Assessment of Sickle Cell Disease Awareness and Knowledge among Saudi Arabians: A Cross Sectional Survey

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Abstract
Objective:
The aim of this study is to assess awareness and knowledge of sickle cell disease (SCD) among Saudi population. This was performed to assess if more awareness educational programs regarding such disease are needed to be held for the community in Saudi Arabia or not.
Methods:
A cross sectional study was conducted from April 2017 to June 2017 by distributing a questionnaire as an electronic form. There were 2968 participants voluntarily answered the questionnaire, 64 participants were excluded because they didn't hear about the disease and 2904 participants were included in the final data analysis. The questionnaire included 4 parts: demographic information, general knowledge about SCD, knowledge about how person can got SCD, and the last part was about SCD diagnosis and management.
Results:
Most of participants (98%) had heard about SCD and 96% of them knew that it can be diagnosed by a blood test and just (60%) knew that it has high prevalence in Saudi Arabia. Nighty-five percent recognized it as a hereditary disorder and 98% of the participants knew that SCD is a blood disorder.
However, in-depth knowledge about pattern of transmission seems to be lacked and respondents showed poor knowledge about management of SCD.
Conclusions:
In conclusion, there was a good level of knowledge about SCD prevalence in KSA among the study participants. They were aware that Saudi Arabia is one of the highest prevalence countries in the world having SCD. Also, there was a good level of knowledge about type of disease , its way of diagnosis, and most of people included in the study knew about the disease triggers. However, in-depth knowledge about pattern of disease transmission seemed to be absent and participants showed poor knowledge of SCD management. Moreover, the majority of participants didn't't know about the vaccinations required for SCD patients. Hence, we recommend sustained efforts to increase awareness and knowledge about SCD. Most of participants suggested that using social media is the best way to increase awareness about SCD.

Index Terms— anemia, sickle cell, sickle, public health, sickle cell trait.

INTRODUCTION

Genetic diseases, especially hereditary blood disorders such as sickle cell disease (SCD) are responsible for considerable morbidity and mortality. Moreover, SCD has a significant burden to the health care system in many countries worldwide (1).

SCD crisis usually manifests as bone pain, which is the most common clinical symptom leading to presentation to hospital. Furthermore, SCD can cause many complications such as strokes, bone necrosis, and kidney failure (2).

SCD crises is precipitated by multiple factors such as infection, dehydration, hyperthermia, hypothermia and physical exhaustion. Moreover, social and environmental factors can play a role in the pathogenesis and psychopathology of SCD (2).
The prevalence of SCD in Saudi Arabia varies significantly in different parts of the country. In particular, it is the highest in the Eastern province, followed by the southwestern province (3).

METHODS

A descriptive, cross sectional study was conducted from April 2017 to June 2017 by distributing a questionnaire as an electronic form. The questions were close ended. There were 2968 participants voluntarily answered the questionnaire, 64 participants were excluded because they didn't hear about the disease and 2904 participants were included in the final data analysis representing different occupations and ages (uneducated, elementary school, intermediate school, high school, university diploma, university bachelor, university master, and university PhD or higher). The questionnaire included 4 parts: demographic information, general knowledge about SCD, knowledge about how person can got SCD, and the last part was about SCD diagnosis and management. The data has been documented and analyzed by using Microsoft Excel.

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RESULTS

DEMOGRAPHIC INFORMATION:

There were (n:1461; 50.3%) females while 1443 (49.7%) were males. The most frequent age group of the participants was between 20-29 years (n: 1016; 35%) while only 146 (5%) were older than the age of 60 years. There were 1756 subjects (63%) had a bachelor degree, 441 (16%) high school student, 343 (12%) diploma degree, 161 (6%) master degree and balance was reported between other degrees. Most of the participants were living in the eastern region (n: 2696; 93%) and the remaining participants were living in central, western, northern, and southern regions, respectively. There were 1858 subjects (64%) free of disease, while 611(21%) were carriers, 232 (8%) had SCD, and 203 (7%) did not know if there were carriers or not. About half of the participants had relative with SCD (n:167;57%). Demographics and characteristics of participants are summarized in (Table 1).

Table1: Demographics and characteristics

Characteristics (Categories)	Number (Percent%)
Age (years)	
10-19	261 (9%)
20-29	1016 (35%)
30-39	622 (21%)
40-49	473 (16%)
50-59	386 (13%)
>60	146 (5%)
Gender	
Male	1443 (49.7%)
Female	1461 (50.3%)
Education level	
uneducated	3 (0.1%)
Elementary school	25 (0.9%)
Intermediate school	97 (3%)
High school	441 (16%)
University, diploma	343 (12%)
University, bachelor	1756 (63%)
University, master	161 (6%)
University, PhD or higher	78 (3%)
Region	
Eastern Region	2696 (93%)
Western Region	76 (2.7%)
Central Region	90 (3%)
Northern Region	21 (0.7%)
Southern Region	19 (0.6%)
Disease Status	
SCD	232 (8%)
Carrier	611 (21%)
Don't know if Carrier or not	203 (7%)
Normal	1858 (64%)
SCD	232 (8%)
Other	
Has relative with SCD	1671 (57%)
Total	**2904 (100%)**

GENERAL KNOWLEDGE ABOUT SCD

Most of participants 2904 (98%) had heard of SCD. Regarding its prevalence in Saudi Arabia, 1004(60%) said it is one of highest prevalence countries in the world, 299(18%) said it is one of modest prevalence countries in the world, 13(1%) said it is one of the lowest prevalence countries in the world, and 354(21%) said they do not know (Figure 1).

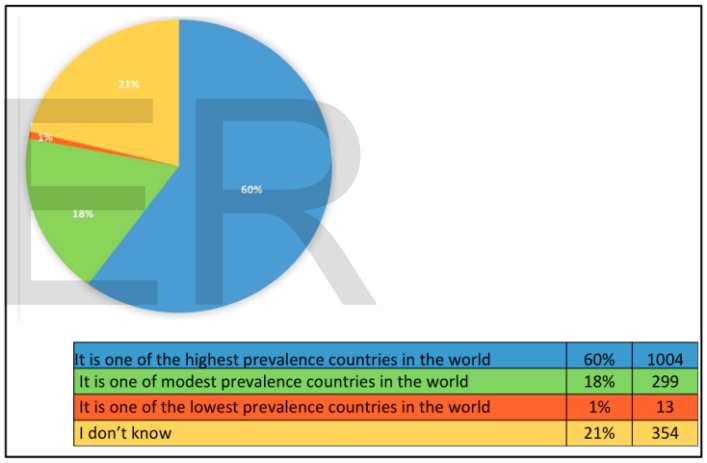

Figure 1 *The prevalence of SCD in Saudi Arabia*

Regarding to type of SCD, most of the participants 2836(98%) knew that it is a blood disorder while 59(2%) of the remaining participants said they do not know, 6(0.2%) thought it is an infectious disease, and 3(0.1%) considered it is a cardiovascular disease (Figure 2).

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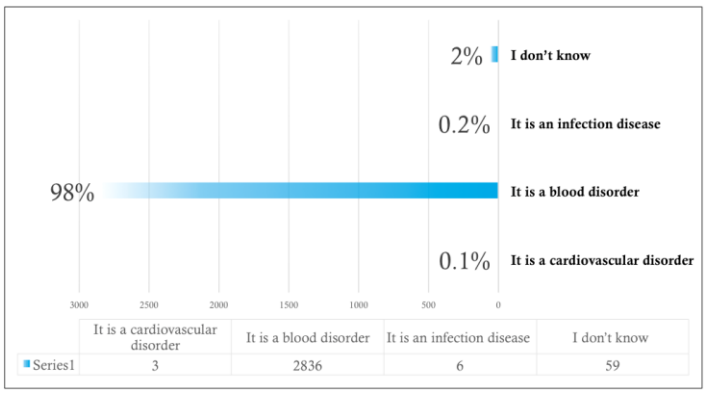

Figure 2 *type of SCD*

KNOWLEDGE ABOUT GETTING AFFECTED WITH SCD

The participants were asked about how can person get affected with SCD, most of them (2770, 95%) thought it is a hereditary disorder, while 75 (3%) said they do not know, 35(1%) expected that one can get it from a blood transfusion and 30 (1%) mentioned that there are other reasons for transmission such as food and airborne transmission. (Figure 3).

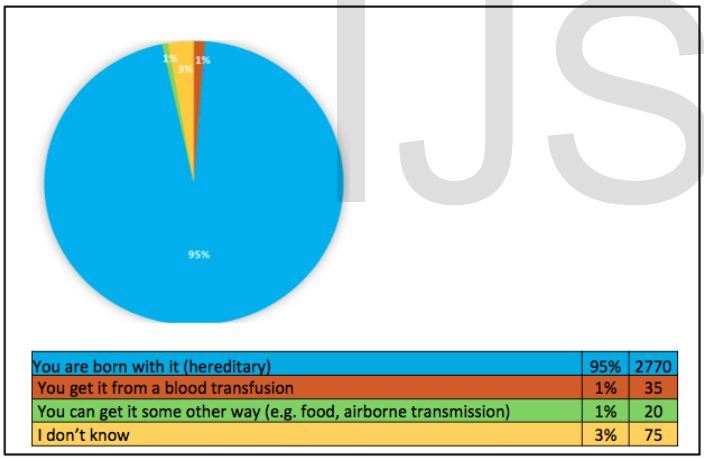

Figure 3 *How can person get sickle cell diseases ?*

The participants were asked: (For which parents a baby with SCD will be born?) The question was composed of multiple choice answers and more than one answer was allowed, 2596(90%) chose SCD mother and SCD father, 2131(73%) chose SCT father and SCT mother, 2220(76%) chose SCT father and SCD mother, 15(0.4%) chose healthy father and healthy mother, 732(25%) chose SCD father and healthy mother, 273(9%) chose SCT mother and healthy father, and 146(5%) said they do not know (Figure 4).

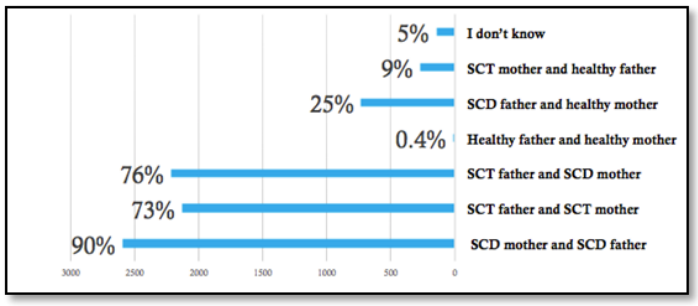

Figure 4 *For which parents a baby with SCD will be born (Multiple answers are possible)*

The participants were asked: (If you have SCT could your brother and sister have it too?), most of the participants 2512(86%) answered No, while 265(6%) answered Yes, and 221(8%) said they do not know (Figure 5).

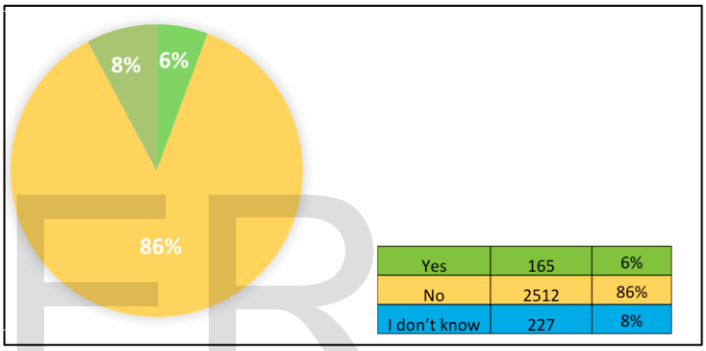

Figure 5 *If you have SCT could your brother and sister have it too?*

Knowledge about SCD diagnosis and management

Regarding the diagnose of SCD, most of the participants 2782(96%) answered that it is diagnosed by a blood test, while 11(0.3%) chose that it is diagnosed by physical examination, 7(0.2%) thought it is diagnosed by Echocardiography, and 104(3.5%) said they do not know (Figure 6).

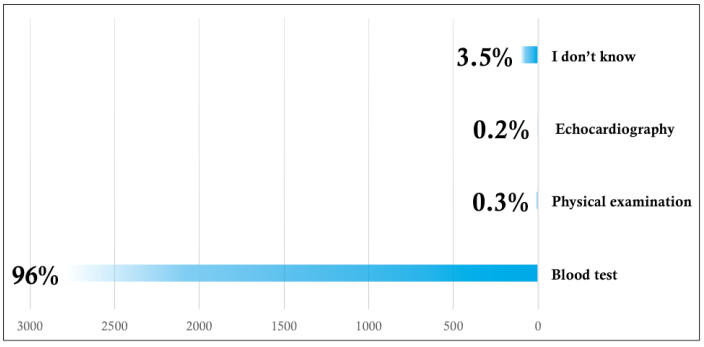

Figure 6 *Diagnose of SCD*

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The participants were also asked: (Do you think that SCD can be a curable by using medication?), most of them (2539, 87%) said No while 60(2%) said Yes, and 305(11%) said they do not know(Figure 7).

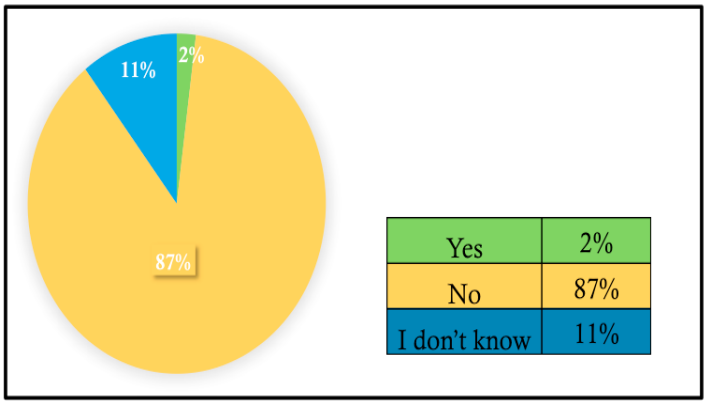

Figure 7 Do you think that SCD can be a curable by using medication?

The participants were asked: (Do you think that SCD can be a curable by using stem cells transplant?), 1042(55%) said Yes, 457(24%) said No, and 405(21%) said they do not know (Figure 8).

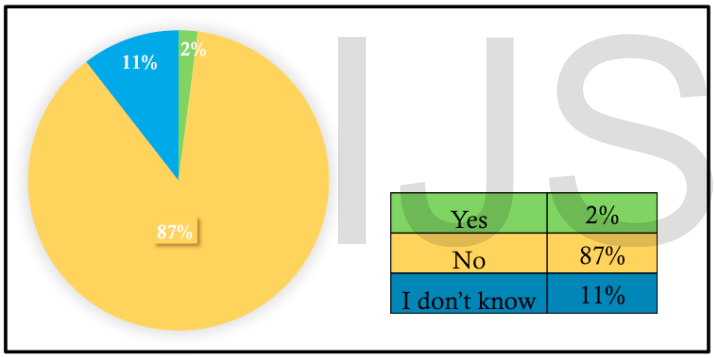

Figure 8 *Do you think that SCD can be a curable by using stem cells transplant?*

The participants were asked: (Do you think that there are some medications could help SCD patient plus blood transfusion ?), 2010(69%) said Yes, 268(9%) said No, and 626(22%) said they do not know(Figure 9).

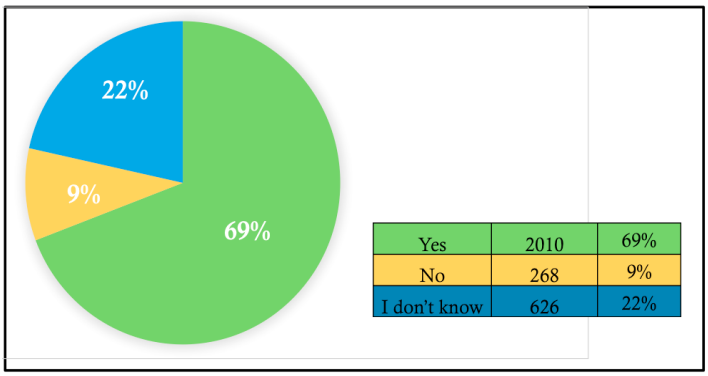

Figure 9 *Do you think that there are some medications could help SCD patient plus blood transfusion?*

The participants were asked: (What conditions do you think may worsen Sickle Cell Disease?) The question was composed of multiple choice answers and select more than one answer was allowed, 2501(86%) chose cold weather, 625(21%) chose hot weather , 1159(40%) chose fever , 526(18%) chose vomiting and diarrhea , 2188(75%) chose fatigue, and 1875(65.5%) chose lack of air (Figure 10).

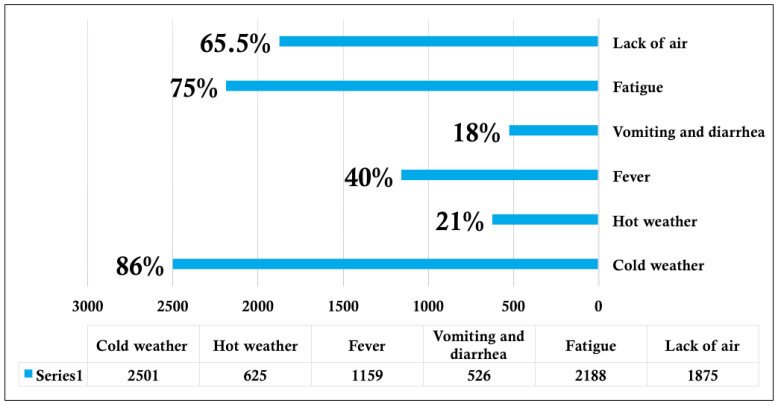

Figure 10 What conditions do you think may worsen Sickle Cell Disease? (Multiple answers are possible)

The participants were asked: (Do you think that children with sickle cell disease are more likely to get the following condition: life-threatening infections, kidney failure, stroke, and be hospitalized), 1263 (43%) agreed that it can cause life-threatening infections, 861(30%) agreed that it can cause kidney failure, and 803(28%) agreed that it can lead to stroke. A majority of 2554(87%) agreed that SCD can have a negative impact on a child's school (Figure 11).

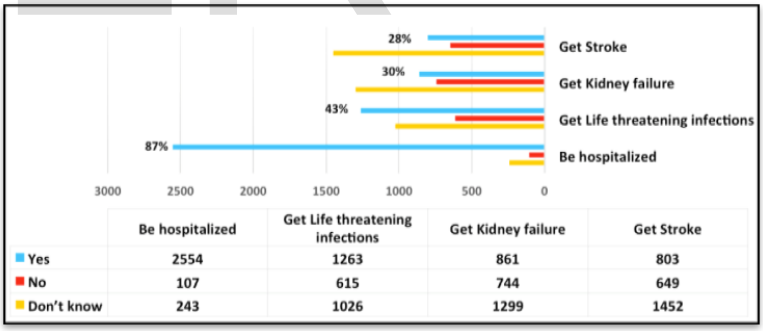

Figure 11 *Do you think that children with sickle cell disease are more likely to get the following condition: life-threatening infections, kidney failure, stroke, and be hospitalized.*

Regarding to the preventive measures of SCD, almost all the participants supported that premarital checking, health education, and enactment of laws will help to prevent SCD (Figure 12).

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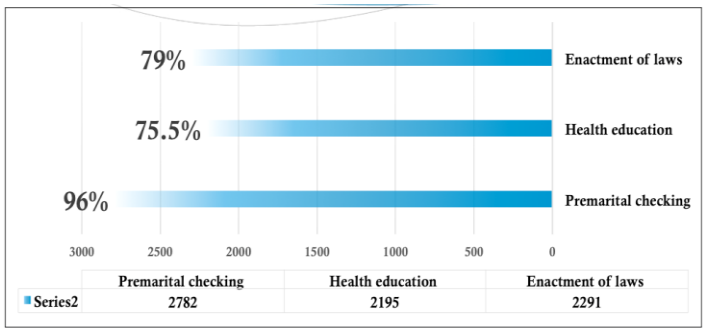

Figure 12 *Which preventive measures do you think will prevent SCD? (Multiple answers are possible)*

Regarding to the best way to increase awareness about SCD, 2547(88%) said by social media, 2163(74%) said by television, 1859(64%) said by healthy education meeting, and 1396(48%) said by written information(Figure 13).

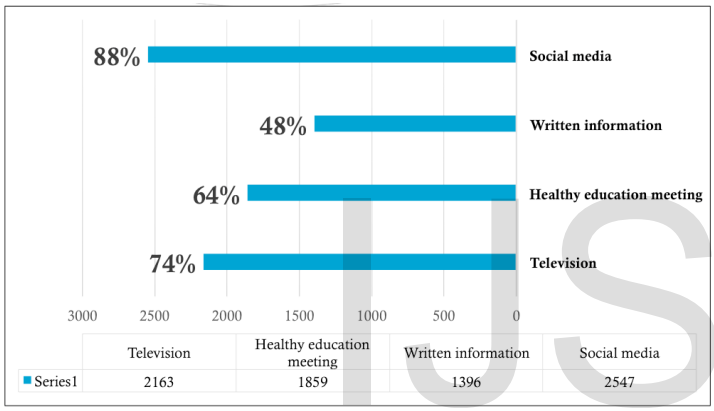

Figure 13 *What is the best way to increase awareness about SCD? (Multiple answers are possible)*

The participants were asked about vaccinations that should be taken by SCD patients and the question was composed of multiple choice answers, 1019(35%) chose influenza vaccine, 488(17%) chose Haemophilus influenzae type B – HiB, 796(27.5%) chose Meningococcal vaccine, 805(28%) chose Pneumococcal vaccine, 1762(605) chose they do not know(Figure 14).

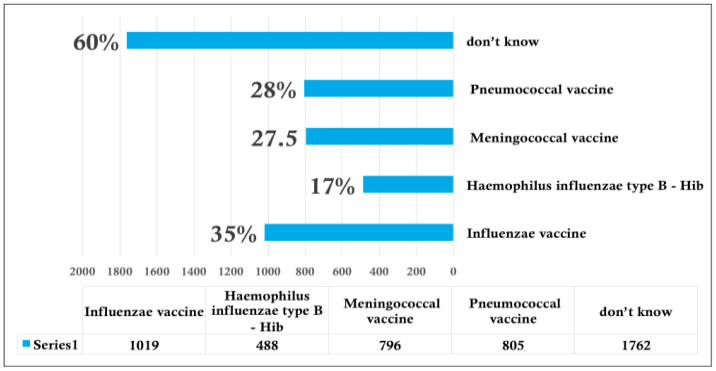

Figure 14 *Any of the following vaccinations should be taken by SCD? (Multiple answers are possible)*

The participants were asked about the kind of medications they are when needed. The question was only for patients or a parent for a patient child and was composed of multiple choice answers, 443(32%) chose Paracetamol, 389(28%)NSAID; Ibuprofen / Diclofenac / Voltaren, 479(34.7) chose Morphine or Tramadol, 95(7%) chose antibiotics, 392(28.5%) chose Folic acid, 167(12%) chose Hydroxyurea, and 282(20.5%) reported that they do not not use anything (Figure 15).

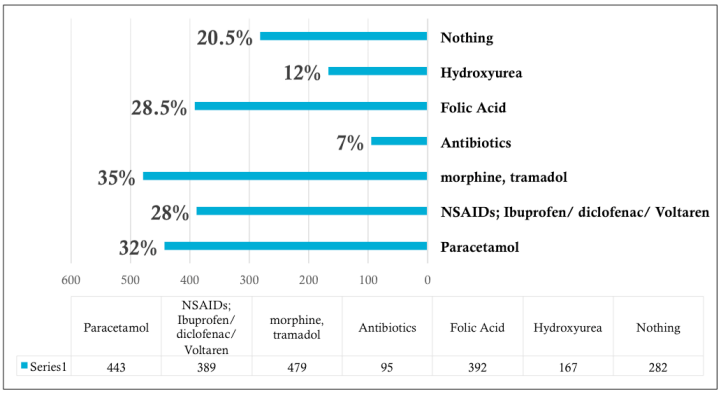

Figure 15 *What kind of medications do you use when needed ? (The question was only for patient or a parent for a patient child and was composed of multiple choice answers)*

The participants were asked about the kind of maintenance treatment they use at the moment. The question was only for a patient or a parent for a patient child and was composed of multiple choice answers, 204(15.5%) chose Paracetamol, 156(11.7%)NSAID; Ibuprofen / Diclofenac / Voltaren, 175(13%) chose Morphine or Tramadol, 60(5%) chose antibiotics, 515(39%) chose Folic acid, 254(19%) chose Hydroxyurea, and 351(26.5%) reported that they do not use anything (Figure 16).

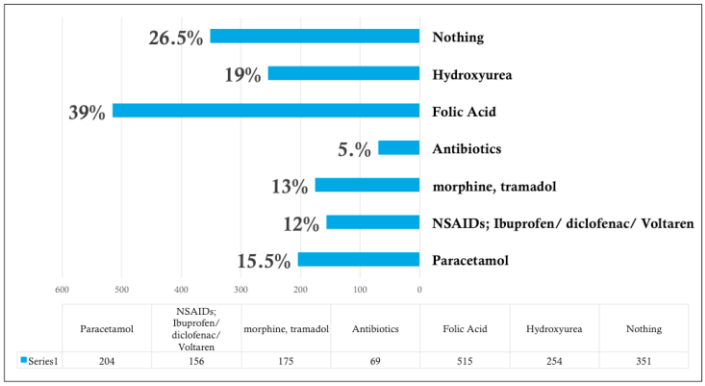

Figure 16 *What kind of maintenance treatment do you use at the moment ? (The question was only for patient or a parent for a patient child and was composed of multiple choice answers)*

DISCUSSION

No other studies that evaluated SCD awareness and knowledge in Saudi Arabia could be found. So results of such study could not be compared with other similar ones.

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Depending on demographic data, there were a balance between male and female and the most frequent age group of the participants was between 20-29 years, concerning the education level, most of participants got a bachelor degree,and most of them were living in the eastern region of Saudi Arabia. Quarter or the participants (21%) were cariers and only 8% of them were SCD patients.

There was a good level of knowledge about SCD prevalence in KSA among the study participants. They were aware that Saudi Arabia is one of the highest prevalence countries in the world having SCD.Also, there was a good level of knowledge about type of disease, Almost all of the participants (98%) knew that SCD is a blood disorder ,95% recognized it as a hereditary disorder and 96% answered correctly that it could be diagnosed by a blood test .

A majority of the participants 87% were aware that SCD couldn't be cured by medication and 55% knew that it is curable by using stem cells.

Subjects included in the study were aware about some SCD triggers, and more education is needed to increase such awareness to include all possible triggers. Almost half of the participants (45%) agreed that SCD can cause life-threatening infections, The third (30%) agreed that it can cause kidney failure, and quarter of them 28% agreed that it can lead to stroke. A majority of 87% agreed that SCD can have a negative impact on a child's school performance, such results indicating a good level of awareness among the study pobulation.

Almost all participants supported that premarital checking, health education, and enactment of laws will help to prevent SCD. Hence, we recommend sustained efforts to increase awareness and knowledge about SCD. Most of participants suggested that using social media is the best way for achieving that.

In-depth knowledge about pattern of disease transmission seemed to be poor, quarter of the participants thought that SCT father and healthy mother can have baby with SCD which is not true and the majority of participants didn't't know about the vaccinations required for SCD patients. Moreover, participants showed poor knowledge about SCD management. Only half of of them knew that there are some medications that could help SCD patient beside the blood transfusion.

LIMITATION

The main limitation of this study was that the questionnaire hadn't been validated before conducting the study. Another limitation was that most of the participants who could be reached were from Eastern Region 2696 participants (93%).

CONCLUSION

There was a good level of knowledge about SCD prevalence in KSA among the study participants. They were aware that Saudi Arabia is one of the highest prevalence countries in the world having SCD. Also, there was a good level of knowledge about type of disease, its way of diagnosis, and most of people included in the study knew about triggers of SCD. However, in-depth knowledge about pattern of disease transmission seemed to be poor and participants showed poor knowledge of SCD management. Moreover, the majority of participants did not know about the vaccinations required for SCD patients. Hence, we recommend sustained efforts to increase awareness and knowledge about SCD, this could be done by making live SCD awareness campaigns in places where people gather such as shopping centers, clinics, hyper markets..etc. Also social media could be used for such purpose to reach larger population.

REFERENCES

(1) Arrayed, S.A. and Hajeri, A.A. (2010) 'Public awareness of sickle cell disease in Bahrain'.
(2) Olakunle, O.S., Kenneth, E., Olakekan, A.W. and Adenike, O.-B. (2013) 'Knowledge and attitude of secondary school students in Jos, Nigeria on sickle cell disease'.
(3) Jastaniah, W. (2011) 'Epidemiology of sickle cell disease in Saudi Arabia'.