Attitude and Knowledge of Participating Couples Towards the Premarital Hemoglobinopathy Screening Program in Duhok–Iraq.

Rebeen Abdulsalam Mohammed Sediq* Salar Ayoub Sulaiman** Nasir Al-Allawi***

Abstract

Background and Objectives: The premarital screening program for hemoglobinopathies was initiated in the Kurdistan region nearly 15 years ago. In the current study we aimed to assess the attitude and knowledge of the targeted couples, since these are among the main determinants of its success.

Methods: In this cross-sectional study we recruited consecutive 1100 couples attending premarital screening center in Duhok-Iraq between November 2022 and March 2023. The participants had their demographic data collected, and attitude towards the premarital screen was assessed. A subgroup was further scrutinized on their knowledge on the program and hemoglobinopathies.

Results: While 99.8% of enrollees considered premarital screen important, only 10.5% choose to abandon their marriage plans if they were identified as couples-at-risk. Of those proceeding with marriage, 94% wanted to do testing to determine whether their babies are affected, yet only 5.7% would consider aborting it, citing religious or cultural prohibition. In the subset where knowledge was assessed, it was found that only 6% and 20% had good knowledge as it related to hemoglobinopathies and premarital program respectively. There was a significant association between positive attitude and knowledge (p=0.019).

Conclusions: The current study underscores the barriers facing the successful implementation of the premarital program and the serious knowledge gaps among the public about it. The need to introduce targeted educational initiatives to better inform the public of their choices is paramount.

Keywords: Hemoglobinopathies, Iraq, Sickle cell disease, Thalassemia.

*MBChB; Senior House Officer, Department of Hematology, Azadi Teaching Hospital, Duhok, KRG, Iraq. Email: rebenamedi@gmail.com. Corresponding author
** MBCHB, MSc, FIBMS; Lecturer, College of Health Sciences, Department of medical laboratory sciences, University of Duhok, KRG, Iraq. Email: salaar72@yahoo.co.uk
*** MBChB, MSc, PhD, FRCPath; Professor of Haematology, Department of Pathology, College of Medicine, University of Duhok, Duhok, KRG, Iraq. Email: nasir.al-allawi@uod.ac

Introduction

Hemoglobinopathies are inherited red cell disorders in which the quantity or the structure of globin chains of hemoglobin are affected.[1] The two most frequent types of these disorders in Iraq are β-thalassemia and sickle cell disorders, with carrier rates of 3.7%-6.9% and 0.1-6.5% respectively in different parts of country.[2] Furthermore, in their homozygous or compound heterozygous state these two autosomal recessive disorders constitute important health problems in Iraq, including the Kurdistan region. In the latter region there are about 3200 registered symptomatic hemoglobinopathy cases, which constitute nearly a quarter of the total number of cases in the country.[2,3] These disorders impose a huge impact on the patients' wellbeing, quality of life, survival, and on the already overstretched health resources [4,5], with no curative management option, except for the very expensive stem cell transplants. Accordingly, it seems imperative to implement appropriate preventive programs aiming at reducing the birth of affected babies. Such programs may be based on premarital, antenatal, or school screening, though the most popular is the former.[6] Several countries with high prevalence rates of hemoglobin disorders, had initiated their preventive programs since the 1970s of the last century, with many particularly those in Cyprus, Greece, and Italy eventually managing to significantly reduce the numbers of newborns with these disorders in these populations and thus decreasing the overall burden of the disease.[7] In 2008 the Kurdistan regional parliament made premarital screening for hemoglobinopathies mandatory by law, and a preventive program based on it was initiated.[8] Furthermore, in its first five years, the program showed promising results in the two provinces of Kurdistan region where data were available, with an overall reduction of affected births by nearly a third.[2]

The hemoglobinopathy premarital screening program (PMS) has now been running for 15 years and in the current study we sought principally to assess the attitude and to lesser extent the knowledge of premarital couples as they relate to various aspects of the program, with the aim of identifying challenges facing it and proposing possible solutions.

Materials and methods

The study is a cross-sectional study which included recruiting consecutive 1100 couples attending premarital screening center in Duhok-Iraq in the period between 2 November 2022 and 8 March 2023. After informed verbal consent, data collection was carried out using an interviewer administered questionnaire on attitude in all enrollees and knowledge in a subset of them. The questionnaire comprised three main parts. The first part is the socio-demographic data, which included questions related to age, sex, highest qualification, residency (urban versus rural), employment status, consanguinity between the couple, and income. The second part is the attitude which included questions regarding the importance of premarital screening, their response if they are identified as couples at risk regarding proceeding with the marriage, if they would be considering doing prenatal diagnosis if they are identified as couple at risk, and what would be their response if they do test and the fetus is affected. The third part relates to the knowledge, and this section was performed on a subset who were the last consecutive 100 couples to be recruited, with questions on extent of participants' knowledge on thalassemia and sickle cell disease, and how did they get this information, and on consanguineous marriage and premarital screening program. Those with good knowledge were scored as 2, no knowledge as 0, while those who were uncertain or had limited knowledge were scored as 1. The study was approved by the Kurdistan Higher

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Council of Medical Specialties and an informed consent was obtained from all enrollees. Statistical analysis was performed using SPSS software (IBM, SPSS v27, USA). Data were described by number and frequency for categorical variables, and mean and standard deviation or median and interquartile range for continuous ones. Mann Whitney U test, Chi Square or Fishers test were used as appropriate. A p value < 0.05 was considered significant.

Results

A total of 1100 couples (2200 individuals) with mean ±SD ages of 29 ±7.0 and 24.6 ±5.7 years for men and women respectively. Table (1) outlines the demographic characteristics of the enrollees. The large majority of these individuals (72.9%) were in age group (15-29 years). Nearly a third of enrollees had college degrees or higher qualifications, while another third was either illiterate or with primary school education. Most of males were employed (87.2%), while most females were not (70.8%). In relevance to the couple residence, it was urban in 79.4%.

Consanguinity was documented in 19.5% of the couples enrolled, Table (1). Table (2) outlines the responses to questions on the attitude in the 1100 couples enrolled. Regarding the attitude towards the premarital screening program almost all (99.8%) thought that premarital screening is important. Nearly three quarters (76.2%) said that they would proceed with the marriage even if they were both carriers (at risk couple). Of the latter individuals 94.2% said they would like to perform testing in early pregnancy to know whether their baby is affected. However, of those couples only 5.3% would resort to termination of an affected baby in early pregnancy, while 86.7% said they would not. The reasons for declining termination were in most cases due to religious in 614 couples (77.8%) and cultural beliefs in 70 (8.9%). The overall number of couples who had the best possible attitude (i.e. either abandon marriage plans or proceed with marriage and opt to terminate affected gestations) was 157 (14.3%), Table (2).

Table (1): Sociodemographic characteristics of the study sample.

Characteristics		Male		Female		Total	
		No.	%	No.	%	No.	%
Age	15 – 29 years	682	62.0	921	83.7	1603	72.9
	30 – 44 years	379	34.5	172	15.6	551	25.0
	45 – 70 years	39	3.5	7	0.6	46	2.1
Occupation	Employee	960	87.2	131	11.9	1056	49.5
	Student	52	4.7	190	17.3	242	11.0
	Unemployed	88	8.0	779	70.8	867	39.4
Education	None	168	15.3	154	14.0	322	14.6
	Primary	187	17.0	137	12.5	324	14.7
	Secondary	376	34.2	456	41.5	832	37.8
	College and above	369	33.5	353	32.1	722	32.8
Residence	Urban	878	79.8	868	78.9	1746	79.4
	Rural	222	20.2	232	21.1	454	20.6
Consanguinity	Consanguineous	214	19.5	214	19.5	428	19.5
	Non-consanguineous	886	80.5	886	80.5	1772	80.5
Income	Adequate*	1033	93.9	1033	93.9	2066	93.9
	Inadequate*	67	6.1	67	6.1	134	6.1
Total		1100	100.0	1100	100.0	2200	100.0

*From the participants' perspective

Table (2): Attitude toward premarital screening.

Attitude questions		No.	%
1- Do you think it is important to do premarital screening?	Yes	1098	99.8
	No	2	0.2
2- If we screen you and find you are at risk of having abnormal children, would you still go on with marriage?	Yes	838	76.2
	No	115	10.5
	Undecided	147	13.4
3- If you get married despite risk, and told that you could do a test to identify an affected fetus in early pregnancy, would you do it?	Yes	789	94.2
	No	37	4.4
	Undecided	12	1.4
4- If you do test during pregnancy and the baby was found to be affected, would you agree to terminate pregnancy or not?	No	684	86.7
	Yes	42	5.3
	Undecided	63	8.0

Associations between various demographic parameters and attitude revealed several significant observations. So, regarding proceeding with marriage despite being identified as couples at risk, it was significantly lower in those with university qualifications (p<0.001), while it was significantly higher in consanguineous couples (p=0.006), and in those with inadequate income (p=0.001), Table (3). Furthermore, regarding the question of taking a test to detected an affected fetus in early pregnancy, this was significantly higher in non-consanguineous couples (p=0.034) Table (4). In relevance to the question of terminating pregnancy of an affected fetus, it was the age group between 30-44 years that was more likely to choose abortion, while the group 45-70 years was least likely (p=0.002), On the other hand, those who were unemployed, had lower qualifications, or inadequate income were each less likely to choose abortion (p=0.048, <0.001, and 0.033 respectively), Tables (5).

Table (3): Associations of question 2 responses (Would you still get married if you were identified as couples at risk?) to sociodemographic characteristics (n = 2200 individuals = 1100 to be couples)

Sociodemographic characteristics		Answer to Question 2: Would you still get married if you were identified as a couple-at-risk?				
		NO	Undecided	YES	Total	
		No. (%)	No. (%)	No. (%)	No.	P value
Age groups (years)	15 – 29	162(10.1)	212(13.2)	1229(76.7)	1603	
	30 – 44	67(12.2)	73(13.2)	411(74.6)	551	0.175
	45 – 70	1(2.2)	9(19.6)	36(78.3)	46	
Current work	Employee	129(11.8)	152(13.9)	810(74.2)	1091	
	Student	19(7.9)	35(14.5)	188(77.7)	242	0.160
	Unemployed	82(9.5)	107(12.3)	678(78.2)	867	
Highest qualification	None/Primary	64(9.9)	64(9.9)	518(80.2)	646	
	Secondary	79(9.5)	107(12.9)	646(77.6)	832	< 0.001
	College and above	87(12.0)	123(17.0)	512(70.9)	722	
Place of residence	Urban	171(9.8)	240(13.7)	1335(76.5)	1746	0.103
	Rural	59(13.0)	54(11.9)	341(75.1)	454	
Consanguinity	Consanguineous	28(6.5)	52(12.1)	348(81.3)	428	0.006
	Non-consanguineous	202(11.4)	242(13.7)	1328(74.9)	1772	
Income	Adequate	214(10.4)	290(14.0)	1562(75.6)	2066	0.001
	Inadequate	16(11.9)	4(3.0)	114(85.1)	134	
Total		230(10.5)	294(13.4)	1676(76.2)	2200	

Table (4): Associations of question 3 responses (would you do a test during pregnancy to identify an affected baby?) to sociodemographic characteristics (n = 1676 individuals = 838 to be couples)

Sociodemographic characteristics		Answer to Question 3: Would do a test during pregnancy to identify an affected fetus?				P value
		NO	Undecided	YES	Total	
		No. (%)	No. (%)	No. (%)	No.	
Age groups (years)	15 - 29	57(4.6)	17(1.4)	1155(94.0)	1229	
	30 - 44	16(3.9)	6(1.5)	389(94.6)	411	0.894
	45 - 70	1(2.8)	1(2.8)	34(94.4)	36	
Current work	Employee	35(4.3)	11(1.4)	764(94.3)	810	
	Student	6(3.2)	4(2.1)	178(94.7)	188	0.790
	Unemployed	33(4.9)	9(1.3)	636(93.8)	678	
Highest qualification	None/Primary	19(3.3)	11(1.9)	488(94.2)	518	
	Secondary	27(4.2)	8(1.2)	611(94.6)	646	0.320
	College and above	28(5.5)	5(1.0)	479(93.6)	512	
Place of residence	Urban	53(4.0)	21(1.6)	1261(94.5)	1335	0.141
	Rural	21(6.2)	3(0.9)	317(93.0)	341	
Consanguinity	Consanguineous	24(6.9)	6(1.7)	318(91.4)	348	0.034
	Non-consanguineous	50(3.8)	18(1.4)	1260(94.9)	1328	
Income	Adequate	74(4.7)	22(1.4)	1466(93.9)	1562	0.058
	Inadequate	0(0.0)	2(1.8)	112(98.2)	114	
Total		74(4.4)	24(1.4)	1578(94.2)	1676	

Table (5): Associations of question 4 responses (If you do test during pregnancy and the baby was found to be affected, would you agree to terminate pregnancy?) to sociodemographic characteristics (n = 1578 individuals = 789 to be couples)

Sociodemographic characteristics		Answer to question 4: If you do test during pregnancy and the baby was found to be affected, would you agree to terminate pregnancy?				P value
		NO	Undecided	YES	Total	
		No. (%)	No. (%)	No. (%	No.	
Age groups (years)	15 - 29	1019(88.2)	89(7.7)	47(4.1)	1155	
	30 - 44	318(81.7)	35(9.0)	36(9.3)	389	0.002
	45 - 70	31(91.2)	2(5.9)	1(2.9)	34	
Current work	Employee	646(84.6)	64(8.4)	54(7.1)	764	
	Student	158(88.8)	13(7.3)	7(3.9)	178	0.048
	Unemployed	564(88.7)	49(7.7)	23(3.6)	636	
Highest qualification	None/Primary	440(90.2)	32(6.6)	16(3.3)	488	
	Secondary	552(90.3)	39(6.4)	20(3.3)	611	< 0.001
	College and above	376(78.5)	55(11.5)	48(10.0)	479	
Place of residence	Urban	1091(86.5)	105(8.3)	65(5.2)	1261	0.528
	Rural	277(87.4)	21(6.6)	19(6.0)	317	
Consanguinity	Consanguineous	282(88.7)	26(8.2)	10(3.1)	318	0.153
	Non-consanguineous	1086(86.2)	100(7.9)	74(5.9)	1260	
Income	Adequate	1266(86.4)	116(7.9)	84(5.7)	1466	0.033
	Inadequate	102(91.1)	10(8.9)	0(0.0)	112	
Total		1368(86.7)	126(8.0)	84(5.3)	1578	

In a subset of 200 individuals (100 couples) knowledge was tested Table (6), and it was found that 62% have heard of thalassemia and/or sickle cell disease, though only 6% had adequate knowledge. Furthermore, 89% thought that consanguineous marriage increases the risk of having these disorders.

When asked whether thalassemia is preventable or treatable: 28% and 12% respectively thought that it was. Regarding of what is included in the premarital program: 53% had no knowledge at all about it, while 20% had fair knowledge.

Table (6): Knowledge toward thalassemia and PMS (and its allocated answer score) among a subset of 100 couples

Knowledge areas		score	No.	%
1A. Have you heard of thalassemia/sickle cell disease, and if yes, what is extent of your knowledge?	Adequate knowledge	2	6	6
	Inadequate knowledge	1	56	56
	No knowledge	0	38	38
1B. How did you get this information?	Public		32	32
	Media		16	16
	School		10	10.0
	Affected relative		4	4.0
	None		38	38
2- Does consanguineous marriage increase the risk of having thalassemia?	Yes	2	89	89.0
	No	0	2	2.0
	Uncertain	1	9	9.0
3- Is thalassemia a preventable disease?	Yes	2	28	28.0
	No	0	14	14.0
	Uncertain	1	58	58.0
4- Does thalassemia have any treatment?	Yes	2	12	12.0
	No	0	35	35.0
	Uncertain	1	53	53.0
5- How much do you know about premarital screening and the tests it includes?	Fair	2	20	20.0
	Limited	1	27	27.0
	No Knowledge	0	53	53.0

In this subset of 100 couples assessed for knowledge, 19 couples had the best possible attitude (i.e. either abandon marriage plans or proceed with marriage and opt to terminate affected gestations) and when the answers to knowledge questions were scored as shown in table (6), it was found that those with the best attitude had a significantly higher median knowledge score compared to that of the remaining 81 couples (p=0.019), Table (7).

Table (7): Association between knowledge score and attitude in 10 couples

	Best Attitude (no. 19)	Less Favorable attitude (no. 81)	P value
Median Knowledge Score (IQR)	6 (5-7)	5 (4-6)	0.019

Discussion

The PMS is based on screening individuals to identify couples at risk (i.e. both are carriers), and then counsel them on their choices, whether to proceed or not with marriage. If they decide to proceed with marriage, then they are offered the option of performing prenatal diagnosis (PND) to identify an affected fetus in early pregnancy, and to terminate such pregnancy. The best outcome from the PMS view point is for a couple at risk to either abandon their marriage plans or proceed with marriage, perform PND and abort any affected fetus. This will ultimately lead to reduction in the number of affected babies born, which is the main objective of the PMS.[8] Almost all respondents thought that premarital screening is important, which is consistent with most earlier studies worldwide, whether on premarital, antenatal, or students screening programs.[6,9-11] However, it is interesting to note that only 10.5% said that they will not proceed with marriage if identified as couples at risk. This is more or less similar to results of earlier studies from the Kurdistan region, Saudi Arabia and Turkey where only 2-13% of such couples abandoned their marriage plans because of this finding.[8,12-15] Results from other Eastern Mediterranean countries like Jordan, Qatar and Bahrain revealed that 33-40% would opt to abandon marriage plans.[16-18] This is likely to be due to social obligations superseding health considerations and risks, particularly when one considers the fact that premarital testing is usually done late in the marriage arrangements, when social commitments have already been made and the premarital testing becomes just a formality. Almost similar reasoning was given by Saudi couples for their high rate of marriage despite being identified to be at risk, and further stressed on the issue of social stigmatization in conservative societies.[7,14,19] Such a situation underscores the need to implement parallel hemoglobinopathy screening programs well in advance of marriage, like those done in schools or college admissions.[17] What is more intriguing is the fact that although nearly 94% said that if they were identified as at risk couples, they would like to perform testing in pregnancy to determine whether their babies are affected. However, only 5.3% would resort to termination of an affected baby. The reasoning for declining termination of an affected fetus were religious or cultural, which is more or less similar to previous observations from Iraq, Iran, Lebanon, Pakistan, and Malaysia.[9,12,17,20] In earlier studies documenting the first five years of PMS in Kurdistan, PND was only offered to those who accepted the concept of termination of an affected baby, and that is why 96% choose it [8,12] ;this is consistent with the attitude towards termination of affected babies in China, Cyprus, UK and to some extent Iran where most or all affected pregnancies were terminated.[20-23] The observation that about 94% of couples in the current study expressed religious/cultural objections to termination of affected gestations is interesting, since it indicates that the public is ill-informed of a fatwa issued in 2013 by the Kurdistan council of Muslim scholars that allows termination of an affected fetus <16 weeks' gestation.[12] Despite the latter fatwa, the religious scholars community throughout Iraq is divided on what is the most appropriate action relevant to this issue. Some scholars believing that termination should not be allowed at any stage of pregnancy except if the mother's life is threatened, while others allow termination of an affected baby before 16 weeks of gestation. On the other extreme, some prohibit marriage of couples at risk all together. In view of this controversy, it is our opinion that a panel of religious and legal scholars as well as medical experts and health policy makers need to set a national consensus guideline on handling this issue,

and the public should be well-informed of these guidelines and their justification. Several socio-demographic/attitude associations were identified. Among which was the association of higher educational qualifications with declining marriage of at-risk couples, and for opting to abortion. This is not unique to this study, and a more positive attitude was also reported in Saudis and Iranians in those with higher qualifications.[20,24] Another association is that consanguineous couples were less likely to abandon their marriage plans, or to perform prenatal diagnosis, and this is expected since strong family ties may make these actions culturally inappropriate. Regarding the choice of abortion as opposed to continuing an affected pregnancy, it was interesting to note that it is less likely in those who were unemployed, had lower income, and in the age group >45 years. This may be due to the fact that termination of pregnancy is not without cost, and thus the unemployed/low-income couples may be less inclined to pursue this option. On the other hand, older couples would be expected to be more eager to continue with pregnancy to its eventual outcome. In the subset assessed for knowledge regarding hemoglobinopathies and PMS, it was noted that while nearly 60% have heard of hemoglobinopathies, this knowledge was limited in most. Furthermore, a majority either did not know or were uncertain whether thalassemia is preventable or treatable, which indicates that the general public is not well informed about a disorder that is quite prevalent among it. The level of knowledge of hemoglobinopathies varies in different countries and is mainly relevant to how prevalent these disorders are in these countries, and how this reflects on the educational programs that the health authorities advocate to address the issue. The use of mass media, lectures, health professionals training, posters and pamphlets at medical and premarital centers has made a

difference in many countries like Greece, Cyprus, Iran and Italy.[6] One notable observation which emerged from the current study is that most couples knew of the risks associated with consanguineous marriage, and this has also been documented among Iranian premarital couples [25] ,and despite that knowledge the rate of consanguineous marriage is still high, which indicates that the continuing unwavering adherence to traditional and cultural norms in the community. The extent of knowledge on what premarital testing includes was either limited or absent in 80% of couples interviewed, despite acknowledging its importance. Such a situation is not unique to our locality, studies from Saudi Arabia, Egypt and Sudan also revealed similar observations.[11,26,27] The association of attitude with knowledge level in the current study is not unexpected and has been documented by previous studies including those from Iran, and Egypt.[25,26]

Conclusion

The current study underscores the barriers facing a successful implementation of the premarital screening program which are mainly related to couples opting to getting married despite being at risk, and declining to terminate an affected pregnancy. This is coupled with serious knowledge gaps among the public about the program and the diseases it addresses. The need to introduce targeted educational initiatives to better inform the public of their choices, the premarital program, and on inherited hemoglobin disorders is paramount.

Conflict of interest:

The authors have no conflict of interests to declare.

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