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## Health and education of children with albinism in Zimbabwe

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### Abstract

Albinism is a relatively common genetic condition in Zimbabwe, a tropical country in southern Africa. Those affected have little pigment in their hair, skin or eyes, in sharp contrast to the normal dark pigmentation. This article describes the responses to a self-report questionnaire covering health, social and educational aspects completed by 138 schoolchildren with albinism living in rural areas of Zimbabwe. They reported persistent skin and a myriad of eye problems. Relationships between siblings appeared good, although problems of antagonism, avoidance and fear were encountered among strangers. Knowledge about albinism was patchy; pupils were keen to be better informed. This research highlights the need for widespread dissemination of accurate information about the genetics and health management of albinism to counter the many myths and misconceptions surrounding this condition. A management programme to promote the health and education of these children in southern Africa is proposed. In conclusion, this study indicated that pupils with albinism could participate in mainstream education, with appropriate intervention to help them manage the problems associated with their low vision and sensitive skins.

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### Introduction

Oculocutaneous albinism (OCA) includes a group of genetic conditions resulting in reduced melanin synthesis, leading to little or no pigmentation in the hair, skin and eyes [reviewed in (Witkop *et al.*, 1989; Oetting *et al.*, 1996)]. One type of OCA (OCA2) is commonly found in sub-Saharan Africa; about 1:4182 indigenous Zimbabweans show this form of albinism (Lund, 1996), compared with 1:37 000 in the US. Those with OCA2 in southern Africa have pale, white to chalky coloured skin, sandy to yellow hair and light brown or blue eyes, a dramatic contrast to the normal dark colouration. Most children with albinism are born to normally pigmented parents, who each carry one mutant (non-working) form of the gene for OCA2. As the parents also have one working copy of the gene, they produce normal pigment. Affected children have inherited two non-working copies, one from each parent, so cannot synthesize pigment. The chances that two normally pigmented carrier parents will have a baby with albinism are 1:4 for each pregnancy.

The lack of protective skin pigment leads to an increase in skin ailments from a young age, with photoageing, lesions and non-melanoma skin cancers common in the tropics (Luande *et al.*, 1985; Kromberg *et al.*, 1989; Aquaron, 1990). Lack of melanin also results in abnormalities of the visual pathway, leading to lifelong ocular problems that are always associated with albinism, including photophobia (disabling sensitivity to bright light and glare), nystagmus (involuntary eye movements), lack of stereopsis (lack of binocular vision), reduced visual acuity and often strabismus

(squinting), and large refractive errors [reviewed in (Biswas and Lloyd, 1999)].

A previous study of Zimbabwean adults with OCA2 indicated that they were well informed about effective strategies to manage their condition, including wearing protective clothing to minimize the deleterious effects of the sun (Lund, 1998). This study also revealed a lack of suitable health care facilities and social welfare support, with most adults relying on assistance from their families. Although close family and community relations seemed good, there was evidence of avoidance and antagonism by strangers, including employers. Zimbabwean adults with albinism found it difficult to obtain salaried jobs and encountered numerous social problems.

The intelligence of children with albinism falls within the normal range (Manganyi *et al.*, 1974; Fulcher *et al.*, 1995) and affected pupils in Zimbabwe are educated within the regular schooling system (Lund, 1997). This paper describes the health, educational and social issues affecting 138 schoolchildren with albinism living outside the capital city, mostly in rural areas of Zimbabwe.

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## Method

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### Recruitment of participants for a self-report questionnaire

In a survey of all secondary schools, and primary schools in five of the nine provinces of Zimbabwe, a total of 384 pupils with albinism were identified (Lund, 1996). Of these, 278 were living outside the capital city. All were invited to respond to a questionnaire including open and closed questions on educational, health and social issues. In total, 138 (49.6%) pupils volunteered to participate; the remainder were either too young, had moved from the area or did not respond. Two were unwilling to participate. All the volunteers replied and 22 were subsequently visited by the author and interviewed in person to corroborate the written answers received.

In response, each participant received two information sheets, one outlining the management

of albinism and details of the local Council for the Blind that offered (when funds permitted) low-cost spectacles. A second sheet described the genetics of albinism. Particular questions were answered in a personal letter.

### The participants

The mean age of the 138 schoolchildren with albinism was 14.4 years (range 9–21); 86 (62.3%) were male and 52 (37.7%) female, with 65 (47.1%) at primary school and 73 (52.9%) attending secondary school. The majority (118 pupils; 85.5%) belonged to the dominant ethnic group in the country, the Shona, 11 (8.0%) to the next most populous group, the Ndebele, and the remainder to minority groups, the Shangaan ( $n = 1$ ), Tonga ( $n = 1$ ) and Venda ( $n = 1$ ). Three pupils were from neighbouring countries and three did not give their ethnic origin.

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## Results

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### Health needs

All subjects stated that their skin went red and blistered when they spent time in the sun. Twenty-seven (19.6%) pupils could not participate in outdoor activities such as sport or gardening as their skin burnt. A third (47, 34.1%) used sunscreen preparations regularly, 48 (34.8%) Vaseline or cosmetic creams to try to soften their skin and the others did not use any preparations at all. A few said they needed but could not afford creams. All students were aware of the need to cover up; 80 (60.9%) reported wearing long skirts or trousers and shirts, and 123 (89.1%) wore a hat.

The main problem encountered at school, mentioned by 132 (95.6%) respondents, was the inability to see the blackboard or print in text books because of poor vision. This resulted in them being constantly behind in their work and making mistakes: 'I am a slow learner as I lose most of the lesson due to poor eyesight'. One pupil found mathematical formulae and map reading particularly difficult, and another said he could not see the blackboard when bright sunlight was shining into the room.

### Knowledge and beliefs

Seventy (50.7%) pupils had no idea why their skin was pale, 15 (10.9%) correctly attributed their condition to a lack of pigment, inheritance or something wrong with their genes ('a mistake in gene structure passed from parents to offspring'), 19 (13.8%) thought it was God's will or choice and 13 (9.4%) made comments that were factually incorrect. The most common misconception was that those with albinism have the 'top' (black) layer of skin missing. Two respondents described the myth that parents who scold or laugh at someone with albinism will themselves produce a baby with the condition and one thought their mother had eaten something during her pregnancy. A few children described the belief that albinism is a result of witchcraft: 'A certain family may hate its neighbour and do something bad'.

### Attitudes at school

A minority of students wrote about social problems at school: five were subjected to name calling, four ridiculed, four bullied and beaten by fellow pupils, three were treated as a misfit or outcast, and six were avoided by their peers, who refused to sit, eat or play with them. The sort of problems encountered are summarized in a list drawn up by a 15-year-old male respondent: 'I cannot see the blackboard clearly. I cannot work in the open doing manual work. I don't like walking long distances to interschool sports. I am always being humiliated by others calling me names'. A few pupils had initially encountered antagonism at school, but their number of friends had increased with time: 'Almost the whole class likes me now'.

### Attitudes at home

The number of siblings ranged from 1 to 11, with an average of 4.5. Sixty-five (47.1%) pupils had at least one sibling with albinism; all had at least one normally pigmented brother or sister. One hundred and eleven (80.4%) respondents did not feel their siblings treated them differently because of their albinism: 'they treat me like an ordinary guy', 'they have full sympathy with me'. Eleven (8.4%) pupils made positive comments, indicative

of siblings offering them extra help or protection, e.g. making sure they did not spend too much time in the sun doing chores such as preparing food (which is often an outdoor activity in rural Zimbabwe) and farming. Eight (6.1%) subjects mentioned negative attitudes, including scolding, mocking or avoidance (not allowing them to wear their clothes, share food with them or to visit them at their work place).

### Health and educational provision

Only 32 pupils (23.2%) had ever had their skin examined by a health professional, often only once when they were babies. Sixty-three (45.7%) respondents had been to a hospital or private optician for an eye test and 34 (24.6%) had prescription glasses, although seven (5.1%) felt these did not improve their eyesight. Twenty-two (15.9%) pupils said their spectacles magnified objects or made them clearer. Only two (1.5%) pupils had self-tinting spectacles, and 14 (10.1%) wore dark glasses to reduce glare and photophobia. Several pupils pulled a cloth hat far down their foreheads to shade their eyes. Nineteen (13.8%) respondents said they needed spectacles but could not afford them.

Eighty-three (60.1%) pupils thought no special provision was made for them in the classroom, whereas 34 (24.6%) thought they were given special consideration. A few did not feel they needed any extra help ('I finish first despite being albino', 'It is not needed as I am the one to finish first'). Provisions made by teachers to assist these pupils included allowing them to sit very close to the blackboard, use large print material, have extra time to complete work, use their own books instead of having to share and providing extra tuition. One 12-year-old pupil described how she knelt close to the board and wrote with her book on the teacher's chair as she could not see properly. One hundred and thirty (94.2%) pupils sat at the front of the classroom.

### Information provision

The open questions asked are presented in Table I. Nearly all pupils wanted to know what caused

**Table I.** *Questions asked by children with albinism<sup>a</sup>*

| Issue                   | Type of question asked  |
|-------------------------|---|
| Information on albinism | 'Why did God make me an albino?'<br>'I would like to know the causes which make me an albino from my mother's womb.'<br>'What is the causative agent of this pale skin?'<br>'Is albinism the result of witchcraft?'<br>'My parents are black, why am I so different?'<br>'What is the difference between albinos and whites?'<br>'Do all tribes have albinos?'<br>'Are there European albinos?'<br>'Are there albinos in the UK, US and other cool places?'<br>'How can I find out more about albinism?'<br>'Are there any books about albinos?'<br>'Do albinos live to a ripe old age?'<br>'Is there a cure for albinism?' |
| Marriage/children       | 'Should I marry a white person or another albino?'<br>'Would my children be black or have albinism, like me?'<br>'If I married a black or an albino wife, what colour would my children be?'<br>'I have problems approaching girls. What can I do?'<br>'Is there a medical investigation to find out whether I will bear albinos?'  |
| Eye problems            | 'What causes my eyes to move about in their socket?'<br>'Why are my eyes jittery?'<br>'Will I become blind?'<br>'Can my eyesight be corrected?'<br>'Are there spectacles which enlarge things?'<br>'Does the food we eat affect our eyes?'<br>'Why are we short sighted?'   |
| Skin problems           | 'Why does my skin burn like fire when I go outside in the sun?'<br>'Why do we feel the sun more than others?'<br>'What is the cause of these blisters that are peeling?'<br>'Is there a layer of skin missing?'<br>'What causes my skin to wear out so easily?'<br>'Is there a cream for the mouth to avoid wounds?'<br>'What creams and soaps should I use for my skin?'<br>'Can you make my skin black?'<br>'Can you remove the black patches on my skin?'<br>'What can I do about my wounds that do not heal?'   |
| Future career           | 'What are the academic possibilities for me?'<br>'What type of work can I do?'<br>'Can we get any assistance in finding a job?'<br>'Is there a government scheme to help us?'   |
| Social                  | 'How can I associate better with other people?'<br>'Is there anything I can do, not to feel out of place when people laugh at me?'<br>'Are all albinos shy and moody?'<br>'Are we important in the world at large?'<br>'Why do people ignore or laugh at us?'<br>'Why are children afraid of us?'<br>'How best can Zimbabwean society help us?'   |

<sup>a</sup>At the end of the questionnaire respondents were asked if there were any particular questions they would like to ask the researcher, who would try to answer them.

**Table II.** *Finding our more about albinism: data from affected children (n = 138)*

| Question  | Yes         | No          |
|---|-------------|-------------|
| Have you tried to find out more about albinism? | 34 (24.6%)  | 104 (75.4%) |
| Would you like to know more about albinism?     | 137 (99.3%) | 1 (0.7%)    |

albinism. The next most frequent questions concerned eye and skin problems, mentioned by 29 (21.0%) and 34 (24.6%) respondents, respectively. Fifteen (10.9%) pupils asked about government or other financial assistance to provide a better education and for the provision of sunglasses and protective clothing: 'Can't the government provide schools where we are always in the shade and where there are teachers that are specialists for albinos and who will take care of us?'. Three (2.2%) older pupils anticipated difficulties in their future education and in finding a suitable job.

A quarter of respondents had tried to find out more about albinism (Table II); 26 (18.8%) had asked parents or friends, four (2.9%) had consulted a doctor, three (2.2%) a teacher and four (2.9%) members in their community with albinism. Three (2.2%) had tried to find out more from books. One respondent had asked his father, who replied that his mother's people were responsible. All but one (who said that it made her too worried to think about her condition) were keen to know more about albinism: 'I have so many questions. No paper to write them all'.

## Discussion

This study revealed a thirst for knowledge about albinism among pupils in rural schools, reflected in the wide scope of questions posed (Table I). The most frequent question took the form: 'My parents are both black, why was I born so different?'. An understanding of the pattern of inheritance, where affected babies are born to two carrier parents, would help to counter stories of albinism being a curse placed on a family or evidence of the mother's infidelity. Genetic education is sorely

needed to improve social integration of this group. As there are no genetic counselling facilities or prenatal diagnosis in Zimbabwe, detection and prevention of albinism is not currently an option and may be inappropriate for a condition where effective management is a viable alternative.

All the pupils in this study reported skin damage. This is both unsightly and disfiguring, especially if open wounds become infected. Sun-induced skin damage is a lifelong problem for those with such sensitive skins living in a tropical environment where most daily activities are conducted outside. Albinism is associated with a high risk of non-melanoma skin cancers (Preston and Stern, 1992), about 80% of which appear on the arms, head and neck, making it crucially important to cover these regions. Most pupils wore some protective clothing, especially hats; this good practice should be actively encouraged by teachers and parents. Sunscreens in Zimbabwe are expensive, not easily available in rural areas and unlikely to be affordable for regular use. Few pupils reported having had their skin examined by a doctor or nurse. Local clinics in rural areas would rarely see a patient with albinism and may not be able to treat their skin lesions and cancers. Sun-protection information should stress low cost-prevention strategies and emphasize sun avoidance: wearing wide brimmed hats and thick weave, dark coloured cotton clothes as well as staying out of the sun in the middle of the day and seeking shade whenever possible.

Most pupils appeared to have adapted well to their visual disabilities. Only half had been for an eye test and a quarter wore corrective spectacles, although some thought theirs inadequate. The improvement in visual performance that can be achieved by correcting refractive errors is limited. Some eye problems, such as nystagmus, cannot be cured and will always restrict their visual ability. Mobile eye clinics service some rural areas and specialist information was provided to eye care charities, NGOs and the Council for the Blind to make them aware of the needs of this group and encourage them to offer tinted spectacles to those with albinism in the communities they visit. A study is currently underway to document more

fully the visual problems of these children, to produce guidelines for the best optometric practice, and to test the efficacy and cost of simple visual aids such as hand-held magnifiers.

The success and interest generated by this study, conducted via teachers at rural schools, suggested an effective route for disseminating genetic and health care information. If teachers, who are well-respected community members, are well informed this will influence local perceptions and attitudes. Pamphlets on albinism sent to schools in response to this survey were positively received and teachers responded enthusiastically to talks given by the author. An article was written for the Ministry of Education's publication *Teachers in Zimbabwe* which is sent to every school. As albinism has been introduced into the medical genetics course at the University of Zimbabwe, newly qualified doctors should be better informed. The recently established self-help group, the Albinism Society of Zimbabwe, may provide a central source of accurate and up to date information to people with albinism, their families as well as teachers and health care workers. Radio talks and newspaper articles have also been used to inform communities.

In Zimbabwe children with albinism are integrated into mainstream education, with 9% of schools educating at least one affected pupil (Lund, 1997). The disadvantage of this strategy is that they are a small minority (sometimes only a few in a large school) and their teachers, although often supportive, are not trained in specialist techniques for aiding the partially sighted. Only two schools had special resource rooms for the partially sighted, although 85.5% reported simple, inexpensive ways in which they helped these pupils (Lund, 1997). In this study, 70% of pupils felt no special provision was made for them at school. Education officials have a role in encouraging the good practice already found in some schools and informing heads of available resources, such as high contrast, large print scripts for national examinations. A few pupils did not feel that they required any special attention, stressing the need for each pupil to be considered as an individual when deciding what intervention may be appropriate and to ensure

these children are not excluded from all group activities.

Their distinctive appearance has a powerful impact on the lives of those with albinism from birth until death. They are always conspicuous, but not always 'seen' as individuals. Relationships between siblings in this study appeared largely positive, with only a small minority reporting negative attitudes. These are encountered mainly from strangers, and suggest fear and a poor understanding of albinism. Knowledge should increase the self-esteem of those with the condition, enhance their self-image, improve their health prospects and empower them to counter negative attitudes within society. This would enable them to cope better in a society where their acceptance in the black community and even within their own family may be questioned. The recognition that albinism is found world-wide, in every population group, would help them come to terms with their place in society and develop a confident sense of self.

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### Acknowledgements

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This research was conducted when the author was in the Department of Biological Sciences, University of Zimbabwe, Harare, Zimbabwe. Special thanks are due to the subjects and the local schoolteachers who participated so enthusiastically in this project. Permission for conducting this study was obtained from the Ministry of Education and Culture, Zimbabwe. Financial support from the University of Zimbabwe and The Leverhulme Trust (grant no. Rf&G/11125) is gratefully acknowledged.

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Received on December 5, 1999; accepted on April 4, 2000