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AWARENESS OF SAUDI POPULATION ABOUT PREVENTIVE MEASURES OF THALASSEMIA AND SICKLE CELL ANEMIA: A CROSS-SECTIONAL STUDY

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Abstract

Background: Thalassemia and sickle cell anemia are prevalent genetic disorders in Saudi Arabia, necessitating public awareness for effective preventive measures. This study aims to assess the awareness levels about these conditions among the Saudi population.

Methods: A cross-sectional study was conducted among 307 Saudi residents, utilizing a stratified random sampling technique to ensure diverse representation. Data were collected through structured questionnaires administered via face-to-face interviews and electronic surveys. Descriptive and inferential statistical analyses were performed to evaluate awareness levels and their associations with sociodemographic factors.

Results: The mean age of participants was 36.8 ± 13.35 years, with a median age of 38 years, ranging from 14 to 70 years. Females constituted 75.9% of the participants. The majority were educated at school (28.3%) or university level (70.7%), and over half were married (57%). Most participants had a good monthly income (68.1%). Awareness of sickle cell disease was good among 42% of participants, significantly influenced by age (P=0.019), educational level (P<0.001), and income (P=0.010). Gender differences were observed, with females showing higher awareness than males, though not statistically significant (P=0.064). Awareness of thalassemia was good among 58% of participants, with significant associations with gender (P=0.001), age (P=0.003), marital status (P=0.012), educational level (P<0.001), and income (P=0.016). Females demonstrated significantly higher awareness compared to males.

Conclusion: The study revealed that awareness about thalassemia is higher than that of sickle cell disease among the Saudi population. Key determinants of awareness included gender, age, education, marital status, and income level. These findings highlight the need for targeted educational programs, particularly aimed at less educated and lower-income groups, to enhance public awareness and preventive practices for these genetic disorders.

Introduction

Reduced synthesis of the globin chain of hemoglobin is the defining feature of the autosomal recessive disease group known as thalassemia [1]. The condition may cause anything from no symptoms at all to stillbirth in the womb [2].

The frequency of thalassemia varies greatly from region to region, from roughly 0-10.5%, with certain ethnic groups and subgroups being more predisposed to the disease than others [3]. Screening carriers and raising awareness of thalassemia are now crucial steps in reducing the disease's prevalence. High carrier rate is a pressing health concern, and raising public knowledge about thalassemia is essential to reducing the disease's devastating prevalence.

Hemoglobin S (HbS) affects an estimated 20–25 million individuals worldwide, according to the WHO. Sub-Saharan Africa is home to around 12–15 million, the Indian subcontinent to 5–10 million, and the rest of the globe to 3 million [4]. The two most successful government intervention programs in Saudi Arabia, the Premarital Genetic Screening (PMGS) and the Genetic Counseling (PMGSGC) programs, are available at no cost to citizens and are administered by government institutions. Because healthcare services in Saudi Arabia are easily accessible both financially and geographically, the PMGS program and free genetic counseling have been very beneficial to the population [5-6]. That is why PMGS has been such a game-changer in the field of preventive medicine.

Research conducted in various parts of the Kingdom of Saudi Arabia (KSA) has shown that sickle cell diseases (SCDs) are more common in certain areas than others [7-13]. One area that has been found to have a particularly high prevalence of SCDs is Jazan Province in southwestern Saudi Arabia. Hospitalization in Jazan was mostly due to SCD-related complications, including acute chest syndrome (ACS) and vaso-occlusive crisis (VOC), according to research by Alhazmi et al., [13].

Publicly available information indicates that Farasan Island is not endemic to any malaria species, including the common jazani Plasmodium falciparum [14]. The urgent need to resolve the public health issues caused by sickle cell anemia and thalassemia in Saudi Arabia justifies this study. These genetic blood abnormalities are important public health problems because of the high frequency of consanguineous marriages and the associated elevated risk of these illnesses. The possible influence of the research on bettering the general health outcomes of the Saudi population provides the rationale. The study seeks to provide significant insights for planning targeted interventions and educational campaigns by analyzing awareness levels, finding gaps in knowledge, and understanding the variables that impact preventative actions. This study's results have the potential to inform healthcare providers, lawmakers, and community leaders on how to better detect and prevent sickle cell anemia and thalassemia, which would ease the strain on healthcare systems and enhance the lives of people impacted by these conditions. But there is a lack of data on SCD knowledge and incidence on Farasan Island. Therefore, it is important to investigate the prevalence and understanding of SCDs among Farasan campus nursing students, as well as their impact on malaria prevention efforts. This study aimed to assess the awareness of the Saudi population about preventive measures for thalassemia and sickle cell anemia and to identify factors influencing knowledge levels.

Methods

Study Design

This research employed a cross-sectional study design to assess the awareness of the Saudi population regarding preventive measures for thalassemia and sickle cell anemia. A cross-sectional approach allowed for the collection of data at a single point in time, providing a snapshot of the population's knowledge and attitudes.

Study Setting

The study was conducted in diverse settings across Saudi Arabia, including urban and rural areas, to capture a representative sample of the population. This ensured that the findings were applicable to a broad spectrum of individuals residing in different geographic and socio-economic contexts.

Population

The target population for this study included Saudi residents of various age groups and backgrounds. Efforts were made to include individuals from both genders and diverse socio-economic statuses to enhance the study's representativeness.

Sample Size and Sampling

A calculated sample size was determined to achieve statistical significance. The sampling method involved a stratified random sampling technique, considering factors such as age, gender, and geographical location to ensure a balanced representation of the Saudi population.

Data Collection

Data were collected through structured questionnaires administered via face-to-face interviews or electronic surveys, depending on the participants' preferences. The questionnaire covered aspects related to awareness, knowledge, attitudes, and practices regarding thalassemia and sickle cell anemia.

Instruments

The primary instrument for data collection was a structured questionnaire developed based on existing literature and validated survey tools. The questionnaire underwent pre-testing to ensure clarity, relevance, and cultural appropriateness.

Statistical Analysis

Data were analyzed using statistical software, employing both descriptive and inferential statistical methods. Descriptive statistics were used to summarize the characteristics of the study population, while inferential statistics such as chi-square tests and logistic regression were applied to explore associations and predictors of awareness levels.

Ethical Consideration

This study adhered to ethical principles, ensuring informed consent from all participants. Confidentiality and anonymity were maintained throughout the research process. The study protocol was submitted for approval to the relevant ethical review board, and participants were informed about their right to withdraw from the study at any stage without consequences. The research was conducted in compliance with the Declaration of Helsinki and other applicable ethical guidelines.

Results

The study included 307 participants. The mean age among study participants was 36.8 $\pm$ 13.35 years with median age of 38 years. Age ranged from 14 to 70 years. Three fourths of study

participants were female participants (n= 233, 75.9%). Vast majority of study participants are educated either at school level (n= 87, 28.3%) or university level (n= 217, 70.7%). More than half of study participants are married (n= 175, 57%). Monthly income was good among most participants (n= 209, 68.1%). Table 1 summarizes sociodemographic characteristics among study participants.

Table 1: Sociodemographic characteristics among study participants

Characteristic		Frequency	Percentage
Gender	Male	74	24.1
	Female	233	75.9
Age group	<20	54	17.6
	20-39	117	38.1
	40-59	121	39.4
	60 or more	15	4.9
Marital status	Single	94	30.6
	Married	175	57
	Divorced	26	8.5
	Widow	12	3.9
Educational level	Illiterate	3	1
	School level	87	28.3
	University level	217	70.7
Level of income	Weak	52	16.9
	Good	209	68.1
	High	46	15

The level of awareness about sickle cell disease was assessed using 17 questions. Nine or more correct answers was considered good awareness. Among study participants, 129 were aware (42%). Table 2 presents level of awareness distribution based on sociodemographic characteristics. Notably, females exhibited a higher awareness (104) compared to males (25), though the difference was not statistically significant (P=0.064). Age significantly influenced awareness, with participants aged 20-39 and 40-59 showing better awareness (52 and 53, respectively) compared to those under 20 (P=0.019). Marital status did not significantly affect awareness levels (P=0.081). Educational level had a strong impact, with university-educated individuals having the highest awareness (P<0.001). Income level also played a significant role, with those having a good or high income showing better awareness compared to those with weak income (P=0.010).

Table 2: Awareness level about sickle cell disease among study participants

Characteristic		Awareness level		P value
		Good	Poor	
Gender	Male	25	49	0.064
	Female	104	129	
Age group	<20	14	40	0.019

	20-39	52	65	
	40-59	53	68	
	60 or more	10	5	
Marital status	Single	34	60	0.081
	Married	83	92	
	Divorced	10	16	
	Widow	2	10	
Educational level	Illiterate	0	3	<0.001
	School level	22	65	
	University level	107	110	
Level of income	Weak	12	40	0.010
	Good	96	113	
	High	21	25	

The level of awareness about thalassemia was assessed using 12 questions. six or more correct answers was considered good awareness. Among study participants, 178 were aware (58%). Table 3 presents level of awareness distribution based on sociodemographic characteristics. Females exhibited significantly higher awareness (147) compared to males (31), with a P value of 0.001. Age was a significant factor, with the 40-59 age group demonstrating the highest awareness (79), and those under 20 the lowest (P=0.003). Marital status also influenced awareness, with married individuals showing better awareness (P=0.012). Education level played a crucial role; university-educated participants had significantly higher awareness (141) compared to other education levels (P<0.001). Income level was another significant factor, with participants having a good or high income showing better awareness (P=0.016).

Table 3: Awareness level about thalassemia among study participants

Characteristic		Awareness level		P value
		Good	Poor	
Gender	Male	31	43	0.001
	Female	147	86	
Age group	<20	23	31	0.003
	20-39	63	54	
	40-59	79	42	
	60 or more	13	2	
Marital status	Single	47	47	0.012
	Married	113	62	
	Divorced	15	11	
	Widow	3	9	
Educational level	Illiterate	0	3	<0.001
	School level	37	50	
	University level	141	76	

Level of income	Weak	21	31	0.016
	Good	127	82	
	High	30	16	

Discussion

According to the results of this study, everyone participating in the research knew a lot about thalassemia but not nearly as much about sickle cell disease. In spite of the fact that most Saudi households are formed via marriages between blood relatives. Fewer students were aware that malaria-endemic areas may experience genetic alterations that provide protection from the disease after prolonged exposure, according to a research on sickle cell anemia awareness among nursing students [15]. Also, a large percentage of people were aware of SCD; in fact, 89.9% of those who took the survey got the general knowledge and awareness questions on the disease right [15]. In addition, the government has been able to launch mitigation initiatives because to the much simplified access to digital services in KSA. The General Authority for Statistics 2021 reports that 98.2% of Saudis own smartphones and 96.3% of the population uses the internet, which may explain why there is a high level of awareness about SCDs even among secondary school students [15-16].

Despite their early age, respondents in one study by Albagshi et al. [17] showed strong understanding of SCD (89.9%), which is rather impressive. In a related survey carried out by Al-ghubishi et al. [18] amongst Al Qunfudah, KSA, high school students, the majority of whom were 71.7 percent knowledgeable of SCD, were the responders. Specialized treatment is necessary for the management of symptoms and improvement of clinical outcomes due to the chronic and acute problems caused by SCD [19]. The participants' poor results on sections devoted to management practices show that these aspiring nurses will not receive adequate education throughout their time in school regarding the specifics of caring for patients with SCD, including the importance of physical examinations, immunizations, medications (including folic acid and prophylactic antibiotics), laboratory testing, and family education [15]. Special consideration should be given to SCD since it is a chronic disorder that often causes increased suffering, particularly in youngsters.

Data for this area shows that, on the whole, 87.8% of respondents had a good attitude and were very accepting of premarital genetic screening (PMGS) when asked about it in the attitude assessment section [15]. The PMS program was known by the vast majority of respondents (96.3% in the survey cited in [15]). Reasons for this might include the availability of free genetic screening facilities and a number of government programs that are easy for individuals to access. A whopping 87.8 percent of those who took the survey agreed that screenings are crucial. As many as 70% of SCD patients were open to marrying someone with SCT [15].

There are two studies that support premarital genetic screening: one by Mirghani et al. [19], in which 99% of participants believe that it is necessary, and another by Al-Shroby et al. [20], in which 98.4% of respondents had a positive attitude toward PMGS and 88.6% still believed that their partner's genotype could impact their decision to marry. Researchers Al-Qahtani et al. [21] found that most people are open to the idea of preimplantation genetic screening (PGS). Of the

people surveyed, 88.6% were in favor of the procedure, 78.2% said they wouldn't marry someone with thalassemia or SCA, and 79.5% said they wouldn't marry someone with a genetic trait if they had it themselves. Alahdal et al. [22] also found that 55.57 percent (N = 354) of Princess Nourah University students were in favor of premarital counseling. This study's results are consistent with those of earlier published studies[16,23–24] in that the majority of participants (93.1%) identified PMGS as a preventative intervention for SCD.

This is in contrast to the findings of premarital testing, which were irrelevant to many participants in a different research by Kotb et al. [23] in Jazan and Alhowiti and Shaqran [24]. Even if the findings were contradictory, 47.3% of the individuals still decided to tie the knot. To ensure the adoption of the healthiest methods for properly managing SCDs, additional awareness campaigns are necessary. In addition, there is a strong positive correlation between when the screening is conducted and the number of incompatible marriages that continue. In this study, most participants wanted to take the PMGS test right before getting married (75.5 percent, N = 142), while 17.6 percent wanted it done while in high school (N = 33) and 6.3 percent wanted it done while in college (N = 13) [15]. According to Al Zeedi and Al Abri [25], taking the test during the engagement stage is one of the key proven important factors for the continuance of the marriage despite abnormal PMS findings. There are a lot of cultural, social, and emotional reasons why couples would opt to dismiss an unexpected aberrant outcome at this vital juncture, and it's understandable that they would. Turkey [26] and Bahrain [27] are only two of several Middle Eastern nations where premarital genetic counseling and testing significantly reduced the incidence of hemoglobinopathies.

Elguero et al. [28] established the well-known link between P. falciparum malaria and SCD. From the time of its discovery till the present day, SCD has primarily been seen in areas where malaria is common [29,30]. This lends credence to the theory, which was advanced a year ago, that the mechanisms of resistance of heterozygous (HbA) malaria might be related to these two disorders [31,32]. A number of studies have shown a link between the sickle cell trait, or heterozygote HbAS, and immunity to malaria, with protection rates of over 90% against severe cases [23,24,25].

Malaria is primarily a problem in the southwestern area of Saudi Arabia, with the Aseer and Gizan regions having the largest number of recorded cases [36]. One of Saudi Arabia's most dangerous regions is the Jazan area, which is also bordering Yemen [37]. Because high humidity (>60%) increases the lifetime of mosquitoes and encourages the formation of parasites in them, Al-Mekhlafi et al. [37] found that average temperature and relative humidity were important climatic determinants of autochthonous malaria in the Jazan area.

The simplest way to define carrier (HbAS) persons is as malaria-protective, as they often show no symptoms of infection [39,40,41]. Malaria parasite Plasmodium falciparum is unable to proliferate when it is present in red blood cells (RBCs) that have a faulty hemoglobin (Hb). The capacity of the parasite to digest hemoglobin is also affected by its polymerization. Therefore, in areas where malaria is a problem, having SCT actually improves one's chances of survival [42,43].

One possible reason is that the immune system is able to remove more parasitized cells from infected red blood cells (RBCs) because the parasites are unable to grow as much and because

their cytoadherence to the endothelium is diminished [41,44]. There may be a correlation between the high malaria prevalence in the Jazan area and the higher incidence of SCDs in the southern province of KSA. Also, it's possible that the high SCD prevalence in certain parts of KSA is related to the reasons why those areas also had a high malaria prevalence in the past, or that it's the result of intermarriage between ethnic groups from areas where SCT or SCD are more common. According to the statistics released by Alzahrani et al. [14], Farasan Island and the Fyfa highlands are remarkably malaria-free. This might explain why Farasan does not have any SCDs.

Conclusion

The study on the awareness of preventive measures for thalassemia and sickle cell anemia among the Saudi population revealed that awareness levels varied significantly based on several sociodemographic factors. The majority of participants were female, educated, and had a good income, which positively influenced their awareness levels. Awareness about thalassemia was notably higher than for sickle cell disease. Females showed significantly higher awareness of thalassemia compared to males. Age and education were significant factors, with the highest awareness observed in the 40-59 age group and among university-educated individuals. Marital status and income also played crucial roles, with married participants and those with better income levels demonstrating higher awareness. This underscores the need for targeted educational initiatives to improve awareness about these genetic conditions, especially among less educated and lower-income groups.

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