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Public Awareness of Beta Thalassemia in Bahrain

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Background: Genetic diseases, especially hereditary blood disorders such as thalassemia syndromes impose a significant burden on many countries. Many educational programs have been implemented in Bahrain to increase public awareness of beta thalassemia and other hereditary blood disorders.

Objective: The aim of the study is to evaluate public awareness level about beta thalassemia.

Design: Cross sectional survey.

Setting: Public in Bahrain.

Method: Questionnaires were distributed to 2000 individuals from December 2006 to February 2007. The participants were interviewed by either a health professional or a trained interviewer.

Result: Two thousand questionnaires were received; nevertheless, not all of them did answer all the questions. One thousand two hundred ninety-seven (65.1%) heard of beta thalassemia and 809 (40.5%) knew that both parents have to be carriers to have an affected child. One thousand five hundred forty-seven (77.8%) strongly agreed that premarital checking could prevent beta thalassemia. Females showed better knowledge than males and married individuals seem to know more about beta thalassemia than unmarried.

Conclusion: The study sample seems to have poor knowledge of beta thalassemia indicating the need for improving their basic knowledge of the disease. Further stress on the importance of continuing the screening campaigns specially the student screening program, premarital counseling and newborn screening service is advised.

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Genetic diseases, especially hereditary blood disorders such as thalassemia syndromes and sickle-cell disease are significant burden on many countries. Their chronic nature with no prospect of

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cure makes them one of the leading causes of morbidity and mortality.

Beta thalassemia is a genetic disorder caused by mutations in the HbB gene on chromosome 11 and inherited as autosomal recessive. The defective gene results in the absence of normal hemoglobin synthesis (β^o) or reduced amount of functional hemoglobin (β^+). Individuals affected by beta thalassemia major (β^o) develop severe anemia necessitating life-long blood transfusion. If untreated, it causes, in addition to anemia, splenomegaly and severe bone deformities with death occurring before the age of twenty. Therefore, a life-long treatment with blood transfusion and iron-overload chelating medications is necessary to maintain life. A cure is possible with bone marrow or stem cell transplantation.

The incidence of genetic blood diseases in Bahrain is considered high. Previous neonatal screening in 1984-1985 showed that the birth prevalence of sickle cell disease (SCD) was 2.1%, sickle cell trait 11% and glucose-6-phosphate dehydrogenase (G6PD) deficiency 25%[1]. In 2008, screening study for beta thalassemia major showed a prevalence of 0.06% and 5% for carriers[2].

Premarital counseling (PMC) service was started in 1993[3]. In 2004, Bahrain government has passed a law of free mandatory premarital counseling[3]. Meanwhile student-screening project has been running annually since 1998[4]. In 2007, newborn screening program for blood diseases has been launched[5]. All these programs have been accompanied by educational campaigns, which aimed at increasing public awareness about beta thalassemia among other common hereditary blood disorders. In Bahrain and as far as we know there is no previous study to measure the public awareness about beta thalassemia.

The aim of this study is to evaluate the public awareness level of beta thalassemia in Bahrain.

METHOD

This is a cross sectional study. A questionnaire was formulated to evaluate the three common inherited blood diseases: Beta thalassemia, SCD and G6PD reduced activity. The first part of the questionnaire was personal information such as age, sex, job, level of education and social status. Beta thalassemia section is presented in this paper. The questionnaires were given to 2000 individuals from the public, which include school teachers, secondary school students and others (non-probability convenience sample). It was conducted from December 2006 to February 2007. The participants were personally interviewed by a health professional or a trained interviewer.

Ethical approval has been obtained from the genetic department and an informed consent was taken orally from the respondents.

The obtained data was coded and processed by using SPSS 15. Frequency tables were obtained and special statistical tests were calculated such as Mann-Whiteny U test (non-parametric tests algorithms) and Kruskal-Wallis One-Way Analysis of Variance (non-parametric tests algorithms).

RESULT

Two thousand copies of the questionnaires were received; nevertheless, not all of them did answer all the questions. One thousand one hundred six were females (55%) and 894 (45%) were males. Six hundred eighty-nine (34.8%) of the respondents were in the age group of 10 to 19 years, only 15 (0.8%) were above the age of 60, see table 1.

Table 1: Age Distribution

Age	Number (%)
10-19	689 (34.8)
20-29	627 (31.7)
30-39	376 (19.0)
40-49	213 (10.8)
50-59	61 (3.1)
>60	15 (0.8)
Total	**1,981 (100)**

*Totals do not add to 2000 because of missing data

Five hundred eight-three (29.5%) were professionals, 406 (20.5%) were students, 273 (13.8%) were laborers, 96 (4.9%) were clerks and 618 (31.3%) were unemployed. The level of education for the interviewers ranged between illiterate to postgraduate. Nine hundred sixty-six (48.8%) are either still at school or have the high school certificate, 900 (45.5%) university graduates and 92 (4.6%) postgraduates, while 22 (1.1%) respondents were illiterate. One thousand fifty (53%) were single and 932 (47%) were married. The totals do not add to 2000 because of missing data.

The questionnaire was composed of multiple choice questions and open-ended questions. The part that tested the level of awareness of beta thalassemia was composed of 12 multiple-choice questions.

A majority of 1297 (65.1%) heard of beta thalassemia, compared to the 500 (25.1%) who have not heard of it. Only 560 (28.1%) knew if they are affected, healthy or a carrier of beta thalassemia, while 1038 (52.1%) answered ‘No’ and 393 (19.7%) answered ‘Did not know’, see table 2.

Table 2: Responses to the Questions of Beta Thalassemia

	Yes	No	Did Not Know	Total
Have you ever heard of beta thalassemia?	1297 (65.1)	500 (25.1)	196 (9.8)	1993*
Do you know if you have the beta thalassemia disease or carrier or healthy?	560 (28.1)	1038 (52.1)	393 (19.7)	1991*
Do both parents have to have beta thalassemia trait for a baby to be born with beta thalassemia?	809 (40.5)	445 (22.3)	742 (37.2)	1996*
If one parent has SCT and the other parent has Beta thalassemia, can they have a baby with sickle cell disease?	891 (44.7)	274 (13.7)	828 (41.5)	1993*
Is beta thalassemia related to food?	344 (17.3)	643 (32.2)	1007 (50.5)	1994*
Do you think that regular blood transfusion is the treatment of beta thalassemia?	670 (33.9)	304 (15.4)	1003 (50.7)	1977*
Can beta thalassemia be cured by :				
a. Bone marrow transplant	542 (27.3)	247 (12.4)	1196 (60.3)	1985*
b. Gene therapy	507 (25.5)	221 (11.1)	1257 (63.3)	1985*
c. Stem cell transplant	394 (19.9)	260 (13.1)	1330 (67)	1984*

* Totals do not add to 2000 because of missing data, values are in numbers and percentages

Genetically, 809 (40.5%) knew that both parents have to be carriers for beta thalassemia to have an affected child, 445 (22.3%) answered 'No' and 742 (37.2%) 'Did not know'.

About the possibility of genetic interaction between sickle cell trait (SCT) and beta thalassemia trait, 891 (44.7%) recognized the possibility of having a child affected with SCD, 274 (13.7%) answered 'No' and 828 (41.5%) 'Did not know'.

Three hundred forty-four (17.3%) thought wrongly that the disease is related to food, 643 (32.2%) answered 'No' and 1007 (50.5%) 'Did not know'. Six hundred seventy (33.9%) knew that blood transfusion is the treatment of the disease, 304 (15.4%) answered 'No' and 1003 (50.7%) 'Did not know'.

The majority did not know that beta thalassemia could be cured by bone marrow (1196, 60.3%) or stem cell transplant (1329, 67%). A majority of 1547 (77.8%) agreed that premarital checking can prevent beta thalassemia, so do health education (1350, 68.1%) and premarital laws (1418, 71.3%), see table 3.

Table 3: Responses to the Questions about Prevention of Beta Thalassemia

Do you think that beta thalassemia is preventable by :	Strongly Agree	Agree	Neither Agree Nor Disagree	Total
a. Premarital checking	1547 (77.8)	309 (15.5)	133 (6.7)	1989*
b. Health education	1350 (68.1)	498 (25.1)	135 (6.8)	1983*
c. Laws	1418 (71.3)	397 (20)	174 (8.7)	1989*

*Totals do not add to 2000 because of missing data, values are in numbers and percentages

Those who had previously heard of SCD correctly answered the 12 questions related to beta thalassemia (100%), $P<0.05$. When we tested the relationship between the level of knowledge and gender, females showed better knowledge of beta thalassemia in relation to the nature of the disease and the mode of inheritance $P<0.05$.

University students gave more accurate answers than the rest of respondents, five out of the 12 questions were answered correctly (42%), $P<0.05$. When we tested the relationship between the respondents' occupation and their level of awareness, the results were significant in six items. Professionals seemed significantly more knowledgeable in answering the questions, $P<0.05$.

Respondents aged 60 and above and those falling in the 40-49 years age group gave equally significant correct answers compared to the rest of age groups. Both gave correct five answers (42%), $P<0.05$. Married individuals correctly answered seven of the 12 questions (58%), which was significantly better than the knowledge of single individuals, $P<0.05$.

DISCUSSION

In general, respondents showed a fair basic knowledge of beta thalassemia. Almost two-third (65.1%) heard of beta thalassemia compared to 93.4% who heard of SCD in the same sample (SS)[8]. Armeli et al showed that 85% of their respondents heard of beta thalassemia compared to 19% among Italian-Americans and 21% of other-Americans[6].

In our sample, the majority did not know about their own status (71.8%). Our result is similar to the Italian study in which 70% of the participants were not tested for beta thalassemia[6]. Only 40.5% understood the basic of inheriting the disease. A higher percentage has been scored in Armeli et al study (67%) but a lower one was found among Americans of non-Italian origin (39%)[6]. Compared to a study done among university students in Turkey, the percentage of students who had accurate knowledge was 25% for thalassemia, but this percentage was raised to 86.2% following an informative lecture[7].

However, 44.7% of our respondents recognized the possible interaction between sickle cell trait and beta thalassemia trait. About one-third of them knew that this disease is not related to ingesting specific food. Only 33.9% knew that regular blood transfusion is the mainstay treatment for beta thalassemia compared to 63% among Italians and 19% among Americans[6]. In a Turkish study, 6.3% of the eleventh grade students wrote that blood exchange was used to treat the disease[7].

Almost two-third of our respondents did not know about bone marrow (60.2%) or stem cell transplant (67%) as curative modalities for the disease. The majority agreed with the importance of premarital checking, health education and laws to prevent or reduce the incidence of the disease.

Those who had good knowledge of the disease had also good knowledge of other common blood disorders such as SCD. In general, females revealed better knowledge than males and these results are consistent with the results we obtained for other hemoglobinopathies; this could be attributed to antenatal care education[8]. Therefore, we recommend educational campaigns targeting male population.

University students are more aware of hereditary blood disease compared to postgraduate. This could be explained that this category had been the target for the annual student-screening program, which started 10 years ago in 1999; most of these students have graduated from school by the time this questionnaire has been conducted, compared to the postgraduates who did not have the exposure because of the time factor. These results are congruent with our findings in testing the awareness of SCD[8]. However, Adewuyi found that undergraduates in Nigeria had markedly deficient knowledge regarding SCD while the undergraduates in our study had a good knowledge regarding beta thalassemia, SCD as well as G6PD

deficiency[9,8]. Lane et al found that knowledge of SCD was closely related to educational level[10].

As expected, married people know better than singles. Married couples have gone through premarital testing and counseling by law. Therefore, they appear to be more knowledgeable about these diseases. Therefore, we recommend the continuation of student screening program, premarital counseling and newborn screening service. We recommend that essential information about common blood diseases, including beta thalassemia to be included in school curriculum. Informational programs should target the male population; educate the public through different media: TV broadcasts, life lectures and seminars.

Even though our study might have some limitations such as the sampling method, whom some might argue against. In this type of sampling, a potential bias might be unknowable and the relationship between the target population and the survey sample might be immeasurable. Nevertheless, our justification is the large number of our sample.

CONCLUSION

In view of the relatively low incidence of beta thalassemia in Bahrain, people seem to have a fair knowledge about the disease. These results show a substantial room for improving the basic knowledge of beta thalassemia among our population. We recommend further studies to test beta thalassemia patients' awareness and attitude toward their illness.

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