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CLINICAL & BASIC RESEARCH

Knowledge and Health Beliefs Regarding Sickle Cell Disease Among Omanis in a Primary Healthcare Setting

Cross-sectional study

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المعرفة والمعتقدات حول مرض فقر الدم المنجلي لدى العمانيين في مراكز الرعاية الصحية الأولية

دراسة مستعرضة

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ABSTRACT: ***Objectives:*** Sickle cell disease (SCD) is a global health concern associated with high childhood morbidity and mortality; in Oman, the prevalence of SCD is 0.2%. Public awareness of SCD and the need for premarital screening (PMS) are essential to reduce the incidence of this disease. This study aimed to assess awareness of and beliefs regarding SCD and PMS among Omanis in a primary healthcare setting. ***Methods:*** This cross-sectional study took place in five health centres located in Al-Seeb Province, Muscat, Oman, between June and August 2015. A total of 500 Omanis aged ≥18 years old attending the clinics were invited to participate in the study. A previously described questionnaire by Gustafson *et al*. was used to measure awareness of and beliefs regarding SCD and PMS. ***Results:*** A total of 450 Omani adults completed the questionnaire (response rate: 90.0%). The majority (67.8%) were aware that SCD is genetically inherited and 85.1% believed in the value of PMS; however, only 24.4% reported having undergone PMS previously. Few participants were aware that SCD can be very painful (20.2%) and can cause strokes, infections and organ damage (20.0%). More than half (56.7%) reported that the availability of educational material on SCD or PMS in Oman was inadequate. Participants' education levels were positively associated with accurate SCD knowledge (P <0.05). ***Conclusion:*** Despite the free availability of PMS services in local health centres, few Omanis reported having undergone PMS previously. Health promotion and education programmes are therefore needed in Oman in order to increase public awareness of SCD and the value of PMS.

Keywords: Sickle Cell Disease; Awareness; Genetic Screening; Primary Health Care; Oman.

الملخص: الهدف: يعتبر مرض فقر الدم المنجلي مرض مثير للقلق في العالم ومرتبط بزيادة معدل الاعتلال و الوفيات بين الأطفال في سلطنة عمان. معدل حدوث مرض فقر الدم المنجلي في عمان هو 0.2%. ان الوعي العام لمرض فقر الدم المنجلي والحاجة للفحص ما قبل الزواج ضروري للحد من انتشار هذا المرض. تهدف هذه الدراسة إلى تقييم مدى الوعي العام والمعتقدات حول مرض فقر الدم المنجلي والفحص الطبي في مرحلة ما قبل الزواج لدى العمانيين الذين حضروا لتلقي العلاج في مراكز الرعاية الصحية الأولية. **الطريقة:** أجريت هذه الدراسة المستعرضة في خمسة مراكز صحية في ولاية السيب في محافظة مسقط عام 2015 في الفترة بين يونيو وأغسطس. تم دعوة 500 من العمانيين أعمارهم 18 سنة وما فوق للمشاركة في هذه الدراسة. تم استخدام أستبيان جوستافسون لقياس المعرفة والمعتقد حول مرض فقر الدم المنجلي والفحص الطبي ما قبل الزواج. **النتائج:** شارك 450 شخصا في الاستبيان (معدل الاستجابة = 90.0%). كانت غالبية المشاركين (67.8%) تدرك على أن مرض فقر الدم المنجلي سببه جينات وراثيه وكذلك 85.1% من المشاركين يعتقدوا في أهمية الفحص الطبي ما قبل الزواج، لكن 24.4% فقط حضروا لفحص الطبي ما قبل الزواج. كان هناك عدد أقل من المشاركين على علم بأن مرض فقر الدم المنجلي يمكن أن تكون له أعراض مؤلمة جدا (20.2%) وقد يسبب السكتة الدماغية، الالتهابات و تلف اعضاء الجسم (20.0%). أفاد أكثر من نصف المشاركين (56.7%) على عدم توفر برامج تثقيف صحي و توعية كافية حول مرض فقر الدم المنجلي والفحص الطبي ما قبل الزواج في عمان. كما اظهرت النتائج أن مستوى التعليم لدى المشاركين يرتبط إيجابيا (P <0.05) مع صحة المعلومات حول مرض فقر الدم المنجلي. **الخلاصة:** بالرغم من توفر خدمات الفحص الطبي المجاني لمرحلة ما قبل الزواج في المراكز الصحية المحلية فإن عدد قليل من العمانيين قد خضع لها سابقا. بالتالي هناك حاجه إلى تعزيز برامج التثقيف الصحي وزيادة الوعي العام في المجتمع العماني حول مرض فقر الدم المنجلي والفحص الطبي في مرحلة ما قبل الزواج.

الكلمات المفتاحية: مرض فقر الدم المنجلي؛ التوعية؛ الرعاية الصحية الأولية؛ عمان.

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Advances in Knowledge

- *To the best of the authors' knowledge, this is the first study conducted in Oman to assess public awareness of and beliefs regarding sickle cell disease (SCD) and premarital screening (PMS).*
- *While the majority of participants in this study were aware that SCD is a serious genetic disease and were alarmed by the thought of having a child with SCD, few participants were aware that SCD can be very painful and can cause organ damage, stroke and infections. Moreover, many participants reported that there was a lack of educational material about SCD or PMS in Oman.*
- *In the current study, only a minority of Omanis reported previously undergoing PMS, even though the majority indicated that they might reconsider a marriage if they were aware that their children might be affected by SCD.*

Application to Patient Care

- *The findings of the current study indicate that more health promotion and education programmes are needed in Oman in order to increase public awareness of SCD and utilisation of PMS services. Promoting the currently available PMS programme and counselling couples who are SCD carriers are essential steps to help reduce the incidence of SCD in Oman.*

The world health organization recognises sickle cell disease (SCD) as a global public health problem.[1] Approximately 5% of the global population and over 7% of pregnant women worldwide are carriers of haemoglobin disorders such as SCD.[2] Moreover, the burden of SCD and other haemoglobin disorders is expected to increase in developing countries; in such countries, SCD is associated with high childhood mortality; many children with SCD die before five years of age, mainly due to infectious complications and severe anaemia.[3,4] In Oman, the local population is comprised of a wide range of ethnic groups; however, the prevalence of consanguineous marriages is 58%.[5] Three infants per 1,000 live births in Oman have major haemoglobin disorders and there are approximately 106 new cases annually.[6] A community-based study conducted in 2001 reported the prevalence of the sickle cell trait (SCT) in the Omani population to be 5.8%.[7] In 2003, another study reported that the prevalence of SCD was 0.2% while incidences of SCD and SCT in Omani neonates were 0.3% and 4.8%, respectively.[5]

Sickle haemoglobin (HbS) is the most common structural mutation of normal adult haemoglobin (HbA), which is inherited as a Mendelian trait.[8] Heterozygous carriers who inherit one HbS allele and one HbA allele are usually asymptomatic; in contrast, homozygous carriers who inherit HbS alleles from both parents suffer from SCD, which often causes intermittent vaso-occlusive crises resulting in tissue *ischaemia*, acute and chronic pain and organ damage.[8,9] Thus, knowledge of the genetic inheritance of SCD is essential for couples where one or both individuals are carriers in order to make informed decisions about marriage and family planning. However, public knowledge of SCD is often limited; one study conducted in the USA showed that, although the majority of African-American women knew that SCD was a hereditary blood disorder, few of them understood its inheritance pattern.[10] In contrast, another study from the USA showed that 86.2% of the respondents had adequate knowledge of the genetic causes and severity of SCD.[11]

In Muscat, the capital city of Oman, a premarital screening (PMS) programme was introduced in 1999; from 2001 onwards, the programme was gradually extended to cover other regions.[12] Currently, the PMS programme includes free optional screening, counselling, health education and advice for carriers of common haemoglobin disorders (e.g. thalassaemia, SCD and SCT). However, a study conducted in 2011 among Omani university students showed that although the majority of the students (79%) were aware of the PMS programme, only half believed that it should be obligatory before marriage.[12] To the best of the authors' knowledge, no previous studies have measured public awareness of and beliefs regarding SCD and PMS in Oman, despite the high prevalence of SCD in the country. This study therefore aimed to assess public awareness and beliefs regarding SCD and PMS in Oman as well as determine associations between demographic factors and knowledge of SCD.

Methods

This cross-sectional study was conducted between June and August 2015 in Al-Seeb Province, Muscat. In 2010, the population of Muscat was over 1.15 million, including both local Omanis and expatriates;[13] there are currently 32 local health centres providing primary healthcare services for those living in the catchment areas. Eight of these health centres are located in Al-Seeb, which had a total population of 223,449 in 2010, of which 47% were Omani.[13] For the purposes of this study, five health centres were randomly selected for the recruitment of participants. As no previous studies have yet established baseline awareness of SCD in the Omani population, the sample size was calculated by assuming that 50% of the participants had adequate SCD awareness, with 10% allowable error. According to these calculations, the required sample size was 400. As

Table 1: Health beliefs regarding premarital screening and sickle cell disease education* among Omani adults in a primary healthcare setting (N = 450)

Questionnaire item	n (%)	
	Yes	No/unsure
Do you believe in the value of premarital screening?	383 (85.1)	67 (14.9)
Have you ever been tested for sickle cell trait?	110 (24.4)	340 (75.6)
If you have been tested, were you found to have sickle cell trait?†	21 (19.1)	89 (80.9)
If you were planning to get married and discovered that there was a chance of having a child with SCD, would you proceed with the marriage?	85 (18.9)	365 (81.1)
Is health education regarding SCD adequate in the community (e.g. via television, radio, school or your health centre)?	195 (43.3)	255 (56.7)

**Health beliefs were self-reported by participants using an Arabic version of Gustafson et al.'s questionnaire.[14]*

† Total dataset for this question was 110 as only those who had been tested for sickle cell trait were included.

such, with an expected non-response rate of 20%, 500 adult Omanis ≥18 years old attending the selected local health centres were invited to participate in the study.

Gustafson *et al*. previously examined the health beliefs of African-American women regarding genetic testing and counselling for SCD using a 12-item questionnaire based on the Health Belief Model (HBM).[14] The same questionnaire was used to deter-mine awareness of and beliefs about SCD and PMS among participants in the current study.[14] The HBM is a widely used psychosocial tool designed to analyse health-related behaviours—including public attitudes towards screening and prevention programmes—and has been used in SCD-related research to explore public understanding of the disease and approaches to its management.[15,16] Gustafson *et al*.'s questionnaire consists of three sections to elicit the following information: socio-demographic characteristics; knowledge and awareness of SCD; and individual health beliefs (including perceptions of susceptibility and disease seriousness as well as benefits and barriers to a specific behaviour).[14] In the original questionnaire, a five-point Likert scale is used to assess the health beliefs of participants, with the following responses: strongly agree, agree, neither agree nor disagree, disagree and strongly disagree. However, for the purposes of the current analysis, strongly agree and agree responses and disagree and strongly disagree responses were combined.

The questionnaire was translated into Arabic and back into English by two different groups of translators to ensure that the original meaning was preserved. A pilot study was conducted on 50 participants to check the clarity and reliability of the Arabic version of the questionnaire; these participants were later included in the full study. Based on standardised items, the Cronbach's alpha of the translated questionnaire was 0.70. A research assistant was in charge of data collection and was trained to administer the questionnaire to illiterate participants and to help those requiring assistance during completion of the questionnaire.

Data were analysed using the Statistical Package for the Social Sciences (SPSS), Version 20 (IBM Corp., Chicago, Illinois, USA). Means, median modes and standard deviations were calculated for continuous variables and percentages were calculated for categorical variables. Sociodemographic variables considered in the analysis included age, marital status, number of children and education level. To determine knowledge of SCD, a score of 1 was assigned to each correct response and the total score was calculated. Mean total knowledge scores were then compared with sociodemographic factors using either a t-test to compare the mean values of two variables or an F-test to compare the mean values for more than two variables, as appropriate. A multiple regression analysis was performed to find associations between sociodemographic variables and total knowledge scores. A Chi-squared test was used to determine significant associations between sociodemographic variables and mean total knowledge scores. The normal distribution of the variables was checked graphically. A P value of <0.050 was considered statistically significant.

This study was approved by the Medial Research & Ethics Committee of the College of Medicine & Health Sciences at Sultan Qaboos University (MREC #902). Medical officers in charge of the selected health centres gave permission for their centres to be involved in the study. The purpose of the study was explained and written consent was obtained from all participants before they took part in the study.

Results

A total of 450 Omani adults participated in the study (response rate: 90.0%). Of these, 201 were male (44.7%) and 249 were female (55.3%). Participants ranged in age between 18–58 years old (median: 29.0 years; mode: 26.0 ± 8.0 years). More than half of the participants (n = 242; 53.8%) were between 18–29 years old, 191 (42.4%) were between 30–49 years old and 17 (3.8%)

Table 2: Health beliefs regarding sickle cell disease* among Omani adults in a primary healthcare setting (N = 450)

Questionnaire item	n (%)		
	Disagree	Neither agree nor disagree	Agree
Severity			
Sickle cell disease is a serious disease	334 (74.2)	84 (18.7)	32 (7.1)
Having a child with sickle cell disease would be very scary	307 (68.2)	97 (21.6)	46 (10.2)
SCD can impact school performance	300 (66.7)	98 (21.8)	52 (11.6)
My life would change if I had a child with sickle cell disease	260 (57.8)	113 (25.1)	77 (17.1)
Susceptibility			
Sickle cell disease could happen in my family	144 (32.0)	215 (47.8)	91 (20.2)
My partner may be a carrier of sickle cell trait	113 (25.1)	185 (41.1)	152 (33.8)
My child is at risk of sickle cell disease	77 (17.1)	222 (49.3)	151 (33.6)
Benefits			
It is useful to know whether I have the sickle cell trait	363 (80.7)	64 (14.2)	23 (5.1)
It is useful to know whether my partner has the sickle cell trait	350 (77.8)	71 (15.8)	29 (6.4)
Knowing the risk of having a child with sickle cell disease would change how I plan a pregnancy	294 (65.3)	101 (22.4)	55 (12.2)
Barriers			
Testing for the sickle cell trait is painful and difficult	157 (34.9)	131 (29.1)	162 (36.0)
My partner would be hard to convince to get tested	155 (34.4)	125 (27.8)	170 (37.8)

**Health beliefs were self-reported by participants using an Arabic version of Gustafson et al's questionnaire.[14]*

were ≥50 years old. The majority (n = 321; 71.3%) were married, 115 (25.6%) were single and 14 (3.1%) were divorced. A total of 230 participants (51.1%) had between one and three children, 138 (30.7%) had no children and 82 (18.2%) had four or more children. The majority (n = 242; 53.8%) had a secondary school education, 136 (30.2%) had a university education and 72 (16.0%) had no formal education.

When asked about screening for SCD, 383 participants (85.1%) believed that PMS was valuable, but only 110 (24.4%) reported having previously had such screening performed. Of those who had undergone PMS, 21 (19.1%) reported having been diagnosed with SCT. Overall, 365 participants (81.1%) reported that they might reconsider getting married if their future children were at risk of having SCD. Only 195 participants (43.3%) reported receiving adequate SCD education from the media, school or their local health centre [Table 1].

Table 3: Levels of accurate* knowledge of sickle cell disease† among Omani adults in a primary healthcare setting (N = 450)

Questionnaire item	n (%)
Sickle cell disease is caused by inheriting genes from parents	305 (67.8)
To have sickle cell disease, someone must inherit two genes (one from the mother and one from the father)	133 (29.6)
Sickle cell disease can cause severe debilitating pain, strokes, infections and organ damage	90 (20.0)
Sickle cell pain can feel worse than a broken bone, a headache and a gunshot wound	91 (20.2)
Sickle cell disease makes red blood cells hard and sickle-shaped	119 (26.4)
You can tell if someone carries the gene for sickle cell disease with a simple blood test	270 (60.0)

**Using correct responses only.*

†Knowledge was self-assessed by participants using an Arabic version of Gustafson et al's questionnaire.[14]

In terms of health beliefs, 334 participants (74.2%) believed that SCD was a serious disease, 307 (68.2%) felt scared by the thought of having a child with SCD, 300 (66.7%) believed that SCD could affect a child's school performance and 260 (57.8%) felt that a SCD-affected child would have an effect on the parents' personal lives. However, fewer participants believed that their child was at risk of having SCD (n = 77; 17.1%), that their partner might be a carrier (n = 113; 25.1%) or that SCD could occur in their family (n = 144; 32.0%). The majority believed that it would be useful to know if they had SCT (n = 363; 80.7%) or if their partner had SCT (n = 350; 77.8%); in addition, 294 participants reported that knowing the risk of having a child with SCD would change their pregnancy plans (65.3%). Many participants believed that SCT testing was painful and difficult (n = 157; 34.9%) and that it would be hard to persuade their partner to get tested (n = 155; 34.4%) [Table 2].

In terms of SCD knowledge, 305 participants (67.8%) were correctly aware that SCD is caused by genes inherited from parents and 270 (60.0%) knew that SCD carriers could be identified via a simple blood test. However, fewer participants were aware

Table 4: Mean total sickle cell disease knowledge scores* by sociodemographic characteristic among Omani adults in a primary healthcare setting (N = 450)

Characteristic	n (%)	Mean score ± SD	*P* value
Gender			0.207
Male	201 (44.7)	2.13 ± 1.61	
Female	249 (55.3)	2.32 ± 1.57	
Number of children			0.138
0	138 (30.7)	2.18 ± 1.57	
1–3	230 (51.1)	2.36 ± 1.63	
≥4	82 (18.2)	1.97 ± 1.48	
Age in years			0.242
18–29	242 (53.8)	2.18 ± 1.61	
30–49	191 (42.4)	2.35 ± 1.55	
≥50	17 (3.8)	1.76 ± 1.71	
Marital status			0.249
Single	115 (25.6)	2.14 ± 1.52	
Married	321 (71.3)	2.29 ± 1.62	
Divorced	14 (3.1)	1.64 ± 1.33	
Educational status			<0.001
No formal education	72 (16.0)	1.52 ± 1.62	
Formal education	378 (84.0)	2.37 ± 1.78	

**Knowledge was self-assessed by participants using an Arabic version of Gustafson et al's questionnaire.[14]*

that SCD is inherited by one gene from each parent (n = 133; 29.6%), that it can be extremely painful (n = 91; 20.2%), that it makes red blood cells hard and sickle-shaped (n = 119; 26.4%) or that it can cause debilitating pain, strokes, infections and organ damage (n = 90; 20.0%) [Table 3]. Total knowledge scores ranged from 0.00–6.00, with a mean score of 2.24 ± 1.59. Mean knowledge scores were significantly lower among those with no formal education compared to those with formal education (*P* <0.001) [Table 4]. A multiple regression analysis revealed that education level was the only sociodemographic factor significantly associated with mean total knowledge scores (*P* <0.001) [Table 5]. On further analysis, significant differences according to level of education were observed in several of the knowledge and health belief questionnaire items [Table 6].

Discussion

To the best of the authors' knowledge, this is the first study determining awareness of and health beliefs regarding SCD among an Omani population. Level of knowledge of SCD, including its genetic causes (67.8%) and the fact that it can be diagnosed by a simple blood test (60.0%), was lower than that reported in other countries; one study conducted in the USA found that 91% of African-American women were aware that SCD is a hereditary blood disorder while 89% of members of the public in a Bahraini study knew that SCD could be diagnosed by a blood test.[10,17]

Table 5: Multiple regression analysis of associations between sociodemographic variables and mean total sickle cell disease knowledge* scores among Omani adults in a primary healthcare setting (N = 450)

Variable	Standardised regression coefficient	*P* value
Gender	0.061	0.201
Age	0.052	0.338
Marital status	0.028	0.630
Number of children	-0.053	0.401
Educational status	0.196	<0.001

**Knowledge was self-assessed by participants using an Arabic version of Gustafson et al's questionnaire.[14]*

Certain beliefs reported by the majority of participants in the current study—that SCD is serious, that it is frightening to have an SCD-affected child, that the disease can have an impact on school performance and that having a child with SCD can affect the parents' personal lives—are supported by findings from other studies in the literature.[18–21] Parents of children with chronic illnesses such as SCD have reported significantly greater stress than the parents of healthy children.[18,19] Research has shown that stress is significantly related to poor psychological adjustment on the part of the parents to the increased demands of children with SCD, including frequent pain and frequent use of both routine and urgent healthcare services, as well as realisation of the short life expectancy of their child.[18,20] A study conducted in Nigeria found that children with SCD reported more frequent absences from school and poorer academic achievement compared to their healthy siblings.[21] Parents of children with SCD have shown increased SCD knowledge compared to parents of children without SCD; moreover, the absence of family discussion about SCD was associated with lower knowledge levels and awareness of SCD and the value of PMS.[16,22]

Education levels were significantly and positively associated with accurate knowledge of SCD in the current study; this positive association is to be expected, as education is an essential component in promoting health, screening behaviours and healthier

Table 6: Significant differences in health beliefs and accurate* knowledge of sickle cell disease† according to education level among Omani adults in a primary healthcare setting (N = 450)

Questionnaire item	n (%)				*P* value‡
	Total	Education level			
		Non-formal	Secondary school	University	
Knowledge					
Sickle cell disease is caused by inheriting genes from parents	305 (67.8)	36 (10.3)	157 (44.9)	112 (32.0)	<0.001
Sickle cell disease can cause severe debilitating pain, strokes, infections and organ damage	90 (20.0)	7 (7.8)	46 (51.1)	37 (41.1)	0.025
To have sickle cell disease, someone must inherit two genes (one from the mother and one from the father)	133 (29.6)	19 (14.3)	67 (50.4)	47 (35.3)	0.36
Sickle cell disease makes red blood cells hard and sickle-shaped	119 (26.4)	7 (5.9)	53 (44.5)	59 (49.6)	<0.001
You can tell if someone carries the gene for sickle cell disease with a simple blood test	270 (60.0)	31 (11.5)	134 (49.6)	105 (38.9)	<0.001
Health beliefs					
Sickle cell disease is a serious disease	334 (74.2)	38 (11.4)	175 (52.4)	121 (36.2)	<0.001
Having a child with sickle cell disease would be very scary	307 (68.2)	31 (10.1)	157 (51.1)	119 (38.8)	<0.001
My life would change if I had a child with sickle cell disease	260 (57.8)	32 (12.3)	134 (51.5)	94 (36.2)	0.002
Sickle cell disease can impact school performance	300 (66.7)	32 (10.7)	159 (53.0)	109 (36.3)	<0.001
It is useful to know whether I have the sickle cell trait	363 (80.7)	50 (13.8)	184 (50.7)	129 (35.5)	<0.001
It is useful to know whether my partner has the sickle cell trait	350 (77.8)	43 (12.3)	181 (51.7)	126 (36.0)	<0.001
Knowing the risk of having a child with sickle cell disease would change how I plan a pregnancy	294 (65.3)	35 (11.9)	147 (50.0)	112 (38.1)	<0.001

**Using correct responses only.*

†Health beliefs and knowledge was self-assessed by participants using an Arabic version of Gustafson et al's questionnaire.[14] ‡Using a Chi-squared test.

lifestyles.[14,23] It is well known that enhancing public understanding of the genetic causes of SCD and providing SCD information to the public reduces SCD-related morbidity and mortality rates.[24,25] However, over half of the participants in the current study reported a lack of educational resources concerning SCD. Although the educational curriculum in Oman covers many health-related topics, none are specifically related to SCD.[26] Secondary school and higher education students are the most suitable targets for information about the prevention and control of SCD.[27] However, health information delivered by physicians is most trusted by the public, despite the availability of other resources.[28]

In the current study, although the majority of Omani adults believed in the value of PMS screening, very few reported having taken part in PMS previously. In a study of 400 Omani adults, Al-Farsi *et al*. reported that while 84.5% believed that premarital carrier screening was necessary, 30.5% were not in favour of taking a blood screening test themselves.[29] The Ministry of Health (MOH) in Oman offers free optional PMS for haemoglobin disorders; low attendance at these services might therefore reflect a lack of health promotion of the availability or need for PMS or insufficient motivation on the part of the individual to take advantage of the services. According to the HBM hypothesis, individuals must believe that they are at risk of the disease in order to be motivated to pursue health screening behaviours.[30] Alarmingly, very few participants in the current study believed that SCD could affect their families personally, that they were at risk of having a child with SCD or that their partner could be a carrier of the SCD gene. To this end, the authors of the current study recommend that the MOH in Oman implements and promotes media and education campaigns in order to increase young people's awareness of the importance of PMS for SCD.

These campaigns could involve the distribution of leaflets and posters in hospitals, local health centres and schools.

Despite the recent decline in consanguineous marriages in Oman, the practice is still relatively common; in 2000, the rate of first-cousin and second-cousin marriages was 35.9% and 20.4%, respectively.[31] Individuals still adhere to cultural norms despite an awareness of the associated risks of congenital and genetic disorders.[32,33] Furthermore, cultural, legal and religious restrictions limit the control of genetic disorders in many Arab countries; for example, termination of a pregnancy is not allowed, even for couples with an affected fetus.[34] Thus, without the option to terminate a pregnancy, couples expecting a child are more likely to go ahead with a planned marriage.[34] These factors may explain why some participants in the current study reported that they would get married even if there was a risk that their future children would have SCD. Alternatively, these individuals might not have been sufficiently aware of the physical, emotional and social impact of SCD.[35] It is therefore essential that Omani couples who are SCD carriers are made fully aware of the medical, psychological and financial consequences of deciding to proceed with the marriage. However, it is important that the counselling of these couples takes place with cultural sensitivity and support from religious leaders within the community.

The current study has several limitations. First, although the study was conducted in one of the largest provinces in Muscat, the results might not be generalisable to the whole of Oman. Nonetheless, the authors believe that these results are likely to have some national relevance as most primary care health centres in Oman are very similar and many patients travel from different regions of the country in order to seek healthcare in Muscat. Second, the study was conducted among Omanis in a primary healthcare setting and this sample may therefore not be representative of the population as a whole. Studies with larger sample sizes conducted among the general public or in communities from different regions of Oman are needed for the purposes of generalisability. Finally, although the majority of participants reported that they had not undergone PMS previously, some of these individuals might not have gotten married yet or may only have had plans to get married.

Conclusion

Despite the availability of free PMS services in all local health centres in Oman, few participants in the current study reported having undergone screening themselves. This is alarming considering the high incidence of SCD in Oman. It is essential that every effort is made to increase awareness of the consequences of intermarriages between SCD carriers, including the possible medical, psychological and financial problems often experienced by parents with SCD-affected children. Health promotion and education programmes are therefore needed in order to increase public awareness of SCD and the value of PMS among the Omani public. Government-mediated media and education campaigns will benefit not only SCD patients but the Omani community as a whole.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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