EDUCATIONAL INTERVENTION TO INCREASE AWARENESS AND KNOWLEDGE OF SICKLE CELL ANAEMIA AMONG ADOLESCENT SCHOOL CHILDREN IN WESTERN KENYA AN EDUCATIONAL INTERVENTION TO INCREAS….

Article *in* East African Medical Journal · October 2022

CITATIONS
0

READS
165

6 authors, including:

Winnie Mucherah
Ball State University
45 PUBLICATIONS **496** CITATIONS
SEE PROFILE

Linda Siktberg
Ball State University
21 PUBLICATIONS **525** CITATIONS
SEE PROFILE

Sheila Abebe
Ball State University
7 PUBLICATIONS **2** CITATIONS
SEE PROFILE

James Aggrey Oloo
Masinde Muliro University of Science and Technology
99 PUBLICATIONS **6,277** CITATIONS
SEE PROFILE

East African Medical Journal Vol. 99 No. 9 September 2022
AN EDUCATIONAL INTERVENTION TO INCREASE AWARENESS AND KNOWLEDGE OF SICKLE CELL ANAEMIA AMONG ADOLESCENT SCHOOL CHILDREN IN WESTERN KENYA
Winnie Mucherah, PhD, Ball State University, Muncie, IN 47306, U.S.A., Sheila Yvonne Abebe, DNP, Ball State University, Muncie, IN 47306, U.S.A., Jayanthi Kandiah, PhD, RDN, LD, Ball State University, Muncie, IN 47306, U.S.A., Linda Siktberg, PhD, RN, ANEF, Ball State University, Muncie, IN 47306, U.S.A., James Aggrey Oloo, FCP (ECSA), Masinde Muliro University of Science and Technology, Kakamega, Kenya, Rachel Nicole Thomas, PhD, Hanover College, Indiana, U.S.A.

Corresponding author: Winnie Mucherah, Ph.D, Department of Educational Psychology, Ball State University, Muncie, IN 47306, U.S.A. Email: wmucherah@bsu.edu

AN EDUCATIONAL INTERVENTION TO INCREASE AWARENESS AND KNOWLEDGE OF SICKLE CELL ANAEMIA AMONG ADOLESCENT SCHOOL CHILDREN IN WESTERN KENYA

W. Mucherah, S. Y. Abebe, J. Kandiah, L. Siktberg, J. A. Oloo and R. N. Thomas

ABSTRACT

***Objective*: Sickle Cell Anaemia (SCA) is an inherited blood disorder that impairs the functioning of the body's red blood cells and is prevalent in sub-Saharan Africa with up to 3% of all births affected. Therefore, the main objective of this study was to explore the level of knowledge and awareness of SCA among high school students in Kenya to determine if an educational presentation can improve that knowledge.**

***Design*: Participants completed a pre-test, listened to and participated in an educational presentation on SCA, and completed a post-test.**

***Setting*: Two single sex boarding high schools in Western Kenya.**

***Participants*: There were 251 adolescent subjects, females = 139; males = 112.**

***Intervention*: An educational presentation on SCA**

***Main outcome measures*: Level of knowledge and awareness of SCA**

***Results*: Overall, participants had the least knowledge about SCA at the pre-test; however, their knowledge increased significantly at the post-test. In general, male participants scored lower than female participants on the pre-test, however, this main effect was qualified by a significant interaction between participants' gender and test occasion. Although male participants scored lower than female participants on the pre-test, post-test scores were very similar between genders.**

***Conclusion*: The pre- and post-test score differences suggest that an educational presentation can significantly improve participants' knowledge regarding SCA. Additionally, these findings provide support for further interventions aimed at improving SCA knowledge and awareness.**

INTRODUCTION

Most healthcare providers agree that public awareness of certain health conditions is critical to prevention and management. Families affected by Sickle Cell Anaemia (SCA) are searching for ways to promote public awareness and knowledge about SCA. SCA is the most common and severe form of sickle cell disease. It is an inherited autosomal recessive blood disorder that occurs when an individual inherits the gene from both parents, which alters the functioning of the body's red blood cells.[1] More than 75% of all those affected with SCA are born within the sub-Saharan Africa region with approximately a quarter of a million new births each year.[2] In SCA, a recessive gene causes the red blood cells to be hard, stiff~~,~~ ~~—~~and sticky, and shaped like a "sickle" or "crescent" that obstructs the transportation of oxygen through the capillaries to the organs and tissues, causing extreme pain in the chest, abdomen~~,~~ and joints, chronic damage to vital organs, strokes, anaemia, and early death.[1]

Since SCA is a multi-system disease, it will likely affect every organ in the body, and besides anaemia, SCA has the potential to result in significant physical and neurocognitive health complications.[3] SCA is associated with high morbidity and mortality[4] and these health-related complications have a synergistic effect on the individual's ability to function. They may have lower cognitive function across domains and lifespans, and executive functioning that affect quality of life for both children and their parents.[3] The prevailing limited medical and financial resources in Africa represents a major health crisis compounded with an apparent lack of knowledge about SCA.

Sickle Cell Anaemia in Africa / Kenya

In the western part of Kenya, approximately "4.5% of the children are born with sickle cell disease" and approximately "18% of children are born with sickle cell trait."[5] In addition, SCA has been found in 1.6% of children, in a survey of 858 children, aged 6-35 months that were randomly selected from 6 villages in Western Kenya.[5] The resource limitations in Africa make it difficult to introduce effective interventions without strengthening health systems, ensuring sustainable financing, and policy improvements.[6]

A prospective cohort study in Kilifi, Kenya indicated half of the caregivers with an infant diagnosed with SCA did not participate in the care regimens resulting in a 4 times higher mortality rate, citing societal attitudes as a significant challenge.[7] A strategy to reduce mortality and the incidence of co-morbidity complications through sickle cell disease (SCD) is public education that would result in increased public awareness, caregiver awareness, and societal acceptance[7,8] Bridging the gap between knowledge and practice is critical, so individuals are not only gaining the knowledge, but also are putting it into practice within culturally relevant contexts.[9] Therefore, the purpose of this study was to explore the level of knowledge and awareness of SCA in high school students in Western Kenya and determine if an educational presentation will improve SCA knowledge and awareness.

METHODOLOGY

Study Participants

A total of 251 high school students in the 12th grade, referred to as Kenyan Form Four, from two public schools namely Musingu boys and Lubinu girls from Kakamega County in Kenya participated in the study. The sample comprised of 139 students from an all-girls boarding school and 112 from an all-boys boarding school. The total student population of the schools typically ranges from 1025 (girls) – 1160 (boys).

In addition, these two high schools are national schools, admitting top performing students (~~those~~ who score 350+ out of 500 points~~)~~ on the 8th grade standardized national

examination.[10] All teachers at the schools are graduates of the two main teacher-training universities in the country.[10] All the students participating in this study were born and raised in Kenya. Both schools are located in the western region of Kenya.

Procedures

In order to recruit the respective schools, the researchers collaborated with faculty from Masinde Muliro University of Science and Technology, a local university in Western Kenya, and sent a letter of request to the principals with whom the authors have a long-standing relationship. The IRB clearance was obtained from the investigators' institution in the US and the School Board of Management (SBM) in Kenya. Student participation in the study was voluntary. Permission was sought through the school principals who presented the request to the SBM. Lecture presentations on SCA were made to the whole school, including teachers and students over a period of two weeks.

However, only 12th graders who were 18+ years old, who did not require parental consent, were invited to provide consent to participate in the study.

Participants completed a pre-test related to SCA, listened to and participated in the educational presentations on the same topic, participants were given an opportunity to ask questions about SCA, and then completed a post-test. Both the pre-test and post-test questionnaires in English language took approximately 35-45 minutes to complete. A flash drive containing the presentation materials were delivered to the school Principals for continued use for public education on SCA.

Measurements

A 16-item instrument designed by the researchers was used to assess the level of knowledge of SCA in high school students in Kenya. The measure was based on the review of the literature and was used to assess knowledge on basic information about SCA, including causes, epidemiology, nutrition, and management. Table 1 illustrates the educational presentation topics.

Table 1

Presentation Topics

Sickle Cell Anaemia (SCA) Educational Presentation
Definition of SCA
Basic pathophysiology
Prevalence of SCA in Africa
Causes of SCA
Genetics and probability
Both parents with sickle cell trait (SCT)
One parent with SCT and one parent with SCA
Truths about SCA
When should one be screened?
Recommended times of screening
Early symptoms and complications
Symptoms of SCA
Signs of a crisis
Tips to prevent infections
Complications
Treatment options
Medication – Hydroxyurea

Who should use Hydroxyurea
Interprofessional collaboration
Role of the educator
SCA and pregnancy
Nutrition - food sources and purpose
Zinc, folate, calcium, vitamin A, vitamin E, protein

The instrument consisted of questions that required participants to write in their responses. For example, "How does a person get Sickle Cell Anaemia?"; "Sickle Cell Anaemia is prevalent in what part of the world?"; and "What are the three main signs and symptoms of Sickle Cell Anaemia." The PowerPoint presentation was used as a rubric to score the correct responses. Each correct response accounted for 1 score, and the scores ranged from 0-34. To ensure accuracy of data collection, between pre-and post-test questionnaires, each participant was assigned a number and that number was written on the pre-test and post-test questionnaires.

The pre-test questionnaire was completed and collected before listening to the SCA presentations while the post-test questionnaire was completed upon the completion of the SCA presentation. After the presentation and post-test, participants were offered the opportunity to ask questions about SCA. The questions collected were later coded to examine emerging themes.

RESULTS

Descriptive Statistics

Table 2 displays percentages of the participants' knowledge on the single response and True/False questions.

Table 2

Percentages of Correct Answers on Pre-test and Post-test N = 251

Question	***% Correct Pre-test***	***% Correct Post-test***
How does a person get Sickle Cell Anaemia (SCA)?	28.8	68.0
Sickle Cell Anaemia is a problem with what type of blood cell?	46.4	71.8
What part of the world is Sickle Cell Anaemia most prevalent?	18.2	65.7
Most infants in Sub-Saharan Africa with SCA die before what birthday?	5.8	58.8
Similar to HIV, SCA can be spread through sexual contact. (T/F)	59.4	77.2
SCA can be caused by sharing water/food from a person with SCA. (T/F)	70.0	83.9
People with Sickle Cell Anaemia are immune to Malaria. (T/F)	37.2	44.4

As Table 2 shows, the participants' performance on the pre-test questionnaire results indicated very little knowledge on the basic information about SCA, including the age an infant with SCA is likely to die (5.8%); the part of the world SCA is most prevalent (18.2%), and the means an individual gets SCA (28.8%). However, they had more knowledge on the blood type related to SCA (46.4%), whether SCA can be spread through sexual intercourse (59.4%), and whether SCA can be spread through sharing water or food (70%). As noted in Table 2, there were significant improvement in participants' scores after the presentation.

Table 3

Pre-test and Post-test Knowledge Scores on SCA

Students	**Pre-test**		**Post-test**	
	Mean	SD	Mean	SD
Male (N = 112)	6.52	3.85	23.10	4.79
Female (N =139)	11.06	5.13	24.71	4.70
Total (N = 251)	9.03	5.12	23.99	4.79

Mean Range: 0-34

Table 3 presents the means and standard deviations of the pre-test and post-test participants' knowledge scores on SCA. Possible scores ranged from 0 to 34. As reported earlier, pre-test answers for both male and female students revealed limited knowledge about SCA (M = 9.03, SD = 5.12), and were possibly increased by 3 points based on a question asking about general strategies to prevent any illness. However, following the presentation, the number of correct answers increased from the mean of 9.03 to 23.99 (SD = 4.79).

Additionally, initial differences in mean scores were observed between male and female participants. As noted in Table 3, during the pre-test, the mean score for the males was much lower (M = 6.52, SD = 3.85) compared to the mean score for the females (M = 11.06, SD = 5.13). Although this difference is lost if the spread of SDs are taken into account. However, after the presentation, the mean scores were relatively similar (Male, M = 23.10, SD = 4.79; Female, M = 24.71, SD = 4.70), but much higher and different from the pre-test scores

Repeated Measures ANOVA

To examine whether the mean scores were significantly different between the pre-test and the post-test, a 2 (test occasion) × 2 (participant gender) repeated measures ANOVA was conducted. The results revealed significant differences in pre-test and post-test scores, $F(1, 249) = 2136$, $p < .001$, $\eta_p^2 = .90$, with post-test scores significantly higher than the pre-test scores.

As previously reported, in general, male participants scored lower than female participants on the pre-test, $F(1, 249) = 38.70$, $p < .001$, $\eta_p^2 = .14$; however, this main effect was qualified by a significant interaction between participant gender and test occasion, $F(1, 249) = 20.01$, $p < .001$, $\eta_p^2 = .07$. See Figure 1 for details.

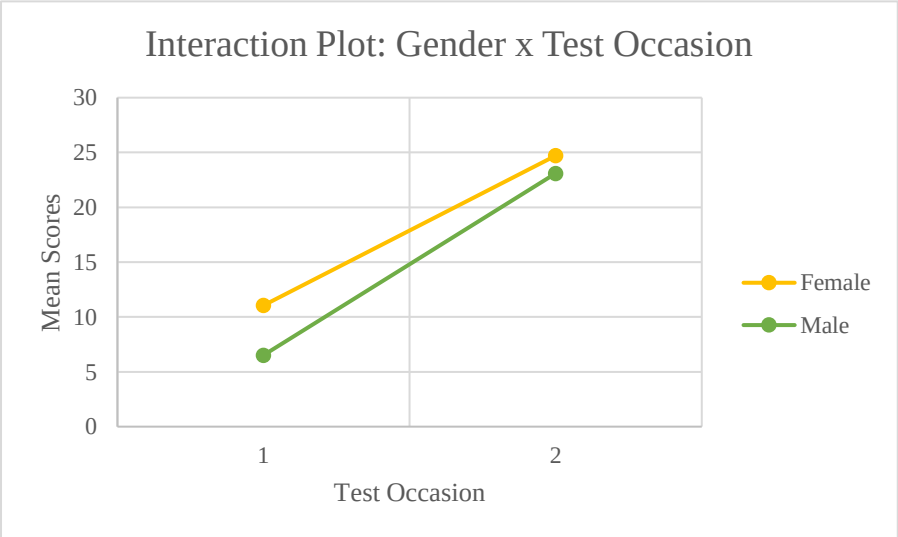

Figure 1. Repeated Measures AN

Qualitative Data

Students' questions collected after the presentation were coded and rated by three independent researchers who were not at the presentations. These questions were related to the presentation. First, the three researchers independently reviewed the students' written responses, coded them and created themes that reflected those questions. Upon completion of the coding, the researchers worked together and compared the themes that emerged (an inter-rater reliability was established at 0.87). Themes that emerged include the lifespan of SCA patient, causes, prevention and treatment, sex/marriage, diagnosis, symptoms, and cure for SCA. Below are the themes and example questions:

Lifespan of a SCA patient

Is it true that someone suffering from sickle cell anemia cannot survive past 20 years of age?

Is it true that people suffering from sickle cell anemia cannot live for more than 21 years?

Does SCA attack ~~the~~ grown-up people?

How long does it take someone affected with SCA to die?

Causes of SCA

Can it be transmitted by kissing, sexual intercourse, and open wounds?

Can it affect a person who receives a blood transfusion from an infected person?

What causes SCA?

Do all children with SCA have parents with SCA?

Prevention and Treatment

What measures can be put in place to reduce SCA?

In the case that one realizes that he/she is a carrier, what can he /she do to prevent it from passing on to offspring?

Can it be prevented from being inherited?

Is there anything that can be done to improve the movement of red blood cells through the vessel to avoid/minimize sticking in order to lessen pain?

Can the disease be completely treated?

Does sickle cell anemia have a cure?

Does the disease have a vaccine?

Sex/Marriage

Is it possible for a person suffering from sickle cell to perform his/her function as a wife or husband?

If you are deeply in love with someone and consult a genetic counselor and discover that the person you are about to have children with has a sickle cell trait what can you do so as to not hurt that individual?

Can you get sickle cell anemia through sexual intercourse with a person who is infected?

From the questions above, it is clear additional education and awareness of SCA is needed. The questions asked by participants point to the misconceptions about SCA. As adolescents are preparing to enter the adult world, issues of intimate relationships, sex, and marriage are central to their thought processes. Of interest are the many questions regarding prevention and treatment of SCA. Overall, these types of questions could likely affect their academic performance, especially if they have SCA themselves or know someone who is affected by SCA.

DISCUSSION

The results of this study demonstrate that students knew the least before the presentation and made some significant learning gains on SCA after the presentation. These results provide more evidence that interventions and further education are needed. Shahine et al.'s[11] study in Lebanon revealed that educational interventions significantly improved caregivers' knowledge of SCA and how to manage complications. Wasonga et al.'s study[9] indicated that SCA education programme improved the male secondary school students' knowledge of SCA. Other studies have found that education and awareness interventions improve the management and care of SCA,[12], improve prevention and monitoring,[13], reduce hospitalization and

excessive mortality rates,[11,12], address the issue of lack of knowledge, prevent the misdiagnosis of malaria and SCA[2], and bridge the gap between knowledge and practice.[9]

Furthermore, knowledge about how one gets SCA is likely to dispel some of the myths and misconceptions about SCA (that were revealed in participants' recorded questions) and decrease the stigma attached to SCA in Kenya[15] and in Uganda.[16] It is interesting that students had more knowledge on questions that compared SCA to HIV. A possible reason could be students have learned a lot about HIV due to the aggressive campaign that was launched by the government to fight HIV for the last three decades since the 90s.[5]

Previous researchers investigated the prevalence and awareness of SCA in other parts of Africa,[2.7.16], survival rates of people diagnosed with SCA, incidence in young children,[16,17], and the need for appropriate health screening associated with SCA.[13.14] However, to date, limited research studies have looked at SCA and the effectiveness of an educational intervention in a high school setting. The present study is an additional contribution to the body of knowledge in SCA for several reasons. Firstly, it targets adolescents, who are mature enough to inquire and ask questions associated with adult life and are uniquely situated in life transitions. Secondly, implementation of an educational presentation improved participants' knowledge about SCA as evidenced from pre-and post- tests results.

Future Implications

Since the outcomes of this research were positive, recommendations for future research would include i) integration of a larger population of adolescents across Kenya including those in mixed-sex day schools; ii) possibly engaging younger adolescents (under 18 years); iii) assessment of SCA knowledge after a few months (e.g., 3, 6, and 12 months) post educational presentation; iv) examination of how education could influence long-term behaviour or attitude of participants, such as having their children screened at birth; v) distinguishing attitudes and knowledge with clear parameters and, vi) a systematic examination of the gender differences in SCA knowledge prior to the presentation to identify reasons for observed gender differences on the pre-test. These recommendations would not only enrich and contribute to the body of knowledge pertaining to the current research, but it would address the clinical and public health care needs of the community. By receiving basic information about SCA, including genetics, epidemiology, signs and symptoms, screening, nutrition, and management, some of the myths (e.g., sex and marriage) associated with having SCA could be modified. Further, health care policies and procedures could be implemented that would help educate the public across Kenya. More aggressive and affordable clinical trials could also be advocated and made available via global support in the successful treatment and management of SCA for future generations.

Limitations: Though this study had unique strengths, it also had some limitations. First, it would have been helpful to have younger adolescents participate in the study to examine whether knowledge of SCA was partly influenced by the amount of time they had been in high school. Also, having adolescents from mixed-sex day high schools would have increased diversity of ideas related to SCA. Additionally, students with SCA mostly attend mixed-sex day schools, therefore, the study would have captured lived in experiences of more students with SCA. Finally, having a small focus group with students who have SCA would have been beneficial. However, since there is a stigma attached to individuals with SCA, the researchers did not want to expose these students.

CONCLUSION

In conclusion, limited knowledge and awareness contribute to myths, misconceptions, and limitations in screening and management of SCA in Kenya, which have resulted in many children suffering and dying undiagnosed. This study provides evidence that knowledge and awareness of adolescents, who may be transitioning to increased autonomy related to their own healthcare, can be greatly increased via educational presentations in schools. Such increased knowledge may serve to reduce stigmas around SCA by dispelling myths and misconceptions. Additionally, adolescents' increased knowledge and awareness of SCA may strengthen broader community awareness as they share their increased knowledge with their families, peers, and others. Given the importance of early detection and treatment to reduce morbidity and extend the lifespan of those diagnosed with SCA, SCA education intervention is essential to increase students' knowledge and awareness of SCA, increase awareness of adolescents' own health, awareness of their families' health, and broader communities' health and knowledge about SCA.

REFERENCES

1. Sahu, M., Biswas, A. K., & Uma, K. (2015). Detection of Sickle cell anemia in red blood cell. *A. International Journal of Engineering and Applied Sciences (IJEAS), 2*(3).
2. Macharia, A. W., Mochamah, G., Uyoga, S., Ndila, C. M., Nyutu, G., Makale, J., et al. (2018). The clinical epidemiology of sickle cell anemia in Africa. *American journal of hematology, 93*(3), 363-370.
3. Allen, T. M., Anderson, L. M., Rothman, J. A., & Bonner, M. J. (2017). Executive functioning and health-related quality of life in pediatric sickle cell disease. *Child Neuropsychology, 23*(8), 889-906.
4. DeBaun, M. R., & Kirkham, F. J. (2016). Central nervous system complications and management in sickle cell disease. *Blood, 127*(7), 829-838.
5. Wanjiku, C. M., Niuguna, F., Asirwa, F. C., Mbunya, S., Githinji, C., & Greist, A. (2019). Establishing care for sickle cell disease in Western Kenya: Achievements and challenges. *Blood Advances, 3*(Supplemental 1), 8-10.
6. Makani, J., Ofori-Acquah, S. F., Tluway, F., Mulder, N., & Wonkam, A. (2017). Sickle cell disease: Tipping the balance of genomic research to catalyse discoveries in Africa. *The Lancet, 389*(10087), 2355-2358.
7. Oron, A. P., Chao, D. L., Ezeanolue, E. E., Ezenwa, L. N., Piel, F. B., Ojogun, O.T., et al. (2020). Caring for Africa's sickle cell children: Will we rise to the challenge? *BMC medicine, 18*, 1-8.
8. Nnodu, O. E. (2014). Interventions for the prevention and control of sickle cell disease at primary health care centres in Gwagwalada Area Council of the Federal Capital Territory, Nigeria. *Cureus, 6*(8), e194.
9. Wasonga, J., Olang'o, C. O., & Kioli, F. (2014). Improving households' knowledge and attitude on water, sanitation, and hygiene practices through school health programme in Nyakach, Kisumu County in Western Kenya. *Journal of Anthropology, 2014*.
10. Kenya Institute of Curriculum Development. (2018). Basic Education Framework. Nairobi, Kenya.
11. Shahine, R., Badr, L. K., Karam, D., & Abboud, M. (2015). Educational intervention to improve the health outcomes of children with sickle cell disease. *Journal of Pediatric Health Care, 29*(1), 54-60.
12. Steele, C., Sinski, A., Asibey, J., Hardy-Dessources, M. D., Elana, G., Brennan, C., et al. (2019). Point-of-care screening for sickle cell disease in low-resource settings: A multi-center evaluation of HemoTypeSC, a novel rapid test. *American journal of hematology, 94*(1), 39-45.
13. World Health Organization. (2019). Regional committee side event on sickle cell disease. World Health Organization. https://www.afro.who.int/regional-director/speeches-messages/regional-committee-side-event-sickle-cell-disease.

14. Lê, P.-Q., Ferster, A., Dedeken, L., Vermylen, C., Vanderfaeillie, A., Rozen, L., et al. (2018). Neonatal screening improves sickle cell disease clinical outcome in Belgium. *Journal of Medical Screening, 25*(2), 57-63.
15. Marsh, V. M., Kamuya, D. M., & Molyneux, S. S. (2011). 'All her children are born that way': gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya. *Ethnicity & health, 16*(4-5), 343-359.
16. Ndeezi, G., Kiyaga, C., Hernandez, A. G., Munube, D., Howard, T. A., Ssewanyana, I., et al. (2016). Burden of sickle cell trait and disease in the Uganda Sickle Surveillance Study (US3): a cross-sectional study. *The Lancet Global Health, 4*(3), e195-e200.
17. Mulumba, L. L., & Wilson, L. (2015). Sickle cell disease among children in Africa: An integrative literature review and global recommendations. *International Journal of Africa Nursing Sciences, 3*, 56-64. https://doi.org/http://dx.doi.org/10.1016/j.ijans.2015.08.002