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ORIGINAL

Awareness of Sickle Cell Disease in the Eastern Region of Saudi Arabia: Study of Medical Specialty Students

Nivel de conocimiento sobre la enfermedad de células falciformes en la región oriental de Arabia Saudita: estudio de estudiantes de especialidades médicas

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ABSTRACT

Introduction: sickle cell disease (SCD) is a major health challenge in Saudi Arabia due to its high prevalence, and healthcare providers play a key role in reducing the prevalence of this genetic disorder.
Objective: to assess awareness and knowledge of SCD among medical specialty students in various medical programs and to explore its differences based on the sociodemographics of participants.
Method: the study included a cross-sectional survey of 302 medical students across different years of study at Medical College in the eastern region of Saudi Arabia. Participants completed a self-administered questionnaire developed based on a literature review. Descriptive analysis using SPSS V 26 and inferential analyses were utilized.
Results: while 61,6 % of participants felt they had sufficient SCD information, only 45 % had previously received SCD education or awareness training. Only 6,6 % reported experiencing college problems due to SCD. Most participants demonstrated good knowledge of SCD's cause, transmission, prevention, and diagnosis. However, fewer were aware of risk factors for children of carriers (6,6 %), the disease's prevalence in Saudi Arabia (45 %), or the possibility of curing SCD through stem cell transplant (49,7 %). The study found married respondents were more aware of SCD than single or divorced students.
Conclusion: while medical students grasp SCD basics, more targeted educational initiatives are needed, especially around risk factors and prevalence, to enhance awareness and control the high SCD rate in Saudi Arabia, particularly in the eastern region where it is most common. Expanding SCD education programs in medical institutions could improve future providers' knowledge.

Keywords: Eastern Region; Knowledge; Medical Specialties; Saudi Arabia; Sickle Cell Disease; Students.

RESUMEN

Introducción: la anemia de células falciformes (SCD) es un importante desafío de salud en Arabia Saudita debido a su alta prevalencia, y los proveedores de atención médica desempeñan un papel clave en la reducción de la prevalencia de este trastorno genético.
Objetivo: evaluar la conciencia y el conocimiento sobre la ECF entre estudiantes de especialidades médicas en varios programas médicos y explorar sus diferencias según la sociodemografía de los participantes.
Método: el estudio incluyó una encuesta transversal de 302 estudiantes de medicina en diferentes años de

estudio en la Facultad de Medicina de la región oriental de Arabia Saudita. Los participantes completaron un cuestionario autoadministrado desarrollado en base a una revisión de la literatura. Se utilizó análisis descriptivo mediante SPSS V 26 y análisis inferencial.
Resultados: mientras que el 61,6 % de los participantes sentían que tenían suficiente información sobre la ECF, sólo el 45 % había recibido educación o formación de concienciación sobre la ECF anteriormente. Sólo el 6,6 % informó haber experimentado problemas universitarios debido a la ECF. La mayoría de los participantes demostraron un buen conocimiento de la causa, transmisión, prevención y diagnóstico de la ECF. Sin embargo, menos eran conscientes de los factores de riesgo para los hijos de portadores (6,6 %), la prevalencia de la enfermedad en Arabia Saudita (45 %) o la posibilidad de curar la ECF mediante un trasplante de células madre (49,7 %). El estudio encontró que los encuestados casados eran más conscientes de la ECF que los estudiantes solteros o divorciados.
Conclusión: si bien los estudiantes de medicina comprenden los conceptos básicos de la ECF, se necesitan iniciativas educativas más específicas, especialmente en torno a los factores de riesgo y la prevalencia, para mejorar la conciencia y controlar la alta tasa de ECF en Arabia Saudita, particularmente en la región oriental donde es más común. Ampliar los programas educativos sobre SCD en instituciones médicas podría mejorar el conocimiento de los futuros proveedores.

Palabras clave: Región Oriental; Conocimiento; Especialidades Médicas; Arabia Saudita; Anemia Falciforme; Estudiantes.

INTRODUCTION

Sickle cell disease (SCD) is one of the most common hemoglobinopathies worldwide. The significance percentage of SCD varies among different regions in Saudi Arabia, with the highest prevalence rate recorded in the eastern region of Saudi Arabia.[1]

In comparing the prevalence of SDC among regions in Saudi Arabia, it was found that there is a high prevalence in the Eastern region, followed by the Southern region.[2] Sickle cell trait states in Saudi Arabia range between 2 and 27 %, while for SCD, there is a 1,4 % higher prevalence rate found in the Eastern Province region with 21 % trait and 2,6 % SCD.[3]

SCD is an autosomal recessive disorder homozygosity (β^S/β^S). As a result, two alleles are needed to produce the phenotypic characters, as illustrated in figure 1. The most heterozygosity situations would be exhibiting an asymptomatic utmost state in which the individual has only a risk for transferring the gene into offspring.[4]

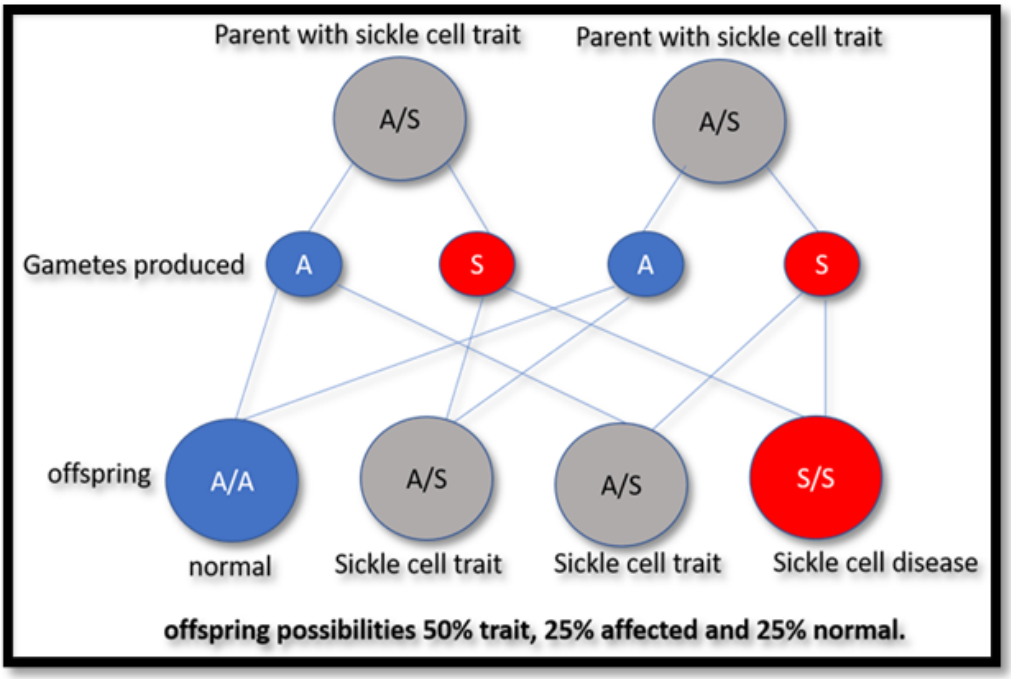

Figure 1. Mode of inheritance for SCD

SCD is caused by substituting glutamic acid with valine in the beta chain of hemoglobin (figure 2), eventually

producing abnormal hemoglobin called HbS. Polymerization Characteristic of HbS leads to decreased oxygen affinity and dehydration of the cell. As a result, it produces abnormal red blood cells, accelerates the destruction, and eventually reduces the life span of red blood cells. In some cases, clinical features are clarified by hemolytic anemia and crises.[5]

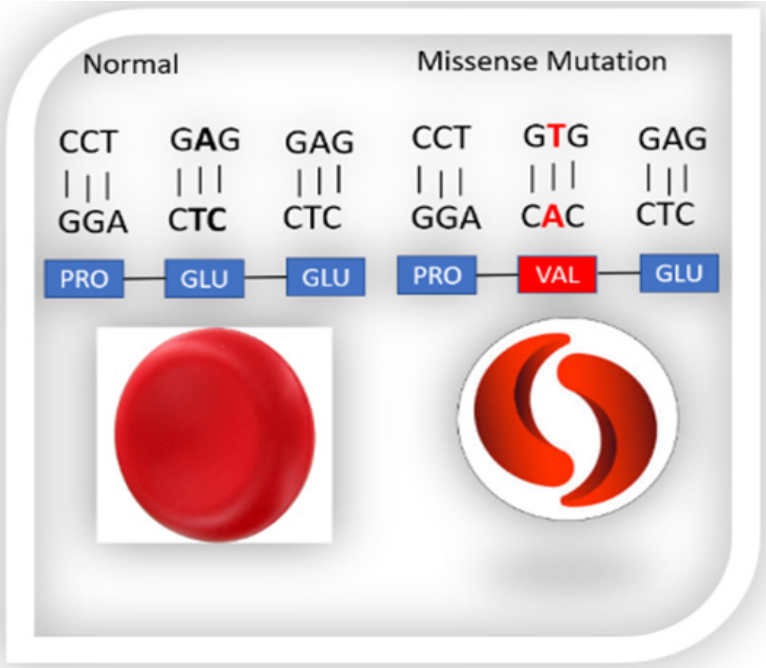

Figure 2. The genetic changes in hemoglobin in SCD

In 1910, SCD was discovered in the United States by James B. Herrick. In 1949, SCD was classified as an autosomal recessive disorder by Dr. James Neel.[6] In addition, Dr. Linus Pauling has identified changing mobility in the electrophoresis pattern among sickle cell hemoglobin compared to normal hemoglobin.[7]

In the 1960s, the first case was described in Saudi Arabia. Since then, several examinations have been conducted to identify clinical manifestations and the causative genes in SCD.[8] However, there have been challenges in diagnosing and treating the disease worldwide. Till the mid-20th century, there were dramatic changes, especially in life expectancy for the disease.[9]

The treatment for SCD was first to relieve the symptoms for a short period and prophylaxis against complications. Moreover, blood transfusion may be required for severe hemolysis.[10] However, the iron overload state is a consequence of recurrent transfusion, which must be chelated as treatment. Also, some dangerous pathogens may be transmitted through the transfusion. The only treatment which is successfully performed for severe cases is allogeneic hematopoietic transplantation. However, it was very limited by the availability of donors and matching those donors to the patients. Moreover, it has side effects and complications, such as rejection and graft versus host disease.[11]

For the study's significance, several cross-sectional studies have been conducted to test the knowledge and perception of SCD of the general public inside and outside Saudi Arabia to find unsatisfactory knowledge and negative attitudes toward SCD.[12,13,14] In contrast, a good level of knowledge about SCD was found in another study.[15] In addition, 21 % had a negative attitude toward the disease among college students.[16] The overall studies indicate the need for improved education and awareness of SCD.

Our study was conducted to evaluate the extent of knowledge among medical college students about SCD and assess the need to improve education and awareness about SCD among them. The study could be utilized to identify any gap in the literature on this concern and to know the lack of medical specialty students' knowledge and work on constructing an educational program that incorporates all necessary information about SCD and focuses more on the SCD in the curriculum of all medical specialties, including nursing, clinical laboratory, pharmacy, and others. The current study aimed to explore medical college students' knowledge about SCD and identify discrepancies in their knowledge based on the sociodemographic characteristics in the Eastern region of Saudi Arabia.

Research hypothesis: Medical specialty students have satisfactory knowledge about SCD in the eastern region of Saudi Arabia.

METHOD

The study used a descriptive, analytic, cross-sectional research design to gather data from medical specialty

students at a selected medical college. The study was conducted in 2023 at Mohammed Al-Mana College for Medical Sciences (MACHS)- a private medical specialty College in the eastern region of Saudi Arabia.

Based on a stratified random sampling selection from the full list of registered students, a representative sample of 302 undergraduate students was chosen from all departments of MACHS to participate in the study. Students from all departments, including pharmacy, clinical laboratory, nursing, physiotherapy, and respiratory care, from all levels were the target population. Based on the power statistical analysis and sample size estimation (figure 3), 300 students were required to participate in the current study, of which there were a total of 1350 students at the college.[17]

Population size(for finite population correction factor or fpc)(*N*): 1350
Hypothesized % frequency of outcome factor in the population (*p*): 50%+/-5
Confidence limits as % of 100(absolute +/- %)(*d*): 5%
Design effect (for cluster surveys-*DEFF*): 1

Sample Size(*n*) for Various Confidence Levels

ConfidenceLevel(%)	Sample Size
95%	300
80%	147
90%	226
97%	350
99%	446
99.9%	602
99.99%	714

Equation

Sample size $n = [DEFF*Np(1-p)]/ [(d^2/Z^2_{1-\alpha/2}*(N-1)+p*(1-p)]$

Figure 3. Sample size estimation
Source: OpenEpi Epidemiologic Statistics for Public Health [17]

A self-administered questionnaire that the researchers developed built on the recent literature review was forwarded to the participants via email to be filled out, considering all scientific research standards. Data was collected using an electronic English survey designed by the researchers based on the recent literature review.

The survey consisted of two parts; the first gathered information about the students' sociodemographic characteristics, including their age, gender, and specialty, while the second part gathered data about the participants' knowledge of SCD using ten multiple-choice questions.

To assess the content validity of the questionnaire, it was sent to three experts in nursing and clinical laboratory specialties for evaluation, and their feedback confirmed the questionnaire's validity. Moreover, the questionnaire was piloted on 20 students to test the clarity and feasibility. Additionally, test-retest reliability was applied through the administration of the survey to a sample of college students, similar to the participants of the inclusion criteria, two times with a short time apart to find that Cronbach's alpha coefficient was 0,812, reflecting the acceptable reliability of the questionnaire. However, the responses were excluded from the final results report.

After data collection, data analysis was performed using the IBM SPSS Statistics 26.[8] The findings analysis used descriptive statistics like mean and standard deviation, as well as the frequency and percentage. T-test and ANOVA were used for inferential statistics to identify the significance of differences in student's knowledge based on some sociodemographic characteristics.

The study extended over nine months in 2023 from obtaining ethical approval from the MACHS Institutional Review Board (IRB) (Decision No. SR/RP/100, meeting # 86) to the distribution of the questionnaires and data collection, passing through statistical analysis, and writing the conclusions and the final report of the research manuscript.

The participant's identity was protected by assigning numbers to their responses. Anonymity, confidentiality, and autonomy to participate in the study were preserved. All ethical considerations of scientific research were strictly followed in this study.

RESULTS

The current study aimed to explore college students' knowledge about SCD in the eastern region of Saudi Arabia. The responses were obtained from 302 undergraduate students from a medical college. presents the sociodemographic characteristics of the participants and reflects that the majority of participants were female

(85,4 %) and single (77,5 %). The age distribution was 18-20 years (29,1 %), 21-23 years (55,6 %), and 24 years and more (15,2 %). The academic years were mostly 3rd year (39,7 %), and the specialties were mainly nursing (40,4 %) and respiratory care (34,4 %).

Table 1. Sociodemographic characteristics of the participants (N=302)

Sociodemographic data		**n**	**%**
Gender	Male	44	14,6 %
	Female	258	85,4 %
Age	18-20 years	88	29,1 %
	21-23 years	168	55,6 %
	24 years and more	46	15,2 %
Marital status	Single	234	77,5 %
	Married	62	20,5 %
	Divorced	6	2,0 %
Academic year	1st year	50	16,6 %
	2nd year	40	13,2 %
	3rd year	120	39,7 %
	4th year	50	16,6 %
	5th years or more	42	13,9 %
Specialty	Nursing	122	40,4 %
	Respiratory Care	104	34,4 %
	Physiotherapy	22	7,3 %
	Pharmacy	32	10,6 %
	Clinical Laboratory	22	7,3 %

Table 2 shows that most participants (61,6 %) reported having sufficient information about SCD. However, only 45 % of participants reported receiving an educational session or having previously been exposed to a specialized awareness program about SCD. In addition, 6,6 % of participants reported having suffered problems at college due to SCD.

Table 2. Exposure to SCD information (N=302)

Exposure to SCD-related education		n	%
Do you consider that you have enough information about sickle cell disease?	Yes	186	61,6 %
	No	116	38,4 %
Have you received an educational session or been exposed to a specialized awareness program about SCD previously?	Yes	136	45,0 %
	No	166	55,0 %
In case you were diagnosed with sickle cell disease, have you suffered any problems at college due to sickle cell disease?	I am not carrier nor diseased with SCD	186	61,6 %
	No	96	31,8 %
	Yes	20	6,6 %

Figure 4 represents the SCD-related knowledge among the participants. The participants were asked ten questions related to SCD, and the results showed that they had a good understanding of the disease and satisfactory knowledge about most SCD issues. The figure shows that the majority of participants knew about the cause of SCD (76,8 %), the mode of transmission (82,8 %), preventive measures (94,7 %), and how SCD is diagnosed (96,7 %). However, only a minority knew about the risk of children becoming sickle cell patients if both parents are carriers (6,6 %), the prevalence of SCD in Saudi Arabia (45 %), or the possibility of curing SCD through stem cell transplant (49,7 %).

Figure 5 presents descriptive statistics of a knowledge scale among the participants, indicating a relatively good understanding of SCD. Therefore, the proposed research hypothesis is accepted based on the findings of the analysis. The mean score on the knowledge scale was 65,56 %, with a minimum score of 20 and a maximum score of 100. The standard deviation was 17,20, indicating a relatively wide range of participant scores.

Table 3 presents the regression analysis results with the knowledge score as the dependent variable and gender, age, marital status, academic year, and specialty as independent variables. The table shows that marital status had a statistically significant positive association with the knowledge scale (beta=0,181, p=0,004), indicating that participants who were married had higher knowledge scores than those who were not. None of the other independent variables had a statistically significant association with the knowledge scale.

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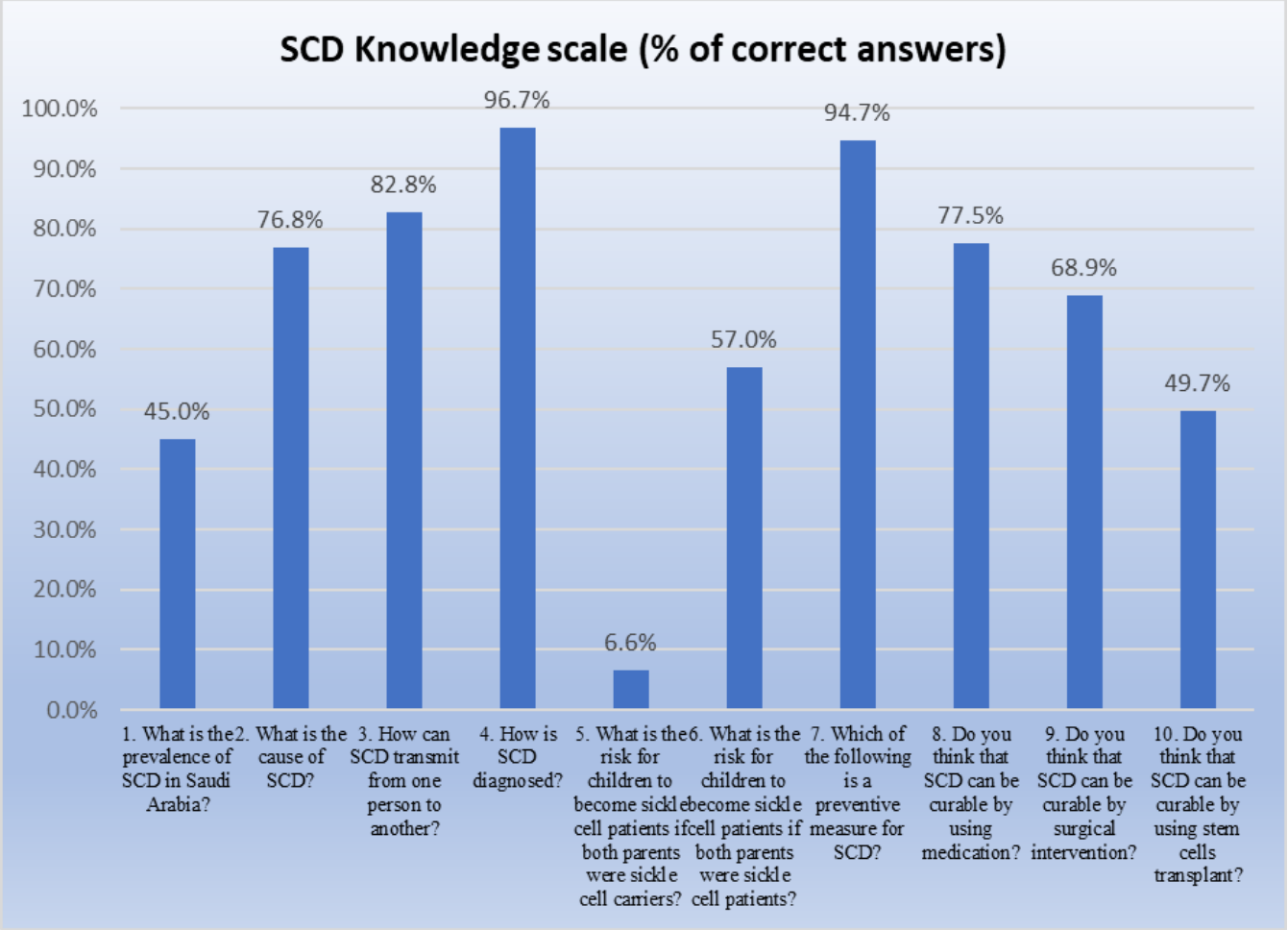

Figure 4. SCD-related knowledge among participants (N=302)

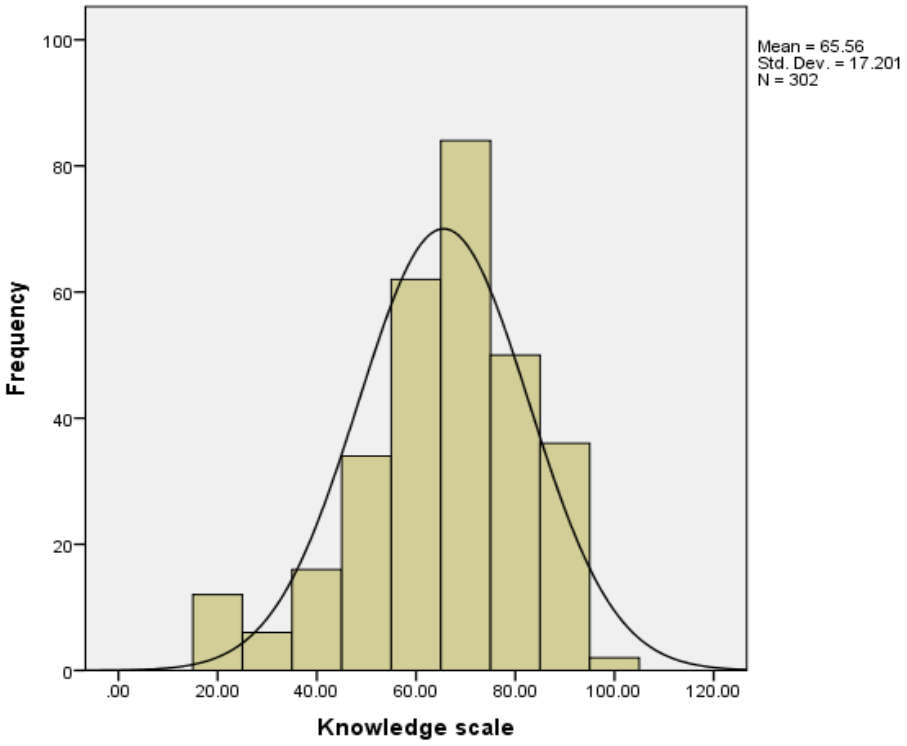

Figure 5. Description of the knowledge scale of the participants

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Table 3. Predictors of participants' knowledge about SCD from their sociodemographic data

Regression Model B		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		Std. Error	Beta			
1	(Constant)	54,323	7,097		7,654	,000
	Gender	1,442	2,955	,030	,488	,626
	Age	,166	1,928	,006	,086	,931
	Marital status	6,572	2,285	,181	2,876	,004**
	Academic year	-,087	,896	-,006	-,097	,923
	Specialty	,159	,791	,012	,201	,841

a. Dependent Variable: Knowledge score
** Significant at 0,01

Table 4 presents the results of ANOVA multiple comparisons for the marital status variable concerning the knowledge scale. The Scheffe test was used to compare the mean difference between the marital status groups: single, married, and divorced. The table shows a statistically significant difference in mean knowledge scores between single and married participants (mean difference=-8,91, p=0,001), indicating that married participants had significantly higher knowledge scores than single participants. The knowledge mean score for married participants was also higher than that for divorced. There were no statistically significant differences in mean knowledge scores between the other marital status groups.

Table 4. Discrepancy in participants' knowledge about SCD based on their marital status

ANOVA -Scheffe (I) Marital status		Mean Difference (I-J)	Std. Error	Sig.	95 % Confidence Interval	
					Lower Bound	Upper Bound
Single	Married	-8,90543*	2,41059	,001	-14,8356	-2,9752
	Divorced	-2,99145	6,97756	,912	-20,1567	14,1738
Married	Single	8,90543*	2,41059	,001	2,9752	14,8356
	Divorced	5,91398	7,21547	,715	-11,8365	23,6645
Divorced	Single	2,99145	6,97756	,912	-14,1738	20,1567
	Married	-5,91398	7,21547	,715	-23,6645	11,8365

Dependent Variable: Knowledge scale
* The mean difference is significant at the 0,05 level.

Table 5 presents the difference in participants' knowledge about SCD based on their previous exposure to information about SCD using an independent sample t-test. The table shows that participants who reported having enough information about SCD had a significantly higher mean knowledge score (M=70,32) than those who did not (M=57,93), with a p-value of less than 0,01. However, the table shows no significant difference in knowledge score between participants who had previously received an educational session or been exposed to a specialized awareness program about SCD and those who had not.

Table 5. Difference in participants' knowledge about SCD based on previous exposure

		N	Mean	Std. Deviation	Std. Error Mean	t-test P-Value
Do you consider that you have enough information about sickle cell disease?						
Knowledge scale	Yes	186	70,3226	14,51572	1,06434	0,000**
	No	116	57,9310	18,43990	1,71210	
Have you received an educational session or previously been exposed to a specialized awareness program about SCD?						
Knowledge scale	Yes	136	66,3235	15,76723	1,35203	0,177
	No	166	64,9398	18,31532	1,42154	

** Significant at 0,01

DISCUSSION

This study aimed to evaluate the level of understanding and awareness of SCD among undergraduate medical college students in the eastern region of Saudi Arabia. Most respondents (84,5 %) were females, which may reflect a greater eagerness to participate and a higher interest in SCD, a trend observed in other studies. For

instance, a study in Bahrain noted that females were significantly more aware of SCD and its prevalence in Gulf countries and were more eager to learn about treatment and preventive measures compared to males. [19] Conversely, the percentage of female and male participants in another study about SCD from Bahrain was almost the same (50,2 % and 49,8 %, respectively).[20]

The current study revealed that a significant proportion of respondents (61,6 %) considered themselves adequately informed and aware of SCD despite more than half not being exposed to any awareness or educational programs about the disease. This highlights a substantial gap in educational initiatives targeting this population. Alarmingly, a very low proportion of respondents (6,6 %) were aware of the risk factors of SCD in children with carrier parents, indicating a crucial need for targeted educational interventions to address this knowledge gap. Additionally, nearly half of the respondents were unaware of the stem cell transplant options available for SCD patients. This aligns with another study in Saudi Arabia that attributed the lack of awareness about transplant options to the low consideration of stem cell transplants among patients.[21]

Furthermore, the study found an interesting trend regarding marital status, as married individuals had much higher awareness levels compared to divorced and single individuals about SCD, with a mean difference of 8,90 in knowledge scores. Conversely, single individuals reported the lowest level of awareness regarding SCD-related issues. This contrasts with another study in Saudi Arabia, which found that single individuals, predominantly females, were significantly more aware of SCD-related issues than married respondents.[22]

Overall, this study indicates that college students have a satisfactory level of knowledge about SCD (Mean score = 65,6). In a study that was carried out on medical students at Al-Baha University in Saudi Arabia, the study found that the majority of male participants (89,6 %) and all female participants (100 %) demonstrated good awareness of SCD.[23] Oppositely, a study conducted in 2015 in Eastern Saudi Arabia found that 56,3 % of respondents had poor knowledge of SCD, suggesting that awareness has increased over time in this region.[22]

Furthermore, as this study involved students specializing in medical fields, a notable 77,5 % knowledge score was observed regarding the curability of SCD with medications, indicating sufficient knowledge in this area. In contrast, studies conducted elsewhere in Saudi Arabia, where respondents were not affiliated with health-related disciplines, reported a markedly lower knowledge score of 49 %.[21] This discrepancy suggests a correlation between academic background and awareness levels, indicating that individuals pursuing healthcare degrees tend to possess a higher understanding of SCD and its potential for treatment or cure.

Comparisons of this study with African studies evaluating awareness among citizens reveal that African students have a higher knowledge score than the respondents in this study. The awareness score in the current research stands at 65,56 %, less than the rates observed in African regions where students and participants had a knowledge score exceeding 80 %.[24,25,26]

A significant percentage of respondents in this study were well aware of the diagnosis (96,7 %), preventive measures (94,7 %), and transmission of SCD from parents to children (82,8 %), as reflected in their knowledge scores. However, it is discouraging to note that only 6,6 % of the students were aware of the risk of SCD in children with carrier parents. These findings are also highly similar to those found in another study performed in Bahrain.[19] Additionally, only 49,7 % of respondents were aware of stem cell transplants as a treatment option for SCD. This data is supported by another study conducted in Saudi Arabia, where respondents severely lacked awareness regarding stem cell transplants and did not consider it a treatment option.[21] Despite the relatively high level of general awareness, comprehensive knowledge regarding risk factors and treatment approaches was found to be lacking among the respondents, which is concerning as the majority belong to nursing and respiratory care.

The respondents' primary sources of information regarding SCD were in a previous study the internet, media, disease awareness programs, and educational programs.[26] Astonishingly, only 45 % of respondents in the current study had been exposed to educational programs regarding SCD, while a significant portion (55 %) mentioned never having been exposed to such programs.

Approximately 68,9 % of respondents were aware of surgical interventions and their potential to cure SCD. This is an encouraging percentage, especially compared to another study where respondents were found to be unaware of surgical interventions and their potential to manage SCD treatment.[27]

The statistical analyses presented in the discussion provide valuable insights into the observed differences and relationships within the data. In Table 5, the t-tests reveal significant disparities in mean knowledge scale scores between respondents based on their awareness level and exposure to educational sessions on SCD. The associated p-values depict the statistical significance of these differences, and the results show that participants who reported having enough information about SCD had a significantly higher mean knowledge score than those who did not. Moreover, the regression analysis results in Table 3 revealed that the marital status of the participants was the only significant independent predictor of their knowledge about SCD. Participants who were married had significantly higher knowledge scores about SCD than those who were not, as shown in table 4. These statistical measures enhance the overall understanding of the data provided.

These findings emphasize the importance of tailored educational campaigns to enhance awareness and

knowledge surrounding SCD, especially for the younger generation about to get married. In Saudi Arabia, SCD is now being taught among school children to raise awareness at an earlier age, preventing the progression of the disease and reducing the chances of consanguineous marriages, which have been linked to the rapid progression of SCD.[28] Such constructive policies will further expand citizens' knowledge of effectively preventing and managing SCD.

CONCLUSIONS

The level of awareness among college students in the eastern regions of Saudi Arabia was recorded and evaluated. The data indicated that most respondents were well aware of the transmission, diagnosis, and treatment of SCD. However, only a few were aware of the risk factors for children with carrier parents. There was a notable lack of awareness programs, as most college students had not experienced such programs in their educational institutions.

Additionally, married respondents were more aware of SCD than single and divorced respondents, which is crucial as it is integral for mothers to be aware of the risk factors for the progression of SCD in children. Currently, educational programs regarding SCD are increasing in Saudi Arabian educational institutions, but further enhancement is necessary to ensure awareness that can help control the prevalence of SCD, especially in the eastern regions where it is most prevalent.

RECOMMENDATIONS

To increase awareness of SCD among medical students, several strategies can be implemented. Firstly, increasing the number of workshops in colleges would provide students with more opportunities to learn about SCD in a hands-on, interactive manner. Secondly, incorporating scientific chapters related to SCD into the curricula of various programs would ensure that all students receive comprehensive education on this disease, regardless of their specific field of study.

Additionally, enhancing the community service activities offered by colleges could raise awareness among the entire population, with a particular focus on young females who have shown a keen interest in SCD issues. Finally, expanding screening programs for the early detection of both cases and carriers is crucial. Early detection can lead to better management and prevention of SCD, ultimately reducing its prevalence in the population. These combined efforts would significantly enhance the overall understanding and awareness of SCD among medical students and the wider community.

Limitations

The study employed a cross-sectional research design and relied solely on a self-reporting questionnaire without conducting interviews. Additionally, conducting the research within a college environment limited the age diversity of the participants.

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