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ALBINISM IN THE SOUTH AFRICAN NEGRO. III. GENETIC COUNSELLING ISSUES

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Summary. A sample of 35 South African Negro albinos and a normally pigmented matched control group have been studied for adjustment problems and attitudes towards this inherited condition. The results showed that although the albinos appeared to be as well adjusted as the controls, significantly more of the albino group had adjustment problems of a physical nature indicated by psychosomatic symptoms. Attitudes were found to be reasonably positive. One common local misconception was revealed: that albinos do not die but disappear or 'vanish away'. There was very little understanding of the cause, mode of inheritance or the problems associated with albinism. It is concluded that relevant genetic counselling should be offered to the Negro albinos to enable them to understand their condition, its implications and the myths which surround it. Because albinism is so common in South Africa the education of the community in this connection is also desirable.

Introduction

Oculo-cutaneous albinism is a recessively inherited disorder characterized by a lack of pigmentation of the skin, hair and irides. Affected individuals would appear to be at a disadvantage particularly when resident in a temperate area at an altitude of 1760 m, where ultraviolet radiation is considerably above that of sea level, and where there is a high proportion of sunny days. When the condition occurs in a Negroid population the contrast between affected and normal individuals is particularly striking and when it occurs in a political and social context such as that found in South Africa it might take on special significance. It might be anticipated that these factors would predispose to social adjustment problems and that the attitude of affected subjects to themselves, as well as society's attitudes to those affected, would merit consideration and scientific study if effective genetic counselling is to be offered.

Albinism is more common amongst South Africa's Negro population than it is among Whites in Europe. The prevalence is approximately 1 in 3900 in Johannesburg Negroes (Kromberg & Jenkins, 1982) compared with 1 in 9650 in

Norway (Magnus, 1922), 1 in 10,000 in Northern Ireland (Froggatt, 1960) and 1 in 20,000 in Holland (Sanders, 1938). It may seem to the local community to be on the increase, but this is probably only because albino infants are now permitted to live, whereas previously many were killed at birth together with other defective children (Livingstone, 1857). They are also now allowed to participate actively in social life instead of being hidden or over-protected, and thus are commonly seen on the streets and in public places. The prevalence in South Africa is higher than in other parts of Africa (Nigeria 1 in 5000, Barnicot, 1952), but not as high as in the Hopi Indians of Arizona (1 in 227, Woolf & Grant, 1962).

The purpose of the present exploratory study was three-fold. It aimed, first, to identify some of the adjustment problems of the young Negro albino, secondly, to examine some of the attitudes of the local Negro society to albinism, and, thirdly, to outline some of the issues which might be encountered when counselling the Negro patient with albinism.

Materials and methods

The present study was carried out in Soweto, a Negro dormitory town adjacent to Johannesburg, the most densely populated city in South Africa. Soweto is an area housing over 1 million people, most of whom have only been urbanized for one or two generations. They live in sub-economic housing and the mean household size is 5·85 (Hellman, 1971) per small four-roomed house. The residents of Soweto work in Johannesburg city, commuting 25 km to and from their employment daily by trains and buses. Compulsory education is being introduced gradually and most of Soweto's inhabitants have had a few years of schooling. Employment opportunities are limited, to a certain extent, to those that fall into the unskilled and semi-skilled groups, but training of Negroes for skilled jobs is increasing (Grant, 1975).

Sample. It was planned to study the 42 albinos who comprised the 13–21 year old group of albinos known to us in Soweto (Kromberg & Jenkins, 1982). Tracing all the subjects in this group proved impossible, due to the time lapse between the ascertainment of the original sample and the present study, and due to the difficulty of finding families who move house in Soweto, or leave the area. As a result the final sample was reduced to 35 albinos in this age group. They were compared with a control group of normally pigmented subjects matched for age, sex and educational level. The two groups were strictly comparable, the mean age for the albinos being 17·29 years (SD 2·63) and for the controls 16·83 years (SD 2·28); the mean number of years of education for the respective groups was 8·35 years (SD 2·06) and 8·11 years (SD 2·26). For purposes of comparison, and to facilitate the matching, the subjects were divided into three groups, the higher primary school (Standards III to VI), high school (Form I to Form V) and a non-school-going group. The latter was composed of subjects who had dropped out of school for a number of reasons (including pregnancy), had the lowest level of education of the three sub-groups, and were unemployed either because of their young age, or because of lack of residence and/or work permits, or job opportunities.

Procedure. A schedule consisting of dichotomous items was designed to cover the first two areas of enquiry. The items on adjustment were chosen to include

social, emotional and physical problems. They were selected from well-known questionnaires such as Bell's Adjustment Inventory (1962) and the Science Research Associates Youth Inventory (1956), as well as from the experience of one of us (JK). The items dealing with attitudes were formulated using some of the concepts and ideas of Adorno *et al.*'s (1950) work on the prejudiced personality. Three additional items were included on the schedule to investigate the beliefs concerning the causes, inheritance and problems of albinism.

The schedule was submitted to a pilot survey with 50 Negro school children of the same age as the experimental group, and difficult and problematic items were subsequently clarified or omitted. The schedule was then taken by a fully-briefed Negro interviewer, fluent in the home language of the subjects, and completed in an interview with each subject, usually in his or her own home. The completed schedules were returned to the writers and analysed. The items were submitted to an item analysis using Likert's method of summated ratings for the testing of internal consistency (as described by Triandis, 1971), and those items which were found to be unreliable were rejected. For this purpose a cut-off point of 1% probability was arbitrarily imposed.

The subjects were then scored on the retained items (the complete schedule may be obtained from the authors). Twenty of these items were concerned with adjustment problems and ten with attitudes towards albinism. The scoring method involved the use of a simple three point scale (Goode & Hatt, 1952) with 3 indicating good adjustment and a positive attitude towards albinism, 1 showing a poor adjustment and negative attitude towards albinism, and 2 indicating an intermediate position. The schedules were scored by one of us (JK) and then sent to two independent judges (clinical psychologists) who rated the responses, where the subjects had qualified their response, on a seven-point scale. On this scale, 7 indicated very good and 1 very poor adjustment. All identification details were removed from the schedules so that the judges each carried out a blind analysis. Correlation coefficients between the two judges were computed and the judges' results were found to be significantly similar ($P < 0{\cdot}01$). The final score for each subject was therefore based on the mean of the two judges' scores.

The scores were then analysed statistically and the t test for matched samples (McCall, 1970) was used to assess the significance of any differences which might exist between the experimental and control groups. Differences were considered to be significant when $P < 0{\cdot}05$ was obtained.

Results

The results of the adjustment measure are shown in Tables 1, 2 and 3. Table 1 reveals that the two groups showed no significant differences at any educational level, for overall adjustment on the combined scores for responses relating to emotional, physical and social problems. The results of the male and female subjects were then analysed and these results are shown in Table 2. Again no significant difference was apparent between the two groups.

Table 3 shows the results of assessment by the two judges. Significant differences were observed between the experimental and control groups on the

Table 1. Comparison of mean scores for adjustment* by educational level

Sub-group	*n*	Albinos Mean	Albinos SD	Controls Mean	Controls SD	*t*	*P*
Higher primary school	14	44·53	8·35	43·57	7·52	0·45	>0·50
High school	10	47·80	6·37	49·80	6·03	0·70	>0·20
Non-school going	11	39·73	7·43	39·54	8·52	0·05	>0·90
Total	35						

* Where highest possible score is 60, indicating very good adjustment.

Table 2. Comparison of mean scores for adjustment* for males and females

	n	Albinos Mean	Albinos SD	Controls Mean	Controls SD	*t*	*P*
Males	21	44·62	8·99	46·67	7·21	−1·00	>0·20
Females	14	43·36	6·51	40·21	8·67	0·91	>0·20
Total	35	44·06	8·08	44·09	8·31	0·015	>0·90

* Where highest possible score is 60, indicating very good adjustment.

Table 3. Comparison of clinical psychologists' assessment of males and females

	n	Mean scores* Albino	Control	*t*	*P*
Males	21	4·08	3·90	0·67	>0·20
Females	14	4·21	3·23	3·39	<0·01
Total	35	4·13	3·63	2·44	<0·05

* Where 7 = very good and 1 = very poor adjustment.

mean scores. The experimental group scored significantly higher than the control group, indicating that according to the two independent judges the albino group showed a better adjustment than the control group. This difference was most apparent and highly significant in the female group.

The two groups were then compared on their results for each item relating to adjustment. Six items showed significant differences between the groups (as shown in Table 4) and four of these related to physical adjustment. The item on blinking was inserted as a test item, since it may be assumed that albinos do blink because of

Table 4. Adjustment items showing statistically significant differences

Item	Mean scores*		t	P
	Albino	Control		
Sweating palms	1·60	2·09	2·19	<0·05
Ashamed of appearance	2·45	1·86	3·21	<0·01
Blinking	1·66	2·47	6·73	<0·001
Headaches	1·74	2·23	2·40	<0·05
Speak to strangers	2·17	1·69	2·15	<0·05
General problems	1·37	1·94	2·62	<0·02

* Where 3 = good and 0 = poor adjustment.

the photophobia they exhibit and, since the albinos admitted to blinking frequently, this was confirmed by the results. Two of the other three items related to psychosomatic symptoms—sweating palms and headaches. The albinos were found to have significantly more problems related to both of these conditions. The final item relating to physical adjustment is most interesting since the albinos claimed to be less ashamed of their physical appearances than did the Negro control group. This finding will be considered further in the discussion. One of the other two items showing significant differences concerned speaking to strangers, and more albinos than controls claimed to do this. Both groups stated that they had various 'troubles', but significantly more of the albinos complained of problems, particularly those of a physical nature.

The results of the attitude study showed that for the items measuring social distance there was very little difference between the albino and the control group. The majority in both groups agreed in principle that normally pigmented people should marry albinos, and that they would allow their children to do so. They also closely agreed that they would travel, work, eat with, and make friends with albinos.

The albino group were significantly more negative than the controls concerning the problem of the albino getting a job ($P < 0{\cdot}01$). Although very few of the present sample had ever tried to get employment, since they were either school-going or recent drop-outs, they seemed to be anticipating that this would be a serious problem.

The most interesting result came in the response to an item in which the subjects were asked what they thought happened to albinos at the end of their lives. True to the popular local belief, significantly more subjects in the control group said that albinos disappear and die in mysterious circumstances ($P < 0{\cdot}02$). Many of the albinos themselves expressed doubt as to the circumstances of their deaths, so they too knew of the myth.

Three further items (not included on the adjustment or attitude scales) on the schedule related to the causes of albinism, the hereditary process and the problems involved. The results of the first of these items indicated that the majority of

subjects in both groups did not know the cause of albinism. It is interesting that six albinos thought that the disorder was due to punishment by God, for example, for 'laughing at albinos', 'chasing them' or being 'afraid of them'. Only one of the control group thought this type of negative attitude or behaviour might cause albinism. There were, however, nine of the albino group and five of the control group who thought the birth of an albino to be a 'gift from God'. Two further controls thought that albinism might be caused by eating the wrong foods, and one control believed that the mother's use of bleaching creams had caused the condition. In response to the second item, only one subject in each group stated that if one parent was an albino and the other was normally pigmented the children would be black, whereas if they were both albinos the children would be albinos (this is true, of course, only if both are homozygous for the same allele). There were nine albinos and eighteen controls who thought the children would be black and ten and two respectively who said they did not know what colour the children would be. The results of these two items clearly indicate that neither the albino nor the control group fully understand the cause or the mode of inheritance of albinism.

The third item relating to problems gave results indicating that most subjects in both groups thought the problems of albinos were chiefly physical, involving the skin and eyes. Psychosocial problems were mentioned by only one of the albino group ('lack of love and tender care from parents and relatives leads to skin and eye problems') and by six of the controls. Some examples of the latter group are interesting: 'being black by birth but not by colour may be one of their major problems; this deprives them of the companionship of other black children'; 'they cannot easily make friends because of skin and eye problems'; 'they keep to themselves'; 'they don't wash'; and 'they are never relaxed in company'.

Discussion

Prior to this study we had thought that albinos might have psychosocial problems related to their apparent rejection by society and might need counselling in respect of this particular aspect of their lives. It appears however from the present study that attitudes are reasonably positive and that albinos are in fact quite well accepted. We have data, however, which suggest that these positive attitudes do not extend to marriage and that the actions of local Negro people do not match some of their attitudes as stated here. For example, out of 20 albino women and 28 albino men of marriageable age (i.e. 20 years or over) we know of only five females and five males who are married. It is accepted that attitudes inferred from what a person says about an attitude object and the way he feels about it, might not be consistent with how he behaves when confronted with an actual situation. 'Attitudes involve what people think about, feel about, and how they would like to behave towards an attitude object. Behaviour is not only determined by what people would like to do but also by what they think they should do, that is, social norms, by what they have usually done, that is, habits, and by the expected consequence of the behaviour' (Triandis, 1971). Other studies in the French Cameroons (Vallois, 1950) and on the Hopi Indians (Woolf & Dukepoo, 1969) have also noted that albinos tend not to

marry, although they appear to be well accepted in their communities and may still bear or father children.

It is interesting too that the attitudes of the albinos themselves so closely reflect the attitudes to albinism of the Negro control group. This may be explained by Gilbert's (1970) statement 'that every human being craves affection, acceptance, belonging and social participation and that he tends to conform to the social mores and values of his culture more or less automatically in order to fill these needs'.

Of the six items (on the adjustment scale) which showed differences between the albino and control group, four could be said to indicate psychosomatic symptoms. It may be that the albinos are expressing anxiety, through these symptoms, such as headaches, at living in a partially rejecting society (indicated by their limited acceptability as marriage partners and by the use of the work 'nkau', which literally translated means 'monkey', for albino, in one major language group). The albinos in this study do not admit to having problems in the areas of interpersonal or psychosocial adjustment. They do however complain of these psychosomatic symptoms and as Vernon (1964) says 'depressive anxious neurotic trends are known to be measurable by psychosomatic or health complaints and food aversions at least as effectively as by more introspective items'. It is possible that the items on this scale were too few and too superficial (owing to the necessity of using a translator and simple concepts, because of the low degree of sophistication at present attained by the local population) to be sensitive to the albino's problems in the social and emotional areas. There is obviously a need for further research with a more sophisticated measuring instrument to clarify this issue.

One intriguing finding in this study was that the control group seemed to indicate feelings of dissatisfaction with their physical appearance to a greater degree than the albino group. Why both groups should exhibit such a trait is difficult to explain but may, in part at least, reflect the accepted teenage conflict related to puberty and the rapid development of body size and shape. Manganyi, Kromberg & Jenkins (1974) studying the same population group, expressed the view that diffuse body boundary features appear to be a consistent possibility in Negro South Africans, and that it seems that there are 'socio-cultural situations which tend to nourish the development of this condition'. Should this be so, they added, it is a 'very serious matter indeed since the body image boundary has been found to be related to many varied areas of personality functioning'. Again Manganyi *et al.*'s study showed that the albinos were slightly less diffuse in their body image differentiation and this would agree with our findings here that albinos claimed to be no more ashamed of their physical appearance than did the normal controls. It may be that because of their uniqueness teenage albinos are better able to establish an identity for themselves than are their normally pigmented contemporaries. Since great significance is attached to skin colour in many spheres of South African life the albino might feel that he will benefit from his colour, whereas the control on the other hand might feel the pressure and dissatisfaction of being one of the vast underprivileged black majority. Woolf & Dukepoo (1969), however, suggest that for the Hopi Indians the admiration of the albinos' whiteness was clearly not 'an identification with white Americans', instead it represented 'an association of whiteness with cleanliness, goodness and purity'. We believe, similarly, that South

African albinos do not consciously identify themselves with whites (in our experience only two have attempted to pass for 'Coloured', the mixed group in South Africa) and therefore they might also, instead, associate themselves with the characteristics attributed to whiteness, such as cleanliness, purity and goodness, which are attributes held in high esteem by local black groups. This suggestion might provide one reason why the albinos in our study did not indicate significant feelings of dissatisfaction with their physical appearance.

As indicated by the results on the item concerned with death, the myth that albinos do not die naturally is widely believed, and this may partly explain why albinos are not ashamed of their physical appearance and are not apparently maladjusted. It is also possible that because of the myth albinos may regard themselves as unique and special. As far as we are aware no obvious spiritual powers, which might be suggested by belief in this myth, are claimed by albinos or attributed to them. We know of only one instance in which an albino displayed such powers: in a rural area an albino clairvoyant was able to locate the forgotten burial place and the bones of an important ancient chief, because she was said to have the 'spirit'. Many local Negro groups, however, attach special significance to the colour white: diviners (the specialists who diagnose the 'real' cause of disease, with help from the spirits of their ancestors) are expected to wear white clothing; white beads, to put in their hair and on to their clothes, are given to them as presents; white goat skins are used to adorn the upper parts of their bodies; and they often hold white cows' tails while dancing. There is also a distinction between 'black' medicines, which nullify evil, and 'white' medicines, which are soothing and purifying in their effects (Hoernlé, 1937). This special meaning of the colour white may be subconsciously transferred by the community to the white, or albino, child who is born into a black family. This phenomenon may have led to the growth of the myth asociated with the condition. If white articles are used by diviners because they have some power to bring them nearer to the spirits of the ancestors, and if the white child is seen as being associated with the spirits in some undefined way, then one conclusion might be that since spirits do not die, neither do albinos. There are many suppositions in this argument, however, and further discussion with diviners, anthropologists, and affected families is required. It may be, as one Negro nursing sister suggested, that the myth has developed simply because albinos are rare and people do not often see them die.

Conclusion

The present study shows that the South African Negro albino is as well adjusted as the normally pigmented individual, and that attitudes of the latter towards albinos are reasonably positive. Certain problems of the albino have been identified and these can, we believe, be dealt with by broadly defined genetic counselling. First, a clear description of albinism and its basic defect should be given. Secondly, an explanation as to cause, mode of inheritance, possible complications such as skin lesions and poor vision, as well as a discussion of its prognosis and the treatment necessary to minimize its side-effects, should be offered. Thirdly, discussion regarding the myth about death should be initiated and the patient should be helped

to accept death as a natural and inevitable fact, so that the myth does not cloud the understanding of the genetic factors involved. Fourthly, a discussion on marriage is indicated, since there is some disparity between the attitudes of the black population as stated here and their actual behaviour in relation to marriage. Fifthly, time should be spent on a consideration of community attitudes and misconceptions regarding albinism. Lastly, discussion on, and if necessary, referral for, vocational guidance is indicated by the albinos' concern that they are unemployable.

Other problems which stem from community attitudes and beliefs need to be dealt with at the level of community education. If issues are tackled at both the level of individual genetic counselling and community education simultaneously, the quality of life of the Negro albino could be significantly improved.

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