

**Educating children with albinism in Tanzanian regular secondary schools:
challenges and opportunities**

BY

EUNICE NDOMONDO (M.A. APPLIED SOCIAL PSYCHOLOGY)
Assistant Lecturer

MKWAWA UNIVERSITY COLLEGE OF EDUCATION,
FACULTY OF EDUCATION,
P.O. BOX 2513.
IRINGA.
TANZANIA.

CURRENTLY

PhD IN EDUCATION STUDENT AT THE UNIVERSITY OF DAR- ES SALAAM,
SCHOOL OF EDUCATION,
P.O. BOX 35048.
DAR-ES-SALAAM.
TANZANIA.

Email address: ndos1974@yahoo.co.uk mobile +255 0754245380

ABSTRACT

The study employed a case study design with unstructured interviews to explore challenges and opportunities for educating students with albinism (SWA) in Tanzanian regular secondary schools. A purposive sampling procedure was used to select 10 respondents who informed this study including one form three student with albinism, one subject teacher, the school headmistress, and four classmates of the SWA; others were three leaders of Tanzania Albino Society in Temeke District. The results from interviews indicate that the knowledge of the learning needs of students with albinism is still low among teachers, school managers and educational supervisors. Hence the students with albinism who are mostly visually impaired lack support and adjustments such as excess teaching, optical devices, text books, examinations and other learning materials with enlarged prints which are necessary for SWA to learn successfully. The lack of proper accommodations was associated with a relatively poor academic performance of SWA. On the other hand attitudes of the school community of the studied SWA was positive and the student had high self esteem contrary to other similar studies which indicated that students with albinism were bullied, nick named and isolated by peers and teachers. These results inform educational officials about the need to incorporate inclusive education component in all the teachers' education programs and on the in-service professional development programmes. Nonetheless the Ministry of Education and Vocational Training and other educational stakeholders should devote more resources to cater for the learning needs of students with albinism.

Key words: Albinism, inclusive education, teaching and learning, teachers' knowledge, regular secondary schools, case study, Temeke

1.0 Introduction

The adoption of the Education for All (EFA) and the Salamanca Framework for Action in 1990s necessitated various countries in the world to shift from special to inclusive education. Inclusive education was coined following an observation that a large numbers of vulnerable and marginalized groups of learners were excluded from education systems worldwide (Miles, 2009). Hence as an agenda for equal opportunity for all, inclusive education emphasize that all children regardless of their physical and psychological characteristics, ethnicity, social class, cultural background, economic status, gender, race, religion, or ability access education in regular schools which should accommodate them within a child centered pedagogy (UNESCO, 1994).

It is evidenced that inclusive education improve learning of all students regardless of significant individual differences (Deppler & Harvey, 2010), improve self esteem, empathy for differences and friendship (Naraian, 2008 in Deppler & Harvey, 2010), promote positive post-school outcomes and enhanced teachers skills in inclusive education (Mariga et al, 2014). Yet providing an effective education for all children and young people is arguably the biggest challenge facing school systems worldwide particularly in Africa (Miles, 2009). Moreover inclusive education is a new phenomenon; hence more researches are needed to ascertain how effectively various groups of learners with special educational can needs be accommodated in the regular schools.

On the basis of this background this study explored the provision of education for children with albinism in Tanzania secondary schools. Specifically to identify challenges and opportunities for students learning in the inclusive schools. This study is significant due to the fact that Tanzania is among countries with largest populations of persons with albinism in the world (UNICEF, 2012); in 2009, 10% of the population was estimated to live with disability and 1 in 4000 people live with albinism (Tanzanian German Programme to Support Health (TGPSH), 2009). However, studies on

the lives of this special group of people are scanty. It is until the recent trafficking and the murder of persons with albinism (PWA) is when they have become visible and captures the attention of the government, media, human right organs and researchers. Nonetheless, current studies on persons with albinism in Tanzania such as that of Burke et al. (2014) and that of Uromi (2014) are focusing on killings of the PWA. Studies regarding to the education of PWA as tool for their emancipation and improved quality life are scarce.

2.0. Literature Review

2.1 Theoretical Perspective of the Study

This study is guided by the social model of disability which views disability not as an individual attribute rather results from attitudinal and institutional barriers which hinder individual with impairment from full and effective participation on an equal basis with other (Aiden & McCarthy, 2014). Institutional barriers encompass among other things, resources and practices that exclude people with disabilities from everyday activities in society (Coe, 2013). In the light of this framework, this study explored challenges and opportunities for the provision of education for SWA in regular secondary schools and recommended for proper strategies of supporting SWA in regular schools.

2.2 Understanding Albinism

The term albinism refers to a group of related inherited conditions which are the result of mutated genes that cause a deficiency or total absence of melanin pigment formed in the skin, hair and/or eyes (Baker, et. al, 2010; NOAH, 2010). The lack of dark pigmentation make people with albinism to have pale skin, sandy colored hair, light brown eyes; they also suffer from nystagmus, photophobia and poor visual acuity (oculocutaneous albinism) (Baker, et. al, 2010; Lund, 2005). Although persons with albinism may be considered “legally blind” with a corrected visual acuity of 20/200 or worse, most learn to use their vision in a variety of ways and are able to perform innumerable activities such as reading, riding a bike or fishing and some have sufficient vision to drive a car (NOAH, 2010). It is only the stigma surrounding people with disability including albinism that hinders their access to opportunity and participations.

Due to the lack of melanin pigment, people with albinism are vulnerable to direct effect of ultra violet of sun rays which damage their skin and may causes skin cancer (Uromi, 2014). However, with appropriate health information, eye care facilities and the provision of skin protection creams, albinism can be managed effectively (Lund et al. 2007). There are other sun protection strategies which are low-cost, such as wearing appropriate protective clothing and sun avoidance, particularly during the middle of the day when ultraviolet levels peak (Baker, et. al, 2010).

2.2.1 Myths and Stigma

In sub-Saharan Africa, the pale physical appearance and vision impairment of persons with albinism marks them as of distinct appearance, among African descent (Burke, Kaijage & John-Langba, 2014) who most of them are black. The different appearance in many cases likes for any other form of disability results to stigmatization, discrimination and social exclusion of persons with albinism. Moreover Tanzania and some other parts of Africa have experience violent attacks and murders of persons with albinism associated with Africa recent mining boom of gold and diamond together with witchdoctors who have created a market in body parts of albino for myth of production of lucky (Burke at.al., 2014). Due to this disaster,

there is extreme insecurity among people with albinism and family members are supposed to escort children with albinism to school while some of hidden them at home. The government has also been moving children with albinism from homes into special schools and camps for the sake of protection (ibid). This form of segregation affects the education of many children with albinism because of poor school attendance, fear and security, and uncondusive learning environment in the crowded and poorly equipped camps.

2.3 Education of Children with Albinism in African Countries

Education systems for the persons with albinism differ across African countries. For example in Zimbabwe children with albinism are educated in mainstream schools within their own community (Lund, 2000) while across the border to the south, in the northern province of South Africa, children with albinism may attend special schools for the visually impaired (Gaigher, Lund and Makuya, 2002). In Malawi government emphasize of the resource centre and the deployment of itinerant teachers for the blind, visually impaired including those with albinism (Lynch and Lund, 2011). In Tanzania, the emphasis is on educating students with albinism in mainstream schools; however less is known about the kind of support these children are receiving in order to learn effectively.

2.3.1 Children with Albinism are Deprived Equal Opportunity to Education

The segregation of people with albinism begins early in their lives, as they are not always allowed to attend school (Baker, et. al., 2010). It was also revealed from interview with the chairman of Uganda Albino Persons Association when there may not be enough money to send every child in the family, the parents may not want to “waste” money on a child with albinism, a tendency which perpetuates the system of exclusion and leads to a high level of illiteracy among the albino person population (Allen, 2012), reducing the chances of succeeding in life hence live in a more miserable life.

In terms of enrollment statistics from Malawi indicate that there is a much higher number of boys enrolled at the resource centers (n=48) than girls (n=22) (Lynch and Lund, 2011). These researcher argue there is disproportionate because the condition affects both girls and boys equally however girls become more disadvantaged than boys.

Children and youths with albinism in the school environment are disadvantaged and vulnerability in different ways. First, their striking difference in appearance i.e. looking ‘white’ in a black population of the mainstream schools can lead to psychological and physical victimization such as bullying and name-calling by students as well as teachers (Wan, 2003). Baker et. al. (2010) reports a case in the University of Venda whereby other students would not sit near students with albinism in classrooms and avoided them at school events. Metcalf (2003) also reports claims from a parent whose child with albinism was placed at the back of the class by the pregnant teachers as far away from her as possible. As a consequence, the child could not see the blackboard and fell behind in her lessons. Such actions not only interfere with the students learning but also affect them socially and psychologically leading to poor self concept and lowered self esteem which further retard their ability to learn successfully.

2.3.2 Learning Needs of Persons with Albinism

Visual impairment associated with albinism can interference with their effectiveness to learn (Lynch and Lund, 2011). They have low vision which is classified in many countries as “legally

blind", the problem which can not completely be correctable with eyeglasses and most do not require Braille as they use the residual vision they have for many tasks including reading (Under the same Sun, 2012). However they cannot read from the black board clearly (ibid) and may require to sit in the front row of the class near the chalkboard and positioned away from direct light entering the room (Lund 2000). Nevertheless because of vision impairment, students with albinism (SWA) may require longer time than others to complete assignments (Baker, et. al, 2010). These are simple and affordable measures which do not require any expenses; however they require teachers' knowledge, positive attitudes and learning expectation towards students with albinism. Visual impairment might also require materials such as large print books, large classroom maps or charts, low vision devices, magnification stands, or tilted reading stands (Ashley, 1992). Computers have also been recommended to be of great use for students with low vision because they have the potential to provide independent access to information (Douglas, et.al., 2001 in Thurston, 2014) both in the classroom and for future employment part of these.

If they do not receive the support they require to learn effectively in the school SWA drop out of school at an early age and most do not have enough education to find work indoors and end up working outdoors in the harsh sunlight they are supposed to avoid in the first place (Under the Same Sun, 2012) hence their exacerbate their health condition and survival.

Despite these challenges very little is known about how the special learning needs of SWA are catered to ensure their effective learning in Tanzanian schools. On this background this study aims at examining the provision of education for children with albinism in Tanzania Secondary schools. Specifically to identify challenges and available opportunities in schools for provision of quality education. The finding of this study will be useful in informing policies, curriculum decisions and improvement of practices education of children with albinism.

3.0 Methodology

This study employed a qualitative approach to explore challenges and opportunities of educating SWA in Tanzanian secondary school. The two cases were studied, (i) a form three secondary school student with oculo-cutaneous albinism, (ii) in Temeke district. Temeke district was chose because it was easy to access persons with albinism. The purposeful sampling was used to get a total of ten respondents including the one student with albinism, his headmistress, and his English language teachers, four classmates of the students with albinism and the three leaders of the Tanzania Albinism Society (TAS) in Temeke districts. The TAS leaders were involved in this study because they themselves live with albinism but they also work closely with persons with albinism; students and children in schools and at home together with their families hence they well informed with their situation. The involvement of different stakeholders in this study deepened an understanding school learning experiences of students with albinism.

Semi-structured interviews were conducted with the student with albinism and with teachers while discussion schedules of open questions (Thurston, 2014) were done with TAS leaders and classmates of the SWA. Data were collected in two different days whereas in the first day, the interview was conducted with leaders of Tanzania Albinism Society (TAS) in their office located at Tandika area. In the second day the interviews were conducted at different times within the school compound located in Tandika area with a student with albinism, his teachers and fellow students.

Data analysis

Analysis of data generated from interviews was informed by Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2010 in Thurston, 2014) which considered participants subjective interpretation of their perception on the challenges and opportunities of students with albinism to learn in regular schools. The conversations were initially read through thoroughly to get the general meaning, and then sorted manually to identify the emerging and recurring themes which were then put together under some sub-themes.

4.0 Research Findings

From these study various issues emerged regarding the education of SWA, how they learn, challenges and opportunities in regular secondary schools. The data are presented according to these themes.

4.1 The Learning of People with albinism

It was explained by one of leaders of Tanzania Albino Society (TAS) leader most of people with albinism are visually impaired therefore cannot take notes from the chalk board. He further explained that we need the notes close to use, we need our own books, so in the environment where books are scarce it becomes a problem. He further explained that because of visual impairment SWA learn slowly compared to students without albinism hence they need extra time to be taught in their own or extra time to learn on their own. Although he insisted that intellectually, persons with albinism do not have any problem and gave examples of students with albinism who passed well their exams and are currently studying in boarding schools in Tanga, Tabora and Morogoro. He said that:

If people with albinism are provided with favourable environment, their learning ability is higher compared with other people. We learn slowly and do not always depend on what we see but on what we hear, so we concentrate more and we keep memory.

In order to address some of the issues rose above, that leader of the association said they visit schools and talk to school management on how students with albinism can be helped. Apart of their learning needs he said that they inform schools managements about the health conditions of students with albinism and advise teachers not to give students with albinism punishment that involve them to stay in the sun, never the less, they should allow them to put on clothes which cover their bodies such as long skirts or trousers, long sleeve shirts and hats. When the TAS leaders were asked about the support which they receive from teachers, one of them commented that:

Teachers are divided into three groups. There are those who are not read to support us, they find it to be a disturbance, but there are others who are ready are curious to known how do we learn and ready to support. But teachers who have passed through special education are better off. Although sometimes you might find special education teacher but do not offers the excepted special attention to the student with albinism.

4.2 Attitudes

The student with albinism was asked of his own view about living with albinism and he had a positive outlook of himself and his situation:

I consider myself to be like any other person. It has pleased God to create me like this.

When he was asked further as to why he feels good about himself he said that he was never stigmatized by his parents since when he was young:

Neighbour to our home there was a child who was like me but his parents were hiding him inside the house. For me I was playing around with other children and friends took me to their homes and my parents had no problem with that, so my parents contributed very much to who I am.

This student held further that even his fellow student consider him as a normal person and involve him in all school activities. He added that currently fellow students were convincing him to protest for a leadership's position in the school. His peers declared their positive attitudes towards the SWA:

We consider him a person like any other persons. We cooperate with him in class discussions and he is very active. Actually we like him; he has also accepted himself very well.

The head mistress also witnessed that the SWA is confident, well presented and whenever he has a problem he did not hesitate to visit her in the office for a discussion.

4.3 Challenges Facing Students with Albinism in School Learning

TAS leaders declared that sometime students with albinism are rejected by their teachers who claim that SWA cannot learn. These leaders said that when such cases happen, the parents would come to report in their offices and TAS leaders usually write letters to teachers telling them to accept those students. Another challenge which was observed by one of TAS leader is that students with albinism attend in to large classes (about 80 students) with only one teacher. He commented:

It is difficult for one teacher to concentrate with all these students and expect that he/she will have time to spend with students with albinism who require even a more special attention than other students.

He further argued that the government has not fully recognized students with albinism as people who have special learning needs. He stated that currently the government gave priority on the improvement of building to support people with physical impairment, Braille machine for visually impaired people, sign language for persons with hearing impairment but no emphasized is given to the needs of persons with albinism such as provision of sun blocks or reading lenses. As a result of the mentioned challenge this respondent commented that SWA have poor academic performance. He narrated:

Student with albinism have very poor performance in inclusive schools, they get 10%, 12%, 20%. We are currently move these students from inclusive schools to special schools where they are going to be taught by teachers who have training in special education and know the learning needs of SWA very well.

This study explored further from one of the subject teacher about the academic progress and the challenges facing a form three student with albinism found in the visited school. This teacher admitted to have no training in special education. He reported that the SWA academic performance is not very good and has failed in form two national examinations for two consecutive years before he passed in third attempt. The teacher observed further that the student experience problems in reading from the chalk board although he sits in front of the class. However he admitted that teacher most of teachers are not aware that the student with albinism cannot see from the chalkboard

without using optical device, hence no special attention had been given to the SWA during teaching and learning. The headmistress also had the similar comment:

This student is so eager to learn but has failed in his form two national examinations for two consecutive years. We had not realized that he is visual impaired until when he repeated the class for the third time. Then we sent his name to the higher levels asking his examinations to be produced in large prints, but it was not implemented instead he was allocated he with extra examination time.

On the other hand, the SWA claimed that he uses a magnifier which he was given by CCBRT since 2007 though it does not help him much. He reported to experience difficulties in reading the school books which he finds to have smaller prints. He said that after he has failed in form two examinations twice, he was confused and decided to inform the headmistress about his vision impairment situation. As a consequence in the following year's national examinations he was provided with extra time.

It was however observed in this study that no any modifications were done at the school level for this SWA. The classmates declared that sometime they had to read notes from the blackboard for their friend, but also they take school exams with similar font size and same sitting duration with the student with albinism. They suggested that perhaps their fellow SWA should be provided with exams in enlarged or bolded prints and extended duration.

4.4 Opportunities for Students with Albinism in School Learning

Despite the challenges encountered by students with albinism in school learning some few opportunities were observed. For example it has been mentioned by the TAS leaders that currently some copies of exams in standard seven national examinations are printed with large prints for students with low vision including those with albinism. Nevertheless extra time had been allocated in the form two national examinations for the SWA who is visually impaired.

The student with albinism in this study declared that he receives maximum cooperation from his classmates who involve him in all academic matters and other school activities. He also mentioned to receive a big support from the head mistress who talk to him, encourages him and also allows him to borrow books so that he can have read them closely at school and even at home. However he requested for more improvement such enlarged printed books and exams as well as extension of time in internal examinations in order to supplement the low vision experience.

5. 0 Discussion

This study explored the challenges and opportunities of educating students with albinism in Temeke district regular secondary schools. Several weaknesses education were observed including (i) lack of knowledge of the learning needs of students with albinism among teachers and educational administrators (ii) lack of learning facilities, and (iii) less commitment of the educational officials to improve teaching and learning materials and examinations to cater for the low vision experience of students with albinism (iv) poor academic performance of the students with albinism

The fact that teachers and even the school mistress had no knowledge that SWA is visually impaired until he repeats form two examination three times indicated the serious level of ignorance among teachers about the learning needs of SWA. Lack individualized support arranged for this student such as excess teaching to compensate for the slow learning due to low vision also implicates this lack of knowledge. The Royal National Institute for the Blind (2009) cited in Thurston (2014) provided that one-to-one support for pupils with a visual impairment it is extremely important.

Nonetheless during the school exams SWA would take the same examination with other students without enlarged prints and extra time. These situations narrowed the chances of SWA learn efficiently and pass his exams. Actually the modification such as extra teaching, magnified exam prints and extended examination duration are affordable within the school expenses, however it depends on teachers' awareness, attitudes and expectation they hold over the students with albinism.

Report from the TAS leaders that the some teachers would neglect children with albinisms for the reason that they are untaught reflects teachers' serious ignorance on how these students can be supported academically. This situation leads not only to discrimination but total exclusion of persons with albinism in the academic world. Uromi (2014) hold that lack of quality education has double effects to people with albinism; first is lack of employment due to lack of specialized skill hence extreme poverty. Poverty will then force PWA to engage into hard manual work in the sun, devastate their health condition and reduce their life span.

Lack of knowledge about the learning needs of the persons with albinism might also facing policy makers and educational manager at different levels; otherwise there is reluctance in providing the required modifications required by SWA to learn effectively. For example the government affords to provide special reading devices and computers, text books and examinations with enlarge prints, and any other support that will benefit SWA in their learning.

This study also observed that students with albinism have poor school achievements in the regular schools; as a result the TAS leaders in Temeke District are transferring students with albinism into special schools. This motive is stirred by belief that teachers in special schools teachers have specialized training hence they can effectively support SWA. Educating children in special schools have been practiced in other countries such as Northern Province of South Africa where students with albinism attended special schools for the visually impaired (Gaigher, Lund, and Makuya (2006). In Malawi the government emphasizes resource centre and deployment of itinerant teachers (Lund & Lund, 2011). However it has been observed that with proper modifications students with albinism can study in regular schools (Uromi, 2014). Only that there is misunderstanding that although competent teachers in inclusive context requires the acquisition of specific set of skills, knowledge and attributes, but doesn't not significantly differ from the skills effective teacher would need to possess in order to teacher in non-inclusive context (Deppler & Harvey, 2010). Hence teachers' attitudes and commitment to help students with albinism are of great important for their success.

Regarding to personal attitudes and the attitude of others towards albinism, the results of this study show that the interviewed SWA was well accepted by family members and the school community hence the student experiences high self-acceptance and self-esteem. These findings are strikingly similar to that of Braathen and Ingstad (2006) who observed that PWA discrimination due to stigma can be experienced in some social settings however treated with respect in other situations, such as in families. Hess (2010) on the other hand found that school characteristics such as leadership and attitude, as it was for the case of the SWA positive attitude of head mistress, contributed to the peers' acceptance of this student.

These findings however differ significantly from that of Dart et. al. (2010) who reported cases of two students in Botswana who experienced low self esteem, loneliness, and lack of acceptance from their fellow students. Likewise, different from Baker et.al. (2010) findings in Venda where by University students would not sit near their colleagues with albinism and avoided in the school events.

Regardless of the challenges some prospects towards the education of students in the inclusive schools have been observed. For example enlarged exam prints in standard seven national

examinations is an indicator that such consideration can be done in examinations of the secondary school level. Nonetheless, the extra time allocated in the form two national examinations forecast the hope that the same can be done in the other higher levels of education. The student with albinism in this study also mentioned to be encouraged by the maximum cooperation he receives from classmate and the head of the school. However the literature suggests for other necessary adjustments for SWA who is also visually impaired to study effectively. These include the assistive technology such as computers, low vision devices and skin protection (Lund & Lund, 2012/13; Thurston, 2014). Itinerant teacher is also important in overall responsibility for supporting their education of SWA; for example training other teachers, liaising for with parents, and ensuring that they have access to all available support, including large print examination scripts (Lund & Lund, 2012/13).

6.0 Conclusion and Recommendation

This study has expressed the challenges and opportunities experienced by students with albinism in school learning. The case study design which was used limits the generalization of the obtained results. However, from the in-depth examinations of the school learning experiences of one secondary school student with albinism and from the conversations with the TAS leaders' two recommendations can be made:

- i. The current shift from special education to inclusive education necessitates a curriculum review in all levels of teacher education in the nation to incorporate aspects of inclusive education. Nonetheless the continued professional development training is necessary whereby albinism and its associated visual impairment should be discussed by teacher on how effectively SWA can be supported to learn in the regular schools.
- ii. The government through the Ministry of Education and Vocational Training and other education stakeholders should devoted more resources and provide necessary support for learners with albinism such optical devices, computer, enlarged print text books, examinations other reading materials in order to facilitate learning.

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