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Investigating Knowledge, Attitude, and Practice of Young Couples Referring to Healthcare Centers of Kashmar City for Thalassemia

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Abstract: Background & Purpose: Since there is no definitive treatment for patients with thalassemia major, prevention is the most effective step in combating this disease. In this regard, the purpose of the present study was to investigate thalassemia knowledge, attitude, and practice of young couples planning to get married in Kashmar City.

Materials & methods: This was a cross-sectional descriptive-analytical study that was carried out on 420 young people planning to get married in Kashmar. The data collection tool included a researcher-made questionnaire. Data analysis was also carried out using Chi-square, Pearson's correlation coefficient, Tukey's test, and group t-test.

Results: The results of the present research showed high knowledge, good attitude, and favorable practice regarding thalassemia in 32.6%, 73.4%, and 11.4% of cases, respectively. Statistical tests also revealed a significant relationship between age, level of education, seeing a patient with thalassemia, knowing about the disease, and the marital status of the couple with the knowledge, attitude, and practice (KAP) of people, that is, increasing knowledge led to an improvement in attitude and practice scores.

Discussion & Conclusion: The higher the participants' knowledge regarding thalassemia, the more acceptable their attitude and practice will be; therefore, it is recommended to develop and implement the necessary educational programs at the social level.

Keywords: Knowledge, Attitude, Practice, Young couples, Thalassemia.

1. Introduction

One of the chronic diseases that threaten children's health is β-thalassemia major (1). B-thalassemia syndromes are a group of hereditary blood disorders that cause an absence or inadequate β-globin chain production, resulting in a decrease in hemoglobin, a decrease in red blood cells and anemia (2). Thalassemia patients are generally characterized by symptoms of chronic and severe anemia, improper growth, enlarged spleen and liver, bone disorders, especially visible changes in the head and face bones along with a change in their appearance (3). The ongoing treatment progress has turned thalassemia major into a chronic disease that requires lifelong care (4). Taking care of thalassemia patients requires huge costs, including the cost of laboratory tests, blood transfusions, and iron chelators, treatment of side effects, periodic visits, and indirect costs such as lost opportunity (5). Thalassemia patients and their families face many stressors, such as feelings of inferiority, hopelessness, anxiety, depression, worries about school, employment, treatment problems, and welfare, cultural, family, and economic problems, all of which affect the quality of life of patients (6). According to the World Health Organization (WHO), there are about 240 million carriers of β-thalassemia, and about 200000 babies with thalassemia are born every year in the world (7). There are more than 20000 patients with β-thalassemia major and about two to three million β-thalassemia gene carriers in Iran (8). Since there is no definitive treatment for patients with thalassemia major, prevention is the most effective step. Identification of thalassemia carriers is one of the basic preventive measures. To prevent thalassemia major, screening and identification of carriers and genetic counseling are essential, especially before marriage and raising public awareness (9). The most important measure is to prevent the birth of a baby with thalassemia. Unfortunately, the guideline of " Prevention before cure " is adhered to less frequently;

however, there are many factors involved in this regard, but poor culture is the most important one. If hereditary diseases are attributed to poor culture, it can be concluded that prevention is very important for these diseases (10).

The results of many studies show that to fight thalassemia, broad-spectrum educational programs should be implemented according to the level of patients' KAP. The treatment of patients with β-thalassemia major, despite being cost-effective, imposes a lot of costs. It seems that increasing the screening cost and preventing the birth of patients with β-thalassemia major can be useful (11). To reduce the number of affected newborn cases, it may be possible to improve the level of public knowledge and culture at lower costs than treatment, especially in deprived areas. It is also possible to identify and guide carrier couples. On the other hand, financial support and timely and proper prenatal testing are useful (12). The results of another study on the level of knowledge and practice of thalassemia carrier couples showed that most of the studied people did not have adequate knowledge about the preventive measures for thalassemia major, therefore, the educational programs should be developed to improve their knowledge (13). The main cause of new thalassemia births is the low screening quality, and there is a need to improve its implementation quality in all aspects. Besides, the implementation of health education programs for the target groups can be effective in eliminating this disease (14). The report of thalassemia prevention plans in other countries, including the United States, France, Italy, Canada, and Cyprus, shows that the successful fight in these countries depends on a long-term public educational program and voluntary participation in the programs to fight against β-thalassemia so that the birth of new affected cases has reached zero in a country like Cyprus, (15). Considering that thalassemia is one of the important health problems in Iran, all medical professionals need to pay serious attention to optimal prevention. Premarital screening is noteworthy, but it is even more advisable to perform it at the right time. The ultimate goal certainly is to reach the maximum number of clients before marriage, because traditionally, it will cause major problems. The longer people date before marriage, the stronger emotional roots become and it is unbearable to accept that two married people will separate after some time due to being diagnosed as thalassemia carriers. Moreover, the smaller their living environment, the more critical this issue becomes, which in turn leads to the acceptance of a stigma by both sides, especially the girl's family, to the extent that having a child with thalassemia is considered less important than separation (16). When screening programs are implemented, there will be lower moral pressure on thalassemia prevention centers and other legal authorities to take serious actions to implement the legal prohibition of the marriage of thalassemia carriers, because before the carriers choose a specific partner and their marriage gets involved with moral, emotional, cultural, family and local restrictions, they become aware of their disease (17). According to the foregoing, the purpose of the present study was to investigate the thalassemia KAP of young couples planning to marry in the city of Kashmar. The results of this research can provide effective information to the officials to plan to prevent this disease and improve the level of public health.

2. Materials & Methods

This was a cross-sectional descriptive-analytical study that aimed to investigate the thalassemia KAP of young couples planning to marry and to analyze the knowledge-attitude, knowledge-practice, and attitude-practice relationships of thalassemia people. The research environment included the health center of Kashmar City, where all couples planning to marry are required to refer to this center to perform the necessary tests and participate in pre-marriage classes. The research sample consisted of 420 people (n= 210 couples) from the couples planning to marry who had been referred to the relevant center and met the eligibility criteria. To select the samples, a pilot study was first conducted and the necessary information was obtained. Afterward, the sample size formula ($N=z2pq/D2$) ($\alpha=0.95$, $pq=0.50$, and $d=0.7$), the minimum sample size in each group was estimated to be 196 people. According to the obtained figure, a total of 210 people was considered for each group, and since each couple includes a husband and wife, the total sample was calculated as 210 x 2 = 420 people. Quota sampling was used and considering the proportion of components in the sample, 210 males and 210 females participated in the study. The researcher visited this center every day until the end of the office hours in a certain period until the required sample size was reached and obtained the necessary information by completing the questionnaire in person. To obtain more reliable results, all the questionnaires were completed by the researcher. Voluntary participation was also taken into account and participants were assured that their opinions would be kept confidential and anonymous. During interviews, if necessary, explanations were provided to the questions raised

by the research subjects. The following criteria have been taken into consideration for all the samples: They need to be residents of Kashmar city at the time of data collection, have chosen their spouse, and be in the process of getting married, all the researched subjects have not been married before and this is their first marriage. The data collection tool was also a researcher-made questionnaire, which was prepared according to the research objectives. In addition to questions on personal characteristics, questions on the KAP of young couples planning to marry have been raised. The Likert scale was used to measure the attitude of the research subject. To ensure the questionnaire validity, the content validity method was used. For this purpose, a questionnaire form was prepared by reading numerous books and articles and asking for the opinions of the relevant experts. To determine the questionnaire reliability, the test re-test method was used. To this end, the questionnaire form was completed by 20 people (n=10 couples) of qualified people on two occasions with one- week interval, and the Pearson correlation coefficient was calculated between the score of the first test and the retest after checking the results and comparing the answers given in two times and scoring the tests (α>0.95). Also, cooperation was made with the health center of Kashmar city to screen and determine the number of thalassemia carriers in all spouses. The data was displayed in the form of absolute and relative frequency distribution tables and mean comparison tables. Chi-square tests, group t-tests, analysis of variance, and Pearson correlation were used in inferential statistics. Data analysis was carried out using SPSS. This article is the result of a research project with the same name and was approved by Islamic Azad University with the code number 227728/73.

3. Results

The results showed that 3% of the research subjects aged less than 15, 15-19, 20-24, and more than 30 years in 34%, 46%, and 2% of cases, respectively. Also, 1.7% of the research subjects were illiterate, low-literate, and had primary education, lower secondary education, second secondary education, and higher education in 1%, 33.1%, 23.6%, 28.3 and 12.4% of cases, respectively. Besides, the absence and presence of contiguous marriage were reported in 57.6% and 42.4% of participants, respectively. Also, 276 participants were married upon visiting the health center. They also had obtained thalassemia-related information from different sources in 158 cases. The level of knowledge of thalassemia in men and women was 7.26 ± 6.96 and 7.36 ± 6.96, respectively. A total of 58.6% of people who had seen a thalassemia patient had a high knowledge of this disease.
Table 1 shows the frequency distribution of the researched subjects by knowledge and level of education. The chi-square test shows a statistically significant relationship between the level of education of couples and knowledge of thalassemia.

Table 1: Frequency distribution of research subjects by knowledge and level of education

Education / Knowledge	Illiterate and low-illiterate		Primary and lower secondary education		Second secondary education		Higher education		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Poor	2	18.2	48	20.2	4	3.4	2	3.8	56	13.3
Average	7	63.6	152	63.9	59	49.6	9	17.3	227	54
Good	2	18.2	38	16	56	47.1	41	78.8	137	32.6
Total	11	100	238	100	119	100	52	100	420	100

$X^2 = 101.38$ df = 6 P< 0.00001

Table 2 shows the frequency distribution of the researched subjects by attitude and level of education. Since there were few people with a poor attitude, to perform statistical tests, poor and average rows were merged. The results showed an improvement in attitude towards the prevention of thalassemia with an increasing level of education.
Table 2: Frequency distribution of researched subjects by attitude and level of education

Education / Knowledge	Illiterate and low-illiterate		Primary and lower secondary education		Second secondary education		Higher education		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Poor	0	0.0	11	44.6	0	0.0	0	0.0	11	2.6
Average	6	54.5	79	33.2	14	11.8	2	3.8	101	24
Good	5	45.5	148	62.2	105	88.2	50	92.2	308	73.4
Total	11	100	238	56.7	119	100	52	100	420	100

$X^2 = 46.86$ df = 3 P< 0.00001

The correlation coefficient test showed a correlation between age and attitude, in other words, attitude toward thalassemia increases with age (r = 0.27, p< 0.001). The mean ± SD of the attitude score of men and women was 5.23 ± 14.28 and 3.30 ± 12.53, respectively. Moreover, 86.1% of the couples who were not married upon visiting the health center had a good attitude towards thalassemia prevention ($x^2 = 18.30$, df=2, P< 0.0001). The results of the chi-square test showed a significant relationship between seeing a thalassemia patient by a couple and the attitude towards disease prevention so that 91.9% of the people who saw a patient with thalassemia had a good attitude towards prevention ($x^2 = 27.22$, df=2, P< 0.00001). The results of the correlation coefficient test show a correlation between age and practice, which means that practice has also improved with age (r = 0.19, p< 0.001). The results of the group t-test show that the average practice scores are slightly higher in men than in women, but there is no statistically significant difference between the two genders in terms of practice (t=1.08, df=418, p>0.05). Table 3 shows the comparison of the average practice scores by the level of education of couples. The results of the analysis of variance (ANOVA) test showed a significant difference among groups with different levels of education in terms of practice scores. The results of the group t-test show that the practice scores of unmarried couples were higher than married ones, which is statistically significant (t=4.77, df=418, P< 0.0001).

Table 3: Comparison of the average practice scores by the level of education of couples

Practice / Education	Mean ± standard deviation	Tukey's test result			
		Illiterate and Low-literate	Primary and lower secondary education	second secondary education	higher education
Illiterate and Low-literate	1.04±2.55			*	
Primary and lower secondary education	0.93±2.87				*
second secondary education	1.21±3.54		*		
higher education	1.19±4.00	*		*	
Total	1.13±3.19			*	

F = 23.14 P< 0.00001

Table 4 shows the frequency distribution of research subjects based on knowledge and willingness to perform the thalassemia test. The results indicate that 86.9% of research subjects who had high knowledge of thalassemia were willing to perform the relevant test.

Table 4: Frequency distribution of research subjects by knowledge and willingness to perform thalassemia test

Knowledge / Willingness to perform thalassemia test	Low		Average		High		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Willing to perform the test	37	66.1	158	69.6	119	86.9	314	74.8
Indifferent	15	26.8	50	22	9	6.6	74	17.6
Worried about the results of the test	4	7.1	19	8.4	9	6.6	32	7.6
Total	56	100	227	100	137	100	420	100

$X^2 = 19.11$ df = 4 P< 0.0007

Table 5 shows the frequency distribution of research subjects by attitude and willingness to perform the thalassemia test. The results show that 83.1% of research subjects who had a good attitude toward thalassemia were willing to perform the relevant test. The results also showed that 27% of the research subjects refused to marry if either the man or woman was a carrier, or 73% decided to get married. Moreover, if the man was healthy and the woman was a carrier, 25% refused and 75% agreed to marry. In the case of a couple being carriers, 35% refused and 65% agreed to marry. In the group with higher education, the rate of marriage cancellation when the couple was a carrier was 67.3%, while in the illiterate and low-literate group, this rate was only 18.2%. Also, 77.2% of the couples who were married upon visiting the health center had married each other and had agreed to continue their married life if couples were carriers. Besides, 91.1% of the couples who had low knowledge and 90.9% of those who had a poor attitude about thalassemia were willing to marry if they were carriers. The Pearson correlation coefficient test showed a significant correlation between attitude and knowledge. It means that increasing knowledge of thalassemia has led to a better attitude toward the disease ($r = 0.49$, $p< 0.001$).

Table 5: Frequency distribution of research subjects by attitude and willingness to perform thalassemia test

Attitude / Willingness to perform thalassemia test	Poor		Moderate		Good		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Willing to perform the test	5	45.5	53	52.5	256	83.1	314	74.8
Indifferent	4	36.4	36	35.6	34	11	74	17.6
Worried about the results of the test	2	18.2	12	11.9	18	5.8	32	7.6
Total	11	100	101	100	308	100	420	100

$X^2 = 44.53$ df = 4 P< 0.00001

Table 6 shows the frequency distribution of the researched subjects by knowledge-practice and attitude-practice. The results show a statistically significant relationship between the knowledge and practice of couples so an increase in knowledge score led to an increase in practice score. There is also a statistically significant relationship between the attitude and practice of couples so an increase in attitude score led to an increase in the practice score.

Table 6. Frequency distribution of research subjects by knowledge-practice and attitude-practice

Knowledge-practice / Attitude-practice	Poor		Moderate		Good		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Poor	18	32.1	7	63.6	70	30.8	49	48.5
Moderate	35	62.5	4	36.4	138	60.8	48	47.5
Good	3	5.4	0	0.0	19	8.4	4	4
Total	56	100	11	100	227	100	101	100

Knowledge-practice: $X^2 = 23.01$, df = 4, P< 0.00001
Attitude-practice: $X^2 = 53.48$, df = 4, P< 0.00001
The results of blood tests showed that 1.7% of thalassemia carriers and 98.3% of them were healthy.

4. Discussion & Conclusion

The results of the present study showed that 42.4% of the research subjects had a consanguineous marriage, which is less than the study by Rezaei Keykha et al. (13) (70.8%) and was almost equal to the results of the study by Jafari et al. (18) (39.4%). Sargolzaei et al. (19) referred to a study in Zahedan on consanguineous marriages as one of the factors that increase the chances of screening in the first trimester of pregnancy. Also, the results of the chi-square test in this research showed a significant relationship between consanguineous marriage and the level of education of the couple; that is 63.6% of illiterate and low-literate people had a consanguineous marriage, while 84.86% of people with higher education had non- consanguineous marriages; therefore, considering the high rate of consanguineous marriages in Iran and the increase in the risk of genetic diseases among these couples, there is a need for more planning and training to improve the level of knowledge, attitude, and practice of them. The present study showed that 65.7% of the research subjects were married at the time of visiting the health center. According to the customs of marriage in Iran, the bride and groom go through certain stages before being introduced to related tests, dissuading them from marriage in case couples are carriers in these stages, causes problems for them and their families. They may thus sometimes not cooperate in this process. Unfortunately, such a high rate of marriage before these tests show the cultural weakness of families and couples.
In a study by Sardo et al. (14), it was also found that 23% of couples had not been screened before marriage, which included couples whose marriages were performed before the prevention program or had informal marriages. This figure was about 80% and 64% in studies by Miri Moghadam et al. (20) in Zahedan and Zinlian et al. (21) in Isfahan, which is consistent with the present research.
Concerning the participants' level of knowledge in this study, the results showed that they had low, average, and high knowledge about thalassemia in 13.3%, 54%, and 32.6% of cases, respectively. The results of the correlation coefficient test also showed that participants' knowledge about thalassemia disease increased with increasing age and level of education, which are consistent with the studies by Rezaei Keykha et al. (13), Jafari et al. (18) because gaining and increasing knowledge is considered the first step to change behavior, therefore, it is very important to

raise the general knowledge of thalassemia prevention and provide the necessary training to low-literate and illiterate people in this regard.

The results of the current research also showed that the participants had poor, average, and good attitudes toward thalassemia in 0.6%, 24%, and 73.4% of cases, respectively. The results of the correlation coefficient test showed a correlation between age and attitude. Moreover, the level of attitude was higher in men than in women. It was also found that participants had a more favorable attitude about thalassemia with an increasing level of education so 92.2% of people with higher education had a good attitude towards thalassemia prevention. Also, the rate of good attitude towards thalassemia prevention was higher among couples who were not married at the time of visiting the health center as compared to married ones. Since attitude is the most important issue in fighting any health problem, when people believe that they are exposed to a disease and its consequences, it is normally easier to fight that health problem (22), which is consistent with the results of a study by Gheraati et al. (23) that show education about the disease, its consequences, and complications have been effective in improving parents' attitudes. Another study on the KAP of mothers with thalassemia showed that low knowledge and inappropriate attitude and practice about thalassemia are the main barriers to preventing the disease (24). In a by study Borhani et al. (25), it was also found that the family-centered empowerment model is effective in increasing the awareness and attitude of thalassemia carrier mothers. Similarly, previous studies on mothers' attitudes show that face-to-face training affected improving mothers' attitudes (26).

To evaluate the practice status among studied couples, i.e. the willingness to perform the thalassemia test, the decision to marry and to cancel it if one or both of the spouses is a carrier, and the main reason for not cancelling marriage in thalassemia carrier couples, the results of the correlation coefficient test showed a correlation between age and practice, and the practice score has improved with age, which is consistent with the results of Beshkar et al.'s research (12). Also, the average practice score in men was slightly higher than that of women. More than half (57.7) of people with higher education had been referred to the health center for thalassemia testing, while 90.9% of the illiterate and illiterate couples were referred to this center regardless of this test. The chi-square test also showed that 79% of married couples did not think about the thalassemia test, while married couples were more likely to perform the thalassemia test. The results regarding one of the couples being a carrier showed an increase in the probability of making the right decision regarding marriage and canceling it in couples with a higher level of education and knowledge as well as in married couples. The results also showed that in the case where both men and women were carriers of thalassemia, the correct answer was more likely with increasing KAP and educational level in married couples as well as unmarried couples. Among married couples, the issue of marriage is the main reason for not canceling the marriage of the carrier couple (36.3%). However, it should be noted that the issue of marriage can affect the response of couples to a great extent, which is consistent with the research by Shahrokhi Sardo et al. (14). Overall, the results of the research indicated that the research subjects had poor, average and good practice in 25.2%, 63.4% and 11.4% of cases, respectively. As people's knowledge of thalassemia has increased, their attitude and practice have also become more favorable, and also an improved attitude has led to good practice in more participants. These results are consistent with those of the research by Rezaei Keykha et al. (13). One of the limitations of this research is the unrealistic answers of the research subjects for various reasons. According to the results of the present study, as people's knowledge of thalassemia has increased, their attitudes and practice have also become more favorable, therefore, it is recommended that the relevant educational programs be developed and implemented at the social level.

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