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Original Article

Parents' Knowledge and Awareness of Sickle Cell Disease in the Jazan Region, Kingdom of Saudi Arabia: A cross-sectional study

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ABSTRACT Sickle cell disease (SCD) is a significant genetic health concern worldwide. The Jazan region in Saudi Arabia has the second-highest rate of SCD, emphasizing the need for comprehensive data on disease knowledge and awareness in this region. This study evaluated parents' understanding of SCD in the Jazan region and determined the knowledge gap. After expert consultation and a literature review, we conducted an online survey to enroll 384 Saudi citizens over 18 years of age living in Jazan, aiming for a 95% confidence level. The data was analyzed using SPSS v23.0. Most participants (n=358; 93.2%) were aware of SCD, with 303 (78.9%) knowing it is a blood disorder. About 331 (82.6%) agreed that premarital investigation is necessary to reduce SCD incidence, and 276 (71.9%) knew that genetic counseling could help manage it, but only 95 (24.7%) had checked their genotype. Over one-third of participants (n=144; 37.5%) believed genetic testing should be conducted in primary school, while 52 (13.5%) understood the likelihood of a child inheriting SCD if both parents had sickle cell traits. The study revealed a good awareness of SCD but significant gaps in the understanding of its genetic transmission, highlighting the need for expansive education and awareness campaigns in the Jazan region to improve genetic counseling and health management decisions.

Keywords: Sickle cell disease, Awareness, Knowledge, Parents, Jazan, Anemia, Saudi Arabia, Sickle cell anemia.

INTRODUCTION

Sickle cell disease (SCD) is an autosomal recessive hereditary blood disease and is the most common single-gene-inherited severe hematological disorder among humans worldwide. SCD is reported mainly in sub-Saharan African countries, Saudi Arabia, South and Central America, India, and the Mediterranean regions, with five main haplotypes linked with specific geographic areas with variations in clinical manifestations and severity, including Senegal, Bantu, Benin, Cameroon, and Arab-Indian variants.[1,2]

Approximately 330,000 newborns are born with severe SCD every year, and it has become more prevalent globally due to migration and population movements with estimated birth rates of 10.68 per 1000 in Africa, 0.68 per 1000 in South and Southeast Asia, 0.49 per 1000 in the Americas, and 0.07 per 1000 in Europe.[1,3]

SCD is caused by a mutation in the beta-globin gene, producing hemoglobin S (HbS), which is abnormal and causes red blood cells (RBCs) to take on a sickle shape, especially under low oxygen levels. The deformed RBCs may block blood vessels, which is a leading cause of the clinical manifestations of SCD, resulting in symptoms including hemolytic anemia, vaso-occlusive painful episodes, priapism, chronic leg ulcers, pulmonary hypertension, renal failure, gallstones, auto splenectomy, and an increased risk of infection, blindness, and stroke.[4] The occurrence of these adverse effects results in increased medical expenses and reduced quality of life for those affected.[5] In contrast, individuals with sickle cell trait (SCT) are usually asymptomatic but may experience vaso-occlusive complications during acute dehydration.[6]

There has been a growing awareness of hemoglobinopathies, including SCD; however, comprehensive epidemiological data on their prevalence and burden is still required. In 2006, the World Health Organization recognized SCD as a global public health problem, which was further strengthened in 2010 when the World Health Assembly adopted a resolution to prevent and manage congenital disabilities, such as SCD and thalassemia.[1,2]

SCD was first reported in Saudi Arabia's Eastern Province in the 1960s. Following this, several national and regional screening studies were performed to identify its clinical characteristics and gene frequency in different Saudi regions.[1,2] The prevalence of SCD in Saudi Arabia is

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common and varies between regions, with the highest rates in the eastern and southwestern provinces. The estimated prevalence of SCD through the Saudi premarital screening program was 3.8 per 1000 people, while newborn screening estimated a prevalence of 2.6% in the Eastern region of KSA.

Jazan has the highest prevalence of SCT, ranging from 2% to 27%, and the second highest prevalence of SCD in the Kingdom of Saudi Arabia (KSA), reaching up to 2.6% and over 20% of Jazan hospital admissions in the medicine and pediatric departments, ranging from a mild to severe phenotype.[3]

The increasing global impact of SCD requires urgent attention and the establishment of clear national guidelines for effective public health planning, which can be accomplished through community education. Assessing the general population's awareness of this common disease will aid in implementing preventive measures.[7] Preventing the birth of infants affected by SCD through prenatal diagnosis and genetic counseling is the most effective long-term solution to reduce mortality and public health costs.[8] Screening newborns for SCD using rapid testing, providing parental education, and offering comprehensive care can significantly reduce SCD-related illness and death. National SCD screening is cost-effective and successful in identifying infants with the disease and preventing fatalities [1, 2].

Multiple studies have indicated considerable gaps in parents' knowledge and attitudes toward SCD worldwide, impacting disease management and prevention. In Nigeria, 45% of parents only discovered their sickle cell genotype after their child's diagnosis.[9] In Uganda, while 57.8% of caregivers had heard of SCD, thorough knowledge about its causes and prevention was limited.[10] Similar gaps were found in Congo and Benin, where parents acknowledged the severity of SCD but lacked awareness of preventive measures.[11,12] At the National Sickle Cell Disease Center in Benin, only 29.1% of 117 parents understood the disease well, with lower health literacy more common among parents of younger children.

There have been no studies in Saudi Arabia of how well children identified as carriers of SCD are informed about the impact of the disease on their health and their ability to have affected children despite 20 years of newborn screening. Understanding parental knowledge about sickle cell inheritance, its effects on health and reproduction, the use of genetic educational resources, and associated stigma is crucial for accurate information transmission.[6] Various studies have examined SCD awareness among parents, students, and medical professionals in Saudi Arabia.

A study in Tabuk (KSA) found that while participants were aware of SCD's prevalence, they had limited knowledge of transmission risks and crisis management.[7] At Al-Baha University (Al Baha, KSA), medical students demonstrated varying levels of understanding, with clinical-year students showing better awareness but only 14% knowing proper SCD management.[13] A study in Al-Ahsa (KSA) found that 89% of high school students had heard of SCD, but many were unaware of its hereditary risks and prevalence.[14] Research in Riyadh (KSA) showed that while most participants lacked symptom and management knowledge, awareness of risk factors and prevention was relatively high.[15] Another cross-sectional study was conducted in the eastern region of Saudi Arabia at different shopping malls in August 2019. Using convenience sampling, 675 participants were randomly recruited, most of whom reported very good knowledge about premarital screening and its importance.[16]

Other studies in Saudi Arabia explored the perceptions of treatment and caregiver burden. A study in Jeddah (KSA) showed diverse attitudes toward hematopoietic stem cell transplantation, with concerns about side effects affecting acceptance.[17] Another study found that caregivers, specifically mothers of SCD children, encountered considerable emotional and financial stress, impacting their quality of life.[18]

Overall, while foundational awareness of SCD exists in Saudi Arabia, significant gaps remain in the knowledge of disease management, treatment options, and crisis prevention. Addressing these issues through targeted education and support programs is essential to improving patient care and family well-being. In 2020, Hazzazi et al. reported that one out of every four patients admitted to Jazan hospitals had SCD, with vaso-occlusive crisis being the most common complication, followed by acute chest syndrome.[3] Based on these findings, our study aimed to evaluate parents' knowledge and awareness of SCD in the Jazan region and analyze existing gaps in this knowledge and determine how demographic factors may influence awareness. Ultimately, our goal is to provide valuable insights that can improve public health education, thereby enhancing SCD awareness in the area.

MATERIALS AND METHODS

This cross-sectional study was conducted in the Jazan region, one of the 13 regions of the Kingdom of Saudi Arabia. It is situated on the Red Sea coast in the southwestern part of the country and covers an area of 11,716 km^2, including around 5,000 villages and towns. According to the last population survey, conducted in 2019, Jazan is a densely populated region with an estimated population of more than 1.6 million individuals. This study targeted parents who met the following inclusion criteria: Saudi citizens, living in the Jazan region, over 18 years old, and agreeing to participate. The data were collected via the Arabic language self-administered electronic questionnaire, which took participants around 4–5 minutes to complete following their consent. The sampling method for this study was a nonrandom convenience sampling technique; mothers were approached through various social media platforms, including WhatsApp and Telegram groups, from January 1 to the end of June 2024. The sample size was estimated to be 384 using the Cochran formula, $n = (z)\ 2 \times p\ (1 - p)/d2$, where P = 50% is the anticipated response and

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z = 95% is the confidence interval, with an error of no more than 5% and a 25% nonresponse rate. The questionnaire was designed after thoroughly analyzing the relevant literature and consulting a field expert. It was reviewed by a panel of experts with extensive experience in SCD, including two consultants from the Family and Community Medicine Department and one from the Pediatric Department at Jazan University. Their expertise and recommendations ensured questions' clarity and standardized response options for more consistent and manageable data analysis. The first section of the survey included sociodemographic characteristics, such as gender, age, education level, and marital status, while the second section assessed participants' knowledge of SCD. The questionnaire underwent pretesting in a pilot study with 20 participants to evaluate completion time and question understanding. The analysis revealed a Cronbach's alpha of 0.79 for reliability, though these data were excluded from the main study.

Ethical approval was obtained from the Institutional Review Board of Jazan University (reference number REC-45/08/1009, dated March 10, 2024).

RESULTS

This study included 384 parents who completed the questionnaire. Most respondents were female (n=227; 59.1%), while males comprised 40.9% (n=157). More than a third of the participants (n=140; 36.5%) were 18 to 25 years old, and a quarter (n=98; 25.5%) were aged 26–35. Approximately half of the participants (n=189; 49.2%) were married, and 173 (45.1%) were single. Nearly two-thirds of the participants (n=268; 69.8%) had a university education, while only four (1%) were illiterate (Table 1).

Table 1: Sociodemographic data (n=384)

Variable	Categories	N (%)
Gender	Male	157 (40.9)
	Female	227 (59.1)
Age (years)	18–25	140 (36.5)
	26–35	98 (25.5)
	36–45	74 (19.3)
	> 45	72 (18.8)
Marital status	Single	173 (45.1)
	Married	189 (49.2)
	Divorced	18 (4.7)
	Widowed	4 (1)
Education	Illiterate	4 (1)
	Primary school	4 (1)
	Middle school	7 (1.8)
	Secondary school	81 (21.1)
	University	268 (69.8)
	Postgraduate	20 (5.2)

N: number, %: percentage

Most participants (n=358; 93.2%) indicated they were aware and familiar with SCD, and 311 (81%) correctly noted that SCD affects RBCs. However, only a quarter of the participants (n=95; 24.7%) reported having checked their genotype, and more than half of the participants (n=224; 58.3%) stated that they knew someone with SCD (Table 2).

Concerning the etiology of SCD, more than three-quarters of the participants (n=303; 78.9%) knew that it was a blood disorder inherited from a person's parents. Additionally, only a quarter of the participants (n=102; 26.6%) knew that a person who carries the sickle cell gene does not experience symptoms, and a small number (n=66; 17.2%) disagree that only one parent is required for transmission of SCD to the offspring. More than two-thirds of the participants (n=276; 71.9%) knew that genetic counseling could help control it. Most of the participants (n=287; 74.7%) knew that pain is one of the most common symptoms of SCD, while a smaller percentage (n=233; 60.7%) knew that SCD is not a curable disease (Table 2).

Table 2: General knowledge and awareness of parents toward sickle cell disease

Question	Yes n (%)	No n (%)	I don't know n (%)
Have you ever heard of sickle cell disease (SCD)?	358 (93.2)	26 (6.8)	-
Have you ever checked your genotype?	95 (24.7)	289 (75.3)	-
Do you know someone who has sickle cell disease	224 (58.3)	160 (41.7)	-
Does sickle cell disease affect red blood cells?	**311 (81) ***	10 (2.6)	63 (16.4)
Is sickle cell disorder a contagious disease?	18 (4.7)	**298 (77.6) ***	68 (17.7)
Sickle cell disease is a group of blood disorders usually inherited from a person's parents.	**303 (78.9) ***	9 (2.3)	72 (18.8)
Can some bacteria in the blood cause sickle cell disease?	77 (20.1)	**114 (29.7) ***	193 (50.3)
Does a person who carries the sickle cell gene experience symptoms of sickle cell anemia?	161 (41.9)	**102 (26.6) ***	121 (31.5)
Some viral infections in the blood can cause sickle cell disease	76 (19.8)	**120 (31.3) ***	188 (49)
Only one parent contributes to the transmission of sickle cell disease to the offspring	217 (56.5)	**66 (17.2) ***	101 (26.3)
Genetic counseling is a way to control sickle cell disease	**276 (71.9) ***	14 (3.6)	94 (24.5)
Pain is one of the most common symptoms of sickle cell disease	**287 (74.7) ***	17 (4.4)	80 (20.8)
Is SCD curable?	151 (39.3)	**233 (60.7) ***	-

* Correct answer, N: number, %: percentage, SCD: sickle cell disease

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Concerning SCD etiology, more than three-quarters of the participants (n=294; 76.6%) knew that SCD is a blood disease (**Figure 1**). A total of 224 (58.3%) participants knew someone with SCD, most of whom (n=155; 69.2%) have a friend with SCD, and 38 (17%) have an affected aunt or uncle (**Figure 2**). Regarding the symptoms of SCD, fatigue and tiredness were the most commonly identified symptoms (n=276; 71.9%), followed by chronic pain episodes (n=264; 68.8%), pale skin (n=243; 63.3%), headache (n=178; 46.4%) and recurrent infections (n=97; 25.3%) (**Figure 3**).

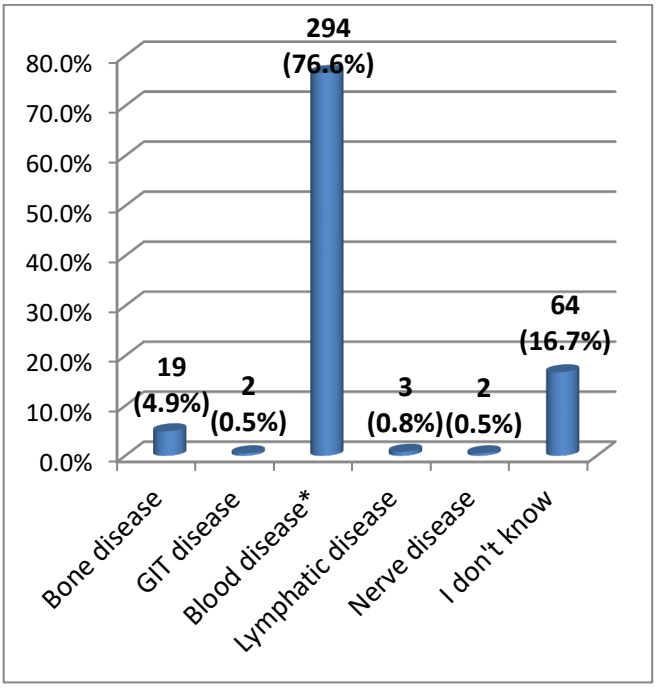

Figure 1: Sickle cell disease etiology
* Correct answer

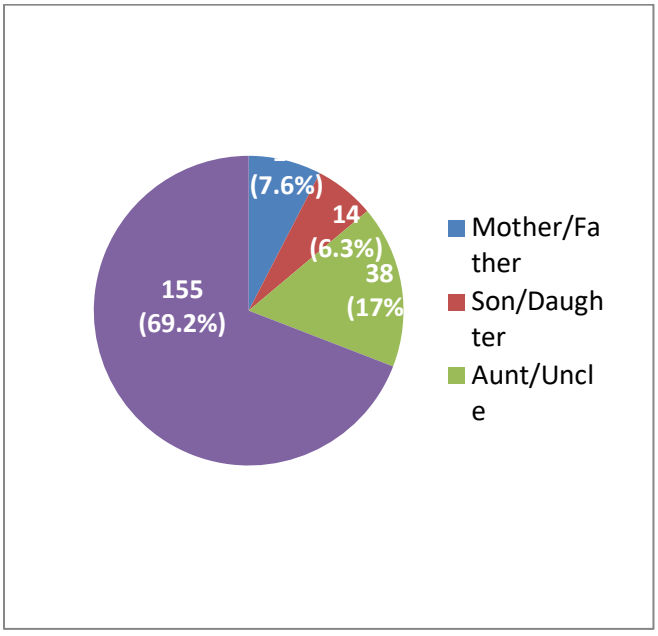

Figure 2: Relatives known to have sickle cell disease.

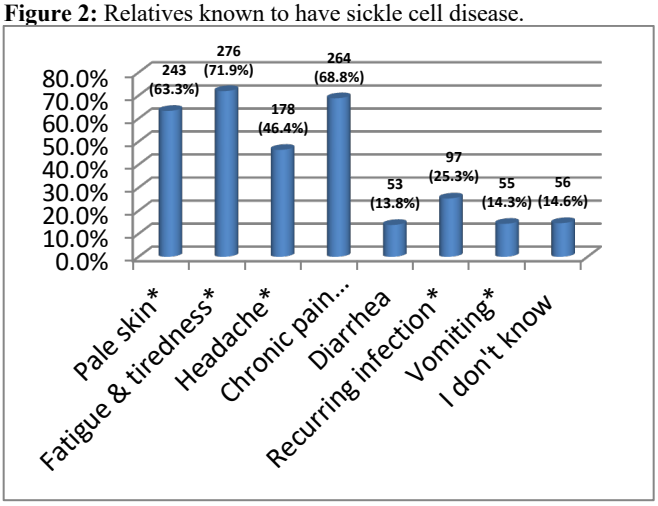

Figure 3: The numbers/percentages of participants who were aware of the symptoms of sickle cell anemia
* Correct answer

Concerning participants' knowledge about SCD severity, nearly two-thirds of the participants (n=245; 63.8%) knew it is a severe disease. When it came to the diagnosis of SCD, more than half of the participants (n=213; 55.5%) were aware that a newborn screening program could diagnose it, while more than a third (n=139; 36.2%) knew it could be diagnosed prenatally. Most participants (n=331; 86.2%) understood the importance of premarital investigation in reducing the incidence of SCD. When asked about the appropriate age for genetic testing to determine carrier status, one-third of participants (n=144; 37.5%) suggested primary school and one-third (n=139; 36.2%) thought it should be done immediately before marriage **(Table 3).**

Table 3: Participants knowledge about Sickle Cell Disease.

Question	Categories	N (%)
What do you think about the severity of SCD?	**Severe** *	245 (63.8)
	Moderate	86 (22.4)
	Not severe	7 (1.8)
	I do not know	46 (12)
Sickle cell anemia can be diagnosed during pregnancy	**Yes***	139 (36.2)
	No	52 (13.5)
	I don't know	193 (50.3)
A newborn screening program can diagnose sickle cell disease	**Yes***	213 (55.5)
	No	17 (4.4)
	I don't know	154 (40.1)
Prenatal diagnosis can help prevent sickle cell disease	Yes	212 (55.2)
	No*	48 (12.5)
	I don't know	124 (32.3)
Do you think that premarital examination is necessary to reduce the incidence of SCD?	**Yes***	331 (86.2)
	No	9 (2.3)
	I don't know	44 (11.5)
Which one of those tests is used to diagnose SCD?	Ultrasound	5 (1.3)
	Blood test*	299 (77.9)
	Urine/feces test	6 (1.6)
	I do not know	74 (19.3)
What is the appropriate age for individuals to undergo genetic testing to determine whether they are disease carriers?	Primary school	144 (37.5)
	Secondary school	23 (6)
	Immediately before marriage	139 (36.2)
	I don't know	78 (20.3)

* Correct answer

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Regarding the probability of a child getting SCD if both parents had the SCT, only 52 (13.5%) of the participants knew that a quarter of offspring would get SCD, while about a third (n=127; 33.1%) think that 50% of offspring will get SCD if both parents have the SCT (**Figure 4**).When asked about the best decision for a couple about to get married if their genetic test shows the chance of having a child with SCD, nearly 50% (n=181; 47.1%) thought that they should consult a doctor, one-third (n=138; 35.9%) believed that they should separate and only seven (1.8%) reported that they should continue their marriage (**Figure 5**).

Regarding the correlation between participants' knowledge and demographic data, nearly half of the participants (n=19; 48%) who were categorized as having good knowledge were within the age group 18–24, while only five (12%) were aged >45. Seventeen (42%) of the participants who had good knowledge were married, half of them were single (n=20; 50%), and 32 (80%) had a university level of education. (Table 4).

Table 4: Correlations of participants' knowledge to their age, marital status, and level of education.

Knowledge	Good Knowledge		Moderate Knowledge		Poor Knowledge		P value
Variable	N	Mean	N	Mean	N	Mean	
Age	40		190		161		p>0.05
18 to 25	19	48%	73	38%	51	32%	
26 to 35	11	28%	49	26%	42	26%	
36 to 45	5	12%	34	18%	35	22%	
More than 45	5	12%	34	18%	33	20%	
Sex	40		190		161		p>0.05
Female	27	68%	118	62%	86	53%	
Male	13	32%	72	38%	75	47%	
Marital Status	40		190		161		p>0.05
Divorced	3	8%	4	2%	11	7%	
Married	17	42%	99	52%	75	47%	
Single	20	50%	85	45%	73	45%	
Widowed	0	0%	2	1%	2	1%	
Education	40		190		161		**P<0.05**
Elementary	0	0%	1	1%	6	4%	
High school	4	10%	31	16%	48	30%	
illiterate	0	0%	0	0%	4	2%	
Postgraduate	4	10%	9	5%	8	5%	
Primary	0	0%	1	1%	3	2%	
University	32	80%	148	78%	92	57%	

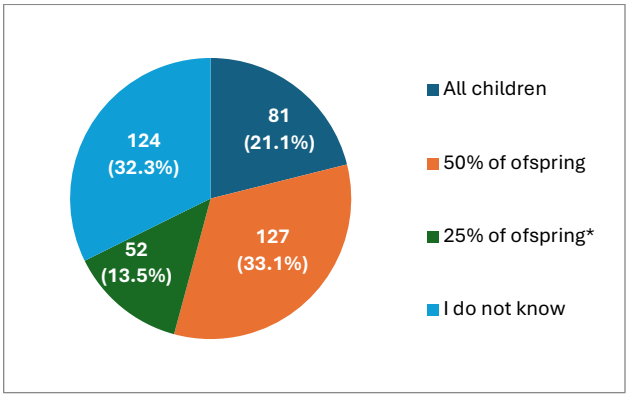

Figure 4: Probability of a child getting SCD if both parents have the sickle cell trait
*: Correct answer, %: percentage

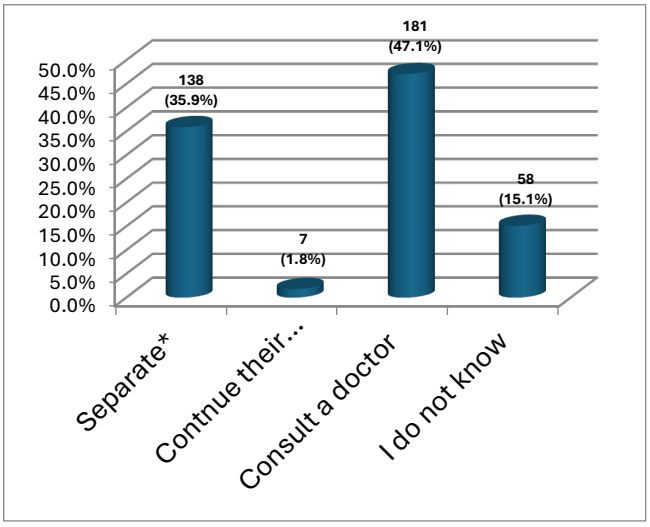

Figure 5: If a couple who are about to get married found out that their genetic test showed the chance of having a child with SCD, what do you think they should do?
* Correct answer

DISCUSSION

This study evaluates the knowledge and awareness of SCD among parents in the Jazan region of Saudi Arabia. Most participants were female (n=227; 59.1%) and had a university education (n=268; 69.8%), indicating a correlation between higher education and improved health literacy. The study found that 358 (93.2%) of parents were aware of SCD, and 224 (58.3%) knew someone affected by the disease (Table 2). This level of awareness aligns with findings from a study conducted in Tabuk, Saudi Arabia, which also reported high awareness among participants.[7] A study in the Al-Darb governorate of the Jazan region found that most participants demonstrated acceptable knowledge about SCD, including general awareness of transmission methods and prevention measures.[9] In contrast, an equivalent study in Riyadh indicated that the level of awareness regarding SCD was low, emphasizing

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the need for increased public education on the disease to address misconceptions and enhance knowledge among the general public.[10] A study in Uganda and Nigeria indicated a high level of awareness of SCD, primarily due to its high incidence in these regions [11,12]. Although participants were aware of SCD, only 95 (24.7%) had checked their genotype (Table 2)**.** This reflects a notable difference between awareness and health monitoring behaviors, revealing common misunderstandings about how the disease is passed on genetically. Similar findings have been reported in other studies from different regions, including the United States, which found that while many parents were aware of SCD, fewer took proactive steps such as seeking genetic counseling.[13-15] This highlights a crucial area for public health intervention.

This study demonstrated a high awareness of SCD as a blood disorder in most participants (n=294; 76.6%; Figure 1), consistent with the well-established characterization of SCD in the scientific and medical literature.[16] Around two-thirds of the participants (n=155; 69.2%) reported knowing a friend with SCD; these findings align with previous studies demonstrating strong community connections and social support systems.[7]

Regarding the symptoms of SCD, fatigue and tiredness were the symptoms most commonly identified in this study, followed by chronic pain episodes and pale skin (**Figure 3**), which aligns with other reports. [17,18] Fatigue and tiredness are common symptoms of anemia, which occur when there are not enough RBCs to carry oxygen throughout the body, leading to exhaustion. Chronic pain episodes occur when sickled cells block blood flow in various body parts.

Most participants (n=245; 63.8%) considered SCD a severe disease (Table 3). This perception reflects the disease's potential complications and impact on individuals' lives, which supports the existing literature indicating that the public generally acknowledges the significant health impact of SCD. [19,20]. In this study, only one-third of the participants (n=139; 36.2%) were aware of prenatal diagnosis of SCD. This finding differs from similar studies, and the variations could be due to differences in geographic regions, demographics, or the effectiveness of local health education programs, which indicates the need for improved public health education about the availability and importance of prenatal screening.[19]

The study findings revealed that a significant number of participants (n=181; 47.1%) believe that consulting a doctor is the appropriate response if a couple about to get married discovers that their genetic test shows the possibility of having a child with SCD, indicating trust in medical guidance. Additionally, 138 (35.9%) suggested that couples should separate, seven (1.8%) supported the idea of continuing the marriage, and 58 (15.1%) were unsure of the correct decision. These results suggest a potential stigma associated with genetic conditions, which contradicts modern views in genetic counseling that emphasize Informed decision-making over separation.[21] Consanguinity plays a significant role in the transmission of SCD in Saudi Arabia. In a study by Alhamdan et al. (2007), approximately 90% of at-risk relatives still opt for marriage despite knowing the potential risks of inheriting the disease. Another study in 2010 by Al-Sulaiman et al. reported an even higher percentage (98%). Reasons for ignoring premarital screening results include family pressures, existing romantic relationships, and a lack of trust in the accuracy of the results.[22] In a study conducted in Jazan in 2020, researchers found that 75.8% (n=69) of sickle cell patients had a positive history of consanguinity. Furthermore, 30% of individuals were born after premarital screening was implemented, showing that a significant percentage of those at high risk still choose to proceed with the marriage.[23] This presents a significant challenge in controlling SCD in Saudi Arabia, especially compared to many other countries where parental counseling and follow-up care for affected cases have led to a decrease in SCD-related morbidity and mortality.[24]

In Saudi Arabia, despite improvements in public healthcare following the implementation of a mandatory premarital screening program and genetic counseling (PMSGC) since 2004 for couples intending to marry, requiring them to undergo screening for SCD, thalassemia, HIV, hepatitis B, and hepatitis C, there is still a need for greater awareness and understanding of PMSGC. A comprehensive study in 2021 involving 6,263 participants found that only 9.2% had satisfactory knowledge about PMSGC and the screened genetic diseases, while 52.4% had fair knowledge and 38.4% had poor knowledge. The median total knowledge score was 21 (IQR 18–25).[23,25] High-risk marriages remain common, partially due to delays in premarital screening and a lack of legal measures to prevent them. Raising awareness of SCD and the importance of premarital screening is essential for informed family planning. Nursing and social work professionals can develop community-based care models to support the well-being of children with SCD and their families.[26] To effectively tackle this issue, it is proposed that premarital screening be made mandatory for students in secondary and intermediate schools in Saudi Arabia. This approach will assist individuals in understanding their health status prior to entering into marriage.[7]

Our study provides valuable insights but has limitations that could significantly influence interpretation and broader application. The study's cross-sectional design means the data represent only a snapshot in time and may not capture changes in awareness or knowledge. Using self-reported questionnaire responses and nonrandom convenience sampling introduces the risk of bias, as the sample may not accurately represent the population, limiting the generalizability of the findings. The reliability of the results can be questioned because the sample may not accurately represent the variables being analyzed.

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CONCLUSIONS

The study found that parents in the Jazan region have good knowledge and awareness of SCD but lack a meaningful understanding of its genetic transmission, highlighting the need for comprehensive genetic education to address misconceptions about SCD inheritance and prevention. It is recommended that public health strategies be enhanced to disseminate accurate information and encourage proactive health management behaviors among at-risk populations. Targeted educational initiatives are required to improve understanding and guide health management decisions. Incorporating educational strategies in schools should include adding SCD education to the curriculum, providing teacher training, organizing student workshops, and conducting awareness campaigns. Schools should establish support groups, conduct regular health screenings, partner with healthcare providers for on-site medical support, and involve parents and the community to create an informed and supportive environment for effectively managing and controlling SCD.

INFORMED CONSENT STATEMENT

Informed consent was obtained from all subjects involved in the study.

DATA AVAILABILITY STATEMENT

The authors will make the raw data supporting this article's conclusions available upon request.

SUPPLEMENTARY MATERIALS

Table S1: Sociodemographic data (n=384). Table S2: General knowledge and awareness of parents toward sickle cell disease. Table S3: Severity and diagnosis of sickle cell disease. Figure S1: Sickle cell disease etiology. Figure S2: Relatives known to have sickle cell disease. Figure S3: The symptoms of sickle cell anemia. Figure S4: Probability of a child getting SCD if both parents had sickle cell trait, Table S5: If a couple who are about to get married found out that their genetic test showed the chance of having a child with SCD, what do you think they should do?

AUTHOR CONTRIBUTIONS:

MM, SA, GG, KM, OH, AN; Concept and design of study, acquisition of data, data interpretation, drafting the article, and revising the article critically for important intellectual content.

AY, AH, NA, YA, MT; Data interpretation, analysis, creation of new software, drafting the article, and revising the article critically for important intellectual content

All authors were involved in the writing and revision of the manuscript and approved the submitted version.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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