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Knowledge and awareness assessment of sickle cell anemia in the Al-Darb governorate, Jazan region

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ABSTRACT

Background: Sickle cell disease is a genetic disease passed from sick or carrier parents to their children. Raising awareness among individuals and couples planning to marry can reduce the spread of the disease.

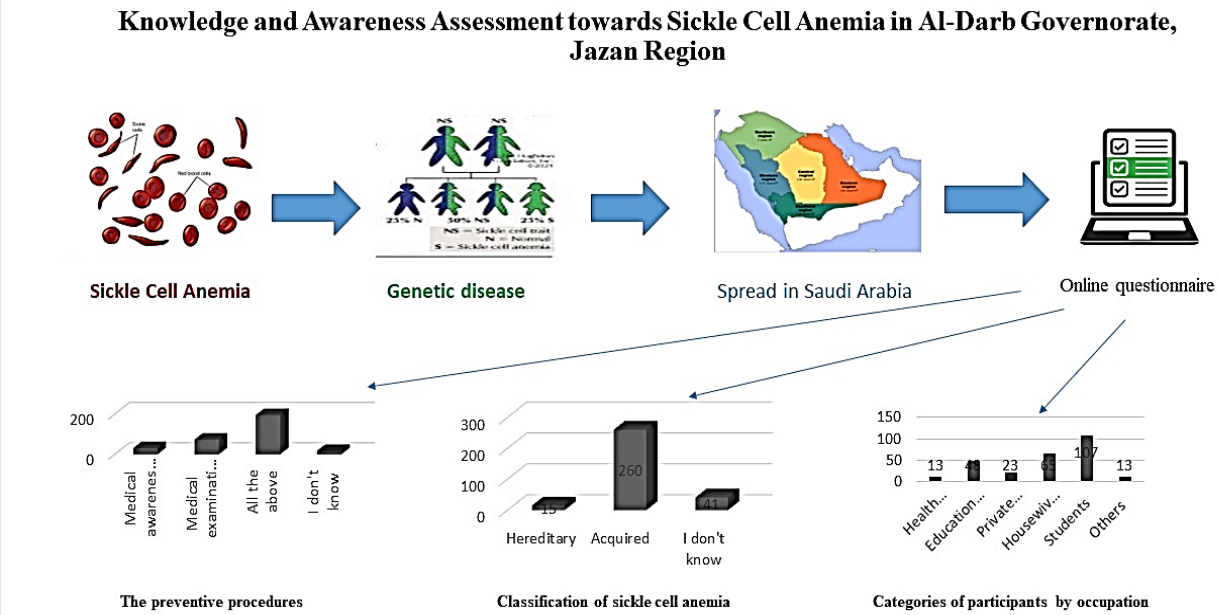
Objectives: This study aims to determine the knowledge and awareness of Al-Darb governorate residents in the Jazan region towards sickle cell anemia.

Methods/Design: A cross-sectional study was conducted in the AlDarb governorate, Jazan region using a close-ended questionnaire. The data was then analyzed with SPSS v.23.

Results: Among the 316 valid, collected, and analyzed questionnaires, 76.9% were completed by females, most of whom were students. About 25.6% of the participants had heard about the disease from their families. Additionally, 59% identified stroke and the acute chest syndrome as the most important complications of the disease. Regarding the individuals' attitudes towards the disease, 95.6% believed that a preventive plan should be followed for infected children. Furthermore, 88% stated that genotype affects their decision to get married.

Conclusions: In general, most participants demonstrated an acceptable level of knowledge about sickle cell disease, including its transmission methods and prevention. However, there is a significant need for increased community awareness regarding proper nutrition, addressing misconceptions about the disease, and establishing blood disease centers within the study population.

Keywords: sickle cell anemia, knowledge, awareness, AlDarb governorate



INTRODUCTION

Normal red blood cells are produced in the bone marrow from immature precursor cells. It takes seven days for these cells to mature and be released into the bloodstream. Mature red blood cells are devoid of a nucleus, circular, and flexible, allowing them to move more easily through the blood vessels. However, in sickle cell disease (SCD), the patient's body produces abnormal, rigid, sticky, and sickle- or crescent-shaped red blood cells. These irregularly shaped cells can become stuck in the blood capillaries, slowing down the flow of blood and oxygen to body parts [1]. Normal red blood cells are replaced every 120 days, whereas sickle cells usually die within 15 days due to their rapid breakdown, leading to a shortage of red blood cells that the body cannot replace quickly enough.

SCD is a genetic disorder passed from parents to children; it is not an infectious disease like those caused by microbial infections [2]. The disease affects both males and females and only occurs if both parents are carriers or infected with the disease. The disease affects millions of people worldwide and is diagnosed through blood testing. While there is no cure, treatments are available to relieve pain and help prevent the symptoms and complications associated with the condition [1].

The prevalence of hereditary blood diseases, including thalassemia and sickle cell anemia, varies across different regions of Saudi Arabia. The highest prevalence rates are recorded in the southern and eastern regions, while rates are lower in the central and northern regions of the kingdom, as seen in Figure 1 [3]. In 2007, the highest rates were observed in the Al-Ahsa region of the kingdom (22.1%), followed by the Jazan region (16.2%) [4].

Despite this, there is a low level of awareness and understanding about SCD among undergraduate students in Dammam, KSA [5]. A 2020 study by Al-Shammari et al. [6] measured the awareness of

community members in the city of Riyadh regarding sickle cell anemia. The study found that while awareness of prevention methods was high, knowledge about the signs and complications of the disease was low

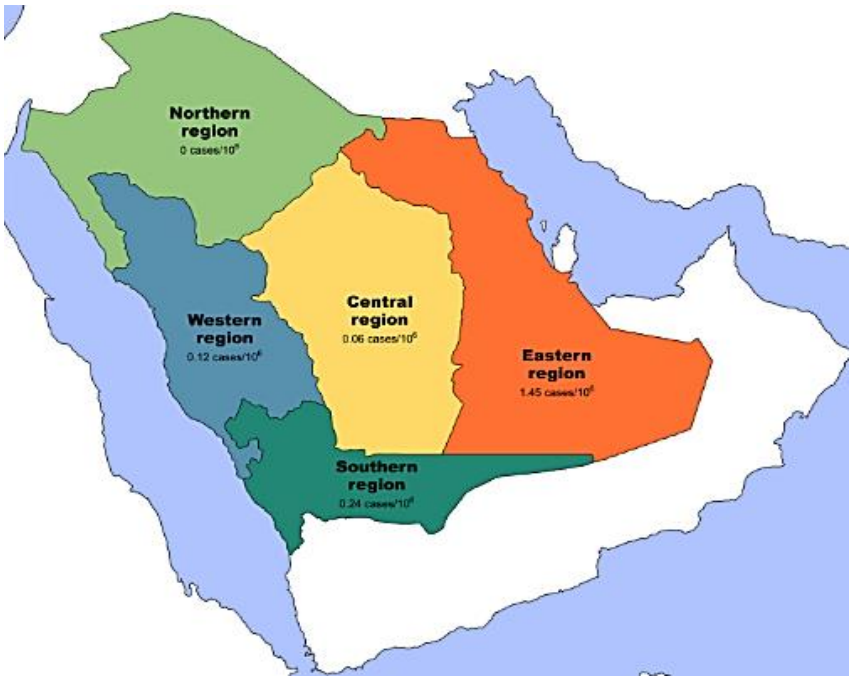


Figure 1. The spread of sickle cell disease (SCD) in regions of the KSA.

Recently, several studies have examined the awareness and knowledge of different groups about sickle cell anemia in both Farasan governorate in the Jazan region, as well as the Al-Baha region. These studies indicated high levels of awareness among participants regarding the disease and governmental health policies but identified gaps in administrative practices. These studies also confirmed the need for awareness campaigns to enhance the comprehensive understanding of sickle cell anemia among college students and the broader study population [7-8].

Significance of the study: Sickle cell anemia is a genetic disorder caused by the substitution of valine for glutamic acid in the beta hemoglobin chain, leading to abnormal hemoglobin synthesis and the production of sickled red blood cells, which are inelastic, sticky, and rigid [9]. Due to the severity of SCD, which can result in mortality, especially among children, there has been a pressing need to spread awareness about managing the disease and supporting those affected by it. Therefore, this study was carried out in a sample population residing in the Al-Darb governorate, Jazan region, to evaluate their knowledge and awareness of sickle cell anemia.

Aim of the work: This study aims to assess the knowledge and attitudes of Al-Darb governorate residents in the Jazan region regarding sickle cell anemia.

METHODS

Study design and population: A cross-sectional study was carried out among the Al-Darb population. Data was collected over 2 months, from January 2024 to March 2024.

Sample size: Al-Darb is a governorate in the Jazan region of Saudi Arabia with a population of 69,134, of which 24% are non-Saudis [10]. The study utilized a non-probability sample, calculated using the online Raosoft sample size calculator.

Data Collection: Data was collected using a structured, closed-ended online questionnaire designed by the

researcher. The questionnaire, distributed online in Arabic via social media, included 3 sections:

- Section I: Demographic data
- Section II: Individuals' awareness about sickle cell disease
- Section III: Individuals' attitudes towards the disease.

Content validity and reliability: To ensure face and content validity, the researcher enlisted the knowledge and experience of five experts, including three from the nursing department and two from the community health department in Ain Shams University, Egypt. These experts provided valuable input that refined the questionnaire by removing unnecessary phrases and rephrasing statements. This collaborative effort aimed to enhance the relevance and clarity of the content, ensuring comprehensive coverage of individuals' knowledge and attitudes towards sickle cell disease. The reliability of the developed tools was evaluated through Cronbach's alpha test.

Pilot study: A pilot study was conducted with 10% of the total study sample to evaluate the feasibility, clarity, and applicability of the study tools. Participants in the pilot study were subsequently excluded from the main study sample.

Data analysis: Following data collection, the information was revised, coded, and entered into IBM SPSS version 23 for statistical analysis.

RESULTS

This descriptive study was conducted among individuals in the Al-Darb governorate to assess their awareness and attitudes towards sickle cell disease using a closed-ended online questionnaire divided into 3 sections. These sections included demographic information, knowledge about sickle cell anemia, and attitudes toward the disease. A total of 316 valid questionnaires were used for statistical analysis. The results, presented in Table 1 and Figure 2, revealed that 76.9% of participants were female. The age group with the highest representation was 15-25 years, comprising 48.7% of the sample. Among the participants, one hundred and seventy-two (54.4%) were married, while 132 (41.8%) were single. The largest occupational category was students (33.9%), followed by housewives (20.6%), and workers in the education sector (15.2%).

Table 1. The results of the questionnaire about demographic information.

Demographic data		n	%
Age	15-25	154	48.7
	26-35	91	28.8
	36-45	40	12.7
	46-55	24	7.6
	> 55	7	2.2
Gender	Male	73	23.1
	Female	243	76.9
Marital status	Single	132	41.7
	Married	172	54.4
	Widower	2	7.3
	Divorced	10	20.6
Occupation	Health sector	13	4.1
	Education sector	48	15.2
	Private sector	23	7.3
	Housewives	65	20.6
	Students	107	33.9
	Others	13	4.1

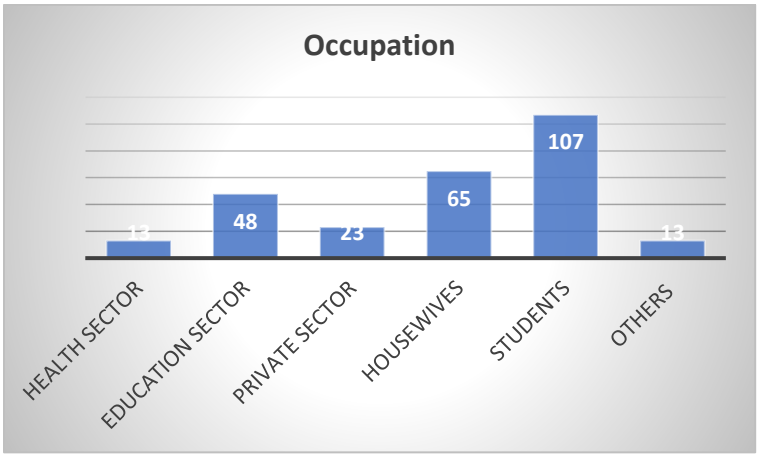


Figure 2. Categories of participants by occupation.

Table 2 and Figure 3 depict the response ratios to the inquiries regarding individuals' knowledge and familiarity with sickle cell disease. Overall, 96.5% of participants reported awareness of the disease, with the majority learning it from friends (25.6%) and family (27.5%), followed by the Internet and social media (21.8%) and healthcare workers (10.8%). A significant portion (82.3%) recognized sickle cell disease as hereditary. Approximately 77.2% of participants were knowledgeable about the methods of diagnosing the disease, and 91.5% were aware of its symptoms. However, only half of the respondents were familiar with the complications of the disease. Additionally, only 38% believed that undergoing a medical examination before marriage is crucial in preventing the disease. Lastly, 70.3% believed that the symptoms of sickle cell anemia vary across different age groups.

Table 2. Results of the questionnaire regarding awareness of sickle cell anemia among participants.

Awareness data		**n**	%
Have you ever heard about sickle cell anemia?	Yes	305	96.5
	No	11	3.5
If the answer is (yes), what is the source of the information?	Healthcare workers	34	10.8
	The internet	69	21.8
	Friends	78	25.6
	Family	81	27.5
	The school	30	9.5
	Others	1	0.3
What is the classification of sickle cell anemia?	Hereditary	15	4.7
	Acquired	260	82.3
	I don't know	41	31
What is the main cause of the disease?	Defect in the gene responsible for the formation of hemoglobin	210	66.5
	Nervous system disorder	7	2.2
	I don't know	99	31.3
How is the disease diagnosed?	Hemoglobin blood test	244	77.2
	Hormone analysis	8	2.5
	I don't know	64	20.3
What are the most important complications of sickle cell anemia?	Stroke	18	5.7
	Acute chest syndrome	74	23.4
	All the above	183	57.9

Awareness data		n	%
	It has no complications	41	13
Is sickle cell anemia contagious?	Yes	13	4.1
	No	303	95.9
What are the risk factors?	Both parents are carriers of the disease or infected	119	37.7
	One of the parents is a carrier of the disease and the other is infected	31	9.8
	All the above	157	49.7
	There are no risk factors	9	2.8
Is there a cure for the disease?	There is no cure, but there are medications to prevent problems associated with the disease	287	90.8
	There is an effective treatment for the disease	29	9.2
How is the disease prevented?	Get tested before marriage	120	38
	See a genetic counselor before making the decision to have children in case of infection	11	3.5
	All the above	168	53.2
	I don't know	17	5.4
What is the difference between sickle cell anemia and Fe- deficiency anemia?	SCA is the breakdown of red blood cells	92	29.1
	Fe-deficiency: The blood cells are healthy, but their number is less than normal	14	4.4
	All the above	182	57.6
	No differences between them	28	8.9
Do the symptoms of sickle cell anemia differ depending on the age group?	Yes	222	70.3
	No	94	29.7

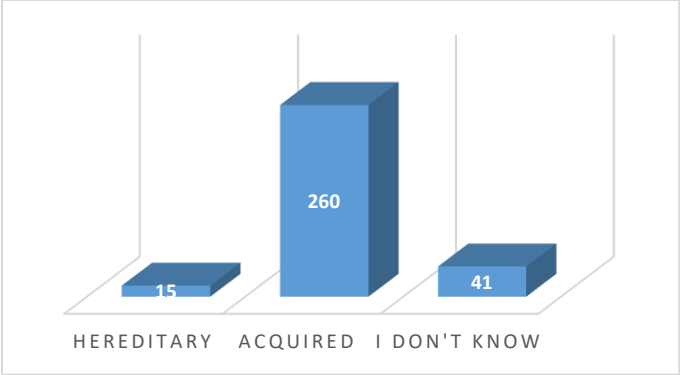


Figure 3. Classification of sickle cell anemia by participants.

Out of the total respondents, 9.5% had sickle cell anemia, and 23.7% had a family history of the disease. A total of 23.1% believed that one of the most important preventive methods for sickle cell anemia is undergoing a medical examination before marriage. While 9.8% favored medical awareness and follow-up, 61.7% chose all the suggested methods. Additionally, 94% of participants knew that sickle cell anemia patients should undergo periodic tests, and 88% agreed that genotype affects marital decisions and plays an important role in choosing a life partner. Furthermore, 86.7% of participants believed that pregnant women, the elderly, and children who are infected with or carriers of sickle cell anima should be receive periodic follow-ups. More than half of respondents (52.5%) were unaware of locations for care and follow-up for sickle cell anemia patients in their city. Additionally, 88.3% are uncertain about the types of healthy foods for sickle cell anemia patients. The findings are detailed in Table 3 and Figure 4.

Table 3. Results of the questionnaire regarding individuals' attitudes toward the disease.

Attitude data		n	%
Do you have sickle cell anemia?	Yes	30	9.5
	No	286	90.5
Is one of your family members infected?	Yes	75	23.7
	No	241	76.3
What is your familial relationship to the person with sickle cell anemia?	Spouse	3	0.9
	Children	19	6
	Brothers	37	11.7
	Others	257	81.3
If one spouse is infected, will the chance of having an infected child be higher?	50% of children are infected	184	58.2
	All children are infected	15	4.7
	There are no infected children	12	3.8
	Children carrying the disease	105	33.2
What are the preventive procedures for sickle cell anemia?	Medical awareness and follow-up of the patient's condition	31	9.8
	Medical examination before marriage	73	23.1
	All the above	195	61.7
	I don't know	17	5.4
Should an anemia patient undergo periodic testing?	Yes	297	94
	No	19	6
Do you think that pre-marital examination is necessary?	Yes	307	97.2
	No	9	2.8
Does genotype affect marital decisions?	Yes	278	88
	No	38	12
Which groups of people with sickle cell anemia or carriers of the disease should receive periodic follow-up?	Children	21	6.6
	Pregnant women	16	5.1
	The elderly	5	1.6
	All the above	274	86.7
Should a preventive plan be followed for infected children?	Yes	302	95.6
	No	14	4.4
Do you know about locations for care and follow-up for sickle cell anemia patients in your city?	Yes	150	47.5
	No	166	52.5
What are healthy foods for sickle cell anemia patients?	Bread and whole grains	5	1.6
	Vegetables containing starches	12	3.8
	Dairy products	3	0.9
	Leafy vegetables	17	5.4
	All the above	279	88.3

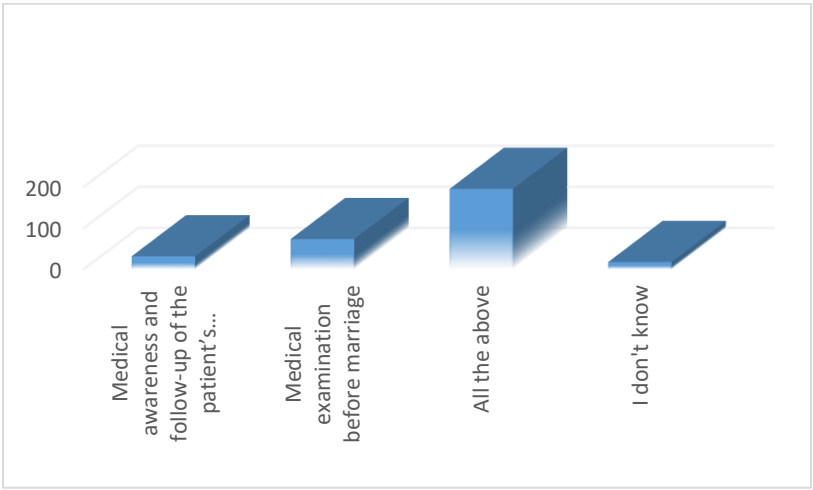


Figure 4. Preventive procedures for sickle cell anemia according to participants.

DISCUSSION

Sickle cell anemia is a recessive disorder affecting the formation of hemoglobin molecules, which carry oxygen to the body's cells. Individuals with this disorder produce hemoglobin S, causing red blood cells to deform into a crescent or sickle shape, impairing their function. Awareness of the disease, its prevention, and treatment varies across different societies [11]. Functional foods, known for their health benefits and role in managing chronic diseases, have been linked to the treatment of sickle cell anemia. These foods are readily available, cost-effective, and have fewer side effects. They play a significant role in reducing the frequency and severity of sickle cell crises and managing the disease [12-13].

Regarding the study's demographics, 76.9% of the respondents were female, a trend also observed in other studies where females participated more than males [14-15]. This discrepancy might be due to survey distribution errors or greater willingness among females to respond. In terms of marital status, over half of participants (54.4%) were married, likely because married individuals and those planning families have a heightened interest in hereditary health issues. In the knowledge assessment section, 96.5% of participants reported being aware of the disease, which is expected given the high prevalence of sickle cell disease in Saudi Arabia. This aligns with findings from previous studies that indicate people generally have good prior knowledge about the disease [8, 16-17]. The primary sources of information were family, the Internet, and healthcare workers. This is unsurprising, as family is often a primary source of knowledge for individuals. Additionally, the Internet provides widely accessible information, reflecting the participants' sufficient general knowledge about the disease.

More than half of the participants were aware that complications of sickle cell anemia include acute chest syndrome, difficulty breathing, and stroke, though 13% believed there were no complications. This finding is consistent with a study conducted in Dammam [5, 18]. Evidently, there is a gap in knowledge about the risk factors associated with sickle cell anemia complications. However, most participants did recognize that having both parents as carriers and having the disease are the most important risk factors.

Regarding the behavior of individuals toward patients and managing the disease, among the infected participants (9.5%), only half were aware that the disease is inherited, and 61% knew how to prevent it. Moreover, a large percentage understood the necessity of pre-marriage examinations, as genotype affects the decision to marry. However, less than half were aware of the locations for care and follow-up for sickle cell anemia patients in their city, as well as the recommended nutrition methods for these patients. In another study on the attitudes of unmarried adults toward sickle cell disease, Adigwe et al., 2022 suggested that their research could guide the stakeholders in issuing policies to reduce the spread of the disease [17]. The results of the current study also agreed with those of Albagshi et al., 2019, who found that about 89% of students had heard of sickle cell disease, although fewer knew how common it was in Saudi Arabia [16]. It is worth mentioning the potential of functional food products to enhance the health of people with chronic diseases [19-20]. Current research strongly recommends their role in treating and preventing the symptoms and complications of sickle cell anemia, reducing crisis and reverse sickling [21-22].

CONCLUSION

This study aimed to assess the general knowledge, awareness, and behavior of the population in the Al-Darb governorate regarding the symptoms, complications, and transmission of sickle cell anemia. Overall, most participants demonstrated an acceptable level of knowledge about the disease, along with general awareness transmission methods and prevention measures. However, there is a clear need for increased community awareness in educating about proper

nutrition, correcting misconceptions about the disease, and introducing blood disease centers to the study population.

RECOMMENDATIONS

This study underscores the importance of hosting awareness programs to disseminate crucial information about sickle cell disease among community members in the Al-Darb governorate. These programs could include school visits; community activities utilizing innovative methods, such as video clips and multimedia; and workshops led by healthcare professionals at educational institutions and community centers. The aim is to enhance public awareness about the disease's risk factors, complications of sickle cell disease, locations for care and follow-up, and the inclusion of functional foods in treatment programs for sickle cell disease patients.

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Conflicts of interest: No conflicts of interest are associated with this study.

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