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RESEARCH ARTICLE

Consanguinity rates among Syrian refugees in Lebanon: a study on genetic awareness

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Abstract

Consanguineous marriage is a deeply rooted tradition in the Arab world. Such marriages are linked to higher rates of recessive genetic diseases. During the Syrian conflict, which started in 2011, around one million Syrian individuals became refugees in Lebanon. This study assessed the consanguinity rates among Syrian refugees living in Lebanon up to three successive consanguineous generations, and examined refugees' awareness of the possible consequences of consanguineous marriage and their attitudes towards consanguinity. Their knowledge of, and access to, premarital screening was also assessed. The study was conducted between January and May 2018. Several study sites representing refugees' distribution within the country were chosen. The study sample included 1008 interviewees from different families. Of those interviewed, 51.9% were in a consanguineous marriage. Interestingly, 23.9% were the product of consanguineous marriages themselves, and 17.9% were consanguineous for three successive generations. The interviewees generally knew about premarital screening, but the majority (61.9%) had not had the screening. The high rates of consanguinity in these Syrian refugees call for immediate action, including raising genetic awareness and providing appropriate genetic counselling. Despite the respondents' familiarity with premarital screening, there was a low rate of uptake of the test, underscoring the importance of providing better education to these refugees.

Keywords: Consanguinity; Genetic Counselling; Refugees

Introduction

The word 'consanguineous' comes from the Latin *con* meaning common and *sanguineous* meaning blood. Consanguinity in its most literal sense refers to the relationship between two people sharing the same blood or having a common ancestor. It has been agreed among clinical geneticists that the definition of a consanguineous marriage is one between two individuals who are second cousins or closer (Bittles, 2001).

Unlike Western populations, consanguineous marriages are common in North Africa, West Asia and South India accounting for 20–50% of marriages, with Arab countries displaying one of the highest rates (Tadmouri *et al.*, 2009). Among these marriages, first cousin marriages have the highest percentages, averaging close to 20–30% (Tadmouri *et al.*, 2009). The limited reports on

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[†]This article was originally published with a spelling error in the name of author Abdul Rahman Akkawi. This has now been corrected and a corrigendum published at https://doi.org/10.1017/S0021932022000499.

consanguinity rates in the Arab countries show variable results and discrepancies in some of these countries. For instance, rates range from 12.8% to 48% in Lebanon, 22% to 67.5% in Syria, 42.1% to 66.7% in Saudi Arabia, 28.5 to 63.7% in Jordan and 20.9% to 80.4% in Egypt; in Qatar the rate is 54%, while in Oman it is 56.3% (Tadmouri *et al.*, 2009). The percentage ranges are distinctively dependent on the areas/regions where the studies were carried out in each country.

There are several social, cultural, psychological and economic factors that favour consanguineous marriages within the Arab population. Consanguineous marriages are thought to strengthen family bonds, maintain marital stability, strengthen familial/tribal relationships with in-laws and reduce dowry (Al-Farsi *et al.*, 2014). Additionally, such marriages maintain family property and assets within the same group of people and offer more financial security. It is generally believed that a couple will be more compatible if they are related, as they will have the same cultural values and traditions (Al-Farsi *et al.*, 2014). As for religious factors, although the percentage of consanguinity is higher among Muslims, Islam does not encourage consanguineous marriage, with consanguinity pre-dating Islam and considered a deeply embedded Arab tribal tradition (Hamamy, 2012). Consanguinity rates have, however, been decreasing in some Arab countries such as Lebanon and Jordan due to increased levels of education, the majority of the population residing in urban areas, enhanced financial and economic situations, as well as increased awareness of the population on the health consequences of consanguineous marriages (Hamamy *et al.*, 2011).

Couples who are planning to get married can undergo premarital screening to test for common genetic blood disorders present in a country, such as haemoglobinopathies, and infectious diseases such as hepatitis B and C. It is used to determine whether individuals are at increased risk of transmitting genetic diseases to their offspring (Bener *et al.*, 2019). This screening, coupled with genetic education, is expected to reduce the burden of these genetic diseases. The effectiveness of premarital screening is highly dependent on governmental policies and the level of education and counselling offered to couples (Alswaidi & O'Brien, 2009), and is aimed at reducing the financial burden of the genetic diseases, which tend to be chronic and require high-cost, lifelong treatment. The tests have been mandated by the Lebanese and Syrian governments before marriage, without which a couple is unable to receive an official marriage certificate. Couples have to pay for the tests as these are not covered by governmental health care services.

Within the context of the Syrian Arab Republic, only two studies have previously looked into the rate of consanguinity within its population. The prevalence of consanguineous marriages in Syria was last studied in 2008, three years before the beginning of the Syrian conflict. The overall frequency was 35.4%, with great variability across provinces, as the rates ranged from 22% in Latakia province to 67.5% in Al Raqqa province. Similar to other Arab countries, first cousin marriages were the most common, followed by double first cousin and second cousin marriages (Othman & Saadat, 2009). There are no current data available on the rates of consanguineous marriages in Syrian refugees after the beginning of the Syrian conflict in any of the countries hosting Syrian refugees.

The Syrian conflict began in 2011, and in 2019 there were an estimated five million Syrian refugees displaced outside of Syria (Inter-Agency Coordination Lebanon, 2019). Among these, in 2019 an estimated 1.5 million Syrian refugees resided in Lebanon, but fewer than one million were officially registered (United Nations, 2019). In Lebanon, around one-third of refugees resided in the Beqaa region, a quarter in Beirut (the capital), a quarter in the North of Lebanon and one-tenth in the South of Lebanon.

This study aimed to assess the levels of consanguinity in Syrian refugees in Lebanon ascending up to three generations, awareness about the link of consanguinity to certain diseases, social factors affecting consanguinity and the perspective of individuals on the advantages and disadvantages of consanguinity, as well as premarital screening. The results should inform organizations in their attempts to improve awareness, health situation, education and other aspects of the lives of the Syrian refugees, which is particularly important as almost 20% of Syrian

refugees worldwide reside in Lebanon (United Nations, 2019). This is relevant to Syrian refugees in Lebanon, but also those in the rest of the world, as these will belong to similar social and economic groups and thus have similar behaviours and attitudes towards consanguinity.

Methods

Design and setting

This was an observational, cross-sectional, community-based research study. To ensure the sample was representative of Syrian refugees in Lebanon, interviews were performed in several areas to reasonably represent the distribution of refugees throughout the country. These included Beqaa, the South and the Beirut governorates of Lebanon. Interviews took place in aid or medical centres visited by refugees from different backgrounds and for distinct purposes. Each centre provides either socioeconomic aid or medical services in different sub-specialties. The visited centres were: Aid Centre Beqaa (Beqaa), Nazih Bizri Centre for Primary Health Care (South), Al-Bounian Medical Centre (South) and Al-Kayan Centre (Beirut).

Sample

The interviewed sample of individuals consisted of Syrian refugees currently residing in Lebanon. The working definition of a Syrian refugee, for the purposes of this study, was a Syrian individual who had entered and stayed in Lebanon after the beginning of the Syrian conflict. Marking an exact date for the beginning of the Syrian conflict might be challenging, so June 2011 was used as an estimation for the study. The inclusion criteria for respondents were: (a) aged 18 years or above and (b) able to provide verbal consent.

Data from the United Nations High Commissioner for Refugees (UNHCR) office in Lebanon, the WHO and the Lebanese Ministry of Public Health were collected and merged to form the sampling frame. The cluster sampling probability method was used because different centres – specifically those that see more than a hundred Syrian refugees a day – in the Beqaa, South and Beirut governorates featured as clusters. One of the clusters was randomly chosen, and the site was visited on several occasions at different times, and the visitors of those centres were interviewed on each visit. The refugees visited the centres only once, which prevented redundancy in the collected data. This ensured the diversity of the captured strata in the study, in terms of sex, employment, age and place of origin in Syria. The total sample size was 1008 individuals, with around half of the participants currently residing in Beqaa, a quarter living in the South and a quarter living in Beirut; this distribution roughly represented the distribution of Syrian refugees living in Lebanon at the time of the study.

Study instrument

Data were collected using an anonymous questionnaire written in English and translated into simple Arabic, the main language of the target population. The questionnaire was initially validated on a small sample of individuals to assess its clarity and relevance. It was then administered by trained members of the research group in face-to-face interviews with refugees.

The questionnaire was divided into three parts. The first part consisted of questions about the interviewee's demographic characteristics, including their age, education level, residential area in Syria, marital status, consanguinity and number of siblings and children. The second part included questions on the refugee's knowledge and awareness of genetic diseases in their family and about their understanding of consanguineous marriage's potential genetic sequelae and on genetic awareness in general through open-ended questions. Finally, the third part assessed the refugee's knowledge of premarital screening and their access to this.

Two forms of the questionnaire were used: the first was addressed to married, divorced and widowed individuals while the second was addressed to the single participants. The main difference between the two forms was that, in the second questionnaire, the single participants were asked about their attitude towards consanguinity and premarital screenings, rather than being in a consanguineous marriage or whether they had had premarital screening.

Data collection

After obtaining the approval of the American University of Beirut Institutional Review Board, as well as the approval of each of the involved centres, several visits to refugee centre took place for data collection. Random individuals were approached on each visit. The participants were assured that their participation was completely voluntary and that the services provided by each centre would not be affected by their choice to participate in the study. After obtaining an individual's verbal consent, the questionnaire was conducted in a private setting. It was first ensured that the interviewee was at least 18 years old at the time of the interview, and that s/he had been residing in Lebanon for less than 7 years (after the start of the Syrian conflict). All interviews took place between January and May of 2018.

Data analysis

Data were categorized for analysis. For those in consanguineous marriages, the degree of family relatedness was categorized as: 1) married to first cousins, either from their mother's or their father's side, and 2) married to second cousins, either from their mother's or their father's side. Those married to a more-distant relative were not considered consanguineous. As for successive consanguinity in multiple family generations, three categories were defined: (1) those who were themselves consanguineous, while their parents were *not* consanguineous; (2) those who were consanguineous up to the second generation, meaning they and their parents were consanguineous, while their grandparents were not; and (3) those who were consanguineous up to the third generation, meaning they, their parents and at least one set of grandparents were all consanguineous.

Data analysis was done using SPSS Version 22.0 (SPSS Inc., Chicago, IL, USA). The information collected fell into two categories: (1) respondents' basic demographic characteristics, and (2) respondents' knowledge of and attitude towards both consanguineous marriages' association with genetic diseases in offspring and premarital genetic screening. The data were thus analysed using: (1) descriptive statistics, to describe the sample's demographic characteristics and (2) Pearson's chi-squared test, to measure the different associations between the respondents' characteristics and the outcomes studied in relation to consanguinity and premarital screening (two-tailed test for statistical significance with $\alpha=0.05$).

Patient and public involvement

Patients were not included in the study. However, the study was conducted with the intention of distributing the results of the project and recommendations to the centres where data collection took place.

Results

The socio-demographic and geographic distribution of the 1008 Syrian refugees in the study sample (from different and unrelated families) is shown in Table 1 with stratification by sex. The majority of the interviewed participants were female (84.4%), and 89% were married. The mean age of the interviewees was 34 years, and their mean age at marriage was 19.4 years. Around a quarter (23.8%) had no education, another quarter (22.4%) had only an elementary school education, the majority (34.8%) had a middle school education and smaller percentages had high

Table 1. Socio-demographic and geographic characteristics of the sample of Syrian refugees living in Lebanon, 2018

Characteristic	Total (N=1008) % (n)	Females (N=841) % (n)	Males (N=167) % (n)	p-value[a]
Age				
18–25	26.9 (271)	27.3 (230)	24.6 (41)	
26–35	34 (343)	34 (286)	34.1 (57)	0.783
36–45	23.6 (238)	23.1 (194)	26.3 (44)	
Above 45	15.5 (156)	15.6 (131)	15 (25)	
Level of education				
No education	23.8 (240)	26 (219)	12.6 (21)	
Elementary school	22.4 (226)	21.6 (182)	26.3 (44)	0.003
Middle school	34.8 (351)	34 (286)	38.9 (65)	
High school and above	19 (191)	18.3 (154)	22.2 (37)	
Residence in Syria				
Urban	42.5 (428)	42.1 (354)	44.3 (74)	0.39
Rural	57.5 (580)	57.9 (487)	55.7 (93)	
Marital status				
Married	89.0 (897)	90.7 (763)	80.2 (134)	
Single	7.2 (73)	5.2 (44)	17.4 (29)	0.45
Divorced	1.7 (17)	1.7 (14)	1.8 (3)	
Widowed	2.1 (21)	2.4 (20)	0.6 (1)	
Location in Lebanon				
Beirut	16.2 (163)	13.1 (110)	31.7 (53)	
Beqaa	51.1 (515)	55.4 (466)	29.3 (49)	0.55
North	0.1 (1)	0.12 (1)	0	
South	32.5 (328)	31.3 (263)	38.9 (65)	

[a]Comparison between males and females.

school (12.9%) and higher education (6.1%). The average number of years spent in Lebanon was 4.3 years. Figure 1 shows the distribution of the interviewed Syrian refugees based on the provinces they came from in Syria.

One of the primary objectives of the study was to determine the consanguinity prevalence in the Syrian refugee population in Lebanon, taking into account successive generations of consecutive consanguinity. In the sample population, the rate of consanguinity was 51.9% (Table 2). Of these, 68.1% were first cousin, while 31.9% were second cousin marriages. Interviewees were not specifically asked about double first cousin or first cousin once removed marriages. Taking it a step further, consanguinity across different generations was assessed among those with consanguineous marriages: 23.9% were consanguineous for two successive generations, and 17.9% were consanguineous for three successive generations (Fig. 2). There was no significant difference in the consanguinity rates of respondents originating from urban and rural areas of Syria (p=0.095). Consanguinity rates were reported to be highest in refugees residing in Beqaa but were not significantly different from those living in Beirut or the South (p=0.627). Also, there was no significant change in consanguinity rates after the beginning of the Syrian conflict, when compared with rates before the conflict (p=0.23). However, factors that did affect the presence of consanguinity were age of
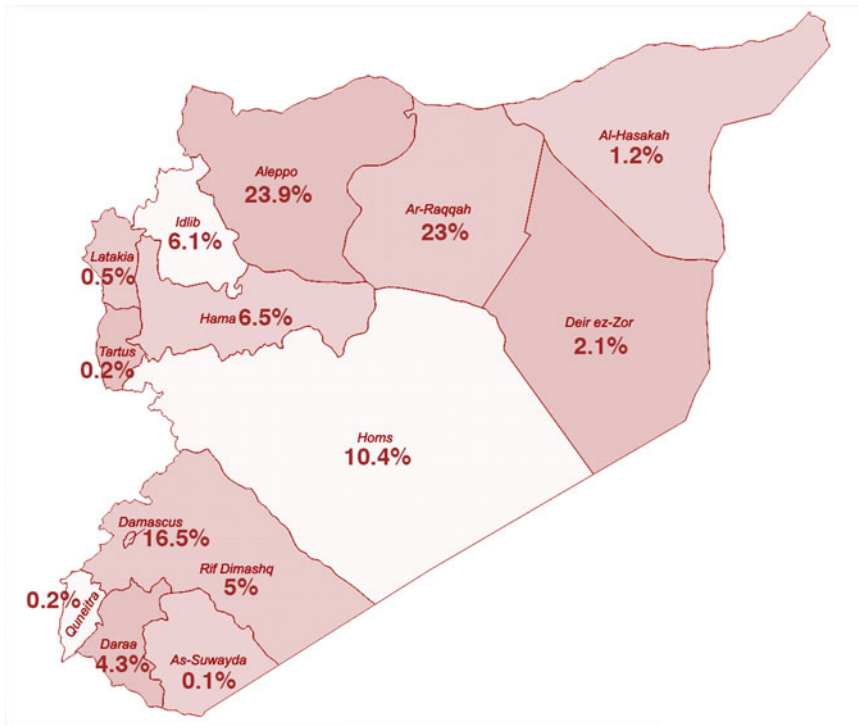
Figure 1. Distribution of Syrian refugees according to the provinces they came from in Syria.

marriage and level of education. Consanguinity rates were significantly higher among individuals who were married at a younger age (<18 years, $p=0.008$) and those with a lower level of educational (less than high school, $p=0.006$). In addition, the majority of interviewed individuals reported consanguineous relationships in the family (80.3%), with more than half of them having siblings and cousins with consanguineous marriages. It was found that individuals were more likely to be in a consanguineous marriage if they came from families with a history of at least one consanguineous marriage ($p<0.001$).

Table 3 shows the attitudes of the interviewed refugees towards consanguineous marriages, with an emphasis on the differences between the sexes. Almost 40% of the participants reported at least one advantage associated with consanguinity, stating that a consanguineous marriage was either a safer option, a more stable marriage in agreement with their traditions or better for keeping wealth within families. On the other hand, the majority of the participants reported at least one disadvantage (71.2%) of consanguineous marriages. Most of the reported disadvantages had to do with genetic diseases and congenital abnormalities. Almost half of the interviewed refugees (49.4%) were against consanguineous marriage, a quarter (26.1%) were supportive and the rest (24.5%) had a neutral opinion.

The second part of the study dealt with the refugees' knowledge of the premarital screening test, and the results of the posed questions are displayed in Table 4. Although the vast majority of refugees had heard of the screening test (90.2%) – primarily from the community (72.4%), a medical doctor (12.0%) or marriage courts that mandate the test (11.1%) – only a third had had the test. For those who had not been screened (68.2%), the primary reason was that they had not heard of the test at the time of their marriage (61.4%). As for individuals who had had the test (31.8%), they did so mostly because the marriage court required them to do so before issuing a marriage certificate (34.2%), or for the couple to check blood compatibility before the marriage (16.8%). Getting married in Lebanon was found to be significantly positively associated with having had the premarital screening test compared with getting married in Syria ($p=0.043$).

Table 2. Characteristics of Syrian refugees living in Lebanon with consanguineous marriages

Characteristic	% (*n*)	*p*-value
Overall consanguinity prevalence	**51.9 (485)**	
Degree of relationship		
First cousin	68.1 (330)	
Second cousin	31.9 (154)	
Consanguinity in consecutive generations		
Couple alone	58.1 (282)	
Couple and parents	23.9 (116)	
Couple, parents and grandparents	17.9 (87)	
Consanguinity in different strata	% Consanguineous from total in each category (*n* consanguineous)	
Residence in Syria		
Urban (394)	48.7 (192)	0.095
Rural (540)	54.3 (293)	
Residence in Lebanon		
Beqaa (488)	53.3 (260)	0.627
South (311)	51.1 (159)	
Beirut (133)	48.9 (65)	
Marriage date		
Before Syrian conflict (602)	53.3 (321)	0.23
After Syrian conflict	49.2 (163)	
Marriage age		
<18 (342)	57.6 (197)	0.008
≥18 (593)	48.6 (288)	
Marriage location		
Syria (789)	52.7 (416)	0.325
Lebanon (139)	48.2 (67)	
Level of education		
No education (230)	52.2 (120)	
Elementary school (211)	59.7 (126)	0.006
Middle school (322)	52.2 (168)	
High school or above (171)	41.5 (71)	
Consanguinity in the family		
Yes (750)	56.4 (423)	<0.001
No (184)	33.7 (62)	

Table 3. Attitudes towards consanguinity among Syrian refugees in Lebanon, *N*=1008

Attitude indicator	Total % (*n*)	Females % (*n*)	Males % (*n*)	*p*-value[a]
Reported advantage	38.5 (382)	37.6 (316)	39.5 (66)	
Safety	23.3 (235)	23.4 (197)	22.8 (38)	
Stability	22.8 (230)	22.8 (192)	22.8 (38)	0.523
Tradition	9.4 (95)	8.3 (70)	15.0 (25)	
Maintains wealth	3.5 (35)	3.0 (25)	6.0 (10)	
Other	13.2 (133)	12.4 (104)	19.2 (32)	
Reported disadvantage	71.2 (718)	71.9 (605)	67.7 (113)	
Genetic diseases/congenital abnormalities	58.8 (592)	59.1 (497)	56.9 (95)	0.265
Problems in family	16.4 (165)	17.6 (148)	10.2 (17)	
Other	13.3 (134)	12.5 (105)	18.0 (30)	
Attitude towards consanguinity				
For	26.1 (260)	25.4 (211)	29.3 (49)	0.142
Against	49.4 (493)	50.8 (423)	41.9 (70)	
Neutral	24.5 (244)	23.8 (198)	27.5 (46)	
Reported advantage and consanguinity				
Consanguineous respondents	49.2 (239)	49.1 (199)	53.3 (40)	0.385
Non-consanguineous respondents	26.9 (121)	27.6 (105)	26.7 (16)	
Reported disadvantage and consanguinity				
Consanguineous respondents	64.7 (314)	65.9 (269)	58.4 (45)	0.896
Non-consanguineous respondents	78.8 (354)	77.8 (302)	85.2 (52)	

[a]Comparison between males and females.
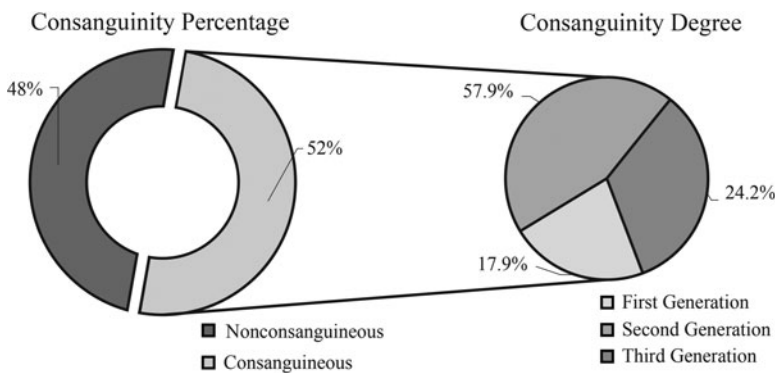
Figure 2. Consanguinity among the sample of Syrian refugees across the different generations.

Discussion

Establishing consanguinity rates and the assessment of knowledge of premarital screening tests are highly important in Arab country settings, where the prevalences of recessive diseases are particularly high (Al-Gazali *et al.*, 2006). To date, no studies have been performed to determine the

Table 4. Knowledge of, and attitudes towards, premarital screening among Syrian refugees in Lebanon, $N=1008$

Characteristic	% (*n*)
Knowledge of premarital screening	90.2 (894)
Knowledge source	
Community	72.4 (643)
Doctor	12.0 (106)
Court	11.1 (99)
TV or radio	2.6 (23)
Social media	1.9 (17)
Had had premarital screening	31.8 (292)
Location of screening	
Syria	83.1 (231)
Lebanon	16.9 (47)
Reason for having screening	
Court	34.2 (100)
Doctor	16.8 (49)
Reason for not having screening	
Lack of knowledge at time of marriage	61.4 (341)
Married regardless of result	20.4 (113)
Didn't know where to do it	4.1 (23)
Worried about expense	2.2 (12)
Didn't trust result	0.7 (4)
Other	11.2 (62)
Location of marriage and having premarital screening	
Syria	30.7 (236)
Lebanon	39.6 (53)

rates of consanguinity among Syrian refugees. Several million people have left Syria to other neighbouring Arab countries, as well as to several European and American countries, since the start of the Syrian conflict in 2011. Thus, it is of utmost importance to study consanguinity among these populations, and the diseases specific to certain populations, as well as individuals' attitudes towards these issues, in order to provide refugees worldwide with the best care possible.

In the present study, 1008 Syrian refugees residing in different areas of Lebanon and originating from several regions in Syria, each from a different family, were interviewed. The overall consanguinity rate among the respondents was 51.9%. This is higher than the consanguinity rate reported in Syria in 2009 (35.4%) 2 years before the beginning of the conflict and could be due to the interviewed refugees being from lower socioeconomic classes (Othman & Saadat, 2009).

One of the primary aims of the present study was to assess the degree of consanguineous marriages across successive generations of refugees, since consanguinity limits the genetic pool and can predispose families to a higher risk of certain recessive conditions. Moreover, to the authors' knowledge, the significance of successive consanguinity among multiple generations within the same

families has not been studied. In this study, around 25% of those who were consanguineous had parents with a consanguineous relationship, and at least 17.9% of those who were consanguineous had both parents and grandparents with a consanguineous relationship; many of those interviewed could not recall the relationship of their grandparents. Interestingly, the genetic skin diseases clinic at the American University of Beirut Medical Center has not encountered two or three recessive diseases simultaneously in the children of partners who are consanguineous and who themselves are the product of consanguineous marriages (personal communication, data not shown).

In the study sample, individuals' level of education was significantly associated with the rate of consanguinity, with consanguinity being higher in individuals with a lower level of education. This might shed light on the effect of higher levels of education and its influence on the better understanding of the sequelae and risks of consanguineous marriages (Kerkeni *et al.*, 2006; Tadmouri *et al.*, 2009).

Another factor that appeared to make it more likely for an individual to marry a relative was having at least one family member in a consanguineous marriage. This possibly reflects the influence the family has on an individual's choice of partner and the deeply embedded cultural behaviours present in the family in Syrian society. Additionally, consanguinity was more likely in individuals who married before the age of 18, as seen in a previous study conducted in Pakistan (Hussain & Bittles, 1999). This emphasizes the aforementioned effects of both education and family pressures, as younger individuals – especially under the age of 18 – might not only lack the understanding of transmission of hereditary diseases but also be more prone to the influence of family trends.

Syrian refugees' attitudes towards consanguinity are of utmost importance when planning awareness campaigns and education about consanguineous relationships. Despite the high rate of consanguinity in the study population, the studied individuals reported having a considerable amount of knowledge about the disadvantages of consanguineous marriages. It appears that even though they knew of the disadvantages of such marriages – particularly the genetic problems and congenital abnormalities – a significant number still went ahead with such marriages for several possible reasons, some mentioned above, and particularly fear of change and the unknown. Moreover, individuals were more likely to report consanguineous marriages as being advantageous if they were already in such a marriage, in an attempt to rationalize their choice, despite having children with congenital abnormalities.

Although the majority of individuals had heard of the premarital screening test at the time of the interview, as seen in a study of young Syrian adults conducted 2 years before the start of the Syrian conflict (Gharaibeh & Mater, 2009), only a third had had the test. Of those who had had it, a significant proportion reported having the test because it was mandated by the marriage court, and not because they were medically convinced to have it. On the other hand, the majority of individuals who had not had the premarital screening test did not know of the test at the time of their marriage, or were married before the implementation of premarital screening. This might be due to the recent (past couple of years) implementation of a law in Syria requiring a screening test before marriage; this also means that it will take more time before a change in the percentage of those having the test is seen, and calls for rigorous awareness campaigns for the rising generation of Syrian refugees about the importance and necessity of this test.

Awareness campaigns will be the cornerstone of any action that must be taken to tackle the problems associated with consanguinity and the genetic transmission of disease in Syrian refugees. Given their limited access to health care in some of their host countries, the prevention of disease becomes even more important in this population. Population-specific genetic screening prior to marriage should determine the risk of the marriage yielding offspring with the common diseases of the region, subsequently dictating appropriate counselling. Although the interviewed single Syrian refugees in the study seemed to show adequate knowledge about consanguinity and premarital screening (personal communication, data not shown), professional educational services will still be important to ensure that they are fully informed.

While these recommendations are especially relevant to the Syrian refugees in Lebanon, they could be expanded to include refugee populations in other countries. Many Western countries currently host Syrian refugees, and thus the data obtained from Syrian refugees in Lebanon could apply to those elsewhere in the world.

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