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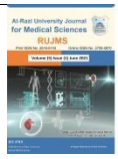

Socio-demographic Profile of Patients Admitted in Thalassemia Center, Sana'a, Yemen

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Abstract:

Background and Objective: Thalassemia is one of the most common genetic blood disorders that result in the production of abnormal hemoglobin (Hb). It is overwhelming the healthcare systems in developing countries including Yemen. Therefore, this study aimed to assess socio-demographic and social factors profiles among thalassemia patients attending at the Yemen Society for Thalassemia and Genetic Blood Disorders in 2020, Sana'a-Yemen. **Materials and Methods:** A retrospective cross-sectional study was conducted to collect data from medical files between July to December 2020 on Yemen Society for Thalassemia patients located in Sana'a capital of Yemen. A total of 344 thalassemia patients aged 5-18 years were enrolled in this study and the related data were obtained by a structured questionnaire. **Results:** Out of 344 thalassemia patients, 54.9% were males, 34.9% were aged between 13-18 years, 60.5% lived in urban areas, and 60.8% had basic education. Also, it was found that 38.7% of patients had a family history of thalassemia, 70.6% of participants were from families with consanguineous marriage, and 57.3% had siblings with thalassemia. Moreover, only 32.6% of patients received chelation treatment while 67.4% did not receive it. Out of 112 who received the chelation (39.3% regularly; 60.7% occasionally), 67.4% of participants measured serum ferritin, 32.8% measured it every six months and 32.6% never measured it. **Conclusion:** The high proportion of thalassemia in this study is a major health problem. Knowledge and counseling are essential to increase awareness about thalassemia risk and prevention.

Keywords: Ferritin Level, Demography, Yemen Society for Thalassemia, Sana'a, Yemen.

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Introduction

β-thalassemia is a recessively autosomal inherited blood disorder characterized by anomalies in the production of the hemoglobin (Hb) beta chain resulting in variable degrees of hemolysis, chronic anemia, and ineffective erythropoiesis [1,2]. Thalassemia is becoming a burden for our country. As the asymptomatic carrier is the reservoir the diseases and the disease are continues to increasing [3].

The broad spectrum of clinical picture of the patients ranges from the silent asymptomatic state to the lifelong transfusion-dependent anemic state, with its related complications [4].

The main treatment option for most patients is supportive care consisting of blood transfusion and iron chelation therapy. Blood transfusion is used to reduce anemia complications, while chelation reduces iron overload caused by chronic blood transfusions. Nevertheless, despite the significant improvements in the management of β-thalassemia, it remains a challenge, especially in low-resource countries, where the burden of thalassemia is the highest [2].

Globally, over 50 000 people are born each year with a severe form of thalassemia – a blood disorder causing the body to make an abnormal or inadequate amount of haemoglobin. The disorder results in large numbers of red blood cells being destroyed, which leads to anaemia. An estimated 80% of these cases occur in developing countries [5].

There are about 65,000-67,000 β thalassemia patient in India and approximately 30 million carriers of β thalassemia with a mean prevalence of 3.3% [6,7]. In Pakistan, an estimated 5000-9000 children with β thalassemia are born per year and the estimated carrier rate is 5-7% [8]. Also, in Palestine, it was estimated that the prevalence of thalassemia carriers in Palestine was around 4% [9].

In Yemen 700 new cases of thalassemia are diagnosed yearly, and 50 000 cases are on record so far according to association of thalassemia. In Yemen, a country ravaged by war, the treatment of thalassemia is a rare but much needed miracle. This is why the support provided is essential. With regular blood transfusions needed by these patients, safe blood saves lives and improves health [5].

“The centre receives 60–70 patients suffering from of thalassemia and anemia every day. Once a case is examined, the patient is referred to the blood transfusion centre to receive a blood transfusion,” said Muktar Alkubati, manager of the Yemen association for Thalassemia patients and genetic blood in Yemen [5].

There is limited data about the profile of thalassemia patients in Sana’a, Yemen. Therefore, this study aimed to assess socio-demographics profile of thalassemia patients in Sana’a, Yemen during year 2020. Also, clinical picture, serum ferritin (SF) level, iron chelation therapy, and some socio-economic parameters were evaluated.

Materials and Methods

Study design and data sources

A retrospective cross-sectional study was conducted between July to December 2020 on Yemen Society for Thalassemia Genetic Blood Disorders located in Sana’a capital of Yemen. The source of data for this study was utilized data from medical records for one year, 2020.

Population and sample of the study

All children and adolescents, aged between 5-18 years, were diagnosed with Thalassemia and registered and followed up at the Yemen society for Thalassemia enrolled in this study.

Inclusion and exclusion criteria

The inclusion criteria for this study were the correct data recorded during the year of 2020 on the base of children and adolescents in the age group of 5-18 years and diagnosed with Thalassemia registered and followed up at Yemen society for Thalassemia. Whereas, the database that is incorrect or missing information or death cases were excluded.

Data collection

A formulated questionnaire was used to collect the retrieved data including the socio-demographic characteristics including age, gender, educational level, residence, and family history of thalassemia. Also, the data of iron chelation treatment and measured serum ferritin were collected.

Ethics statement

An approval statement was obtained prior to carrying out this study from the Research Ethics Committee at the College of Medical Sciences of Al-Razi University.

Also, it was permitted by the Yemen Society for Thalassemia and Genetic Blood Disorders to conduct this study. The obtained data was only used for the study proposal.

Statistical analysis

The obtained data were analyzed by using Excel Microsoft program 2010. The data was presented in the forms of tables and graphs.

Results

Demographic characteristics of thalassemia patients

Table 1 shows that high rate of thalassemia among patients between the age of 13-18 years with 120(34.9%). Also, more than half of thalassemia patients 189 (54.9%) were males. Most of the participated Thalassemia patients with number 208 (60.5%) lived in urban and approximately two-thirds (60.8%) of them had a basic education level.

Social characteristics of thalassemia patients

The present result showed that 133(38.7%) patients had a family history of thalassemia, 243(70.6%) participants were from families with consanguineous marriage, and 197 (57.3%) had siblings with thalassemia (Table 2).

This finding revealed that only 112 (32.6%) receive chelation treatment while 232 (67.4%) did not receive it. Out of 112 who received the chelation, it was found that 44 (39.3%) and 68 (60.7%) regularly and occasionally, respectively, received chelation therapy. Also, 67.4% of participants measured serum ferritin and most thalassemia patients (32.8%) measured ferritin level every six months whereas 32.6% of patients never measured the ferritin level (Table 3).

Table 1. Demographic characteristics of participants study

Categories	Variables	Frequency (%)
Age group (Year)	5-7	108 (31.4)
	8-12	116 (33.7)
	13-18	120 (34.9)
Gender	Male	189 (54.9)
	Female	155 (45.1)
Residence	Urban	208 (60.5)
	Rural	136 (39.5)
Educational level	Not at school	109 (31.7)
	Basic	209 (60.8)
	Secondary	26 (7.6)

Table 2. Distribution of thalassemia according to clinical characteristics

Variables	Frequency (%)
Family history of thalassemia	
• Yes	133 (38.7)
• No	211 (61.3)
Parents consanguinity	
• Yes	243 (70.6)
• No	101 (29.4)
Siblings with thalassemia	
• Yes	197 (57.3)
• No	147 (42.7)

Table 3. Distribution of thalassemia according to treatment characteristics

Variables	Categories	Frequency	Rate (%)
Receive chelation therapy (n=344)	Yes	112	32.6
	No	232	67.4
Regimen of chelation therapy (n=112)	Regularly received	44	39.3
	Occasionally received	68	60.7
Measured serum ferritin (n=344)	Yes	232	67.4
	No	112	32.6
Frequency of ferritin level measured (n=232)	Every month	5	1.5
	Every tow month	6	1.7
	Every three month	42	12.2
	Every six month	113	32.8
	Every twelve month	66	19.2

Rate access to thalassemia center for treatment

Figure 1 shows that among the 344 patients, 140 of them (40.9%) explained that access to the treatment center was difficult, 109 (31.9%) patients stated easy access to the treatment, 32 (9.4%) patients answered very easy and very difficult and 29 (8.5%) said it was available but too expensive.

School absenteeism per year

Out of 344 patients in this study, 266(78.2%) patients missed between 1-5 days per year to attend school due to thalassemia treatment, 43 (12.6%) stated over 6 days, and 31 (9.1%) patients answered none (Fig. 2).

Type of payment for treatment of thalassemia

Figure 3 shows that 255 (74.1%) patients explained that the pays for treatment was by him/herself or by his/her family, 77 (22.4%) patients stated other model of payment, 12 (3.5%) patients answered though health insurance (private).

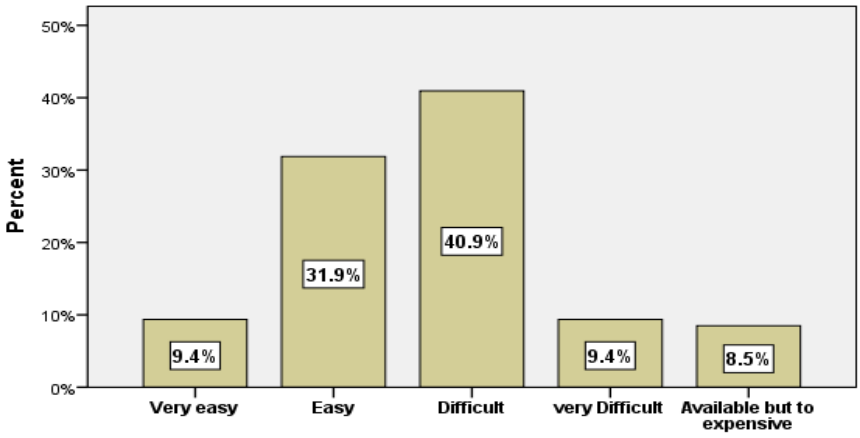

Figure 1. Rate access to thalassemia center for treatment

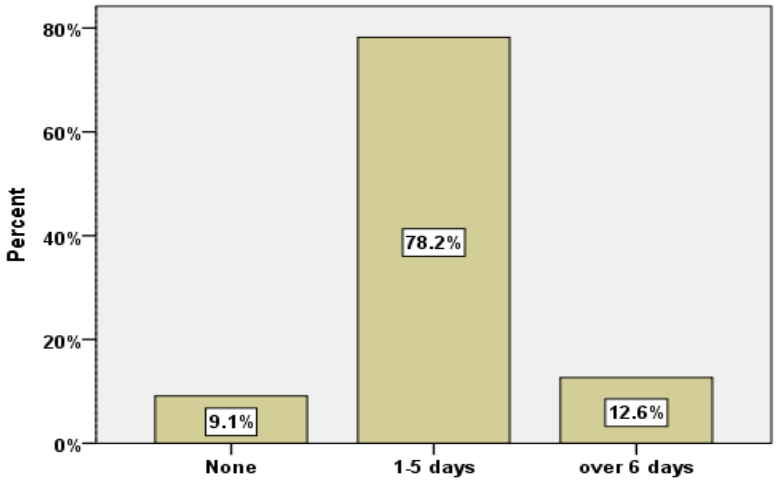

Figure 2. School absenteeism due to attend treatment for thalassemia

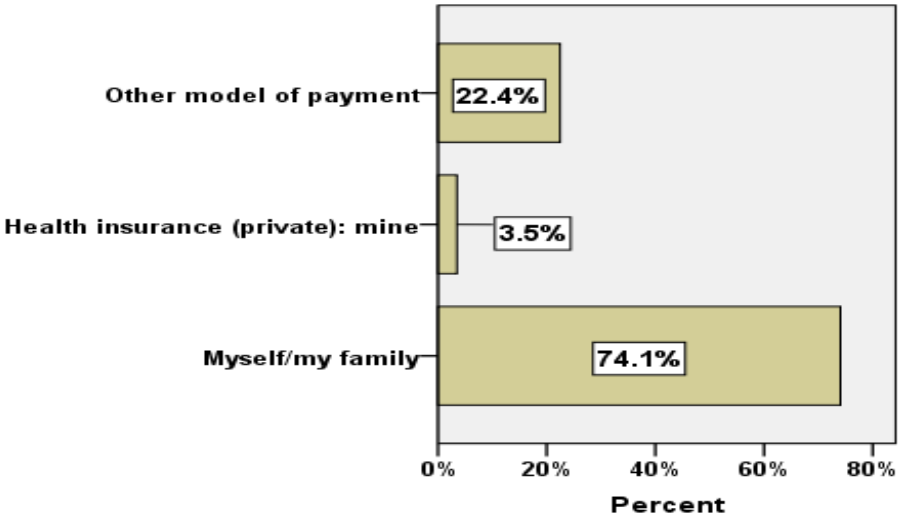

Figure 3. Pays for treatment of thalassemia

Discussion

The present study found that a higher rate of thalassemia was reported among the age group of 13-18 years at 34.9% and this in agreement with Chin *et al*. [10]. In another finding observed that the age group less than 5 years had a higher rate of thalassemia [11]. The difference in results may refer to the type of thalassemia and clinical diversity.

The current result showed that the male participants had a higher rate of thalassemia compared with females. This finding is consistent with previous reports conducted on different regions [11,12]. This might indicate that thalassemia are more common in males than in females because the parents give more attention to their male child and are ready to spend more money on a male child compared to a female one.

Most of the participated thalassemia patients in this study (60.5%) are coming from urban areas and this result is inconsistent with a report by Barua *et al*. [11].

However, the majority of thalassemia patients (60.8%) had a basic level of education. Similar studies documented that the most frequently of thalassemia presented among the low level of education [10,11].

This result revealed that the highest rate of thalassemia was recorded (61.3%) among patients who didn't have a family history of thalassemia. Similar reports in Iran by Sattari *et al.* [13] found that 44% of patients had a family history of thalassemia.

In the existing result, most of the participating patients (70.6%) were from families with consanguineous marriages.

Similar findings showed that 57.8 % of the patients had a parent with a history of consanguineous marriage [14]. In this regard, Ghazanfari *et al*. reported this rate to be 58.3% [15]. Marriage among relatives has been reported to be an important factor in congenital anomalies, which is common in Iran. Studies showed that the chance of giving birth to children with disabilities was twice or three times more than in normal marriages [16]. It could be said that the acceptable and effective ways to avoid cases of thalassemia are carrier screening and genetics counseling among people at high risk [17]. In this regard, it is suggested to make use of genetic counseling strategies before marriage and pregnancy, and also to screen carrier couples and thalassemia gene carriers in the health system [14].

Moreover, it was found in this result that 57.3% of patients had siblings with thalassemia and this is supported by Bhatia *et al*. [12].

This finding revealed that only 32.6% (39.3% regularly; 60.7% occasionally) of patients received chelation treatment while 67.4% did not receive it. This rate is lower than the finding reported in Palestine by Aldwaik *et al.* [18].

Furthermore, only 67.4% of participants in this study measured serum ferritin and most thalassemia patients (32.8%) measured ferritin levels every six months whereas 32.6% of patients never measured the ferritin level.

The present result observed that 40.9% of patients explained that access to the treatment center was difficult, 31.9% of patients stated easy access to the treatment, 9.4% of patients answered very easy and very difficult, and 8.5% said it was available but too expensive. These problems may be referred to bad circumstances due to war since 2015 and so on that directly influence and limited the health care services in Yemen.

On the other hand, previous investigation suggested that individuals with thalassemia had the feelings such as shame, lack of confidence in the disease outcomes and fear of stigma or sudden death. Also in developing countries, adults with thalassemia avoid their treatment due to lack of general information on the field, high expenses of treatment or no access to drugs, therefore, experience severe emotional problems such as despairing, sadness, animosity, depression, anxiety, fear of death, lack of self-confidence, insularity and anger [19].

In this study, 78.2% of patients missed between 1-5 days per year to attend school due to thalassemia treatment, 12.6% stated over 6 days, and 9.1% of patients answered none. It is important to encourage parents of thalassemia patients to continue their child's education despite regular blood transfusions and other required treatments related to their thalassemia patient.

This finding showed that 74.1% of patients explained that pays for treatment were by him/herself or by his/her family, 22.4% of patients stated other models of payment, and only 3.5% of patients depend on health insurance. The cost of ideal treatment for one child with thalassemia is substantial. It is observed that 70% of the families had to spend up to 20% of their yearly income on the treatment of thalassemia [12].

Conclusion

Thalassemia is overwhelmed the public health problems in Yemen. Therefore, significant efforts must be invested in improving the medical care of thalassemia patients to prolong and improve the quality of their life. Also, knowledge and counseling are essential to these parents to ensure their understanding of thalassemia's major risk and prevention. Finally, further studies are required for identifying genetic disorders and related risk factors to control thalassemia in Yemen.

Conflict of interest

No conflict of interest is associated with this work.

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