

Measuring the Awareness of Thalassemia in Saudi Arabia

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Abstract

Introduction: Thalassemia disorder is a genetic disease that causes the blood to have less hemoglobin than normal, the main requirement to control thalassemia's propagation is to educate the entire society. **Methodology:** A descriptive survey was taken to evaluate the awareness of thalassemia among Saudi Arabia's society, with a sample size of 384. **Results:** The results were written in frequencies, and it shows that most of the participants were unaware and lacking information on thalassemia syndrome. **Discussion:** The results of this study provide valuable insights into the awareness of thalassemia in Saudi Arabia and highlight the need to raise awareness of this disease. **Conclusion:** This study is not comprehensive because the survey was not disrupted evenly, but it can give us an overview of the awareness of thalassemia in Saudi Arabia, and it shows that most of the participants were unaware and lacked information on thalassemia.

Keywords

Thalassemia, Genetic Disorder, Thalassemia Syndrome, Awareness, Survey, Saudi Arabia

1. Introduction

Hemoglobin is a vital element that plays an important role in the structure and function of the cell [1], and hemoglobinopathies are one of the prevalent ailments in some parts of the world, it is a genetic abnormality in red blood cells [2].

Thalassemia disorder is a genetic disease that causes the blood to have less hemoglobin than normal. It affects 15 million people worldwide, and 240 million people have Thalassemic carrier status [3].

Thalassemia syndrome can be divided into two groups “alpha” or “beta”, this refers to the part of hemoglobin that isn’t being made, thalassemia can be described with the words “trait”, “minor”, “intermedia”, or “major” to evaluate how severe the condition is [4].

A person who has thalassemia trait may not have any symptoms at all or may have only mild anemia, while a person with thalassemia major may have severe symptoms and may need regular blood transfusions [4] [5].

For the phenotype: the first type is Transfusion-Dependent Thalassemia (TDTs) required regular blood transfusion to live. The second type is Non-Transfusion-Dependent Thalassemia (NTDTs) which describes patients who do not require lifelong regular transfusions to survive [6].

The main treatment for patients with thalassemia is blood transfusion, in case the patients do not get the appropriate blood transfusion, they will suffer from a series of complications which leads to a shorter life span.

Iron chelation therapy is indispensable to avoid the complications of overloaded iron that may arise lifelong, and a bone marrow transplant can be a solution. These treatments put the patients and their families in a significant stress and emotional burden [4] [5].

One of the main requirements to control thalassemia’s propagation is to educate the entire society, therefore it is necessary to measure the awareness of thalassemia and help raise it among people in Saudi Arabia.

2. Objectives

- The main goal of this current study is to measure the awareness about thalassemia syndrome in society.
- Raise awareness of blood donation since it is the main requirement in life for people with thalassemia.

3. Methodology

A descriptive survey was taken to evaluate the awareness of thalassemia among the society in Saudi Arabia, the survey was posted online, therefore; the sample was random and did not focus on specific age or gender during collection. The survey lasted for two weeks starting from 8th of June 2023 until the 21st of June 2023. The goal was to achieve 400 sample but after disposing the contradictory answers, the sample size decreased to 384. Thus; we identify that the study demands a minimum sample size of 384.

The questionnaire used in this study was designed after we achieve an overview on other questionnaires had the same purposes as ours for different types of disease.

Prior permission was obtained from the participants before filling out the survey to achieve a smooth conducting. The survey can be divided into three parts, the first part includes a demographic history (sex, age, educational status, administrative region the participant belongs to).

The second part of the survey was directed to the people who have thalasse-

mia, and so if the participant has it, he will address his age.

The next part was basic information on thalassemia if the participant knows someone who has it if it is hereditary or not, whether can it affect both genders or not, does it have different types or not, and whether it is treatable or not. The last part of the survey was focusing on blood donation to measure the number of people who donate blood. The responses were categorized as “yes” “no” or “I do not know”, each question had one correct answer [7].

4. Data Analysis

Data were expressed as a frequency (%). The analysis was expressed by IBM SPSS Statistics for Windows, Pearson chi-square test was used to compare between groups, <0.05 significant.

5. Results

Table 1: the majority of the participants were females with 241 (62.8%) and 143 males (37.2%). In terms of age, the participants were between 18 - 25 with 267 (69.5%), and the rest were distributed between preposition mistakes the other categories, 28 (7.3%) were less than 18 years old, 42 (10.9%) were between 25 - 30 years old, 21 (5.5%) were between 30 - 35 years old, 3 (0.8%) were between the age 35 - 40 years old and 23 (6.0%) were older than 45.

The central area was having the majority of the respondents with 238 (62.0%) the rest was as follows, 54 (14.1%) in the western area, 29 (7.5%) in the eastern area, 35 (9.1%) in the northern era and 28 (7.3%) in the southern era.

For the educational statute, the majority of the participants had completed university and achieved their bachelor’s degree 257 (66.9%), 100 (26.0%) completed high school, 6 (1.6%) completed middle school, 4 (1.1%) completed elementary school and 17 (4.4%) had their master degree.

Table 2 (N = 384): the first question of this part was if the participants have information on thalassemia in general, 310 (80.7%) answered with “no” and 74 (19.3%), then a couple of questions about the majority of people who have thalassemia, only 4 (1.0%) of the participants has thalassemia, two (0.5%) of them was under 18 years old, one was between 18 - 25 years old (0.3%) and one was between 25 - 30 years old (0.3%).

The last question was if some of the participants knows someone who has thalassemia, the majority which are 352 (91.7%) answered with “no” while 32 (8.3%) answered with “yes”.

Table 3 (N = 384): this question was about how the disease is transmitted, 19 (4.9%) answered with “by infection”, 102 (26.6%) answered with “transmitted genetically” and 263 (68.5%) do not know, the next question was if the disease has types or not, 86 (22.4%) answered with “yes”, 8 (2.1%) answered with “no” while 290 (75.5%) do not know.

Next question was if the disease is linked to a specific sex, 5 (1.3%) answered with “males only”, 167 (43.5%) answered with “both”, no one answered with “females only” 0 (0%) and 212 (55.2%) did not know.

Table 1. Demographic characteristic of participants (N = 384).

Characteristics	Frequency (%)
Gender	
Male	143 (37.2%)
Female	241 (62.8%)
Age Group	
Less than 18	28 (7.3%)
18 - 25	267 (69.5%)
25 - 30	42 (10.9%)
30 - 35	21 (5.5%)
35 - 40	3 (0.8%)
45 and above	23 (6.0%)
Regions	
North	35 (9.1%)
South	28 (7.3%)
Center	238 (62.0%)
West	54 (14.1%)
East	29 (7.5%)
Education	
Primary	4 (1.1%)
Middle	6 (1.6%)
High school	100 (26.0%)
Bachelor's	257 (66.9%)
High education	17 (4.4%)

Table 2. Participants knowledge about thalassemia (N = 384).

Do you have information on thalassemia?	Frequency
Yes	74 (19.3%)
No	310 (80.7%)
Are you...	
Thalassemia carrier	6 (1.6%)
Has thalassemia	4 (1.0%)
Healthy	374 (97.4%)
If you have thalassemia, please choose your age...	
Less than 18	2 (0.5%)
18 - 25	1 (0.3%)
25 - 30	1 (0.3%)

Continued

Do you know someone who has thalassemia?	
Yes	32 (8.3%)
No	352 (91.7%)

Table 3. Awareness of thalassemia (N = 384).

How is thalassemia transmitted?	Frequency
Transmitted by infection	19 (4.9%)
Transmitted genetically	102 (26.6%)
I do not know	263 (68.5%)
Are there types of thalassemia?	
Yes	86 (22.4%)
No	8 (2.1%)
I do not know	290 (75.05%)
Thalassemia infects...	
Males only	5 (1.3%)
Females only	0 (0%)
Both	167 (43.5%)
I do not know	212 (55.2%)
Is thalassemia treatable?	
Yes	74 (19.3%)
No	34 (8.9%)
I do not know	276 (71.8%)

The last question of this part was if the disease had a treatment or not, 74 (19.3%) answered with “yes”, 34 (8.9%) answered with “no” and 276 (71.8%) did not know.

Table 4 (N = 384): the last part of the survey was about blood donation, if it is prevalent in the environment of the participant or not, 233 (60.7%) answered with “yes” and 151 (39.3%) answered with “no”.

The final question was if the participant is donating blood or not, 12 (3.1%) answered with “once a month”, 18 (4.7%) answered with “once every three months”, 64 (16.7%) answered with “once a year” lastly, 290 (75.5%) do not donate blood.

The purpose of this section was to measure the number of people that donate blood and aware of how important it is.

Table 5 (N = 384): this table shows the amount of knowledge among the participant about thalassemia by clarifying the right and wrong answers.

Table 4. Awareness of blood donation (N = 384).

Is blood donation widespread in your area?	Frequency
Yes	233 (60.7%)
No	151 (39.3%)
How often do donate blood?	
Once a month	12 (3.1%)
Once every three months	18 (4.7%)
once a year	64 (16.7%)
I do not donate blood	290 (75.5%)

Table 5. Participants awareness about thalassemia right answers and wrong answers (N = 384).

	Right answer	Wrong answer	Significant
How is thalassemia transmitted?	102 (26.6%)	282 (73.4%)	0.014
Are there types of thalassemia?	86 (22.4%)	298 (77.6%)	0.020
Thalassemia infects...	167 (43.5%)	217 (56.5%)	0.006
Is thalassemia treatable?	74 (19.3%)	310 (80%)	0.008

The first question is “How is thalassemia transmitted?” 102 (26.6%) of the participants selected the right answer and 282 (73.4%) selected the wrong answer, as well as for the next question which is “Are there types of thalassemia?” The majority of 298 (77.6%) selected the wrong answer although, 86 (22.4%) selected the right answer.

Also, in the question about who may be infected with the disease which is “Thalassemia infects...” Most of the participant selected the wrong answer with the majority of 217 (56.5%) and 167 (43.5%) selected the right answer.

The last question was about the possibility of treating the disease which is “Is thalassemia treatable?” The majority of the participants selected the wrong answer with 310 (80%) and 74 (19.3%) selected the right answer.

Table 6 (N = 384): this table shows a comparison between right answers among participants awareness in relation to gender.

The answers showed an enormous difference between the number of right answers among males and females participants with 24 (16.7%) males selected the right answer to the first question while 78 (32.3%) females selected the right answer, as well as to the second question, 18 (12.5%) meals selected the right answer while 68 (28.2%) females selected the right answer.

The next question had 26 (18.1%) males selecting the right answer while 141 (58.5%) females selected the right answer. Lastly the final question had 17 (11.8%) males selecting the right answers while 57 (23.5%) females selected the right answer.

Table 6. Comparison between right answers about participants knowledge and awareness about thalassemia concerning gender (N = 384).

Questions	Males (n = 143)	Females (n = 241)	Significant
How is thalassemia transmitted?	24 (16.7%)	78 (32.3%)	0.005
Are there types of thalassemia?	18 (12.5%)	68 (28.2%)	0.005
Thalassemia infects...	26 (18.1%)	141 (58.5%)	0.002
Is thalassemia treatable?	17 (11.8%)	57 (23.5%)	0.004

6. Discussion

The results of this study provide valuable insights into the awareness of thalassemia in Saudi Arabia and highlight the need to raise awareness of this disease.

According to the results, raising the awareness is much needed, as (68.6%) did not know how the disease is transferred. Also, the majority of the participants did not know that thalassemia has different types with (75.5%) answers.

Based on the results (55.2%) answered that they did not know which gender thalassemia infects which is the majority of the participants.

The last question was if thalassemia has a cure, (71.9%) do not know, and only (19.3%) answer with “yes” which is the right answer.

After the comparison between the males and females right answers, in this study the results showed that females are slightly more aware than men when it comes to thalassemia syndrome.

The purpose of the last part of the survey was to measure the amount of people who donate blood since transfusion is the main treatment for thalassemia patients. (60.7%) responds that blood donation is prevalent in their environment, although (75.5%) responds that they do not donate blood, also (16.7%) donate blood once a year.

There is an international day for thalassemia (international thalassemia day) on the 7th of May, this day has a great impact on the society to raise and extend the awareness and knowledge on thalassemia syndrome [4].

Overall, the study shows that most of the participants were unaware and lacking information on thalassemia syndrome.

7. Conclusions

This study shows that most of the participants were unaware and lacked information on thalassemia syndrome.

Based on this study the genetic disorder needs to be highlighted in an early educational statute as well as in colleges and universities to raise the awareness on hematogone disorders in general and thalassemia specifically.

8. Limitations

One of the limitations in this study is that it is not comprehensive because the

survey was not distributed evenly, but it can give us an overview of the awareness of thalassemia in Saudi Arabia.

There must be an awareness on the potential errors that can occur in this survey studies [8].

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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The Questionnaire

Gender

Male

Female

Age

Less than 18

18 - 25

25 - 30

30 - 35

35 - 40

40 and above

Region

North

South

Center

West

East

Education

Primary

Middle

High school

Bachelor's

High education

Do you have information on thalassemia?

Yes

No

Are you...?

Thalassemia carrier

Has thalassemia

Healthy

If you have thalassemia, please choose your age ...

Less than 18

18 - 25

25 - 30

Do you know someone who has thalassemia?

Yes

No

How is thalassemia transmitted?

Transmitted by infection

Transmitted by genetically

I do not know

Are there types of thalassemia?

Yes

No

I do not know

Thalassemia infects ...

Males only

Females only

Both

I do not know

Is thalassemia treatable?

Yes

No

I do not know

Is blood donation widespread in your area?

Yes

No

How often do you donate blood?

Once a month

Once every three months

Once a year

I do not donate blood