



Outcomes of the Effect of Premarital Counseling for Sickle Cell Disease and β -Thalassemia on Marital Decisions in the Kingdom of Bahrain

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Abstract

Background: Hemoglobinopathies such as sickle cell disease and thalassemia pose a major burden on health services in the Kingdom of Bahrain. Premarital screening and counseling programs were implemented in order to reduce the incidence and prevalence of such diseases.

Aim: To promote the role of premarital counseling in the prevention of sickle cell disease and β -thalassemia in Bahrain.

Setting: Ten governmental health centers in Bahrain in different geographical regions.

Study Design: Comparative study to analyze retrospective data from January 2017 to May 2019.

Materials and Methods: Data was collected from I-SEHA database at Ministry of Health and a sample of convenience was taken to administer questionnaires to couples by phone calls. Study sample data was analyzed using SPSS version 23. Chi-squared test was done with a p-value of 0.05 to be considered statistically significant.

Results: Out of the 92 couples identified from health centers, 47 couples continued through with the marriage and 45 couples did not. 126 subjects were interviewed and asked about the reasons behind their decision and their perception towards quality of the counseling. Analysis revealed the educational level to be the only significant factor. As for the perception towards the quality of genetic counseling in Salmaniya Medical Complex, most respondents, irrespective of their marriage decision, rated it as good.

Conclusion: The implementation of the premarital counseling program in Bahrain is considered effective with 48.9% of the couples not proceeding through with the marriage proposal.

Keywords: Premarital counseling; Premarital screening; Genetic counseling; Sickle cell disease; beta Thalassemia; Hemoglobinopathies; Bahrain

Abbreviations

SCT: Sickle Cell Trait; SCD: Sickle Cell Disease; α -thalassemia: Alpha Thalassemia; β -thalassemia: Beta Thalassemia; SMC: Salmaniya Medical Complex; SPSS: Statistical Package of Social Science; WHO: World Health Organization; MENA: Middle East and North Africa region; RBCs: Red Blood Cells; UAE: United Arab Emirates

Introduction

Hemoglobinopathies are inherited blood disorders caused by genetic defects resulting in abnormal hemoglobin structures. Hemoglobinopathies such as sickle cell disease and β -thalassemia are worldwide spread [1].

In the Arabian Gulf region, prevalence of hemoglobinopathies is high, which is thought to be due to consanguinity and large family sizes [2]. In the last century, malaria was endemic in Bahrain which led to the malaria selection hypothesis, making the malaria-associated genetic defects of

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Received Date: 11 Aug 2021

Accepted Date: 15 Sep 2021

Published Date: 20 Sep 2021

Citation:

Bubshait JA, AlJazeera FS, AlMahmood AA, AlMadahki AA, AlAlawi MA, Hasan YH, et al. Outcomes of the Effect of Premarital Counseling for Sickle Cell Disease and β -Thalassemia on Marital Decisions in the Kingdom of Bahrain. *Int J Fam Med Prim Care*. 2021; 2(3): 1041.

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RBCs common for their coping ability to survive the disease crisis [3]. In 1985, prevalence of sickle cell disease among non-neonates was 10.44% [4]. As of 2008 on the other hand, prevalence of β -thalassemia dropped to 5%. In comparison to studies conducted in other Gulf countries, the frequency of sickle cell disease in Bahrain is among the highest in its region while β -thalassemia prevalence in Bahrain is not as high as that of its neighboring countries [5].

A Bahraini research conducted in 2010 shows the prevalence of SCD in newborn babies to be 0.41% in the context of the national program for newborn screening of hemoglobinopathies [6]. In 1993, the Ministry of Health (MOH) launched the premarital counseling service in all health centers, though it was an optional measure until a royal decree enacted a Law for the year 2004, requiring mandatory premarital screening and counseling for all couples planning to get married. A newborn screening program for hematological disorders was established in 2007 [3].

The fundamental objective of premarital screening and counseling program in the Kingdom of Bahrain is to diminish the prevalence of common hemoglobinopathies such as sickle cell disease and thalassemias [7]. There has been an established link between having children with these blood disorders and a low quality of life among the family members, owing to financial, emotional, and time-consuming liabilities. Premarital counseling, if successful in preventing at-risk couples from getting married, can spare families the lifelong burdens previously mentioned. Moreover, elective abortion is not an option in most countries in the MENA region, excluding the voluntary termination of pregnancy as an alternative choice if prenatal screening results were positive [8].

Premarital screening is performed using low-cost laboratory tests which diagnose both hemoglobinopathies (inherited) and sexually transmitted diseases (acquired). Positive individuals and couples are identified, counseled and if possible, treated. Those with an abnormal genetic history are referred to the Department of Genetics at Salmaniya Medical Complex. The counseling does not hinder the couples from getting married; however, it gives them an insight on their future as a couple [9].

Although positive premarital testing for hemoglobinopathies provides reliable results that determine risks of having an affected child, not everyone responds suitably. The outcome is influenced by personal, social, ethical, and educational factors. In 2007, a study based on the Saudi premarital screening program, conducted by Al Hamdan et al. reported that 90% of couples found to be carriers did not comply with counseling recommendations and went through with their marriage [10]. A similar study was conducted by Al Sulaiman in 2010 reported their findings of a sample of 129 couples identified by the premarital screening program as at-risk couples, where 98% proceeded with their marriage despite the risk [11].

Social determinants are known to be the most significant factor affecting the outcome of premarital counseling in Arabian countries, in view of societal or familial pressure on individuals due to financial or cultural issues.

Consanguinity is considered to be a major social factor that influences the outcome as well. In Arabian countries, 25% to 60% of marriages are consanguineous [12]. Many factors encourage this type of marriage such as strengthening family connections and retaining wealth. A study in Al-Ramadi city, Iraq concluded that there is a significant association between consanguinity and women's

educational status [13].

Educational level of individuals plays a crucial role in the outcome of premarital screening. A cross-sectional study was conducted at King Khalid University to assess students' knowledge, attitude and practice toward Pre-Marital Counseling (PMC) which concluded that 73.4% of students were aware of PMC and 95.2% acknowledged its importance. 96.5% of the students reported their free will to undergo PMC and 72.1% thought that it should be mandatory. This study is a great demonstration that educational level plays a major role in the viewpoints of PMC, regardless of the innate cultural beliefs in the region [14].

Ethical values also play a role in the outcome of counseling, since the Islamic religion allows consanguineous marriages, leading to more positive results from premarital testing, as well as noncompliance to counseling, in favor of religious guidance instead. A study conducted in the Jazan region of Saudi Arabia demonstrated that 192 of 413 participants had attended premarital counseling clinics, as most individuals viewed their marriage unions as fate, regardless of the outcome [8].

Outcomes are also believed to be influenced by the approach of counselors to provide the couple with information on the diseases' risks, complications, and future management. The possibility of inadequate approach by counselors may deprive couples' rights to be fully informed, adversely affecting their judgment and autonomy [10].

This study was conducted in order to explore the factors contributing to the decision to continue/discontinue with the marriage proposal among couples at risk of procreating off springs with hemoglobinopathies (SCD and β -Thalassemia) following premarital counseling in Kingdom of Bahrain during January 2017 to May 2019. Also, the study assessed the proportion of couples, who after going through premarital counseling, have decided not to proceed with the marital union. In addition, the perception of couples towards the quality of the counseling process in Salmaniya Medical Complex was evaluated.

Materials and Methods

Information was collected retrospectively from the databases of 2017, 2018 and the first 5 months of 2019. A descriptive comparative study was used to analyze the data.

The population sample, consisting of 294 individuals (147 couples), was selected from the couples who appeared to be at risk of passing on hemoglobinopathies to their offspring after attending premarital screening during the months of January 2017 to May 2019, in chosen public health centers. Those at-risk couples include relationships between two carriers, a carrier and diseased individual, or two diseased individuals, of both SCD and β -thalassemia. Information was obtained from documented premarital screening records in assigned archives and the I-SEHA database at Ministry of Health. The information included individuals' test results along with their phone numbers, age, gender, nationality, occupation, and the educational level.

A sample of convenience was taken, including all at-risk couples for SCD and/or β -thalassemia who attended the chosen health centers during January 2017 to May 2019. Out of 294 individuals obtained, a sample of 184 individuals (92 couples) was reached, after applying the exclusion criteria. Out of those, 126 individuals have answered the

phone and were willing to participate.

Ten out of 25 public health centers in Bahrain which offer the premarital screening program were selected based on premarital 2016's data provided by the Ministry of Health, stating that these ten health centers had the highest number of attendees with hemoglobinopathies [15].

A questionnaire was administered by phone call and filled by researchers based on respondents' answers. The questionnaire sought information on:

1. Socio-demographic information of the respondents including age, gender, education level, and occupation.
2. Perception towards the quality of the premarital counseling.
3. Questions related to the reasons behind the decision of continuing/discontinuing the marriage proposal.

The study included couples, where both individuals are positive for SCD and/or β -thalassemia, irrespective of having other positive results along with it. Couples who were positive for hereditary hematological diseases like G6PD deficiency, α -thalassemia and Hemoglobin C disease were excluded. Also, females aged 50 years or older were excluded based on the average age of menopause according to the data found [16]. A positively affected/trait individual whose partners information wasn't documented was also excluded. Individuals, who did not respond, refused to participate and those with outdated phone numbers in I-SEHA were excluded from the study. Lastly, couples who were still considering their decision to go through with the marriage were excluded as well.

The Statistical Package of Social Science (SPSS) version 23 software program was used to analyze the data and produce tables and cross-tabulations. A Chi-squared (X^2) test was employed to assess the level of significance. P-value less than 0.05 were considered statistically significant.

The study proposal was reviewed and approved by the Research and Ethics Committees in both the Arabian Gulf University and Ministry of Health. A verbal consent was taken from participants,

in assurance that all information obtained will be confidential, after adequate explanation of the study aims and objectives.

Results

The study sample included 92 couples (184 individuals) identified from health centers of different geographical regions in Bahrain. The demographic data and laboratory results were obtained from I-SEHA database of Ministry of Health and analyzed as shown in Table 1. It was found that 47 out of these 92 couples continued (51.1%), while 45 (48.9%) discontinued the marriage process.

The demographic data was analyzed to find a relation between age and educational level with the marriage decision taken by the couple. In addition, the perception towards the premarital counseling and the reasons behind the marriage decision were also obtained from the 126 individuals who were interviewed.

Table 1 show that the age group 18 to 25 makes up the majority of both groups. Based on a Chi-squared test results at a significance level of 0.05, the data showed that age appears to be an independent factor when it came to the decision taken. When comparing the educational levels based on those who continued with marriage and discontinued, it was found that most of respondents had a secondary level of education. Educational level was the only significant factor, based on a p-value of 0.038. As for the type of hemoglobinopathy, most individuals had sickle cell trait.

Respondents were asked about the reasons behind their marriage decision and the question was left open ended. Some of the participants gave more than one reason, but in general, all reasons fell under six main categories for those who continued. The majority, 41 out of 64 individuals who continued (64.06%) stated that the main reason behind their marriage decision was being advanced in the relationship. Those who discontinued with marriage decision were asked the same question. Some of the respondents had more than one reason which eventually fell into five main categories. 53 out of the 62 individuals who chose to discontinue (85.48%) gave the reason of being aware of the consequences on their future children lives. Furthermore, 42 of them (67.74%) feared that it would affect their

Table 1: Demographic data and type of hemoglopinopathy of the study sample.

| Variable | Decision | | p-value |
|-----------------------------|-----------------------------------|--------------------|---------|
| | Continued N (%) | Discontinued N (%) | |
| Age category | 18-25 | 59 (62.77%) | 0.261 |
| | 26-30 | 16 (17.02%) | |
| | 31-35 | 9 (9.57%) | |
| | >35 | 10 (10.64%) | |
| Education level | Primary | 3 (3.19%) | 0.038 |
| | Intermediate | 11 (11.70%) | |
| | Secondary | 41 (43.62%) | |
| | Undergraduate | 9 (9.57%) | |
| | Graduate or Postgraduate | 27 (28.72%) | |
| Type of hemoglobinopathy | Sickle cell trait | 80 (85.11%) | 0.346 |
| | Sickle cell disease | 6 (6.38%) | |
| | B-thalassemia trait | 8 (8.51%) | |
| | Sickle cell/ β -thalassemia | 0 (0%) | |
| Total number as couple | 47 | 45 | |
| Total number as individuals | 94 | 90 | |

Table 2: Reasons given by the couples for their decision.

| | | Reasons | N | % |
|----------|--------------|--|----|-------|
| Decision | Continued | Advanced relationship | 41 | 64.06 |
| | | Availability of preventative measures | 21 | 32.81 |
| | | Unclear premarital counseling | 9 | 14.06 |
| | | Accepted the results as fate | 6 | 9.38 |
| | | Poor knowledge about the consequences of the disease | 5 | 7.81 |
| | | Family pressure | 1 | 1.56 |
| | Discontinued | Fear of the health consequences on their children | 53 | 85.48 |
| | | Fear of quality of parents' lives | 42 | 67.74 |
| | | Cost | 5 | 8.06 |
| | | Counseling advice | 5 | 8.06 |
| | | Family advice | 4 | 6.45 |

Table 3: Perception of couples towards the quality of premarital counseling in Salmaniya Medical Complex.

| | | Perception | | | |
|----------|--------------|------------|--------------|-----|----------------|
| | | Good | Intermediate | Bad | Did not attend |
| Decision | Continued | 43 | 13 | 3 | 0 |
| | Discontinued | 38 | 3 | 3 | 18 |
| Total | | 81 | 16 | 6 | 18 |
| | | 103 | | | |

quality of life (Table 2).

Finally, respondents were asked to rank their perception towards the quality of premarital counseling in Salmaniya Medical Complex, on a scale of good, intermediate or bad (Table 3). Some individuals did not attend the counseling session held in SMC. Those individuals were counseled by their primary care provider in the health center once their results were issued. This led to awareness of the health consequences that would arise from going through with the marriage decision, which made them discontinue the marital union. As a result, 103 individuals in total were referred to premarital counseling in SMC, where the majority agreed that the counseling was good, with it being the common opinion between both groups- those who continued and those who discontinued.

Discussion

Information on the couples was taken from I-SEHA to build our study population which added up to 294 individuals. Health centers were chosen based on a 2016 data representing high prevalence of sickle cell trait/disease and β -thalassemia trait/disease in health centers all over Bahrain [15]. Both partners were approached to participate in the study. Some individuals did not participate due to refusal, inconclusive contact information, or were simply unavailable. As a result, 92 couples have agreed to participate, with either one or both partners included, leading to a total number of 126 participants. 45 couples (48.9%) discontinued with the marriage process after the genetic counseling process, whereas 47 couples (51.1%) continued regardless of the outcome.

In analyzing the factors that determined the respondents' decision, it was found that only educational level has had a significant role on the marital decision. The majority of the sample population was in the age category of 18 to 25 (58%). As for the educational level, irrespective of 3 individuals with incomplete educational data, it was found that contrary to popular expectations, most of those with a

graduate degree went through with the marriage rather than not.

Participants were asked about the reasons behind their decision and being in an advanced relationship was the main motive to continue with marriage. In fact, it was not surprising to have the majority under this category, because it is known in Bahrain that couples attend the health center when family agreements have already been made and marriage arrangements were in process. It was also noted that the couples felt safe to go through with the marriage due to the availability of preventive alternatives, such as in vitro fertilization. Family judgment was a main concern for one participant to continue with the marriage as the potential partner was a relative.

On the other hand, the most common reason behind discontinuing the marriage is the fear of disease severity on children and how it would affect their quality of life. These concerns were highly attributed to the counselors' efforts in conveying beneficial information in the aim to incite an informed decision. Furthermore, other individuals were already aware of consequences and hardships accompanying hemoglobinopathies due to having previously affected family members.

One of the main objectives of the research was to explore participants' perception of the counseling part of the premarital program. Hence, respondents were asked to rate their experience as good, intermediate, or bad. It is worthwhile to note that 18 individuals did not attend for genetic counseling at SMC since they have made their decision to discontinue the marriage process as soon as they knew the results of the premarital screening. This demonstrates that the counseling sessions that were conducted at health centers have already helped them reach a decision. Moreover, 5 respondents attended the counseling at private facilities and have continued with marriage.

Overall, counseling was perceived to be good by the couples, regardless of their marital decision. There was a recurrence of certain

opinions justifying why they felt the counseling was good, most frequently being that the counselor was understanding and not judgmental of the situation. Counselors explained all the possibilities as well as alternative solutions in case couples decided to continue, rendering them well informed and confident prior to their decision taking.

For those who opted for intermediate counseling, reasons included feeling rushed and that sessions did not provide sufficient information regarding their situation. As for the 6 individuals who viewed the counseling program as bad, 3 continued regardless of their opinion towards the counseling quality. One individual stressed that the experience was very unpleasant since the counselor was not a native speaker, causing a language barrier which led to distorted communication and an oblivious couple. As for those who discontinued, they collectively agreed that the counseling experience was disappointing as they sensed the feeling of being blamed for their incompatibility, without being given additional details.

The findings of this study were similar to the results of previous studies with some notable differences. The proportion of those who continued with the marriage proposal was higher (50.8%) than that reported from similar premarital screening programs. For example, 21.05% of couples went through with their marriage proposal in the 2015 Nigerian study [17].

A Saudi Arabian study concluded that with almost half of those who continued, cultural pressure was the main reason [18]. However, in Bahrain, only one couple proceeded with the marital decision due to family pressure, since it was a consanguineous marriage. Moreover, it was also mentioned in the Nigerian study that age and educational qualifications were significant to their decision. Nevertheless, only educational level was found to be significant in this Bahraini study.

In regards to the 2009 Saudi Arabian study, only 26.5% of their population changed their decision about going through with their marriage [18]. Possible reasons for such a small percentage were brought up in a Nigerian study published in 2015, stating that both Saudi Arabian and Nigerian participants believed strongly in God's will to prevent having a child with sickle cell disease, leading them to continue with the marriage [17]. This belief was also seen in our study with some individuals supporting this opinion, even if it was not the main driving force behind their decision.

The study conducted in UAE in 2016 concluded that although the screening program was successful in identifying couples at risk, it failed in achieving its goal of discouraging high risk marriages, as all those identified continued though with the marriage [19]. Fortunately, this is not the case in Bahrain, as 48.9% of the potential couples discontinued their marriage after the genetic counseling, proving that it is a successful measure in preventing increasing incidence of inherited hemoglobinopathies in Bahrain. The fact that there was a positive response from almost half of participants clearly demonstrates the necessity of such a program as a primary preventative tool in healthcare.

According to a survey conducted in Oman in 2018, it was revealed only 14.8% of screened couples would marry their future spouse even if it made their offspring at-risk. This finding in Oman was mainly attributed to low awareness of the general population about the consequences of marriage between couples who carry genetic blood disorders [20]. However, the situation in Bahrain appears to be more related to social circumstances such as couples being in advanced

relationships rather than poor knowledge of genetic diseases.

Our speculations suggest that with further measures in promoting awareness of the society, at-risk marriages could encounter a progressive and steady decline in incidence. For example, the implementation of mandatory screening programs performed at schools could drastically help in early recognition and awareness promotion of those at risk.

Researchers encounter limitations that restrict their ability to freely gather and process information which they are seeking, potentially affecting their study's outcome. From our experience, we feel that in view of the topic's sensitivity, some couples did not want to participate. Furthermore, difficulties contacting couples due to the unavailability of an official line supported by a governmental body, some couples refused to cooperate with us.

In addition, healthcare and screening programs are never completely flawless and there are always opportunities to enhance methods and tools used, and this usually comes with experience and time. During our data collection, we recognized the eminence of having the I-SEHA database regularly updated and the importance of having all health centers in Bahrain follow the same methods of data registration.

Conclusion

The premarital screening and counseling program in Bahrain appears to be effective since 48.9% of the couples did not proceed with their marriage proposal. The plan should aim at improving the efficacy of the counseling in order to further minimize the percentage of those who continued.

Almost two thirds of the study participants thought that the quality of the genetic counseling is good. However, a room for further improvement always remains.

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