



Attitudes and impact among people with abnormal premarital screening test results in Muscat governorate's primary healthcare centers in 2018

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Abstract

Hereditary hemoglobin disorders are among the most common inherited diseases globally. In Oman, the burden of hereditary hemoglobin disorders has long been recognized as a major public health problem. In Oman, the prevalence of SCD ranges between 0.2 and 0.3% and of homozygous B-thalassemia was 0.07–0.08% while the prevalence of sickle cell trait and B-thalassemia trait reached up to 4.8–6% and 2–2.6% respectively. Glucose-6-phosphate dehydrogenase (G6PD) had a high prevalence in Oman, being 25% in males and 10% in females. The premarital screening and counseling (PMSC) program is an important preventative service for the most common hereditary hemoglobin disorders in Oman. The aim of this research is to study the attitude of those with abnormal premarital screening results and the impact of these results. This cross-sectional study was carried out in all primary healthcare centers in the Muscat governorate in 2018 to analyze abnormal premarital screening (PMS) tests results which mainly include sickle cell disease, thalassemia, and G6PD deficiency. Data were collected through telephone questionnaires with those with abnormal PMS test results. The questionnaire consisted of 3 parts investigating sociodemographic characteristics, attitudes toward PMS, and impact of the screening on participants. Of the 159 participants, 72.3% were between 20 and 29 years of age. Over two-thirds (71.5%) took PMS test while engaged. Consanguineous marriage was reported in 38.4% of married participants. The majority (94.3%) of participants believed PMSC to be important and (90%) agreed PMS should be obligatory before marriage. Half took the test as a personal decision while 17% complied with their spouse. Healthcare worker advice accounted for 21.4% of participants' decisions. Participant response to positive PMS results showed that 23% canceled their engagement, while 13.8% continued with marriage. Overall, 57.9% believed that PMS affected their lives positively. There is a relatively high favorable attitude toward PMSC. More effort is needed to raise public awareness regarding early PMS. Additionally, further genetic counseling before and after PMS testing is essential for the program's success.

Keywords Premarital screening and counseling · Abnormal result · Attitude · Impact · Oman

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Introduction

Inherited hemoglobin disorders are predominantly single-gene autosomal recessive disorders that result in production of structurally abnormal hemoglobin variants (sickle cell disease [SCD]) or a reduction in the synthesis of structurally normal globin (thalassemia disease) (Memish and Saeedi 2011). It could be also enzymatic like glucose-6-phosphate dehydrogenase (G6PD). Both SCD and thalassemia major are the most common inherited hemoglobin disorders worldwide. According to WHO, these diseases affect as much as 5% of the world's population, constituting a major public health problem in certain parts of the world including the Mediterranean area and the Middle East (WHO 2006a, b). Yearly, approximately 240 million cases of heterozygous B-thalassemia are diagnosed worldwide, mostly in the Mediterranean islands and in parts of Southeast Asia (Alsaeed et al. 2018).

Worldwide, SCD incidence in newborns was estimated to be 300,000 in 2008 and SCD prevalence has significantly increased in most of Sub-Saharan Africa, the Mediterranean, and the Middle East (Alsaeed et al. 2018).

In the Sultanate of Oman, the burden of hereditary hemoglobin disorders that affect a great number of Omanis has long been recognized as a major public health problem. A population-based survey conducted in Oman in 2003 revealed that the total hereditary hemoglobin disorder prevalence in Oman was 9.5% (Al Kindi et al. 2012). The prevalence of SCD ranges between 0.2 and 0.3% and of homozygous B-thalassemia between 0.07 and 0.08% while the prevalence of sickle cell trait and B-thalassemia trait reached 4.8–6% and 2–2.6% respectively (Al-Kindi et al. 2019a; Al Riyami et al. 2001; Al-Riyami and Ebrahim 2003). Other abnormal hemoglobin present at a lower percentage were HbD (0.6%), HbE (0.3%), and HbC (0.02%) (Al-Riyami and Ebrahim 2003). Glucose-6-phosphate dehydrogenase (G6PD) had a high prevalence in Oman, being present in 25% in males and 10% in females (Al-Riyami and Ebrahim 2003). At present, according to a survey put out by Al-Riyami and Ebrahim, the yearly increase of sickle cell anemia is 120 cases among newborns and 18–20 cases for B-thalassemia trait (Al-Riyami and Ebrahim 2003).

It was estimated that the annual cost for solely managing hereditary hemoglobin disorders in Oman (without including staff salaries and cost of recurring laboratory tests) would be between 770,000 and 1.36 million USD. Such financial demands on health resources warrant attention toward appropriate cost-effective prevention strategies and measures (Alkindi et al. 2010).

Preventive screening programs have been adopted in several countries around the world to reduce the prevalence of these hereditary hemoglobin disorders. Initial attempts to establish premarital screening programs

occurred in the 1970s in Canada, UK, Cyprus, Greece, and Italy (Alswaidi and O'Brien 2009).

After this, many countries worldwide also adopted different types of preventive programs in which PMS and genetic counseling programs were central. Programs like these were recommended by the WHO as a measure for the prevention of genetic disease (WHO 2006b).

Premarital screening is defined as a panel of tests in which couples planning on having children are tested for genetic, infectious, and blood-transmitted disease to prevent risk of transmitting disease to their children (AlKamyani and Al Hinai 2018).

In the Middle East, 8 countries have established premarital screening and genetic counseling programs which constitute a mandatory step prior to receiving a marriage license and offer genetic counseling to couples at risk for hemoglobin disorders (Alsaeed et al. 2018). Many of these countries have proven the effectiveness of such programs in decreasing disease incidence. For example, it has been reported that in Turkey, Iran and Iraqi Kurdistan achieved reduction in B-thalassemia birth of approximately 90, 80, and 65% respectively (Saffi and Howard 2015).

In a 6-year study done in Saudi Arabia between 2004 and 2009, the frequency of B-thalassemia cases steadily decreased from 0.8–0.4 per 1000 persons. The study clearly showed the success of the premarital screening test and genetic counseling program in reducing the detection of at-risk marriages by about 60% (Memish and Saeedi 2011).

In Oman, the premarital screening and counseling (PMSC) program was introduced in 1999 with the main aim of reducing the incidence of congenital anomalies and inherited hemoglobin disorders (Rya AlKamyani, Fatma Al Hinai 2018). It is conducted in all primary healthcare centers in the country. According to the latest update of the PMSC programs in 2018, the test is not compulsory and is offered on voluntary basis to all Omani couples willing for screening. It is also offered for all Omani students in grade 12. Preferably, the couple should come together for screening but if not possible, the service can be done on an individual basis. The PMSC program screens for the most common hereditary hemoglobin disorders, namely sickle cell disease and thalassemia. G6PD test was removed from screening program in this update (Rya AlKamyani, Fatma Al Hinai 2018).

In the first visit of the screening, the doctor counsels the client about the service, explains the type of tests to be done, provides basic information about the diseases to be screened for, and obtains a signed consent from the client. Personnel data gathered includes age, occupation, education, consanguinity, medical history, personnel, family history of congenital and hereditary hemoglobin disorder, and general clinical

examination must be documented in this visit. Laboratory tests include CBC, sickling test, HPLC, ferritin, and iron profile. In the second visit, hematological result explained to each partner privately even if they took the test together. Counseling regarding disease and consequence is explained in this visit. In addition, the counselor encourages the affected client to disclose his/her result with his partner, if he/she agrees to proceed in the marriage and before their final appointment with the doctor. If both agree to proceed, then a referral to specialized clinic, either genetic counselor or hematologist, should be made for further explanation of condition and available management (Rya AlKamyani and Fatma Al Hinai 2018).

In a study done in Oman among university students in 2011, the majority (92%) thought it was important to take a test and 53% of them favored having it as an obligatory procedure before marriage (Al Kindi et al. 2012). In another study conducted among Omani adults who attended primary healthcare in 2011, the majority of the participants (84.5%) believed that premarital screening testing was necessary, and about half of them supported the view of making premarital screening testing compulsory. However, 30.5% were opposed to taking the test themselves. The reason for this reluctance might be related to fears that positive carrier results could lead to the cancelation of a marriage and that this could have a variety of social, cultural, psychological, and financial implications (Al-Farsi et al. 2014).

All previous research examines attitudes of people before testing, but there are no studies which examine attitudes following testing and the effect of positive results on peoples' lives.

The purpose of this research is to study attitudes and the impact premarital screening tests have among adults with abnormal test results in Muscat governorate primary healthcare centers.

Methods

This cross-sectional study was carried out in all primary healthcare centers in Muscat governorate. Muscat is the capital city and one of the 11 governorates of the Sultanate of Oman. The total number of marriages in 2018 was 3290 (National Centre for Statistics and Information, Oman 2020). There were 29 health centers in Muscat governorate. Each health center keeps a registry for any PMS test completed in the health center. There were 1794 PMS tests registered in a total of 26 health centers in Muscat governorate in 2018.

The target population of this study was all persons with abnormal PMS results for sickle cell disease, thalassemia, and G6PD deficiency in Muscat governorate during 2018. The total number of registered abnormal PMS tests was 195. Any person not willing to participate, not answering phone

calls (3 calls on 3 different days), or whose identity was not identical to the one in the registry was excluded from the study.

The data were collected through telephone interviews by a researcher after confirming the identity of the person called. A verbal consent was taken after giving a brief explanation about the main aim of the study. The participants were assured that their participation was voluntary, and all the information would be confidential. A pilot study was conducted on 15% of the sample (29 persons) to assess the reliability of the questionnaire.

A structured questionnaire with closed-ended questions was developed based on different findings in available journals and research papers on this topic with a previous validated questionnaire (Al Kindi et al. 2012; Al-Farsi et al. 2014; Binshihon et al. 2018; Al Sulaiman et al. 2008). The questionnaire was designed in English and then translated to Arabic by an expert. The questionnaire consisted of 3 main parts: the first part was on the sociodemographic characteristics of participants including gender, age, employment, marital status at the time of study and at the time of test, consanguinity, and family history of hereditary disease; the second part tested the participant's attitude toward PMS, while the third part consisted of items that explored the impact of PMS test on the participant's life. Neither the identity of participants nor the abnormal result was included in the questionnaire form. Therefore, separate data of sickle cell disease, thalassemia, or G6PD deficiency cannot be obtained.

Collected data were presented in numbers and percentages and analyzed using the Statistical Package for Social Science (SPSS), version 20 (IBM, Armonk, NY). Chi-squared test was used for testing the association between categorical variables. A *P* value of < 0.05 was considered statistically significant. This study was approved by the Regional Research and Ethical Committee of Muscat governorate.

Results

The total number of premarital screening tests done in Muscat governorate's primary healthcare system in 2018 was 1794 in a total of 29 health centers. Out of the 1794 registered tests, a total of 195 tests were abnormal. This gives a prevalence percentage of abnormal PMS tests of 10.4%. The total number of persons who participated in the study was 159. Thirty-six people were excluded from the study as they were either not willing to participate (2 people), not answering the calls (3 calls on 3 different days), or had changed their phone numbers.

Of the 159 participants, 49.05% ($n=78$) had sickle cell trait, 11.94% ($n=19$) had B-thalassemia trait, 2.51% ($n=4$) had sickle cell/beta thalassemia trait, and other abnormal HBs (HbD, HbE, HbC) constituted 8.8% ($n=14$). Sickle cell anemia accounted for 1.25% ($n=2$) and 26.41% ($n=42$) has G6PD deficiency. The updated national PMSC guideline was released late in 2018. Therefore, G6PD data was included in this study.

There were more male participants than female with a percentage of 64.2% ($n=102$) and 35.8% ($n=57$) respectively. The majority was in the age group of 20 to 29 years (72.3%, $n=115$), then from 30 to 39 years (26.4%, $n=42$) and only 1.3% ($n=2$) were over 40 years. Family history of hereditary disease was reported by 66% ($n=105$) of participants.

Approximately 62.7% ($n=99$) of participants were married at the time of study, followed by 33.5% ($n=53$) single and 3.8% ($n=6$) divorced. The rate of consanguinity among married participants was 38.4% ($n=43$), 18.8% ($n=21$) were first cousins, 19.6% ($n=22$) second cousins, and the remainder (61.6% [$n=69$]) reported to be distantly related or of no relation.

Concerning marital status at the time of the test, 39.9% ($n=63$) took the test after engagement, while 31.6% ($n=50$) did it in the process of engagement, 20.9% ($n=33$) went through testing before planning to get married, and only 7.6% ($n=12$) did it once already married (Tables 1, 2, and 3).

Regarding attitude, the vast majority of participants (94.3%, $n=150$) thought it important to carry out PMS and agreed to advise their future spouse on taking the test (98.2%, $n=157$). More than two-thirds (72.3%, $n=115$) of the participants believed PMS beneficial to control and reduce hereditary disease, and less than one-third (20.8%, $n=33$) did take the results into consideration.

When asked about the appropriate time to undergo PMS, most participants (75.5%, $n=120$) preferred to take the PMS test just before marriage, while 17.6% ($n=28$) chose during high school and 6.9% ($n=11$) in college.

Around half of the participants (54.1%, $n=86$) took the PMS test as a personal decision and 17% ($n=28$) took the test in compliance because of spousal request. Less than one-third (21.4%, $n=34$) of participants were tested in response to healthcare workers' advice. Almost 90% ($n=144$) of the participants agreed on taking PMS as an obligatory procedure before marriage, 5% ($n=8$) disagreed and 4.4% ($n=7$) were neutral.

The participants' response to positive PMS results showed that 23% ($n=37$) canceled their engagement while 13.8% ($n=22$) of the respondents continued with marriage for either emotional or family reasons. On the other hand, 18.9% ($n=30$) of participants did not know what to do as an initial response to positive results.

Overall, 57.9% ($n=92$) of participants believed that going through PMS testing affected their life positively and only one person reported that it negatively affected his life. In 27.7% ($n=44$), there was no effect reported on their current life. The majority of the participants (89.9%, $n=135$) said they would take a PMS test if time were to be turned back while 15.1% ($n=24$) were not sure if they were to do it over again.

Table 1 Sociodemographic characteristics of participants

Characteristics	Total <i>N</i> = 159 <i>N</i> (%)	Men <i>N</i> = 102 <i>N</i> (%)	Women <i>N</i> = 57 <i>N</i> (%)
Age group (years)			
20–29	115 (72.3)	70 (44)	45 (28.3)
30–39	42 (26.4)	31 (19.5)	11 (6.9)
>40	2 (1.3)	1 (0.6)	1 (0.6)
Marital status			
Married	99 (62.7)	62 (39.2)	37 (23.4)
Single	53 (33.5)	37 (23.4)	16 (10.1)
Divorced	6 (3.8)	3 (1.9)	3 (1.9)
Widowed	0	0	0
Marital status at time of test			
No plan for marriage	33 (20.9)	18 (11.4)	15 (9.5)
In the process of engagement	50 (31.6)	37 (23.4)	13 (8.2)
Engaged	63 (39.9)	42 (26.6)	21 (13.3)
Married	12 (7.6)	5 (3.02)	7 (4.4)
If married, consanguinity			
1st cousin	21 (18.8)	16 (14.3)	5 (4.5)
2nd cousin	22 (19.6)	9 (8)	13 (11.6)
No relation	69 (61.6)	46 (41.1)	23 (20.5)
Employment			
Yes	129 (81.6)	92 (58.2)	37 (23.4)
No	29 (18.4)	10 (6.3)	19 (12)
Family history of hereditary disease			
Yes	105 (66)	69 (43.4)	36 (22.6)
No	54 (34)	33 (20.8)	21 (13.2)

Table 2 Attitudes of participants toward PMS test

Attitudes	N (%)
Thinking that carrying PMS is important	
Agree	150 (94.3)
Disagree	3 (1.9)
Neutral	6 (3.8)
Thinking of benefit of PMS	
To control and reduce hereditary disease	115 (72.3%)
To take result into consideration	33 (20.8%)
As a routine requirement	8 (5%)
Do not know	3 (1.9%)
Thinking about the appropriate time of doing PMS	
In high school	28 (17.6)
On joining college	11 (6.9)
Before marriage	120 (75.5)
After marriage	0
Agreement on advice future spouse to take PMS	
Yes	157 (98.20)
No	2 (1.3)
Reasons for carrying out PMS	
Respondent believe	86 (54.1)
Spouse advice	28 (17.6)
Healthcare workers' advice	34 (21.4)
Other	11 (6.9)
Agreement on making PMS as an obligatory procedure before marriage	
Agree	144 (90.6)
Disagree	8 (5)
Neutral	7 (4.4)

Table 3 Impact of PMS on participants

Impact	N (%)
Initial response to abnormal PMS result	
Do not know what to do	30 (18.9)
Cancel engagement	37 (23.3)
Continue for emotional reason	15 (9.4)
Continue for family reason	7 (4.4)
No effect	70 (44)
Effect of PMS on participants' current life	
Yes, in a good way	92 (57.9)
Yes, in a bad way	1 (0.6)
No effect	44 (27.7)
Neutral	22 (13.8)
Agreement on doing PMS If the chance to do things over again	
Yes	135 (84.9)
No	0
Do not know	24 (15.1)

Discussion

On planning any preventive program, many aspects need to be considered to ensure its success. In a program like premarital screening, there is a great need to focus on the target population and to understand their attitude toward testing and its impact on their life.

This study was conducted in 26 primary health centers in Muscat governorate in the Sultanate of Oman. It included all registered abnormal PMS test results. The prevalence of abnormal results found in this study was 10.4%.

Nearly three-quarters of participants (73.58% $n = 117$) had sickle cell trait, anemia, or beta thalassemia trait. Approximately half of the participants have sickle cell trait.

More than two-thirds of participants (72.3%, $n = 115$) were in the 20- to 29-year age group, a typical time of life for Omanis to marry. This is supported by the finding that around 70% of participants were either in the process of engagement or already engaged and only 20% ($n = 33$) of participants participated in screening before choosing their partner. When asked about the appropriate time to go through PMS, the majority of participants (75.5%, $n = 120$) answered that just before marriage was the ideal time. This is the same percentage (75%) stated in a previous study from Oman in 2012 (Al Kindi et al. 2012). This illustrates that PMS is still generally considered an accessory to the process of marriage preparation, not an essential step. This is supported by the finding that only 20% of the participants in this study believed in taking PMS test result into consideration and not necessarily acting on the results.

Most participants were male (64.2%, $n = 102$). One factor could be that G6PD in Oman is more common in men than women with a percentage of 25% and 10% respectively (AlKamyani and Al Hinai 2018).

Consanguineous marriage accounts for 38.4% of the total married participants in this study. Two studies conducted in 2011 and 2016 showed consanguineous marriages were reported by 36% and 39.6% respectively (Al-Kindi et al. 2019), while the reported percentage in a previously published survey in 2003 was 58% (Al-Riyami and Ebrahim) and to exceed 50% in most of Arab countries (Al-Kahtani 2000). Limitations of this finding in our study were the small number of participants as well as the fact that the study was done only in the Muscat region where preservation of rural tribal communities is less common.

The participants' attitudes toward PMS were favorable. The majority believed that PMS is important (94.3%, $n = 150$) and agreed to take the test again if given the chance (84.9%, $n = 135$). This is a similar finding to what had been reported in previous studies in either Oman (Al Kindi et al. 2012; Al-Kindi et al. 2019) or others Arab countries such as Egypt, Syria, and Saudi Arabia (Al-Kahtani 2000; Eshra et al. 1989; Gharaibeh and Mater 2009). In addition, most of

the participants reported that they would advise a future spouse to take PMS test before deciding to marry. These findings reflect that the participants had a positive attitude toward PMS.

Although participant personal choice was the most common reason to take the test in both genders, spousal request was the second most common reason in men while healthcare workers' advice is the second in women with a significant statistical correlation ($P = 0.04$). In general, health workers' advice plays a role in only 20% of participants. This percentage is fairly close to previous result in where healthcare service was a source of information for only 16.8% of participants (Al-Kindi et al. 2019). This indicates that the healthcare services are not as efficient as expected in the PMS program and more effort is required in this regard. Knowing that their advice correlates significantly ($P = 0.001$) with the timing of testing—at an early stage before engagement—made healthcare workers' roles even more important.

In our study, close to a quarter of participants (23.3%, $n = 37$) canceled engagement upon positive PMS results. On the other hand, 13% of participants continued with marriage for either emotional or family reasons. This is almost the same finding to a previous study conducted in the South Batinah region of Oman in where 14% of respondents refused to change their decision if both couples were carriers (Al-Farsi et al. 2014). One highly significant reason reported in a previous study was the timing of the test (Al-Aama 2010). This study confirms this finding with a significant statistical correlation ($P = 0.002$) between testing in the period between the engagement and marriage and continuation of marriage despite abnormal PMS results. This unexpected abnormal result in this critical time may be ignored by couples for various cultural, social, and emotional reasons. The recommendation for those couples is to seek genetic counseling before conception. Pre-implantation genetic diagnosis is available in Oman but restricted only to thalassemia carriers. Furthermore, termination of pregnancy is not a management option for inherited hemoglobin diseases. Thus, testing should be done at an early stage so that individuals know the results prior to engagement. Another suggestion could be to perform the test during the high school or college stage, although the participants in this study as well as in another previous study (Al-Kindi et al. 2019) said this was not a preferable time to be screened.

While 85% of all participants agreed that they would take the test again if they could turn back time, 15% of them did not know if they would go through it again. This hesitancy correlates significantly ($P = 0.001$) with the time of screening, as half of them took a PMS test before planning to get married. There is also a significant correlation between participants' reluctance in taking the test if they could turn back time and

the impact of test results on their life, as around 80% of them reported either no effect or neutral in terms of the effect that test results had on their lives ($P = 0.001$). Moreover, 62.5% of these participants took the PMS test either after receiving advice from a healthcare worker or because it was included in another test such as a pre-employment physical screening. The above listed correlation could reflect that these participants were still not fully aware of the importance of PMS and more health education is needed in this regard. Furthermore, widespread genetic counseling prior and after PMS testing is essential for understanding and success of the PMSC program.

Making PMS an obligatory procedure before marriage was favored by approximately 90% of the participants. This is far higher than what was stated in at least 3 previous studies in Oman where only 50% agreed on making PMS a mandatory procedure before marriage (Al-Kindi et al. 2012; Al-Farsi et al. 2014; Al-Kindi et al. 2019). Similar views have been reported in multiple Saudi studies where 42% endorsed the compulsory implementation of PMS in the city of Riyadh and 29% in city of Abha (Al-Kahtani 2000; Al-Khaldi et al. 2002). The fact that all the previously mentioned studies were done on people prior to PMS testing might explain the difference in legalization acceptance by respondents.

Limitations

Despite a high response rate, the study has some limitations. First, it included only registered cases in the PMS registry book of each health center; therefore, it is likely that cases not written were not included. In addition, as any other questionnaire-based survey, potential bias of participant's responses to the questionnaire could be another limitation. Third, the study includes only the Muscat region which culturally could be different from interior rural region and hence cannot be generalized as the result for the whole country.

Conclusion

In conclusion, this study showed a favorable positive attitude toward PMS testing and the majority agreed on making it as a mandatory procedure before marriage. One of the reported significant reasons for continuation of marriage despite abnormal PMS results is taking the test during the engagement period. Thus, more effort is required to be tested at an early stage. In addition, this study highlighted the importance of healthcare workers' role in implementing the PMS program. Further public education and widespread genetic counseling prior to testing is essential for the success of the program.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12687-020-00493-1>.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical considerations This study involved human participants who were included in accordance with the ethical standards of the national research committee and approved by the research and ethical committee of the Directorate General of Health Services of Muscat Region, Oman.

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