LIVED EXPERIENCES OF ADOLESCENT LEARNERS WITH SICKLE CELL DISEASE

Research Article

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Introduction

Sickle Cell Disease (SCD) is a chronic disease that is inherited. It is categorized as a disease accompanied by frequent pain, low red blood cell count, and infection [1]. People who have SCD produce abnormal type of haemoglobin, this is sickle haemoglobin and is shaped like a sickle or other cells would say, like a banana. Normal cells are shaped like a ring doughnut, and can move freely through blood vessels carrying much needed oxygen to all parts of the body. In addition to all this, sickle cells clog the flow of blood and can break apart as they move through the blood vessels. Implying that, they do not deliver oxygen throughout the body as well as normal cells do. This means that a person living with Sickle Cell Disease (SCD) suffers from chronic, debilitating pain, also known as pain crisis, anaemia or even stroke. They also suffer from leg ulcers, avascular necrosis of the hip or shoulder; acute chest syndrome, organ failure and also vision loss [2].

The statistics on the exact number of people living with SCD in the whole of Zambia are not very clear. However, the University Teaching Hospital (UTH) claims to have close to 4,000 people of all ages, with SCD who attend their Friday outpatients’ clinic. Changufu [4] wrote that in Zambia, 17 or more of every 100 indigenous Zambians carries the sickle cell trait and about 200 or even more out of every 10,000 births per year are infants who have SCD. According to his research findings [4], SCD is among the top diseases that leads to morbidity among children in countries where SCD is prevalent, most commonly in Africa and India. This genetic disorder is one of the causes of high morbidity and mortality. The recurrent pain and complications caused by the disease can interfere with many aspects of the patients’ lives including their education, employment and psychological development.

SCD can have a great impact on the patients’ psychological development. Psychological complications in patients with SCD stem from the pain and symptoms that they suffer throughout the day and night, also in retrospect, society’s attitude towards the sufferer. There is a great deal of literature on the experiences of adolescent learners with SCD. The current study therefore sought to explore the experiences of adolescent learners with SCD as they pursue their education. A phenomenological qualitative research design was used. The target population comprised adolescents with SCD, their caregivers and their teachers. The adolescents were randomly selected from among those who attend the Sickle Cell clinic every Friday at the University Teaching Hospital. Purposive sampling was used to identify caregivers and teachers. In line with the phenomenological requirement of using small samples, 5 adolescents, 5 parents and 5 teachers were used in order to more comprehensively capture their experiences. Semi-structured interviews were used to collect the data. The data from the interviews was analysed, coded and grouped according to emerging themes. The Interpretative Phenomenological Analysis (IPA) technique was used to interpret the experiences of adolescent learners with the SCD, as well as the experiences of parents and teachers. Among the adolescent learners the themes that emerged were: Being sick often; Repeating grades; need for extra lessons; and Teachers not understanding the SCD condition.

Among the parents the themes included: Children with SCD missing school often; Children with SCD needing more attention in class; Need for Extra lessons, and Teachers not understanding sickle cell disease. Among the teachers, the following were the themes: Parents and learners not wanting the SCD condition to be known; Lack of knowledge by teachers about the SCD; Need for learners with SCD to have individualised attention during lessons; and Inadequate support given to learners with SCD in schools. The physical and psychological burden that SCD has on school attendance by adolescents, may have a bearing on their future employment prospects, ability to form healthy relationships, and may further lead to poor mental health and to the increase in health care needs. Based on these findings, the current study recommends that the Ministry of education pays particular attention to the plight of adolescent learners with SCD in schools so that they too can be given optimal chances to succeed.

Sickle cell disease (SCD) is an inherited chronic disease characterised by low red blood count and infection. SCD taxes the cardiovascular system and results in reduced exercise tolerance, delayed growth and sexual development. Adolescence is a developmental stage with numerous challenges, more so for adolescents with SCD. Adolescents who suffer from chronic pain due to the SCD are usually alienated from their peers and may also be victimised by them. As a result, adolescents with SCD commonly do not disclose their condition, which may lead to further alienation and stigmatisation by their teachers as well as their peers. There is a dearth of literature on the experiences of adolescent learners with SCD. The current study therefore sought to explore the experiences of adolescent learners with SCD as they pursue their education. A phenomenological qualitative research design was used. The target population comprised adolescents with SCD, their caregivers and their teachers. The adolescents were randomly selected from among those who attend the Sickle Cell clinic every Friday at the University Teaching Hospital. Purposive sampling was used to identify caregivers and teachers. In line with the phenomenological requirement of using small samples, 5 adolescents, 5 parents and 5 teachers were used in order to more comprehensively capture their experiences. Semi-structured interviews were used to collect the data. The data from the interviews was analysed, coded and grouped according to emerging themes. The Interpretative Phenomenological Analysis (IPA) technique was used to interpret the experiences of adolescent learners with the SCD, as well as the experiences of parents and teachers. Among the adolescent learners the themes that emerged were: Being sick often; Repeating grades; need for extra lessons; and Teachers not understanding sickle cell disease. Among the teachers, the following were the themes: Parents and learners not wanting the SCD condition to be known; Lack of knowledge by teachers about the SCD; Need for learners with SCD to have individualised attention during lessons; and Inadequate support given to learners with SCD in schools. The physical and psychological burden that SCD has on school attendance by adolescents, may have a bearing on their future employment prospects, ability to form healthy relationships, and may further lead to poor mental health and to the increase in health care needs. Based on these findings, the current study recommends that the Ministry of education pays particular attention to the plight of adolescent learners with SCD in schools so that they too can be given optimal chances to succeed.

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more recognition of the psychological difficulties that take place because of the biological challenges that come with the disease. Due to the many stressful experiences that commonly occur, children with SCD who have not suffered stroke may inadvertently be potentially prone to excessive anxiety, depression, moods, poor self-concept and difficulties with being accepted socially [5].

There are issues that affect their self-esteem and poor body images. The disease can also affect the physical appearance of adolescents. Small stature and delayed menarche and physical development, complications of SCD, can affect self-esteem and peer relationships. It can also limit the learners’ ability to take part in sport. This may lead to a feeling of not belonging which can affect their self-esteem [6]. Studies have identified a relationship between chronic disease and the adolescents’ physical development. The combination of psychological problems such as learning disabilities, small stature and chronic fatigue places children with SCD at a high risk of having problematic relationships [7,8].

Sickle Cell Disease taxes the cardiovascular system, or the circulatory system; which results in reduced exercise tolerance, delayed growth and sexual development. Also, a majority of males with sickle cell anaemia are likely to experience ‘priapism’ which is the painful or undesired erection that lasts from four to twelve hours. It occurs between the ages of 5 to 40 [9].

Adolescents who suffer from chronic pain are usually alienated from their peers and may also be victimised by them. It is common for SCD adolescents not to disclose their condition, and this may lead to alienation and stigmatisation by their teachers as well as their peers. There is a psychological and physical burden that SCD has on school attendance which may unknowingly prevent the patient from getting any future employment and relationships; and may further lead to poor mental health and to the requirement of higher healthcare needs. Studies have shown that the most frequent psychological problems encountered by learners with SCD include an increase in anxiety, depression, as well as social withdrawal, aggression and poor relationships [10].

In addition to this, lower educational achievement, limitations in occupation, frequent truancy and psychiatric disorders have been noted. Symptoms of anxiety, including feeling tense, worry and fearfulness are prevalent in the adolescents with chronic illness [11]. These adolescents also face problems with parental and peer relationships are also a source of psychological distress for them. The severity of the disease also has a role to play in the academic performance of these children. Eaton, Haye, Armstrong, Pegelow and Thomas [12] came to the conclusion that adolescents who were hospitalised more frequently for pain missed a significant number of days from school as compared to the other adolescents.

Another issue that is said to influence the academic outcomes of adolescents with SCD is how the family functions. It is quite possible that this factor directly affects the academic outcome of adolescents with SCD. However, it is another factor that still needs to be researched. When we speak of family functioning, we are talking about the relationship between and among family members [13]. A family that functions well is characterised as adaptive, cohesive, and low in conflict, organised and using good communication styles [14].

Children with chronic diseases that constantly need management tend to remain dependent on their families for care and emotional support. A negative outcome of this is the overprotectiveness of the parents over their children. Parents’ anxiety and overprotectiveness can lead to restrictions of activities for the adolescent with SCD; which in turn leads to the restriction of autonomy that the adolescent desires. The manner in which parents respond to a child can lead to anxiety and distress but can also lead to much needed support that the patient requires in order to gain confidence in their ability to cope with their disease.

A third aspect that should be taken into consideration when dealing with the psychological impact of sickle cell disease on children is the attitude of teachers towards them. There has been evidence that the teachers do not take the symptoms that the child has seriously because they think it is just an attention seeking tactic or merely being disruptive [15]. It has been noted that children and adolescents with SCD often have a different set of feelings from their peers and most of the time wish to hide their disease in order to avoid constant scrutiny, judgement and isolation by peers. At times the SCD sufferer is called lazy when in fact they are just suffering from fatigue due to anaemia.

The school environment is an important aspect of the child’s life. It is one that can help the child make sense of their illness and may even help them cope better. It is evident too that interaction with peers and teachers is beneficial to the adolescent with SCD. It is possible that the positive attitude from their teachers will help the child handle their pain better and may even help them get through crisis better. Though there is little literature in Zambia that has been published on this aspect, it is true to say that the coping with chronic pain, can be handled better when other people are involved than when one is alone [16]. Teachers are an integral part of any child’s life and their positive outlook can help the child with their psychological issues.

A lack of understanding on the part of the school can create many difficulties for the child with SCD which in turn means that, the child may not achieve or attain their potential. Teachers mostly are not able to deal with crises in school. Parents feel that teachers are ignorant and more often than not, misjudge their children in the sense that, they feel that these children exaggerate or even just pretend to be sick. About 10% of parents do not tell the school the child has SCD [17, 18].

**Method**

The Phenomenological design was used in this study. This is because it focuses on how people perceive the world around them, and their experiences as they go through a phenomenon. The Phenomenological Research Design is concerned with what phenomenon would present itself as we interact with the world [19]. The target population comprised adolescents with Sickle Cell Disease, one or both their caregivers (parents or guardians) and their teachers. These were drawn from the children who attend the Sick Cell clinic every Friday at UTH. The parents were those of the adolescents and the teachers were those who have experience teaching adolescents with SCD. The sample size consisted of 5 adolescents, 5 parents and 5 teachers. These were taken from UTH in Lusaka as the starting point. In line with the interpretive phenomenological analysis which seeks to capture participants’ lived experiences, the number of participants used had to be small [19].
The adolescents who suffer from SCD were selected using purposive sampling. This is because there are close to a thousand adolescents who attend the Sickle Cell clinic at UTH. However, the research design only required a small population. Purposive sampling was carried out to target the adolescents, care givers as well as the teachers of adolescents who suffer from SCD; one of whom was a guidance teacher (as this is the teacher to whom learners are most likely to report bullying and other challenges faced) [20]. This is because purposive sampling allowed the researchers to identify the respondents who fit the required criteria. The researcher used semi structured interviews to capture participants’ experiences [21]. There were interview guides for the three groups of participants namely, the adolescent learners with SCD, their parents/ caregivers and their teachers. By using this type of interview, the researchers’ were able to steer the participants towards the discussion that were deemed important for this project.

The data from the interviews were analysed, coded and grouped according to emerging themes. Interpretative Phenomenological Analysis (IPA) was used in this study. Through phenomenological analysis a researcher produces and in many ways interprets the experiences that participants go through [19].

**Findings**

From the study conducted, a number of themes were generated that bring out the experiences that learners go through as they attend school. They reflect the experiences that the adolescent learners have as well as those of their parents and their teachers.

From the interviews that were carried out with the learners who suffer from SCD, a number of themes emerged that bring out the experiences that they have had. The themes are as follows: Being sick often; Grades are repeated; studies and extra lessons; Exemption from strenuous activities and Teachers do not understand the condition.

From the interviews that were carried out with mothers, a number of aspects were brought out. These highlighted the experiences that their children had as learners who suffer from sickle cell disease. The themes that were generated are as follows; Children with SCD miss school often; Children with SCD need more attention in class; Extra lessons and classes are repeated and Teachers do not understand sickle cell disease.

The themes that were generated from the interviews carried out with teachers bring out the perspective that teachers have about learners with sickle cell disease. The themes are as follows: Parents and learners not wanting the SCD condition to be known; Lack of knowledge by teachers about the SCD; Need for individualised attention for children with SCD; Inadequate support given to learners with SCD in the schools.
Table 1: Respondent groupings and identified themes

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Age/Grade of learners</th>
<th>Identified themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Adolescent learners (n=5)</td>
<td>i. 16 years – Grade 5</td>
<td>• Concerns regarding being sick often and missing classes;</td>
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<tr>
<td></td>
<td>ii. 14 years – Grade 9</td>
<td>• Often being required to repeat certain grades due to poor performance;</td>
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<tr>
<td></td>
<td>iii. 13 years – Grade 5</td>
<td>• Requirement for extra studies and lessons to catch up with peers;</td>
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<tr>
<td></td>
<td>iv. 14 years – Grade 9</td>
<td>• Need to be exempted from strenuous activities; and</td>
</tr>
<tr>
<td></td>
<td>v. 17 years – Grade 11</td>
<td>• Lack of understanding from teachers regarding the condition and the toll it takes on the learner.</td>
</tr>
<tr>
<td>2. Parents/Guardians (n=5)</td>
<td>-</td>
<td>• Children with SCD miss school often;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Children with SCD need more attention in class;</td>
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<tr>
<td></td>
<td></td>
<td>• Extra lessons are often required and classes are repeated; and</td>
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<tr>
<td></td>
<td></td>
<td>• Teachers do not understand SCD.</td>
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<tr>
<td>3. Teachers (n=5)</td>
<td>-</td>
<td>• Parents and learners do not disclose the SCD condition to teachers;</td>
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<tr>
<td></td>
<td></td>
<td>• Lack of knowledge by teachers about the SCD;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Need for individualised attention for children with SCD;</td>
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<td></td>
<td></td>
<td>• Inadequate support given to learners with SCD in the schools</td>
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Discussion
The study’s purpose was to find out the experiences of adolescent learners with sickle cell disease as they pursue their education. From the themes that have been generated from the interviews, a number of issues can be outlined, that were similar in all three respondent groups. The first is the theme of parents and learners not wanting the SCD condition to be known. Under this theme, it was revealed that teachers felt frustrated by parents and learners hiding the SCD condition from them. This did not help the teachers as it led to the child being treated in the same manner as other learners. A study by Afolayan and Jolayemi [22] brought out frustration by parents, while others never come to terms with their child’s condition. Hence, they are never ready to reveal their condition to teachers or society.

I also feel that there are other teachers who do not know about this condition and so you find that because of government policy, if a child misses school for two weeks, this teacher won’t bother to find out why the child has been absent, instead, they will just cross the child out of the register. So I think parents should also be talked to so that they inform the class teachers of their child’s illness and also help this teacher to understand exactly the disease the child suffers from (Teacher 3).

Another theme is the need for individualised attention and extra lessons. These learners miss classes more often than their healthy counterparts. This absenteeism affects their studies and their performance. … It’s not easy to study alone. I ask for help from friends. I even asked my mother to pay for extra lessons so that I can be at the same level as my friends… (Child 1) I would…love that when he misses classes, teachers take it upon themselves to help him catch up. But this doesn’t happen. I have to go and ask the teacher to help him with school work. Usually, the teacher will first say that I should take him for extra lessons, but I cannot afford it (Mother 2). One study [23] noted that the complications of SCD further set a student with this disease apart from the others and with this reduced quality of life, which may in the end lead to a great deal of lost time from academic and vocational training.

Another pertinent theme is that of grades being repeated. This again stems from the fact that these learners miss school more often than their classmates. Ogunfowora, Olanrewaju and Akenzu [24] state that it is not possible for a learner to achieve academic prowess if they are constantly absent from school. These learners are often in and out of hospital and so are not able to be part of the learning process as their peers would be. One mother narrated her experience:

She, (her daughter), suffered a stroke in 2017 so I had to make her repeat. She stayed at home for a whole year, she should have written her grade 12 exams last year (Mother 5).

The repetition of grades also affects the learners in that they are forced to make new friends in the new grade and so have to explain their condition again to these new friends. Because of this, it is not far-fetched to conclude that, these children end up being isolated from their fellow learners.

The findings that have been presented in this paper bring out a number of issues that need to be considered. Adolescent learners with SCD need a great deal of support. From the analysis of the data collected, it shows that parents do not want to expose their child’s condition, fearing that this same society would stigmatise them. There is also an aspect of the learners themselves not wanting to let society know that they have the SCD for fear of being stigmatised and side lined in various aspects of their educational journey as well as in various school activities.

Another factor is that not all the teachers who handle these learners understand what it entails to have this disease. It is one drawback for these learners. When a learner does not have adequate support while they are in school, their educational journey becomes difficult. The teachers hold the biggest key to the success of any learner, but more so for one who has a chronic illness such as sickle cell anaemia. Therefore, the teachers’ understanding of the disease and what a learner with this disease goes through, is important so that they can help these learners progress successfully. As stated in the report by Schartz [25], teachers who do not understand SCD tend to be harsh or treat learners with SCD with suspicion especially when the concerned learner is constantly tired, or unable to perform tasks given to him or her with the same dexterity as their counterparts.

From the interviews conducted with parents, teachers and the adolescent learners, it became apparent that the learner who suffers from SCD require more attention than the average student. They needed to be given more time to study and extra lessons outside of normal class time. These learners, require more attention from their teachers since most of the time during the term, they miss classes and have to find a way to catch up to their classmates.

The manner in which this adolescent learner with SCD is treated can affect their psychological demeanour and may then affect their self-esteem and self-concept. From the interviews the researcher discovered that the aspect of missing school more often than not meant that the learner could not build meaningful relationships with their peers because a bigger part of their lives is spent in bed at home or in hospital. This is an issue that affects their lives a great deal.

Conclusion
It would be prudent for teachers to be sensitised on how to help these learners have a better learning experience. This will require the involvement of both the parents and adolescent learners, as well as disclosure of the condition to the teachers so as to enable them better understand the unique needs and challenges of the learners. Additionally, relevant authorities, including the Ministry of Education, must look into the plight of these adolescent learners with SCD and find ways to help both the learners and teachers such as support for the much needed extra lessons and sensitisation of the parents on the need to partner with school authorities to help their children.
Declarations

Ethical Consideration: Clearance was sought from the University of Zambia Humanities and Social Sciences Research Ethics Committee. The study was conducted with the informed consent of all participants. Anonymity and confidentiality of participant data was maintained by ensuring that no names appeared in the research findings; the information collected from the participants was recorded anonymously and used purely for research purposes. Only the researchers had access to the information.

Availability of data and materials: The data that support the findings of this study are available from the authors upon reasonable request.

Competing Interests: The authors have declared that they have no competing interests.

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Author contributions: BM conceptualised the study and drafted the manuscript. EM and ANM contributed substantially to the literature review and manuscript writing. All named authors read and approved the final manuscript.
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