ISBN 978-93-86878-04-5
International Conference on Advances in Nursing, Pharmaceutical and Medical Sciences (ANPMS-2017)
Kuala Lumpur (Malaysia) Nov. 20-21, 2017

The Knowledge, Attitude and Perception of Saudi Adult Population on Consanguinity and Genetic Disorders

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Abstract*: *Introduction: *Consanguineous marriage has had considerable attention as a causative factor in the prevalence of genetic disorders. Several genetic disorders, congenital malformations, and reproductive wastage are more frequent in consanguineous mating's in Saudi Arabia. The aim of this study was to assess the knowledge, attitude, and perception of Saudi adult population on consanguinity and genetic disorders.*
Method: *This was an observational study using the cross-sectional study design. The data was obtained from an online survey designed to elicit self-reported information about knowledge, attitude and perception of Saudi adult population on consanguinity and genetic disorders from the various provinces and regions of Saudi Arabia in 2016.*
Result: *The self-reported online data was collected from 2024 Saudi adult citizens. A large proportion (97%) of respondents had good knowledge about consanguinity and genetic disorders. Higher education level (91%) was significantly associated ($p<0.05$) with knowledge about consanguinity; genetic disorders; premarital screening and not supporting consanguineous marriages. More females than males reported they would not continue with a marriage proposal if their premarital screening indicated risks for genetic disorders. Majority (83%) of the adults acknowledged that Saudi family tradition plays a dynamic role in the prevalence of consanguinity and related genetic disorders.*
Conclusion: *The knowledge, attitudes and perception on consanguinity and genetic disorders was adequate among the Saudi adult respondents. Consanguineous marriages and genetic disorders were prevalent in the study sample. Although the respondents acknowledge the role of family traditions in consanguinity and resulting genetic disorders, the societal norms may not recognize this as a risk factor. Therefore, there is a need to create awareness on consanguinity and genetic disorders in Saudi Arabia.*

Keywords: *Consanguinity, Genetic Disorders, Saudi Arabia, KAP, Premarital Screening*.

1. Introduction

Several factors contribute to consanguinity. These are economic and cultural factors, that encounter social and cultural isolation. In Bedouin society, the reasons given for favoring cousin marriages were clan solidarity, interpersonal compatibility, preservation of family property, parental authority, and social protection for women, first and second cousin marriages favored among most tribes in Saudi Arabia. In some areas of Saudi Arabia, the prevalence of consanguineous marriages is as high as 80.6 % [1]. A consanguineous union between second cousins or closer could lead to an inbreeding coefficient (F) of 0.0156 or higher, which indicates how likely the offspring would inherit identical genes from both parents. A high prevalence of inborn errors of metabolism and congenital malformations in Saudis is believed to result from a high rate of consanguinity, though the relationship between consanguinity and other genetic diseases awaits studies of consanguineous and non-consanguineous marriages in Saudis. Consanguineous marriages are common in many Middle Eastern countries, with first-cousin types being the most common. To cite a few examples: The reported prevalence of consanguinity in Jordan was 51.3% [2]; in Qatar, 54.0% [3] ; in the United Arab Emirates , 50.5%[4]; and in Yemen,

40% [5].In Saudi Arabia, reports from Saudi cities such as Riyadh and Dammam indicated prevalence rates of 51.3% and 52.0%, respectively[6,7]. However, El-Hazmi et al reported the first national consanguinity prevalence of 57.7%, with first-cousin marriages being the most frequent [8]. In a more recent survey of a representative sample of Saudi families defined by a multistage random sampling procedure representing both urban and rural settlements, the prevalence of consanguinity was 56%, with the first-cousin type being the most common. [9] Sickle cell disease (SCD) is endemic in certain regions of the country, with a prevalence ranging between 91 and 99 per 10,000 live births in the Eastern Province. [10,11] Similarly, there are areas of increased prevalence of Glucose-6-Phosphate Dehydrogenase (G6PD) deficiency where a prevalence of 20 per 1000 births has been reported. [12] However, apart from isolated reports, data on the prevalence of major congenital malformations are lacking. For example, although the pattern of congenital heart disease (CHD) has been reported, the prevalence remains unknown [13,14] A prevalence of infantile hydrocephalus between 0.81 and 1.6 per 1000 live births has been reported, [15,16] which is higher than most reports from other countries. Studies on the relationship between consanguinity and genetic disorders have been reported from many parts of the world. However, there are only a few reports from Saudi Arabia, [6,8] where a high prevalence of consanguinity and many genetic disorders coexist. In populations with high consanguinity rates and common inherited blood disorders, community programs for premarital screening to detect carriers of hemoglobinopathies such as thalassemia and sickle cell anemia are in progress as for example in Jordan [17] , Saudi Arabia[18], Iran [19] , Iraq [20] , Bahrain [21] and Turkey [22]. Carrier detection and genetic counseling programs have been very successful in reducing the birth prevalence of inherited disorders in some populations, such as in Iran [23,24,25] These programs are most successful when they are sensitive to the cultural backgrounds of populations in which they are applied. In Saudi society, although premarital screening to identify carrier status and the provision of appropriate counseling has tremendous potential to prevent inherited disease [26] , results from a screening program for sickle cell disease and β-thalassemia indicated that about 90% of couples in Saudi Arabia at risk of having affected children still decided to marry because of fear of social stigmatization and/or because wedding plans could not be cancelled, which emphasizes the need to conduct premarital screening well in advance of the wedding. One option to be explored is the introduction of screening during secondary school [27]. Thus, the aim of this study was to assess the KAP of Saudi adults on consanguinity and genetic disorders.

2. Methodology

This was an observational study using the cross-sectional study design. The data was obtained from an online survey with information about Knowledge, Attitude and Perception (KAP) of Saudi adult population on consanguinity and genetic disorders from various provinces and regions of Saudi Arabia in 2017.

2.1. Operational Definitions:

Knowledge: was defined as the Saudi population knowing what is consanguinity and genetic disorders from consanguineous marriages; Attitude: Saudi population attitudes toward consanguineous marriages and consanguineous genetic disorders; Perception: Saudi population perceptions on consanguineous marriages and carriers of genetic disorders; Demography was measured by Age, Gender, Education level, Income, Occupation, Marital Status, and Type of marriage; Family History of Genetic Disorders: in this study, the most prevalent genetic diseases among family members of Saudi respondents were classified as Chromosomal disorders represented by Down syndrome, single gene defects by Sickle cell disease and G6PD deficiency, whereas congenital malformations and type 1 diabetes mellitus were considered as two examples of Multifactorial disorders; Family History of Consanguinity: The numbers and patterns of consanguineous marriages as reported types: (First cousin marriage, second cousin marriage, Double first cousin marriage, marriage beyond first cousin) of the respondents and among members of their immediate family; Media: Defined as sources of situational awareness of consanguineous marriages and genetic disorders; including Television, Radio, Social media such as Twitter, Facebook, WhatsApp, YouTube and public health messages from hospitals and clinics.

2.2. Study Sample:

The study included all Saudis above 18 years from different provinces and regions in Saudi Arabia. Inclusion criteria: All Saudi adult population over 18 years of age, female and male who were willing to participant in the study after giving their informed consent. Exclusion criteria: Non-Saudi adults; Saudi teenagers and children, and those adults who were not willing to participant in the study.

2.3. Data Collection:

A structured online Questionnaire was designed with multiple choice and open-ended questions to get both qualitative and quantitative data. The questionnaire was designed to elicit demographic data; and questions to measure the KAP about effects of consanguinity and genetic disorders; and, the reasons which drive Saudi adult population to favor Consanguinity.

2.4. Statistical Analysis:

Analysis of data was done using the statistical software SPSS v21. Descriptive statistics were used to examine the distribution of each study variable individually by mean and standard deviation for continuous variables and frequency and percent for categorical variables. Comparative measures of association using quantitative variables was analyzed by correlation analysis. The measures of association were considered significant with a p-value less than 0.05.

3. Results

The study sample comprised of 2024 Saudi adults; with 60% female and 40% male participants who gave informed consent and filled the online questionnaire. A greater proportion (69%) of the participants were in the age group of 18 to 29 years, which is considered the most relevant age for planning a marriage. It was of immense value to obtain KAP measurements from this young generation on consanguineous marriages and genetic disorders in Saudi Arabia. Most participants (59%) reported to be single and about 39% were married. A prominent level of education was reported by 98% of the respondents. As presented in Table 1, much of the study sample (>90%) were aware of consanguineous marriages and its related consequences of genetic disorders in offspring. The availability of pre-marital screening in Saudi Arabia was a known fact with more than 95% of married participants reporting the use of this service offered by the Ministry of Health in KSA.

TABLE I: Knowledge & Attitude on Consanguineous Marriages Among Study Population

Factors of Consanguineous Marriages	Number (%) n=2024
Have you heard about consanguineous marriages and genetic disorders in Saudi Arabia?	
Yes	1965 (97.08)
No	59 (2.92)
TOTAL	2024 (100.00)
If YES, from where did you obtain this information about consanguineous marriages and genetic disorders? -more than one choice*	
People and Friends	1147 (56.5)
Books and education	897 (44.31)
Internet	827 (40.85)
Media	703 (34.73)
Work environment	188 (9.28)
Other	107 (5.28)
Do you know about premarital screening – *a service offered by the Ministry of Health, KSA that is used to identify genetic disorders inherited by children from their parents*?	
Yes	2008 (99.21)
No	16 (0.79)
If you are married, did you undergo the pre-marital screening? (n=444)	
Yes	423 (95.27)
No	21 (4.73)

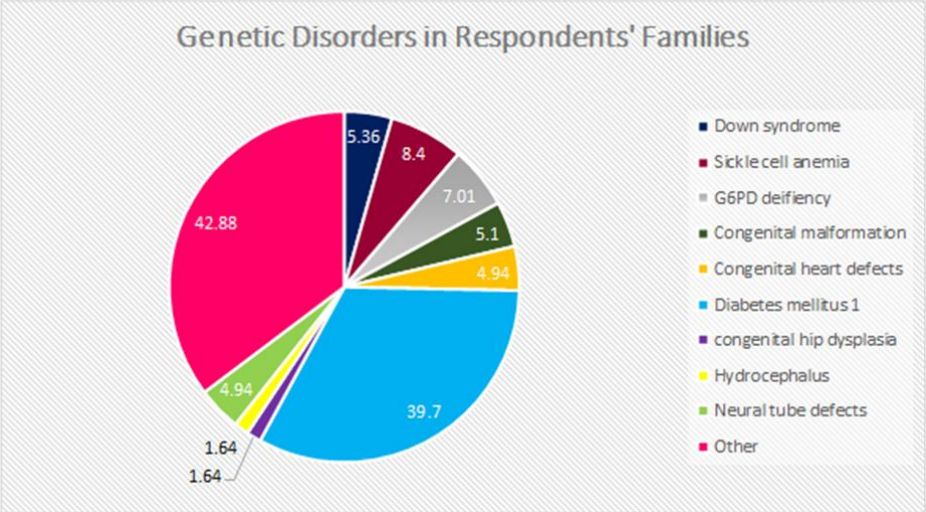

Fig 1: Genetic Disorders in Immediate Family Members as Reported by Respondents

The genetic disorders observed among family members as reported by the respondents' (Figure 1) in descending order of magnitude included, Sickle cell anemia, Glucose 6 Phosphate Dehydrogenase deficiency, Down Syndrome, Congenital malformations, Congenital heart defects, Neural tube defects and others.

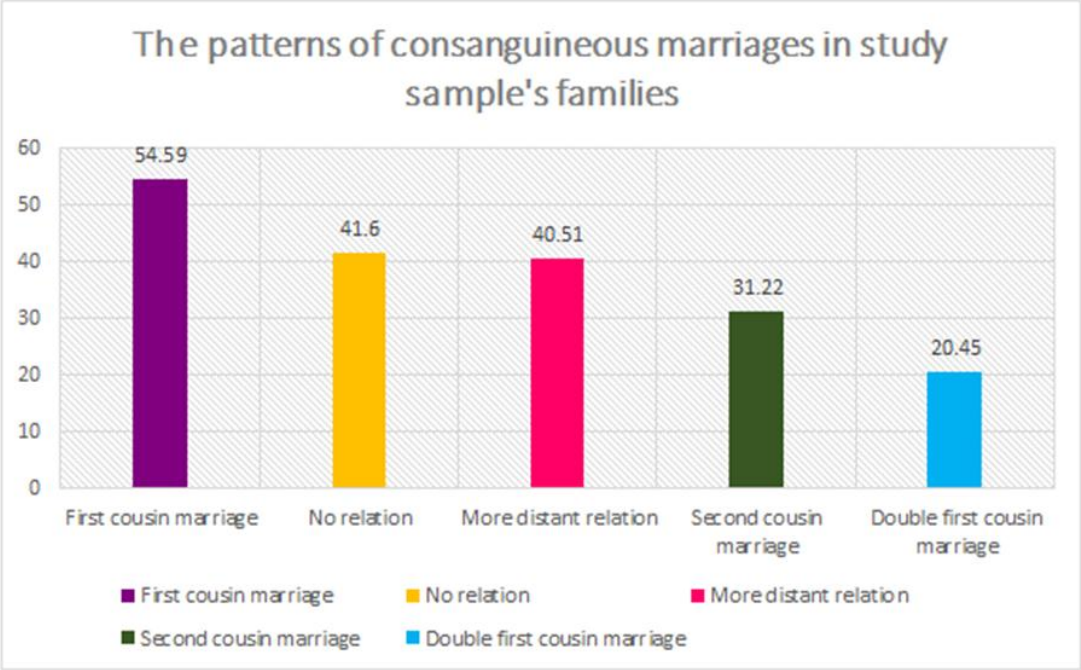

Fig 2: Several types of marriages in respondent's immediate family

First cousin marriage, was the most predominant type of consanguineous marriage, (Figure 2) followed by no relation, then the more distant relation marriage, then second cousin marriage and about 20% reported double-first cousin marriage in their immediate family.

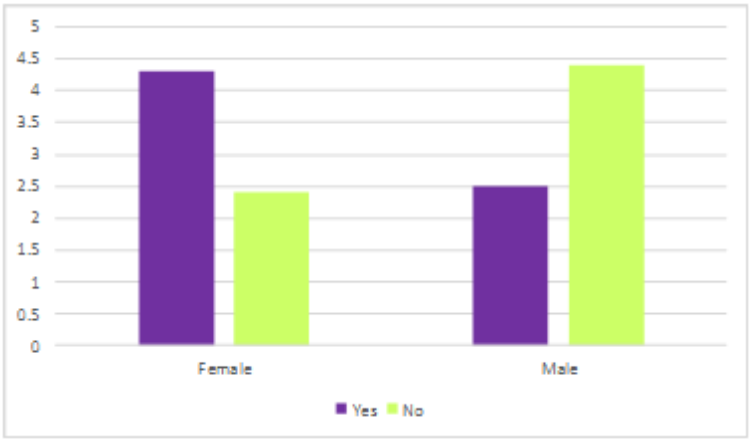

Fig 3: Association of Gender and Attitude towards a marriage that may be associated with the risk of producing children with genetic disorders.

There was a statistically significant ($p < 0.05$) difference in the responses to accept (No) or not accept (Yes) a marriage proposal that may be associated with a risk of producing children with genetic disorders among female & male respondents (Figure 3). In that, more female than male respondents reported that they will not accept a marriage proposal with an associated risk of producing children with genetic disorders.

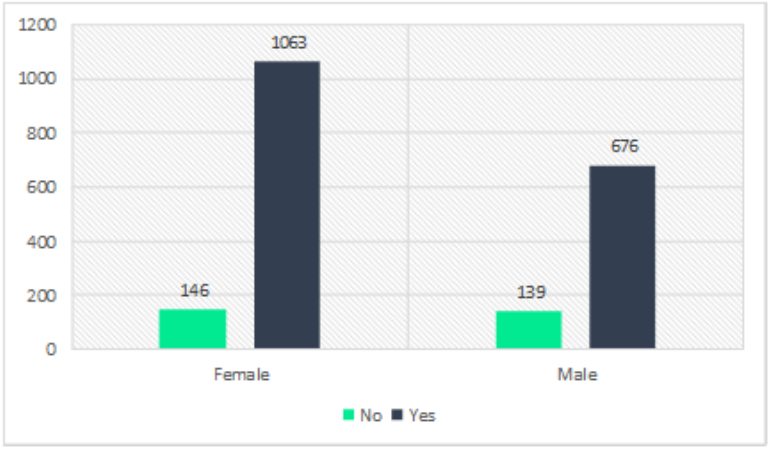

Fig 4: Do you think that families do not accept the fact that consanguinity is a risk factor for genetic disorders

There was a statistically significant ($p < 0.05$) difference in the responses of male and female participants (Figure 4) to the question of whether the respondent agrees or not, that some families do not accept the fact that consanguinity is a risk factor for genetic disorders. Also, 85% of female respondents indicated that some family tradition plays an important role in the prevalence of genetic disorders through consanguineous marriages and only 32% male participants agree.

4. Discussion

Consanguinity is a worldwide issue, but particularly so in the Middle East. Saudi Arabia was ranked as the second highest Arab country to have a high frequency of consanguineous marriage, with the prevalence varying in different studies from 22–55% [28] The data was collected from 2024 Saudi adult citizens by online survey with information about knowledge, attitude and perception of Saudi adult population on consanguinity and genetic disorders from various provinces and regions of Saudi Arabia. Most of the respondents were aware of genetic disorders caused by consanguineous marriage and premarital screening, where the most common source that respondents received their information was from friends and family's meetings. Married respondents underwent premarital screening before their marriage, while those who did not undergo premarital screening

attribute the reason to nonexistence of services in the past. A Royal decree was passed in 2003 making it mandatory for all those who plan to marry, men and woman, to take a Pre-marital screening test". [29] Diabetes Mellitus type 1 was the most common genetic disorder mentioned by respondents, while neural tube defects and Hydrocephalus less reported. It is plausible that the respondents were unaware of the technical terminologies of genetic disorders unlike Diabetes Mellitus which is common language in Saudi society due to high prevalence in Saudi Arabia. Consanguineous marriages in our study was reported to be highly prevalent among respondents' family, in that half the respondents reported more than five consanguineous marriages in their families. Elhazmi et al reported the first national consanguinity prevalence of 57.7% with First Cousin Marriage being most frequent [30] , similar to our study results that revealed First Cousin Marriage was most prevalent among the study population in Saudi Arabia. As study conducted in Morocco where most respondents had, on average, neither a positive nor a negative attitude towards consanguinity [31] In our study support for Consanguinity seemed to be decreasing in frequency among the younger generation with high educational level. Although the respondents had good knowledge about genetic disorders; and many of them do not support consanguineous marriages, the prevalence of consanguineous marriage in their families was still high. This could be attributed to the dominance of customs and traditions that prevail and support consanguineous marriages. A study conducted on Attitude of Saudi Arabian adults towards consanguineous marriage showed that Saudi men and women differ in their attitudes towards consanguineous marriage. [32] In contrast, our study results indicated that a greater proportion of females than males responded they would not continue with a marriage proposal if their premarital screening indicated risk for genetic disorders. Most of the respondents acknowledged that family tradition plays a vital role in the prevalence of consanguinity and genetic disorders and thereby refusing to acknowledge the fact that consanguinity is a known risk factor for genetic disorders in Saudi Arabia.

5. Conclusion

The knowledge, attitudes and perception on consanguinity and genetic disorders was adequate in this group of Saudi adults. Consanguineous marriages and genetic disorders were prevalent in the study sample. There is a need for more awareness on consanguinity and genetic disorders in Saudi Arabia.

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