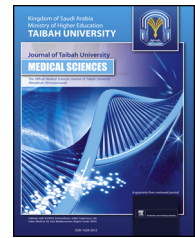




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Letter to the Editor

The need for population-based studies to estimate the rate of consanguinity in Almadinah Almunawwarah



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Dear Editor,

The term ‘consanguinity’ refers to the marital relationship between two people with common ancestors, i.e., those genetically related by descent. Such marriages constitute a high level of inbreeding, resulting in a high incidence of autosomal recessive genetic disorders in human populations.^{1–6}

Several publications suggested that the rate of consanguinity is very high in the Kingdom of Saudi Arabia (KSA), which may be the cause of the relatively high incidence of various genetic diseases there.^{1–5} The rate of consanguinity varies not only from one population to another but also in different geographic regions of a country, such as the KSA.^{1,5–11} While the lowest rate of consanguinity has been reported to be <0.5% in European populations, it varies from 10.6 to 67.7% in the Middle East^{1–5,12–16} with KSA showing the highest. El-Hazmy et al.¹ mapped the certain areas of the KSA, which indicated regional variation in the prevalence of consanguinity, with the North-western Province (Khaibar, Makkah and Taif) showing the highest rate (67.7%). However, this study did not specifically analyse the rate of consanguinity in the Almadinah Almunawwarah region, which is believed to have a substantial tribal population, with large families descended from common ancestors and migrant families originating from diverse ancestries, some of whom tend to form minority groups with high consanguinity rates. According to a few reports, the rate of consanguinity (approximately 60–67%) appears to be high in the Almadinah Almunawwarah area;^{14,17,18} however, based on undocumented observations, this region is perceived to have one of the highest consanguinity rates in the KSA. There is certainly a lack of published population-based data to confirm this notion. In fact, the consanguinity rate has been reported to be much higher (>80%) in smaller rural areas in other provinces in the KSA.^{1,14} For example, the Samtah area in the South-Western Province

of the KSA reportedly has a consanguinity rate as high as 86.6%.¹ Additionally, the urban areas have consistently shown lower rates of consanguinity when compared to other regions in the KSA and to other Arab countries.^{14,19–22} The two reports^{17,18} on consanguinity rates in Almadinah Almunawwarah were based on information from selected groups of subjects; these reports certainly did not draw on population-based studies that were designed to generate data that considered the urban and rural origins of the studied populations or their educational, socio-economic and ethnic backgrounds, nor did they identify the specific areas of Almadinah Almunawwarah with the highest or the lowest rates of consanguinity. Furthermore, in some Arab countries, the higher levels of women’s education has reportedly resulted in a decline in the consanguinity rates.^{22–26} With the establishment of two major universities in Almadinah Almunawwarah, both men’s and women’s education levels have increased, but their impacts on consanguinity rates, if any, will not be known until new studies are conducted to address these issues.

An observation of an extremely high incidence of juvenile diabetes in the Almadinah Almunawwarah region¹⁷ has led some to assume that other genetic diseases in this ‘believed to be’ highly consanguineous population may also be very common. However, the paucity of unbiased reports and population-based studies on the consanguinity rate and the prevalence of various genetic diseases in the Almadinah Almunawwarah region make establishing their connections based on quantitative estimates difficult.

In a study of only 600 Saudi women (421 university students and 179 women attending outpatient clinics), Warsy et al. (2014) addressed the potentially declining rate of consanguinity in the Saudi population, as in some other Arab countries, due to increasing education and awareness of the connection between consanguinity and genetic diseases.¹⁹ These authors could not find a decline in the rates of consanguinity in this study population. Larger population-

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based and unbiased studies are clearly needed to uncover the actual trends in consanguinity rates in different regions of the KSA. For such studies, Almadinah Almunawwarah would be an ideal context for two reasons. First, a tribal population adheres to the practice of cousin marriage; second, the classification of groups with varying socio-economic and ethnic backgrounds and education levels and the increasing adoption of the urban lifestyle offer an opportunity to analyse the impact of these factors on the prevalence of consanguinity in different sectors of the population over time.

In any case, to prioritize the research efforts on important diseases that aim to provide both therapeutic and preventive measures to minimize the burden of genetic diseases in the Almadinah Almunawwarah population, it is imperative to generate population-based data on the relationship between the rate of consanguinity and the prevalence of genetic diseases as well as changes in such trends due to any identifiable factors in the region as a whole and its specific districts. Taibah University has established a Centre for Genetics and Inherited Diseases (CGID) in Almadinah Almunawwarah with three main goals (i.e., research, education and services) that aim to generate and translate data into action for the benefit of the population. Generating reliable information on relationship between the prevalence of consanguinity and the pattern of genetic diseases in Almadinah Almunawwarah region is the most important step towards planning and prioritizing appropriate projects for CGID to achieve its goal of improving the genetic health of its population. In addition, the government has also recognized the impact of consanguinity on genetic diseases and has emphasized the importance of premarital screening.²⁷

As such, we feel that there is an urgent need to conduct unbiased, population-based studies that address multiple factors such as demography, family origin, marital relationship (first-, second- or distant-cousin marriage), education and socio-economic background to estimate the consanguinity rate and its changing patterns, if any, in the population of the different districts of Almadinah Almunawwarah. The significance of such studies lies in the usefulness of the new data in determining the actual trends in consanguinity rates and the impact of any modifying factors, thus developing registries for the relationship between consanguinity and the prevalence of genetic diseases and prioritizing research and education strategies to control genetic diseases in the population of Almadinah Almunawwarah.

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