

STRESS, ANXIETY AND DEPRESSION AMONG ADOLESCENTS SUFFERING FROM THALASSEMIA

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ABSTRACT

Background: Thalassemia a serious, life-limiting disease that can be life-threatening and cause great disruption in all dimensions of life. **Aim:** This study aimed to evaluate stress, anxiety and depression in adolescents with thalassemia. **Subjects and Method: Design:** A descriptive research design was utilized. **Setting:** Pediatric Hospital in Mansoura University and an inpatient department of El- Tadamon Hospital in Port-Said city. **Subjects:** The studied subjects consisted of 112 adolescents whom selected from above mentioned settings. **Tools:** Data were collected through Depression Anxiety Stress Scale (DASS21), in addition to personal and clinical data questionnaire. **Results:** The study revealed that, approximately half of the studied adolescents (48.2%) had extremely severe level of stress, more than half of them (54.5%) had extremely severe level of anxiety, and less than one quarter of them (23.2%) had extremely severe level of depression. **Conclusion:** Adolescents suffering from thalassemia are exposed to multiple health problems especially what related to psychological and emotional dimensions represented in severe anxiety and stress. **Recommendations:** The main recommendation was designing and applying continuous educational programs for adolescents with thalassemia regarding their disease to maintain compliance to the therapeutic regimen and prevent negative impacts of thalassemia on their psychological status. These programs should be led by health professionals.

Keywords: Anxiety, Depression, Stress, Thalassemia.

INTRODUCTION

The term thalassemia refers to a group of hereditary blood diseases caused by defects in the gene responsible for producing globin chains. (Boonchood uang, Louthrenoo, Choeprasert & Charoenkwan, 2015; Higgs, Engel & Stamatoyannopoulos, 2012). It is a hereditary disease that is transmitted by parents to their children and has no definitive treatment (Renani, Dashtbozorgi, Papi, Navah & Latifi, 2016). Thalassemia is the most common inherited hemoglobin disorder in Egypt, with transmission rate ranging from 5.3 to 5> 9 % (Hisham, Bishr & Khalifa, 2018).

Thalassemia can cause different physiological, emotional, social, financial and behavioral problems that affect the life of both patients and their families, its effects are stronger particularly during school age and adolescence. It can greatly affect the sense of autonomy and mental health (Hassan & El Azzab, 2016). Adolescents with thalassemia experience stress, anxiety and depression which constituted 18.8 %, 60.9 % and 59.4 % respectively (Khamoushi et al., 2015).

Stress among adolescents with thalassemia can be attributed to number of reasons like frequent treatment procedures and hospital visits, decreased life expectancy, expected complications from disease or treatment procedures and the monetary burden on parents. Also, the long painful treatment sessions such as to remove iron as iron overload being a complication of frequent blood transfusions, and an eight hour long painful procedure when injecting chelators by chelation pump is carried out, adding to the stress factor (Hisam et al., 2018).

Depression is a common psychological complication of any chronic disease, and it can be seen widely among patients with thalassemia, and the natural history of the disease, associated complications, treatment methods and its adverse effects, especially iron overload, can be associated with depressive disorder (Johnson, 2019; Shafi'i, Nizar, Gorjani, Bahramina & Kubay, 2014).

Adolescents with thalassemia need additional psychological support to reduce emotional stress, to enhance efficiency and for better compliance with therapy in daily life (Jain et al., 2013). Psychological treatments such as cognitive behavioral therapy (CBT) is a deliberate attempt to preserve the positive effects of behavioral therapies in a less dogmatic context and to coordinate the cognitive activities and emotional

experiences of patients with treatment cycles. It should improve patients' feelings and performance (Muhammadiyah, Bagheri, Hashemi & Sani, 2018).

SIGNIFICANCE OF THE STUDY

Adolescents with thalassemia experience feelings of shame or denial, uncertainty about the outcome of the disease, fear of stigma or imminent death that imposes restrictions on social life (Koutelekos & Haliasos, 2013). Thalassemia affects approximately 4.4 out of every 10,000 births worldwide (Smith, 2018). There are 10,000 thalassemia cases recorded in Egypt, 95% of which are beta thalassemia major, and 5% are thalassemia intermedia or hemoglobin H disease (Mahmoud, 2009).

The psychiatric nurse and support network for adolescents and their families play a crucial role in making them feel confident, building self-esteem, and eventually becoming a self-sufficient individual. Teens with thalassemia try to live a normal life and try hard to deal with the nature of their disease, they need more attention and evaluation (Koutelekos & Haliasos, 2013). Therefore, this study could help to evaluate stress, anxiety and depression among adolescents suffering from thalassemia.

AIM OF THE STUDY

This study aimed to evaluate stress, anxiety and depression among adolescents suffering from thalassemia.

Research Objectives:

- 1) Determine the levels of stress among adolescents suffering from thalassemia.
- 2) Measure the levels of anxiety among adolescents suffering from thalassemia.
- 3) Assess the levels of depression among adolescents suffering from thalassemia.

SUBJECTS AND METHOD

Study Design:

A descriptive research design was utilized for the current study.

Study Settings:

The present study was carried out in outpatient clinic of Pediatric Hospital in Mansoura Governorate which is affiliated to Ministry of Higher Education (Mansoura University), and in an inpatient department for blood transfusion of El- Tadamon Hospital in Port-Said Governorate which is affiliated to comprehensive health insurance organization.

Study Subjects:

A purposive sampling was used to select the subjects for the study. The study subjects comprised a total 112 adolescents aged from 10 to 19 years old with thalassemia either males or females who attending the above mentioned hospitals. According to fluency rate, 92 adolescents from outpatient clinic of Pediatric Hospital in Mansoura University and 20 adolescents from inpatient department of El- Tadamon Hospital in Port-Said city. They were recruited within 7 months from the first of February 2020 and ending August 2020.

Tools for Data Collection:

The study data were collected by using the following tool:

TOOL: Depression Anxiety Stress Scale (DASS21):

This scale was developed by Lovibond & Lovibond (1995) in an English language and translated into Arabic language by Ali et al. (2017), the DAAS21 consists of 21 statements which include three self-report sub-scales designed to measure the severity of negative emotional states including depression, anxiety and stress. Each of the three subscales contains 7 statements questioning about the severity of a reported symptom over the past week.

Scoring System:

The study subjects responses rated on a 4-point Likert scale ranging from did not apply to me at all (0), applied to me some degree or some of time (1), applied to me to a considerable degree/ good part of time (2), applied to me very much/ most of the time (3) in order to rate the extent to which they have experienced each state. Scores for depression, anxiety and stress are calculated by summing the scores for the relevant items.

Because DASS 21 is a short form version of the DASS which was a long form that had 42 items, the final score of each item groups (depression, anxiety and stress) needs to be multiplied by two (x2). The score for each of the subject over each of the sub-scale is then evaluated as per the severity rating index below:

Severity	Stress	Anxiety	Depression
Normal	0-14	0-7	0-9
Mild	15-18	8-9	10-13
Moderate	19-25	10-14	14-20
Severe	26-33	15-19	21-27
Extremely severe	34+	20+	28+

In addition to **a personal and clinical data part**, this part was developed by the researcher in an Arabic language after reviewing the related literature. It comprised personal data as age, gender, educational level and birth order. It also included clinical data related to duration of illness, severity and effects of thalassemia.

Reliability and validity:

The Arabic version of DASS21 showed excellent significant reliability and satisfactory validity (Ali et al., 2017). The Pearson correlations were highly significant for stress, anxiety and depression ($r= 0.835, 0.839$ and 0.759 respectively).

Pilot Study

Before entering the actual study, a pilot study was carried out on 10 % of the study subjects (11 adolescents) suffering from thalassemia. It was done in order to ascertain the relevance, clarity, applicability and feasibility of the used tool, and to estimate the time required to fill in the tool. Based on the findings of the pilot study, necessary modifications were done in relation to personal and clinical data sheet and hence the subjects who shared in the pilot study were excluded from the main study sample. The pilot study was conducted at the time from the first to the middle of January 2020.

Field Work:

The data was collected through two days per week on Saturday and Monday. Collection of data covered a period of seven months from the first of February 2020 and ending August 2020, one month in El- Tadamon Hospital in Port-Said city and the other six months in outpatient clinic of Pediatric Hospital in Mansoura University. The process of data collection was stopped for approximately two months due to the spread of Covid 19.

The data collection process was conducted using face to face interview technique that was done on an individual basis and this was done on a private area in the hospitals to ensure privacy and confidentiality of the collected data. A number ranging from 4-5 adolescents with thalassemia were interviewed daily from 10 a.m. to 2.00 p.m. each interview lasted from 10- 25 minutes depending on responses of the subjects, the interview takes place before the blood transfusion and personal and clinical data was collected from the adolescents and their caregivers. After completion, the researcher ensured that all statements included in the tool were completed. Then, the studied adolescents were thanked for their cooperation.

III. Administrative Design:

Before starting any step in the study, an official letter from the Dean of the Faculty of Nursing, Port Said University was sent to the directors of the above mentioned setting requesting their permission and cooperation to conduct the present research after explaining the aim of the study.

Ethical Considerations:

The study protocol was approved by the Scientific Research Ethics Committee of the Faculty of Nursing; Port Said University. An informed consent was obtained from the studied subjects and their caregivers after explaining the aim of study. Ensuring the confidentiality of the collected information and anonymity is guaranteed. Voluntary participation of the studied adolescents was confirmed as they will be informed that

they have the right to withdraw from study at any time. Finally, the process of data collection was not disturbing the harmony of the work of the above mentioned settings.

IV. Statistical Design:

Data entry and statistical analysis were done using statistical package for social science (SPSS) version (20.0). Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and means and standard deviations for quantitative variables. Qualitative categorical variables were compared using chi-square test. Moreover, Person coefficient test was used for the assessment of the inter-relationships among quantities variables. Statistical significance was considered at $P\text{-value} \leq 0.05$, and highly significant at ≤ 0.01

RESULTS:

Table (1): reveals that more than half of the studied subjects (52.7%) were males and 54.4% aged between 10 to less than 14 years with a mean \pm SD of 12.45 ± 3.54 years. It is also observed that, more than one third (38.4%) of the studied adolescents had primary level of education. Regarding their birth order, more than one third (35.7%) of the studied adolescents were the first child. Additionally, the majority of the studied adolescents (83.9%) were living in rural area.

Table (2): presents the clinical data and effects of thalassemia among the studied adolescents. As shown, more than two thirds (66.1%) of the studied adolescents had thalassemia at age of less than one year. The majority of them (99.1%) had major thalassemia. More than three quarters of the studied adolescents (78.6%) played with their college and the cause of not playing for adolescents who didn't play was their illness. Results revealed that, more than two thirds of studied adolescents (69.5%) had a feeling of shy because of knowing of their friends and relatives of the disease. In relation to body image change as a consequence of the disease, most of the studied subjects (91.1%) had body image changes, and 87.2% of them were annoying because of these changes.

Figure (1): denotes that, approximately half of the studied adolescents (48.2%) had extremely severe level of stress.

Figure (2): shows that, more than half (54.5%) of the studied adolescents had extremely severe level of anxiety.

Figure (3): it was clear from the figure that, less than one quarter of the studied adolescents (23.2%) had extremely severe level of depression.

Table (3): it was evidenced that there was a highly statistical significant positive correlation between total score of stress and severity of thalassemia where ($r= 0.009$). Also, there were statistical significant positive correlations between total scores of depression, and anxiety and severity of thalassemia where ($r= 0.036$ and 0.021) respectively.

Table (1): Distribution of the studied adolescents with thalassemia according to their personal characteristics (n=112).

Personal Characteristics	Studied adolescents	
	No.	%
Sex		
Male	59	52.7
Female	53	47.3
Age (years)		
10 - <14	61	54.4
14 - <17	33	29.5
17 -19	18	16.1
Min-Max, Mean \pmSD	10-19 12.45\pm3.54	
Educational level		
Not read and write	1	0.9
Read and write	1	0.9
Primary education	43	38.4
Preparatory education	39	34.8
Secondary education	28	25.0
Birth order		
The first	40	35.7
The second	36	32.1
The third	17	15.2
The last	19	17.0
Residence		
Rural	94	83.9
Urban	18	16.1

Table (2): Distribution of the studied adolescents according to clinical data and effects of thalassemia (n=112).

Items	Studied adolescents	
	No.	%
Age of onset of thalassemia (years)		
< 1	74	66.1
1-≤3	18	16.1
>3	20	17.8
Severity of thalassemia		
Minor	0	0.0
Moderate	1	0.9
Major	111	99.1
Regulatory of the study		
Regular	48	43.6
Sometimes regular	36	32.7
Irregular	26	23.6
Playing with colleagues		
Yes	88	78.6
No	24	21.4
Reason for not playing with colleagues (n=24)		
Because of illness	14	58.3
Other reason	10	41.7
Colleagues and relatives are knowing of disease		
Yes	82	73.2
No	30	26.8
Feeling shy because of their knowledge of disease (n=82)		
Yes	57	69.5
No	25	30.5
hiding the disease from them (n=30) Causes of		
Stigma	25	83.3
Ignorance	5	16.7
Body image change		
Yes	102	91.1
No	10	8.9
Annoying because of body image change (n=102)		
Yes	89	87.2
No	13	12.8

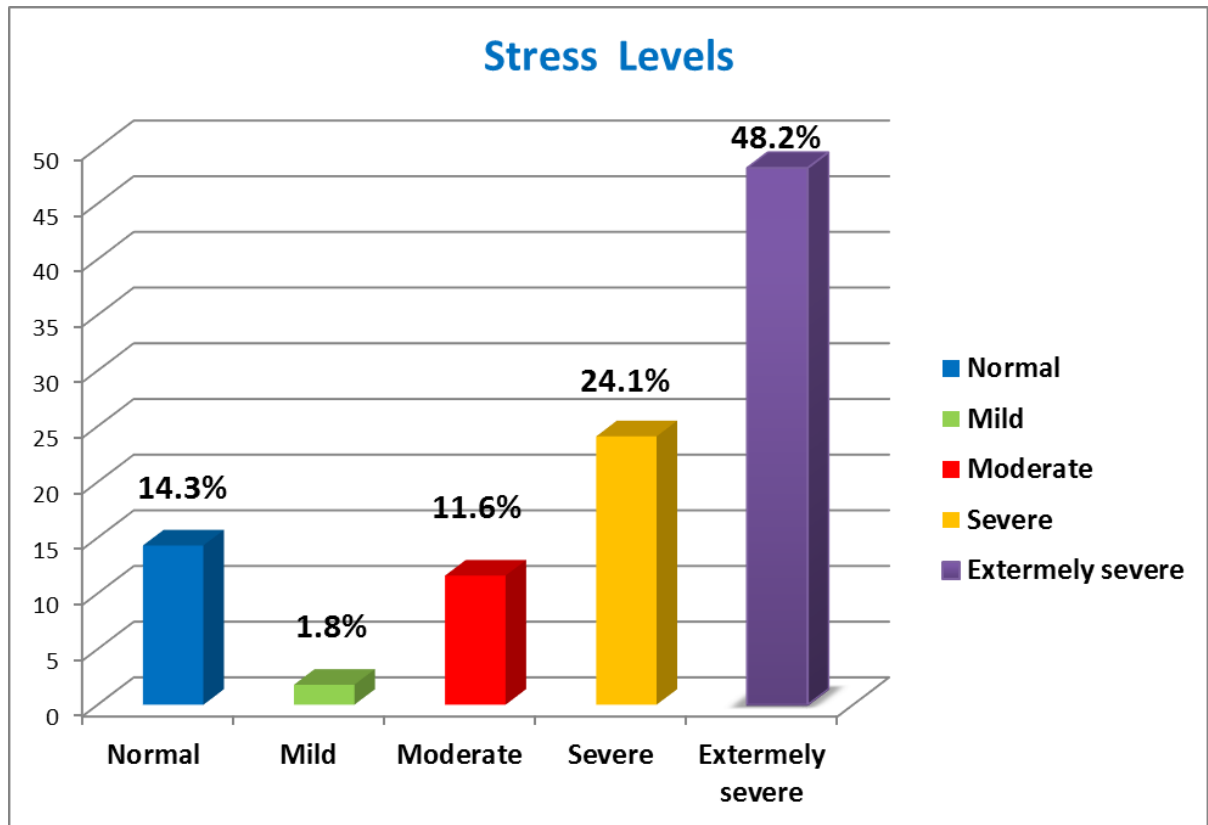


Figure (1): Distribution of levels of stress among the studied adolescents with thalassemia (n=112).

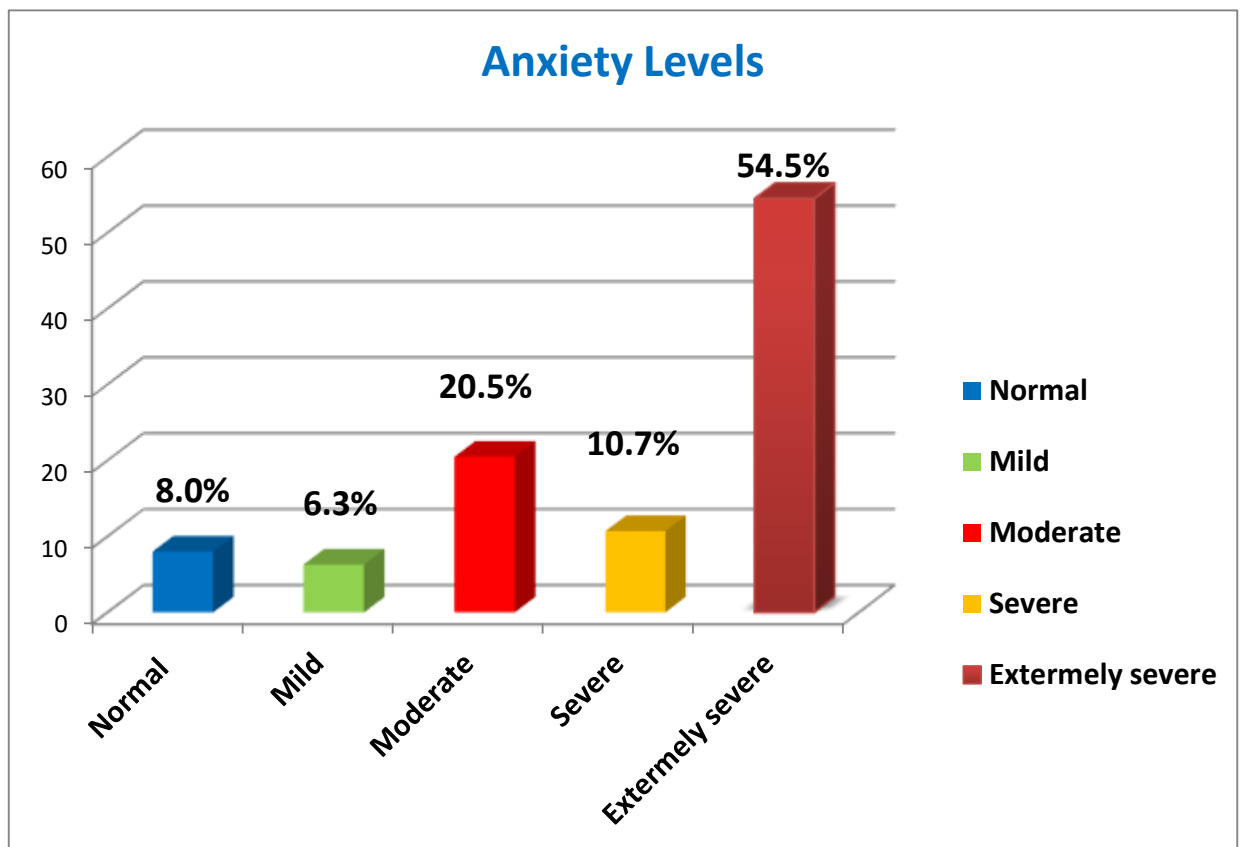


Figure (2): Distribution of levels of anxiety among the studied adolescents with thalassemia (n=112).

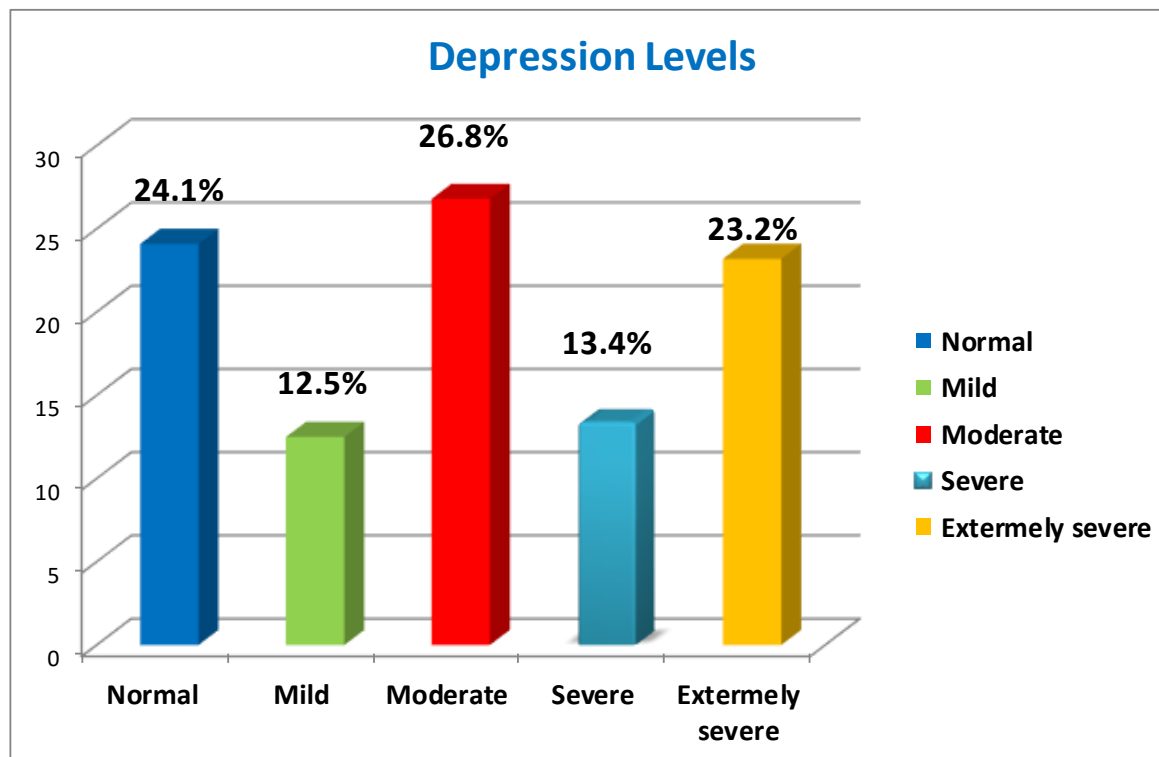


Figure (3): Distribution of levels of depression among the studied adolescents with thalassemia (n=112).

Table (3): Correlation between total scores of stress, anxiety, and depression and severity of thalassemia among the studied adolescents with thalassemia (n=112).

Total scores of	Severity of thalassemia	
	r	P
Stress	0.282	0.009**
Anxiety	0.261	0.021*
Depression	0.326	0.036*

r=Pearson correlation

*Significant at $P \leq 0.05$

**Significant at $P \leq 0.01$

DISCUSSION

Thalassemia is a chronic illness that could badly affect self-esteem and future life among teenagers. This low self-esteem is expected to increase the prevalence of anxiety and depression (Zolaly et al., 2020). Many authors have evaluated psychiatric disorders in thalassemic patients, but relatively little is known about predictors of these disorders, thus the aim of this study was to evaluate stress, anxiety and depression among adolescents with thalassemia.

This study demonstrated that, thalassemia doesn't effect on regulatory of the study among studied adolescents, while the study by Nashwan et al., (2018) entitled quality of life among adolescents aged 14 to 18 years with beta-thalassemia major in Qatar, concluded a significant reduction in school and social functioning in children with thalassemia compared to healthy participants. Besides, Caocci et al., (2016) carried out a study termed health related quality of life in Middle Eastern children with Beta-thalassemia, mentioned that patients with thalassemia often forced to miss school because of hospital appointments or admissions for regular monthly blood transfusion and treatment of complications.

The results of the study revealed that the majority of adolescents studied hid their disease due to stigma, most of the adolescents studied reported a change in body image, and more than three-quarters of them were disturbed by this change. This could be explained by that, the studied adolescents hid their disease because of stigma due to the changing body image compared to their healthy peers in the same age, in addition to the signs and symptoms associated with thalassemia such as slowed growth and delayed puberty, bone problems, an enlarged spleen, pale and listless appearance and jaundice, which keep them different from others. Thus patients with thalassemia usually prefer social isolation to avoid people talk, bullying from other and embarrassment, especially in the Egyptian rural area. In addition to ignorance and lack of information about the nature of the disease and knowing people harm the girls reputation, especially in the countryside.

This result was in a harmony with the results of Vahed, Firouzkouhi, Mohammad & Ghalgaie, (2017), in the study about experiences of Iranian parents of children with Beta-thalassemia, showed that, children with thalassemia feel anger, shock and guilt. In addition,

social attitudes, stigma and discriminations toward their chronic conditions which keep them always away from people and their talk.

Results of the concurrent study illustrated that, less than one quarter of the studied adolescents had extremely severe level of depression. While, more than half of them had extremely severe level of anxiety. Concerning to stress, nearly half of the studied adolescents had extremely severe level of stress. This may be related to that, depression, anxiety and stress among the studied adolescents with thalassemia is not an unexpected issue and it has been confirmed by the numerous studies, which could be due to chronic nature of thalassemia, clinical protests, unpleasant side effects of treatments, medical costs, and premature death expectancy. In addition, thalassemia is a chronic disabling illness which is usually associated with feelings of being different and inferior, leading to decreased self-esteem and a feeling of constant stress.

As a result of bone expansion, a characteristic mongoloid faces occurs. This bone affection with anemia and iron overload among adolescents with thalassemia often leads to short stature and delayed puberty. These features increase the adolescents' feeling of oddness which, in turn, leads to anxiety, stress, reduced self-esteem, feelings of difference, poor self-image, being dependent which make them more socially isolated and depressed. Moreover, illness is usually associated with pain and frustration which are the source of anxiety and suffering. More importantly, patients with a chronic illness over time believe that they will never be well. They are confident that they will always carry this illness with them as the illness is a part of them. Therefore, adolescents with thalassemia were not allowed to play or to be involved in all the normal activities that their same age children be involved. So, they develop a bad self-image and low self-esteem. They do not talk to friends about the illness, fearing that they will be rejected and treated differently.

Additionally, suffering from low self-esteem and a devalued sense make adolescents to be always looked for approval and acceptance from others, and they felt very easily hurt and rejected which make them to accept things that they actually dislike. All these factors increase anxiety, stress and depression in such adolescents with decreased self-esteem.

These findings were in agreement with Yengil et al., (2014) who studied anxiety, depression, and quality of life in patients with Beta thalassemia major and their caregivers in Turkey, depicted that beta thalassemia major leads to an increase in the frequency of depression, stress and anxiety in both patients and their caregivers, and affects negatively physical and mental components of quality of life. Furthermore, Khamoushi et al., (2015) carried out a study entitled prevalence and socio-demographic characteristics related to stress, anxiety, and depression among patients with major thalassemia in the Kermanshah county, elaborated that the respondents were suffering from extremely severe anxiety, depression, and stress.

In the same spoken, Zolaly et al., (2020) in the study named depression, anxiety, and stress symptoms in patients with Beta thalassemia major in Almadinah Almunawwarah, Saudi Arabia, indicated that depression symptoms were detected in two thirds of patients, anxiety symptoms were detected in half of the studied group, and stress symptoms were detected in more than one third of patients with thalassemia. Also, a study named prevalence of depression and anxiety in patients with β -thalassemia major, reported similar findings where the highest percentage of patients were depressed (Khoury et al., 2012).

Furthermore, Maheri et al., (2018) carried out a study about depression, anxiety, and perceived social support among adults with Beta-thalassemia major, Iran, revealed that adolescents with thalassemia major have more psychological problems than healthy ones. Patients with thalassemia have a lower quality of life than their peers, the rate of depression, anxiety and stress is higher more than healthy subjects. therefore, an effort should be made to design and evaluate a variety of interventions, including those for health education and promotion, in order to decrease the level of depression and anxiety among these patients.

The present study also showed that there were statistically significant positive correlations between depression, anxiety, and stress and severity of thalassemia among the studied adolescents. This result highlighted the fact that thalassemia is a serious and catastrophic disease that affects all dimensions of health more specifically the psychological aspect which represented in severe depression, anxiety, and stress.

This finding was in agreement with Hajbaghery & Ahmadi (2015), who performed a study entitled health related quality of life, depression, anxiety and stress in patients with beta-thalassemia major, in addition, Hassan & El Azzab (2016), in the study of the health instructions effect on quality of life and psychological problems among children with thalassemia in Egypt, found out that there was positive statistically significant correlations between depression, anxiety, stress and severity of thalassemia among the studied group with thalassemia.

Eventually, the study confirmed that adolescents suffering from thalassemia are exposed to multiple health problems especially what related to psychological, mental and emotional dimensions represented in severe depression, anxiety and stress.

CONCLUSION

Based on the findings of the present study, it can be concluded that more than half of the studied adolescents with thalassemia had extremely severe level of anxiety, also, approximately half of them had extremely severe level of stress. Meanwhile, less than one quarter of the studied adolescents had extremely severe level of depression. In conclusion, adolescents suffering from thalassemia are exposed to multiple health problems especially what related to psychological, and emotional dimensions represented in severe anxiety and stress.

RECOMMENDATIONS

In the light of the results of the present study, the following recommendations are suggested:

- 1-** Continuous educational programs for adolescents with thalassemia regarding their disease to maintain compliance to the therapeutic regimen and prevent negative impacts of thalassemia on their psychological status. These programs should be led by health professionals.
- 2-** Rehabilitation programs should be held for the adolescents with thalassemia and their caregivers to teach them stress management technique as progressive relaxation techniques, meditation and mindfulness.

- 3- Self regulation of stress and anxiety should be planned through proper nutrition, regular exercises and adequate rest toward improving body image and resistance to stressors.
- 4- Designing and applying educational programs for the health care team members for the following purposes:-
 - Increase their awareness about the importance of dealing with patients with thalassemia holistically as whole bio-psycho-social being.
 - Teach them how to induce hope in the patients with thalassemia regardless the severity of their disease, allow them to express their feelings freely, and accept their fears, anxiety and their native questions.
- 5- The health care team members particularly nurses should assume the responsibility to develop adequate social support from a diversity of source as caregivers, relatives, friends and members of self-help group with thalassemia to help adolescents with thalassemia to cope with stressors related to the disease and reduce their stigma felt.
- 6- There is a great need to increase public awareness in order to reduce the marriage of relatives because of its dire consequence including reproduction of children with thalassemia.

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الضغط النفسي، القلق والاكتئاب لدى المراهقين المصابين بأنيميا البحر الأبيض المتوسط

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الخلاصة

المقدمة: إن مرض أنيميا البحر الأبيض المتوسط يسبب العديد من المشكلات الصحية، والنفسية، والاجتماعية، والمادية للمراهقين وعائلاتهم ويؤثر مثله مثل أي مرض مزمن آخر على كل جانب من جوانب حياة المرضى ، وتؤدي أعراضه ومظاهره الإكلينيكية إلى مواجهة المريض للضغوط النفسية والقلق والاكتئاب. **الهدف :** تقييم الضغط النفسي، والقلق، والاكتئاب لدى المراهقين المصابين بأنيميا البحر الأبيض المتوسط. **طرق وأدوات البحث:** أجريت هذه الدراسة في مستشفى الأطفال الجامعي بمحافظة المنصورة التابعة لوزارة التعليم العالي، ومستشفى التضامن ببورسعيد التابعة لمنظومة التأمين الصحي الشامل ، وقد تألفت عينة الدراسة من 112 من المراهقين المصابين بمرض أنيميا البحر الأبيض المتوسط. وتم تجميع البيانات عن طريق المقابلة الشخصية لكل مريض باستخدام مقياس الاكتئاب، القلق، و الضغط النفسي ، بالإضافة إلي استمارة البيانات الشخصية والإكلينيكية للمريض. **النتائج:** أوضحت الدراسة أن ما يقرب من نصف المراهقين الخاضعين للدراسة (48,2%) يعانون من مستوى شديد للغاية من الضغط النفسي، وأن أكثر من نصف المراهقين (54,5%) يعانون من مستوى شديد للغاية من القلق. في حين أن أقل من ربع المراهقين الخاضعين للدراسة (23,2%) لديهم مستوى شديد للغاية من الاكتئاب. **التوصيات:** تقديم البرامج التعليمية المستمرة للمراهقين المصابين بمرض أنيميا البحر الأبيض المتوسط عن مرضهم، وذلك لتشجيعهم على الالتزام بالنظام العلاجي، ومنع الآثار السلبية للمرض على حالتهم النفسية.

الكلمات المرشدة: القلق، الاكتئاب، الضغط النفسي، أنيميا البحر الأبيض المتوسط.