginning of the study and understood Greek with ease.

Research tools

The research tools deployed in this study were the Health Review questionnaire SF-36 and the modified Greek version of the fatigue scale Multidimensional Fatigue Inventory (MFI).[14,15] The SF-36 Health Review questionnaire aims at measuring the health-related quality of life of individuals through 36 questions, which comprises eight dimensions: physical functioning, physical role, bodily pain, general health, vitality, social function, emotional role, and mental health.[16] SF-36 presented with very high reliability and validity levels, as Cronbach's alpha reliability index for all its subscales ranged from 0.79 (social functioning subscale) to 0.95 (physical role subscale). SF-36 was translated and weighted for the Greek population.[17]

The Greek MFI consisted of 20 questions that formulated five subscales: general fatigue, physical fatigue, mental fatigue, decreased mood and decreased activity. In the Greek version of the scale, the overall score scale is more adequate for this population group than the partial scoring of each respective dimension.[15] As every question could be answered via a five-item Likert scale, the total score ranged between 20–100, with higher scores implying greater fatigue levels.[18] For this study, MFI-20 showed excellent internal reliability (Cronbach's α=0.91). MFI was translated and weighted in healthy and multiple sclerosis patients, women with breast cancer and beta-thalassemia.

Statistical analysis

First of all, descriptive statistics were performed. The Shapiro-Wilk test indicated that the variables of interest followed roughly the normal distribution (criterion's value >0.900). The parametric Student's t-test was then applied in two independent samples. For some variables, subcategories were merged to ensure sufficient data provision for each subcategory to facilitate the analysis. For more samples, the ANOVA test with *post hoc* analysis was implemented, as well as Pearson's correlation, along with the application of linear regression models. Variables associated

with total fatigue in the univariate analysis at a significance level p<0.1, were introduced into a multiple linear regression model, after dummy variables generation, depending on the indications and collinearity's evaluation. The Statistical Package for Social Sciences (SPSS IBM), version 22.0 was used. The level of statistical significance was set to p=0.05.

RESULTS

Women constituted 57% of the study sample, while 98% of the participants were Greeks. Most of them were between 18–45 years old (71%), married (50%) with no children (55%). Forty seven percent of those who participated in the study were civil servants, residing in Larissa (58%) and holding a bachelor's degree (56%). Participants' demographics are displayed in table 1.

Seventy four percent of those participating in the beginning reported having started receiving transfusions prior to their 5th year of age, while 25% of them had comorbidities as well; 24% reported intra-family onset of the disease. Among the participants, 96% attributed a positive aspect to the role of family in the disease treatment, while 23% evaluated their illness as serious, and 62% as of intermediate severity. Despite 51% declaring the disease not affecting their love life at all, 22% reported affecting it at least moderately, and 27% affecting it a little. Thirty three percent of the patients enrolled in the study were undergoing subcutaneous chelation, 31% were receiving oral administration, and 36% a combination of the two. Hemoglobin levels were identified within the desirable limits in 79% of the patients during the last six months prior to their regular blood transfusion. The time interval between transfusions was on average 15.87±4.20 days, with a maximum of 30 and a minimum of 7 days. The participants' nosological characteristics are presented in table 2.

As for the correlation of participants' socio-demographic characteristics with their quality of life and level of fatigue, men expressed significantly higher fatigue levels than women (p=0.027), while women manifested a marginally significant better overall health (p=0.046). However, women scored lowered in the physical functioning scale (p=0.065), whereas those who did not have children scored higher than those having 1–2 (83.55±15.13 versus 75.06±19.44, p=0.016); they presented with better mental health (71.00±18.91 versus 63.22±19.69, p=0.047) as well.

With respect to the correlation of the participants' educational level with quality of life dimensions, primary school graduates pointed a lower score, indicative of a worse life quality, while they also reported significantly higher levels of fatigue (p<0.01). The *post hoc* analysis identified the

Table 1. Sample demographics.

	n (%)
Sex	
Male	43 (43)
Female	57 (57)
Total	100 (100)
Age group (in years)	
18–35	17 (17)
36–45	54 (54)
46–55	27 (27)
56–65	0 (0)
66+	2 (2)
Total	100 (100)
Marital status	
Married	50 (50)
Single	48 (48)
Divorced	
Widowed	2 (2)
Total	100 (100)
Number of children	
0	55 (55)
1–2	44 (44)
3+	1 (1)
Total	100 (100)
Area of residence	
Larissa	58 (58)
Other	42 (42)
Total	100 (100)
Level of education	
Illiterate	0 (0)
Elementary school	9 (9)
Middle/High school	24 (24)
Bachelor's degree	56 (56)
Master's degree	11 (11)
Total	100 (100)
Occupation	
Unemployed	4 (4)
Stay-home	10 (10)
Pensioner	21 (21)
Civil servant	47 (47)
Private employee	9 (9)
Student	3 (3)
Other	6 (6)
Total	100 (100)
Citizenship	
Greek	98 (98)
Other	2 (2)
Total	100 (100)

Table 2. Sample nosological characteristics.

	n (%)
Transfusion initiation age (in years)	
0–5	74 (74)
6–10	20 (20)
Other	6 (6)
Total	100 (100)
Is there another family member diagnosed with the same condition?	
Yes	24 (24)
No	76 (76)
Total	100 (100)
Which is your family's role in your disease's treatment?	
Positive	96 (96)
Negative	1 (1)
Indifferent	3 (3)
Total	100 (100)
Disease severity	
Severe	23 (23)
Intermediate	62 (62)
Not know	15 (15)
Total	100 (100)
Does your state of health affect your love life?	
Non at all	51 (51)
A little	27 (27)
Moderately	16 (16)
A lot	4 (4)
Very much	2 (2)
Total	100 (100)
What kind chelation treatment is applied in your case?	
Subcutaneous	33 (33)
Per os	31 (31)
A combination of the above	36 (36)
Total	100 (100)
During the last six months, your hemoglobin levels were at an average, before the transfusion, more frequently were:	
Within the desired levels	79 (79)
Lower than the desired levels	16 (16)
Not know	5 (5)
Total	100 (100)
Comorbidity	
Yes	25 (25)
No	75 (75)
Total	100 (100)
Transfusion frequency (time interval between transfusions in days)	15.87±4.20* (min: 7 days, max: 30 days)

*Mean±standard deviation

master's degree holders as patients with lower fatigue levels when compared to primary school graduates and bachelor holders (MFI score: 34.64±6.96 versus 46.13±13.15, p=0.002). In addition, participants who were not actively part of the workforce, as they were unemployed, stay-home, retired or studying, presented with a lower score in the physical functioning (74.16±22.36 versus 82.73±13.42, p=0.018) and mental health scales (61.96±20.40 versus 70.52±18.48, p=0.033), compared to those working.

The correlation of the nosological characteristics of patients with their quality of life dimensions and fatigue levels are depicted in table 3. Those who reported transfusion initiation between the age of 6–10 years had a significantly greater burden on the dimensions of physical functionality and role, social function, as well as emotional role. Moreover, those who did not have another person with the same condition in the family demonstrated with higher physical functionality compared to the rest as well as higher overall health; a corresponding finding with regard to social function was also observed. Social function, bodily pain, emotional role and general health were the quality of life dimensions in which those who were suffering from a severe disease manifested the greater retardation.

Furthermore, those who reported that their state of health greatly affected their love life, scored lower in all subscales relevant to life quality and higher in the ones relevant to fatigue, noting a significant difference (p<0.001). With the exceptions of the scales of emotional role and mental health, those who reported comorbidities presented with a significant burden on all other subscales, in particular those of vitality (p=0.016), social function (p=0.001), physical role (p=0.002), bodily pain (p=0.007), physical functionality (p=0.019), and general health (p=0.002).

Physical functionality appeared increased in those patients who follow a combination schema of oral and subcutaneous chelation, maintaining ferritin levels <1,000 μg/L (p=0.051). A statistically significant difference in fatigue levels was also observed between those who were receiving oral chelation and those following the other methods, regardless of their ferritin levels (39.97±11.93 versus 47.14±13.61, p=0.010). While the combinatorial method outweighs the subjective sense of physical functionality when ferritin levels are low, if ferritin levels are not taken into consideration, the *per os* method beats the others. Concerning the nosological characteristics of the sample, those who had desired hemoglobin levels 6 months prior to their last transfusion stated feeling less fatigue, compared to the other patients (p=0.021).

When investigating the relation between life quality

Table 3. Correlations among transfusion initiation age, existence of another family member with the same condition, and disease severity, with life quality and fatigue.

Variables	Transfusion initiation age				Another family member with the same condition			Disease severity			
	0–5 years (n=74)	6–10 years (n=20)	Other age (n=6)		Yes (n=24)	No (n=76)		Severe (n=23)	Intermediate (n=62)	"Don't know" (n=15)	
	M±SD	M±SD	M±SD	p	M±SD	M±SD	p	M±SD	M±SD	M±SD	p
Physical functioning	81.33±14.93	70.95±24.02	85.00±20.49	*0.019*	71.830±22.86	82.38±15.05	*0.011*	78.26±22.74	80.44±14.84	77.33±21.12	0.779
Physical role	82.89±26.12	68.75±33.32	75.00±38.73	*0.046*	73.96±34.17	80.61±27.07	0.332	69.57±32.82	83.21±27.42	80.00±25.35	0.151
Emotional role	79.44±31.01	48.33±42.54	72.22±44.31	*<0.001*	63.89±40.43	75.05±35.01	0.196	53.62±48.97	77.08±30.48	84.44±24.77	0.010
Vitality	62.27±19.25	57.50±15.77	65.83±27.82	0.311	58.33±23.53	62.51±17.89	0.363	57.39±19.53	61.18±18.87	69.33±18.31	0.166
Mental health	67.82±18.98	61.20±20.77	80.67±18.14	0.178	66.67±22.25	66.83±18.88	0.972	66.61±19.84	65.33±20.03	76.27±15.53	0.150
Social function	78.41±21.41	62.75±19.55	60.42±21.53	*0.004*	66.88±23.54	76.40±21.49	*0.069*	65.00±24.66	75.20±21.05	84.17±17.34	0.026
Bodily pain	79.70±21.34	72.00±25.24	86.67±20.90	0.172	74.79±26.17	79.84±21.04	0.341	64.65±26.42	81.66±19.51	87.17±17.27	0.001
General health	58.67±24.88	56.45±23.44	56.19±22.98	0.721	49.54±30.20	60.80±21.89	*0.051*	44.26±23.43	62.21±23.18	62.15±23.66	0.007
Fatigue	44.62±13.46	49.51±9.99	36.17±20.60	0.134	46.93±14.37	44.32±13.55	0.423	50.02±13.17	43.29±13.58	44.95±12.85	0.126

M: Mean, SD: Standard deviation

and fatigue, fatigue was negatively correlated with each respective quality of life dimension (Pearson r coefficient from -0.368 for physical pain to -0.739 for vitality, p<0.001). Higher fatigue levels were associated with lower quality of life (Pearson linear correlation). Note that all dimensions of the SF-36 were significantly correlated with each other as table 4 displays.

The variables that were significantly associated with fatigue at the level of p<0.1 during the univariate analysis, were incorporated to multivariate analysis as well.

Table 4. Correlations between life quality dimensions and fatigue.

n=100		Physical role	Emotional role	Vitality	Mental health	Social function	Bodily pain	General health	Fatigue
Physical functioning	r	0.324	0.270	0.491	0.410	0.336	0.409	0.522	*-0.439*
	p	0.001	0.007	<0.001	<0.001	0.001	<0.001	<0.001	<0.001
Physical role	r		0.662	0.482	0.302	0.445	0.435	0.391	*-0.414*
	p		<0.001	<0.001	0.002	<0.001	<0.001	<0.001	<0.001
Emotional role	r			0.488	0.352	0.521	0.509	0.408	*-0.557*
	p			<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
Vitality	r				0.740	0.606	0.502	0.530	*-0.739*
	p				<0.001	<0.001	<0.001	<0.001	<0.001
Mental health	r					0.575	0.366	0.409	*-0.424*
	p					<0.001	<0.001	<0.001	<0.001
Social function	r						0.551	0.504	*-0.481*
	p						<0.001	<0.001	<0.001
Bodily pain	r							0.449	*-0.368*
	p							<0.001	<0.001
General health	r								-0.569
	p								<0.001

Oral chelation therapy, emotional role and vitality were identified as fatigue's independent predictors, while the corresponding results for pain and general health were marginally significant. Ergo, vitality, ones' emotional role and oral therapy chelation treatment are correlated with lower fatigue levels. Fatigue's linear predictive model can be found in table 5.

DISCUSSION

According to our findings thalassemic patients present with a significantly burdened life quality, especially with regards to its emotional and social dimensions, and increased fatigue levels. However, there have been identified important variations among patient socio-demographic characteristics and their treatment schemas. Both the life quality and fatigue levels of thalassemic patients were associated with their financial status and the type of chelation therapy they were undergoing. In addition, life quality was related to the participants' educational level, the age they initiated receiving transfusions, and comorbidity. Those with a higher level of education, that received transfusions from an early age, without any comorbidities, reported more than adequate life quality. Life quality and fatigue were found to be correlated, as specific life quality dimensions, that mostly refer to a good emotional state act as predisposing factors of patients fatigue levels.

The correlations between sex, life quality and fatigue, resulted in men presenting higher fatigue levels than women, with women demonstrating better overall health and scoring lower, though, on the physical functioning scale. In corresponding studies, women showed a better social functioning[19] and a higher life quality, generally,[20] indicative of the impact the social environment and its requirements have on the relation between sex and life quality, mostly attributed to the pressure they pose to men to accommodate more social expectations and increased obligations than women, hence the difficulty of thalassemic patients to meet these demands due to their disease. Interestingly enough, a study conducted in Saudi Arabia highlighted the lower social and emotional functioning of women rather than men, explained by the role of women in this country.[21] Family obligations combined with social stereotypes may as well provide reasoning for this additional burden posed on patients in different societies. This notion is supported by our findings when considering how having children or another family member with the same condition can impair the patients' physical functioning potentially due to their increased family obligations.

Many studies have supported the correlation between age and fatigue with younger patients reporting fatigue more often than older ones.[22] However, older patients have a lower life quality[9,23] as they traditionally face difficulties that affect them negatively, like finding a job and having a partner or children. Also, as older patients have more complications due to treatment, their life quality is further

Table 5. Fatigue linear predictive model.

Dependent variable: Fatigue, R^2=0.773	Unstandardized coefficients		t	p	B's 95% CI	
	B	Std error			Lower limit	Upper limit
(Invariables)	60.104	10.456	5.748	<0.001		
Sex	-1.139	1.904	-0.598	0.551	0.614	1.629
Educational level	0.098	1.269	0.077	0.939	0.538	1.858
Commorbidities	3.880	2.131	1.821	0.072	0.628	1.593
Personal life impact	-0.0186	1.155	-0.161	0.872	0.468	2.138
Per os treatment	*-3.965*	1.828	-2.168	0.033	0.749	1.334
Hemoglobin levels	-3.555	2.311	-1.538	0.128	0.602	1.661
Physical functioning	-0.044	0.060	-0.732	0.467	0.472	2.121
Physical role	0.011	0.039	0.293	0.770	0.464	2.157
Emotional role	*-0.098*	0.034	-2.58	0.005	0.366	2.730
Vitality	*-0.297*	0.062	-4.814	<0.001	0.406	2.460
Social function	0.061	0.049	1.227	0.223	0.461	2.172
Pain	0.088	0.045	1.943	0.055	0.540	1.851
General health 95% CI: 95% Confidence interval	-0.098	0.052	-1.888	0.063	0.348	2.876

declined, with regular chelation being tiresome to them, so that they consequently become more stressed by the treatment process than by the disease itself.[24] Notwithstanding, no correlation among age, life quality and fatigue was observed in our study.

In our study, education was identified as one of the most prominent determining factors of life quality. Primary school graduates reported worse life quality and significantly higher fatigue levels. The *post hoc* analysis showed that holders of master's degrees demonstrated lower fatigue levels when compared not only to primary school graduates but also to holders of bachelor's degrees as well. In a similar Greek study, high school graduates predominated in the scoring of the physical functioning scale, while holders of master's and PhDs, in the general health one.[25] Internationally, it has also been noted that those with a higher educational level have a better overall life quality,[26] when among the factors that pose to it a drawback for thalassemic patients are unemployment and low educational attainments.[27] With higher educational level been commonly acknowledged as linked to a higher socio-economic status, its correlation with multiple aspects of life quality observed in our study comes unsurprisingly.

Age of transfusion initiation seemed to have a significant effect on the life quality of the study participants. Those who reported having initiated transfusion at the age of 6–10 years old demonstrated a greater burden on physical functioning and role subscales, and a more grave one on the social function and emotional role subscales. This finding resonates with the one of a previous study, according to which the late onset of transfusion initiations that comes as a consequence of an also late diagnosis, is correlated with a worsened quality of life.[28] Transfusion early initiation may potentially lead to better adaptability to disease requirements and improved adherence, that result in patients coping better with their chronic treatments' burden. In addition, it has been highlighted that delayed chelation treatment onset in thalassemic children deteriorates their and their families' quality of life.[8] Moreover, as adaptation to treatment occurs gradually over time, several patients report that accepting the disease, coming to terms with it, while adapting to their new lifestyle, is a time-consuming process when occurring in an older age.[25,29] Thalassemic children in Malaysia were found to have a significantly lower quality of life by 10–24% than healthy children, with regard to several aspects of their lives.[30] Similar findings emerge from studies in the United Kingdom (UK) and Cyprus also, indicating a reduced quality of life, especially with respect to transfusions organizational problems, chelation therapies and socialization.[10] This might be attributed to patients' mental strain, as they often experience anxiety and depression, conditions that undermine their life quality, whereas they inhibit their social function.[31,32]

Ninety six percent of the patients participating in the present study acknowledged the positive role their families have in assisting them manage their condition, possibly explaining why few life quality dimensions are affected slightly by it. Indeed, the supportive role of family and social environment is important for combating the disease, while improving patients' life quality through helping him financially, remaining well-informed, assessing the situation and his treatment options, or fulfilling his everyday obligations.[33]

With patients' undergoing chelation treatments psychopathology affecting both their disease outcomes and the exacerbation of psychiatric symptoms, social, family and nursing personnel's support to patients constitute a determining factor to their adherence, thus posing an effect to their prognosis, and, therefore their quality of life.[3,34] Concerning disease severity, social function, bodily pain, emotional role and overall health, the life quality dimensions were identified as retarded for patients in a more serious condition; a rather common finding of corresponding studies.[26–28,34]

Regarding the type of chelation therapy followed, in this study, a significant difference was observed in fatigue levels between those undertaking the oral schema and the rest of the participants, while physical functionality was increased in those following the combined schema, maintaining ferritin levels <1,000 μg/L. Patients on a *per os* regimen oftentimes demonstrate better overall health than those following another treatment or combination of them,[25] whereas those on the *per os* regimen present with a better quality of life as well,[9,26,35,36] as numerous studies have indicated over the years.

At the same time, those with the desired hemoglobin levels in the last six months prior to the beginning of the study, reported feeling significantly less fatigue compared to other participants. Indeed, desired hemoglobin levels positively affect patients' physical functioning[37] when pre-transfusion hemoglobin levels (>9 mg/dL) have been associated with a better life quality.[28]

Comorbidity impairs physical functionality[38] and disease management.[39] In our study, those with comorbidities manifested a significant burden on the subscales of vitality, social function, physical role, bodily pain and physical functionality.

In this study, fatigue was negatively correlated with all

dimensions of life quality. Poor health self-assessment was been associated with an increase in the levels of inflammatory markers, such as interleukin 6, which could be responsible for the feeling of fatigue. However, increased fatigue levels can lead to a lower assessment of one's health, thus, by extension, a lower quality of life.[22] In addition, depression is not uncommon among chronic patients, while closely related to fatigue. In patients receiving multiple transfusions, depression occurs at higher rates[29] where psychiatric and behavioral disorders are anticipated to be manifested more frequently in patients with major thalassemia; studies have shown that at least 80% of these patients suffer from a mental disorder.[40]

The main limitation of the present study was the convenience sampling method deployed, as it had been deemed suitable for serving adequately the research scope. With the population under study consisting of patients from a sole provincial hospital, it becomes apparent that our results can not be generalized. For safer conclusions to be drawn, analogous studies in corresponding population samples are required.

In conclusion, life quality determining factors of thalassemic patients may be modifiable, as they concern their educational level, comorbidities, treatment options and mental well-being. In particular, the improvement of their educational status ought to be taken into consideration by the different stakeholders involved with issues relevant to thalassemia, in general. Furthermore, their low educational level hinders the monitoring of therapeutic developments, while making it difficult for them to adhere to their treatment or cope with their disease management requirements. Through targeted interventions, an improvement in the quality of life of patients is to be expected, leading them to enjoy further beneficial effects on their productivity and functionality, and consequently to have a positive impact on society and economy, as well.

ΠΕΡΙΛΗΨΗ

Ποιότητα ζωής και κόπωση των ασθενών με β-θαλασσαιμία που ακολουθούν διαφορετικές θεραπείες αποσιδήρωσης

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ΣΚΟΠΟΣ Η διερεύνηση της ποιότητας ζωής και της κόπωσης των ενηλίκων ασθενών με β-θαλασσαιμία, η μεταξύ τους συσχέτιση, καθώς και η συσχέτιση με τα κοινωνικο-δημογραφικά και νοσολογικά χαρακτηριστικά των πασχόντων. **ΥΛΙΚΟ-ΜΕΘΟΔΟΣ** Πρόκειται για συγχρονική μελέτη στην οποία συμμετείχαν 100 ασθενείς, επί συνόλου 122 ασθενών με β-θαλασσαιμία (ποσοστό ανταπόκρισης 81,9%) που επισκέπτονταν τη Μονάδα Μεσογειακής Αναιμίας του Γενικού Νοσοκομείου Λάρισας «Κουτλιμπάνειο και Τριανταφύλλειο». Η έρευνα έλαβε χώρα από τον Νοέμβριο του 2019 μέχρι τον Ιανουάριο του 2020 χρησιμοποιώντας το ερωτηματολόγιο επισκόπησης της υγείας (SF-36) και την κλίμακα κόπωσης (Multidimensional Fatigue Inventory, MFI) για τον προσδιορισμό της ποιότητας ζωής και της κόπωσης των ασθενών, αντίστοιχα. Η ανάλυση των δεδομένων πραγματοποιήθηκε με το λογισμικό πρόγραμμα Statistical Package for Social Sciences (SPSS IBM), έκδοση 22.0. **ΑΠΟΤΕΛΕΣΜΑΤΑ** Η πλειοψηφία του δείγματος ήταν γυναίκες (57%), ηλικίας 18–45 ετών (71%), έγγαμοι (50%), δεν είχαν παιδιά (55%) και ήταν πτυχιούχοι Ανώτατου Εκπαιδευτικού Ιδρύματος/Τεχνολογικού Εκπαιδευτικού Ιδρύματος (ΑΕΙ/ΤΕΙ) (56%). Το 74% άρχισε τις μεταγγίσεις σε ηλικία <5 ετών, ενώ υπήρχε συννοσηρότητα (25%) και ενδοοικογενειακή εμφάνιση της νόσου (24%). Η κοινωνική λειτουργικότητα, ο σωματικός πόνος και η γενική υγεία είναι οι τομείς της ποιότητας ζωής στους οποίους υστερούσαν όσοι ανέφεραν ότι πάσχουν από σοβαρή νόσο, σε σχέση με τους υπόλοιπους. Παράλληλα, οι απόφοιτοι Δημοτικού εμφάνισαν χειρότερη ποιότητα ζωής ενώ ανέφεραν και σημαντικά υψηλότερα επίπεδα κόπωσης. Επίσης, οι άνδρες δήλωσαν σημαντικά υψηλότερη κόπωση, ενώ οι γυναίκες εμφάνισαν οριακώς σημαντικά καλύτερη γενική υγεία. Επιπρόσθετα, η

από του στόματος θεραπεία αποσιδήρωσης, ο συναισθηματικός ρόλος και η ζωτικότητα αναδείχθηκαν σε ανεξάρτητους προγνωστικούς παράγοντες της κόπωσης. **ΣΥΜΠΕΡΑΣΜΑΤΑ** Οι ασθενείς με β-θαλασσαιμία εμφανίζουν σημαντικά ελλείμματα στην ποιότητα ζωής τους και αυξημένη σωματική κόπωση. Απαιτούνται κατάλληλες νοσηλευτικές και κοινωνικοπολιτικές παρεμβάσεις προκειμένου οι συγκεκριμένοι ασθενείς να απολαμβάνουν τη βέλτιστη δυνατή ποιότητα ζωής και να συνεχίζουν απρόσκοπτα τις κοινωνικές και τις επαγγελματικές τους δραστηριότητες.

Λέξεις ευρετηρίου: Θαλασσαιμία, Κόπωση, MFI-20, Ποιότητα ζωής, SF-36

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