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Review Article

Global Sickle Cell Disease and Impact on School Education in Children: A Focus on Interventions for Improving Academic Performance

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ABSTRACT

Haemoglobinopathies are primarily associated with thalassemia and Sickle Cell Disease (SCD). SCD is one of the severe inheritable illnesses in world. Mutations in the HBB gene cause SCD. Patients with SCD experience a variety of excruciating sensations, as well as headaches, liver and splenic sequestration issues and jaundice. Children are unable to attend school as a result. The main things impacted are low academic performance, grade retention, intellectual disability and absenteeism. This review article examines the impact of SCD on children's schooling and also suggests interventions which can be carried on for better performance of children with SCD. SCD is a heritable (genetic) disorder and is marked by sporadic episodes of severe pain and hosts other health issues. About 5% of people worldwide suffer from this most common haemoglobinopathy. More than 7% of expectant mothers have haemoglobinopathies in their genetic composition. Each year 330,000 newborns are born with haemoglobinopathies. Nearly 80% of them are born in Africa, Nigeria, Congo and India. Children with SCD have health challenges that impact their education. Absence from school, grade retention, academic performance and dropouts from school are major issues for children with SCD in the context of academic goals. The main objective of this paper is to understand how SCD affects the school performance of children globally, impact on their education and possible interventions and strategies to reduce school absenteeism. Studies suggest that parents, patients, educators and healthcare professionals can work together to comprehend and manage the effects of SCD on student attendance. Awareness campaigns for educators and care givers, remedial classes for SCD children in schools and policies aligning to the education of children with major disabilities like SCD may compensate the attendance and academic performance of the SCD children.

Keywords: Absenteeism; Academic performance; Grade retention/intellectual disability; Sickle cell disease; School education

INTRODUCTION

The prevalence of SCD is rising worldwide. It is associated with an autosomal recessive condition where persistent hemolytic anemia is caused by structurally defective Hemoglobin (HbS) [1]. Mutations in hemoglobin, particularly in hemoglobin subunit β, cause SCD. There are around 3 to 4 lakh new born SCD children estimated to be born worldwide. SCD is the most common haemoglobinopathy globally, accounting for 275,000 of the 330,000 newborns born with a significant haemoglobinopathy globally [2]. Majority of new born children with SCD are born in sub-Saharan Africa [3]. Infants with SCD are born in low and middle-income countries, which accounts over 250,000 births in Africa and 30,000 in South Asia each year [4]. Approximately 50%-80% of patients will die before reaching adulthood in sub-Saharan Africa, compared to over 90% of SCD children in western nations who live till adulthood [5].

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The estimated number of new born with SCD may increase to more than 400,000 each year by 2050. SCD gene is present in Sub-Saharan Africa, the Arabian Peninsula, Eastern Province, sections of Sicily and Southern Italy, Northern Greece, Southern Turkey and Equatorial Africa and central, southern and western regions of India [6-8]. Highest prevalence of the disease is reported in tropical regions, due to migration and other factors, incidence is increasing in other regions also.

Different countries started screening programs to determine the prevalence of SCD. The screening provides distribution and mapping of the HbS gene. Lehmann and associates reported SCD in Saudi Arabia in 1963 and the Government of Saudi Arabia initiated the national wide screening program in 1982, in which 36 distinct locations were covered [9]. In 1986 another investigation on Bahrain females revealed the prevalence of sickle cell carriers (Hb AS) was about 7% [10]. A study conducted on 56,198 Bahrainis in hospitals revealed that 2% of babies had SCD, 18% have sickle-cell trait and 24% carry the thalassemia gene [11]. In an another report in Madagascar showed the prevalence of 2.4% SCD and 23.8% were trait [12]. On an average 10,000 SCD births per year occur in high-income nations like the United States and Europe, where SCD is uncommon [13].

In the world, over 70% SCD patients are present in Africa. As per World Health Organization (WHO), 10-30% prevalence of sickle-cell trait is seen in African nations like Democratic Republic of the Congo, Ghana and Nigeria. This means that the majority of Africa is considered to have at least 2% of the condition [14]. As per United Nations, there are between 20 and 25 million SCD patients globally, of which 12-15 million reside in Africa. 75%-85% of infants with SCD are born in Africa. Further, in Africa, nearly 120,000 newborns are diagnosed with SCD per year. Even though HbSS is the most common kind, HbSC and Hb thalassemia are also prevalent in west Africa [15]. Out of 160 million people 2%-3% Nigerian population is affected with SCD. In benign city of South Nigeria, it was found that the carrier rate was approximately 23% and the prevalence of SCD was 2.39% [16]. Tanzania is home to one of the highest rates of SCD cases worldwide, with an estimated 11,000 cases each year [17]. In Africa three haplotypes in SCD are reported [18-20]. The Central African Republic haplotype (Bantu halo type) is found in Zaire, Central Africa, Angola and Kenya. Atlantic coast of West Africa has The Senegal haplotype. The Benin haplotype in Ghana, Nigeria and Cote d'Ivoire (central West Africa) [21]. SCD affects the school going children's attendance, academic performance and grade retention due to pain episodes and frequent visits to hospitalization. Children with SCD have health challenges that affect their school lives. A study showed there is an increase in their school-related absences due to health-related and psychological factors, students with SCD teenagers, aged 12 to 18, out of 40 patients, missed an average of 12% of the school year and more than 35% missed at least one month. Parent-reported teen pain frequency and frequent trips to health facilities; linked to absenteeism. Despite having academic ambitions, school absenteeism is a serious issue for adolescents with SCD [22]. A cross-sectional study including 107 patients was conducted in the Sudanese Misseria tribe. Research revealed that 17.8% of patients missed school owing to bedwetting, 29.6% to bullying, 23.4% to embarrassment from jaundice, failure to participate in extracurricular activities at school and depressive symptoms [23]. Children in Tanzania with SCD showed signs of neuropsychological impairment. A study found a substantial difference in the neurocognitive scores between children with SCD and their normal siblings. Among the 313 children, those with SCD showed a higher percentage of IQ impairment (85.4%) than did those without SCD (72.5%). One of the factors linked to neurocognitive impairment is school absenteeism [24]. In Nigeria, a research comparing 52 children with SCD (ages 6 to 17) and their 42 siblings revealed that the SCD patients' school absence rate was much greater than that of their siblings' and they also had a significantly higher percentage of below-average students. A study on low and high frequency hospitalizing of SCD children showed higher absenteeism in higher frequency hospitalized children in Nigeria. Out of 212 days' school working days' period, the average absenteeism of SCD children (9.3) were more than siblings (4.1). The study indicates that a greater number of Nigerian children with SCD exhibit underachievement in school [25]. Children in Nigeria who have SCD exhibit absence from school.101 people with low hemoglobin levels and SCD were included in the study. Students with SCD showed higher absenteeism than other students, but their academic performance remained unchanged [26]. A qualitative study on 140 teenagers with SCD in Uganda, showed frequent hospital visits and absences from school due to pain in teenagers with SCD and it showed impact on school performance [27]. In sub-Saharan Africa, longer hospital stays and crises episodes are resulting in longer absences from school [28].

In USA, it has been determined from testing those African-American neonates, the frequencies of SCD gene thirty years ago was between 32,000 and 50,000. There have been approximately 50,000 to 80,000 cases of SCD. National estimates of the SCD population varied from 104,000 to 138,900 based on birth-cohort illness frequency; however, the estimates decreased between 72,000 and 98,000 when early death was considered [29]. A study revealed that 89,079 Americans with SCD were present in USA; of these, 8928 were Hispanic and 80,151 were Black. With 8308 cases, New York had the largest sickle-cell population. Florida stands in second place with 7539 cases, while Texas in third with 6765 cases [30].

Every year, about 2000 children in the United States are born with SCD, affecting 1 in every 2474 live births. Approximately 1 in 1900 babies in the United States are affected by SCD, which is the most prevalent disease in neonates [31]. SCD affects 1 in 400 newborns in the African American community [32]. 215 children (0.16%) with SCD were found among the 133,481 children (mean age 8.5 years, SD: 0.02) in the National Health Interview Survey (NHIS) data over a 12-year period. 49.1% of children with SCD are from the United States South. The prevalence of SCD was greater in black children (7.83 per 1000) [33]. Children with SCD have issue in grade retention.

Grade retention problem was found in a study involving 370 children, ages 6 to 16, that included comprehensive data on past grade retention. One of the factors influencing grade retention

in children with SCD is decreased reading achievement [34]. Children with high and low frequencies perform similarly academically, yet the high frequency group saw noticeably more absences than the low frequency group [35]. A baseline study on SCD children focused on Individualized Education Plan (IEP) which includes grade retention and days missed from school in the year before to the intervention are among the assessment parameters. Children with SCD had a higher likelihood of absence and grade retention which was observed according to King A et al., [36]. A study done on 197 SCD patients had deficits in cognitive and academic functioning and had trouble maintaining a grade. Higher percentage of children with SCD received special education services than the national, state and local school district rates for African American students [37]. The school attendance of patients with SCD is impacted by pain episodes [38]. Vaso-Occlusive Crisis (VOCs) associated with SCD are linked to frequent hospitalizations, absenteeism from school, emotional anguish and financial difficulties [39]. Eighty-two SCD youngsters answered questions about their IQ and academic performance. A study on 82 youngsters results of hierarchical regression studies showed that IQ, parent education, chronic transfusion status and other factors explained 55% of the variance in academic skills [40]. One more study showed problems with academic attainment were more common in SCD patients than in their contemporaries. 22 of the 50 SCD children experienced issues with their academic performance; compared to controls, children with SCD also had multiple grade repetitions more frequently. Children with SCD were more likely to experience attainment issues [41]. 30 adolescents aged between 12 to 20 years, completed demographics and SCD school performance questionnaires. Approximately 37% of participants reported receiving special education services, but more than 60% reported that SCD interfered with their school performance [42]. According to National Health Interview Survey Child Sample Score, special education services use was generally higher for black children with SCD than for black children in the general population [43].

Countries provide nationwide population-based newborn screening for SCD in the US, Brazil and Costa Rica. Based on published and extrapolated data, SCD affects 100,000-150,000 Latin Americans and over 6,000 infants every year [44]. The HBS gene spread widely throughout North and South America, the Caribbean and Africa could be as a result of the slave trade. A study includes 31 healthy participants and 31 SCD participants, ages 8 to 17, underwent auditory system evaluation showed poor academic performance due to Sensorineural hearing loss and increase the risk of attentional and cognitive impairment in children and adolescents with SCD [45].

Later, immigrants from the Caribbean who travelled directly from Africa to the UK, France, Belgium and Holland as well as from Turkey to Germany carried SCD to Northern Europe. Given the diverse African ancestries of the continent's populations, the HBS gene is widely distributed in America. The reports suggest that SCD gene is also present in Jamaica [46]. In Europe, 5.4 infants have been screened and, among 7,644 were diagnosed with SCD between 1995 and 2016. England and France are initiated the SCD screening National wide and UK countries also started New Born Screening (NBS) for SCD. European countries take initiation for NBS programs in Belgium, Spain, Netherlands and Matla. Italy and Germany did many studies on SCD and they are now ready for NBS program for SCD [47]. NBS program identified the birth prevalence of 1 in 1836 in France. Out of 431 cases 356 cases were diagnosed from Metropolitan France. In these cases, 218 cases from Ile de France and Parisian area. It showed Ile de France's birth prevalence was 1 SCD in 824. The birth prevalence is varying in Island of Reunion (1 in 525) and French Guina (1 in 206). 75 In the French Overseas, babies were affected by SCD. Australia has registry data on 359 SCD patients. There are 180 children and 179 adults among the 359 SCD patients. Given that the majority of the patients had a predominately sub-Saharan African ancestry, the majority of them had SCD diagnosis with a HbSS phenotype [48].

The prevalence of SCD is high in Bangladesh, Nepal, Pakistan and the Maldives [49]. It is estimated that the prevalence SCD is 1 in 1000 in Bangladesh (Right diagnosis,2016). 4% of anemic patients are suffering from SCD in Pakistan [50]. A study in Karachi city of Pakistan on 202,600 subjects of blood samples resulted in 5.1% of SCD in patients [51]. One more cross-sectional study in Karachi included 2731 patients showed 3.9% were SCD patients [52]. According to a study of 2899 SCD patients has been detected in the indigenous Tharu population of Nepal [53]. Another study in western Nepal diagnosed 92 SCD patients out of 1250 individuals [54]. A study on 100 patients in western Nepal diagnosed at least 5% SCD patients [55].

When it comes to India, there are about 8.6% of the 67.8 million tribes and India is home to about 461 different tribes. India is home to more than 20 million SCD sufferers, has the greatest disease prevalence in all of the South Asia [56]. This population is concentrated in a belt that stretches from south-eastern Gujarat to south-western Odisha in central India. Eighty-three percent of the tribal population is distributed across Madhya Pradesh, Maharashtra, Odisha, Gujarat, Rajasthan, Jharkhand, Chhattisgarh, Andhra Pradesh, West Bengal and Karnataka, among other states [57]. Madhya Pradesh has a higher than average prevalence of SCD (1 to 40%). In Madhya Pradesh, there are 9, 61,492 sickle cell characteristics and 67,861 ill people [58]. In the Vidarbha region of Maharashtra, sickle cell carriers account for 1%-35% of the population [59]. The frequency of HbS in certain tribes in Kerala is incredibly high (18.2 to 34.1%) [60]. In the Gujarat State, 1,68,498 tribal people from 22 districts underwent screening and found that at least 11.37% of tribal population is effected by SCD overall [61].

In 2016, The Ministry of Tribal Affairs reported 9,49,057 (8.75%) sickle cell trait and 47,311 SCD patients after screening more than 1.13 crore persons [62]. In Tamil Nadu, India, SCD was first discovered among India's numerous indigenous populations. It has been established in every demographic as of late. Over 120,000 individuals suffer from SCD, with Madhya Pradesh housing the majority of these cases. Additionally, 44,000 infants with sickle cell anemia are thought to be born in India each year; it's possible that comparable amounts are born with HbS/β-thalassemia as well. It is well known that India has

the third-highest birth rate after Nigeria and the Democratic Republic of the Congo [63]. This review article's goal is to understand the impact of SCD on academic performance of children. The health issues that SCD children face have an effect on the academic performance. Their absenteeism from school has increased. Underachievement, academic performance and grade retention are all impacted by SCD.

REVIEW OF LITERATURE

To comprehend the impact on education, we looked through and analyzed papers from a variety of sources, including PubMed, Google Scholar and Scopus up to June 2024. The key words used to search for this article are SCD children, absenteeism, academic performance and grade retention and also includes discussion of research on academic achievement, grade retention and absenteeism in school-age SCD children.

DISCUSSION

In this review we illustrated the prevalence of SCD in different countries and how SCD affects the children and their academic performance of students. In this context, we also present a comprehensive understanding on the strategies needed based on the interventions taken up in different countries to improve health quality of life and performance in academics of SCD children.

Interventions for improving the health quality of SCD students

Our study observed that including children with SCD and also care givers do not have adequate knowledge on SCD and its management globally. Few intervention studies are tabulated in (Table 1) in which one of the intervention studies showed that education along with tailored written materials on awareness about SCD changed way of behavior of caregivers to help and provide better care for SCD children patients. A pre-intervention and post-intervention study on 43 caregivers of 57 children after conducting educational sessions in Children's Cancer Center in Lebanon showed the reduction in Emergency department visits and hospitalizations. After holding an educational session on SCD management, caregivers' understanding of the disease's etiology, symptoms and therapy has significantly increased. Education and written materials in a simple language has improved the knowledge on SCD among children and caregivers [64].

Table 1: Intervention studies to improve SCD patient's health and education.

S. No.	Country	Cohort	Intervention Factors	Results	Reference
1	Lebanon, Northern Arabian Peninsula	43 caregivers of 57 SCD children	Tested knowledge of SCD before & after educational sessions	Significant decrease in the number of hospitalizations before & after educational sessions	Shahine R et al., [64]
2	Jazan Province, Saudi Arabia	339 SCD Students	Grade point averages	More performance seen in 60% SCD students and less performance seen in 40% non SCD students while providing online activities.	Alhazmi A et al., [70]
3	USA	One girl with SCD and chronic illness	Focus to improving academics	She improved and over come previous class and promoted to next grade.	Harden C et al., [71]
4	Oman	37 parents of children with SCD	parent educational intervention program	Parent education utilizing a smart phone was successful in raising parents' perceptions. They gain good knowledge of' Health Related Quality of Life of children and self-efficacy in managing SCD.	Al Nasiri, Y et al., [72]
5	Jeddah, SaudiArabia	60 with SCD children	Depression in SCD children	Children with sickle cell disease (SCD) had greater quality of life and less depressive symptoms when they	Sehlo, M.G., et al., [73]

				had higher levels of parental support.	
6	USA	17,AYA(Adolescents and young adults) and 15 care givers	Problem-solving education (PSE)	We can better prepare adolescents and young adults for transition if we understand how they, together with caregivers, perceive the obstacles and enablers of transition in people with SCD.	Melita, N.,et al., [74]
7	African American	Parents of children with SCD-SS between ages of 5 & 13 yrs	Nutritional study	Overall physical health andparental emotional impact improved to normative levels.	Wrotniak, B. H., et al., [75]
8	Texas, USA	80 college students selected Sickle cell disease and sickle cell trait students	SCD health education	Promoting college-based health education raise the knowledge on SCD which can lead to social change.	Guobadia, E. A., et al., [76]
9	USA	22 SCD chidren	CD-ROM educational game (developed specifically for children with SCD)	Participants' SCD knowledge and confidence levels increased significantly with CDROM educational game	Yoon SL et al., [77]
10	USA	90 SCD patients from sevent standard to collge level.	Depressed symptoms assessed	The findings revealed that use of social support improved the adaption of SCD Patients.	Burlew, K et al., [78]

Adolescent peer education programs have demonstrated encouraging outcomes in terms of increasing awareness, enhancing understanding and encouraging preventive behaviors among those who are impacted [65]. School based initiative programs support early diagnosis, intervention and proactive treatment of the disease by incorporating SCD education into curricula and by raising staff and teacher awareness [66]. Family physicians play a key role in treatment of SCD patients. They are essential in implementing evidence-based preventive care plans, identifying life-threatening events, treating acute illnesses promptly and acting as a multidisciplinary management team's medically at home [67]. The management of SCD in children involves providing high-quality care while also empowering parents and the child to take on active roles in the treatment plan throughout time [68]. Nigerian doctors' increased understanding of SCD phenotypes and comprehensive care while improving the standard of care for SCD patients [69]. A cross-sectional study conducted on 339 SCD students in Jazan Province of southwest corner of Saudi Arabia showed that online classes had improved the academic performance in SCD students when compared to healthy students during the COVID pandemic. In comparison to the healthy group, the SCD group reported higher academic performance (59% *vs.* 42%) during the COVID-19 pandemic. Female sex, younger age, higher education level of parents, monthly income of parents reported improved performance during the COVID-19 epidemic, strongly correlated with better academic achievement among SCD participants [70]. A case study on a SCD girl with chronic illness from USA failed in the exam but with frequent tutoring in online passed the previously failed classes and advanced to next grade [71]. Unpublished data of our research work in Tribal area of Visakhapatnam, India includes, there are 29 sickle cell disease students were taken into study aged between 6-11 years. Out of 29 students, 5 were became school drop outs due to heavy pain episode of sickle cell disease. Remain 24 students were compared with controls. The study showed that the average attendance in sickle cell students were 120 days out of 134 working days of school. The average attendance for controls is 132days. It shows the absenteeism is more in sickle cell disease students when compared to controls. Many research papers showed that sickle cell disease students have high absenteeism, grade retention and low Academic performance.

CONCLUSION

Many studies indicate that different ailments like epilepsy, diabetes and SCD impact student's capacity and performance. Our review focused on the general prevalence of SCD globally limiting the data to the percentage of school going children all around world. Absenteeism, grade retention, poor academic performance and dropout rates from school are major issues for children with SCD even in the context of academic goals.

Various reports have been collected aiming at the strategies and interventions needed and taken up for better academic performance of SCD children. These reports suggest that parents, patients, educators and healthcare professionals work together to comprehend and manage the effects of SCD on student attendance. Addressing the unmet basic needs of SCD students are very important in improving academic of SCD children. Government has aim to arrange the doctor and regular visit to the SCD students in schools which can improve the health quality of students and improve the attendance of SCD students. Government should take steps to provide nutritional food to SCD patients in schools, which can improve health quality of SCD patients. Arrangement of psychological counselors in schools will improve the academic performance. Financial support to SCD students for better medication can be useful for urgent and basic needs of the SCD children. Very few studies have been conducted on SCD student's academic performance, absenteeism and grade retention. More studies may help in formulating policies which can influence SCD student's academic performance. Government of India is making significant efforts in conducting talk sessions and counseling at schools and colleges including tribal residential schools, tribal hostels and Ekalavya colleges model schools to create awareness on SCD in students. Subsequent investigations should employ outcome measures that are conceptually grounded in prospective, continuing and community-based studies to determine which behavioral, pharmacological and educational treatments can enhance the academic and educational results of children diagnosed with SCD. Through this review article we propose that the SCD students to be monitored regularly for the drug consumption in schools under the supervision of a school teacher can improve the quality of life and may overcome majority of the SCD related issues and those students can lead normal life on par with other students.

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