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What should be the focus of counseling in parental consanguinity: genetic disorders or underlying beliefs

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Dear Sir,

The consanguineous union is one of the cultural related events worldwide, particularly in low-income countries [1, 2]. Depending on cultural, legal, and religious background, the prevalence of consanguinity ranges from less than 1% in American countries to over 50% in the Middle East. More precisely, its prevalence is estimated to be between 20% and 50% in the Middle East and in Northern Africa; 1 to 5% in Southern Europe, South America, and Japan; and less than 1% in Western Europe, North America, and Oceania [3]. One of the consequences of this type of marriage is the occurrence of genetic disorders or congenital malformations in the offspring of parents. In a retrospective study, Siong and colleagues [4] investigated the characteristics of parental consanguinity in multi-ethnic groups ($n = 56,657$ fetuses) and its effects on health outcomes. In that study, 0.6% of fetuses were conceived by consanguineous parents. Of those, 85% were Pakistani, 6.2% were Indian, 2.7% were Nepalese, 0.4% were Filipino, and 0.04% Chinese. More than 76% of all consanguineous unions were categorized as first cousins. The authors did not find any significant differences between the consanguineous group and the non-consanguineous control group in terms of education and religion. However, pre-eclampsia was significantly higher in the consanguineous group than those of the non-consanguineous group (4.2% vs 1.2%; $P = 0.02$). Of remarkable findings of this study were that during their previous pregnancy, women in the consanguineous group had a significantly higher rate of congenital abnormality, fetal demise, and neonatal death than those of the non-consanguineous group [4].

Consanguineous marriages can increase the financial, physical, and psychological burden of congenital defects and genetic disorders [1]. A study showed that offspring of consanguineous couples had a more than 4 times higher risk of having congenital anomalies, compared with those of non-consanguineous couples. In addition, parental consanguinity significantly increased the risk of developmental delay, autism, and the prevalence of structural malformations such as cardiovascular, musculoskeletal, and urological systems compared with non-consanguineous couples [4]. In addition, consanguineous marriage is found to be associated with an increased risk for autosomal recessive diseases [5], such as beta-thalassemia major [4, 6], cystic fibrosis, and Tay–Sachs disease [6], a deficiency of hydrolase β -hexosaminidase. Given the excessive burden of genetic and congenital diseases on the family and society, therefore, premarital or preconception counseling programs are an indispensable necessity for consanguineous couples. However, the question is what the focus of this consultation should be: genetic counseling or counseling to change couples' attitudes and beliefs.

Over the past years, many marital researchers and maternal health centers have focused on preventing consanguineous unions to reduce congenital anomalies. Nevertheless, these unions are still carried out in the world [1], especially in Asian and African countries. One of the biggest challenges in this regard is that these unions are highly dependent on the cultural context, educational background, and individuals' preferences [1]. It is believed that in most cultures, many young individuals may not prefer to marry a cousin; however, their parents choose a cousin as a spouse for them [7]. In addition, previous studies showed that many young individuals have a negative attitude to marrying a cousin for religious reasons, not for genetic defects of their offspring [7]. Furthermore, cousin marriage was considered to prevent the division of family property and to preserve the unity of family [5, 7, 8].

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Although several attempts have been made to prevent this type of marriage, existing literature shows that most of the parental counselling is regard to the genetic counseling [8] and limited attempts have been made to change the attitudes of couples. In a semi-structured interview study, Shiloh et al. found that more than 70% of the consanguineous couples who received premarital genetic counseling married their relatives. These couples perceived consanguinity as an ordinary form of marriage and had satisfactory attitudes towards it [9].

Undoubtedly, reducing these marriages can reduce the incidence of congenital defects and their burden on society. The main message of this article is that pre-marriage counseling should be more serious about changing attitudes and beliefs about preventing family marriage. Couples should be made more aware of congenital malformations and their burden on the family. Health authorities should be more responsible for designing and implementing premarital preventive counseling programs. In this respect, informing men and women early in life about the dangers of the consanguineous union can provide a platform for changing their attitudes toward this type of marriage. Certainly changing people's beliefs and attitudes is difficult, particularly in Asian countries; however, diagnosis and treatment of congenital defects are more difficult for health systems, families, and the community. Thus, along with genetic counseling, people should be counseled to change their attitudes and beliefs before marriage age in a gradual and progressive process. Thus, informing cousins about the dangers of the consanguineous union will be an important step to reduce the incidence of consanguinity-related congenital defects. As a last resort, like developed countries, a specific set of rules need to be established to prevent such marriages.

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