Perceptions of Sickle Cell Disease Among Undergraduate's University Students in Selected University At KSA

Shereen Ahmed AhmedQalawa[1 2]*, Manal Tharwat Soliman[3 4]
[1]Department of Medical-Surgical Nursing, College of Nursing, Qassim University, KSA
[2]Professor of Medical-Surgical Nursing Department, Faculty of nursing, Port-Said University, Egypt
[3]Nursing Department, College of Applied Medical Science, University of Hafr Albatin,
[4]Medical - Surgical Nursing, Mansoura University Egypt

Abstract
Background: Hemoglobin disorders such as Sickle cell disease (SCD) have been acknowledged to be of great public health concern by the World Health Organization (WHO) in 2016. To reduce the tremendous public health and economic burden SCD exerts on many countries, the WHO is urging countries, especially those in Africa, to increase public awareness of the disease. Such awareness programme among the university students will go a long way to prevent the birth of children with this painful genetic condition. Aim: To assess the level of perception with SCD, among undergraduate students of the University of hafr Albatin KSA. Subject and methods: A descriptive cross-sectional study was carried out. A total of 172 participants were selected using multistage sampling technique. Data was collected using a self-administered questionnaire and analyzed using SPSS software, version 25. Results: there are a statistically significant correlation between student's anxiety during exams and their quality of life ((p <0.001). Conclusion &recommendations: In general, there was inadequate knowledge on SCD despite the high level of awareness among participants. Recommendation: Findings of the study highlights the need for continuous effective health education on sickle cell disease to students whose reproductive health choices will either increase or decrease the sickle cell disease burden in the very near future.
Keywords: Sickle cell disease, Undergraduate's University students, Perception.

1. Introduction

Sickle cell disease is a genetic blood sickness with varied clinical inconsistency, which disposes patients to additional complications and recurrent hospitalizations (Faremi et al.,2018) . It is the most public, genetic, blood disorder in the USA according to Genetic Home Reference. Approximately 100,000 individuals are affected individuals of African origin (Centers for Disease Control and Prevention ., 2020) However , Sickle-cell disease (SCD) is considered as a group of genetic disorders characterized by abnormally shaped red blood cells (RBCs), which are removed from the circulation and destroyed at increased rates, leading to anemia (Lonergan et al 2021) which linked with abnormal hemoglobin and sickle-shaped red blood cells that result in vaso-occlusion,ischaemia, tissue damage, progressive organ damage and early death (Ballaset al.,2019, Darbariet al.,2018, Olo-woyeye & Okwundu ., 2020). It is generally characterized by chronic pain with periods of acute, severe pain (called pain crises) that occur all over life and are often unpredictable (Howard & Oteng-Ntim., 2021). Bone marrow or stem cell transplantation is the only preserve for SCD but this is not possible for various because of limited, potential donors. The presence of hemoglobin S is the key pathological factor for the development of SCD. When hemoglobin S becomes deoxygenated, it forms aggregates with other hemoglobin molecules within the RBCs (Centers for Disease Control and Protection.,2019). In addition to anemia, SCD can lead to blood vessels obstruction and infarction of different body organs. A point mutation in the gene coding the β chain of the hemoglobin molecule resulted in a single amino acid substitution (valine for glutamic acid), which leads to hemoglobin S. It is appraised that more than 200 000 babies are born with the disease each year in Africa alone (Weatherall., 2018).

In addition, it is a widespread syndrome among those from Mediterranean area countries like Turkey and the Arabian Peninsula (Piel et al., 2020). Recently, a marked enhancement in life expectancy and quality of life among SCD patients have been recounted, which is mostly recognized to the progress in general prophylactic and other curative actions (Elion et al.,2021). Nevertheless, appropriate public health alertness about SCD and its complications remains a significant item in the controlling of SCD.

Moreover, the success of pre-marital screening in the prevention of sickle cell disease has been found to be subjective by the knowledge and attitudes of community participants regarding sickle cell disease and how it is treated (Elion et al.,2021).

Key target populations for any sickle cell prevention fights in the community as students especially those in tertiary institutions because most of them are unmarried and may be considering on finding suitable marriage spouses which numerous researches

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(Motulsky., 2018 &Gravitz and Pincock.,2019) have reported that more than half of couples enter marriage inattentive of their sickling position. Aditionally, Vassiliou et al., 2020 have documented low levels of knowledge on sickle cell diseases and pursued to assess the knowledge, attitude, and perception in the direction of Sickle Cell Disease among students at the University of hafr Albatin.

As individual's intention to endure daily activities and live a good life even with having a chronic illness (Audulv., 2017), challenges often arise. This is particularly true for young adults living with SCD ages 18-39 with experience of the highest rates of pain crises, typically between ages 18 and 25, there is a high risk of early death (Yusuf et al.,2018 & Quinnet al.,2019). Furthermore, young adults are not knowledgeable of the adult SCD care system and they have limited decision-making (Jenerette & Brewer., 2019)

Therefore, Health care is additional significant feature of SCD management. Attainment access to this care is often difficult. In general, African Americans experience less access to care than Caucasians, they experience higher rates of being uninsured are most likely to use the emergency department (ED) for primary care (Cheatham et al.,2018), United States Department of Health and Human Services, (Agency for Healthcare Research and Quality.,2020). Individual's with SCD experience disease trials that result in a deficiency of awareness, thus financial poverties. Altogether, these factors limit the ability of young adults with SCD to regularly access health care and/or afford some management modalities. There is also a lack of providers with SCD capability, especially in low-income areas (Sobotaet al.,2019). Few care properties are available to those who are uninsured and there are likely to be compensation issues and low incomes linked with coverage through support programs; providers are less appropriate to receive patients with this type of coverage. Accordingly, young adults with SCD often use the ED as a primary source of care.

Aim

To assess the level of perception with sickle cell disease (SCD) among undergraduate students of the University of hafr Albatin KSA.

2. Research Question

What are the awareness levels of sickle cell disease among undergraduate's students in selected KSA University?

Conceptual framework

Awareness is considered as a perception of the actions being carried out by members of a team in a given background. The usage of alertness support diminishes the power required to recognize unrestrained jobs. Hence, this leads to a growth in group work efficiency by taking the dimension of awareness into consideration Gallego et al.2011 through Key dimensions of conceptual framework (Fig.1)

** Fig 1. Presenting by Kortjan & Von Solms., 2014*

3. Subjects and Methods

A descriptive cross-sectional design was utilized in this study at the healthy and non-healthy Colleges, University of Hafr Al-Batin (UHB), and KSA on convenience sampling of all available students during the data collection period from both health & non health Colleges (172) students. The inclusion criteria of participants entail their approval to participate in the study.

Tools

One tool was used after revised literature divided into 2 main parts as follows

Part (I): It includes student's Sociodemographic characteristics of university students as (age, sex, marital status, and level, etc).

Part (II): It includes awareness of students on sickle cell disease: it includes 10 selected items adapted from Al-ghubishi et al., 2021 and Khalifa et al.,2022 addressing student's perception of sickle cell anemia as risk factors, causes, diagnosis, preventive measure, etc.

Scoring system

All questions in the tool were scored according to model answer for corrected one and the total perceptions scores of the tool was classified as when it was Low <50%, Moderate 50–<75%, High ≥75%.

Content validity

Validity was used for the modified tool to assure that it covers the objectives. The phase was developed by a Jury of five experts from Medical-surgical and pediatrics Health nursing staff at the College of Nursing, Qassim & Hafr Al-Batin (UHB) Universities, KSA. Reliability of the proposed tool was done using Cronbach's alpha test which revealed high reliability (.950).

A pilot study was done on 20 students to approximation the clarity of the tool then excluded them from the total sample number. The questionnaire

sheet submitted online and then contact the students via their what's-up media and explain the purpose of the study to them and invited them to participate in the study though an online link also the sheet contains a paragraph explain the study aim and assuring them that their participation was voluntary and they have the right to withdraw at any time.

Ethical Considerations

The study was approved verbally by the Applied Medical Sciences College administrative authority. Additionally, the participants were informed online of research purpose before they start to answer the questionnaire by the Google form and their answers would be kept confidentially and the answers not affect or interfere with their evaluation.

4. Statistical Analysis

Data were fed to the computer and analyzed using IBM SPSS software package version 20.0. (Armonk, NY: IBM Corp) Qualitative data were described using number and percent. The Kolmogorov-Smirnov test was used to verify the normality of distribution Quantitative data were described using range (minimum and maximum), mean, standard deviation, Significance of the obtained results was judged at the 5% level. The used tests were Mann Whitney test for abnormally distributed quantitative variables, to compare between two studied groups ; Kruskal Wallis test for abnormally distributed quantitative variables, to compare between more than two studied groups.

5. Results

Table (1) illustrates a total of 172 students who participated in the study, (67.4%) of the students were female in the age 20-22 years followed by (90.7%) of them single. Additionally, nearly half (48.3%) of them in the fourth level. The highest number of participating students (91.3%) was lived with their family. Finally, (76.7%) from health colleges ,(59.9 %) of them from Nursing Department in the applied health College.

Table (2) shows that (91.3 %) of the students haven't a sickle cell anemia followed by (40.7%) of them have good and enough eating pattern. Additionally, more than half (69.8%) of them neither not sure nor sure to do something to relieve the pain. On the other hands, (43.6%) heard about Sickle cell diseases from their study

As indicated in Table (3), Mean± SD of knowledge was 55.67 ± 27.32 while the total mean scores of knowledge were 62.50.

Table 4: shows that there are statistically significant correlations between student's knowledge and their demographic data only in the item related to student's level of study ((p = 0.015).

Table 5: shows that there is no statistically significant relationship were found between student's knowledge levels with their type of college

Table (1): Distribution of the studied students according to demographic data (n = 172)

Demographic data	No.	%
Age		
below 20 year	17	9.9
20-22	116	67.4
22-24	34	19.8
More than 24 year	5	2.9
Gender		
Male	37	21.5
Female	135	78.5
Marital status		
Single	156	90.7
Married	12	7.0
Divorced	4	2.3
Living with		
Single	10	5.8
Family	157	91.3
Friends	2	1.2
Others	3	1.7
Level		
First	16	9.3
Second	26	15.1
Third	47	27.3
Fourth	83	48.3
College Name		
Health Colleges	132	76.7
Non health colleges	40	23.3
College of applied medical science Nursing Department Clinical laboratory Department Health information management and technology Department Medical College Pharmacy College Engineering and computer science College Science College	103 12 7 13 4 18 15	59.9 7.0 4.1 7.6 2.3 10.4 8.7

Table (2): Distribution of the studied students awareness of SCD (n = 172)		
	No.	%
Are you have sickle cell anemia?		
No	157	91.3
Yes	15	8.7
If you have what 's the duration of Sickle cell anemia with you?		
Didn't have	148	86.0
Below 5 years	13	7.6
5-7 year	6	3.5
7-10 year	2	1.2
More than 10 year	3	1.7
Eating Pattern		
Anorexia nervosa	9	5.2
Anorexia	20	11.6
Poor eating pattern	41	23.8
Moderate eating pattern	32	18.6
Good and enough eating Pattern	70	40.7
Are you sure that can do something to relieve the pain		
Not sure	52	30.2
Neither not sure nor sure	120	69.8
From where have you heard about SCD		
study	75	43.6
Family	28	16.3
internet/ media	38	22.1
TV	10	5.8
Health care workers	14	8.1
friends	7	4.1

Table (3): Mean and Standard deviation of the studied students according to their knowledge regarding SCD (n = 172)		
Knowledge (0 – 8)	Total score	% score
Min. – Max.	0.0 – 8.0	0.0 – 100.0
Mean ± SD.	4.45 ± 2.19	55.67 ± 27.32
Median	5.0	62.50
SD: Standard deviation		

Table (4): Relation between student's Knowledge regarding SCD with their demographic data (n = 172)					
Demographic data	N	Knowledge		Test of Sig.	p
		Mean ± SD.	Median		
Age					
below 20 year	17	58.09 ± 22.94	62.50	H=1.332	0.721
20-22	116	56.68 ± 27.46	62.50		
22-24	34	50.74 ± 29.67	50.0		
More than 24 year	5	57.50 ± 24.37	50.0		
Gender					
Male	37	49.66 ± 28.79	50.0	U=2120.50	0.156
Female	135	57.31 ± 26.77	62.50		
Marital status					
Single	156	55.77 ± 26.58	62.50	H=0.044	0.978
Married	12	55.21 ± 36.72	62.50		
Divorced	4	53.13 ± 32.87	50.0		
Living with					
Single	10	60.0 ± 31.07	62.50	H=7.668	0.053
Family	157	56.53 ± 26.58	62.50		
Friends	2	31.25 ± 26.52	31.25		
Others	3	12.50 ± 21.65	0.0		
Level					
First	16	41.41 ± 25.71	37.50	H=10.418*	0.015*
Second	26	47.12 ± 28.79	50.0		
Third	47	55.85 ± 25.91	62.50		
Fourth	83	60.99 ± 26.72	62.50		
College Name					
Health College	132	57.10 ± 27.42	62.50	U=2297.50	0.210
Non health college	40	50.94 ± 26.76	50.0		
SD: Standard deviation U: Mann Whitney test H: H for Kruskal Wallis test p: p value for comparing between the studied categories *: Statistically significant at p ≤ 0.05					

Table (4): Relation between student's Knowledge regarding SCD with their type of College (n = 172)					
College Name	N	Knowledge		Test of Sig.	p
		Mean ± SD.	Median		
	132	57.10 ± 27.42	62.50	U=2297.50	0.210
	40	50.94 ± 26.76	50.0		
Health College Applied Health College Nursing Department	103	59.83± 26.42	66.50	H=16.749	0.053
Clinical laboratory Department	12	76.04 ± 15.50	75.0		
Health information management and technology Department	7	44.64 ± 30.50	50.0		
Medical College	13	54.81 ± 24.76	50.0		
Pharmacy College	4	78.13 ± 6.25	75.0		
Non health college					
Science college	4	39.50 ± 12.50	41.50		
Engineering and computer science	29	65.93 ± 34.17	70.75		
SD: Standard deviation U: Mann Whitney test H: H for Kruskal Wallis test p: p value for comparing between the studied categories *: Statistically significant at p ≤ 0.05					

6. Discussion

Sickle-cell disease (SCD) is considered as a cluster of hereditary disorders categorized by abnormally formed red blood cells (RBCs), which are damaged at increased rates, leading to anemia. Newly, Saudi Arabia has been revealed to have an enlarged incidence rate of SCD (Alghamdi et al,2018). Consequently, Awareness materials in a simple language that is understood by 5th-graders were helpful in educating the caregivers and in reducing children hospitalizations with SCD. (Shahine et al.,2015)

Concerning student's sociodemographic characteristics, the present study exposed that more than half of students were female in the age 20-22 years followed by the majority single, nearly half of them in the fourth level. The highest number of participating students was lived with their family. Finally, about two-third of students from health colleges and more than half of them from Nursing Department in the applied health College. These findings go in the same line with Adediran et al., 2016 who reported from their study on 265 participants containing 120 males and 145 females. One hundred and seventy-one (64.5%) participants were aware of BMT for the treatment of SCA. About 67.8% (116 of 171) of those who were aware believed SCA can be cured with BMT (p = 0.001) and 49.7% (85 of 171) of the participants accepted BMT (p = 0.001). Additionally, Adewoyin et al.,2015 revealed that Most participants of the study were aged 22 - 29 years. A great proportion (63.5%) of the participants was females. Only 17.8% of the participants had a good knowledge of SCD regardless of high level of awareness (98.4%).

In South Western Nigeria, Faremi et al., 2018 imposed on that female Student's were more than male Student's (58.4%, 47.3%). Most Students were knowledgeable about SCD and have heard of sickle cell disease through the media and concluded that high level of awareness of SCD among participants a good number still did not know their genotype despite their level of education and there is essential for health programs for targeting students in order to reduce incidence and burden of SCD, which has become a public health problem.

Regarding student's awareness of SCD, the most of students haven't a sickle cell anemia followed by below have of them have good and enough eating pattern. Furthermore, more than half of them neither not sure nor sure to do something to relieve the pain. On the other hands, below half of them heard about Sickle cell diseases from their study. These findings go in the same line with Oluwadamilola et al., 2021 In Nigeria who stressed on there are a high level of general awareness on SCD, though comprehensive knowledge as regards the numerous genotype related to SCD, tests to be prepared for genotype screening among others is low. In addition to, there area need to enhance their performance regarding the disease is highly recommended because having a good knowledge is not as significant as applying the knowledge in a way to stop the extent of the disease.

Furthermore, Smith & Brownell., 2018 necessitated on that the majority of participants (79%) reported previous SCD knowledge; however, 21% of the participants reported no previous SCD knowledge and there is a need of support for enhanced awareness for at risk groups. The deficiency of SCD knowledge among African Americans shows a necessity for enhanced education, awareness, and screening efforts geared toward at-risk populations.

Therefore, in southeast Nigeria, Ezenwosu et al, 2015 revealed that timing of awareness various as follows: following birth of a child with sickle cell disease (45 %); during marriage (21.5 %); school admission (9.6 %); during pregnancy (9.6 %); and other times (14 %). About 35.5 % of participants thought that sickle cell trait was a mild form of sickle cell disease. Radio (43.9 %), informational community meetings (27.7 %), and television (21.9 %) were recognized by participants as the most

effective method of increasing sickle cell trait awareness. Original strategies are needed to increase the proportion of individuals who are aware of their own sickle cell genotype previous to having a child with sickle cell anemia.

In Oman, Al-Azri et al,2016 emphasize on that a few participants were aware that SCD can be very painful (20.2%) and can cause strokes, infections and organ damage (20.0%). More than half (56.7%) reported that the availability of educational material on SCD or PMS was inadequate. Participants' education levels were positively associated with exact SCD knowledge ($P < 0.05$). Even with the readiness of PMS services in local health centres. Health promotion is required in Oman with the intention of increase public awareness of SCD and the significance of PMS.

Concerning, relationship between student's knowledge and their demographic data, the present study revealed that there are statistically significant relationship between student's knowledge and their demographic data only in the item related to student's level of study. These findings go in the same line with Boadu .,2018 who highlighted on that there was a restricted understanding and insufficient knowledge of SCD between the students mainly on the design of inheritance. There are a highly needs for effective public health education SCD in confidence sources such as schools, media (radio/Television), health centers and churches and essential to increase awareness level besides understanding of the child risks for SCD.

In Nigeria, Ugwu., 2016 highlighted on knowledge gaps regarding SCD between the participants. Health education should be strengthened to impact adequate comprehensive information of SCD to allow the students take knowledgeable decision towards their marriage and prevent reproduction of children affected with SCD. However, Crosby et al.,2015 stressed on the importance of demographic risk factors and maintenance the requirements for educational plans and programs for adolescents with SCD.

In KSA, Kotb et al., 2019 revealed that student knowledge total mean scores was 6.04 ± 3.02 on the pretest, which improved to 10.73 ± 3.47 on the posttest, with a statistically significant difference ($t = 15.2$, $p < 0.001$) and there was no significant difference in the responses pertaining to attitude before and after the health education intervention. These findings emphasized on the needs to improve the performance of the Saudi healthcare system in dealing with this costly inherited disease.

In India, Bindhani et al.,2020 originated that people are aware of SCD and SCT which the most of them believe that sickle cell carriers transmit the disease and they do not know that marriage between sickle cell carriers requisite to be avoided.

In Nigeria, Kanma-Okafor et al.,2022 conveyed that 63.0% had good knowledge, although less than half of them (46.3%) knew SCD to be a blood illness, whilst about two-thirds (53.1%) knew that it was an inherited condition. Over two-thirds (72.6%) were aware of their genotype. The prevalence of SCD was 2.0%, whilst 18.9% of them were carriers of the sickle cell trait.

In KSA , Albagshi et al.,2019 discovered that Females showed better knowledge than males and married people knew more about SCD than unmarried ones. There was a good level of knowledge about SCD . Also, awareness in secondary school educational program should be merged, and recommended public awareness message in media. Additionally , Ezenwosu et al .,2021 reported that Participants with tertiary education were significantly more likely to score high on the knowledge score (74.5 %) compared to individuals with lower education (53 %). Men also had significantly higher knowledge score (74.5 %) compared to women (56.2 %).

In eastern KSA, Al-Suwaid et .,2015 About 58.3% had good knowledge of the genetic transmission. The knowledge of 46.7% regarding the precipitating factors was poor. Moreover, 59.3% had poor knowledge of the nutrition of people with SCD and 81.3% had poor knowledge of the nutrition specifically with suffering G-6-PD deficiency which there is a major extensive misconception of patients with sickle cell anemia especially relating to their proper nutrition.

In Democratic Republic of the Congo, Africa , Kambale-Kombi et al.,2020 Most university students' 92.9% were knowledgeable about SCD and have heard about it through schools and/or universities (46.3%), followed by family (34.5%) and health-care workers (23.5%). Moreover, about 85.6% were unaware of the risk of children becoming sickle cell patients when both parents have SCD. To prevent SCD, pre-marital screening was cited by only 7.7% and concluded that the Kisangani university students' knowledge regarding SCD is poor and needs to be improved; education programs and motivational campaigns to be improved.

In Ghana, Obed et al.,2017 harassed on that the majority of participants were aware of their trait status (87.4%), only 29% of knowledge questions were answered correctly; participants who self-identified as having sickle cell trait did not do better. Additionally, there is an insufficiency in the knowledge of sickle cell disease among Ghanaian pregnant women. Therefore, there is the need for public education on sickle cell disease.

In contrast, Alghamdi et al.,2018 from KSA proved that more than two-thirds of the respondents (68.80%) had good knowledge about elementary of sickle cell disease. Those with poor knowledge (31.20%) were mostly younger males and works as businessmen and housewives, and all of them had no previous experience with SCD child.

Concerning, relationship between student's knowledge and their type of college, the present study revealed that there is no statistically significant

relationship were found between student's knowledge levels with their type of college. These findings go in the same line with Adewoyin et al.,2015 who considered courses related to medical sciences had significantly higher mean knowledge score. About 94.6% of the students knew their SCD carrier conditions and 80.8% were ready to avoid carrier marriages and recommended stronger works should be focused on primary prevention through public teaching and screening regarding SCD.

In North Texas, Smit & Praetorius.,2019 reported that the university students regardless types of college have a lacked awareness regarding the differences between the disease and carrier prestige, prevalence, reproductive consequences, prevention, and testing. Most students had not undergone SCD carrier screening and had no interest in screening and they recommended the implementation of The Universal Prevention strategies and should be employed in educating students regarding SCD.

7. Conclusion and Recommendations

Based on study findings we can conclude that there is a statistically significant correlation between student's knowledge and their demographic data only in the item related to student's level of study Also, there is no statistically significant relationship were found between student's knowledge levels with their type of college. From the foregoing conclusion, students must receive regular; periodic in-service educational program contains information of sickle cell disease, risk factors and how to compliance with diseases if they have it which indirectly promote their quality of life. There is an obvious need for designed scheme instructional manual regarding Sickle cell diseases. Further studies are needed to study the factors that influence university students' awareness and coping with this disease if faced rather than attitude and response actions for SCD.

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