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Original article

Sickle Cell Anemia: Knowledge and Attitudes Toward the Disease Among the Population in Western Libya

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Abstract
Sickle Cell Disease (SCD) is one of the most common hereditary disorders worldwide, with variable prevalence across Libya. While high rates are observed in the Marzouk and Taourga populations, most other regions report lower incidence. Existing literature underscores the urgent need for improved public education and awareness regarding SCD. This study assessed the level of SCD awareness among college students, healthcare workers, and the general population in western Libya, aiming to identify gaps and inform future awareness programs. A cross-sectional questionnaire-based survey was conducted among healthcare workers, medical students, and the public. The instrument, prepared in English and translated into Arabic, was distributed both electronically (Google Forms) and in printed form. It comprised 15 items assessing SCD knowledge and awareness. Data were summarised as frequencies and percentages, and associations were evaluated using the Chi-square test. Of 999 respondents, 739 (74%) had heard of SCD, with the highest proportion among healthcare workers (46%), followed by college students (40%) and the general public (13%). The most common source of information was college education (349; 47.2%). Awareness was significantly higher among females (78%) than males (65%), with females demonstrating greater overall knowledge. Awareness of SCD in western Libya is moderate overall, with notable differences by gender and occupation. Healthcare workers and college students exhibited both higher knowledge levels and healthier attitudes toward preventive behaviours, including marriage decisions. These findings highlight the need for targeted educational campaigns, integrating SCD into broader health education initiatives to enhance public understanding and preventive practices.
Keywords: Sickle Cell Awareness, KAP, West Libya.

Introduction

Sickle Cell Disease (SCD) is one of the most common monogenic blood disorders, primarily affecting red blood cells and associated with significant morbidity and mortality [1]. Globally, an estimated 100 million individuals carry the sickle cell trait (SCT), and according to the World Health Organization, more than 300,000 infants are born each year with SCD [2]. The highest burden is observed in sub-Saharan Africa, where the majority of affected children fail to survive beyond the age of five [3]. SCD comprises a group of autosomal recessive genetic disorders of the red blood cells, caused by a single-point mutation (Glu→Val) in the β-globin gene. This mutation results in the production of abnormal haemoglobin S, which polymerises under deoxygenated conditions, distorting red blood cells and impairing normal blood flow [4]. These pathophysiological changes lead to recurrent vaso-occlusive crises and a range of severe complications. Patients frequently require hospitalisation, and pain, often affecting the abdomen, lower back, joints, and chest, is a hallmark symptom [5].

In Libya, population-based studies have reported regional variability in SCD prevalence. A national screening program documented a generally low frequency of SCD [6]. However, data from southern Libya indicate a considerably higher prevalence in certain communities. In the Marzouk region, the sickle cell trait (HbAS) was identified in 53.34% of individuals, while sickle cell anaemia (HbSS) was present in approximately 10% of the population. Additionally, 0.95% of cases exhibited sickle cell–haemoglobin C (HbSC) disease [7]. The same study reported a high rate of consanguinity (72%), suggesting that interrelated marriages are a major contributing factor to the elevated HbAS prevalence in the region [7]. Similarly, a study in the Taourga region, located in central Libya, found haemoglobin S in 12.5% of the 491 individuals tested, comprising 4.3% of males and 8.4% of females, indicating that SCD represents a significant public health concern in this community [8]. Sickle cell disease (SCD) remains a significant global health concern, posing considerable challenges to healthcare systems. Despite its impact, there is limited information on public awareness and understanding of the condition, particularly in Libya. This study was designed to evaluate the knowledge and attitudes toward SCD in western Libya, with a focus on three key groups: college students, healthcare workers, and the general public. By identifying gaps in awareness, the findings can serve as a needs assessment to guide future educational and preventive initiatives.

Materials and Methods

Study Design and Setting

A cross-sectional study was conducted between April 2024 and September 2025 among college students, healthcare workers, and residents in western Libya to assess knowledge and attitudes toward sickle cell disease (SCD).

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Survey Instrument
The questionnaire was developed in English and translated into Arabic to enhance accessibility, with back-translation performed to ensure accuracy. It contained yes/no and multiple-choice questions aimed at assessing awareness, perceptions, and attitudes toward SCD, as well as relevant sociodemographic information (e.g., gender, age). Attitudinal items explored perceptions of the disease, its impact, and preventive measures.

Participants and Recruitment
Participants were recruited through two modes: (1) in-person administration, where questionnaires were completed in the presence of the researcher, and (2) online distribution via a secure Google Forms link. The first page of the online survey outlined the study objectives, the voluntary nature of participation, and the right to withdraw before submission.

Measurements and Data Collection
The primary questionnaire, completed by 999 participants, comprised 15 items. A pilot test involving 30 participants was conducted to evaluate question clarity, and minor adjustments were made accordingly. Content validity was assessed by two independent subject matter experts, who reviewed each item for relevance and alignment with study objectives. Both single- and multiple-response items were included, with predetermined correct and incorrect answers where applicable.

Ethical Considerations
The study protocol was reviewed and approved by the Department of Molecular Biology and Biochemistry, Faculty of Sciences, Sabratha University. Written consent was not required as no biological samples or personally identifiable data were collected; verbal informed consent was obtained from all participants. Names and signatures were omitted from the questionnaires, and both paper and electronic responses were collected directly by the research team to ensure confidentiality.

Data Analysis
Data were coded and summarized in Microsoft Excel, then analyzed using SPSS version 26 (IBM Corp., Armonk, NY, USA). Categorical variables were reported as frequencies and percentages. Associations between demographic/occupational variables and SCD-related knowledge and attitudes were assessed using the Chi-square (x^2) test. Statistical significance was set at $p < 0.05$

Results

Knowledge of Sickle Cell Disease among residents in Western Libya
A self-administered questionnaire was distributed to college students, healthcare workers, and members of the general public in western Libya. In total, 999 questionnaires were distributed; however. The sample comprised 392 college students (39.5%), 406 healthcare workers (40.5%), and 201 members of the general public (20%). Females accounted for 663 participants (66.5%), while males represented 336 (33.5%). More than half of the respondents (55%) were under 25 years of age (Table 1).

Table 1. Demographic profile of the participants (n=999)

Demographical Characteristics	N	%
Gender		
Males	336	33.5
Females	663	66.5
Age		
20-30	451	45
31-45	379	38
>45	169	17
Occupation		
Healthcare workers	406	40.5
Students	392	39.5
General public	201	20

Of the 999 participants surveyed, 739 (74%) reported having heard of SCD. Awareness was highest among healthcare workers (46%), followed by college students (40%) and members of the general public (13%) (Table 2). Among those aware of SCD, 78% of female respondents answered “yes” to Q1 (“Have you heard of SCD before?”), compared with 65.5% of male respondents. Awareness was also significantly higher among healthcare workers (84%) and college students (76%) than among the general public (47%) (Table 2).

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Table 2. Participants' answers for the questions (n=999)

Question	N=999	%	M (n=336)	F (n=663)	HC (n=406)	S (n=392)	P (n=201)
Q1/Have you heard of SCD before?							
Yes	739	74	220 (65%)	519 (78%)	343 (84%)	301 (77%)	95 (47%)
No	260	26	116 (%35)	144 (%22)	63 (16)	91 (23)	106 (53%)

As shown in Table 3, the most frequently reported source of information about SCD was college education (349 participants; 47.2%), followed by the internet or other media sources (23.3%). Regarding disease knowledge, 75% of respondents correctly identified SCD as an inherited blood disorder, and 70% recognised heredity as its cause. Knowledge levels were lower among the general public for these questions. The vast majority of participants (92%) knew that SCD is diagnosed by a blood test, with no significant differences between the study groups. Only 26% of participants correctly answered that all children of two parents with SCD will also have the disease. Knowledge of inheritance patterns was highest among genetic students, with 32% answering this question correctly. Most participants (68%) did not know the estimated life expectancy of individuals living with SCD, and more than half correctly identified potential complications, with no significant differences among the groups.

More than half of respondents were unaware of whether a cure exists for SCD and did not know the appropriate action for a person of childbearing age diagnosed with the disease. Premarital screening was identified by over half of the participants as the main preventive measure, and this proportion increased to 82% when they were asked directly whether premarital screening for SCD is necessary. Except for the general public, 71.4% of respondents stated that a partner's genotype would influence their decision to marry. Similarly, 63% indicated they would not marry someone with SCD. Finally, 82.2% of participants reported they would seek medical advice or genetic counselling if they discovered their genotype put them at risk of having a child with SCD (Table 3).

Table 3. Occupation-based and Gender-based comparison of answers (n=739)

Q2/From where have you heard about SCD	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Health care worker	164	22.2	30	18.4	34.98	8.9	15.7
Internet/media	172	23.3	26.81	21.7	17.7	23.5	42.1
Friends	31	4.5	5.45	4.23	3.25	4.3	10.5
Family	20	2.7	2.72	2.67	0.87	2.19	10.5
College	349	47.2	35.05	53.1	43.19	61.1	21.1
			p-value = 0.02		p-value = 0.01		
Q3/What is sickle cell disease?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Inherited blood disorder	558	75.5	72.27	76.3	83.09	69.64	60
Infectious disease	15	2	0.9	2.5	1.45	2.99	0
Sexually transmitted	4	0.54	0.45	1.15	0.87	1.39	1.05
I Don't Know	162	21.9	26.36	20.03	13.7	25.91	38.94
			p-value = 0.117		p-value =0.01		
Q4/What is the cause of SCD?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Acquired	77	10.4	11.81	9.82	6.99	12.9	18.9
Hereditary	517	69.9	66.36	71.67	76.9	66.11	54.7
I don't know	145	19.6	21.81	18.5	16.03	20.93	28.1
			p-value = 0.38		p-value = 0.01		
Q5/How is SCD diagnosed?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
By blood test	682	92	90.5	93.3	96.2	87.7	91.6
Urinary Test	8	1.08	2.3	0.57	0.29	1.7	3.2
I Don't Know	49	6.6	7.27	6.35	3.4	10.6	5.3
			p-value = 0.603		p-value = 0.09		
Q6/What is the risk for children to become sickle cell patients if both parents are sickle cell patients?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
All the children	197	26.6	24.54	27.16	21.57	31.89	26.31
A quarter of the children	105	14.2	17.27	12.9	18.95	10.29	13.68
Half of the children	188	25.4	22.72	26.58	26.23	25.54	22.1

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I Don't Know	249	33.6	35.45	32.98	33.23	32.29	37.89
			p-value = 0.60		p-value = 0.12		
Q7/What is the estimated life expectancy of people living with sickle cell disease	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
75 years	73	9.8	15	7.51	11.07	6.9	13.6
20 years	111	15	13.18	15.79	18.07	13.6	8.4
35 years	194	26	25	26.78	26.53	26.9	23.2
40 years	240	32	40.45	29.09	34.69	28.2	37.9
I Don't Know	121	16.3	6.36	20.8	9.62	24.3	16.8
			p-value = 0.88		p-value = 0.44		
Q8/What medical complications are caused by sickle cell disease	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Stroke	72	9.7	13.18	8.28	11.37	6.9	12.63
Lung tissue damage	27	3.6	5.45	2.89	3.49	2.9	1.5
Pain episode	61	8.2	12.72	6.35	8.16	4.9	18.9
All of the above	403	54.5	48.18	57.22	58.6	52.2	47.3
I Don't Know	176	23.8	20.45	25.24	18.36	32.8	19.7
			p-value = 0.33		p-value = 0.22		
Q9/Is there a cure for sickle cell disease?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Yes	383	51.8	56.36	49.9	44.6	52.8	74.7
No	323	43.7	36.36	46.82	50.5	42.8	22.1
I Don't Know	33	4.4	7.27	3.27	4.95	4.38	3.1
			p-value = 0.06		p-value = 0.63		
Q10/What is the appropriate action for a person of childbearing age diagnosed with sickle cell disease?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Exercise	14	1.8	3.18	1.34	2.3	1.32	2.1
Vitamins	61	8.2	10.45	7.37	7.78	6.9	14.7
Genetic counseling	324	43.8	31.85	48.94	46.93	45.1	27.4
Prevention medicine	221	29.9	41.81	25	32	24.9	37.89
I Don't Know	119	16.1	12.7	17.34	11	21.26	17.89
			p-value = 0.4		p-value = 0.33		
Q11/Which of the following is a preventive measure for SCD?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Medical advice	88	11.9	35.4	30.3	32.9	27.5	42.1
Pre-marital screening	413	55.8	50.9	57.9	58.3	56.5	45.2
I don't know	238	32.3	13.6	11.7	8.7	15.9	12.6
			p-value = 0.89		p-value = 0.51		
Q12/Do you think it is necessary to do the pre-marital screening for SCD?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Yes	607	82.15	85.9	80.53	77.84	87.72	80.5
No	125	16.9	12.72	18.68	20.69	11.6	18.62
I Don't Know	7	0.94	1.36	0.77	1.46	0.68	0.98
			p-value = 0.46		p-value =0.45		
Q13/Can your partner's genotype influence the decision to marry them?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Yes	528	71.4	68.63	72.63	71.72	77.55	50
No	196	26.5	28.63	25.62	26.53	20.1	40.19
I Don't Know	15	2	2.72	1.73	1.74	2.38	9.8
			p-value = 0.33		p-value = 0.08		
Q14/If your partner has SCD, are you going to marry them?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Yes	252	34	31.36	35.56	31.19	32.69	42.45
No	467	63	63.63	62.69	66.47	65	47.67
I Don't Know	20	2.9	5	1.73	2.04	2.38	9.88
			p-value = 0.56		p-value = 0.36		
Q15/What should a couple do if they discover that their genotypes predispose them to give birth to a child with SCD?	**739**	**%**	**M (n=220)**	**F (n=519)**	**HC (n=343)**	**S (n=301)**	**P (n=95)**
Separating	49	6.6	9.54	5	6.99	4.46	8.82
Continue with married life	24	3.2	4.54	3.27	4.34	1.06	9.94
Consult a doctor (Genetic Counselling)	608	82.2	74.54	85.56	81.96	87.07	69.5

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I Don't Know	58	7.8	11.36	6.16	6.7	7.48	11.76
			p-value = 0.65		p-value = 0.66		

Discussion

This study aimed to assess the level of knowledge regarding sickle cell disease (SCD) among the population in western Libya, to identify the need for targeted awareness campaigns, particularly for the younger generation. Although the survey included both male and female adult participants, the data analysis revealed a marked gender disparity in participation, with females representing 66.5% of all responses. Similar trends have been reported in previous studies, where female respondents outnumbered males, reaching 87.5% in some cases (9, 10). Possible explanations for this imbalance include the absence of many men due to work commitments or a generally lower willingness among men to engage in such surveys, a finding also reported in earlier studies [10].

Results indicate that the majority of participants (74%) had heard of SCD, suggesting a general awareness of its existence. Notably, there were significant gender differences in responses, consistent with the findings of [11]. Among women, 78% reported prior awareness of the disease—a noteworthy observation given the relatively low incidence of SCD in Libya, particularly in the northern region. Occupational differences in knowledge were also evident, with statistically significant variations among the general public, students, and healthcare workers. As anticipated, prior knowledge was highest among medical staff (84.5%) and university students (77%). These findings align with previous reports [9,12], which similarly observed substantial awareness of SCD among student populations.

Furthermore, the analysis revealed differences in the primary sources of information across occupational groups, with distinct patterns among healthcare workers, students, and the general public. For both students and healthcare workers, the most common source of information about SCD was college. This finding is consistent with previous studies [12,13], which reported that schools serve as the primary source of information on SCD. This may be attributed to students' access to educational resources, such as the Internet, and the inclusion of hereditary disease topics in their curriculum. In many schools, SCD and other genetic conditions are covered in social studies, making formal education an important channel for disease awareness. Similar results were reported by previous studies [12,14] in which schools accounted for 36.4% of SCD information sources, followed by radio (5.7%), television (9.8%), and internet/social media platforms (6.7%). These findings suggest that the integration of SCD-related content into university curricula has a positive impact on students' knowledge. In contrast, the general public predominantly relied on the internet and media for information. The internet, in particular, offers accessible and immediate information, especially for younger individuals. Comparable patterns were observed by Albagshi and Alghamdi [9,15], who also identified online platforms as a major source of SCD information. However, the fact that only a small proportion of respondents reported obtaining such information from healthcare professionals or community-based initiatives highlights a potential gap in health education within clinical and public health settings.

When asked about the cause of SCD, 70% of participants correctly identified it as a hereditary condition, indicating a generally sound understanding of the disease's nature. Comparable results have been reported in studies assessing SCD knowledge among university students [9.16,17]. Similarly, in a study done among students in Saudi Arabia, most respondents were able to identify its genetic basis [12]. In contrast, Oluwadamilola and Namukasa [12,13] found that fewer than one-third of their participants could correctly define the disease. The present study also revealed significant differences in knowledge between participant groups. As expected, the majority of healthcare workers and students demonstrated an accurate understanding of the disease and its causes. This contrasts with findings by Tusuubira [10], who reported a relatively lower proportion of participants with knowledge of SCD aetiology, possibly reflecting broader knowledge gaps that could hinder disease control strategies.

Regarding diagnostic methods, 90% of participants correctly identified the use of a blood test for SCD detection. This high proportion is likely due to the overrepresentation of healthcare workers and genetics students in the sample. Similar findings were reported by Ghimire [18], where 63.1% of respondents recognized that SCD can be detected through blood testing. In contrast, Tusuubira et a [10] observed much lower awareness of diagnostic methods among the general public, highlighting the influence of participant background on knowledge levels.

When asked how many children could be affected if both parents had SCD, only 27% of participants answered correctly. This result highlights a notable knowledge gap regarding the inheritance patterns of the disease, even among students and healthcare workers who are expected to have received relevant instruction. Similar trends have been observed in previous research. For example, Boyd [19] reported that only 9% (15/162) of students demonstrated an accurate understanding of SCD inheritance patterns, while Osbourne [20] found that just 25% of participants answered such questions correctly. These findings suggest that many individuals remain unaware that they may be carriers of the sickle cell gene and therefore at risk of having children with either SCD or the sickle cell trait. In contrast, the present study found that 82.7% of participants recognised that carriers can pass the sickle cell gene to their offspring. Similarly, Tusuubira [10] reported that more than half (54.0%) of their respondents understood that SCD is inherited

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from both parents. Together, these results indicate that while there is general awareness of carrier transmission, detailed knowledge of specific inheritance probabilities remains limited.

Similarly, when asked about the estimated life expectancy of individuals living with SCD, only 32% of participants provided the correct answer. Regarding recognition of SCD complications and the challenges faced by affected families, approximately half of the respondents answered correctly. In terms of preventive measures, 60% of students and healthcare workers correctly identified premarital screening as a strategy to prevent SCD transmission. This relatively high proportion is likely due to the inclusion of genetics students and healthcare professionals in the study sample. Comparable findings have been reported by Albagshi and Oluwadamilola [9,12], where approximately three-quarters of participants answered premarital screening questions correctly.

Overall, participants demonstrated a positive attitude toward all attitude-related questions. When asked about the importance of premarital screening, 88% of college students, 78% of healthcare workers, and 82% of all participants agreed on its necessity. Furthermore, when asked whether a partner's genotype could influence the decision to marry, 82% of respondents answered affirmatively. These findings reflect a generally accurate understanding of the implications of SCD in marital decision-making.

In the demographic analysis of knowledge and attitude, females were significantly more knowledgeable than males, suggesting that awareness campaigns may need to place greater emphasis on engaging male audiences. Occupational comparisons also revealed expected differences, with a clear knowledge gap between the general public and both students and healthcare workers. The findings of this and other studies [9,10,11,12] highlight the importance of health authorities providing targeted awareness of SCD through social media and other communication channels to reach all age groups effectively. Further, the analysis revealed that the educational level of respondents was statistically associated with awareness of SCD, including knowledge, sources of information, and perceptions of the disease. The students and healthcare workers demonstrated significantly greater understanding and more informed perceptions compared to those in the general public. These results are consistent with the findings of Awad [11], Alzahrani [21]. [6], Shahin [22], and [23], who similarly reported that individuals with higher educational attainment have greater access to health information and are better equipped to comprehend complex medical concepts such as SCD. While respondents in the present study generally exhibited moderate knowledge of SCD, there remains a need to improve attitudes and practices related to the disease. Knowledge alone is insufficient; its application toward prevention and control is equally essential. To enhance preventive practices and reduce the burden of SCD, university colleges, identified in this study as the primary source of information, should place greater emphasis on educating students about how to apply their knowledge in practical ways to prevent disease transmission.

Limitations

As with any research, this study has certain limitations. The sample was restricted to medical and genetics students, excluding students from other disciplines who may have less exposure to SCD in their academic curriculum. As a result, the findings may overestimate the general level of knowledge, and different outcomes might have been observed with a larger, more diverse sample that included students from non-medical fields.

Additionally, the questionnaire used in this study had specific limitations. It did not include questions assessing whether participants themselves had SCD or knew someone living with the disease. Such information would have been valuable in determining whether familiarity with SCD was influenced by direct personal or social exposure, potentially affecting both knowledge and attitudes toward the condition.

Conclusion

The study results revealed a moderate overall awareness of sickle cell disease (SCD) among respondents, with particularly low knowledge regarding genotype screening tests and their benefits. Awareness levels varied by gender and occupation, although healthcare workers and college students demonstrated a notably positive attitude toward SCD. These groups exhibited responsible behaviors regarding marriage decisions, reflecting a sound understanding of the disease. Conversely, the questionnaire highlighted a significant knowledge gap among the general public. Given that college students represent the future generation of parents and thus have a critical role in influencing the prevalence of SCD, it is imperative to enhance their knowledge and promote effective practices. Since educational institutions were identified as the primary source of information in this study, schools and colleges should prioritize not only increasing awareness but also equipping students with practical strategies to prevent the transmission of SCD.

Conflict of interest. Nil

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