Attitudes and Beliefs of an Albino Population Toward Sun Avoidance

Advice and Services Provided by an Outreach Albino Clinic in Tanzania

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Objective: To determine an albino population’s expectations from an outreach albino clinic, understanding of skin cancer risk, and attitudes toward sun protection behavior.


Setting: Outreach albino clinics in Tanzania.

Participants: All albinos 13 years and older and accompanying adults of younger children attending clinics. Unaccompanied children younger than 13 years and those too sick to answer questions were excluded. Ninety-four questionnaires were completed in 5 villages, with a 100% response rate.

Interventions: Interview-based questionnaire with scoring system for pictures depicting poorly sun-protected albinos.

Results: The most common reasons for attending the clinic were health education and skin examination. Thirteen respondents (14%) believed albinism was inherited; it was more common to believe in superstitious causes of albinism than inheritance. Seventy-three respondents (78%) believed skin cancer was preventable, and 60 (63%) believed skin cancer was related to the sun. Seventy-two subjects (77%) thought sunscreen provided protection from the sun; 9 (10%) also applied it at night. Reasons for not wearing sun-protective clothing included fashion, culture, and heat. The hats provided were thought to have too soft a brim, to shrink, and to be ridiculed. Suggestions for additional clinic services centered on education and employment. Albinos who had read the educational booklet had no better understanding of sun avoidance than those who had not (P = .49).

Conclusions: There was a reasonable understanding of risks of skin cancer and sun-avoidance methods. Clinical advice was often not followed for cultural reasons. The hats provided were unsuitable, and there was some confusion about the use of sunscreen. A lack of understanding of the cause of albinism led to many superstitions.

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Oculocutaneous albinism type II is an autosomal recessive condition resulting from a mutation in the P gene encoding for a transmembrane melanosomal transport protein. The consequent reduction in cutaneous melanin increases the risk of nonmelanoma skin cancer. In the eye, a reduction in pigment at the fovea leads to poor central vision, nystagmus, and photophobia. The overall incidence of oculocutaneous albinism type II in Tanzania is 1 in 1400 people per year. In tropical countries where there is an additional risk factor of continual daily sun exposure, many albinos die in their 20s and 30s of nonmelanoma skin cancer.

There are estimated to be 660 albinos in the Kilimanjaro region of Tanzania, 420 of whom attend a mobile outreach clinic for albinos that was started by the Regional Dermatology Training Centre at Kilimanjaro Christian Medical Centre in 1993. Clinicians visit 10 villages in the Kilimanjaro region twice a year and provide health education, sunscreen, hats, long-sleeved school shirts, sunglasses, and skin examinations to all albinos who attend. At each visit, the albinos are given a hat and sunscreen and examined for evidence of photodamage and malignant and premalignant cutaneous tumors. They are taught how to apply sunscreen regularly and to wear sun-protective clothing. Any skin tumors are excised in the clinic, or the patient is brought to the medical center, where the tumor is excised within a few days. In 1996, an educational booklet was produced, which is given to all families with albinos. The booklet explains the basic genetics of albinism, the risks of developing skin cancer, and methods of sun protection. Education is, therefore, in 2 forms, verbal and written.
SUBJECTS AND METHODS

A cross-sectional survey in the form of an interview-based questionnaire was performed between June 1, 1997, and September 30, 1997, in the outreach albino clinics in the Kilimanjaro region of Tanzania. When designing the questionnaire, we sought the advice of the Public Health Department at Kilimanjaro Christian Medical Centre and of local Tanzanians. The questionnaire was written in Swahili, and to maximize continuity in interpreting answers to questions, the interviewers remained unchanged throughout the study.

The questionnaire was tested with a group of albinos for cultural acceptability before commencing the study. Following the pilot study, the wording of questions that had been poorly understood was changed. The questionnaire was administered by face-to-face interviews, thereby ensuring complete data collection, and took approximately 20 to 30 minutes to complete. Questions were asked regarding the respondent's understanding of the cause of albinism, the risk of skin cancer, their expectations of the clinic, and their attitudes toward the suggested sun protection methods. Most questions were in a multiple-choice format, with an option to answer “don’t know” and “other” where appropriate. Questions regarding beliefs about the cause of albinism and alternative services that the clinic might be able to provide were open ended. Understanding of sun avoidance was further evaluated with drawings of individuals wearing various outfits; respondents were asked to indicate which items of clothing did not provide adequate sun protection and where, if wearing these garments, sunscreen should be applied. A scoring system was used in which 1 point was given for each item of clothing noted to provide inadequate sun protection and 1 point given for indicating a relevant part of the body to which sunscreen should be applied, eg, arms, legs, and face. A maximum score of 36 was possible. All albinos 13 years and older and accompanying adults of younger children attending an outreach clinic were asked to answer the questionnaire. If adults accompanied more than 1 child, the responses to 1 questionnaire were applied to each of the children. Unaccompanied children younger than 13 years and those too sick to answer questions were excluded.

Although clinics were well attended, the albinos were often poorly sun protected, despite several visits to the clinic. The reason for this was not clear and led to concern that the true needs of the albino community might be different from those originally perceived by the clinic founders. A questionnaire was devised to ascertain what the albino population had from the clinic, and their expectations the albino population had from the clinic, and their attitudes toward the suggested sun protection behavior.

RESULTS

There was a 100% response rate, ie, all of those approached agreed to answer the questionnaire, and there were no missing data. Ninety-four questionnaires were completed in 5 villages. The median age of the albinos was 16 years (range, 4 months to 68 years); most albinos responding to the questionnaire and attending the clinic were adults or children younger than 13 years (Figure 1). Two adults responded for more than 1 child, with one responding for 2 children and the other for 4 children. There were approximately equal numbers of male (49% [n=46]) and female (51% [n=48]) respondents. More than half (n=53) of those answering the questionnaire had attended the clinic on more than 4 occasions, and only 12% (n=11) were first-time attendees.

REASONS FOR AttENDING THE CLINIC

The most common reasons given for attending the clinic were health education, skin examination, to obtain a wide-brimmed hat and sunscreen, and concern about the condition of the skin (Figure 2).

SUPERSTITIONS AND THE CAUSE OF ALBINISM

Although 59 (63%) respondents had an albino relative, only 13 (14%) believed albinism to be an inherited condition. More common were beliefs in numerous local superstitions explaining the cause of albinism. Most of these concerned a curse being put on the family or the mother eating with an albino or shaking hands with an albino. These activities were perceived as most sinister if per-
formed in the morning. Many thought it was “God’s will” that they, or their child, were albino.

RISK OF SKIN CANCER

Among the 47 (50%) albinos who claimed to have read the educational booklet, 73 (78%) thought that skin cancer was preventable, and 59 (63%) believed that cancers were related to the sun and could be prevented by sun-avoidance behavior.

SUNSCREEN

All albinos attending the clinic are provided with a sunscreen. Seventy-two (77%) believed it was to protect the skin from the sun, but it was also thought to have numerous other qualities, such as making the skin soft and preventing injury. Ninety (96%) reported using the sunscreen at least once a day, but 9 (10%) also applied it at night.

SUN-PROTECTIVE CLOTHING

The most common reasons given for not wearing sun-protective clothing were that it was unfashionable (34% [n=32]), too hot (13% [n=12]), and not available (10% [n=9]). The hats provided in the clinic, although “liked” by 92 (98%) respondents, were thought to have too soft a brim, to shrink, to be unfashionable, and to be ridiculed by others.

SUGGESTIONS FOR THE CLINIC

Suggestions from respondents about additional services that they would like the clinic to provide were mainly about education and employment. They included a boarding school for albino children or for the visually impaired, a place for albinos to study at the Regional Dermatology Training Centre, and assistance with finding employment and developing income-generating projects.

ANALYSIS OF DRAWINGS

The maximum score for indicating items of clothing not providing adequate sun protection and the number of body sites to which sunscreen should be applied in the drawings was 36 points. Scores ranged from 6 to 35 (mean [SEM], 24 [0.7]; 95% confidence interval, 22.2-25.1). The mean score for those who had read the educational booklet was 23.2 (95% confidence interval, 21.3-25.1), and the mean score for those who had not read the booklet was 24.2 (95% confidence interval, 21.9-26.5) (P=.49, unpaired t test) (GraphPad Prism 2.01; GraphPad Software, Inc, San Diego, Calif).

COMMENT

The aim of this study was to gain insight into the beliefs and attitudes of an albino community toward health education and services provided by a dedicated clinic, with a view to adapting the services to better meet the needs of the community. There are cultural difficulties in performing a study of this kind, which we attempted to minimize by seeking advice from local Tanzanians when writing the questionnaire and testing the study.

The young median age of attendees at the clinic (16 years) may be the result of many factors, including the youthful population of Tanzania (47% of the population are younger than 14 years, and only 3% are older than 65 years), the tendency of the older population to seek their health care from traditional medical sources,9 early death from nonmelanoma skin cancer,6 and the practice, until approximately 45 years ago, of killing albino newborns at birth. Teenagers are underrepresented in this survey, possibly because of pressures to attend school rather than the clinic or because of poor attitudes and behavior toward sun protection in this age group, which would be in keeping with survey results in Western cultures.10,11 We are reluctant to draw comparisons between results of our study and those of studies based on Western white populations because of cultural differences in our group, which forms a subsection of the predominantly black population of Tanzania, and the absence of tanning ability in the albino population. This study does, however, suggest that albino teenagers may be a group to target for sun-avoidance education and further studies. The high response rate is indicative of the willingness of the albino community to participate in studies such as this, or it may reflect a general wish to please the clinic organizers.

The reasons given for attending the clinics were similar to those perceived by the clinic founders,9 ie, health education, skin examination, and treatment of cutaneous tumors, but did not explain the respondents’ poor compliance with sun protection behavior. A good understanding of the risk of skin cancer and of sun protection behavior was demonstrated by the questionnaire results and was verified by scores on sunscreen application and clothing anomaly assessment. Health education covering this information had been given verbally by the clinic staff and in the educational booklet. There was no difference in the scores between those who claimed they had read the booklet and those who had not, implying that the booklet, in its present form, may have limited educational benefit, although we had no method of verifying that the booklet had been read. In support of this, there was little understanding of the cause of albinism, information mainly covered in the educational booklet and not covered in the verbal health education. This gulf in knowledge was bridged by numerous superstitions. These superstitions conveyed negative connotations, such as a curse having been put on the family, misbehavior of the mother, or derogatory name-calling such as zervu zervu (ghost), mzungu (white person), and “pig.” This has highlighted the need for educating not only the albino population but also the wider community about the etiology of albinism.

The group’s understanding of the use of sunscreen was reasonable, but there was some confusion about its purpose. This may be in part because the sunscreen is made using a moisturizing base that is in popular use to soften and provide sheen to the skin. The sunscreen is distributed in the original moisturizer bottle but with an affixed label in Swahili giving directions for use. The clinic...
has recently received a donation of commercial sunscreen, which may cause less confusion.

Some reasons for noncompliance with suggested sun protection methods were elucidated. It is not fashionable to wear a large hat, long sleeves, and socks. It is not practical to wear this clothing in equatorial sunshine when doing manual labor. The hats given out in the clinic were impractical, with large floppy brims obscuring vision, and were ridiculed. Politeness may have motivated almost everyone to say they liked them, however.

Suggestions for additional services to be provided by the clinic related to education and employment. The educational needs of albino children are not being met by the state school system. A letter is sent to head teachers explaining the problems of albinism and requesting permission for albino children to wear long sleeves, long trousers or skirts, and hats when outside. Unlike other African countries, there are no provisions for children with poor vision, such as reading glasses, magnifying glasses, and large-print books. Adult albinos are, as a consequence, often poorly educated and have few employment options other than farming, which exposes them to almost constant sun exposure.

Education of teachers and inclusion of the educational needs of albino children in the teacher training curriculum in Tanzania may eliminate the need for separate educational institutions, thus reducing segregation of this stigmatized community. This would need to be assessed and provided for on a national scale.

**CONCLUSIONS**

Albinos attending the clinic had a reasonable understanding of the risks of skin cancer and of sun-avoidance methods. They did not always follow the advice given in the clinic, however, because of cultural or fashion reasons, heat, or lack of availability of suitable clothing. There were no difficulties with the application of sunscreen in terms of acceptability, but there was some confusion about its exact purpose. The lack of understanding of the cause of albinism seemed to perpetuate numerous abusive superstitions surrounding the albino community.

Since this study was performed, some changes have been instituted. The emphasis of health education in the clinic has been changed. Verbal education now includes the etiology of albinism. Sun-protective clothing is the preferred method of sun avoidance, but the importance of applying sunscreen to any exposed body parts in the absence of ideal clothing is stressed. This will have implications for provision of adequate volumes of sunscreen.

It is beyond the scope of the clinic and the Regional Dermatology Training Centre to provide jobs for a significant number of the albino community. However, thanks to a donation of sewing machines from a local company, albino women now make and supply the clinic hats. The new hats have a stiff brim and are in various colors, making them more practical and less stigmatizing. Two of the local albino coordinators have recently started a series of 5-minute programs on local radio, with the aim of educating the wider community. If this is successful at a local level, national media sources may be targeted in the future.

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**REFERENCES**