

Perceived stress among patients with Thalassemia attending selected thalassemia centers in UAE

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Abstract: Thalassemia is a chronic inherited disease that leads to stressful life among those affected by it. It causes burden to physical, mental, social and financial aspects to both patient and family. The aim of this study was to assess the perceived stress among patients with thalassemia. A study using descriptive cross-sectional design among 52 patients with thalassemia selected by consecutive sampling technique was carried out in selected thalassemia centers of UAE. The data was collected using perceived stress questionnaire. Half of (50%) the participants were between 13-37 years of age. Majority (54%) of them were males and about 57.7% of the participant had secondary level of education. Majority (92%) of them had type B thalassemia (87%) and were receiving blood transfusion (66%) every three weeks. Majority (80%) of the patient perceived their stress as moderate level, statistically significant $p < 0.05$. Selected sociodemographic variables such as age, gender and education level were noted to be significantly associated to the perceived stress level ($p < 0.05$). Clinical variables such as type of thalassemia and treatment modality were also found to be significantly associated with the perceived stress levels ($p < 0.05$). Patients with thalassemia experience moderate to high levels of stress and can be attributed to selected demographic and clinical variables influencing it.

Key words: Thalassemia, perceived stress

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I. Introduction

Thalassemia is a chronic hemolytic anemia inherited in an autosomal recessive manner, (Fibach E, Rachmilewitz EA, 2017). According to the WHO, (2019) statistics, thalassemia affects approximately 4.4 of every 10,000 lives, both males and females equally. About 5% of the worldwide population has a variation in alpha or beta part of the disease, however not all of them show the sign or symptom who eventually become a carrier. According to the Ministry of Health and Prevention (MOHAP- UAE), 8.5% of UAE population have thalassemia minor or carry the gene, (Khaleej times, 2019). A systematic review was by Abu Shaheen, (2020) show that in countries like United Arab Emirates, Saudi Arabia, Kuwait, Kingdom of Bahrain and Qatar, the prevalence of thalassemia among children below five years were ranged from 0.25% to 33%, while it was 0.9% in children above five years old and for adult frequency were from 0.035% to 43.3%.

Thalassemia is a chronic disease that can lead to physical, mental, congenital, and economic effects on both patient and their families. A descriptive study from Iran revealed that 51.7% have severe stress among the patients with thalassemia, 38.5% had average stress and 10.3% had mild stress (Hisam, A, 2018). According to Zaheer et al., (2015) the stress among patients with thalassemia are attributed to number of reasons mostly related to frequent treatment procedures and hospital visits, decreased life expectancy, expected complications from disease or treatment procedures and the monetary burden on parents/guardian. The long painful treatment sessions, such as chelating therapy add to the stress factor. (Hisam, et.al, 2018). The overwhelming effects of stress may lead to depression and mental illness. In a study done by Heidari, (2020), among parents having a child with thalassemia, identified factors that contribute to high level of stress among them as non-acceptance, disbelief, non-compliance of treatment, resort to termination of pregnancy or abortion, and psychological stress symptoms. They continue to experience unhappiness, high level of anxiety, mental confusion, isolation, dissociation and social stigma.

The physiological side effects brought by the iron chelator therapy causes a high level of perceived stress and non-compliance further ineffective of the treatment. Issues with poor compliance can be linked to loss of hope and low self-esteem in these patients, (Habeib, et.al, 2013).

II. Material & Methods

Study design: A quantitative, descriptive, cross-sectional research design employing survey techniques was utilized to conduct this study

Study location: The research study was done in two selected thalassemia centers in the Emirates namely Ibrahim Obaidullah Hospital Thalassemia center and the Fujairah Thalassemia center. The Ibrahim Obaidullah

Hospital Thalassemia Center is located in Ras Al Khaimah, UAE. There are 24 patients presently visiting the center. Clinic hours starts at 7 am until 3 pm, while the Fujairah Thalassemia Center is located in Fujairah, UAE. There are 57 patients visiting the center. Their clinic hours start also at 7 am until 3 pm weekdays, there is no clinic during weekends. Patients are coming on appointment basis, usually every two weeks and others every three weeks.

Sample size: A total of 52 patients from RAK and from Fujairah who attend for clinic were included to this survey. About 24 patients attend the RAK thalassemia center and 57 patients attend the Fujairah thalassemia center.

Sample size calculation: since the sample size available was small, all patients were included except the samples below 13 years of age.

Subject & selection method: In the present study, consecutive sampling technique was used

Inclusion criteria: In this study, prerequisite factors for participation included patients between 13 - 60 years of age, who have been diagnosed with thalassemia A or B, sampled respondents from both genders, who were able to speak Arabic and English.

Exclusion criteria: Patients with neurological impairment or hemodynamically unstable were not included in the survey. The patients who were critically ill admitted in ICU were also not involved in the study.

Procedure Methodology: The data gathering procedure began after obtaining ethical approval from RAKMHSU REC and RAKREC respectively. Patients at the centers were approached to complete the survey after obtaining their consent, among those who expressed their willingness to participate in the study. To obtain data from the respondents, the researcher utilized a demographic Performa and the PSS questionnaire. Questionnaires were distributed to the patients of RAK thalassemia center and Fujairah Thalassemia center to fill in, which took ten minutes to answer. The participation of the respondent and their details in this research was entirely anonymous, voluntary and confidential.

Statistical analysis: Data collected analyzed using SPSS version 25. The descriptive statistics is used to describe the demographic data of the participants. Inferential statistics to test the research hypothesis such as t-test to assess the level of perceived stress, while Chi- square test was used to assess the association between the selected demographic and clinical profile with the perceived stress scores. The cut off value of significance was set at $p < 0.05$.

III. Result

Table 1: Distribution of participants based on demographic variable (n=52)

Demographic Profile		F	%
Age	13-23	26	50.0%
	24-34	17	32.7%
	35-45	9	17.3%
Educational level	Primary	5	9.6%
	Secondary	30	57.7%
	Higher Education	17	32.7%
Marital status	Single	35	67.3%
	Married	15	28.8%
	Divorced	2	3.8%

Table 1 shows that half the samples were between 13 – 23 years of age. Majority had secondary education and they were mostly single.

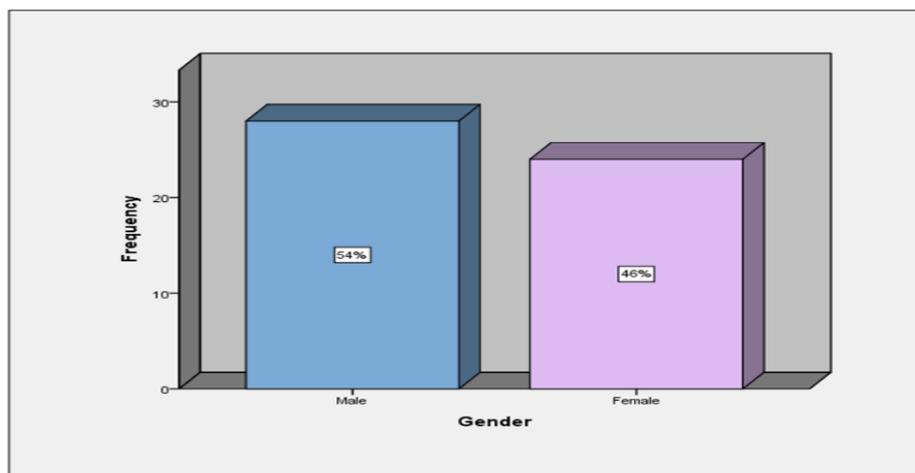


Figure 2. Shows that majority (54%) of the participants were males with thalassemia.

Table 2: Distribution of participants based on financial support (n=52)

Financial Support	F	%
Parents	26	50
Monthly Salary	11	21
Business profit	5	10
Spouse	3	6
Charity office	1	2
Government Support	6	12

Table 2 shows that 50% of the participants received financial support from parents while the other 50 % obtained support from other financial source like monthly salary, business profit, spouse, charity office.

Table 3 Distribution of participants based on type and duration of thalassemia (n=52)

Thalassemia Profile		F	%
Thalassemia type	Alpha	4	8
	Beta	48	92
Duration	Since Childhood	52	100

Table 3 shows that majority (92%) of participants had type beta of thalassemia and all of them had thalassemia since childhood.

Table 4: Distribution of participants based on treatment modalities and treatment frequency (n=52)

Treatments		F	%
Modalities	Blood Transfusion	45	87%
	Blood transfusion and chelator drug	7	13%
Frequency	Weekly	1	2%
	Every 2 weeks	17	33%
	Every 3 weeks	34	66%
	Every 4 weeks	0	0%
	more than 4 weeks	0	0%

Table 4 shows that majority (87%) of participants were on treatment modalities such as blood transfusion alone and most of them (66%) took their treatment every three weeks.

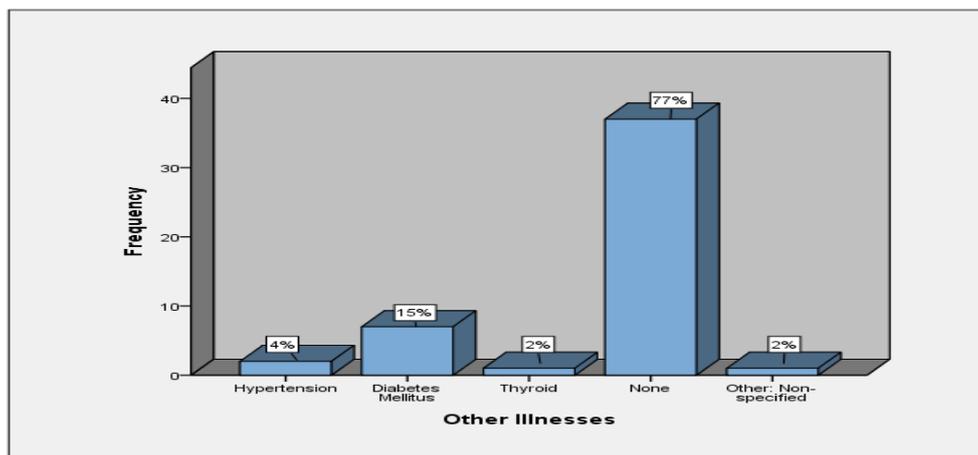


Figure 5. Distribution based on presence of other illnesses (n=52). Majority (77%) of the participants were not having any other illnesses.

Table 5: Distribution based on perceived stress level (n=52)

Perceived Stress level	F	%	Mean	SD	T	Df	Sig. (2-tailed)
Low stress	5	9.6	10.2				
Moderate stress	42	80.8	21.14	5.362	27.985	51	.000*
High stress	5	9.6	28.8				

*Significant difference at p< 0.05 levels

Tables 5 shows that majority (80.8%) of the participants were having moderate level of stress and statistically significant (p= .000), therefore, H1 is accepted at p<0.05 level of significance.

Table 7 Distribution of perceived level of stress based on to clinical profile (n=52)

		Low stress		Moderate stress		High stress		F	Sig.
		F	%	F	%	F	%		
Thalassemia type	Alpha	0	0%	2	3.8%	2	38%		
	Beta	5	9.6%	40	76.9%	3	5.7%		
Treatment modalities	Blood Transfusion	5	9.6%	36	69.2%	4	7.6%		
	Blood transfusion and chelator drug	0	0%	6	11.5%	1	2%		

Table 7 show that the perceived stress among thalassemia patient with Beta type was in moderate level of stress at 76.9%. The participants having treatment modalities of blood transfusion alone had moderately perceived stress (69.2%).

Table 8 Association between perceived stress score and selected demographic variables (n=52)

Demographic Variables	Low		Moderate		Severe		X ²	P value
	f	%	f	%	f	%		
Gender								
Male	2	4%	23	44.2%	25	47.8%	8.380	*.004
Female	3	5.7%	19	36.5%	2	3.8%		
Age								
13 -23	2	4%	23	44.2%	1	2%	186.557	*.000
24 -34	1	2%	13	25%	3	5.7%		
35 -45	2	4%	6	11.5%	2	3.8%		
Educational level								
Primary	0	0%	5	9.6%	0	0%	425.187	*.000
Secondary	1	2%	26	50%	3	5.7%		
Higher education	4	8%	11	21.1%	2	3.8%		

*Significant difference at p< 0.05 levels. Table 8 shows association for gender, age and educational level.

Table 9 Association between perceived stress score and selected clinical variables (n=52)

Clinical Variables	Low		Moderate		High		X ²	P value
	f	%	F	%	F	%		
Type of Thalassemia								
Alpha	0	0%	23	8%	2	3.8%	37.231	*.000
Beta	5	9.6%	40	6.9%	3	5.7%		
Treatment Modalities								
Blood transfusion	5	9.6%	36	69.2%	4	7.6%	27.769	*.000
Blood transfusion and chelator drugs	0	0%	6	11.5%	1	2%		

*Significant difference at p< 0.05 levels

IV. Discussion

In the present study, (50%) of the participant were at the age range of 13-23 years. It is depicted on the study by Maheri, et.al, (2018) to among 62 thalassemia patients in Iran with mean age 24.32, majority among them were above 18 years and rest between the ages 14 to 18 years. In a study done in Saudi Arabia participants of all three age groups, and the overall prevalence of thalassemia was found to be 30.72% in United Arab Emirates (UAE), the affected age group were children below five years of age (0.25% to 33%), while 0.9% of children were above five years and 0.035% to 43.3% was among adult patients (Abu Shaheen, et.al, 2020). It shows that the affected age group are higher in these regions, which could be due to high-risk consanguineous marriages.

In UAE, prevalence among females was higher with 58.8% when compared with male in relation to beta thalassemia, (Taha, et al., 2016). According to Kim, et.al (2017) thalassemia major was noted in both genders and is on increase as birthrates increases. The participants in this study (67.3%) were single with a mean age of 25.7. A single young adults and marriage reconsideration rates has increased among population with thalassemia in UAE, with the average marriage age being 24.5, (Statistics Center Abu Dhabi, 2013). On the other hand, there were 28.8% of the participants who were married knowing the risk of producing a child with thalassemia. In UAE, marriages between carrier-carrier couples are increasing as the population grows with an increased potential for child with thalassemia. About 57.7% who completed secondary level of education and the author found that educational status was related to understanding of the importance of premarital screening. Education factor was found to be indirectly influencing the marriage reconsideration of carrier-carrier couples among both genders. In the present study (40%) had an occupation while 19% were students. It was observed in this study that 50% of the participants had financial support from their parents. The average monthly household income of UAE residents either in private and government sectors is AED18,248.60, according to a new survey by the UAE Ministry of Economy, (2020). This shows that 31% percentage of the participants were well-paid and were hence the breadwinners. However, the financial status of the family or the patient is one of the most important factors to access the available treatment or resources. According to Zolaly, Al Belawi (2020) thalassemia causes a huge impact on financial aspect and having the possibility of losing a family member who supports financially. Chronicity of thalassemia hinders continuation of employment (40%) even stops them from working. Younger adults were mostly diagnosed as early childhood were able to attend school despite of the severity of their condition which causes absenteeism later with poor academic performance. In UAE, the children with thalassemia who attend the Arabic pre-school were estimated at 8.7%, (Barakat-Haddad, H, 2013). In the present study 19% of them were still going to the schools. About 62% of the participants were Emirati nationals, whereas other nationality consisted of Asian, Arabs, Cyprus, Yemeni, Comoran and other nationals. Globally, approximately 4.4 of every 10,000 births are affected by thalassemia, (WHO,2019), wherein alpha and beta type of thalassemia have high prevalence rate in Asia and Middle Eastern regions (Weatherall, 2010). Recent census in UAE, thalassemia is the most common inherited blood disorders among Emirati national according to Ministry of Health and Prevention (MOHAP, 2019) about 8.5% of UAE population is suffering with thalassemia minor or gene carrier (Khaleej times, 2019). The clinical profile of the participants shows that majority (92%) of the participants had type beta of thalassemia since childhood. About 5% of affected population has either alpha or beta type, (WHO, 2019) while in Arab regions, beta thalassemia frequency was about 1% to 11%, (Hamamy and Al-Alawi, 2013). The prevalence of beta thalassemia in Saudi Arabia was high in comparison to other Middle Eastern countries, (Alsaed, et.al, 2018). In UAE the prevalence of beta thalassemia major and carriers were found to be higher than alpha thalassemia, (Kim and Tridane, 2017).

Most common treatment among the participants was blood transfusion (87%) every three weeks. The combination treatment of blood transfusion and chelator drug were 13% with the same frequency of every three weeks. A study by Maheri, Sadeghi, Shojaeizadeh, Tol, Yaseri, & Rohban (2018) reported that serious complications of repeated blood transfusion which cause iron overload and depositions of iron occurs chelators

therefore are given as part of treatment modalities. Among the participants about 77% were not having any other diseases while 15 % were with diabetes mellitus, 4% with hypertension, 2% with thyroid problem and 2 % nonspecific symptoms.

The chronicity of the nature of thalassemia disease can influence to emotional imbalance that affect physical, mental, social and financial burden to both patient and families, (Hisham, A., 2018). Study reported that majority (51.7%) had high stress level, 38.5% with moderate whereas 10.3% had low stress level while in the present study, the overall stress levels among the participants perceived it as moderate stress, whereas comparing the three mean, there was a higher mean in high stress level. This difference was noted to be statistically significant at ($p < 0.05$) level of confidence. The findings of Hisham, and et.al, (2018) also demonstrated that there was significant high perceived level of stress regardless of gender, age and diagnosis among majority of the patients. The study done in Saudi Arabia by Zolaly, M., and et.al, (2020) regarding depression, anxiety and stress among thalassemia patients, observed that the mean stress score was 6.37. In this study majority (61.3%) were having normal level of stress, whereas 16% having moderate stress and 9.7% with a high stress level. Which is contrary with the present study where majority had moderate stress, this could be attributed with few factors like, age, gender, educational level, marital status, nationality, financial status, type of thalassemia, type of treatment and frequency. Harley, & Eskenazi (2006) emphasize the relationship of stress to the different demographic profile of the patient such the age, gender, marital status, education level and nationalities. These factors may have impact to the perceived stress.

In the present study the mean age of the participants was 25.7. There were 44.2% who perceived stress level to be moderate. It is noted in this study that most of the participants were young adults in a phase of life where many of them experience a sense of optimism towards adulthood. It can be inferred that the young adult participants were more affected by the stressors than the older adults. This could be related to the socioeconomic status of the patient since majority (64.7%) of them had no occupation and (76.9%) received financial support from parents. Similar findings of Maheri and et.al (2018) are noted that there was statistically significant relationship with age and the perceived stress. They reported that 18 years and younger patient had lower depression, anxiety and stress level. In contrary, to this finding the study by Zolaly and Belowi, (2020), reported that the mean age was 30.23 years and had no association between age to the level of stress found in Zafae Adult Thalassemia Center in Saudi Arabia. Various of studies report that perceived stress among men and women to have differences, this can be due to certain aspects such as vulnerability, response to stress and coping mechanisms. About 44.2% of men acknowledged moderate degree of stress level and were noted to have an association of the perceived level of stress with the gender. As similar findings are noted in a study by Zolaly and Belowi, (2020) that men had higher level of stress compared to females.

The level of educational attainment of every individual account to level of understanding. Education bridges the gap through accessing information about the disease which benefits to have knowledge of coping. The patient's understanding regarding his disease process, treatment, stress level or prognosis may be associated with compliance or adherence and tolerance, these factors were to contribute higher level of patient's satisfaction perhaps quality of life. In the study, majority (50%) were having the secondary level of education with moderate level of perceived stress, statistically significant association was observed. It shows that individuals who are educated are in better position to understand the disease and the treatment modalities. It helps to develop coping skills to battle with thalassemia. Similar study findings were found by Maheri and et.al, (2018) that there was significant association of education to the level of stress, anxiety and depression. It can be inferred that education plays an important role in maintaining compliance and cope with stress. Furthermore, in the present study, it was observed that single individual had more received stressors brought by the disease condition as they perceived a moderate level of stress. However, there were 13 of married participants who had also moderate level of perceived stress at (25%), this observation can be implied that married has also more stressors in addition to the role and responsibilities to their family.

The patient who has beta type perceived moderate stress level (76.9%) whereas the alpha type of thalassemia perceived stress at high level (3.8%). This highlights the effects of the stressor that bring physiologic change increasing the stress levels. Although, both types have almost the same symptoms and yet it is according the defect genes which were inherited. The alpha type having four mutated or defective genes that made the condition become severe and life threatening. These individual need bone marrow transplant, while beta type is considered as a milder form of thalassemia there were two genes involved to mutated or inherited from the parent (mayoclinic.org., 2021). The analysis from Zolaly, M. and et.al (2020) that there was very high level of anxiety and stress among patient with the beta type of thalassemia at (38.7%) while 16% had moderate stress. Patient receiving blood transfusion were found to have moderate stress level (69.2%) when comparing to participants receiving combination treatment such as blood transfusion and chelator. Physiological adverse reactions and psychological disorders are expected complications among patients with thalassemia, (Al-Hakeim, HK, et.al, 2019). Although, 11.5% of participants perceive moderate stress who received the combination treatment, the findings from the study by Zolaly, M, et.al, (2020) on patient receiving injectables

iron chelator reported a higher mean of depression, anxiety and stress. In contrary, an oral chelating agent reported to have an improved compliance thus decreasing level of stress, (Habeab, AM., et.al, 2013). The nature of treatment as invasive and type of treatment which is considered as palliative or supportive treatment can contribute to the perceived stress level. In addition, the number of times of hospitalization or visit to the clinic can also trigger stress. In contrary, a study by Maheri and et.al (2018) reported that higher levels of depression and stress among those patients receiving supportive treatment when compared to patients receiving blood transfusion and chelator drugs. Various side effects and the need to frequently visit the clinic can influence their stress levels.

V. Conclusion

Assessment is the integral part of nursing practice in caring for patient with thalassemia. The findings of this study emphasize the need to manage the emotional well-being of the thalassemia patient since their childhood. Despite the nature of the disease that can lead to deterioration of the patient, maintaining mental health is the focus to cope with crisis situation that occur with the disease. The physical, psychological, social and financial aspects are also the focus among nurses providing holistic care. The holistic approach management of the perceived stress level could achieve a low stress level among patient with thalassemia. Although, in this study, the perceived level of stress among thalassemia is moderate of regardless sociodemographic and clinical profile.

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