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ORIGINAL RESEARCH

To Join Or Not To Join? A Case Of Sickle Cell Clubs, Stigma And Discrimination In Secondary Schools In Butambala District, Uganda

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Background: People living with sickle cell face a lot of stigma and discrimination in Uganda. This stigma is as a result of the lack of the general conceptualization of this condition. For students, the stigma is often due to their differences like jaundice, delayed sexual maturation, and physical growth. This makes individuals with SCD targets for teasing and bullying. This study assessed the knowledge and perception among secondary school students in a rural district of Butambala at nine selected schools. The study also evaluated the use of sickle cell clubs as a tool for behavior change towards the associated stigma and discrimination.

Methods: A school-based cross-sectional study design was used to assess knowledge and perception towards sickle cell disease in secondary schools in Butambala district using self-administered questionnaires prior to and after set up of the sickle cell clubs.

Results: Out of the 375 student participants (59.5% female, 40.5% male) the majority (87.5%) were below 18 years; 68% of the respondents did not know that sickle cell is a genetic condition; 87.5% of the respondents highlighted that it is important for people with SCD to attend school; 54.4% of the respondents reported that people with SCD should not be given equal rights, while 56.0% of the respondents noted that people with SCD should not socialize.

Conclusion: It is evident the there is a big gap in sickle cell awareness among secondary school students coupled with a high level of stigma and discrimination. Sickle cell clubs have a positive effect towards behavior change while providing SCD knowledge and information.

Keywords: stigma, discrimination, awareness, sickle cell disease, schools

Introduction

Worldwide, sickle cell disease (SCD) is the commonest inheritable blood disorder.[1] It is associated with episodes of acute illness resulting from stiff and sticky red blood cells clogging tiny blood vessels.[2,3]

The global burden of SCD is increasing, with an estimated 14,242,000 newborns between 2010 and 2050.[4] A great proportion, 82%, of these births will occur in Sub Saharan Africa.[5] Uganda has the fifth highest sickle cell burden,[6] with 13.3% of the population being sickle cell heterozygous carrier state (HbAS).[7] It is estimated that 15,000 to 20,000 babies are born annually with SCD in Uganda.[6,7]

SCD is linked with a lifelong risk of hospitalization, decreased life expectancy, and a poor quality of life.[8] In Uganda, there are concerted efforts to address this burden from the Ministry of Health, cultural institutions (Buganda Kingdom), and

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non-governmental organizations like the Uganda Sickle Cell Rescue Foundation. These efforts are geared towards improving awareness, reducing mortality, while increasing sickle cell management and care outcomes.

Sickle cell management and care outcomes are complicated by the interaction of SCD patients with the socio-ecological system.[9–11] SCD patients often experience numerous physical and psychosocial complications.[12] In Uganda, this situation is worsened by inaccessible formal social support structures to aid families and patients to cope better with the associated psychosocial burden.[6]

As children with SCD mature into adolescence, they face several challenges in addition to the typical adolescent challenges. These children have been observed to have a deterioration in physical, social, and emotional functioning which affects their self-esteem.[13] The adolescents with SCD also have more frequent hospitalizations, and a longer length of stay.[14–16] SCD associated challenges like nonattendance of school, lower academic performance (at times), and delayed sexual maturation and physical growth[17–19] often make individuals with SCD targets for teasing and bullying.

Individuals with SCD in resource limited settings like Uganda face many impediments while receiving an education, but stigma is one of most powerful and threatening. According to one person living with SCD, "I was often discriminated in school; none of my fellow students would want to share utensils with me Keep Smart".[20] For school-going children with SCD, the attitude of classmates is vital, as stigmatizing attitudes can lead to peer rejection. Peer rejection is associated with emotional distress, academic underachievement, school avoidance, and long-term occupational failure in adulthood.[21] This study therefore set out to assess the knowledge and perception of secondary students towards sickle cell disease before the creation of sickle cell clubs in the select schools. This study later evaluated the student's experiences 4 months after creation of sickle cell clubs. This work was part of the school outreach initiative run by the Uganda Sickle Cell Rescue Foundation. This information is crucial in understanding stigma in secondary schools in order to make schools positive and safe for adolescents and young adults living with sickle cell disease. In addition, this work is key in drawing attention to potential areas for intervention and improvement to foster better outcomes in sickle cell prevention, awareness, and management. This will contribute to building an inclusive, educated, and empowered population of young people in Uganda.

Methods

A school-based cross-sectional study design was employed to assess knowledge and perception towards sickle cell disease in secondary schools in Butambala district using self-administered questionnaires prior to set up of the sickle cell clubs. The questionnaire was distributed after a detailed explanation on how to fill it. After 4 months, student's experiences from the sickle cell clubs were evaluated using an interviewer administered questionnaire.

Study Area

The study was carried out in Butambala district, rural area located in central Uganda.

Sample Size And Sampling Technique

The survey considered a sample size of 375 participants, who were obtained using the formula by Kish Leslie (1965) for cross-sectional studies.[22] A 95% level of confidence, 50% proportion was estimated and a 5% level of confidence were used in the sample calculation. Random sampling was used to select eligible participants. Eligible participants for the knowledge and perception survey were students who have studied in the select schools for more than two terms. Eligible participants for the sickle cell club experience survey were club members who have attended two or more sickle cell club meetings.

Statistical Analysis Plan

The data were analyzed using descriptive statistics in SPSS version 17.

Sickle Cell Clubs

Uganda Sickle Cell Rescue Foundation (USCRF) works to promote sickle cell awareness while advocating against the associated stigma. USCRF initiated a project of sickle cell clubs in schools for the promotion of behavior change towards associated stigma and discrimination. This sickle cell club project is based on the assumption that existing sickle cell awareness initiatives can be strengthened for greater impact by providing education, counselling, and technical assistance within a school setting. The clubs target youth aged 10–25 years in mostly secondary schools towards promoting positive attitudes for sickle cell and SCD patients. Butambala district served as a pilot area for this club initiative.

Results

Characteristics Of Respondents

From Table 1 it can be seen that more than half of the respondents (59.5%) were female, the majority (87.5%) were below 18 years with the highest proportion (34.7%) of respondents in S.1. The majority (96.3%) of the respondents did not have SCD and many of the respondents had never tested for SCD.

Table 1 Characteristics Of Respondents

Demographics Characteristics Of The Respondents		
Variable	**Frequency (N=375)**	**Percentage**
Sex		
Male	149	39.7
Female	226	59.5
Age (years)	44	16.9
<18	328	87.5
18–25	42	11.2
>25	5	1.3
Class		
S.1	130	34.7
S.2	89	23.7
S.3	64	17.1
S.4	39	10.4
S.5	31	8.3
S6	8	2.1
Teachers	15	4.0
Have Sickle cell		
Yes	14	3.7
No	361	96.3
Tested for SCD		
Yes	39	10.4
No	338	89.6

Characteristics Of The Selected Schools

Table 2 shows a detailed description of each of the select schools where the pilot of the sickle cell clubs was implemented.

Knowledge On Sickle Cell Disease

Table 3 shows that 68% of the respondents did not know that sickle cell is a genetic condition. The highest proportion of respondents (44.8%) was not sure whether SCD could be transmitted through physical contact. A total of 53.3% of the respondents were not sure whether one could develop SCD over time. The highest proportion (43.2%) of respondents were still not sure whether SCD could be inherited when both parents have the trait. The highest proportion (37.9%) of respondents knew that you could have SC trait even if both parents have no trait, as shown in Table 3.

Perception Towards SCD

The students' perception about SCD was assessed with seven statements to which the students indicated "yes", "no", or "not sure" responses. Table 4 shows the highest proportion (59.7%) of respondents reported that people with SCD should be employed. A total of 56.0% of the respondents noted that people with SCD should not

Table 2 School Information

	Secondary School	**School Description**	**Location/ Village**
1	Kibibi Muslim Secondary School	Privately owned, admits both males and females, and has both boarding and day sections, with the majority of students in boarding.	Kibibi
2	Sayidina Abubaker Secondary School	Government school, admits both males and females, it has a boarding and day section with the majority of students in boarding.	Kabasanda
3	Kibibi Parents School	Privately owned, admits both males and females, with a boarding and day section.	Mirembe
4	Kaggulwe Secondary School	Privately owned, admits both males and females, with a boarding and day section.	Kabasanda
5	Kibibi Central College School	Privately owned, admits both males and females, and has a boarding and day section.	Kibibi
6	Gombe Secondary School	Government school, admits both males and females, has both day and boarding section and the majority of students are in boarding.	Gombe
7	Lukalu Secondary School	Government school, admits both males and females with a boarding and day section.	Lukalu
8	Kawami Secondary School	Privately owned, admits both males and females and has only O level.	Kawami
9	Kibibi Secondary School	Government school, admits both males and females and it has a boarding and day section.	Kibibi

Table 3 Knowledge On Sickle Cell Disease

Variable	Frequency (n=375)	Percentage
SCD is a genetic condition		
Yes	120	32.0
No	50	13.3
Not sure	205	54.7
SCD transmitted through physical contact with infected person		
Yes	55	14.7
No	152	40.5
Not sure	168	44.8
Can develop SCD over time		
Yes	98	26.1
No	77	20.5
Not sure	200	53.3
SCD can be inherited when both parents have trait		
Yes	138	36.8
No	75	20.0
Not sure	162	43.2
You can have SC trait even if both parents have no trait		
Yes	142	37.9
No	99	26.4
Not sure	134	35.7

Table 4 Perception Towards SCD

Variable	Frequency	Percentage
Should people with SCD be employed		
Yes	224	59.7
No	64	17.1
Not sure	89	23.7
People with SCD should not socialize		
Yes	62	16.5
No	210	56.0
Not sure	103	27.5
SCD is a shameful disease		
Yes	86	22.9
No	175	46.7
Not sure	114	30.4
People with SCD die at certain age		
Yes	141	37.6
No	75	20.0
Not sure	159	42.4
Important for people with SCD to attend school		
Yes	328	87.5
No	47	12.5
Should people with SCD get special treatment		
Yes	352	93.9
No	23	6.1
Should people with SCD be given equal rights		
Yes	171	45.6
No	204	54.4

socialize. The highest proportion (46.7%) of respondents noted that SCD is not a shameful disease. In regards to whether people with SCD die at a certain stage, the highest proportion (42.4%) was not sure. The vast majority (87.5%) of the respondents noted that it is important for people with SCD to attend school. The vast majority (93.9%) of the respondents acknowledged that people with SCD should get special treatment. More than half (54.4%) of the respondents reported that people with SCD should not be given equal rights, as shown in Table 4.

Evaluation Of Sickle Cell Clubs And Students' Experiences

The study evaluated the sickle cell clubs through questionnaires answered by select club members. They revealed the number of club meetings held in two school terms or between the surveys, as shown in Table 5.

For student's experiences, students were asked to share how they feel about the clubs, their perception of club importance, and expectations from the clubs. Students who identified as living with sickle cell (n=14) shared their experiences as well. Table 6 shows selected responses.

Discussion

This study presents the first evaluation of how sickle cell clubs can be used in the fight against sickle associated stigma in schools. This survey further provides an understanding of how Ugandan students comprehend and perceive SCD.

As shown in the study; for knowledge, 68% of the respondents did not know that sickle cell is a genetic condition, while 37.9% of respondents knew that you could have SC trait even if both parents have no trait. For perception; 56.0% of the respondents noted that people with SCD should not socialize, while 54.4% of the respondents reported that people with SCD should not be given equal rights. Students gave a good evaluation of the

Table 5 Number Of Club Meetings Held At Each School

School	Number Of Meetings	School	Number Of Meetings
Lukalu Secondary School	5	Kibibi Central college	5
Kaggulwe Secondary School	3	Sayidinah Abubakar Secondary School	5
Kibibi Secondary School	3	Gombe Secondary School	2
Kibibi Muslim Secondary School	2	Kawami Secondary School	2
Kibibi Parents School	2		

Table 6 Evaluation Of Sickle Cell Clubs And Students' Experiences

Theme	Quote
(A)	
Club importance	
Education	"Yes, it's because I have learnt many things about the disease which was not the case before"; a student at Kibibi Central College.
Service	"Yes, the club has an importance to me as a member because it inspires me to also do anything to help those who are living with sickle cell"; a student at Sayidinah Abubakar Secondary School.
Social	"Yes, it is because I get to interact with people with and without sickle cell"; a student at Kibibi Central College.
Self-Esteem	
Communication	"Yes, because now I talk about sickle cell"; a student from Kibibi Central College.
Leadership	"The club, is helping me become a better leader through the talks we give in my community"; a student at Lukalu Secondary School.
Advocacy	"Yes, the club is helping me become a sickle cell advocate"; a student living with sickle cell at Gombe Secondary School.
Organization	"Yes, I now coordinate the sickle cell activities"; a student at Kaggulwe Secondary school.
Club expectations	
Behavior change	"I expect the club to reduce stigma and discrimination of sickle cell patients"; a student at Gombe Secondary school.
Service	"To help our fellows in schools and societies around us who are sickle cell positive"; a student at Sayidinah Abubakar Secondary school.
(B)	
General experience of living with sickle cell in school	
Education	"I expect the club to teach more and make people like us comfortable in the way that people stop discrimination"; a student at Kibibi Secondary school.
Stigma	"I dropped out of biology class because the teacher said that sickle cell people die before 20 years of age"; a student at one of the schools.
Lack of care	"The nurse does not attend to us when we receive sickle cell crises after her work hours"; a boarding female student.
Happiness	"I am very happy about the club, because now I can free and openly talk about my sickle cell without worry"; a student at Kibibi Secondary School.

clubs highlighting important roles in building esteem among members, providing social, service, and educational roles. Students living with sickle cell highlighted the stigma and lack of appropriate care in the school settings.

More than half of the respondents (59.5%) were female; this could be attributed to the high proportion of females in this district.[23] In addition, this could be related to the health seeking behavior often exhibited by females.[24] In a school setting, this could be related to the flexibility of girls to

socialize and participate in social events. The majority of the participants (87.5%) were 18 years and below, this is in agreement with the school going age for secondary school in Uganda, ie, lower secondary ("O" level) 13–16 years and upper secondary ("A" level) 17–18 years.[25] The highest proportion of 96.3% of the students did not have sickle cell disease, this may be due to low prevalence of sickle trait in the area.[7] This could also be attributed to a lack of awareness of the disease[26] and of the lack of priority in taking a sickle cell test.[20]

The participants knowledge towards SCD was generally lacking, demonstrating a big gap among students, this might be associated to the lack of awareness and stigma associated with the disease.[6,20,27] In addition, located in Buganda kingdom this district is mostly inhabited by Baganda who have not had a local name for sickle cell until 2017 through the advocacy initiative of the Uganda Sickle Cell Rescue Foundation. This initiative gave birth to the name "*Nalubiri*" in the local dialect, this literally means "small bodied". The absence of a name in the local dialect further demonstrates the stigma and discrimination associated with sickle cell in this community. As evidenced through some families hiding their sick for the fear of being ostracized in society.[20]

For perception towards SCD, 93.9% of the participants acknowledged that people with sickle cell disease should get special treatment. This might have been due to the complexity of managing the condition or the lack of knowledge regarding this disease. In regards to school attendance, 87.5% of the participants believed that people with sickle cell disease should attend school. This is a key step in supporting students with sickle cell while in school.[28] This also provides a good platform to students to support their fellow students affected by SCD. Sadly, the greatest proportion (54.4%) of the respondents indicated that people living with sickle cell should not be given equal rights, and 56.0% noted that people with SCD should not socialize. This is a clear display of stigma and discrimination exhibited by these secondary school students. This is in agreement to Bazuaye and Olayemi[26], who indicated that secondary students stigmatize those living with sickle cell. This further indicates a bigger problem in Ugandan communities where people living with sickle cell do not have rights to independent thinking, to participate freely in community activities or further agency, and enjoy the same privileges like the "normal" people.[20]

For sickle cell clubs, the majority of the respondents linked the sickle cell awareness clubs to a degree of importance. The students also felt that the clubs are contributing to their continued learning and engagement. This is similar to other studies that have shown a similar positive effect associated with HIV/AIDS school clubs.[29,30] This concept of sickle cell awareness clubs is built on the model of peer education for behavior and attitude change among students.[31] We believe this initiative of peer education can be employed in sickle cell awareness and advocacy against associated stigma and or discrimination.

The study findings build on the existing body of knowledge of sickle cell associated stigma among adolescents and young adults.[13,27] However, the study particularly highlights a novel aspect of using a peer behavior change model to address sickle cell associated stigma and discrimination in a resource limited setting like Uganda.

The study limitations include the limited geographical coverage of the study. This study was done in one district, this geographical area could have people of different cultural beliefs as compared to the rest of the country. This affects the generalizability of the study findings. The study might also have been limited by the selection bias of students due to the self-selection for participation in sickle cell club initiative. We recommend future studies to involve more student numbers in several districts of the country so as to give a better picture of the knowledge and perception of students towards SCD. Future studies should also look at tools like mobile technologies that could be employed to support students or persons living with sickle cell in coping with associated stigma in resource limited settings.

Conclusion

From this study, it is evident the there is a big gap in sickle cell awareness among secondary school students. This study also shows a high level of stigma and discrimination in schools, as evidenced by the belief that students living with sickle cell should not have equal rights. This study indicates that sickle cell clubs have a positive effect towards behavior change while providing SCD knowledge and information.

Recommendations

There is a need for more action towards addressing sickle cell associated stigma and discrimination in schools and communities at large. There is a need to adopt and promote sickle cell clubs as a tool for promoting awareness

and advocating against associated stigma in secondary schools in Uganda.

Abbreviations

SCD, sickle cell disease; HIV/AIDS, Human Immunodeficiency Virus infection and Acquired Immune Deficiency Syndrome.

Ethics Approval And Consent To Participate

The ethics and research committee of Clarke International University approved the study procedures. Administrative clearance was obtained from the District Education officer of Butambala district and school head teachers. Written consent was obtained from participants above 18 years of age. All participants were informed about the study and participation was voluntary. For those below 18 years, written informed consent was sought from the parents while they gave verbal assent to participate. Information provided by the participants was anonymous and was kept confidential.

Availability Of Data And Materials

The authors confirm that the data and materials from this study are available

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Author Contributions

ST drafted the manuscript. ST, TN, and VN participated in the design of the study and data collection. ST and TN participated in the data collection. All authors contributed to data analysis, drafting or revising the article, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

The authors declare that they have no competing interests in this work.

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