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Assessment of disease knowledge gaps among beta thalassemia major patients and their caregivers

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Abstract

Background: Thalassemia constitutes a major health issue in Egypt. It is associated with significant mortality and morbidity that arise mainly from iron overload secondary to blood transfusions.

Methods: We conducted this cross-sectional study at Cairo University children hospitals aiming at assessing the patients' and their caregivers' knowledge about thalassemia, and to identify factors affecting their knowledge in the period from December 2020 to August 2021.

Results: The study included 45 thalassemia patients aged 10–14 years and 45 caregivers of patients who were less than 10 years of age. A knowledge questionnaire was generated from an educational script prepared by the investigators and translated into Arabic language. Thirty-one patients and 44 caregivers responded to the questionnaire individually, while 15 patient/parent pairs worked on the questionnaire together at their request. Age of patients ranged from 2 to 14 years, majority were males. Disease duration ranged from 0 to 13 years and the majority were following in the pediatric hematology clinic on a monthly basis. Candidates showed strong knowledge in areas related to symptoms and signs. On the other hand, they showed critical knowledge gaps in the areas of blood transfusions complications and iron chelation. Patients and caregivers scored similarly in various questionnaire topics with no significant difference. Gender, consanguinity, similar conditions in the family and frequent follow-up did not affect the score of the study participants, though longer duration of illness was positively correlated with the overall scores.

Conclusions: Thalassemia patients and their caregivers have significant knowledge gaps in areas of chelation therapy and transfusion complications.

Keywords: Thalassemia major, Knowledge, Questionnaire, Caregivers

Background

Beta thalassemia is a genetic, autosomal recessive disorder, that is present worldwide but with a higher prevalence in Mediterranean countries, North Africa and Southeast Asia [1]. It occurs when there is absent or reduced production of beta globin chains resulting in precipitation of excessive unbound alpha chains in erythroid precursors leading to ineffective erythropoiesis. It is usually suspected when a child below two years develops severe microcytic hypochromic anemia and jaundice. Regular blood transfusion every 4–6 weeks is the main therapy for thalassemia major patients, to correct anemia, suppress ineffective erythropoiesis and allow for normal growth and functions [2].

Iron overload is an inevitable complication to regular blood transfusion. If left untreated, iron accumulates in different organs leading to hypogonadism, hypothyroidism, hypoparathyroidism, diabetes, hepatic fibrosis, and myocardial dysfunction [3]. Timely treatment of iron overload by oral or subcutaneous chelators is an essential

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part of thalassemia major management. Bone marrow transplantation is the only available curative option for thalassemia major [4].

In Egypt, beta thalassemia major is considered the most common chronic hemolytic anemia with an estimated carrier rate of 9–10.2% [5]. The disease represents a significant psychological and financial burden on the affected families and the Egyptian government [5]. It also requires significant resources and is considered a challenge in constrained healthcare systems. Patients' and families' understanding of the genetic nature of the illness, its clinical spectrum, and lifelong commitment to transfusion and chelation, is vital for the planning of effective prevention programs and for ensuring their adherence to the prescribed care. Enhancing the knowledge about thalassemia may result in the reduction of its incidence [6] and consecutively may reduce the governmental financial burden.

The aims of this study are to assess patients' and parents' knowledge about beta thalassemia major, its etiology, presentation, treatment, and complications, to identify factors that could affect the knowledge state of the patients and parents like education, age, disease duration, and residence and to define areas of knowledge gaps that could benefit from the design and implementation of educational interventions for patients and their families.

Methods

This is a cross-sectional descriptive study design, where convenient sampling used. The study included 45 patients with thalassemia major aged 10–14 years old and 45 care givers of thalassemia major patients less than 10 years old, all attending the Pediatric Hematology Clinics, Cairo University Children Hospitals, in the period between December 2020 and August 2021.

Study participants

Patients diagnosed as thalassemia major older than 10 years who are literate or in school and can read without assistance and parents of thalassemia major patients who are younger than 10 years of age, who are literate and can read without assistance were included in the study.

Ethical considerations

Informed verbal consent describing the nature of the study and its benefits for the patients and the general population was obtained from participating patients and caregivers. The study had been approved by the Faculty of Medicine, Cairo University. Egypt on 15 August 2018.

Questionnaire design

One of the researchers retrieved full information about thalassemia major from Thalassemia International Federation [7] and Cooley's Anemia Foundation [8]. The researcher then summarized the most important and relevant information, that should be known by thalassemia patients and their families. She composed a patients' education script that will later be the base for development of different education tools for thalassemia patients.

The information script was then reviewed, summarized and translated to simple Arabic language in order to be easily understood by thalassemia patients and their caregivers. This process was performed by three members of the research team, two of them are expert pediatric hematologist. The final educational material (the guiding script) was the knowledge base used to guide the design of the patients' knowledge test

Development of the questionnaire items

The questionnaire consisted of two parts:

The first part inquired about the socio-demographic data: patients age, gender, consanguinity and its degree if present, age of child at diagnosis, other thalassemia patients in family, educational level (of the child/ parent) and follow-up frequency in Pediatric Hematology Outpatient Clinic. The second part consisted of 22 multiple choice questions: 14 questions with correct single answer and 8 questions with more than one correct answer with an overall 36 correct answer. The questionnaire was divided into five different themes covering different aspects of thalassemia major both as a disease and its management. Three questions to assess general knowledge about thalassemia major Q1, Q2, and Q3; three questions about symptoms and signs Q4, Q5, and Q15; three questions about treatment modalities of thalassemia Q6, Q7, and Q16; two questions about prevention Q8 and Q9; seven questions about complications of blood transfusion Q10, Q11, Q14, Q17, Q18, Q19, and Q20; and four questions about iron overload and chelation therapy Q12, Q13, Q21, and Q22.

Content validity and reliability

The content validity of the questionnaire was confirmed by the research team as knowledge experts and its reliability was verified using the reliability coefficient, Cronbach alpha (α) for the questionnaire which was 0.757 indicating acceptable reliability and internal consistency [9]. In addition to that, its validity was established using a pilot test by collecting data from six participants. The purpose of the pilot study was to test the clarity of the questionnaire items and to find out any obstacle that may interfere with data collection. Based on finding of the pilot study, the knowledge questionnaire was edited, adjusted, and prepared in its final format (English translation attached).

Scoring

For each question, a correct answer was scored as 1 and incorrect answer scored 0, and each area of knowledge was summed up alone and then the total score of each patient/parent was calculated.

Technique for data collection

A total of 90 knowledge questionnaires were individually administered by a researcher to eligible candidates (patients/parents) in the pediatric hematology clinic on days of blood transfusion in which 44 parents took the questionnaire individually, 31 patients took the questionnaire individually, 15 patient/parent pairs (30 participants) worked on the questionnaire together at their request.

All participants were allowed to inquire and request clarification if they needed to.

Statistical methods

Data were analyzed using R version 4.1.2 (2021-11-01) (R Foundation for Statistical Computing). Descriptive statistical methods were used, where Frequency and percent were recorded for all categorical variables and both mean ± standard deviation, median, and range for continuous variables. We used The Shapiro–Wilk test to assess the normality distribution for continuous variables and Spearman's rank correlation to examine the relationships between participants' knowledge score and their age and disease duration. Kruskal-Wallis test and Mann–Whitney *U* test were used to test the differences in participants knowledge scores according to demographic and disease variables. We used ltm package to calculate Cronbach alpha (α) in order to assess the internal consistency of the knowledge questionnaire.

Results

The study group consisted of 45 parent of thalassemia major patients and 45 patients. The demographic data of all patients participating in the study (whether by themselves or by their parents) were collected and is shown in Table 1. Their age ranged between 2 and 14 years, average age = 8.7 (SD = 3.6). The median age was 9.5 years. The disease duration ranged between 0 and 13 years, average duration = 7.8 (SD = 3.65). The median duration since diagnosis of thalassemia was 8.3 years. All participants were regularly following up at hematology clinics with 88% following on monthly basis and 12% following more frequently.

Regarding their education, all participants were able to read independently. Patients who completed the questionnaire alone were students in various grades from primary to high schools. Parents who completed the questionnaire alone or with their children have the following education levels; 42(71%) received lower schooling at the level of primary or preparatory schools while 17(29%) were graduates of high schools or university.

Table 1 Demographic data of the patients ($N = 90$)

Age in years	8.66 ± 3.587	
Age at diagnosis in months (mean ± SD)	10.27 ± 8.169	
Gender %	Female	44.4%
	Male	55.6%
Parent consanguinity %	Yes	73.3%
	No	26.7%
Degree of consanguinity%	2nd degree	83.3%
	Distant relatives	16.7%
Other thalassemia patients in family%	Yes	42.2%
	No	57.8%
Governorate %	Cairo	21.1%
	Giza	58.9%
	Others	20%
Follow-up frequency%	Monthly	87.8%
	More than once in month	12.2%

Participants' knowledge about thalassemia and its management

Because participants response to each item in the knowledge questionnaire were not normally distributed, we used the non-parametric statistical test, Kruskal-Wallis rank sum test to compare the different groups median score in each item. We then adjusted the *P* value for multiple comparisons using Bonferroni correction and found that there was no statistical difference between patients' response, parents' response, and patient/parent pairs' response, regarding each individual items in questionnaire. The median total scores for patients were 19/36, range = 7–27, for parents was 17/36, range = 3–26, and for pairs was 18.0/36, range = 12–32 with a *P* value of 0.3 and a clear overlap of score ranges as shown in Fig. 1.

Table 2 shows the percent of all participants who answered each question correctly. Knowledge items answered by less than 50% of participants is highlighted in grey.

Specific knowledge gaps

To identify knowledge gaps, we used Kruskal-Wallis rank sum test to compare the three participants' groups in the areas of knowledge described in the methodology and found that the three groups' knowledge are not significantly different (Table 3). The groups' median scores were higher than 65% in general knowledge, symptoms, signs, and treatment modalities. It was 50% in questions

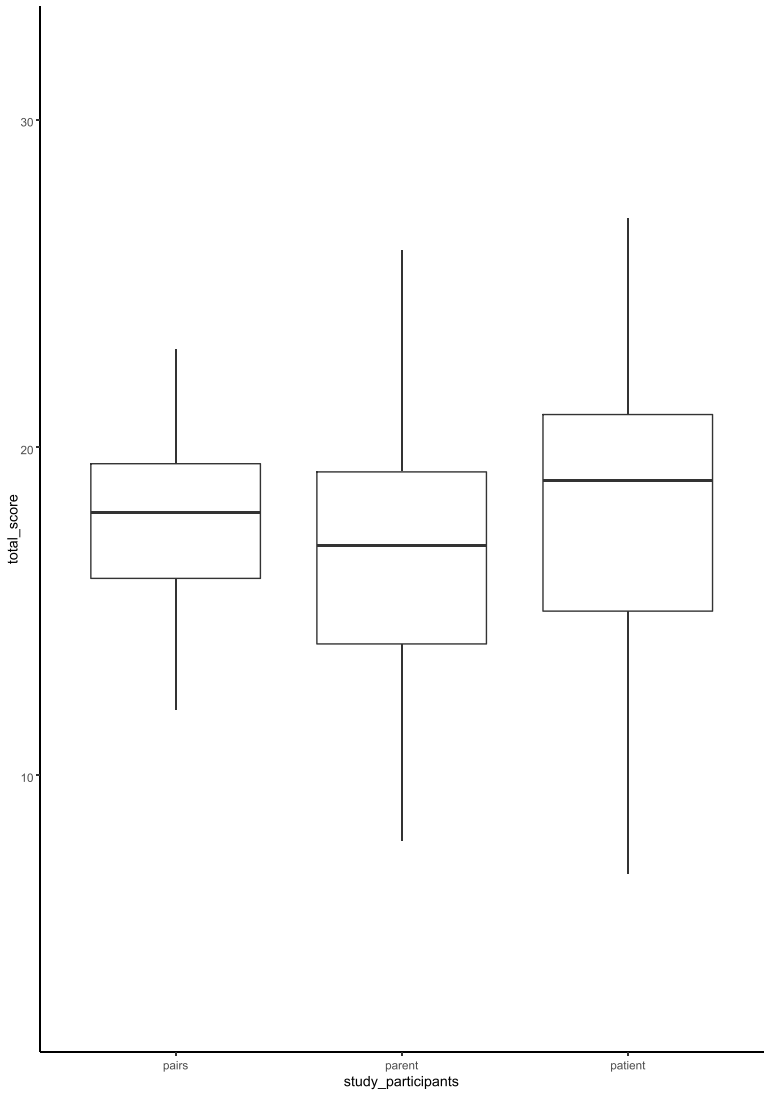

Fig. 1 Overall scores range, median, and interquartile range in the 3 groups. This boxplot was created using ggplot graphic package for R and saved as pdf file. Wickham H (2016).ggplot2: Elegant Graphics for Data Analysis.Springer-Verlag New York. ISBN 978-3-3119-24277-4, hhtp://ggplot2.tidyverse.org

relevant to thalassemia prevention. While the median scores didn't reach 40% in questions relevant to transfusion complications and chelation therapy.

Demographic and disease features affecting the score

Study participants were divided into two groups according to the patients' gender, consanguinity, the presence of similar condition in the family, frequency of follow-up and their education. Using Mann–Whitney test, we did not find significant difference between the overall score when males versus female were compared (p value = 0.1), consanguineous versus non consanguineous marriage (p value = 0.39), frequent versus less frequent follow-up (p value = 0.33), nor according to their education level (p- value = 0.48) or the presence of a previously affected family member (p value = 0.65). On the other hand, using Spearman's rank correlation, there was significant positive correlation between the disease duration and the participants' score (rho = 0.22 p = 0.04).

Discussion

The purpose of this study, conducted at the pediatric hematology clinics, Cairo University, was to assess beta thalassemia major patients/parents' knowledge about the disease, its complications, and treatment and to identify factors that might be associated with the acquisition of

Table 2 Questions and percent of correct responses:

Questions	Percent of correct responses
1.Beta thalassemia major is a genetic disease	72%
2.Beta thalassemia major leads to decrease in number of red blood cells	91%
3.Symptoms of beta thalassemia major appears several months after birth	74%
4.Beta thalassemia major affect growth and physical activity	83%
5.Splenomegaly occurs in beta thalassemia major	93%
6.Blood transfusion is considered the main treatment of beta thalassemia major	89%
7.Sometimes beta thalassemia major patients need to remove their spleen	93%
8.The probability of giving birth to a thalassemic child if both parents are carriers is 25%	28%
9.For prevention of beta thalassemia major, genetic counselling and investigations should be done premarital	86%
10.Filtered blood should be used to prevent febrile reactions during transfusion	47%
11.Washed blood should be used to prevent allergic reactions during transfusion	51%
12.Desferal is given by pump over 8-12 hours subcutaneously	40%
13.Iron overload can be monitored by ferritin level	42%
14.The most common complication that can occur during blood transfusion is fever	41%
15.Symptoms of thalassemia major include jaundice	83%
15.Symptoms of thalassemia major include pallor	59%
16.To maintain health of thalassemia major patient, folic acid tablets should be given	52%
16.To maintain health of thalassemia major patient, iron chelation therapy should be given	43%
17.Complications of blood transfusion can occur immediately on beginning of transfusion	48%
17.Complications of blood transfusion can occur after the transfusion	41%
18.Viruses that can be transmitted through blood transfusion include hepatitis C virus	60%
18.Viruses that can be transmitted through blood transfusion include hepatitis B virus	14%
18.Viruses that can be transmitted through blood transfusion include human immunodeficiency virus (AIDS)	6%
19.Symptoms of acute hemolytic reaction include hypotension	19%
19.Symptoms of acute hemolytic reaction include fever	23%
19.Symptoms of acute hemolytic reaction include dark urine	79%
20.Delayed complications of blood transfusion include transfusion transmitted viral infection	12%
20.Delayed complications of blood transfusion include iron overload	60%
20.Delayed complications of blood transfusion include delayed transfusion reactions	11%
21.Iron overload can cause glands disorders	13%
21.Iron overload can cause growth affection	28%
21.Iron overload can cause cardiac disorders and liver affection	48%
21.Iron overload can cause short stature	21%
22.Iron chelating drugs include Desferal	41%
22.Iron chelating drugs include Deferasirox	37%
22.Iron chelating drugs include deferiprone	22%

this knowledge. The study was conducted as the first of a two-step process for the design and implementation of an educational program aiming for improving the disease knowledge for the patients and their caregivers.

This cross-sectional study included 90 participants, 45 thalassemia patients, and 45 thalassemia caregivers, who visited the hospital for regular follow-up and blood transfusion at the period between December 2020 and August 2021. Parents and children received the questionnaire in Arabic language which they can read and understand independently. The majority of participants came from Giza and Cairo governorates (80%) and they had primary or secondary schooling. Few parents studied at high schools or universities (29%).

Most of our study participants knew that thalassemia is a genetic disease (72%), that RBCs are the affected cells (91%), that the disease affects growth and physical activity (83%), and that patients clinically present by pallor (59%), jaundice (83%), and might have splenomegaly during the course of the disease (93%). As for treatment

Table 3 Comparison between three groups regarding different domains of the questionnaire

Variable	Group	N	Median score	Range	*P* value
General Knowledge (3)	Both	15	100%	33–100	0.875
	Parent	44	67%	33–100	
	patient	31	67%	33–100	
Symptoms and signs (4)	Both	15	100%	50–100	0.354
	Parent	44	75%	0–100	
	patient	31	75%	0–100	
Treatment (4)	Both	15	75%	25–100	0.098
	Parent	44	75%	0–100	
	patient	31	75%	50–100	
Prevention (2)	Both	15	50%	0–100	0.116
	Parent	44	50%	0–100	
	patient	31	50%	0–100	
Transfusion complications (14)	Both	15	36%	21–86	0.309
	Parent	44	36%	0–71	
	patient	31	36%	0–64	
Chelation therapy (9)	Both	15	22%	0–89	0.058
	Parent	44	22%	0–89	
	patient	31	33%	0–78	
Total score (36)	Both	15	50%	33–89	0.3
	Parent	44	47%	8–72	
	patient	31	53%	19–75	

Kruskal-Wallis rank sum test used

modalities, the majority of our study participants know that blood transfusion is the main treatment for thalassemia major (89%) and that splenectomy might be needed during the course of the disease (93%). On the other hand, they did not recognize the important role of iron chelation in thalassemia major treatment, as less than half of them (43%) knew that iron chelation should be given regularly. Regarding prevention of thalassemia major, we found that most of the study participants know the importance of premarital counselling in the prevention of thalassemia (86%).

The good general knowledge of our study participants regarding thalassemia signs and symptoms, genetic nature and the importance of blood transfusion may be attributed to the fact that this is the initial information they receive from healthcare providers after diagnosis. It is also available on national TV media, during interviews with recognized hematologists in the country. In addition, waiting time during blood transfusion and follow-up visits allow thalassemia families to communicate with each other and share their general information about the disease.

Different authors reported different results on comparable thalassemia knowledge tests for their participants [10–12]. Some authors showed significantly higher knowledge gaps than ours [13]. A study by Kalra and colleagues in 2019 reported nearly perfect knowledge test scores across different disease domains [14]. This may be attributed to different practice environments and whether systematic health education is routinely available as a part of the disease prevention/management program or not. It could also be attributed to different education background of study participants, different role for national media in health education and the nature of service provision in their respective institutes. It is important therefore that any health education program aiming thalassemia patients be designed according to the needs assessment performed locally in the target institute. The designed health education intervention should address identified knowledge gaps and treatment compliance problems in that particular institute. A study by Abu Samra and colleagues in 2015 concluded that periodic educational programs based on the actual need assessment of thalassemia children to improve their QOL are important [15].

We found that specific knowledge about probability of inheritance is not as commonly available for patients/parents. Most of the study participants (72%) failed to answer correctly the question about the probability of having a thalassemia child if both parents are carriers.

A study by Lee and colleagues in 2007 found that most patients believed that parents with the thalassemia major gene would automatically give birth to a thalassemia major child [16]. This kind of misinformation may affect the patient's thoughts about marriage and perpetuate public misconceptions about people who carry the gene giving birth.

Lifelong regular blood transfusions, usually administered every two to five weeks, to maintain the pre transfusion hemoglobin level above 9–10.5 g/dl is the recommended treatment for thalassemia major [7]. As a result, blood transfusion related complications both acute and delayed are very important consequences that thalassemia patients and caregivers need to be acquainted with for optimum prevention and management. In the current study, we did not find that this is the case. In fact, we found substantial knowledge gap and lack of awareness regarding blood transfusion related complications and iron chelation therapy, where most of the participants' scores were below 40%. Patients/caregivers knowledge deficits regarding the importance of management of iron overload was similarly mirrored by Zagamir and colleagues in, 2019, who interviewed 50 thalassemia children and their parents and found that most of them did not have knowledge about available iron chelating agents, their side effects, and the means of its management [13]. There are several explanations for the knowledge gap we encountered in our patients/

caregivers including the following; the lack of sufficient communication and patients' education sessions due to the over busy under staffed hematology clinics in our center. On average, each hematologist encounter 30 patients per clinic day. This leaves limited time for repeatedly communicating important health messages and ensuring patients/caregiver retention of the message. Second, the lower level of schooling we encountered in our study participants could be a contributing factor. Third, psychological factors might be contributing to the findings. Patients/parents denial and avoidance of talk about disease serious complications and possible ominous outcomes were proposed as a contributing factor by (Zagamir et al. 2019) and (Lee et al. 2007) [13, 16]. Specific health education programs targeting the areas of knowledge gaps and delivered by trained health professionals other than physicians is needed to address this problem as thalassemia patient's adherence to treatment is positively correlated with their knowledge about the disease management [15].

In our study, there were no significant differences in the knowledge test scores between different study groups. Thalassemia patients and caregivers tended to have similar knowledge or lack of it. When both patient and parent choose to take the test together, their scores tended to be higher but did not reach statistical significance. Similarly, Lee and colleagues in 2007, found that patients and caregivers scores are similar and correlated [16].

Designed educational interventions should address patients alongside primary caregivers in order to ensure proper knowledge acquisition and avoidance of misinformation. This will lead to stronger commitment to treatment regimen, proper utilization of health services, and shall improve the overall quality of life of the patients and their families. The importance of caregivers' education was concluded in the study by Ali and colleagues in 2015 who stated that parental awareness regarding various aspects of beta thalassemia is of great importance not only for the proper management and improved quality of life of the patient with thalassemia but also for the prevention of the disease [10]. Similarly, Lee et al. 2007 showed that mothers' knowledge about TM is the most significant variable influencing patients' knowledge [16].

In this study, we found that gender, consanguinity, the presence of affected family member, follow-up frequency, and education level did not have an impact on the results of the knowledge test. On the other hand, disease duration was positively correlated with the knowledge score of the study participants, indicating that their prolonged exposure to the healthcare system might modestly improve their knowledge about the disease. Kalra et al. 2019 did not found any effect for age, education, occupation, income, and socio-economic status on the thalassemia parents knowledge scores. However, the knowledge score of the parents in their study was up to 100%. They attributed this adequate knowledge to the efforts of social workers in their center [14].

The absence of impact of educational level on the knowledge score in our study participants is contrary to reasonable evidence from other studies that found that education is important to enhance individuals' health and also influence their ability and well-being [11]. Caregivers' educational level was significantly associated with knowledge level about the disease. Those who would have more years of schooling will tend to have better health behavior [17]. We explain our findings by the fact that most of our study participants have lower levels of schooling (71%). A larger sample size with more representation of higher educated caregivers/patients is needed to statistically test if education has an impact on their thalassemia knowledge.

Limitations of the study

This is a single-center-based study that is located in urban area which may not reflect the effect of health education patient in rural area or far away from the center. The small sample size may not represent the community of thalassemics in our country.

Conclusions

Thalassemia major patients and caregivers' knowledge was fairly satisfactory about nature of the disease, its signs and symptoms, importance of blood transfusion as the main modality of treatment, and genetic counselling for the disease prevention. However, their knowledge was not satisfactory regarding complications of blood transfusion, iron overload and iron chelation therapy. Gender, consanguinity, the presence of affected family member, follow-up frequency, and education level did not have an impact on the results of the knowledge test. Only the disease duration was positively correlated with the knowledge score of the study participants.

Recommendations

Implementation of educational programs by non-physician healthcare professionals based on actual needs assessment of thalassemia children and their caregivers targeting both of them using different health education modalities and a national educational program about the whole disease aspects through T.V media and primary health units using simple education messages, may have great role in raising awareness about the disease and the importance its prevention.

Abbreviations

SD: Standard deviation; CI: Confidence interval; QoL: Quality of life.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s43054-022-00143-w.

Additional file 1.

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We would like the names of the individual members of the Group to be searchable through their individual PubMed records.

Authors' contributions
MSN: study design, methodology, writing—original draft, writing—review and editing of the final manuscript. MAM: data curation, resources, investigations, discussion, and references preparation. HA: visualization and methodology. EAM: conceptualization, formal analysis, revision and editing of the final manuscript, and project supervision. All authors read and approved the final manuscript.

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Availability of data and materials
The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
The study has received the approval of the Faculty of Medicine Cairo University, Cairo, Egypt, on 15 August 2018. Informed consent was obtained from all individual participants included in the study.

Consent for publication
Not applicable

Competing interests
The authors declare that they have no competing interests.

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