

Awareness about Sickle Cell Disease among the Female Students in KAU-Rabigh, Saudi Arabia, 2020, A Cross Sectional Study

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Abstract

Background: In Saudi Arabia, Sickle cell disease (SCD) is a relatively common inherited disorder. In spite of obligatory premarital genetic counseling, no significant changes in SCD prevalence over the last 15 years. Awareness regarding SCD is a way in trying of controlling and modify the problem. The aim is to assess the level of awareness about people living with SCD among undergraduate female Students at King Abdulaziz University, Rabigh Branch.

Methods: A total of 351 female students were included in our cross-sectional study. Data were collected by a self-administered questionnaire.

Results: Good awareness regarding SCD was detected only in 26.78% of the participants. Association between awareness and socioeconomic data detected that most of the students with good awareness were unmarried (97.9%), a higher level of awareness was in the medical students (51.1%), and in the higher academic years (59.5% were in fifth and fourth years).

Conclusion: There was inadequate awareness of SCD, to reduce the incidence, we suggest effective public health education for sickle cell trait and SCD in strategic places such as schools, media, and health centers to address misconceptions and increase knowledge as well as an understanding of the risks of having a child with SCD and influence the personal reproductive decision.

Keywords: Sickle cell disease, Inheritance, female Students, Rabigh.

Introduction

Sickle cell disease (SCD) is an inherited autosomal recessive blood disorder^[1], and it is associated with several life-threatening complications^[1,2,3]. SCD is

one of the most common monogenic diseases in the world, with more than 300,000 babies born with SCD every year^[3,4]. In Saudi Arabia, SCD is a relatively common genetic disorder. Up to 27% of the Saudi population have the sickle cell trait (SCT), with 2.6%–

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4.2% of which being manifested as SCD^[2,5,6]. Despite, the implementation of obligatory premarital genetic counseling (PMGC), no significant changes in SCD prevalence in Saudi Arabia over the last 15 years as documented by many researchers^[1, 7, 8, 9]. Moreover, the lack of KAP concerning SCD results in an increase in the disease prevalence and a poor quality of life among the diseased persons ^[1, 2, 7, 8, 9].

Different previous studies detected variable levels of awareness about SCD. In Saudi Arabia, Al-Qattan's study^[10] detected good awareness only among 28.8% of the participant (general Saudi population in King Khalid University Hospital), while El-Hamzi's study ^[11] detected good awareness among 94.3% of participants who were attendees of conferences, symposia, and awareness lectures. Studies outside Saudi Arabia detected good levels of awareness among 93%, 96%, 17.8%, and 96% of the participant in Bahrain ^[12], Oman^[13], Nigeria^[1], and Sudan^[14] respectively.

Nowadays, SCD is considered one of the major unspoken matters Facing Saudi Arabia. Even with the developments in public healthcare procedures, still many gaps to be filled concerning the knowledge, attitude, and practice of SCD^[2,10]. Awareness regarding SCD is a way in trying of controlling and modifying the problem since society will be better prepared to take an informed decision regarding their marriage and the youths are a good entry point for interventions in a trial of controlling the prevalence of the disease ^[15].

The objective of this study is to assess the level of awareness and knowledge about people living with SCD among undergraduate female Students at King Abdulaziz University Rabigh Branch.

Materials and Methods

Study design

cross-sectional study was conducted in between October 2020 and December 2021 at King Abdulaziz University, Rabigh Branch, Female section, Saudi Arabia.

Sample size determination (Include power calculations or provide justification for their absence (pilot/feasibility study):

It was calculated by the sample size equation, the prevalence of good awareness about SCD in SA was approximately 29% ^[11], with a significance level of $\alpha=0.05$.

The minimum required sample was 316 and we will approximate it to 350 to cover the response rate and the pilot study (10% of the sample size will be calculated for the pilot study and will be excluded from the final study result) to represent a population of students enrolled at colleges at King Abdul-Aziz University calculated by the equation:

$$X = (Z^{1-\alpha/2})^2 * p * (1-p) / d^2$$

$Z_{1-\alpha/2}$ = Is standard normal variate (at 5% type 1 error ($P<0.05$) it is 1.96 and at 1% type 1 error ($P<0.01$) it is 2.58). As in the majority of studies, P values are considered significant below 0.05 hence 1.96 is used in the formula.

p = Expected proportion in population based on previous studies or pilot studies.

d = Absolute error or precision - This has to be decided by the researcher.

$$SS = (3.841) * 0.29 * (0.71) / (0.0025)$$

Pilot study

Was carried out on 10% over a period of 15 days to test the applicability of the questionnaire. This pilot sample was excluded from the study analysis.

Sampling procedure

The randomized sample was selected over 3 to 4 months in two stages, the first one did by the proportional allocation to choose a proportional number of students from different colleges. The second stage was performed by a systematic random technique to choose the students from the administration lists in each college included in the study.

Statistical methods and Data management:

We used a self-constructed questionnaire based on previous similar studies^[15, 16]. The questionnaire was validated by experts and by a pilot study. Data were analyzed using SPSS version 24. The collected data was coded, described, and cleaned, and quantitative data were described by means and

Standard Deviation (SD). Qualitative variables were described by proportions and Chi-Square. Regression models may be used for multivariable analysis.

Confidentiality:

Data were anonymized once it has been collected. The original list of participants, all field assistants was trained in matters of confidentiality and had access to primary data only when necessary

Ethical Approval

This study was approved by the Unit of Biomedical Ethics and Research Committee, King Abdulaziz University with Reference No 479-20.

Data Analysis

Fifteen variables on the research questionnaire were analyzed to evaluate participants' awareness about SCD including source of information about SCD, etiology, role of consanguinity, modes of inheritance, component of blood affected by SCD, signs and symptoms, diagnosis, treatment and methods of prevention. One mark was given for every question answered correctly while zero was given for each question incorrectly answered or unanswered. Students correctly answered all the fifteen questions about SCD awareness were scored as 100%. Students who scored 50% and more were considered as having good or adequate awareness, while students scored less than 50% were considered as having bad or inadequate awareness.

Results

Our sample is Female university students only (351 students). 325 (92.6%) were singles. majority of age were 20 years The majority of participants (59.8%) study at the Scientific College, 53.3% are living in Jeddah.

297 (84.6%) did not have any chronic diseases, about the sickle cell status the majority are not patients or have a patient from their family with 314 (89.5%), 6 (1.7%) were patient, 31 (8.8%) have family member affected. The main source of knowledge about SCD from health professional community meetings which was about 136 (38.7%)

A total of 244 (69.5%) were aware that sickle cell is not a contagious disease, when asked about their

opinion in what is the cause of sickle cell most of them agreed that it's inherited 271 (77.2%), about the type of the of genetic disorder the sickle cell is 48 (13.7%), 162 (46.2%), 141 (40.2%) chose autosomal dominant, autosomal recessive, don't know respectively, when asked about does consanguinity increase the risk of SCD 68.7% chose yes.

Minority of the participants who have the correct information about chances of sickle-cell disease in a child if both parents are carriers. Only 115 (32.8%) of the participants had correct information in chance of getting a healthy baby with all parents have SCD. Most of the participants 242 (68.9%) have a good awareness about that red blood cells are the component of blood that is affected in patients with sickle cell anemia.

51% of the participants answered about the signs and symptoms that comes with SCD is yellow eyes, 77.8% answered that SCD diagnosed by blood test which are the right answers

45.9% of the participants didn't know if SCD is curable or not.

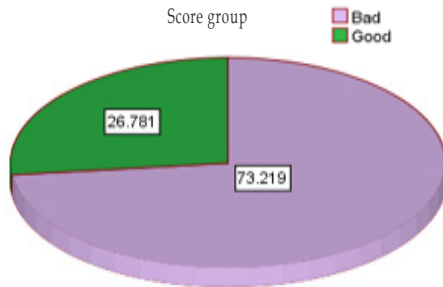
72.9% of the participants answered that can prevent SCD through genetic counseling, and 14.5% by testing before marriage. 61.5% of the participants answered the medications are herbal medicines and 2.6% by folic acid and blood transfusion. 44.4% of the participants answered can take any medicine and 8% there is a contraindication.

We found in our study that marital status was statistically significant with the awareness about SCD, and the academic level also was statistically significant. Out of the participants who had good knowledge of SCD, 55.3% were residents of Jeddah, while 44.7% lived in other cities ($p = 0.66 > 0.05$). 72.3% of the participants who had good knowledge of SCD were relatively low income. 89.1% of the participants not patient, with bad knowledge and the SCD status was statistically nonsignificant ($p > 0.05$)

However, both residence, monthly income, and SCD status were statistically no nonsignificant ($P > 0.05$). The majority heard about SCD 73.5% with bad knowledge, and this was statistically significant ($p < 0.05$). The sample selected was all female college students ($n = 351$). 59.8% of participants went to scientific college. 83.8% of the participants reported

not having any chronic disease, and 92% reported not having any genetic disorders.

Of all the participants, only 26.7% had good knowledge of sickle cell. **Figure.1**



Only, 26.78% of the participants have good awareness regarding sickle cell disease.

Discussion

The present study aimed to assess the level of awareness about SCD among undergraduate female Students at King AbdulAziz University, Rabigh Branch. A total of 351 students were answered a self-administered questionnaire. Data analysis revealed that only 26.7% of the students had good awareness about SCD. This level of awareness were closely similar to a study held in Saudia at King Khalid University by Al-Qattan etal^[11], who detected good knowledge among 28.8% of the participant. Similar level of awareness were also detected in closely related studies in Sudan (26.9%)^[14] And in Nigeria (17.8%)^[1]. But in contrast to our study higher levels of awareness were detected in other studies in Saudi Arabia (94.3%)^[11], Bahrain(93%)^[12], and Oman (96%)^[13].

Explanation of large difference in the level of Knowledge between our study (26.7%) and El-Hazmi's study (94.3%)^[11]. Despite both were in Saudi Arabia, is due to the participants of El-Hamzi's studies were health educated with awareness lectures, conferences and symposia, while our participants were young students. This also explained similar level of awareness (28.8%) in Al-Qattan etal^[11] to our results, because their participant were people from the general Saudi community.

In our study, despite the fact that many of our participant heard about SCD (78.9%), and knew that SCD is an inheritance disease (77.2%)

but unfortunately only few knew about mode of inheritance, manifestation of the disease, role of premarital counselling in disease prevention and 61.5% thought that SCD may be treated with herbal. This explained because only 38.7% obtained their knowledge from health professional community meetings, while many of them receive their knowledge from friends and internet. Similar observations were detected by Al-Qattan etal^[11], who recorded that only 10% the participants got their awareness of Premarital genetic counseling clinic from healthcare workers. They stated that reason of bad SCD awarenessbetween the Saudi peoples is not only a shortage in seeking awareness butalso a shortage in receiving awareness from healthcare workers. However, WHO recommends that special genetic counseling facilities and carrier detection tests be offered at special centers located in regions where Hb disorders are common^[1]. In our study and other related one^[1]no respondents indicated screening/ counseling facilities as sources of information about SCD.

Similar to our finding that most (78.9%) of the participant heard about SCD, which is the result of more awareness about it in the last few years, Durotoyeetal^[17], reported that 79.5% of their participants had heard about SCD this is possible due to the selected sample of university students only similar to our study.

77.2% of the participants agreed that the SCD is inherited and most of the participants 68.9% know that red blood cells are the component of blood that is affected, 77.8% answered the SCD is diagnosed by a blood test this is also the same as what was found by a Nigerian study published in 2016, 96.4% of participants were aware that SCD is an inherited disease; 93.9% were aware that SCD affects the red blood cells and can be diagnosed through a blood test^[15].

Similarly in this research and previous Nigerian study^[15] found the students from the faculty of medicine had significantly more adequate knowledge than students from other faculties. Association between knowledge and faculty was highly significant ($p=0.00$). Moreover, data analysis, showed association of awareness with academic level with the higher level of awareness detected in fifth years

(30.8%) and the lowest level was in first academic year(93.2%). The association between knowledge and the academic level was significant ($p=0.02$)

In our study, the participants were mostly unmarried young adults between 20 and 30 years, which made them ideal for studying SCD knowledge, as also suggested by previous related studies [15,18,19]. We found that good awareness was found mostly in unmarried (97.9%) with significant association ($p=0.00$) between awareness and marital status. But in contrast to our, Adewoyin et al [1] found that good knowledge about SCD was more in older and married participants, this is due to the fact that unmarried people, did not move to the stage of marriage and the responsibility to know about genetic diseases. This is attributed that advancing age and marriage entails greater societal responsibility [1].

In spite of that, we support more related studies to be conducted in young unmarried due to the fact that the good knowledge of the disease will allow them to make informed decisions concerning their marriage so as to avoid having children affected by SCD.

Strength

Our research adds to the limited literature in the King Abdulaziz university's Rabigh branch

Limitations

This particular study targeted only female university students, so it restricted the sample.

Conclusion

There was inadequate awareness of SCD particularly on the pattern of inheritance. To reduce the incidence of SCD, we suggest effective public health education for SCT and SCD in strategic places such as schools, media (radio/Television), and healthcenters to address misconceptions and increase knowledge as well as understanding of the risks of having a child with SCD and influence personal reproductive decision.

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Conflict of interest: None

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